Establishing and Enhancing Services for Childhood Cancer Survivors

LONG-TERM FOLLOW-UP PROGRAM
RESOURCE GUIDE

Children's Oncology Group Nursing Discipline
Clinical Practice Subcommittee/Survivorship
in collaboration with the Late Effects Committee

CureSearch
Children's Oncology Group

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Editor: Wendy Landier

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LTFU PROGRAM RESOURCE GUIDE

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Children's Oncology Group

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FOREWORD

Many of us trace the roots of our hospitals' survivorship and transition programs back 25 to 30 years to the pioneering influence of individuals we worked with in the legacy cooperative groups (CCG and POG).[1, 2] I remember that in the 1970's, as treatment advances led to prolonged remissions in children with acute lymphoblastic leukemia, a new question arose: how long should maintenance therapy be given? Because part of the answer to that question depended on the potential long-term adverse effects of treatment and because reports of late effects were appearing in the literature, the first long-term follow-up protocol in the CCG (CCG-101L) was opened in 1980.[3] Participating institutions like mine needed to coordinate the evaluations required by the study (i.e., neuropsychologic testing, gonadal evaluation, ophthalmologic evaluation, thyroid evaluation, physical examination, reporting of any second tumor, history of inpatient hospitalizations). For many of us, that was our first foray into the world of establishing services for childhood cancer survivors. The experience showed us the importance of comprehensive late effects evaluations, and emphasized the difficulty of incorporating this type of follow-up care into routine outpatient off-therapy visits. In that sense, CCG-101L opened a Pandora's box of issues related to the workforce, resources, and systems needed to implement long-term follow-up care.[4] Meanwhile, the population of survivors continued to grow, and a heterogeneous group of long-term follow up programs using diverse homegrown models developed in response. Those of us who shared an interest in survivorship and transition eagerly sought each other out to compare experiences. We kept an eye on the literature, networked at conferences, and consulted each other by telephone and later by email and listservs. But we didn't have (and would have given our "eyeteeth" for) the practical assistance for developing and sustaining a long-term follow up program that's available between the covers of this *Resource Guide*.

There is no question that pediatric health care providers have led the way in survivorship care, education, and research. A partial list of milestones would include recognition of the incidence and impact of late effects among cancer survivors, dissemination of information and guidelines for follow up care, development of survivor "passports" in various formats, and publication of health education materials for survivors. Yet, despite a growing library of articles, books, and reports, as well as media attention to survivorship after cancer treatment, until now there has been no single guide to help interested health professionals and their institutions develop and enhance long-term follow-up services. This *Resource Guide* meets that need and represents one more milestone in survivorship care by pediatric oncology thought leaders and clinical experts.

For me, one of the special joys of working in pediatric oncology has been that colleagues far and wide always have been so willing to share their knowledge, insights, and experience. With the advent of the Children's Oncology Group in 2000 and the collaboration of the COG Late Effects Committee and the Nursing Discipline, a critical mass of shared survivorship expertise coalesced. I hope that you will join me in gratitude for all the individuals involved in this collaborative effort who generously contributed their time and survivorship savvy to put this much-needed *Resource Guide* at your fingertips, and that you will find it very helpful in your practice.

Kathleen Ruccione, MPH, RN, FAAN, CPON®
COG Nursing Discipline Chair

FOREWORD

The last three decades have seen tremendous improvements in survival of children diagnosed with cancer, with the 5-year survival rate approaching 80%. This improvement in survival has resulted in a growing population of childhood cancer survivors. Use of cancer therapy at an early age can produce complications that may not become apparent until years later. Approximately two-thirds of the survivors of childhood cancer will experience at least one late effect, and about one-third will experience a late effect that is severe or life-threatening. Even more important is the observation that the risk of developing these long-term complications does not appear to plateau with time, hence the emphasis on long-term follow-up of childhood cancer survivors.

An especially high-risk population, childhood cancer survivors seek and receive care from a wide variety of health care professionals, including oncologists, medical and pediatric specialists, surgeons, primary care physicians, gynecologists, nurses, psychologists and social workers.[5] Providing appropriate health care for survivors of cancer is emerging as one of the major challenges in medicine. The challenge arises from the heterogeneity of this patient population treated with numerous therapeutic modalities in an era of rapidly advancing understanding of late effects. The Institute of Medicine has recognized the need for a systematic plan for lifelong surveillance that incorporates risks based on therapeutic exposures, genetic predisposition, health-related behaviors, and comorbid health conditions. Optimal healthcare delivery to this unique population requires the establishment of necessary infrastructure, including several key components:[6] (1) longitudinal care utilizing a comprehensive multidisciplinary team approach, (2) continuity, with a single healthcare provider coordinating needed services, and (3) an emphasis on the whole person, with sensitivity to the cancer experience and its impact on the entire family.

Academic settings allow for establishment of a specialized multidisciplinary follow-up team to care for large numbers of survivors; however, the paucity of such centers and their limited geographic access make these specialized centers an option only for survivors who live nearby or who can afford time and expenses in order to travel to a distant center. Until now, there have been no resources available that describe the process of developing a long-term follow-up clinic. Therefore, the development of a resource to help institutions provide the necessary follow-up in a comprehensive yet standardized fashion has been a priority of the Children's Oncology Group.

The Children's Oncology Group's *Long-Term Follow-Up Resource Guide* is an outstanding and much-needed review of the entire process required to establish the necessary infrastructure in order to conduct long-term follow-up by interested institutions. The material included in the *Resource Guide* represents the expertise of individuals who have successfully established such centers at their institutions, and therefore captures a wealth of experience from experts who have demonstrated successful execution of this endeavor at the local level. The text is practical and hence readily applicable across a variety of institutional settings and patient demographics. Finally, this piece of work, led by the COG Nursing Committee, with review and input from the Late Effects Committee, represents the consensus of national experts in this field, and is truly a success story in terms of how the total effects of such collaborative efforts equal greater than the sum of individual pieces. I believe that this landmark effort will greatly benefit institutions interested in initiating survivorship programs, and most importantly, will provide childhood cancer survivors with the standard of care that they deserve.

Smith Bhatia, MD, MPH
COG Late Effects Committee Chair

INTRODUCTION

As more and more children survive childhood cancer, late and sometimes serious therapy-related complications continue to emerge. Ongoing care for long-term survivors is thus being recognized as an essential part of the cancer care continuum. Developing and implementing a long-term follow-up (LTFU) program for childhood cancer survivors can be challenging. It can also be deeply rewarding. In order to support the development of such programs, the Children's Oncology Group Nursing Discipline's Clinical Practice Sub-committee - Survivorship Section embarked on a collaborative effort with the Late Effects Committee to develop this practical guide. Under the leadership of a core group of dedicated editors, over 50 individuals participated in the development of this guide in order to provide a broad perspective reflecting a wealth of experience from a variety of LTFU programs affiliated with Children's Oncology Group institutions. Whether you are planning to establish a new LTFU program or to enhance an existing program, we are hopeful that you will find the information in this *Resource Guide* helpful.

This *Resource Guide* is organized in five sections, as follows:

1. Foundations for Long-Term Follow-Up:

This section serves as an introduction that will assist those without a pediatric oncology or late effects background (such as hospital administrators or potential program donors) to understand the importance of LTFU for childhood cancer survivors. It can be used to provide justification as to why a LTFU program should be established (or why an existing program should be enhanced), and includes basic information regarding program organization and design, care delivery methods, transition issues, and challenges/barriers to delivering survivorship care. This section is intentionally written at an introductory level so that those without a clinical background will easily be able to understand the issues discussed.

2. Program Development:

This section is targeted to both healthcare professionals and administrators. Issues important in developing a long-term follow-up program are defined and discussed, and the reader is provided with information to assist in weighing options and setting parameters for a LTFU program that best meets the needs of individual institutions.

3. Delivering Long-Term Follow-Up Care:

This section provides the "nuts-and-bolts" of how to organize and run a long-term follow-up clinic (including clinic operations, preparation for clinic visits and post-clinic follow-up). It is designed for use by healthcare professionals who will be directly involved in planning and delivering care in the clinic. The information may also be useful for administrators and others who will be supporting clinic operations.

4. Survivorship Research:

This section describes methods for incorporating multidisciplinary survivorship research into LTFU programs. Topics include identification of research priorities, database development, regulatory issues, and research opportunities, including development of research partnerships and participation in Children's Oncology Group and other collaborative studies.

5. Issues in Survivorship:

Common psychosocial, educational, and legal issues facing survivors (such as problems with employment or insurance, and the importance of advocacy skills) are discussed in the context of how these issues affect the services required by survivors in LTFU programs.

Appendices:

The appendices provide a wealth of resources available through the Children's Oncology Group and their affiliated institutions.

Appendix 1 is a guide to several Children's Oncology Group (COG) resources that specifically address the long-term follow-up needs of childhood cancer survivors. It includes a sample from the COG *Long-Term Follow-Up Guidelines for Childhood, Adolescent, and Young Adult Cancers*, a sample patient education guide (*Health Link*) targeted to a specific guideline-related topic, copies of COG's *Summary of Cancer Treatment* templates (comprehensive and abbreviated versions), information about the *Late Effects Web Forum* (a web-based discussion board open to COG members), and information about the *Late Effects Directory of Services* (a web-based directory of LTFU programs at COG institutions).

Appendix 2 provides a summary of the Institute of Medicine's recommendations for improving care and quality of life in childhood cancer survivors, and includes commentary regarding progress that has been made since the release of the report and ongoing challenges in survivorship care.

Appendix 3 provides a generous sample of forms and letters used by established LTFU programs in their day-to-day operations, including clinical summary forms, annual questionnaires, history and physical forms, patient education checklists, forms for tracking test results, and assessment forms for use by multidisciplinary team members (such as social work, psychology, and nutrition). Sample patient appointment letters, insurance authorization letters, and follow-up letters to referring physicians are also included. Sincere gratitude is expressed to the institutions that generously agreed to share their sample forms and letters for inclusion in this *Resource Guide*.

We hope that the materials contained within this *Resource Guide* will be useful to you in your practice, and that as a result, you too will be able to establish or enhance a long-term follow-up program for childhood cancer survivors. We wish you well as you embark on this very worthwhile endeavor.

- Wendy Landier, Editor

"The cancer experience is a process that extends throughout a lifetime, a looking glass through which all future health and illness behaviors of the survivor must be interpreted. . . ."

- Oeffinger, 2003[6]

SECTION 1:
FOUNDATIONS FOR LONG-TERM FOLLOW-UP

EDITOR:

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THE IMPORTANCE OF LONG-TERM FOLLOW-UP

Imagine being cured of a life-threatening childhood cancer only to discover that long-term health problems may develop as a result of the very treatments that cured the cancer. Such is the case for the estimated 270,000 childhood cancer survivors living in the United States today. . . .

> *When Ian was nine years old, he was diagnosed with medulloblastoma, a malignant brain tumor. Curative therapy required treatment with surgery, chemotherapy and radiation. Prior to his diagnosis, Ian was a healthy, bright boy who was active in sports. After his diagnosis and treatment, Ian struggled with balance, coordination, and gastrointestinal problems. When Ian completed all of his treatment, he was able to return to the fourth grade, but he was thin and frail, and he required a wheelchair to help him get around and a tutor to help him learn. Keeping up with schoolwork was difficult, and balance and coordination continued to be an issue, particularly during physical education classes.*
>
> *Fortunately, Ian is cured of his brain tumor. Despite his many challenges, with perseverance and hard work, he has managed to complete high school and recently graduated from a community college with a culinary arts degree. His love of cooking developed out of the necessity to overcome appetite loss associated with his treatment. Today, Ian continues to struggle with other effects related to his treatment, including cognitive deficits, short stature, hearing loss, hypothyroidism, thyroid nodules, and thinning of the hair, all of which are life-long challenges. He also remains at risk for additional problems such as osteoporosis, cataracts, kidney problems, hormone deficiencies, and second cancers.*

Over the last three decades, survival rates for childhood cancer have improved dramatically, resulting in a large population of childhood cancer survivors. Today, with the help of chemotherapy, radiation, surgery, and improved supportive care, nearly 80% of children treated for cancer will become long-term (at least five year) survivors.[5] With approximately 20,000 children in the United States diagnosed each year with cancer, the number of individuals cured of cancer will continue to grow by more than 15,000 each year.[7]

As survival rates improved over the last several decades and children with cancer reached the second and third decades of life, it became increasingly clear that cure had not come without a price. Researchers confirmed that survivors were at risk for a multitude of chronic or late-occurring health problems caused by their cancer or its treatment, often referred to as “late effects.” Late effects can affect a survivor’s physical, cognitive, and psychosocial health, and survivors remain at risk for developing many of these late effects over time.

Late Effects After Childhood Cancer

Treatment for childhood cancer can have a lasting effect on the brain, eyes, ears, lungs, heart, liver, gastrointestinal tract, kidneys, and bladder, as well as the skeletal, reproductive and endocrine systems. Survivors may face many challenges, such as learning and memory difficulties, anxiety, depression, hearing loss, cardiac dysfunction, cataracts, obesity, thyroid problems, infertility, and other medical problems, including second cancers. The risk of late complications depends on the survivor's diagnosis and the specific treatment that they received. Adverse health behaviors, such as smoking, drinking, and poor diet or exercise habits, may magnify the risk of developing some of these complications. Survivors may also face problems related to attaining their desired level of education, finding and holding a job, assuming expected societal roles, and other factors that can affect their quality of life.

Survivors at highest risk for late effects include patients treated for bone tumors, central nervous system tumors, and Hodgkin lymphoma. Survivors treated for bone cancer commonly experience disfigurement and functional limitations caused by amputations or other surgeries. Additional risks for these patients may include problems with fertility, heart and kidney dysfunction, and second cancers related to radiation and/or chemotherapy. Some patients treated for Hodgkin lymphoma experience lung damage, abnormal skeletal growth and maturation, infertility, or hypothyroidism, and girls who received chest radiation are at increased risk of developing breast cancer. Young people with brain tumors are often the most severely affected, particularly if they received radiation and chemotherapy in addition to surgical removal of their tumor. Potential late effects for this group are numerous and include cognitive impairment, short stature, hearing loss, problems with balance and coordination, hypothyroidism, thyroid nodules, kidney damage and second cancers.

In addition to the many physical late effects that may develop in survivors of childhood cancer, there are also a host of psychosocial issues that may emerge. Long-term educational, social, behavioral, and vocational difficulties are all common. Furthermore, survivors may face barriers related to obtaining ongoing medical care, support, and surveillance for late effects; these services are critical to their efforts to attain optimal health. Obtaining gainful employment with adequate insurance coverage is crucial but often difficult, particularly for survivors who have cognitive impairments. Some survivors may not be able to obtain health or life insurance or may be forced to pay high insurance premiums because of their cancer history. Still other survivors may not be able to complete school or even minimal job training, placing the burden of care on their families and society.

> ***A recent report compared the health status of 10,397 survivors of childhood cancer treated from 1970 to 1987 with 3,034 of their siblings. Among the survivors, 62% had at least one chronic health condition, and 27% had a serious or life-threatening condition, such as stroke, heart disease, or kidney failure. Survivors were 54 times more likely to have a major joint replacement, 15 times more likely to have congestive heart failure or to develop a second cancer and 10 times more at risk for cognitive problems than their siblings. In fact, only about one in three survivors remained free of long-term problems related to their cancer diagnosis or treatment.***
>
> ***- Oeffinger et al. 2006*** [8]

Research is Key to Determining Risks of Late Effects in Pediatric Oncology

Pediatric oncologists have long recognized the risk of late-occurring complications in childhood cancer survivors. The Late Effects Study Group, an international consortium of pediatric cancer centers, was organized in the early 1970s to track delayed complications in childhood cancer survivors. Led initially by Giulio D'Angio, MD and later by Anna Meadows, MD, the research conducted by this group established the relationship between many therapeutic exposures used for curative therapy in childhood cancer and the late toxicities associated with those exposures. The National Wilms Tumor Study Group (NTWS), the Pediatric Oncology Group (POG) and the Children's Cancer Group (CCG) have all made significant contributions in identifying late complication related to childhood cancer therapy. Today, this work continues to be carried out by the Children's Oncology Group (COG) and by researchers worldwide. Some of the key publications in the childhood cancer survivorship research literature to date include:

- Meadows AT, D'Angio GJ. Late effects of cancer treatment: methods and techniques for detection. *Semin Oncol.* 1974 Mar;1(1):87-90.
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The Key Role of Nurse Practitioners in Development of Long-Term Follow-Up Programs

Advance practice nurses forged their role in the long-term follow-up of childhood cancer survivors shortly after the need for continued care of this vulnerable population was identified. The role of the Pediatric Nurse Practitioner (PNP) specializing in the care of children with cancer had its beginnings in 1965 at St. Jude Children's Research Hospital (SJCRH). At that time, PNPs received on-the-job training provided by the SJCRH medical director. The St. Jude program served as the inspiration for the PNP/O program developed by Jean Fergusson in Philadelphia in the 1970s. As much of the medical literature on late effects was published by Dr. D'Angio and Dr. Meadows, both from the Children's Hospital of Philadelphia (CHOP), assessing patients for late sequelae of treatment became an integral component of the Philadelphia PNP/O program.

The earliest nursing papers on the subject provide descriptions of "late effects" and guidance for nurses regarding how best to provide care for childhood cancer survivors. June McCalla at the National Cancer Institute and Jean Fergusson at CHOP contributed some of the first papers. Numerous other nurse authors (listed below) contributed to the description and development of the role of the NP in caring for childhood cancer survivors. Wendy Hobbie from CHOP has published widely on the topic, providing concrete theory, practical guidance and role definition, emphasizing the many-faceted components of advanced practice nursing in long-term follow-up care, including clinician/caregiver, educator, and researcher.

- Greene PE, Fergusson JH. Nursing care in childhood cancer: late effects of therapy. *Am J Nurs*. 1982;82(3):443-6.
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Long-Term Follow-Up Care

Long-term follow-up programs and services are essential in order to address the unique needs of the growing population of childhood cancer survivors as they navigate the challenges of today's healthcare system. Prevention and/or early identification of complications are crucial in order to decrease the long-term health risks associated with curative treatment for childhood cancer. Although many long-term follow-up programs already exist, additional comprehensive, accessible services are needed to accommodate this ever-growing population of young people who are being cured of cancer.

Key services provided by LTFU programs should include:

- Monitoring for and managing physical late effects
- Providing health education to survivors regarding their diagnoses, treatment exposures, and potential late effects
- Providing referrals to specialists and resources as indicated
- Encouraging wellness and health promotion activities
- Addressing psychosocial needs of survivors and affected family members
- Assessing and providing intervention for educational and/or vocational needs
- Assisting with financial and insurance issues
- Guiding transition from pediatric to adult-focused healthcare
- Empowering survivors to advocate for their own healthcare needs
- Facilitating survivorship research

Survivors often lack knowledge regarding their cancer diagnosis, treatment, and potential risks for developing late effects.[9] Long-term follow-up programs can address these needs by providing survivors with information regarding their long-term health risks. Because the risk for many late effects increases over time and will likely be exacerbated by co-morbidities related to the aging process, the importance of providing ongoing LTFU care for this population is clear. This necessity prompted the Institute of Medicine (IOM) to release a report detailing steps for improving care and quality of life for survivors of childhood cancer[5] (see Appendix 2, which includes comments regarding the progress that has been made since the report's release, and a discussion of ongoing challenges in survivorship care). The IOM report recognizes the need for risk-based lifelong healthcare integrating the cancer survivorship experience with the survivor's overall healthcare needs.[10] Each survivor's plan for lifelong screening and prevention should incorporate risks based on previous cancer history, treatment, genetic predisposition, lifestyle behaviors, and co-existing medical conditions, with an emphasis on surveillance for late effects, health promotion, and education regarding risk reduction.

Resources are now becoming available to guide LTFU care for childhood cancer survivors. The Children's Oncology Group (COG) has developed *Long-term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*[11] (www.survivorshipguidelines.org). These risk-based, exposure-related guidelines provide recommendations to direct follow-up care in this unique population. Patient education materials to complement these guidelines, known as "Health Links," have also been developed by COG in order to enhance LTFU care and health promotion for childhood cancer survivors.

It is essential that survivors receive appropriate education and screening so that late effects can be recognized at their earliest, most treatable stage. LTFU programs, whether large or small, can be instrumental in providing these much-needed follow-up services to childhood cancer survivors.

Resources for Long-Term Follow-Up Programs

Textbooks:

- Schwartz CL, Hobbie WL, Constine LS, Ruccione KS (Editors): *Survivors of Childhood and Adolescent Cancer: A Multidisciplinary Approach.* Heidelberg: Springer, 2005.
- Wallace WHB, Green DM (Editors): *Late Effects of Childhood Cancer*. London: Arnold, 2004.

Institute of Medicine Report:

- Hewitt ME, Weiner SL, Simone JV (Editors): *Childhood Cancer Survivorship: Improving Care and Quality of Life.* Washington, DC: The National Academies Press, 2003.

Clinical Guidelines:

- Children's Oncology Group *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*. Children's Oncology Group. Version 2.0, 2006. Available: www.survivorshipguidelines.org.

Patient Education Materials:

- Keene N, Hobbie W, Ruccione K: *Childhood Cancer Survivors: A Practical Guide to Your Future (2nd Edition)*. Sebastopol, CA, O'Reilly Media, Inc., 2007. (Currently available free of charge to "needy" patients at the following web address: www.candlelighters.org/Book_Order_Form.pdf)
- Children's Oncology Group *Health Links*, 2006. Available: www.survivorshipguidelines.org

> ***"A young woman cured of Acute Lymphoblastic Leukemia was having academic difficulties at the college level. Her father recognized that her scholastic challenges were related to her therapy, which had included cranial irradiation. This gentleman led the way to educate key medical personnel and the leadership of our parent organization about late effects of childhood cancer treatment and the importance of an organized program for follow-up and intervention…..It was our parent organization, 'Parents Against Cancer' which was instrumental in generating the funds needed to create our program."***
>
> **- Jerry Z. Finklestein, MD**
> **Pediatric Hematologist/Oncologist**
> **Miller Children's Hospital, Long Beach, CA**

MODELS OF LONG-TERM FOLLOW-UP CARE

Caring for the rapidly growing population of childhood cancer survivors requires both flexibility and creativity. Survivors represent a heterogeneous population with a wide range of diagnoses and treatment exposures, and the intensity of necessary follow-up varies from patient to patient. Survivorship care also requires a variety of approaches to meet the changing needs of survivors as they move through the lifespan, from childhood to adolescence and then into adulthood.

Determining the Model of Care

There are a variety of models for delivering care to survivors, all of which have distinct advantages and disadvantages[12]. The model best suited for your institution depends in large part on the population of survivors served and the resources available in your facility. It can also be argued that the best model may vary from patient to patient, with those with the most complex treatment histories and at-risk treatment exposures requiring a more specialized level of care. Many survivors are thriving; their cancer treatment may have had little long-term impact on their current health status and specialized LTFU care in an oncology setting or specialized late effects clinic may not be a high priority in their lives. For other survivors with chronic health conditions or increased potential for treatment related sequelae, ongoing care is an integral part of their survivorship experience. Regardless of where the survivors from your institution fall on this continuum, all survivors require education about their health risks and ongoing screening for potential late effects that may occur as they age.

***No matter what model is chosen,
an educated survivor who is empowered
to be an active participant in their own
life-long care is the cornerstone of all
successful survivorship care.***

Choosing a Model: Considerations

- How many survivors will be cared for in your institution’s program?
- How large is the geographic catchment area that your institution serves?
- Is it convenient for patients to continue to return to your institution?
- How diverse is your survivor population (types of cancer diagnoses and treatment exposures)?
- Will the majority of patients seen by your institution have had minimal treatment exposures, or will you have more complex patients with exposures that place them at greater risk for the development of late effects?
- What resources (physical, personnel, financial) are available to your institution?

Finding a model for delivering LTFU care that works best for both your facility and your patient population requires careful consideration, with a focus on maximizing available resources to address the core goals of survivorship care in any setting. Practitioners have developed a variety of methods to address the healthcare needs of childhood cancer survivors. The key differences in these approaches lie in the physical location for care delivery and the type of healthcare practitioner who provides care, recognizing that the pediatric cancer center is not the only place suitable for LTFU. With the proper infrastructure for transition and education for healthcare providers, survivors can receive LTFU care throughout their lifespan, provided by a wide range of practitioners including oncologists, nurse practitioners, internists, and family practice physicians.

Cancer Center Models

Primary Oncology Care:

In this model, patients continue to see their treating oncologist in the oncology clinic. Although this model is often the most comfortable for the patient who has developed a relationship and a level of trust with the treating physician, the focus may remain on disease surveillance rather than the potential for late effects and associated opportunities for health promotion.

***Specialized LTFU Clinic*:**

This is probably the most common model for long-term follow-up, and the number of formal LTFU programs in COG is increasing each year. Examples include: Survivors of Childhood Cancer Clinic at UCSF Children's Hospital, the Perini Clinic at Dana Farber Cancer Institute, the After Completion of Therapy (ACT) Clinic at St. Jude Children's Research Hospital, the Survivorship Clinic at City of Hope, the Long-Term Follow-Up Program at Memorial Sloan Kettering Cancer Center, and the Cancer Survivorship Program at The Children's Hospital of Philadelphia.

The specialized LTFU program model involves transitioning the patient from the primary oncologist to a specialized LTFU team within the same cancer center, typically when the patient has been off active therapy for at least two years. The team provides expertise in the long-term effects of therapy and has a health promotion/wellness focus. This type of clinic is designed to examine and evaluate the patient as well as to provide risk-based screening recommendations and education about potential late effects. Periodic (often yearly) evaluations continue in this clinic for varying amounts of time. In some programs, the team provides support for transitioning the patient to adult-focused care; other programs follow patients for life. The patient is encouraged to establish an ongoing relationship with a community healthcare provider for routine healthcare needs.

***Shared Care*:**

In this model, a clinician specializing in LTFU is "embedded" within a specialized program (e.g., leukemia/ lymphoma, solid tumor) within the cancer center and directs the LTFU care for these patients. An example of this model is the LIFE Program (Long-Term Information, Follow-Up and Evaluation Program) at Childrens Hospital Los Angeles.

Young Adult Transition Models

Formalized Transition Programs:

Many pediatric institutions have upper age limits for care, recognizing that older survivors may not be able to receive appropriate care in a pediatric setting and that their needs may be better served in an adult-focused healthcare environment. Some pediatric academic institutions have successfully developed formal programs for young adult survivors in partnership with neighboring adult institutions. Examples include the ACE (After the Cancer Experience) Program for Young Adult Survivors (a partnership between Dallas Children's Medical Center and the University of Texas Southwestern), Living Well After Cancer (LWAC) Program at the Hospital of the University of Pennsylvania (a partnership between The Children's Hospital of Philadelphia and the University of Pennsylvania) and the STAR Program (Survivors Taking Action and Responsibility), a partnership between Children's Memorial Hospital and Northwestern University in Chicago. These clinics may be staffed by pediatric and/or adult oncology practitioners or with family practice or internal medicine physicians or nurse practitioners whose focus and expertise are the care of the pediatric oncology survivor. Patients are seen solely by these practitioners, and multidisciplinary referrals to other subspecialties are made on an as-needed basis, often to an established network of adult providers with knowledge of the specific needs and risks of this patient population.

Adult Oncology-Directed Care:

Another option for transitioning young adult patients is to refer them to an adult oncologist for LTFU. However, once minimal risk for disease recurrence has been identified, care is frequently transitioned to a primary care provider in the community.

Community-Based Models

Community-Based Care:

Armed with the appropriate knowledge of late effects related to childhood cancer treatment, pediatric and adult primary care practitioners can successfully provide LTFU care to survivors. In this model, the pediatrician, family practice physician, advanced practice nurse, or internist in the community provides LTFU care. Ideally, the community provider maintains close contact with the pediatric oncology team that provides, on a consultative basis, explanations regarding the patient's risk factors and updates regarding changes in screening recommendations. This model can be useful for both pediatric patients and for transitioning young adult survivors to community-based care. One example is the ACT Clinic at St. Jude Children's Research Hospital, which has been successful in helping survivors make the transition to community healthcare providers when the survivor reaches 10 years off therapy and is at least 18 years of age.

Need-Based Models

In the United Kingdom, models based on intensity of treatment are being explored to guide decisions about type and frequency of long-term follow-up for pediatric cancer survivors. Three levels of follow-up care have been proposed by Eiser et al.[13] and include: (1) “Level 1” follow-up by mail or telephone every 1 to 2 years for patients who had only surgical treatment or “low-risk” chemotherapy, such as Stage I or II Wilms tumor or germ cell tumors treated with surgery alone; (2) “Level 2” follow-up by nurse or primary care provider every 1 to 2 years for patients who received chemotherapy alone or chemotherapy with low-dose (<24 Gy) cranial irradiation, such as those with A.L.L. in first remission; and (3) “Level 3” follow-up in a medically supervised late effects clinic annually for patients who received any radiation (with the exception of low-dose cranial irradiation), and for patients who received “megatherapy,” such as patients with stage IV tumors, brain tumors, or those who underwent bone marrow transplant.

Several models for providing care to childhood cancer survivors are summarized in Table 1, which includes advantages and disadvantages of each model.

> ***“At our institution, we started to get phone calls from our long term survivors who were no longer seeing their primary oncologist. Through websites and conversations with other survivors, patients and parents had heard about special programs just for survivors, and wondered if this sort of program existed at our hospital. Initially, we were referring patients to other facilities or to practitioners in the community. But then our Division started to wonder if we could and should be doing better.***
>
> ***Was this a missed opportunity and, more importantly, was there a way that we could improve the care we were offering to our long-term survivors? These kinds of questions led us to pull together a think tank of oncologists, nurse practitioners and administrators . . .we started to answer the questions: Who are our survivors? Where are they now? What do they need? We aren’t the biggest facility in the area, but our pool of survivors was larger than we expected. We considered a partnership with another local children’s hospital and with a family practice physician with interest in long term survivors. Before we knew it, we were taking the first steps to developing our monthly long term follow-up clinic, and laying the groundwork for a transition program for our young adults.”***
>
> ***- University Hospital Program Administrator***

Table I: Models of Care: Advantages and Disadvantages of Various Types

MODEL	ADVANTAGES	DISADVANTAGES
CANCER CENTER: Primary Oncology Care LTFU occurs as continuation of on-therapy experience with treating oncologist in pediatric oncology clinic	▪ Comfortable for patients and family who have developed relationship with treating oncologist ▪ Continuity of care ▪ Oncologists don't feel they have to "give up" their patients to another provider	▪ Provider attention may be distracted by acuity of on-therapy patients ▪ Illness (not wellness) focus ▪ Potential lack of provider interest in or knowledge of late effects ▪ Relapse-focused follow-up rather than risk-adapted screening and health promotion focus ▪ Research may be difficult to coordinate
CANCER CENTER: Specialized LTFU Clinic LTFU handled by a designated late effects team in a separate clinic within or outside of the pediatric oncology clinic setting	▪ Providers with expertise in late effects ▪ Emphasis on improving survivor knowledge of cancer treatment and risk ▪ Comprehensive risk-based screening and follow-up care ▪ Continued connection with cancer center provides "comfort zone" for survivor ▪ Focus on modifiable risk factors ▪ Health education ▪ Opportunity to train healthcare professionals ▪ Access to established network of sub-specialists with commitment to survivor care ▪ Structure for research	▪ Cancer center may have negative connotations for survivors who want to "move on" ▪ Survivors may not feel comfortable in pediatric setting as they get older ▪ May not be geographically convenient ▪ May discourage survivor use of primary care ▪ Protects patient from having to negotiate their own healthcare in the community ▪ Requires multiple hospital resources ▪ Lack of familiarity and expertise of pediatric team with adult issues that arise as survivor enters adulthood
CANCER CENTER: Shared Care Care provided within a specialized cancer center program (e.g., Neuro-oncology; Leukemia/Lymphoma); LTFU clinician directs LTFU aspects of care	▪ Patient benefits from combined expertise of primary treatment team and late effects specialist ▪ Structure promotes opportunities for research and training of healthcare professionals ▪ Continued connection with treatment team and clinic setting provides "comfort zone" for survivor ▪ Allows for continuity of care and ease of communications between oncologist and LTFU clinician ▪ Provides smooth transition	▪ May discourage use of primary care provider (PCP) ▪ Requires substantial hospital resources and dedicated clinicians as survivor population grows ▪ Protects patient from having to negotiate their own healthcare
YOUNG ADULT TRANSITION: Formalized Transition Program Follow-up in a specialized clinic staffed by adult oncologist/nurse practitioner or family practice physicians/nurse practitioners with expertise in late effects of therapy; often in a partnership between treating pediatric institution and adult-focused academic setting	▪ Pediatric providers facilitate smooth transition to adult program ▪ Collaborative approach to care ▪ Established relationship with pediatric provider makes transition more comfortable for survivor ▪ Multidisciplinary approach with access to adult-focused specialists as needed ▪ Rich environment for ongoing research with young adults survivors as they age; ability to access ongoing studies at treating institution	▪ Not designed to provide primary care services ▪ May not always be geographically convenient for survivors as they age and become more independent/transient

Table I: Models of Care (continued)

MODEL	ADVANTAGES	DISADVANTAGES
YOUNG ADULT TRANSITION: Adult Oncology-Directed Care Adult oncologist in the cancer center or community provides LTFU care	▪ Specialized oncology-focused care ▪ May be more convenient for patient (if in local community)	▪ Provider attention may be distracted by acuity of on-therapy patients ▪ Illness (not wellness) focus ▪ Potential lack of provider interest in or knowledge of late effects ▪ Relapse-focused follow-up rather than risk-adapted screening and health promotion focus ▪ Research may be difficult to coordinate
COMMUNITY-BASED CARE: The pediatrician, family practice physician, advanced practice nurse, or internist within the community handles LTFU	▪ Promotes independence and reintegrates survivor into primary care ▪ Wellness focus ▪ Convenience for survivor	▪ Limited provider knowledge and training regarding late effects and risk-based screening (particularly relevant for survivors with more significant exposures) ▪ Provider may lack time to devote to complex physical and psychosocial needs of survivors ▪ Lack of sub-specialist resources with survivorship expertise ▪ Requires survivor to know risks and advocate for their own needs ▪ Difficult to coordinate research ▪ Difficult to update survivors regarding new information as it becomes available
COMBINED APPROACH: (Consultative Model) Initial follow-up in cancer center-based program with transition to community-based PCP; ongoing interaction with cancer center as needed or at request of PCP	▪ Allows for partnership between oncologist and primary care provider ▪ Cancer center is always available as a resource ▪ Access to cancer center network of specialists ▪ Enhances local provider knowledge of late effects ▪ Encourages PCP utilization of published screening guidelines for survivors	▪ PCP not an expert on childhood cancer late effects or issues ▪ Difficult to keep PCPs up-to-date on new information as it becomes available ▪ Initial transition may be difficult for survivor ▪ May not be well-suited for survivors with more complex follow-up requirements ▪ Potential loss of patient for research initiatives
NEED-BASED CARE: Type and intensity (“level”) of follow-up care determined by intensity of cancer treatment that survivor received	▪ Allows for more equitable distribution of healthcare resources (survivors with greatest need receive most intensive follow-up care) ▪ May be more convenient for lower-risk survivors (follow-up for most survivors is by mail, phone, or with PCP in local community) ▪ Encourages involvement of primary care providers in long-term follow-up ▪ Promotes continued contact with patients, potentially enhancing research efforts	▪ PCP not an expert on childhood cancer late effects or issues ▪ Difficult to keep PCPs up-to-date on new information as it becomes available ▪ Survivors triaged to lower levels of care do not receive care from late effects expertise

Based on data from references [12, 13,] and [14]

TRANSITION ISSUES

To optimize the health and quality of life of childhood cancer survivors, it is important to develop a systematic plan of care that continues beyond the childhood years. To achieve ongoing care, two phases of transition are key (see Table 2).

Phase I: Transition to LTFU

Following completion of cancer treatment, patients enter an initial phase of follow-up care, which focuses on surveillance for disease recurrence. Following completion of this initial phase of follow-up, patients should transition from disease-focused care to survivorship-focused care, where the emphasis is now placed on risk-based screening and health promotion.

When and where the transition to survivorship-focused care takes place, which patients are followed, and what services are offered in the LTFU program varies from one institution to the next. There is no one ideal model. Factors that may affect the planning for and implementation of survivorship care programs include institutional commitment, finances, and resources.[15] In general, most centers provide follow-up care to all survivors, but some may also have specialized programs for specific patient groups, such as brain tumor survivors. Common services provided include physical exams, risk-based late effects screening, education and counseling regarding late effects and health promotion, and referrals to specialists and community resources. The setting in which LTFU care takes place may also vary, but common settings include children's hospitals, cancer centers, or academic medical centers.

Phase II: Transition to Adult Healthcare

An additional transition occurs when the survivor moves from pediatric LTFU care to adult-oriented healthcare. This transition phase is a necessary component of most (but not all) LTFU programs. Whether or not this phase of transition needs to occur depends largely on the type and scope of the facility providing follow-up care. Transition to adult healthcare occurs at a developmentally important time, as the survivor moves from a pediatric setting where responsibility for care lies with the parent, to an adult setting in which the survivor assumes primary responsibility for their own care. This type of transition can be particularly challenging, because it generally requires locating, educating and communicating with appropriate healthcare providers in an adult-focused facility or in the community, and some of these providers may have little knowledge or expertise in the care of childhood cancer survivors. Ideally, this phase of transition should incorporate some overlap between the pediatric and adult provider in order to allow for a smooth transition of care, and to allow for the parent and young adult to become comfortable with the new healthcare provider. Addressing the transition process well in advance of its occurrence is essential in order to equip the survivor and family with knowledge and skills that will allow them to advocate for their own healthcare by the time of this transition. Additional information regarding the transition to adult healthcare is included in Sections 2 and 5.

Table 2: Key Aspects of Transitions in Survivorship Care

TRANSITION FROM ACUTE CARE TO LTFU	TRANSITION FROM PEDIATRIC TO ADULT CARE
▪ Transition time points may vary between institutions ▪ Emphasis on risk-based screening and health promotion ▪ May caused mixed emotions (e.g., excitement versus anxiety) about leaving trusted staff who were involved in treatment and visiting the clinic less frequently	▪ Occurs as adolescents and young adults "age out" of pediatric healthcare system ▪ Preparation of survivor and family assists in successful transition ▪ May cause mixed emotions while transitioning from familiar to unfamiliar setting

CHALLENGES/BARRIERS TO DELIVERING SURVIVORSHIP CARE

There are numerous barriers that can make survivorship care a challenge, including knowledge deficits among survivors[9] and healthcare professionals[16], psychosocial issues[17], and the complexities of the healthcare system[18, 19]. Common barriers are highlighted below:

Knowledge Deficits - Survivors

- Many asymptomatic survivors do not realize the importance of ongoing cancer-related follow-up care
- Survivors who are unaware of actual or potential late effects are unlikely to seek appropriate cancer-related healthcare or advocate for their personal healthcare needs

Interventions for Knowledge Deficits

- Communicate a plan for follow-up care to the patient/family early (while the patient is still receiving therapy)
- Inform survivors regarding their cancer diagnosis, treatment history, and risk of developing late effects
- Present information at an age- or developmentally-appropriate level
- Provide ongoing education as the survivor matures and assumes more independence
- Keep survivors up-to-date regarding available resources, such as the *COG Long-Term Follow-Up Guidelines, COG Health Links*, and *Childhood Cancer Survivors: A Practical Guide to Your Future* (N. Keene, W. Hobbie & K. Ruccione Eds, O'Reilly Media, 2007)

Knowledge Deficits - Professionals

- Primary care providers (PCPs) may be unfamiliar with the ongoing healthcare needs of childhood cancer survivors, including cancer-related health risks, screening guidelines, and risk-reduction methods
- PCPs may lack experience and expertise in managing childhood cancer survivors with complex healthcare needs
- There may be limited local resources to assist the PCP in providing follow-up care for childhood cancer survivors
- There may be deficits in communication between pediatric cancer centers and primary healthcare providers regarding follow-up care and late effects issues.

Interventions for Knowledge Deficits

- Develop regional educational programs for healthcare professionals to increase awareness of survivorship issues
- Advocate for development of survivorship programs
- Provide funding incentives to assist with establishment of specialty programs
- Establish programs to train healthcare professionals and promote expertise in survivorship care
- Use technology (e.g., the Internet) to distribute survivorship resources and information to healthcare professionals in readily-accessible and user-friendly formats

Psychological Factors Affecting Care

- Fear or anxiety of another cancer diagnosis, or of being diagnosed with a serious late effect of cancer treatment
- Desire to leave cancer diagnosis in the past
- Avoidance of follow-up care due to unresolved feelings related to cancer diagnosis and treatment during childhood

Interventions for Psychological Factors

- Introduce the concept of long-term follow-up to the patient/family before treatment is completed
- Allow sufficient time for the survivor to become familiar with the process of

LTFU and to anticipate planned transitions in care

- Encourage survivors to be proactive in their healthcare and to adopt healthy lifestyle behaviors in order to minimize additional risk factors

Healthcare System Issues

- Lack of standardization in delivering cancer-related healthcare to childhood cancer survivors
- Pediatric health systems are often family-oriented, while adult healthcare is directed at the individual and requires independence and self-advocacy skills in order to attain required care successfully
- Survivors may have limited knowledge or experience in navigating the complex healthcare delivery system
- Some survivors may lack the cognitive ability and skills to deal with the complexities of the adult healthcare system
- Distance to a specialized follow-up center may be prohibitive
- The transition from childhood to young adulthood accentuates common barriers to healthcare (e.g., lack of knowledge, financial issues, etc.), making compliance with ongoing cancer-related healthcare particularly challenging.

Interventions for Healthcare System

- Explore the feasibility of satellite clinics to service remote areas
- Develop outreach programs to assist community providers in providing care
- Initiate the transition process early
- Provide patients/families with education regarding the transition process

Financial/Insurance Issues

- Survivors with multiple or complex late effects may be unemployed, and thus unable to obtain insurance coverage
- Young adults are more geographically mobile with respect to school and employment, which may result in difficulty obtaining health insurance
- A diagnosis of childhood cancer may be considered a pre-existing condition, thus it may be difficult for a survivor to acquire health insurance
- Survivors may “age-out” of private or public insurance coverage
- Survivors who have insurance may face restriction of coverage with regard to providers and/or screening tests
- Outright cost of healthcare is often prohibitive for uninsured survivors

Interventions for Financial/Insurance

- Provide survivors with information regarding government programs for adults with special needs and/or disabled adults
- Develop a directory of community resources and referrals for survivors
- Provide survivors with access to personnel with expertise in financial and insurance issues

Overcoming Barriers/Challenges in LTFU

Late effects programs are in a unique position to minimize some of the barriers for childhood cancer survivors in obtaining appropriate healthcare, both by providing this healthcare and serving as a resource for survivors and the healthcare community. Education of the survivor and the healthcare community about the importance of LTFU care is also a critical responsibility of late effects programs. In addition to providing essential education, late effects programs can provide information about community resources and assist survivors in overcoming barriers related to financial/ insurance issues and psychological factors, and they can promote self-care and independence in the young adult population. Ideally, childhood cancer survivors and their families will receive education regarding the need for long-term follow-up care throughout the continuum of care. Once survivors formally enter into a LTFU program, education is an integral component of the process. Gradually, the educational focus regarding potential late effects and the importance of continued follow-up should transition from the parent to the maturing child, in preparation for the survivor's entry into the adult healthcare system. As young adults, survivors should see themselves as their own advocates in obtaining necessary services in order to continue their LTFU care. Barriers to risk-based healthcare and methods to help facilitate the transition process are summarized in Table 3.

Table 3: Barriers to Risk-Based Healthcare in Childhood Cancer Survivors

FIRST TRANSITION PERIOD: FROM ACUTE CANCER CARE TO LONG-TERM FOLLOW-UP (LTFU) PROGRAM	SECOND TRANSITION PERIOD: FROM LTFU PROGRAM TO YOUNG ADULT CARE
BARRIERS: ▪ Lack of adequate number of LTFU programs ▪ Fear of continued care ▪ Financial or distance constraints ▪ Lack of understanding of the need for continued surveillance	**BARRIERS:** ▪ **Survivor-specific barriers:** – Lack of understanding or knowledge of risks – Fear of transitioning ▪ **Healthcare professional-specific barriers:** – Few programs for young adult survivors – Community healthcare physicians unfamiliar with the risks and problems of the population – Lack of communication between cancer center and community physicians ▪ **Medical system-specific barriers:** – Difficulty finding affordable insurance, especially for survivors in rural settings or self-employed survivors – Limitations on medical insurance coverage of some screening tests in young adults – Restrictions of managed care organizations
METHODS TO FACILITATE TRANSITION: ▪ Clearly explain the purpose of risk-based care ▪ Discuss long-term plans for follow-up through the survivor continuum ▪ Address emotional issues of survivorship ▪ Provide a summary of the cancer diagnosis and treatment ▪ Educate regarding risks and methods to reduce risk ▪ Foster self-care practices ▪ Promote positive decision-making skills for healthy lifestyles	**METHODS TO FACILITATE TRANSITION:** ▪ **Survivor in a LTFU program:** – Develop a policy for the process of transition – Identify qualified and committed healthcare providers – Involve the survivor and the family in the process – Assess the expectations and healthcare beliefs of the survivor and the family – Emphasize the goals of risk-based healthcare – Highlight the importance of the survivor/family as the key providers of healthcare information – Focus on the survivor as self-advocate – Stress the ongoing communication between the LTFU team and new providers – Discuss the transfer of medical records and the oncology medical summary ▪ **Survivors in general (and not in a LTFU program):** – LTFU community as activists for survivorship – Raise public awareness – Educate insurance companies and managed care organizations – Communicate with state and federal legislators

From: Oeffinger KC and Eshelman DA “Transition Issues” in Schwartz CL, Hobbie WL, Constine LS, Ruccione KS (eds.), *Survivors of Childhood and Adolescent Cancer: A Multidisciplinary Approach*, Heidelberg: Springer, 2005. Used with kind permission of Springer Science and Business Media.

SECTION 2:
PROGRAM DEVELOPMENT

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INITIAL CONSIDERATIONS

There are multiple factors to consider when developing or evaluating a LTFU program for survivors of childhood cancer. These include (1) determining program goals, (2) assessing institutional needs, (3) assessing patient needs, and (4) patient identification and recruitment.

Determining Program Goals

Planning for a LTFU program begins with a clear delineation of goals. These may vary based on institutional, community and patient needs, and may include:

- Clinical care
- Psychosocial support
- Education (e.g., patient/family, healthcare professional)
- Research

Assessing Institutional Needs

The specific needs and resources of an institution are closely linked with program goals. Consider how the LTFU program will help fulfill your institutional needs:

- Will a LTFU program strengthen and/or extend the range of services already offered?
- Will the LTFU program serve to extend your institution's referral base?
- Will the program exist to provide clinical care, or will there be another concurrent goal or emphasis (e.g., research, education)?
- Is there a plan to incorporate an educational component into the program, such as seminars for healthcare providers or workshops for patients and families?
- Will subspecialty care be available (in the clinic, on a referral basis)?
- Will this program fill an unmet need in the communities that your institution serves?

Assessing Resources

- What resources are available to establish and maintain the program?
  - What personnel are available to support LTFU patients?
  - What clinic space is available for use? When is it available?
  - What are the possible funding sources?
- Does your institution have the resources (e.g., administrative personnel, space, money, devoted staff) to support a formal clinic or are your patients better served in a community network?

> ***"To facilitate the transition from pediatric oncology to community providers, our clinic has focused its efforts on educational interventions to empower the survivor with the resources to advocate for appropriate community health care. The broad mission of the ACT Clinic is to improve the quality of life of the long-term childhood cancer survivor . . . .***
>
> ***Patients who are in remission 5 years after diagnosis and at least 2 years following completion of antineoplastic therapy are eligible for transfer to the ACT Clinic. . . . Survivors are evaluated annually by the clinic staff until they are 10 years' post-diagnosis. . . or at least 18 years of age, whichever comes last. After alumni survivors are discharged to the care of community physicians, the St. Jude Cancer Registry continues to perform annual follow-up for the lifetime of the patient."***
>
> ***- Hudson et al. 2004[20]***

Identifying, Recruiting & Retaining Patients

Establishing a plan for patient identification and recruitment is an integral part of the program development process. Consider the following issues:

- What are the eligibility criteria?
- What are the referral source(s)?
- How will eligible patients be identified and approached?
- Will services be limited to patients treated at your institution – or will patients from outside institutions be eligible to participate?
- What process will be used for patient recruitment?
- Is there a clinical database in place to maintain the following information:
    - Current address and phone number
    - Updated insurance information
    - Contact information for next-of-kin
- How will patients be tracked and notified of return appointments in a timely manner?

Assessing Patient Needs

In addition to the needs and resources of each institution, one should consider the needs of the patients and families participating in a LTFU program.

- Where will services be provided?
- Who will be providing the services?
- Will providers be familiar with the needs of this patient population?
- What types of payment will be accepted?
- Will there be opportunities for patients to participate in clinical research?
- What role will the survivors themselves have in planning for and evaluating LTFU services?

> ***“Our clinic realized that many of our patients lived over an hour away and could not easily travel (which included taking time off of work and/or school) for an appointment now that their cancer was in remission. We recognized that they still needed specialized follow-up care after treatment for cancer. So, we decided to bring the clinic to them. Once per month we hold an out-reach clinic for survivors. We come to them (MD, the PNP or RN, and the social worker) and ensure that they obtain the services they need.”***
>
> ***- Genevieve Sylvain, RN, Coordinator LTFU Program***
> ***The Children’s Hospital, Denver, CO***

DETERMINING PROGRAM PARAMETERS

Once you have considered the initial issues in program development, it is important to determine specific parameters for your LTFU program. To do so, weigh the options listed below:

Initiation of Long-Term Follow-Up Care

- Decide when transition to the LTFU program will occur. Possibilities include:
  - At a set time interval (e.g., one or two years) following completion of active treatment
  - At a set time interval (e.g., five years) following diagnosis
  - Differing criteria based on diagnosis or mode of treatment (e.g., transplant patients may enter the program at different times than patients treated with conventional therapy; children who have survived a brain tumor may not be ready for LTFU until they have been off therapy longer than other patients)
- Most criteria require that the patient be in remission and fully recovered from the acute effects of therapy

Transition from Acute Care to LTFU

Transition from acute care to LTFU is a process rather than an event. In advance, the LTFU team and other staff within the department should discuss how and when transition to LTFU will occur (see also: Section 1). The following are suggestions to ease the transition process.

- **Plan ahead**: Planning for entry into the LTFU program should be taken into consideration before the patient is formally ready to enter the program. The concept should be introduced early on so that LTFU becomes a logical continuation of care.
- **Inform the patient and family** regarding how the LTFU program differs from regular oncology follow-up (e.g., emphasis on health education and monitoring for late effects of cancer therapy)
- **Identify barriers** to transition, such as:
  - Primary oncologist not wanting to give up care
  - Patient/parents not wanting to transition
  - Scheduled clinic time inconvenient for family
  - Financial/insurance status (e.g., may be unable to pay for follow-up visits and/or tests not covered by insurance)
- **Have a familiar staff member in clinic**, if possible, during the patient's first visit, if the LTFU staff is not known to patient/ family

Age Range/Age Limits

Determine the upper and lower age limits for the LTFU program. Considerations include:

- Is the upper age limit determined by an institutional policy? (e.g., patients older than 18 or 21 years of age may not be accepted at some pediatric institutions)
- If there is no upper age limit at your institution, a decision must be made regarding whether the LTFU program will continue to see patients throughout the lifespan, or whether patients will be transitioned at some point to the adult medical care system
- Some insurance companies may not approve charges for an adult to be seen in the pediatric setting despite the fact that the patient is a childhood cancer survivor
- Patient eligibility for LTFU research protocols (see Section 4)

> ***"We recently saw a 60 year old woman who was treated in the 1950's for Wilms tumor. She found us on our website and said she wanted us to see that children did survive back then. There was no chemo, but she had radiation. She has tremendous scoliosis. She said, 'I survived . . . now you can learn and I can learn.'"***
>
> ***- Brian Greffe, MD, H.O.P.E. Clinic Director***
> ***The Children's Hospital, Denver, CO***

General versus Specialized LTFU

Consider what type of general and/or specialty services will be provided by your LTFU program:

- Will the LTFU program best serve your survivor population with a general clinic for all survivors?
- Is there a need for specialized LTFU programs for specific populations?

  For example, all brain tumor survivors may attend a separate LTFU clinic that is staffed by a neuro-oncologist, neurologist, endocrinologist, pediatric neuro-oncology nurse, and social worker. Likewise, many bone marrow transplant programs provide specialized follow-up care that can track immune reconstitution, monitor chronic graft-versus-host disease, and provide neurocognitive testing.
- Are there resources to support both a general and specialized clinics?
- Will your research or educational programs have a specialized focus?
- How will you recruit and structure clinics requiring specialists from other fields?

Determining Frequency of Clinic Visits

The number of survivors who need to be seen, the frequency of their follow-up visits, the clinical resources available to provide service to patients, and the number of survivors that can be physically accommodated in a single clinic session will ultimately determine how frequently to schedule LTFU clinics.

- **Staffing:** Is there a physician and/or nurse practitioner who will be allocated solely to the LTFU program? If not, what is the availability of clinicians to see these patients? How often are they available?
- **General versus specialized long-term follow-up:** Will the program include a specialized clinic such as Neuro-Oncology or BMT? These specialty clinics are sometimes scheduled less frequently than general LTFU clinics, depending on how many patients need to be seen.
- **Exam room availability:** Where will the patients be seen? Do you have the space to see these patients within your oncology outpatient area? Are there alternate or off-site locations where the clinic may be held?
- **Follow-up:** Who will follow-up on the results of screening evaluations for each patient (e.g., yearly ECHOs, CBCs, etc.)? Is there an existing system with personnel to track and report these results? If results are abnormal, what will the process be to provide intervention and/or referral?
- **Risk-Based Stratification for Long-Term Follow-Up Care:** Some cancer survivors may need more frequent, intensive and detailed assessment and follow-up than others.[21] For example, those with stage I or II Wilms tumor or germ cell tumor requiring surgery alone may need only limited follow-up. On the other hand, ongoing intensive follow-up would be mandatory for a transplant

survivor, a patient with a stage IV tumor, or a patient who received radiation or "megatherapy."

Transition to Adult Healthcare System

Determine if/when transition from your LTFU program will occur. Possibilities include:

- When the patient reaches an age when he/she is no longer eligible to be seen at the pediatric institution
- When the patient has been seen a certain number of years in the LTFU clinic and is ready to transition to community-based care
- No transition (the patient continues to be seen in the LTFU clinic for life)

Resources for Assisting Patients with Healthcare Transitions

Patient Guides:

Closing the Umbrella: When Your Child's Treatment Ends, American Cancer Society: www.cancer.org

Facing Forward: Life After Cancer Treatment, National Cancer Institute: www.cancer.gov

Duffey-Lind E., Diller L, O'Halleran E. *Transition to Survivorship – What Parents Should Know.* Dana-Farber Cancer Institute, 2006 (available for purchase)

The Mountain You Have Climbed. National Children's Cancer Society. www.nationalchildrenscancersociety.org (click on "Publications")

Websites:

The Healthcare Transition Initiative at the University of Florida: http://hctransitions.ichp.ufl.edu

University of Illinois at Chicago Transition Information and Resources: http://internet.dscc.uic.edu/dsccroot/parents/transition.asp

Maternal and Child Health Library: http://www.mchlibrary.info/KnowledgePaths/kp_CSHCN.html#transition

BUILDING A MULTIDISCIPLINARY TEAM

Survivors have unique needs that are frequently medical, educational and psychosocial in nature. To promote the coordination and teamwork to ensure that these needs are met, and to promote health and prevent future illness, many LTFU programs have established multidisciplinary teams consisting of professionals from nursing, medicine, education, social work, psychology, and related fields. The core team often includes a nurse coordinator, pediatric oncologist, social worker, psychologist, and school liaison.

The keys to the formation and operation of a successful multidisciplinary team include:

- Committed members who have the support of their department/supervisor
- An initial meeting during which each member's role and previous experience in pediatric oncology are respectfully discussed
- A mission statement that clearly sets forth the purpose of the team, the scope of its activities, and its guiding principles. (This may be the LTFU program's mission statement with which all team members are in agreement.)
- Creation of a team protocol that specifies the roles and responsibilities of team members in all aspects of the program (e.g., clinical care, education, and/or research)
- Periodic internal program analysis and outside evaluation of how the team is functioning, so that it continues to achieve the purposes for which it was established

Building Specialty Teams

Surrounding the core survivorship team are a group of physicians and specialists familiar with evaluating problems in childhood cancer survivors. Such specialties typically include radiation oncology, cardiology, pulmonary, orthopedics, neurology, and endocrinology. A LTFU program may partner with certain specialty practitioners to answer research questions or to provide specialty clinical services, such as "cardiac clinics" for those who received high doses of anthracyclines and/or mantle radiation, or endocrine clinics for those with thyroid problems or growth and development concerns. Regardless of the model of care that is implemented, LTFU programs must be committed to a partnership with healthcare providers across a wide range of specialties to optimally meet the needs of childhood cancer survivors.[14]

Mission Statement: Example

"The mission of the Survivors of Childhood Cancer Program is to provide clinical care and education for survivors of childhood cancer and improve outcomes through research and discovery."

- Robert Goldsby, MD, Medical Director
UCSF Survivors of Childhood Cancer Program

PROGRAM FUNDING

All LTFU programs need funding. The resources you have or are able to obtain will directly affect your clinic and the services you have to offer. In this section you will find information about some of the different funding sources available and how to work with them.

Funding is often needed for:

- Salary support, to include personnel to provide:
  - Clinical care
  - Database development
  - Survivor education
- Community outreach
- Assisting uninsured patients
- Staff development
- Program marketing
- Survivorship research

Sources of Funding

The function and operation of funding sources varies greatly depending on the type of institution (e.g., free-standing children's hospital, private or corporately-owned hospital, large or small institution). Get to know your institution's guidelines for funding sources. Table 4 below provides examples of possible funding sources in various financial sectors.

> ***"We have been able to help uninsured survivors through an endowment, gifted by an adult cancer survivor who worked in our program. Her legacy was to specifically help uninsured survivors. It is important to build on an endowment that will generate interest and be self-sustaining. This will allow you to help survivors on an ongoing basis."***
>
> ***- Brian Greffe, MD, H.O.P.E. Clinic Director***
> ***The Children's Hospital, Denver, CO***

Table 4: Potential Sources of LTFU Funding

FUNDING SOURCE	EXAMPLES	URL
Federal, State, and Local Government	**National Institutes of Health (NIH)** **National Cancer Institute (NCI)** **Health Resources and Services Administration (HRSA)**	**www.grants.gov**
National, Local and Family Foundations	**Lance Armstrong Foundation** **Hope Street Kids** **Children's Cancer Fund** **Leukemia and Lymphoma Society**	**www.livestrong.org** **www.hopestreetkids.org** **www.childrenscancerfund.org** **www.leukemia-lymphoma.org**
Associations	**American Cancer Society** **American Academy of Pediatrics** **Candlelighters**	**www.cancer.org** **www.aap.org** **www.candlelighters.org**
Internal Sources	**Hospital Foundation** **Research Institute** **Philanthropy Department** **Endowments**	
Fundraising	**Swim Across America**	**www.swimacrossamerica.org**

> ***"No matter where your funding comes from, LET PEOPLE KNOW WHAT YOU ARE DOING! Develop a long-range plan for your program. Have measurable goals that are compatible with your institution's mission. Build a relationship with your hospital's Foundation and Public Relations Department. Initiate a simple meeting or presentation to educate people about your program. The more people know about your program, goals, and potential impact on survivors, the better off you will be."***
>
> ***- Katy Murphy, RN***
> ***Children's Hospital of Wisconsin***

Potential Sources of Funding Assistance

- ***Grant writers:*** These specialists are sometimes housed within the hospital, research center, or foundation.
- ***Hospital foundation staff:*** May be able to make connections with potential donors.
- ***Departmental staff*:** Nursing director, medical director, or administrator – again, make sure your plan is known!
- ***Survivors and their families*:** They can be the most articulate and convincing voice for a program. A survivor's story can validate a LTFU program with real life stories and a unique eloquence.

What Works?

- ***Know your funding source*:** What are their areas of interest, average gift size, typical organization funded? Some grants are specific regarding the types of salary support they will support, (e.g., MD/PhD, RN, Social Work, Psychiatry, Child Life Therapy, etc.)
- ***Subscribe to listservs*:** Join a listserv and receive e-mails regarding grant opportunities and guidelines; scope can be broad or narrow (See Table 5 for suggestions).
- ***Collaborate with community groups*:** Partner your medical expertise with the "social" expertise of grass-roots organizations, such as Gilda's Club. You can apply for the funding, or if better suited, your community partner can apply.
- ***Know your budget*:** Apply for appropriate grants that match your needs.
- ***Apply appropriately*:** Be aware of grants with state-specific requirements.
- ***Avoid competition*:** To avoid competing against your colleagues, make your application process known within your institution.
- ***Be specific*:** Be aware that there are grant opportunities for minority researchers and research focused on minority populations.
- ***State your needs*:** Have your program development plan ready. Know what you need – details should be concrete.

> ***"I speak to groups in the community whenever I can about survivorship. We have someone in the foundation who we work with, and whenever she asks me to speak, I talk about survivorship."***
>
> ***- Brian Greffe, MD, H.O.P.E. Clinic Director***
> ***The Children's Hospital, Denver, CO***

Table 5: Listservs

LISTSERV	URL
The Commonwealth Fund	www.cmwf.org
The Federal Register	www.gpoaccess.gov
Human Resources and Services Administration	www.hrsa.gov
The Robert Wood Johnson Foundation	www.rwjf.org

Third Party Payors

Potential sources of health insurance coverage for patients may include:

- Private insurance through employer
- Private health insurance purchased by the patient or through family coverage
- Government insurance programs such as Medicaid, Medicare, or State Children's Health Insurance Program (SCHIP)
- Continuation of health coverage (through COBRA coverage - the Consolidated Omnibus Budget Reconciliation Act)

Children and adolescents with cancer are often covered under state Medicaid programs, but coverage under these programs often ends when the patient reaches a certain age (the age varies by state, and is usually between age 18 and 21). Private insurance coverage under parental policies also generally ends when the patient reaches a certain age, depending on the policy. With some policies, coverage may continue while the child is a full-time student, but there is generally an upper age limit, which varies depending on the insurance plan and state of residence. Many young adults lack the insurance benefits traditionally associated with full-time employment, and others are unable to secure full coverage due to their previous cancer diagnosis. Thus, many adult survivors of childhood cancer may be uninsured or under-insured.

It is imperative to pre-screen patients scheduled to be seen in long-term follow-up to ensure adequate insurance coverage, because it is not uncommon for a patient to have changed insurance carriers, or to have lost insurance coverage altogether. A comprehensive follow-up visit that includes "routine" laboratory and other commonly-ordered studies (such as echocardiograms or pulmonary function tests) may be very expensive. Patients who are uninsured or under-insured may face years of payments for such services. Early efforts to confirm insurance coverage decrease potential problems related to delays or cancellation of services, financial burdens for the patient, and lack of reimbursement for the clinic.

Survivors who are uninsured, underinsured, or who are reluctant to keep LTFU appointments because of insurance concerns can be directed to the Medical Social Work Department or a Patient Financial Representative in the institution's billing department for assistance. Ultimately, each LTFU program must decide how the billing for uninsured and under-insured patients will be managed, based on their available resources, including institutional, governmental, and philanthropic sources.

PROGRAM MARKETING

Creating an effective marketing strategy starts with a dedicated LTFU team, including a medical director and program coordinator committed to sharing in the marketing responsibilities. In addition, partnerships with your institution's business development division and public relations department are invaluable because of their connections and ability to highlight your LTFU program.

Marketing Plan

Define Goals: The first step in a marketing plan is to define goals clearly. The medical director, program coordinator and other team members need to collaborate and determine the major objectives for the LTFU program. Suggestions regarding potential goals can be obtained through:

- Patient and family interviews
- Patient surveys
- Focus groups
- Suggestion box
- Survey of healthcare team members

Define Audience: Consider both internal and external marketing. Internal marketing to other medicine subspecialties within your institution (such as cardiology, endocrine, and psychiatry) - and to multidisciplinary groups (such as child life, social work, physical therapy, and nursing) – can be a powerful mechanism to recruit patients and advertise services. When targeting the external market, be aware of whether you would like your marketing approach to reach only survivors and families and/or others, such as pediatric providers in private practice, external specialty providers, and insurance companies.

Examine Current Competition: The next step in the marketing plan is to determine your target market, based on the local environment and knowledge of consumer use trends. Are there other LTFU programs in the area? If so, would your institution and survivors benefit from developing and marketing a specialty survivorship program rather than a general LTFU program?

Develop Marketing Tools: Finally, determine a plan for promoting your program in conjunction with the business development office. Potential marketing tools include:

- Brochures or handouts
- Website
- Newsletter
- Annual survivor events
- Educational sessions
- Fundraising events
- Posters
- Publicity via patient/parent support groups
- Internal news releases

In summary, the success of a LTFU program depends not only on the structure of the program and clinic – factors determined by assessing program goals, and institutional and patient needs – the program must also market and communicate the availability of its services in order to maximize utilization and ensure that survivors are able to access the LTFU services that they need.

SECTION 3:
DELIVERING LONG-TERM FOLLOW-UP CARE

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CLINIC OPERATIONS

While the number of survivors has grown, so has the need for special programs for childhood cancer survivors who experience late effects of treatment. A multidisciplinary team approach is ideal for the long-term follow-up of survivors who often have multiple health and psychosocial needs that require a comprehensive approach. The team works together to evaluate the patient and provide medical management, education, screening, and referrals to appropriate community resources.

Care Delivery Methods

The LTFU team generally follows the survivor on an annual basis and provides risk-based survivor care, which includes surveillance for late effects and targeted education and counseling focused on health maintenance and promotion. Patients attending the LTFU clinic undergo a complete physical exam and targeted studies to evaluate organ function and monitor for late effects; these studies are individualized based on the survivor's treatment history. A comprehensive LTFU program also provides psychosocial evaluation, guidance, and vocational assistance.

There are a variety of care delivery models that may be utilized in LTFU, all of which can be effective. In some programs, physicians may provide most of the care, including not only the traditional history and physical exam, but also the educational and anticipatory guidance components. In other programs, nurse practitioners provide similar services, and rely on the physician, who serves as the Medical Director, for consultation and guidance as needed.

Clinic Staff

Requirements for clinic staff will vary with each program, and you may find that as your program grows, you may need to increase or change members of your team. However, most programs will require at minimum the following staff members:

Medical Director: A physician who is responsible for the medical care provided by the program. The medical director may or may not be involved in the everyday operation of the clinic, but should provide oversight and be available for consultation as necessary based on patient needs.

Clinician: A healthcare professional who provides direct patient care in the clinic. The clinician may be a physician (who may also serve as the medical director), nurse practitioner (NP), or physician assistant (PA). The clinician obtains the history and performs the physical exam, orders specific screening evaluations and tests, and prescribes recommended follow-up. The clinician works closely with the medical director. Many LTFU programs are nurse-led, with the NP acting as the primary coordinator of the program. Nurse practitioners specializing in childhood cancer survivorship often have prior experience managing pediatric oncology patients during the acute treatment phase and therefore are knowledgeable regarding the entire illness continuum. The NP is capable of evaluation, management and follow-up of patients in a late effects program. In many settings, the NP sees patients autonomously and may also function as educator, researcher, and program manager in addition to serving as the program's clinician. The role of the nurse practitioner specializing in childhood cancer survivorship has been described by Hobbie.[22]

Nurse Coordinator: A nurse who is responsible for overall care delivery within the program. The role of the nurse coordinator may vary depending on the program's needs, but often includes responsibility for reviewing medical records, generating treatment summaries and screening recommendations, coordinating referrals after patients are seen by the clinicians, and providing extensive patient/family education. The nurse coordinator often provides test results to the family and/or patient, and maintains contact with primary care physician. In some programs, the clinician (e.g., nurse practitioner) also functions as the nurse coordinator.

Social Worker: The social worker is responsible for providing psychosocial assessment, education, and support to the patient and their family members, and refers patients to resources as needed based on individualized assessment.

Secretary/Receptionist: This team member is generally responsible for the clinic organization. Scheduling appointments, registration of patients, organizing charts and a variety of other daily activities are critical to clinic flow.

Additional Staff:

As the LTFU program develops and grows, additional staff members, who see patients on an "as needed" basis, may be added, such as:

Nutritionist: The nutritionist obtains a diet history, calculates body mass index and discusses nutritional issues.

Dentist: The dentist performs a basic oral examination, and provides information, guidance and referrals for care.

Physical Therapist: The physical therapist provides assessment of physical performance (or physical function) for patients in the program. The physical therapist may also provide specific physical activity recommendations for patients whose impairments and activity limitations prohibit their participation in usual physical activity and/or exercise.

Psychologist: A licensed mental health professional who provides psychological assessment and referral as indicated for patients in the program. The psychologist may perform or schedule standardized tests as dictated by follow-up in protocols.

Clinical Research Assistant (CRA): An individual with background and experience in clinical research who is responsible for data collection and coordinates research activities within the program.

Outreach Educational Coordinator: Staff member responsible for assisting with school issues; often makes school visits and helps schools implement or develop individualized education programs.

Neurologist, Neurosurgeon, and Neuro-oncologist: Specialists who may participate in or provide follow-up care for patients with cancers of the brain or spinal cord.

Bone Marrow Transplant Physicians: Specialists who may participate in or provide follow-up care for patients who have undergone a bone marrow (hematopoietic stem cell) transplant.

Pediatric Nurse Practitioners: Scope of Practice

Many pediatric oncology NPs are trained and certified as pediatric nurse practitioners (PNPs). Although the scope of practice for PNPs is generally limited to patients within the pediatric age range (birth to 21 years), the National Association of Pediatric Nurses Practitioners (NAPNAP) provides guidance regarding circumstances when the scope of PNP practice may extend beyond the pediatric age range, as follows:

> *"There are special situations in which it is appropriate for the PNP or other pediatric healthcare providers to care for an individual older than age 21 years until appropriate transition to adult healthcare is successful. There is a growing population of adolescents and young adults with special healthcare needs, chronic conditions, and disabilities who need transition care from pediatric to adult healthcare settings. These adolescents and young adults face unique challenges in accessing adult healthcare providers who can provide adequate primary and specialized healthcare services.*[23, 24]
>
> *Pediatric healthcare providers have an extensive knowledge base regarding developmental issues and a unique awareness of the concerns pertaining to adolescent and young adult healthcare provider transitions and are qualified to assist these patients during the transition phase.*[25] *Establishing exclusive upper age limits to PNPs' practice may create a significant barrier for PNPs and may limit access to healthcare for this population.*
>
> *In summary, the PNP is highly qualified to provide care to individuals from birth to age 21 years, and in special circumstances beyond age 21 years. NAPNAP firmly supports the scope of practice for PNPs to be inclusive of newborns, infants, children, adolescents, and young adults.* ***NAPNAP additionally supports the PNP's role as a provider of healthcare for individuals older than 21 years with unique needs and for young adults during the transition to adult healthcare.****"*

National Association of Pediatric Nurse Practitioners
Position Statement on Age Parameters for PNP Practice, 2002 [26]

Clinic Space

Ideally, the LTFU clinic should have a designated space away from the active ("on-therapy") pediatric oncology setting. If space is shared within the pediatric oncology clinic, every attempt should be made to schedule the LTFU clinic during the least busy clinic days and times. It is important to dedicate time, space and personnel to a new LTFU program. If the program is "squeezed in" within the normal clinic day, it is easy to become overwhelmed with the needs of patients currently receiving therapy at the expense of the LTFU patients.

A multi-disciplinary clinic requires more rooms than are typically needed for a traditional clinic setting. Because more than one caregiver will see each patient, each room will be occupied for a significantly longer time than during a traditional clinic visit. Room space can be allocated as follows:

- ***By personnel*.** Each member of the comprehensive team is assigned a room, and the patients move from room to room.
- ***By patients*.** The patient remains in one room, and the team members move from room to room.

To make a comprehensive clinic move smoothly, regardless of which room allocation system is used, the team needs to determine how much time each member requires with a typical patient and allocate room/schedules accordingly.

Schedules

The size of the LTFU program and frequency of clinics will vary depending on the type of care offered, as well as the population served.

- Frequency of clinics varies with program size, funding and needs.
- Many programs begin with monthly clinics and increase the frequency as necessary and as available resources allow.
- Yearly comprehensive visits take considerable time; most programs see 6-10 patients per scheduled clinic day.
- Many programs are set up to have the patient evaluated by all members of the multi-disciplinary team at the initial visit; therefore, additional time should be allotted to accommodate these multiple encounters.
- Subsequent visits generally require less time, because the patient may not need to be seen by all multidisciplinary members.
- Scheduling additional clinics during summer, spring and winter breaks will allow students to attend without missing school.
- Some centers follow specific populations with unique needs (e.g., brain tumor, bone tumor, or bone marrow transplant recipients) in dedicated clinics. Allotment of rooms and schedules will need to be tailored to the specific needs of these specialized teams.
- Some centers schedule patients with similar needs for visits on the same day, thereby utilizing multi-disciplinary staff most efficiently. For example, a clinic dedicated to bone tumor patients may have a physical therapist, orthotist/prosthetist, and orthopedist present. Another way to group patients is by treatment modality; for example, a radiation therapist may be on hand for clinics attended by patients who were treated with radiation.

> ***Every patient in our long-term follow-up clinic is seen by the Nurse Practitioner, Social Worker, Nutritionist and Physician. To allow a smooth schedule, we have learned that we allow a 2-hour time slot for each patient, and schedule four patients per each time slot. We use four rooms and each of the team members rotates through all four patients, spending about 20 to 25 minutes with each patient. We can then chart/dictate/discuss all four patients before the second group arrives.***
>
> ***- Marcia Leonard, RN, PNP***
> ***Coordinator, LTFU Clinic, University of Michigan***

Clinical Databases

Establishing a clinical database is critical for tracking patients and providing continuity of care. Each new patient seen in the LTFU clinic should be added to the clinical database. Some centers may have access to a web-based, hospital-wide database. If you are developing your own database, computer software programs, such as Excel® or Access® are generally straightforward and easy to use. Institutional CRAs or others with expertise in clinical research or data management may be able to provide guidance regarding development of a clinical database for the LTFU program. Other centers may continue to utilize an index card file system successfully. As patient numbers increase, some method of tracking appointments and follow-up should be in place.

Forms and Supplies

Most programs develop and stock specialized LTFU forms and supplies to facilitate patient visits and to capture and manage the large amount of data collected during comprehensive annual visits. The following forms and supplies are suggested. Sample forms are available in Appendix 3.

FORMS

- **Initial visit form** - to include patient demographics, relevant medical and social history, and comprehensive data capture
- **Subsequent visit form** - to include interval history and brief data update
- **Caregiver report form** (if applicable)
- **Growth chart** (should be updated regularly until full growth is achieved)
- **Patient education tracking form**

SUPPLIES

Staff Resources:

- Copies of COG *Long-Term Follow-Up Guidelines* (or computer and printer to allow access to use as needed)
- Lists of local/state subspecialists and referral guidelines
- Dental eruption chart
- Tanner staging chart
- Immunization guidelines
- Reference books (see Section 1)

Patient Education Materials:

- Treatment summary/recommendations for follow-up
- Copies of the COG Health Links (or computer and printer to access as needed)
- Breast self-exam teaching model and video
- Sun safety and skin cancer teaching materials
- Tobacco education/cessation program teaching materials
- Nutrition/calcium/exercise handouts
- Information about sexuality/safer sex practices
- Information about camps, support groups, and scholarships for childhood cancer survivors
- A handout regarding how to order: *Childhood Cancer Survivors: A Practical Guide to Your Future (2nd Edition)* by Nancy Keene, Wendy Hobbie and Kathy Ruccione, Sebastopol, CA: O'Reilly Media, Inc., 2007. This book is currently available free of charge to "needy" patients at the following web address: www.candlelighters.org/Book_Order_Form.pdf

PREPARING FOR THE CLINIC VISIT

Preparation for the clinic visit should begin well before the scheduled date. Essential elements include reviewing and extracting data from the medical record and preparation of a comprehensive treatment summary. Exposure-based screening recommendations and a comprehensive medical summary are compiled and shared with the multidisciplinary team.

Medical Record Review

Ideally, a comprehensive treatment summary should be prepared as patients complete the acute phase of their treatment. Unfortunately, in most institutions, this is not usually done. Therefore, a comprehensive treatment summary must be compiled prior to the initial visit in the LTFU clinic. A thorough review of the medical record is the first step. Arrangements should be made with your institution's medical records department to ensure regular delivery of archived medical records well in advance of the scheduled visit. The chart review can be done by a nurse, clinical research associate, or clinician. The purpose of the review is to summarize the pertinent information regarding the cancer history and treatment, generate a comprehensive summary, and determine appropriate recommendations for risk-based care, screening, and education. See box on Page 46 for details regarding preparation of treatment summaries and Appendix 1 for treatment summary templates.

Medical Record Issues

One of the most challenging record reviews will be for the patient who was not treated at your center. In order to provide a clinical summary, you will have to try to obtain medical records from the previous center of treatment. A signed "release of information" form will need to be obtained from the patient authorizing release of medical records. It is helpful to specifically request treatment roadmaps or treatment summaries.

This can be a time-consuming process, so requests for information from other centers should be made well in advance of the scheduled LTFU visit. A good initial contact person for assistance in obtaining this information is often the CRA at the treating institution. His/her name can be obtained from the COG website. It may be possible to send/fax the release of information directly to the CRA, and receive the treatment roadmaps or summary sheets directly.

Screening Recommendations

Based on the treatment summary, the COG *Long-Term Follow-Up Guidelines* should be used to determine the need for specific laboratory work, radiologic evaluations, cardiac studies, etc. Timing of these studies should be determined (e.g., whether they will be scheduled on the same day as the LTFU visit; and if on the same day, before or after the clinic appointment).

> ***"When we first started our clinic, we "pre-ordered' laboratory studies, based on treatment exposures and had the patient visit the blood drawing station before their appointment. Not infrequently, issues arose following the history and physical that prompted the clinicians to request additional blood studies. Many of our patients weren't happy about going back for a second blood draw. We changed our practice and now schedule blood work at the conclusion of the visit to eliminate this problem."***
>
> ***- Marcia Leonard, RN, PNP***
> ***Coordinator, LTFU Clinic, University of Michigan***

Numerous studies on the same day make for a very long time at the clinic, which may be exhausting for some families. Other patients, especially those who live a considerable distance from the center, may prefer scheduling everything at one time.

Good health habits and regular check-ups can keep a survivor healthy and reduce the risk of developing late effects. Many adult cancers are caused by detrimental lifestyle factors. Good nutrition, regular exercise, sunscreen use, avoidance of tobacco products or exposure to second hand smoke, moderate use of alcohol, and maintaining a healthy weight can contribute to healthy survival. Using proper safety equipment such as bicycle and motorcycle helmets, seat belts and safety goggles can protect a survivor from injury. Never driving while under the influence of alcohol or drugs can save lives.

- Every survivor should be counseled regarding the risks associated with tobacco use, illegal drugs (e.g., "party drugs"), and other high-risk activities. Referrals to appropriate substance abuse clinics, counselors or tobacco cessation programs should be provided as needed.
- Every survivor should be counseled regarding safe sex practices and the use of preventive measures to prevent unplanned pregnancies and sexually transmitted diseases
- Female survivors at increased risk for breast cancer should be taught breast self-exams and the current recommendation for mammograms and clinical breast exams. Contact your local American Cancer Society for free brochures that you can distribute during the visit.
- Every survivor should be counseled about sun protection strategies, and those at high risk should be taught skin self-exam and counseled regarding the importance of regular clinical exams

Team Meetings

Once the initial information has been gathered and the clinical summary is prepared, this information should be shared with members of the multi-disciplinary team. Dissemination of information may occur during a pre-clinic team meeting, in written summary form or via a computerized medical summary. In many clinics, the nurse practitioner determines which team members will need to evaluate an individual patient prior to the visit.

In some clinics, the multidisciplinary team meets to review new patients prior to their first visit to the LTFU clinic. The survivor's history is presented and existing and potential late effects are reviewed. From this meeting, the plan is set for the clinic visit, the necessary tests are ordered, and referrals are written.

PREPARING THE TREATMENT SUMMARY

Include the following information in the Treatment Summary. Once completed, the treatment summary should be incorporated into the survivor's medical record. *(See Appendix 1 for Treatment Summary Templates).*

- **General background information**, including:
  - Demographics (e.g., name, sex, date of birth, contact information, insurance)
  - Pertinent medical history prior to the cancer diagnosis (e.g., Down syndrome, congenital heart defects, prematurity)
  - Diagnostic details (e.g., diagnosis, date of diagnosis, presenting symptoms, sites involved, stage, pertinent diagnostic features such as physical exam and radiologic findings, histology, morphology, flow, tumor markers, and cytogenetics)
  - Name of treating institution/physician
  - Complications and significant events
  - Transfusion history
  - Hepatitis C and HIV history/test results
  - Adverse drug reactions/allergies
  - Date treatment completed
  - Date of any relapses or second malignancy and associated treatment
- **Therapeutic summary**, including:
  - **Treatment protocol** number and description, if applicable
  - **Chemotherapy** agents, including:
    - Route of administration for all agents
    - Cumulative doses for alkylators, heavy metals, bleomycin, and anthracyclines (many programs calculate cumulative doses for all agents used)
    - Designation of "high dose" versus "standard dose" for methotrexate and cytarabine ("high dose" refers to any single dose ≥1000 mg/m^2; "standard dose" refers to all single doses <1000 mg/m^2)
  - **Radiation therapy,** including:
    - Field(s)
    - Laterality (if applicable)
    - Start/stop dates
    - Total radiation dose, number of fractions, dose per fraction, and boost dose/location (if applicable). Record doses in Gy (1 Gy is 100 cGy or 100 rads)
    - Radiation type (e.g., proton, photon)
    - Institution/facility and treating radiation oncologist
  - **Hematopoietic cell transplant(s)**, if applicable, including:
    - Type(s)
    - Date(s)
    - Conditioning regimen(s)
    - GVHD prophylaxis and/or treatment, if applicable
  - **Surgical summary**, including:
    - Dates of surgical procedures
    - Names of procedures
    - Site (and laterality) of procedure, if applicable
- **Potential long-term effects** by organ system
- **Recommendations** for necessary screening tests and follow-up exams based on age and treatment received

STRUCTURING THE CLINIC VISIT

During the initial comprehensive LTFU clinic visit, the medical, family, and psychosocial history should be reviewed. The team should decide which members will collect each component of the history (e.g., the social worker or psychologist may assume responsibility for the psychosocial details, whereas the clinician may focus on the medical and family history). In a multidisciplinary clinic, to avoid repetition, it is important that not every member of the team ask the same questions. However, critical history may be missed if important questions are not assigned to a specific team member.

The focus of the history should be relevant to the treatment exposures that the survivor had. The COG *Long-Term Follow-Up Guidelines* should be used as a reference to identify history questions relevant to the survivor's exposures.

The physical exam should be performed by the clinician (nurse practitioner, physician, or physician assistant) evaluating the patient. A comprehensive exam should be performed, with a focus on organs at risk due to the underlying disease and therapeutic exposures. It is important to identify portions of the exam that cannot be performed in your clinic setting. For example, pelvic examinations or vision screening may require referral to a subspecialist. The *Long-Term Follow-Up Guidelines* should be used as a reference to identify critical components of the physical exam worthy of focus.

Health counseling should be done by the clinician or nurse coordinator and targeted to the survivor's treatment exposures. "Health Links" (patient education materials accompanying the COG *Long-Term Follow-Up Guidelines*) can be reviewed with the survivor during the visit, and a copy given to the survivor for further review at home. Emphasis on a healthy lifestyle should also be discussed during this visit. For example, avoidance of tobacco use, and the importance of a healthy diet and adequate exercise should be stressed. Documentation of health counseling should be recorded in the patient's medical record.

A comprehensive psychosocial assessment should be done by the social worker or psychologist. This interview should elicit information related to the impact of the cancer diagnosis on the survivor's current psychosocial adjustment. In addition, crisis intervention services and referral to local behavioral health providers in the community are key psychosocial services that should be provided as indicated.

The need for subspecialty care will be dictated by the survivor's underlying medical conditions and the effects of the cancer diagnosis and its treatment. Attention should be paid to thorough follow-up of active medical problems as well as screening for asymptomatic complications. As survivors reach adulthood, facilitating the transition from pediatric to adult medical care providers may be a primary goal of some late effects clinics.

> ***"At our institution the NP who completed the chart review and screening recommendations is responsible for the flow of that particular patient through the actual clinic day. Responsibility falls on this NP to educate the patient on their disease/treatment, the actual and potential late effects, and ways to promote wellness. Also, the responsible NP receives all multidisciplinary notes, obtains lab and screening results, makes necessary referrals, communicates the plan to the team at the post follow up meeting and summarizes the visit."***
>
> ***- Kathy Martin, RN, CPNP***
> ***Carolinas Medical Center, Charlotte, NC***

POST-CLINIC FOLLOW-UP

Post clinic follow-up begins immediately after the clinic visit. A meeting to summarize patient status and further recommendations should be scheduled and held on a regular basis. In an effort to minimize the number of meetings, some centers may combine follow-up meetings with the subsequent clinic's pre-planning session, while other centers "wrap up" an active clinic day with a short team conference. Key components of post clinic follow-up include sharing and discussing the impressions of the various team members, tracking results of lab work and screening tests, making referrals, summarizing the patient visit in writing and managing contact/ongoing communication. Most centers have a single staff person responsible for summarizing the entire visit. A mechanism should be developed for contacting patients who did not arrive for their scheduled clinic visits. This can be done in writing or by phone and should be documented in the medical record.

Tracking Results/Information

A single staff member should assume responsibility for tracking results of screening tests (e.g., echocardiograms, pulmonary function tests). These results need to be forwarded to the staff person responsible for the patient's overall summary, so that necessary interventions (such as making referrals or ordering additional tests) may proceed promptly and be available for discussion at the next follow up meeting.

In addition to test results, receipt of notes from multidisciplinary team members who evaluated the patient is critical to summary development. Incorporation of notes from social work, nutrition, and other team members is as important to the summary as the physical exam. Thus, the staff person responsible for summarizing the patient's visit should collect these data.

Making Referrals

Many childhood cancer survivors will require some level of care from subspecialists. Referring patients to subspecialists with expertise and interest in cancer survivors is ideal, but not always possible. As LTFU clinics are developing, emphasis should be placed on networking with subspecialists to help develop their interest and expertise in the unique population of childhood cancer survivors. Many LTFU programs follow patients from large geographic areas, so locating subspecialty caregivers close to the patient's home is helpful. As LTFU clinics become more established, relationships with specific subspecialists may become apparent and help direct referrals. Common subspecialty referrals include:

- Audiology/ENT
- Endocrinology
- Cardiology
- Pulmonology
- Ophthalmology
- Nephrology
- Gynecology
- Reproductive endocrinology
- Orthopedics
- Psychology/Neuropsychology
- Adult primary care or internist

Other specialists to consider include:

- Developmental medicine
- Neurology
- Genetics
- Surgery (general, plastics, etc)
- Gastroenterology
- Urology

Summarizing the Visit

Summarizing the LTFU visit within a single document can accomplish several goals. The visit summary is a valuable tool for educating and counseling patients regarding their specific risks and the subsequent need for continued monitoring. It is also an informative tool for primary healthcare providers to assist them in directing further care. Finally, the summary can be used for reimbursement documentation and subspecialty referrals, particularly for patients with late effects that result in significant functional limitations and/or disabilities.

The following pertinent information should be available at the time the visit summary is developed:

- Medical records
- Treatment summary
- Multidisciplinary notes (e.g., history and physical, social work assessment, child life summary, dietitian's assessment, information from any additional team members.)
- Data from screening evaluations (e.g., lab values, echocardiogram, pulmonary function tests, audiogram reports, imaging reports, etc.)
- COG *Long-Term Follow Up Guidelines*
- List of educational handouts provided (see Appendix 3)
- Referral list

Each LTFU clinic needs to develop a format for the visit summary document. Consideration should be given to who will receive the summary, and whether the summary can stand alone or whether it needs a letter to explain the findings.

Most clinics send the visit summary to the primary and/or referring healthcare provider and to the patient or parents. The LTFU clinic staff should decide if the same summary will be sent to the patient, or if a different "lay" format will be used. In addition, consideration should be given to documentation for subsequent visits. Some programs send the complete summary only after the initial visit to the LTFU clinic and send a shorter version at subsequent visits. Other uses for the visit summary include annual updates to agencies involved with the survivor's care (e.g., Medicaid) and documentation in the medical record.

Standardizing Documentation

Templates help to standardize and decrease the time required for clinic documentation. Consideration should be given to developing or using pre-existing templates for the following (Samples in Appendix 1 and 3):

- Treatment summary
- Visit summary
- Letter to primary care provider
- Referral letters
- Letter to patients/family

Managing Ongoing Communication

Once the visit summary (and letters, if applicable) are complete, distribution of information is critical for ongoing communication. The following is a potential distribution list for LTFU clinic communications:

- Primary care provider
- Medical chart
- Involved specialists (e.g., endocrine)
- New referrals
- Patient/family

> ***"Each team member documents their encounter on a progress note, which is placed in the chart. The NP incorporates the individual notes into the main summary which is sent to the primary care provider and subspecialists."***
>
> ***- Kathy Martin, RN, CPNP***
> ***Carolinas Medical Center, Charlotte, NC***

Patients Lost to Follow-Up

Finding patients lost to follow-up and bringing them back into the healthcare system will minimize potential long-term problems, enhance the patient's quality of life, and is potentially more cost-effective. In addition, capturing data from patients lost to follow-up is critical to the success of future clinical trials development. Therefore, developing a system for tracking patients is important. If a scheduled patient does not keep an appointment, a follow-up letter and/or phone call may be necessary to reschedule.

Locating patients can sometimes be challenging. The institutional CRA and/or tumor registrar are adept at searching for patients lost to follow-up. Also, social workers may provide insight into community resources that may link you to a patient who is lost to follow-up. When standard attempts to contact a patient regarding a LTFU appointment fail, additional strategies may include:

- Contacting the primary care provider
- Contacting the last known employer
- In the U.S., checking the Social Security Death Index (http://ssdi.rootsweb.com/) to determine if the patient is deceased
- Contacting next of kin, if contact information is available
- Utilizing professional tracking agencies

Individual institutions will need to determine HIPAA and other compliance factors related to tracking patients, and set their own limits as to how many "reminders" are acceptable before assuming a patient is "lost to follow up". Some centers send a letter to "lost" patients stating that there is no longer a patient-provider relationship as a result of multiple missed or cancelled appointments. (This decreases the risk of the LTFU clinic being accused of "abandonment of care"). Always become familiar with and follow your institution's policy regarding release of medical information prior to contacting anyone other than the patient directly.

BILLING AND FINANCIAL ISSUES

> ***"We feel our survivors should begin to assume responsibility for their healthcare, and this includes knowing the extent of their insurance coverage. Within our appointment confirmation letter are instructions to check level of coverage with their insurance carrier, prior to their annual long-term follow-up visit. We teach patients that they need to call the 800 number on the back of their insurance card, and inquire as to whether our clinic is within their 'network' and whether services will be reimbursed."***
>
> ***- Marcia Leonard, RN, PNP***
> ***Coordinator, LTFU Clinic, University of Michigan***

Patient billing and reimbursement issues are directly related to the type of healthcare system with which the LTFU clinic is associated. For institutions located in countries with universal healthcare coverage, and for institutions that receive philanthropic or research funding to support their LTFU services, these issues may not be relevant. However, for the majority of institutions in the United States, billing and financial issues are often the determining factors in survivor access (or lack thereof) to the LTFU clinic and associated screening tests and subspecialty care.

Coding/Billing

In order to seek reimbursement from insurance carriers in the United States, clinics must first generate a diagnosis code (ICD-9-CM; International Classification of Diseases, 9th Revision, Clinical Modification) for the visit; most commonly this is the survivor's cancer diagnosis (e.g., leukemia). All services performed are then billed using CPT (Current Procedural Terminology) codes.

In addition to use in federal programs (Medicare and Medicaid), CPT is used extensively throughout the United States as the preferred system of coding and describing healthcare services. CPT codes differentiate between levels of service and incorporate physical examination, evaluation, treatments, conferences with or concerning patients, preventive pediatric and adult health supervision, and similar medical services, such as the determination of the need for and/or location of appropriate care. There are strict criteria that define the complexity level of an outpatient clinic visit. The highest level translates to the highest patient bill, and the greatest reimbursement to the clinic/hospital.

Reimbursement generated directly for the clinic is almost exclusively derived from clinician billing, which should be done utilizing the highest levels of available billing codes, with consideration given to:

- Time spent reviewing referrals
- Physical exams
- Consultations
- Documentation
- Referrals to additional subspecialists

Meeting with billing specialists from both the facility and professional billing departments, as well as with specialists in the medical coding offices will help to ensure that the clinic or institution will receive the maximum potential reimbursement.

Reimbursement Issues

Those familiar with the comprehensive (and often-lengthy) clinic visit required for LTFU care understand the amount of time and effort necessary to ensure that the patient receives high quality care.

To offset the costs associated with developing and running a LTFU program, it is important to consider the potential reimbursement generated for the clinic/institution. Some of the tests or procedures commonly required during an evaluation include:

- Lab work (blood, urine)
- Echocardiogram
- EKG
- Audiogram
- Neuropsychological evaluation
- Pulmonary function testing
- Chest x-rays

These tests, although not directly revenue-generating for the clinic, do generate revenues for the institution, especially if done "in network."

Reimbursement Issues for NPs

The rules and regulations for NP practice vary from state to state. The Pearson Report provides a comprehensive summary of each state's practice realities and healthcare practice specifics. Each center should determine how NP billing should be handled in light of their current state regulations. The Pearson Report is updated annually; the 2007 version can be accessed on-line at http://www.webnp.net/images/ajnp_feb07.pdf

Conclusion

A Long-Term Follow-Up Program is a uniquely different entity than a standard hematology/oncology outpatient clinic. Clinic preparation, clinic visits, and follow-up are labor intensive. When launching a new program, phasing the program in at a reasonable pace and obtaining the commitment of key personnel can be instrumental in establishing a successful program.

SECTION 4:
SURVIVORSHIP RESEARCH

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CANCER SURVIVORSHIP RESEARCH

> ***"Cancer survivorship research encompasses the physical, psychological, and economic sequelae of cancer diagnosis and its treatment among both pediatric and adult survivors of cancer. It also includes within its domain, issues related to healthcare delivery, access, and follow-up care, as they relate to survivors.***
>
> ***Survivorship research focuses on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase. It seeks to both prevent and control adverse cancer diagnosis and treatment outcomes, such as late effects of treatment, second cancers, and poor quality of life, to provide a knowledge base regarding optimal follow-up care and surveillance of cancers, and to optimize health after cancer treatment."***
>
> ***- NCI-Office of Cancer Survivorship, 2004***

The advances in the treatment of childhood cancer over the past four decades and the resultant increases in rates of survival can largely be attributed to a pediatric oncology ethos that highly values a rigorous scientific approach to the care of children with cancer, including careful evaluation of treatment regimens through collaborative research.[27] Cancer survivorship research in pediatric oncology (research focused on long-term survivors of childhood cancer) has allowed us to anticipate certain organ-specific complications, potential secondary malignancies, and psychosocial issues.[15] Much research is still needed to refine chemotherapy regimens that will minimize late effects without compromising survival rates, as well as to determine effective interventions for screening and managing late effects.[28-30]

Cancer survivorship research is a formal, systematic approach to both identifying and examining the various late complications of childhood cancer.[31, 32] Whether the focus of a specific research study is a physical, psychosocial, or care-delivery issue, the overall objective of cancer survivorship research is to improve medical outcomes and enhance quality of life in cancer survivors. As an integral part of a comprehensive LTFU program, cancer survivorship research is an important means of identifying measurable outcomes, and further supports the need for comprehensive survivor programs**.** Ideally cancer survivorship research is collaborative in nature, but often the research process begins with smaller descriptive studies conducted at a single institution.

Survivorship research is characterized by focus and usefulness. Some common areas of focus in survivorship research include:

Research Focus	Example
Disease	▪ **Childhood brain tumor**
Treatment exposure	▪ **Cranial radiation**
Age group	▪ **Adolescents**
Concept	▪ **Uncertainty** ▪ **Decision-making**
Symptom	▪ **Fatigue** ▪ **Cognitive impairment**

Research about late effects following childhood cancer can be used to:

- Build a body of knowledge
- Build evidence-based practice in pediatric oncology
- Improve outcomes for childhood cancer survivors
- Improve treatment and outcomes for future pediatric oncology patients

Ultimately, research regarding late effects can be used to improve the cancer experience and a wide range of outcomes for people who have been treated for childhood cancer and for their families, as well as for those children who will be diagnosed and treated in the future.

IDENTIFYING RESEARCH PRIORITIES

Survivorship research has been carried out on a wide range of subjects, including cognitive issues in patients following cranial radiation, risk of breast cancer in patients who have received mantle radiation for Hodgkin lymphoma, and quality of life in childhood cancer survivors. There are still many topics to be explored. For instance, we have a very poor understanding of how cancer treatment affects the normal aging process. Ultimately, ongoing identification of research priorities will be critical to improving the quality of care for long-term survivors of childhood cancer; however, research priorities will vary among LTFU programs depending on multiple factors, including institutional resources, population and expertise. Things to consider when identifying research priorities include:

Research Focus:

- Is the problem significant?
- Will this research contribute new knowledge to the field?
- Is the topic of genuine interest to the researcher?

Feasibility:

- Can the question be answered?
- Is this a moral or ethical problem for which there is no right or wrong answer, but rather an opinion?
- Can the problem be studied in the allotted time frame?
- Can enough subjects be accrued within the time constraints?
- Will subjects be willing to comply with study requirements?
- What facilities and equipment will be needed and are they available to the researcher?
- Is funding available?
- Are the budgeted costs appropriate for the expected procedures and manpower necessary?

Research Team:

- Does the researcher have sufficient knowledge and expertise in this area?
- Is the researcher familiar with the instruments that will be used to collect the data?
- Does the problem require expertise from multiple disciplines (such as nurses, physicians, psychologists, social workers, child life specialists, dietitians, neuropsychologists)?

Regulatory Issues:

- Are there measures in place to protect the patient's rights and privacy?
- Will the Institutional Review Board (IRB) have any problems with the study design (particularly in the area of ethics)?
- If the sample includes children, will parents be willing to allow their children to participate?
- What is the process for re-addressing consent as minor children reach adulthood?

CONDUCTING SURVIVORSHIP RESEARCH

An institutional electronic clinical database is an essential element to be considered when establishing a program of comprehensive LTFU care. Electronic clinical databases for long-term survivor programs may be an extension of the clinical database that already exists in the institution's general pediatric oncology or transplant program. If there is not an existing electronic clinical database for the institution's pediatric oncology program, creating a basic LTFU database should be an initial goal of the LTFU program.

Clinical Databases Set the Stage for Cancer Survivorship Research

Microsoft Access® and Microsoft Excel® are widely available user-friendly software programs that can be used to enter, summarize, search and analyze clinical data and support survivorship research. A feasible and generally useful clinical database is comprised of basic elements that can be queried to identify persons who are potentially eligible for a study. For example, one could query for the number of patients who have a specific diagnosis, are within a specific age range or are a specific number of years off therapy, etc.

Developing a Clinical Database

Basic elements of a clinical database that can be used for survivorship research include:

- **Demographic data:** Name, date of birth, gender, race/ethnicity and contact information (address, home and/or work telephone, cell phone and email for both the survivor and an alternate contact, i.e., someone who will always know where the patient can be reached). Complete current contact information is critical to both quality clinical care for long-term survivors and to reduce potential sampling bias in cancer survivorship research.
- **Disease-related data**: Childhood cancer diagnosis, date of diagnosis, disease stage, and significant histological and biochemical features.
- **Treatment-related data**: May include dates of initiation and completion of therapy, therapeutic exposures, and specifics regarding treatment, such as radiation fields and doses, cumulative chemotherapy doses, etc.
- **Clinical outcomes**: May include results of tests and procedures, known late effects, and an objective rating of late effect severity per the Common Toxicity (CTC) criteria.
- **Other program-specific data**: May include data specific to specialized programs, such as neuro-oncology or transplant evaluation measures.

Other considerations in the development and maintenance of a high quality institutional database for long-term follow-up include:

- ***Who will be included in the database?*** When starting a LTFU program, the emphasis should be on enrolling long-term survivors in the database. While ideally patients would be entered into the database at diagnosis so treatment exposures can be tracked and entered in real-time, few institutions have sufficient resources to do so. For most programs, the initial step may be either enrolling patients attending the LTFU clinic, or entering all patients at the institution when they complete active therapy. The latter is preferable, for this allows a determination of the entire population of survivors at the institution, and not just survivors who attend the LTFU clinic.
- ***When will data be collected?*** Medical record abstraction and data entry can take place in advance of the patient's visit, with review and update of the

information (especially the patient's contact information and information about actual late effects and their severity) being done at the clinic visit. For returning patients, especially for late adolescent and young adult survivors whose care has been transitioned to an adult oncology or primary care provider, changes in demographic information (name, address, telephone numbers, email address) and late effects or other data elements can be updated at the start of the annual clinic visit, or during a "virtual" visit by phone or mail for those who are not seen in person on an annual basis.

- **How can quality data collection be assured?** Rigorous training in medical record abstracting, patient interviewing and data entry for all personnel who will be engaged in these activities is fundamental to the development of a complete and accurate clinical database that can be useful for research. Developing systems for updating contact information is critical if quality research is to be conducted in your LTFU program. Study results are potentially biased if a large number of patients cannot be located and included in the study.
- **How will the data be collected?** There are several potential methods for data collection in LTFU programs. Possibilities include:
  - Patients complete standardized paper-and-pencil data collection forms prior to their LTFU visit (see Appendix 3 for sample clinic intake forms)
  - A clinician elicits and records information during the clinical interview using standardized data collection forms
  - Patients or interviewers enter responses directly into a computerized database
  - Data are collected by mail or telephone surveys or through in-person interviews conducted outside of the standard LTFU clinical encounter. This type of data collection may be preferable if there are competing demands for time and space in the clinical setting
  - Whatever data collection method is selected for use in developing the clinical database, it should be used consistently to allow meaningful comparisons between patients or groups of patients over time
- **Who will provide information?** Survivors age 18 and over can generally respond for themselves, unless they are cognitively impaired or developmentally unable to complete the forms. Younger survivors may complete age-appropriate forms with parent/guardian consent. Family members can be proxy respondents for children too young to complete the forms and for those survivors who are cognitively impaired or developmentally delayed. For survivors being screened for problems with memory, attention, or psychological distress, the perspective of the parent or spouse may be essential.

> ***"We designed a very basic Excel® database when we started our Long-Term Follow-up Program. We were fortunate to have a medical student join us for a summer. He upgraded our system while keeping it user-friendly."***
>
> ***- Kathy Meeske, RN, PhD***
> ***HOPE Program, Childrens Hospital Los Angeles***

Regulatory Issues

An essential component of developing institutional data collection procedures is obtaining Institutional Review Board (IRB) approval (or the approval of a similar regulatory oversight body). Generally, clinical databases developed solely to track patient visits, capture other clinical information, and improve patient care do not require IRB approval as long as the data are stored and utilized only for clinically related matters. However, if the healthcare provider plans to use the clinical database to answer research questions that arise over time, then IRB approval is required. Therefore, it is important to consider submitting an IRB application for general data collection at the time you are developing the clinical protocol for your LTFU program. The essential components of an IRB application include:

- Specific protocol to be followed for collection of personal health information that will be entered into the database
- Sample recruitment materials (e.g., letters or telephone scripts) that will be used when contacting potential research subjects to introduce a study
- Identification of specific members of the research team who will have access to the data, along with assurance from the principal investigator that all members of the research team will have training in IRB and HIPAA regulations
- Explanation of the research questions and protocol to be followed for data collection in layman's terms
- IRB approvals from other institutions (if there are research partners/collaborators outside of your institution)
- Consent documents for:
  - Participants 18 years of age or older
  - Parents/guardians of participants under 18 years of age
  - Participants between 7 and 17 years of age (assent form documenting the minor's willingness to participate)
  - Patients previously consented as minors, who have turned 18 during the course of the research or data collection

Although you may have a clinical database for your LTFU clinic, you generally cannot access this patient data for research questions unless specific consent is obtained. It is recommended that you consult with your IRB concerning your institution's requirements for research databases. In addition to IRB consents, you may need to obtain Health Insurance Portability and Accountability Act (HIPAA) consents for each element of personal health information (PHI) that can be made available to those not directly involved in the patient's care, including the research team or others involved in the study.

Consider submitting and obtaining an IRB approval from your institution for general data collection and follow-up of your patient population. For example, you can submit an IRB application requesting survivor consent to store his/her demographics, disease characteristics, treatment received and identified late effects, making it available (without patient identifiers) for future analyses.

In summary, although you may not have a specific research question in mind at the time you are developing your survivorship clinic, in recognition that research is an essential part of improving the care of this at-risk population, consider developing a general research protocol that would allow you to store data that can be used to answer questions that may arise over time.

> ***"The IRB at our institution asked us to develop a standard operating procedure (SOP) for our database. In the SOP, we had to address issues such as database security and access. I would recommend that you meet with a representative of your IRB, as regulations regarding databases are evolving rapidly and are institution-specific."***
>
> ***- Kathy Meeske, RN, PhD***
> ***HOPE Program, Childrens Hospital Los Angeles***

Research Opportunities within COG

One of the first steps in incorporating survivorship research into a new LTFU program may be the implementation or facilitation of late effects studies that are open within COG. Your program may participate in COG late effects research by opening a new late effects study and/or facilitating accrual on a study that is already open at your institution.

Current COG late effect studies that are open to patient accrual are listed in Table 6 and also can be accessed on the Children's Oncology Group member website at https://members.childrensoncologygroup.org (click "Protocols" and then "LTE"). Obtain specific information regarding a study's eligibility and methodology by downloading the protocol from the COG website.

Table 6: Currently Open COG Late Effects Studies*

PROTOCOL	TITLE	DATE OPENED
ALTE02C2	**Neurobehavioral Outcomes in Childhood ALL**	**May 2004 (Limited institutions)**
ALTEO3N1	**Key Adverse Events after Childhood Cancer**	**March 2004 (Groupwide)**
ALTEO4N1	**Health Related Outcomes for Hodgkin Disease Survivors**	**October 2004 (Limited institutions)**
NWTSG 4941L	**National Wilms Tumor Late Effects Study**	**October 1995 (Groupwide)**
ACNS0331	**Newly Diagnosed Standard Risk Medulloblastoma: Limited Target Volume Boost Irradiation & Reduced Dose Radiotherapy and Chemotherapy**	**June 2004 (Groupwide)**
ACNS0221	**Conformal Radiation in Low-Grade Gliomas**	**November 2005 (Groupwide)**
AALL0331	**Standard Risk B-precursor Acute Lymphoblastic Leukemia (includes longitudinal assessment of health-related quality of life)**	**April 2005 (Limited institution for HRQL component)**
AOST0331	**A Randomized Trial of the European and American Osteosarcoma Study Group to Optimize Treatment Strategies for Resectable Osteosarcoma Based on Histological Response to Pre-Operative Chemotherapy**	**November 2005 (Groupwide)**

***As of September 2007**

The Research Process

Clinical practice can spark potential areas of interest in survivorship research; for example, observation of a pattern of multiple occurrences of a distressing symptom in patients or their family members, or a desire to identify or establish an evidence base for current practices or practice improvements. Other sources that can inspire potential areas of interest are the scientific literature, calls for applications for grant funding in an area related to long-term childhood cancer survivors and/or late effects, previous work in programmatic survivorship research about late effects or other issues of relevance to long-term childhood cancer survivors, and strategic thinking about future programmatic research.

Steps in the Research Process

The following are essential steps to follow when designing and conducting your own research study.[33-35] A flowchart summarizing this information is presented in Figure 1.

1. Define the research question. Determine a general topic or clinical problem and then discuss your ideas with others, narrowing the focus to a specific research question. Consider the potential implications of findings related to this research: Is this question worth your time and effort to study? Is it a new idea? How will patients or healthcare professionals benefit from your research?

2. Review the literature. Determining what is known and identifying gaps in the literature are critical in the development of a research project. Reviewing previous studies helps the investigator identify a suitable framework for the study, which in turn guides the selection of relevant variables and suitable methods and measures. The process of conducting the literature review also may present an opportunity for developing a review or clinical paper for publication.

3. Refine the research question and develop a research concept. Based on the literature review, the research question may need further refinement. Once this is accomplished, it is a good idea to write up a brief research concept proposal and have this reviewed and approved by the individuals whom you have identified as key to the success of your project. In some institutions, a research concept may be required as part of the formal approval process. Feedback from this process will be valuable as you develop your research proposal.

In order to obtain meaningful analysis, some cancer survivorship research requires larger numbers of survivors than may be available at a single institution. For example, a randomized control trial (RCT) assessing the outcomes of a specific intervention in comparison to those who receive “standard of care” would normally require multi-institutional recruitment because, for this research design, the sample size must be large enough to allow the detection of a statistically significant difference between the two groups, if one exists. The researcher could collaborate with clinicians and scientists at other centers and/or use a pre-existing database to recruit for the study.

4. Develop the research protocol. The research concept should now be used as a platform for development of the full research protocol which should include title, abstract (summary), background, aims/objectives, hypothesis, eligibility criteria, conceptual framework, study design, sampling, variables, statistical analysis, identification of study measures and instruments, ethical considerations, risks and benefits, and determination of the composition of your research team.

Adding research expertise to your team is key to developing the research question(s) and methods. The type of expertise that will be needed to conduct a study becomes clearer as the research topic and questions evolve. Bring together a core team of experts in key areas. The study will develop further based on the interests and perspectives of the various experts who form the research team. The research team should include individuals from multiple disciplines who have essential and complementary skills including study design, theoretical frameworks, statistics, database design and programming, grantsmanship, and clinical expertise.

Considerations for institutional support may include access to populations of interest and potential research participants, existing systems for obtaining, processing and storing research data (including tissue samples and medical record information), and availability of research office space and clinical facilities (including a private area for obtaining informed consent and conducting data collection).

5. Develop a budget and identify funding sources. Institutional and financial support are also important for the development of survivorship research within a program of comprehensive LTFU care for childhood cancer survivors. Consider both internal and external sources of funding. Potential funding sources are listed in Table 7.

6. Prepare and submit your IRB application. Once the research plan is in place, you should proceed with the process of obtaining regulatory approval to conduct the study. Many funding agencies will not release funds until there is IRB approval for the research project.

7. Collect your data. Follow the plan approved by your IRB to collect your data. Be sure measures are in place to assure data security and confidentiality.

8. Analyze your data. Perform the statistical analysis as outlined in your research plan and then interpret your findings.

9. Report your results and disseminate your findings. Prepare manuscripts for submission to scientific journals, poster abstracts, and conference presentations. Let the world know the results of your research!

> ***"We recently published a case report because the late effect we detected in a long-term survivor of childhood cancer had not been previously reported in the literature."***
>
> ***- Mary Nelson, RN, MS***
> ***HOPE Program***
> ***Childrens Hospital Los Angeles***

Figure 1: Development of a Research Project

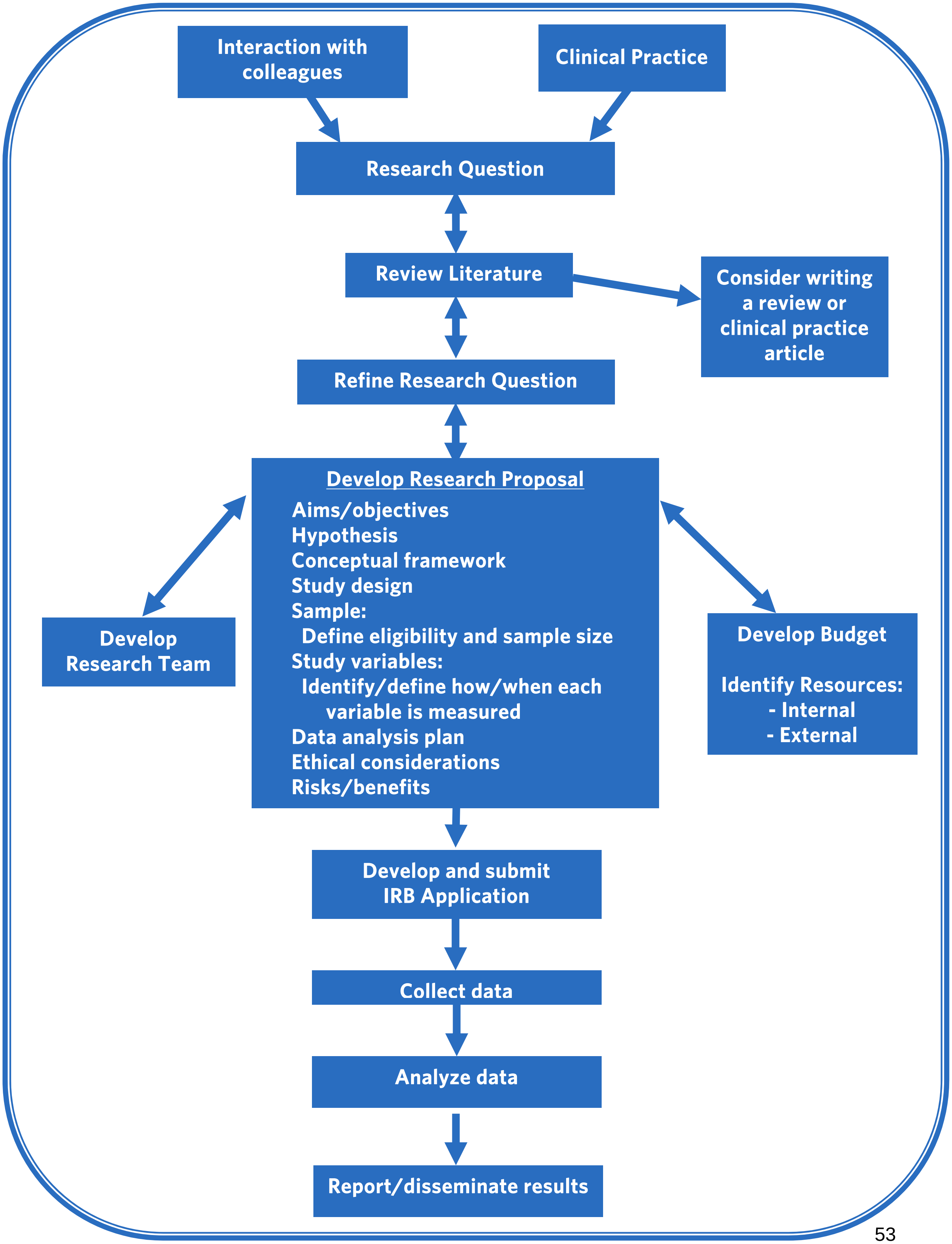

Table 7: Examples of Potential Funding Sources for Survivorship Research

Professional Organizations

- Oncology Nursing Society www.ons.org
- Sigma Theta Tau www.nursingsociety.org
- National Association of Pediatric Nurse Practitioners www.napnap.org
- Association of Pediatric Hematology Oncology Nurses www.aphon.org

Institutional

- Fellowships (e.g., St. Jude EBM fellows, Research Scholars)
- Departmental research awards
- P20, P30, P50-funded Center pilot studies program
- NCI Comprehensive Cancer Center pilot studies program

Private Agencies and Foundations

- American Cancer Society
- Lance Armstrong Foundation
- Hartford Foundation
- National Brain Tumor Foundation

Corporations

- Computer hardware and software
- Pharmaceuticals
- Electronic devices
- Healthy lifestyle

Government

- National Cancer Institute (NCI) www.cancer.gov
- NCI Office of Cancer Survivorship http://dccps.nci.nih.gov/ocs
- National Institute of Nursing Research (NINR) www.ninr.nih.gov
  - Career development awards (K-level awards)
  - R-level awards (for example R01, R03, R21)
- National Institute of Health (NIH) Research Training Opportunities:
  - National Research Service Award (NRSA) http://grants.nih.gov/training/nrsa.htm (individual and institutional; pre- and post-doctoral)
  - National Heart Lung and Blood Institute (NHLBI) www.nhlbi.nih.gov

Cooperative Clinical Trials Groups

- Children's Oncology Group (Nursing Traineeships) https://members.childrensoncologygroup.org/Disc/nursing/default.asp

Other Research Considerations

Secondary Analysis. If the researcher wants to answer a question from previously collected data, gaining access to the pre-existing database is necessary. Several US databases exist that may offer access to information about survivors of childhood cancer, including:

- **The Children's Oncology Group (COG)** [http://members.childrensoncologygroup.org] is a National Cancer Institute (NCI) supported cooperative clinical trials group that conducts multi-institutional studies and can provide access to previously collected data for secondary analysis. COG investigators must submit a research proposal to the appropriate study committee (e.g., Late Effects, Cancer Control, Nursing) for review and approval in order to access COG data.
- **Childhood Cancer Survivor Study (CCSS)** [www.stjude.org/ltfu] is an NCI-funded resource established to promote and facilitate research regarding long-term survivors of childhood cancer. CCSS has enrolled 14,370 five-year survivors of childhood and adolescent cancer diagnosed between 1970 and 1986 and a sample of 3,737 sibling controls. Enrollment of a more contemporary cohort is currently in progress. CCSS has detailed information on cancer diagnosis, therapy received, and health/quality of life. The CCSS dataset is a resource that can be used to investigate questions regarding quality of life and late effects of therapy in childhood cancer survivors. Additional information regarding the process by which qualified investigators can access the CCSS dataset is available by e-mailing ccss@stjude.org.
- **Surveillance Epidemiology and End Results (SEER)** [http://seer.cancer.gov] is an NCI resource that collects and publishes cancer incidence and survival data from 18 population-based cancer registries covering approximately 26 percent of the US population.

Building Research Partnerships

Partnerships and cross-institutional collaboration are important because of the relatively small number of childhood cancer patients and survivors at most institutions. Sharing ideas with colleagues between and across institutions facilitates successful completion of research projects. The novice researcher should consider initiating a small working group with other colleagues from which pilot data can be obtained. The researchers can then build on their collaborative data, and potentially expand the project to include additional sites, or in some instances, expand to a COG or CCSS group-wide project once feasibility has been worked out in the smaller group setting.

- **Internal and external partnerships**
  A group of researchers within or between institutions with a similar area of interest, but often with different areas of research expertise, who regularly schedule conference calls or meetings to brainstorm ideas for research and to share opportunities for funding, publication, leadership, and teaching.
- **Clinical partnerships**
  Clinical partnerships are an effective way of promoting research within institutions that have different requirements regarding time dedicated to clinical and research responsibilities. A clinician who is interested in conducting survivorship

> ***"A physician and nurse team in survivorship may have an interest in examining AVN, and may require a larger sample than that available within their own institution. They may want to seek collaboration with another institution that has resources to assist in conducting this study."***
>
> **- Sheila Santacroce, APRN, CPNP, PhD**
> **HEROS Program, Yale University**

research but has a great deal of clinical responsibility could partner with others who have more dedicated time for conducting research. Clinical partnerships may work well for multidisciplinary research studies (studies involving multiple disciplines, such as nursing, medicine, social work, psychology, and/or neuropsychology). For example, examination of the various psychological effects of cancer requires expertise in identifying these issues, and support from physicians and nurses who follow these patients and families during treatment. Another example may be the survivorship nurse who wishes to conduct a research study and who may need to seek clinical/research expertise from psychology in order to examine coping and adjustment in cancer survivors.

Conclusion

Cancer survivorship research has the potential to decrease physiologic and psychological morbidity in childhood cancer survivors by addressing specific issues that have an impact on health and quality of life in this vulnerable population. LTFU clinics should strongly consider incorporating research into their program, in order to contribute new knowledge and insights that may potentially improve future outcomes for childhood cancer survivors.

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> ***"A person with heavy clinical responsibilities is still able to contribute to the research project by recruiting study participants from their institution, participating in conference calls about the progress and findings of the study, and assisting with manuscript revisions."***
>
> **- Sheila Santacroce, APRN, CPNP, PhD**
> **HEROS Program, Yale University**

SECTION 5:
ISSUES IN SURVIVORSHIP

EDITOR:

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ADVOCACY

Parents and patients must learn to advocate for themselves in order to navigate through a lifetime of survivorship issues. Ideally, parents and patients should learn advocacy skills throughout their treatment. However, advocacy issues become essential in survivorship, since parents and patients must address important issues as they arise. [5, 36, 37]

> ***"If I didn't know how to advocate for myself, I would not have received the mammogram I really needed as a survivor who had mantle radiation. My doctor said I did not need a mammogram until I was 40 years old. I insisted on a test that could possibly save my life. I was able to do this because I was educated and confident."***
>
> ***- Angie, Survivor***

Developing Advocacy Skills

Successful advocacy begins with education, because when parents and patients become equipped with an understanding and acceptance of survivorship issues, they become confident enough to advocate for themselves. Suggestions for assisting survivors to develop advocacy skills include:

- Make parents and patients aware that advocacy is a necessary skill, and one that will enhance survivorship
- Discuss advocacy, including how and why to be a personal advocate, during the initial LTFU visit
- Include the following in each subsequent LTFU visit:
    - Discussion and assessment of advocacy skills
    - Discussion of survivorship issues
    - Psychosocial support
    - Distribution of information and resources

Essential Skills

Four basic self-advocacy skills have been studied and identified as essential.

- Information-seeking
- Communication
- Problem-solving
- Negotiating

These skills should be taught throughout treatment and evaluated during visits to the LTFU clinic.[38] It is important for survivors to be proactive in developing these self-advocacy skills in order to maximize their overall health and well-being throughout the cancer experience.

Advocacy: What, Why, How?

Parents and patients may know intuitively that they should advocate for themselves. However, many do not understand the types of advocacy, why advocacy is necessary in order to navigate through survivorship successfully, and how they can become an effective advocate. An important goal for LTFU clinics is to educate survivors and their families so that they are able to make knowledgeable decisions about the future that are in their best interest.

> ***"I knew I should stand up for my child, but I would not call myself an advocate. To me, an advocate was someone who stands up for legal or financial rights. It took me a while to learn the broad scope of advocacy and what it meant for me and my child."***
>
> ***- Mary, Parent***

Characteristics of a successful advocate.

First and foremost, an advocate cares about the overall well-being of the survivor, regardless of whether the advocate is a parent or a survivor. Overall well-being includes both physical and psychosocial issues. An advocate must be willing to ask questions, proactively seek out information, and take some positive risks that will lead to greater benefit in the future. Not all patients and parents will embrace advocacy in the same way or to the same degree, but fundamental education and advocacy are necessary for all survivors. It is also important to note that an advocate who stands up for an individual survivor is also advocating for childhood cancer survivors in general. The more educated the population, the easier it will become for future survivors to function.

Unfortunately, advocacy sometimes means stepping out into an area that others have not yet explored. An advocate may experience challenges along the way, such as healthcare professionals or insurance companies that are unaware of certain issues that survivors face. Because advocacy can at times be frustrating and discouraging, it is important for LTFU clinic staff to support advocacy efforts. The clinic should serve as a safe foundation where parents and survivors can develop advocacy skills. Part of this encouragement should include pointing out that advocacy skills can be used beyond the childhood cancer arena. The education and skills developed for advocacy related to survivorship can also be applied in other situations that arise, both at work and at home.

Types of advocacy. While each institution has its own interests in mind, parents and patients should be educated regarding national and local childhood cancer issues and initiatives. Encourage parents and patients to get involved on a national, local, and personal level. Make them aware of programs available to discuss important issues such as, but not limited to, volunteering, fundraising, laws and legislation, treatment choices, and wellness issues. Networking serves to connect survivors and their families to a much bigger picture, which in turn often allows them to find meaning and purpose in their experiences. A list of organizations that provide information and advocacy for survivors is included in Table 8.

Promoting advocacy. Promote advocacy skills for patients and/or parents during LTFU clinic visits. For example, structure clinic visits to allow time for questions and discussion, and for dissemination of information that will promote a better understanding of survivorship issues and ways in which to advocate. Establish an environment that is consistent, up-to-date, and comfortable. Develop a “library” of resources, including web-based technology if possible, so that parents and patients have access to information that they might not have the tools to access at home. Make the LTFU clinic a “home base” from which other resources and specialists can be accessed.

Parents and Patient Advocates

Depending on age, diagnosis, and treatment, survivors of childhood cancer may be too young or cognitively impaired to advocate for themselves. Therefore, begin survivorship education by teaching parents to advocate for their children. Parents may in turn teach their child the skills of successful self-advocacy.

“I needed to feel like there was time for me to just talk about the issues, feelings, and struggles we were facing but not expecting to face, following treatment. Now that she was out of immediate danger, I just wanted a chance to talk about what we had been through and what was ahead for us.”

- Arlene, Parent

It should also be noted that parents and patients will have unique perspectives and possibly different goals in mind for the future. Therefore, teaching parents and patients to achieve developmentally appropriate independence may be one of the essential skills taught to both parent and patient. Professional assistance may be needed to assist with the transitions that occur in the relationship between parent and patient, especially as the patient becomes more independent.

Parents and patients should also be made aware of the unique advocacy opportunities available to each of them. A parent may desire to be much more or less involved in the childhood cancer survivorship arena than the survivor, or vice versa. Therefore, both patient and parent should be equally addressed and given ample and unique opportunities to become involved.

Common Survivorship Issues

An aspect of LTFU clinics that should ideally be separate from the medical aspects of the clinic is built-in time for discussion and processing. The long-term follow-up phase lacks the kind of intensity present during active treatment, but does carry a different sort of intense emotional and physical experience that can many times be eased through discussion and processing.

Life Immediately Beyond Treatment

Survivors should be educated about the possible physical and emotional issues facing them and their families soon after treatment. These issues can be unique and separate from those issues survivors face further out from treatment.

***Anxiety**: Patients and their families expect and are expected to be thrilled with finishing treatment. However, the thrill of finishing treatment is most often mixed with an intense anxiety when faced with the idea of no longer actively "fighting" the disease. Addressing this issue is an important step in creating a strong foundation for future mental and emotional stability.

Returning to Normalcy: Parents should be educated regarding the frustration, anxiety, and depression felt by patients and members of their family when a realization is made that "back to normal" may not be a possibility and that a "new normal" may need to be established.

Physical Effects: Immediately following treatment, parents should be informed about what to expect for their child in terms of physical condition and ability. At this time, parents should be made aware of immediate side effects of treatment as well as possible long-term effects.

Future Issues: Long-term follow-up clinics should also point out to survivors that physical and psychosocial effects of treatment are sometimes delayed and do not present themselves until many years after treatment. Addressing this possibility up-front, frankly and openly, prevents survivors and their families from feeling they are "weird," "weak," or "going crazy" when issues arise at a much later time.

> ***"I hit a huge amount of stress and had a scare that the cancer had come back and suddenly everything that I'd been locking up for the past 4.5 years (since treatment) came out. This goes so much deeper than you realize, and it's important to have a professional, outside perspective to help you stay on top of your mental /emotional health."***
>
> ***- Kara, Survivor***

Long-Term Psychosocial Issues. Dealing with a lifetime of psychosocial issues might be both unexpected and overwhelming to parents and survivors. Parents who advocate for their children find themselves dealing with their own emotions, as well as assisting their child in dealing with their own issues. Appropriate support and education on the emotional issues related to survivorship should be made available to parents for their own use as well as for the use of their child. Parents and patients may need to be made aware of the possible issues through discussion, and they should also be given the opportunity to express concerns at each clinic visit. Specific issues that need discussion are as follows:

Post-Traumatic Stress Disorder: Survivors and their families should be made aware of the signs and symptoms of PTSD. A discussion of the possibility of this issue may avoid the added stress survivors and/or their families may feel if they are unaware of this issue and simply feel they are "going crazy."

Fear of Late Complications: Some survivors may remember hearing about a potential late complication from their doctor when they were in treatment, or they may know or have heard about other survivors developing physical late effects, such as congestive heart failure or second malignancies, years following treatment. The fear of developing a new health problem may sometimes lead to avoidance of long-term follow-up appointments in the hope that new problems will not be "discovered". It is important to help survivors understand that participating in long-term follow-up will not cause complications to happen, and that regular long-term follow-up allows these complications to be caught early, when they are most treatable.

> ***"I didn't come to the long-term follow-up clinic for a very long time. I thought 'I am done with that – I've paid my dues – I don't want to know if anything else can go wrong.' I was really scared that they would find something seriously wrong with me, and that I just couldn't face having to deal with that, so I thought I would just take my chances.***
>
> ***. . . But then, gradually, I began to realize that if I didn't take charge, the cancer and everything I had gone through was going to take charge of me. Because it was always there, in the back of my mind, and I was always worried about what might happen. So I finally went in for a visit, and now I know the risks that I face. And I actually feel better knowing that, because now I have a plan to deal with it, and I know the things I can do to keep myself as healthy as possible. And if anything does go wrong, they'll catch it early, and I'll have a better chance of beating it. So, I never miss my appointments anymore."***
>
> ***- Laura, Survivor***

Fear of Recurrence: Possibly the most universally talked about "issue" facing survivors is a very intense, sometimes debilitating fear of their cancer coming back. Parents and survivors should have the discussion, support, and information available to them at LTFU clinics to address this fear. This is one area in particular where the "voice" of other survivors aids in easing the two-fold anxiety: (1) that the cancer will come back and (2) that you are obsessing about the cancer coming back.

> ***"I am constantly fighting a battle inside my head. One side of me constantly worrying that I will get sick again, the other side fighting what could become my obsession. It helps me so much to hear that other survivors are feeling the same way. At least I know this is normal."***
>
> ***- Angie, Survivor***

Social Relationships: Having experienced a life-threatening situation at such an early age certainly affects the social relationships of the survivor and the family. Survivors struggle with many questions: How do I tell people I am a cancer survivor? What are people going to think? Why do people not understand me? Will anyone want to date me? Is it okay for me to have sex or be on birth control pills? Will my parents ever let go of me enough to let me be a 'normal' teenager/young adult? These are just a few of the many questions facing survivors as they approach different stages and situations in life. Again, open and frank discussion of these sensitive topics may prevent unnecessary hurt and stress.

> ***"I can't have kids because of my treatment. When do I tell a girl that? Do I wait until we are really involved, or should I tell her upfront? What woman is going to want to be with a man who can't have kids? I am trusting the right person is out there for me, but it is something I struggle with daily."***
>
> ***- Jon, Survivor***

Self-Esteem/ Self-Confidence Issues:

Depending on the type of treatment they received, survivors may face possible life-long effects of cancer, such as an amputation or cognitive damage. If the impact of these effects is not addressed in terms of self-esteem, a person's ability to function in particular situations can be adversely affected. Low self-esteem can also severely limit a person's visions and goals. Discussion and support of this particular issue is vital in LTFU clinic visits. Learning to advocate for oneself generally increases self-esteem and confidence.

Long-Term Physical Effects of Treatment. Managing the long-term physical effects of treatment is an overwhelming, daunting, and complicated task for most survivors. Without a central location, such as a LTFU clinic, from which to coordinate follow-up, many survivors are left without appropriate follow-up care. Appropriate information must be given out at each clinic visit to ensure the education of the survivor. Ultimately, the survivor knows his/her own body best. Still she/he must be "armed" with evidence to present to family care practitioners, ER doctors, or others with whom the survivor comes in contact.

> ***"I went to student health for something little. After I rattled off my long medical history, the doctor was afraid to treat me and wanted to order several unnecessary tests. It is very frustrating to know more than the doctors about yourself and have to convince people all the time of what you know is right. Survivors need help coordinating their care."***
>
> ***- Kara, Survivor***

Appropriate information should be given to survivors regarding late effects of treatment and appropriate screening. In addition, LTFU clinic visits should include discussion and teaching regarding potential cognitive changes, the developmental implications of cancer therapy during childhood, how to talk to other healthcare providers about issues related to childhood cancer survivorship, and preparation for the transition to the adult healthcare system.

Table 8: Information and Resources for Survivors

About Face
http://www.aboutfaceusa.org
888-486-1209
- Oral, Head and Neck

Alliance for Technology Access
http://www.ataccess.org
- Technology access resources for children and adults with disabilities

American Association of Sex Educators, Counselors & Therapists
http://www.aasect.org
319-895-8407
- Fertility & Sexuality

American Brain Tumor Association
http://www.abta.org
800-886-2282
- Brain

American Cancer Society (ACS)
http://www.cancer.org
800-ACS-2345 (227-2345)
- General Resources
- Insurance/Financial Assistance

American Chronic Pain Association
http://www.theacpa.org
916-632-0922
- Pain Management

American Pain Foundation
http://www.painfoundation.org
888-615-PAIN (7246)
- Pain Management

Association of Cancer Online Resources
http://www.acor.org
212-226-5525
- Cancer Information
- On-line peer support

Blood & Marrow Transplant Information Network
http://www.bmtnews.org
888-597-7674
- Bone Marrow Transplants

The Brain Tumor Society
http://www.tbts.org
800-770-8287
- Brain

Cancer Care, Inc.
http://www.cancercare.org
800-813-HOPE (4673)
- General Resources
- Patient Support

Cancer Hope Network
http://www.cancerhopenetwork.org
877-HOPENET (467-3638)
- Patient Support

Cancer Information Service
(National Cancer Institute)
http://www.cancer.gov
800-4-CANCER (422-6897)
- General Resources

Cancer Research & Prevention Foundation
http://www.preventcancer.org
800-227-CRFA (227-2732)
- Prevention
- Research

Candlelighters Childhood Cancer Foundation
http://www.candlelighters.org
800-366-2223
- Pediatric & Young Adult

Childhood Cancer Survivors: A Practical Guide to Your Future
http://www.oreilly.com/catalog/chsurviv2/
- Guidebook to Survivorship Issues

The Children's Cause
http://www.childrenscause.org
301-562-2765
- Pediatric & Young Adult

Coalition of National Cancer Cooperative Groups
http://www.cancertrialshelp.org
877-520-4457
- Clinical Trials

CureSearch
http://www.curesearch.org
800-458-6223
- Pediatric & Young Adult
- Cancer Information
- Research/Clinical Trials
- Survivorship Guidelines & Information

Table 8: Information and Resources for Survivors (continued)

Employment Discrimination Advocacy
http://www.washlaw.edu/subject/emp.html
- Employment Discrimination Resources

Family Caregiver Alliance (FCA)
http://www.caregiver.org
800-445-8106
- Caregiving/Family Support

Fertile Hope
http://www.fertilehope.org
888-994-HOPE
- Fertility & Sexuality

Genetic Alliance
http://www.geneticalliance.org
202-966-5557
- Genetic Discrimination

Gilda's Club Worldwide
http://www.gildasclub.org
888-GILDA-4-U
- Patient Support

Group Loop
http://www.grouploop.org
- Teens with Cancer

Healthcare Transitions
http://hctransitions.ichp.ufl.edu/resources.html
- Transition Resources

http://mchnetlinkplus.ichp.edu/training_materials.html
- Transition Training Materials

Health Links
http://www.survivorshipguidelines.org
- Individual Survivorship Topics

i[2]y
http://imtooyoungforthis.org
- Young Adults with Cancer
- Blogs

Intercultural Cancer Council (ICC)
http://www.icc.bcm.tmc.edu
713-798-4617
- Minority/Special Population

Kidney Cancer Association
http://www.kidneycancerassociation.org
800-850-9132
- Kidney cancer

Lance Armstrong Foundation
http://www.laf.org
512-236-8820
- Education and Research

Let's Face It
http://www.faceit.org
360-676-7325
- Oral, Head and Neck

The Leukemia & Lymphoma Society
http://leukemia-lymphoma.org
800-955-4572
- Leukemia & Lymphoma

Lymphoma Research Foundation (LRF)
http://www.lymphoma.org
800-500-9976
- Lymphoma

National Bone Marrow Transplant Link
http://www.nbmtlink.org
800-LINK-BMT (546-5268)
- Bone Marrow Transplants

National Brain Tumor Foundation
http://www.braintumor.org
800-934-CURE (2873)
- Brain

National Cancer Institute (NCI)
http://www.cancer.gov
800-4-CANCER (422-6897)
- Research & Information
- Clinical Trials

National Children's Cancer Society
http://www.beyondthecure.org
314-241-1600
- Support of local late effects programs
- Educational programs for families

National Coalition for Cancer Survivorship
http://www.canceradvocacy.org
877-NCCS-YES (622-7937)
- General & Online Resources
- Programs & Publications

Planet Cancer
http://www.planetcancer.org
- Young Adults with Cancer
- On & Off Treatment Issues

Special Education Advocacy
http://www.wrightslaw.com
- Special Education Laws
- Advocacy for Children with Disabilities

EDUCATIONAL ISSUES

Cancer treatment and late-effects can have a negative impact on the survivor's education.[39] Treatment may have caused the child to miss an inordinate amount of school, resulting in difficulty returning to school, missed assignments and tests, and missed opportunities to grasp facts and concepts. When patients return to school, treatment-related fatigue, frequent absences for scheduled treatments or for unscheduled treatment-related complications, and difficulties with fine and gross motor skills resulting from cancer treatment all set them apart physically and socially from their classmates. Many survivors fall behind their peers academically.

Educational Assessment and Planning

One of the most serious effects related to treatment involving the central nervous system in childhood cancer survivors is cognitive impairment. Learning difficulties, social difficulties, behavioral adjustment problems, and long-term educational and vocational difficulties may occur.[5] The signs of possible learning difficulties may include problems with:

- Handwriting
- Spelling
- Reading and comprehension
- Understanding math facts and concepts
- Difficulty in sequencing
- Auditory or visual processing
- Attention deficits
- Short-term memory and information retrieval
- Planning and organizational skills
- Social maturity and social skills

Neuropsychological testing is done routinely for children with certain cancers, such as brain tumors, or for children requiring cranial radiation or intrathecal chemotherapy. However, all patients should be monitored for difficulties such as those outlined above, and offered psychological testing to target any learning disabilities.

Neuropsychological assessment of the patient may begin with a referral from the oncology department to the pediatric psychologist, or through a referral from the survivor's school psychologist. Based on the results of these tests, the survivor may be eligible for supportive educational programs such as tutoring, remedial classes for certain difficult subjects, and Individualized Educational and/or Transition Plans (IEPs/ITPs) that are tailored to meet the survivor's specific academic needs.

Educational Interventions

Examples of classroom strategies that may be helpful for survivors with educational problems related to their treatments include:

- Preferential seating in classroom
- Minimizing the amount of written work required
- Use of tape-recorders
- Use of computer keyboards instead of handwriting
- Use of calculators for math
- Modification of test requirements (extra time, oral instead of written exams)
- Extra help with math, spelling, reading, and organizational skills
- Assignment of a classroom aide

Parents may wish to enlist the help of a private tutor or consider home-schooling if they feel their child's needs are not being adequately met; however, this may not be financially feasible for many families.

> ***"The school worked with us to help John in school, especially in reading and math, but they admitted they didn't have the staff or resources to make an impact on his special learning needs. We finally decided to home-school him so that we could focus on his problem areas."***
>
> ***- Sharon***
> ***Mother of 7-year-old ALL patient***

Legal Issues

Some of the laws in the United States that protect the rights of students with learning disabilities related to cancer treatment include:

Rehabilitation Act of 1973 – Section 504

This legislation mandates that every public school and every educational institution in the United States receiving federal funding (including colleges and universities) must provide accommodations for students with a physical or mental impairment which substantially limits one or more major life activities. Cancer is one of the qualifying conditions for services. Additional conditions include hearing problems, vision problems, learning disabilities, speech disorders, and orthopedic limitations. Detailed information regarding Section 504 is available at http://www.hhs.gov/ocr/504.html.

The Individuals with Disabilities Education Act of 2004 (IDEA 2004)

The major provisions of this law insure a free and appropriate education in the least restrictive environment to all students with a physical or mental impairment which substantially limits one or more life activities. A student with the qualifying condition of cancer is eligible for the following services free of charge:

- Special education programs
- Speech therapy
- Occupational and physical therapy
- Psychiatric services
- Alternative communication techniques and technology, such as oral tests or the use of a computer for taking notes
- And other interventions or exemptions from rules and policies as needed to help the child learn

Under this act, a student can qualify for special education services by initiating an Individualized Education Plan, or IEP, through their school. Once an IEP is requested, the child will be evaluated and tested by a school psychologist to determine if services are required. Following this assessment, teachers and parents meet to discuss the testing results and develop the student's individualized plan. If parents disagree with the IEP, feel that the IEP is inadequate, or that it is not being followed correctly, they can withdraw consent and ask that a new IEP be drafted, or request a review by an independent hearing officer. Additional information about the IDEA law is available at http://idea.ed.gov and from the National Information Center for Children and Youth with Disabilities (phone: 1-800-695-0285; website www.nichcy.org).

Americans with Disabilities Act of 1990

The ADA law protects against discrimination of disabled people with regard to employment, transportation, communication, and access to public facilities, spaces, events and opportunities. It is important for survivors with disabilities, or their caregivers, to have adequate knowledge of this act as it pertains to school, higher education (Student Disability Services), and potential employment. This information is available at www.ada.gov.

Special Education Advocacy

The field of special education is complex, and navigating the educational system can be challenging. A wealth of information and assistance with special education issues is available at advocacy-oriented websites such as www.wrightslaw.com.

EMPLOYMENT ISSUES

Cancer affects a person on a physical, emotional, and psychological level. In some survivors, the effects of treatment are minimal, but in others, the effects can be disabling. As a childhood cancer survivor enters the period in their life when employment becomes a practical matter, the type of job or career they choose may be influenced by physical, emotional, and psychological response to treatment.[40]

Perhaps the survivor has a physical disability that makes it difficult to work in a job that is physically taxing, involving activities such as lifting, walking, balancing, or seeing clearly. Perhaps a survivor has had to deal with emotional issues that might preclude employment that involve activities such as meeting new people, being in a crowd, or being self-motivated, or that may arouse feelings of stress, depression, or anger. A survivor may have psychological or cognitive issues as a result of treatment that would make it difficult to work with numbers and letters, organize ideas, or remember details and recall them later. For some survivors, these issues will not affect their career choices, but for those who live with significant late effects from cancer treatment which have an impact on career options, support services are available.

Vocational/Career Choice Considerations

Vocational education prepares learners for careers that are traditionally non-academic, based on manual or practical activities, and directly related to a specific trade, occupation, or vocation. Vocational education is sometimes also referred to as "technical education," because the learner develops expertise in a particular group of techniques or technology. Vocational education generally focuses on specific trades such as an automobile mechanic, welder, plumber, electrician, or nurses' aide. At the post-secondary level, vocational education is typically provided by an institute of technology or by a local community college.

School-to-work transition refers to on-the-job training, apprenticeships, cooperative education agreements or other programs designed to prepare students to enter the job market. These programs expose middle and high school students to potential future careers.

Rehabilitation services programs assist individuals with disabilities to achieve employment and self-sufficiency. Training programs may include:

- Automotive technology
- Business support services
- Millwork
- Culinary arts
- Custodial
- Grounds maintenance/landscaping
- Machine technology
- Nurse assistant
- Retail

Support services offered often include:

- Career assessment/planning
- Reading and math remediation
- High school completion
- Nursing and psychiatric services
- Occupational therapy
- Accommodation services
- Job placement services

In the United States, qualification requirements for rehabilitation and vocational training vary by state. For further information, contact the Department of Education or Office of Vocational and Adult Education in your state, or visit www.ed.gov.

Legal Issues Related to Employment

While medical care is essential for childhood cancer survivors, it is just as important for them to return to their "normal" life as soon as possible, especially with regard to employment or searching for employment. Unfortunately, cancer survivors are sometimes treated unfairly due to preconceived ideas about cancer that may lead employers to make inaccurate assumptions about a cancer survivor's ability to work. It is important for employers to understand issues facing workers with a history of cancer. In order to counteract the possibility of workplace discrimination, survivors must promote a new understanding of their ability to contribute to the workforce. The key to this new understanding is education and communication with potential employers.

Employment discrimination laws. In the United States, the Americans with Disabilities Act (ADA) and Federal Rehabilitation Act prohibit certain types of job discrimination by employers against people who have had cancer. Under federal law and in many state laws, an employer with 15 or more employees cannot treat cancer survivors differently from other workers because of a cancer history, as long as the survivor is qualified for the job in question.

A prospective employer may not ask about health history during an interview unless there is a visible disability that the employer believes may affect the potential employee's ability to perform the job. This law also requires an employer to provide “reasonable accommodations” for employees during or following cancer treatments. This may include time off or changes in work hours. However, an employer does not have to make changes that would cause the company an “undue hardship.” For example, if an employee had to take time away from work that would prove costly or disruptive to the operation of the business, the employer may replace the employee. It is therefore always important for the employee to speak with a supervisor to discuss alternatives to missed work days or potential solutions to any problems the employee may be having in performing assigned job duties.

Family Medical Leave Act. The Family Medical Leave Act (FMLA) requires employers with 50 or more employees to provide up to 12 weeks of unpaid, job-protected leave for family members who need time off due to their own illness or to care for a seriously ill family member. The employee must have been employed for one year and must have worked for at least 25 hours per week. Some provisions under the act are:

- Provides 12 weeks of unpaid leave during any 12 month period
- Requires employers to continue to provide health insurance benefits during the leave period
- Requires employers to restore employees to the same or an equivalent position at the end of the leave period
- Allows intermittent or reduced work schedule when medically necessary
- Requires employees to make reasonable efforts to schedule foreseeable medical care so as not to disrupt the workplace unduly

Federal Equal Employment Opportunity (EEO) Laws. Federal laws in the United States prohibiting job discrimination are:

***Equal Pay Act of 1963* (EPA)**:
Protects men and women who perform substantially equal work in the same establishment from sex-based wage discrimination

***Civil Rights Act of 1964* (Title VII)**:
Prohibits employment discrimination based on race, color, religion, sex, or national origin

Age Discrimination in Employment Act of 1967 (ADEA): Protects individuals who are 40 years of age or older

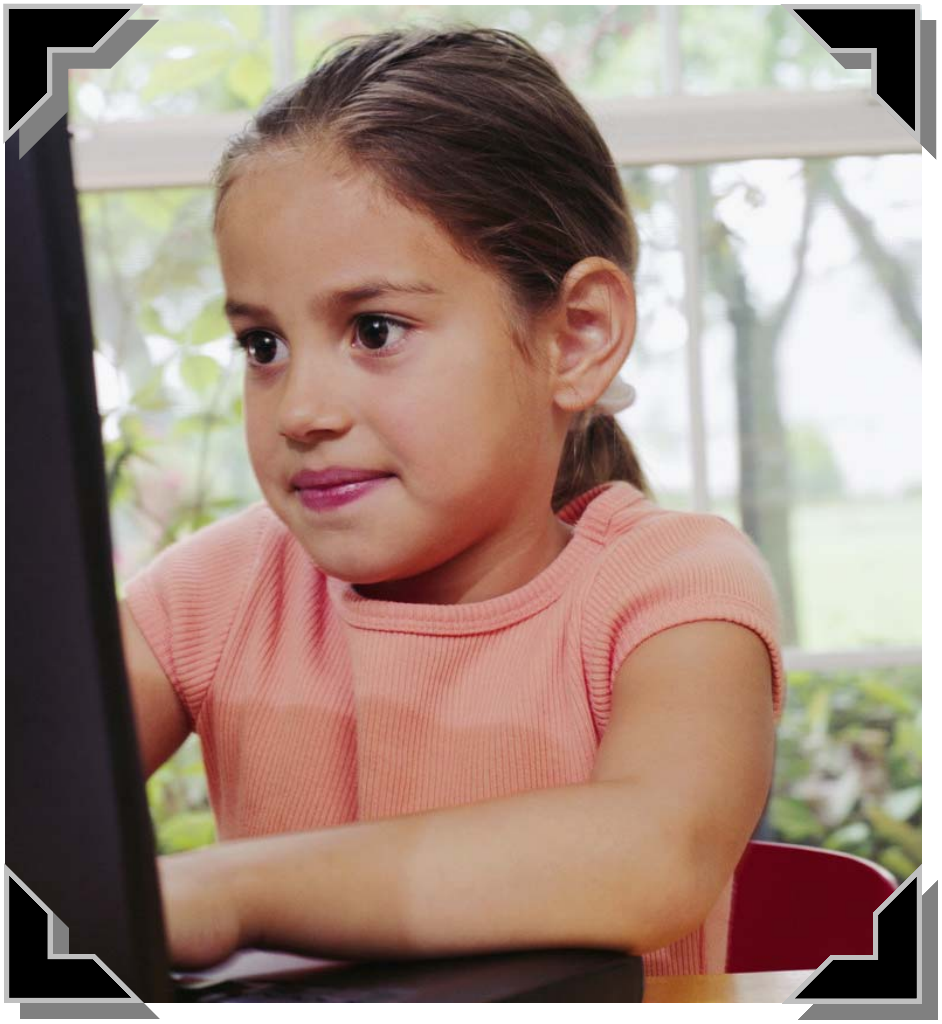
Rehabilitation Act of 1973, Sections 501 and 505: Prohibits discrimination against qualified individuals with disabilities who work in the federal government

Americans with Disabilities Act (ADA) of 1990, Titles I and V: Prohibits employment discrimination against qualified individuals with disabilities in the private sector, and in state and local governments

Civil Rights Act of 1991:

Provides monetary damages in cases of intentional employment discrimination

The U.S. Equal Employment Opportunity Commission (EEOC) enforces all of these laws. EEOC also provides oversight and coordination of all federal equal employment opportunity regulations, practices, and policies. Additional information regarding employment discrimination, including links to websites, resources and listservs is available on the Washburn Law website at http://www.washlaw.edu/subject/emp.html.



INSURANCE ISSUES

Health insurance coverage is an important issue for everyone, but it is particularly important for cancer survivors due to their unique needs for follow-up care related to their treatment.[40] There are many types of policies available to the public, although not all offer the same coverage.

Obtaining Insurance

Private insurance. Most people who obtain insurance through their employer have what is called private comprehensive health coverage. This type of coverage generally pays for all basic healthcare needs, such as hospital and physician care, tests, medical equipment, supplies, and prescription drug coverage. The most common types of private insurance plans are the indemnity or "fee-for-service" plan, the managed care or "HMO" plan, the preferred provider organization or "PPO" plan and the point-of-service or "POS" plan. The defining differences in these policies are the amount of money the individual is required to pay in the form of premiums, deductibles and co-payments, and the choice of medical providers and hospitals to which the patient has access.

Public insurance coverage. Instead of private insurance, some people are eligible for health insurance through the government. Qualifications are based on age, income, health status and/or disability. Medicare and Medicaid are the largest public programs in the United States and are available in every state.

Medicare. Medicare is provided by the United States government. Survivors may qualify for Medicare for a variety of reasons, such as disability (regardless of age) or collection of Social Security benefits for 2 years. Further information is available at www.medicare.gov/MedicareEligibility.

Medicaid. Medicaid is also a United States government program that provides health insurance to those with limited incomes. Additional qualification requirements for Medicaid vary by state and may include age, disability, pregnancy, or having a dependent child. Some types of cancer and/or cancer treatment are considered disabilities. Additional information regarding Medicaid eligibility criteria is available at www.cms.hhs.gov/MedicaidEligibility .

State Children's Health Insurance Program (S-CHIP). Health insurance for low-income, uninsured children under the ages of 19 or 21 (depending on the state) is available through the State Children's Health Insurance Program (S-CHIP). Generally, this is a form of public insurance associated with the Medicaid program in each state. Further information is available at www.cms.hhs.gov/schip.

Preventing loss of insurance coverage. If survivors find themselves in a situation where they are about to lose their health insurance coverage (either private or public), it is imperative for them to obtain alternate insurance prior to the end of their current policy coverage. It can often be very difficult to obtain insurance after a lapse in policies. Medical Social Workers or Patient Billing Representatives are often helpful in providing assistance for survivors in this situation.

Supplemental Security Income (SSI). The Supplemental Security Income (SSI) program provides coverage (such as insurance and financial assistance) to individuals with disabilities who qualify for federal disability benefits in the United States.[41] Eligible children must have evidence of severe functional limitations related to a condition that is expected to last at least 12 months. Cancer and its treatment are often qualifying events for this program. A Medical Social Worker can often assist survivors in accessing SSI information. Additional information is available through the Social Security Administration (www.ssa.gov/d&s1).

Legal Issues

Barriers to obtaining insurance coverage. It is not uncommon for cancer survivors to encounter barriers to obtaining health insurance coverage, including refusal of new applications, policy cancellation or reduction, higher premiums, excluded pre-existing conditions, and extended waiting periods.[36] Among survivors of childhood cancer, problems obtaining health insurance may be compounded because most survivors have been insured under family-related policies prior to their cancer diagnosis.[40]

Adolescents and young adults may be especially vulnerable to insurance problems as they "age out" of coverage from their parents' policies or from public insurance, because they may also encounter other common barriers facing young adults, such as not having an employer that offers health insurance benefits, and the prohibitive costs of individual private insurance. For those survivors who do obtain or retain insurance, there may be difficulties in obtaining reimbursement for costs associated with screening intended to prevent or reduce the impact of cancer-related late effects, because these tests are often not included as benefits offered by health insurance plans.

Insurance-related laws: In the United States, three federal laws provide some protection for survivors related to health insurance obtained from employment:

- **Americans with Disabilities Act** (ADA 42 U.S.C. 12101 et seq.): Prohibits employers from denying health insurance to cancer survivors if other employees with similar jobs receive insurance
- **Health Insurance Portability and Accountability Act (HIPAA):** Helps cancer survivors retain their health insurance by:
  - Allowing individuals who have been insured for the previous 12 months to change jobs without losing coverage
  - Preventing group health plans from denying coverage based on past or current health status
  - Ensuring portability of insurance for those changing from group to individual insurance coverage
  - Requiring that health plans renew coverage for groups and individuals in most cases
- **The Consolidated Omnibus Budget Reconciliation Act (**COBRA PL 99272): Requires employers to offer group medical coverage to employees and their dependents who otherwise would have lost their group coverage due to individual circumstances. This law applies to public and private employers with 20 or more employees. By allowing survivors to keep group insurance for a limited time, COBRA allows time for the survivor to search for and obtain alternative long-term coverage.

Cancer survivors who are having trouble getting insurance authorization for follow-up care may need the LTFU clinic staff to provide letters justifying the rationale for these services. Survivors who are having difficulty obtaining or maintaining insurance coverage should contact the Medical Social Work Department at their institution for assistance.

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APPENDIX 1: COG Resources

- **Sample Section from *COG Long-Term Follow-Up Guidelines***
- **Sample COG *Health Link***
- **COG Treatment Summary Templates:**
  - **Abbreviated**
  - **Comprehensive**
- **Late Effects Web Forum**
- **Late Effects Directory of Services**

RESOURCES AVAILABLE FROM COG

Long-Term Follow-Up Guidelines

The Children's Oncology Group's *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*, with instructions for use, are available at www.survivorshipguidelines.org (click on "Long-Term Follow-Up Guidelines") [see Figure 2].

The *LTFU Guidelines* and accompanying materials are updated periodically by the COG Late Effects Task Forces; therefore, it is advisable to check the website periodically for updates.

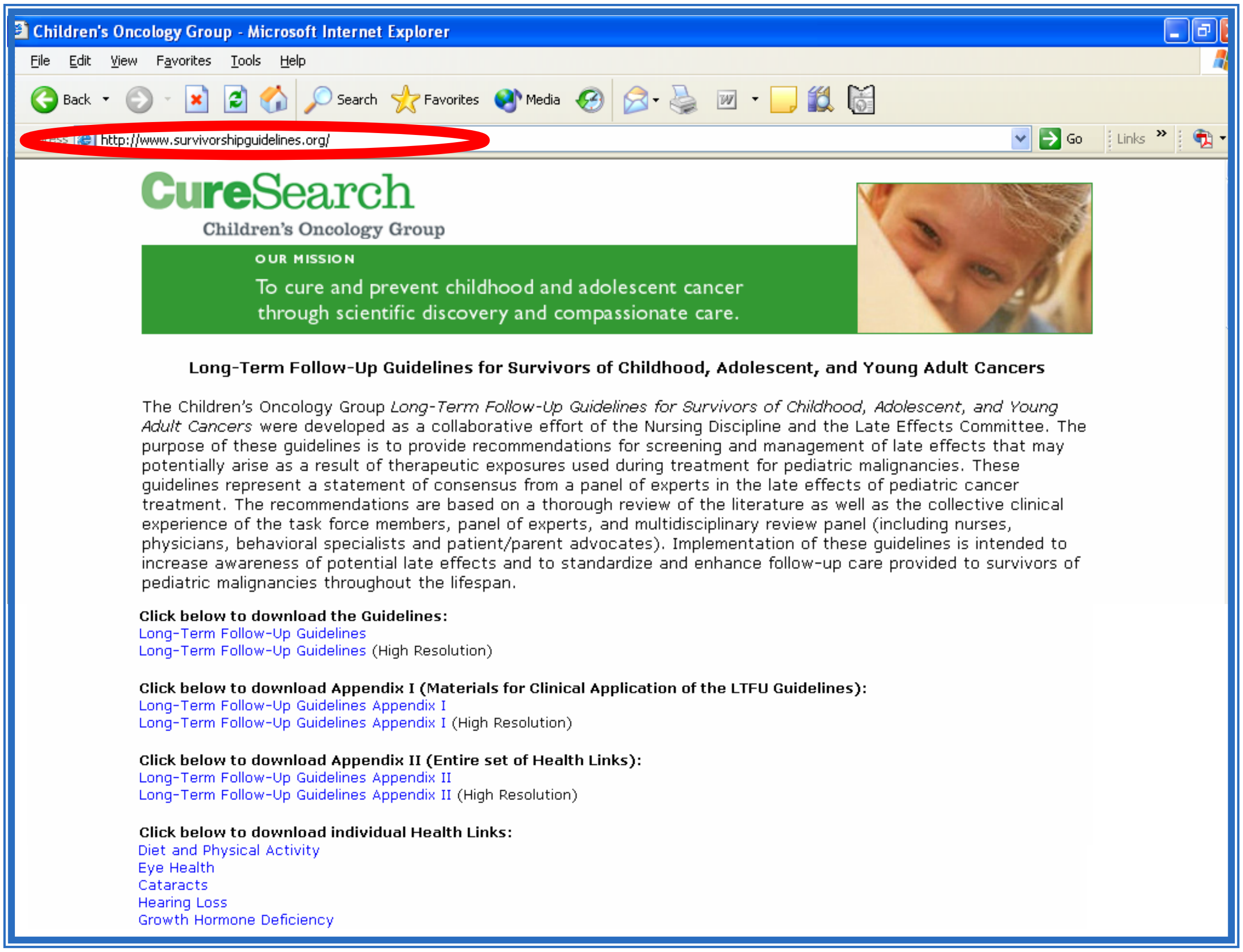
Summary Form Templates

Templates and instructions for creating Cancer Treatment Summary Forms (in abbreviated and comprehensive formats) are available by clicking on "Appendix I" at www.survivorshipguidelines.org [see Figure 2].

Health Links

Patient education materials, known as "Health Links," expand upon topics from the *Long-Term Follow-Up Guidelines* in lay language format. All 42 “Health Links” are available by clicking on "Appendix 2" at www.survivorshipguidelines.org [see Figure 2].

Figure 2: COG Long-Term Follow-Up Guidelines Website
www.survivorshipguidelines.org



Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers

The Children's Oncology Group *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* were developed as a collaborative effort of the Nursing Discipline and the Late Effects Committee. The purpose of these guidelines is to provide recommendations for screening and management of late effects that may potentially arise as a result of therapeutic exposures used during treatment for pediatric malignancies. These guidelines represent a statement of consensus from a panel of experts in the late effects of pediatric cancer treatment. The recommendations are based on a thorough review of the literature as well as the collective clinical experience of the task force members, panel of experts, and multidisciplinary review panel (including nurses, physicians, behavioral specialists and patient/parent advocates). Implementation of these guidelines is intended to increase awareness of potential late effects and to standardize and enhance follow-up care provided to survivors of pediatric malignancies throughout the lifespan.

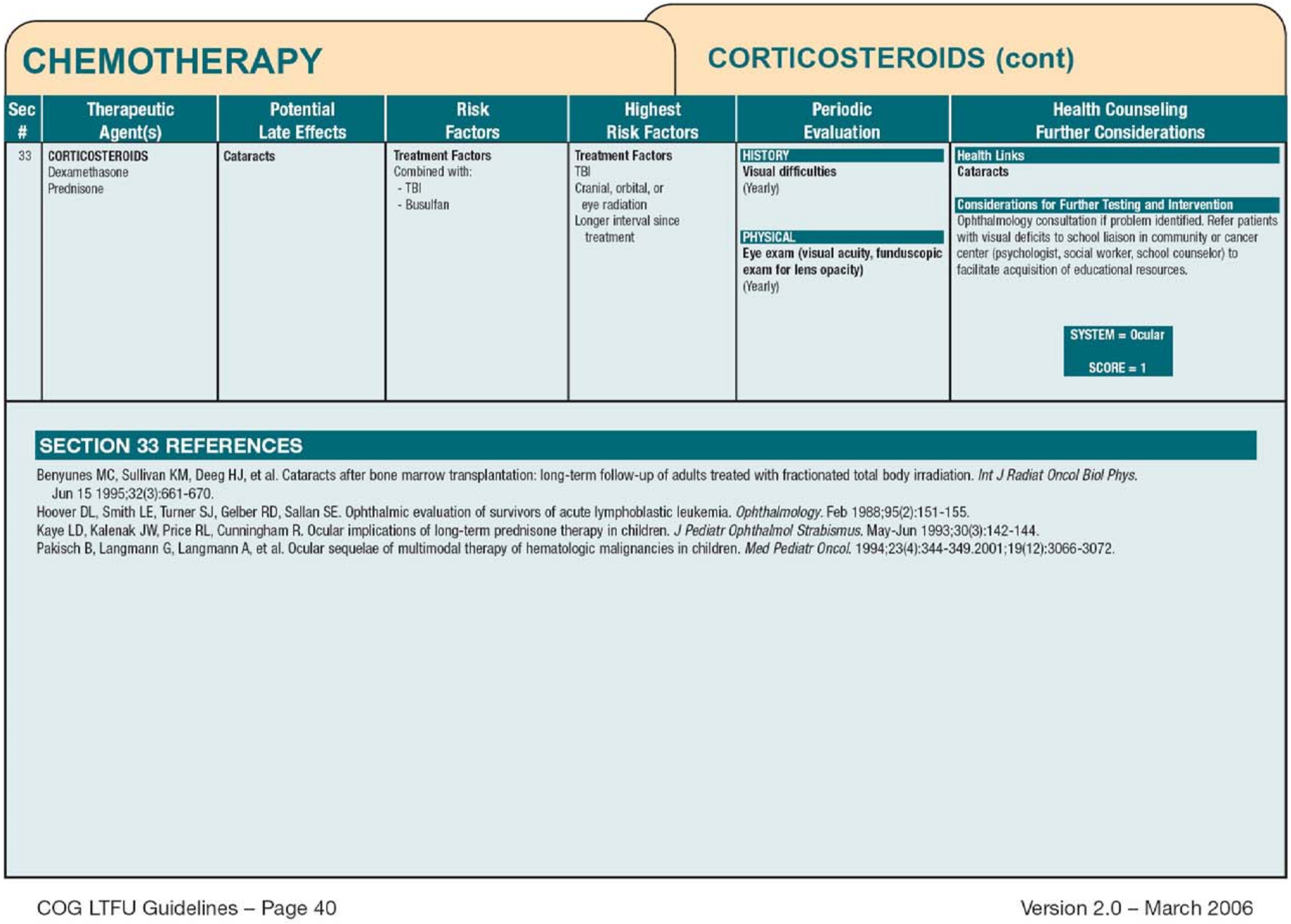
Click below to download the Guidelines:
Long-Term Follow-Up Guidelines
Long-Term Follow-Up Guidelines (High Resolution)

Click below to download Appendix I (Materials for Clinical Application of the LTFU Guidelines):
Long-Term Follow-Up Guidelines Appendix I
Long-Term Follow-Up Guidelines Appendix I (High Resolution)

Click below to download Appendix II (Entire set of Health Links):
Long-Term Follow-Up Guidelines Appendix II
Long-Term Follow-Up Guidelines Appendix II (High Resolution)

Click below to download individual Health Links:
Diet and Physical Activity
Eye Health
Cataracts
Hearing Loss
Growth Hormone Deficiency

Figure 3: Sample page from COG *Long-Term Follow-Up Guidelines*
(Entire set of *COG LTFU Guidelines* is available at www.survivorshipguidelines.org)



CHEMOTHERAPY

CORTICOSTEROIDS (cont)

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
33	**CORTICOSTEROIDS** Dexamethasone Prednisone	**Cataracts**	**Treatment Factors** Combined with: - TBI - Busulfan	**Treatment Factors** TBI Cranial, orbital, or eye radiation Longer interval since treatment	**HISTORY** **Visual difficulties** (Yearly) **PHYSICAL** **Eye exam (visual acuity, funduscopic exam for lens opacity)** (Yearly)	**Health Links** **Cataracts** **Considerations for Further Testing and Intervention** Ophthalmology consultation if problem identified. Refer patients with visual deficits to school liaison in community or cancer center (psychologist, social worker, school counselor) to facilitate acquisition of educational resources. **SYSTEM = Ocular** **SCORE = 1**

SECTION 33 REFERENCES

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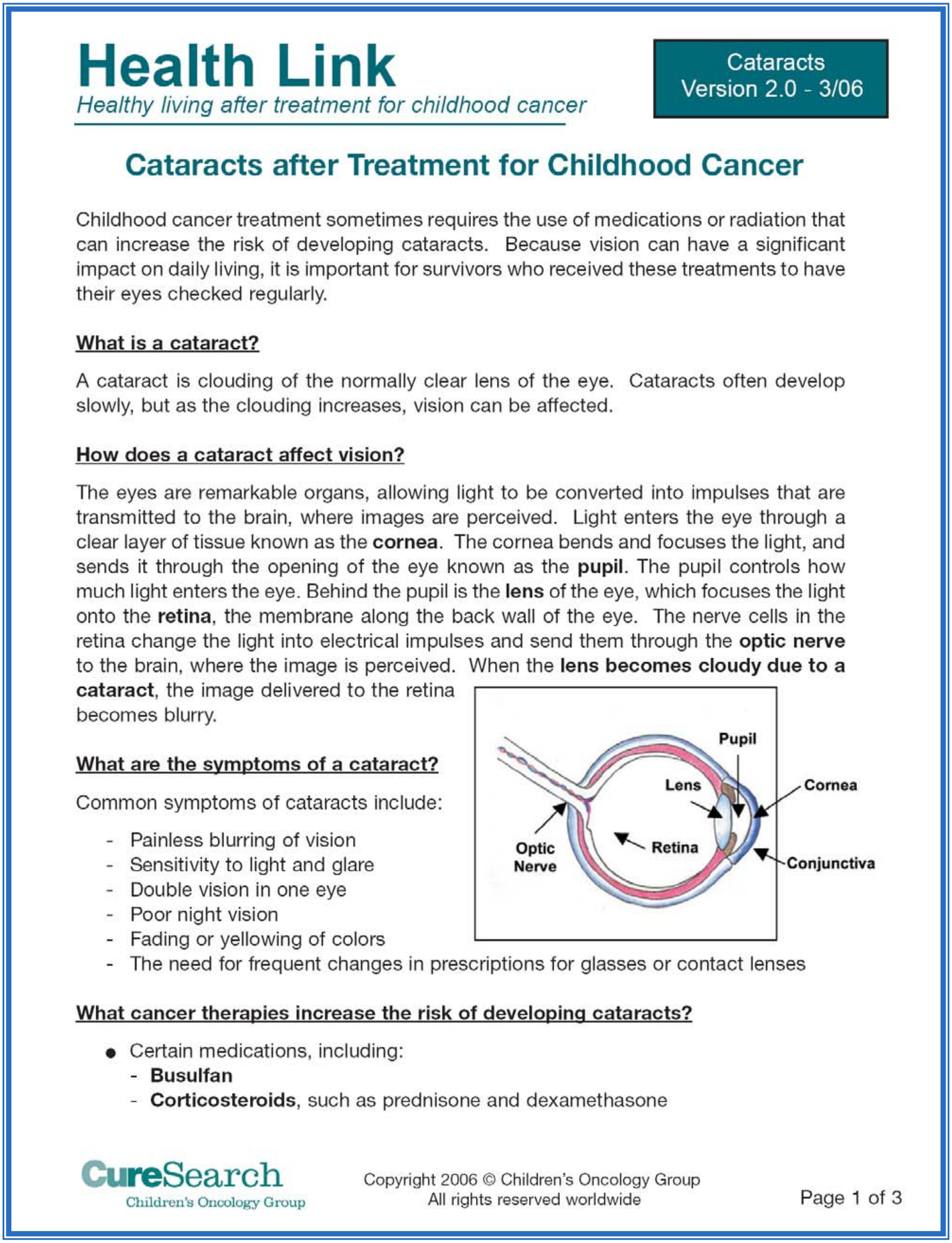
Version 2.0 – March 2006

Figure 4: Sample page from COG *Health Link*
(Entire set of *Health Links* is available at www.survivorshipguidelines.org)



Health Link

Healthy living after treatment for childhood cancer

Cataracts
Version 2.0 - 3/06

Cataracts after Treatment for Childhood Cancer

Childhood cancer treatment sometimes requires the use of medications or radiation that can increase the risk of developing cataracts. Because vision can have a significant impact on daily living, it is important for survivors who received these treatments to have their eyes checked regularly.

What is a cataract?

A cataract is clouding of the normally clear lens of the eye. Cataracts often develop slowly, but as the clouding increases, vision can be affected.

How does a cataract affect vision?

The eyes are remarkable organs, allowing light to be converted into impulses that are transmitted to the brain, where images are perceived. Light enters the eye through a clear layer of tissue known as the **cornea**. The cornea bends and focuses the light, and sends it through the opening of the eye known as the **pupil**. The pupil controls how much light enters the eye. Behind the pupil is the **lens** of the eye, which focuses the light onto the **retina**, the membrane along the back wall of the eye. The nerve cells in the retina change the light into electrical impulses and send them through the **optic nerve** to the brain, where the image is perceived. When the **lens becomes cloudy due to a cataract**, the image delivered to the retina becomes blurry.

What are the symptoms of a cataract?

Common symptoms of cataracts include:

- Painless blurring of vision
- Sensitivity to light and glare
- Double vision in one eye
- Poor night vision
- Fading or yellowing of colors
- The need for frequent changes in prescriptions for glasses or contact lenses

What cancer therapies increase the risk of developing cataracts?

- Certain medications, including:
  - **Busulfan**
  - **Corticosteroids**, such as prednisone and dexamethasone

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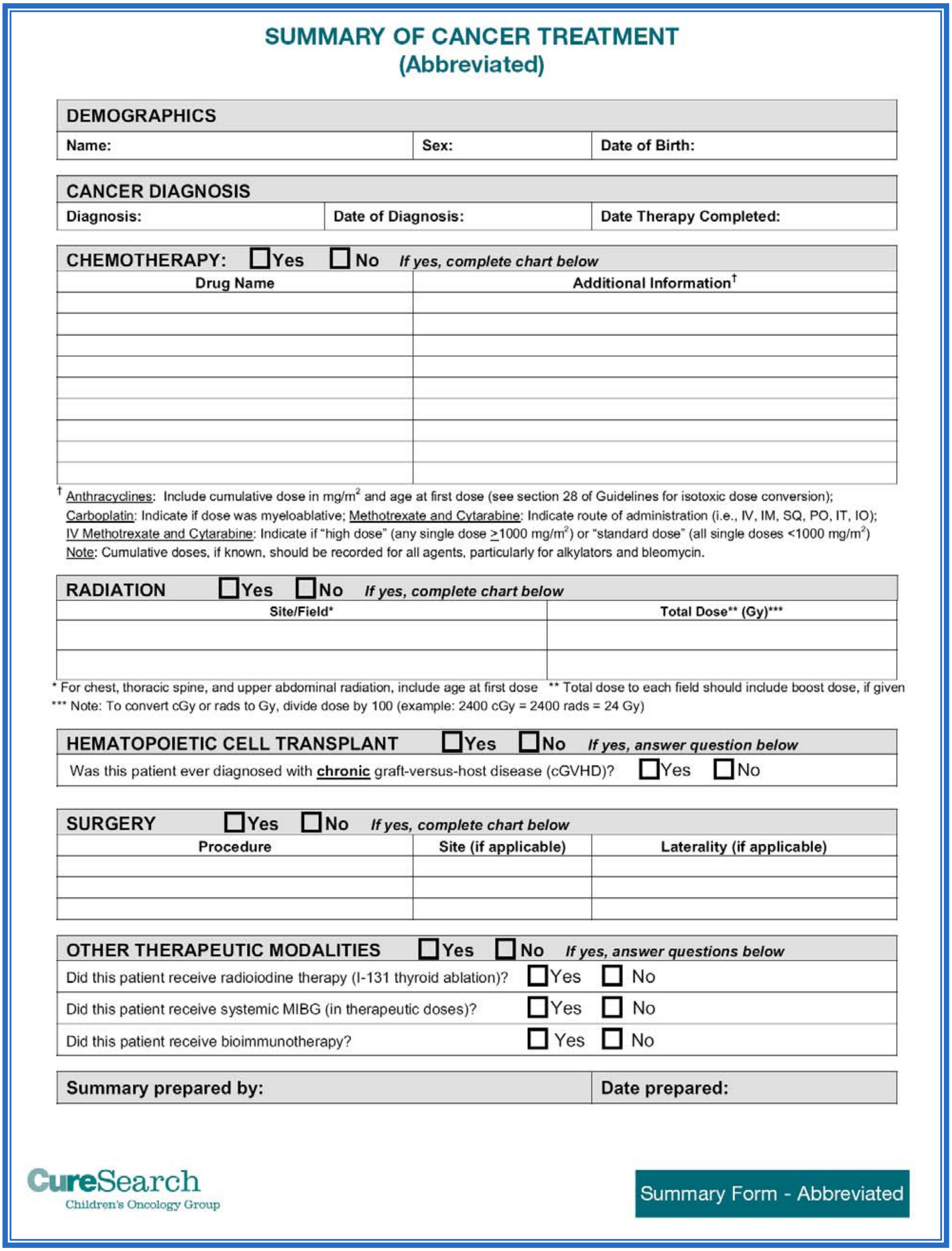
Figure 5: Abbreviated treatment summary
(Summary form and instructions are available at www.survivorshipguidelines.org)



SUMMARY OF CANCER TREATMENT
(Abbreviated)

DEMOGRAPHICS		
Name:	**Sex:**	**Date of Birth:**

CANCER DIAGNOSIS		
Diagnosis:	**Date of Diagnosis:**	**Date Therapy Completed:**

CHEMOTHERAPY: ☐ Yes ☐ No *If yes, complete chart below*

Drug Name	**Additional Information**†

† Anthracyclines: Include cumulative dose in mg/m^2 and age at first dose (see section 28 of Guidelines for isotoxic dose conversion); Carboplatin: Indicate if dose was myeloablative; Methotrexate and Cytarabine: Indicate route of administration (i.e., IV, IM, SQ, PO, IT, IO); IV Methotrexate and Cytarabine: Indicate if "high dose" (any single dose $\geq$1000 mg/m^2) or "standard dose" (all single doses <1000 mg/m^2)
Note: Cumulative doses, if known, should be recorded for all agents, particularly for alkylators and bleomycin.

RADIATION ☐ Yes ☐ No *If yes, complete chart below*

Site/Field*	**Total Dose** (Gy)*****

* For chest, thoracic spine, and upper abdominal radiation, include age at first dose ** Total dose to each field should include boost dose, if given
*** Note: To convert cGy or rads to Gy, divide dose by 100 (example: 2400 cGy = 2400 rads = 24 Gy)

HEMATOPOIETIC CELL TRANSPLANT ☐ Yes ☐ No *If yes, answer question below*

Was this patient ever diagnosed with **chronic** graft-versus-host disease (cGVHD)? ☐ Yes ☐ No

SURGERY ☐ Yes ☐ No *If yes, complete chart below*

Procedure	**Site (if applicable)**	**Laterality (if applicable)**

OTHER THERAPEUTIC MODALITIES ☐ Yes ☐ No *If yes, answer questions below*

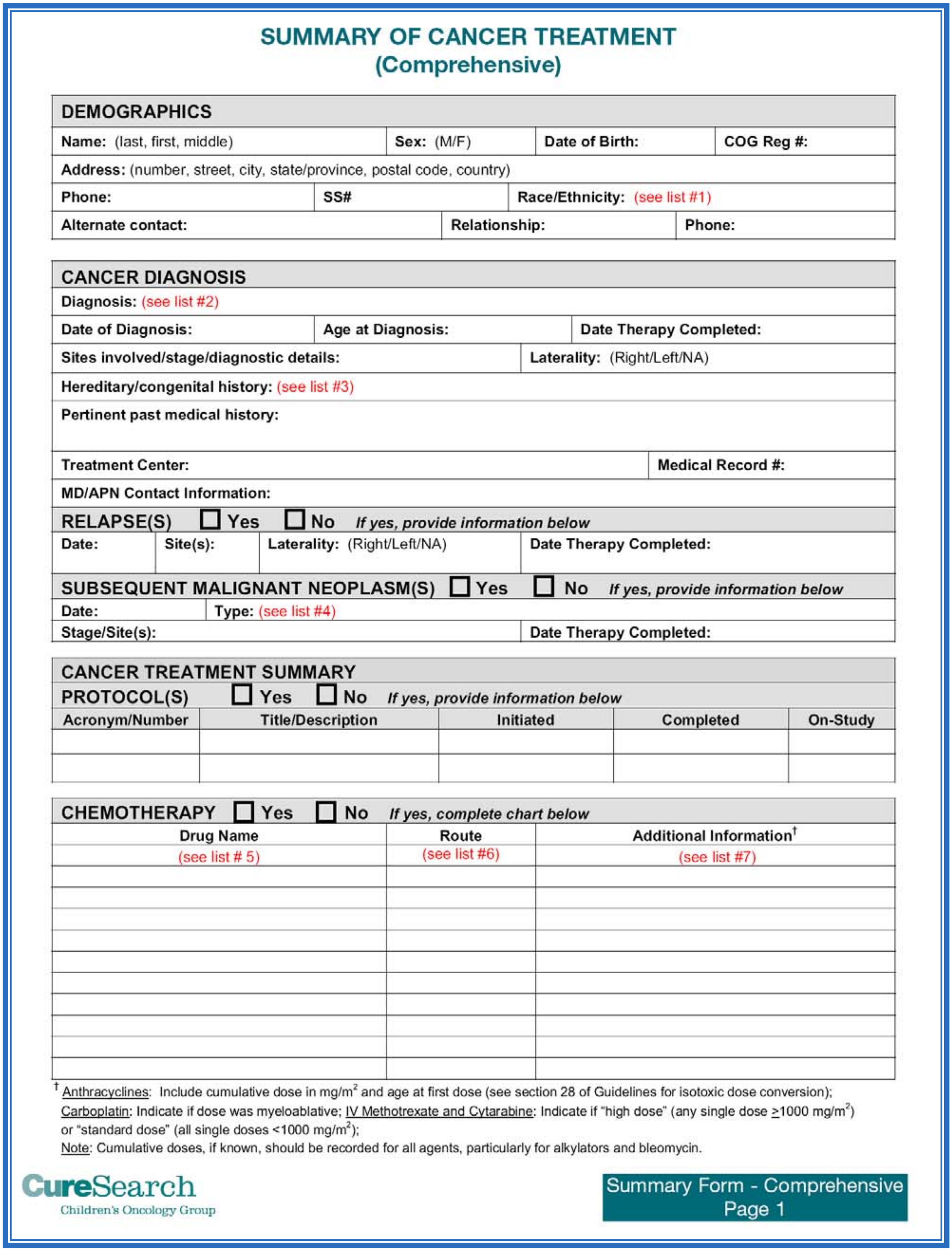
Did this patient receive radioiodine therapy (I-131 thyroid ablation)?	☐ Yes	☐ No
Did this patient receive systemic MIBG (in therapeutic doses)?	☐ Yes	☐ No
Did this patient receive bioimmunotherapy?	☐ Yes	☐ No

Summary prepared by:	**Date prepared:**

CureSearch
Children's Oncology Group

Summary Form - Abbreviated

Figure 6: Comprehensive treatment summary (page 1)
(Summary form, instructions, and key for completion are available at www.survivorshipguidelines.org)



SUMMARY OF CANCER TREATMENT
(Comprehensive)

DEMOGRAPHICS

Name: (last, first, middle) | **Sex:** (M/F) | **Date of Birth:** | **COG Reg #:**
Address: (number, street, city, state/province, postal code, country)
Phone: | **SS#** | **Race/Ethnicity:** (see list #1)
Alternate contact: | **Relationship:** | **Phone:**

CANCER DIAGNOSIS

Diagnosis: (see list #2)
Date of Diagnosis: | **Age at Diagnosis:** | **Date Therapy Completed:**
Sites involved/stage/diagnostic details: | **Laterality:** (Right/Left/NA)
Hereditary/congenital history: (see list #3)
Pertinent past medical history:
Treatment Center: | **Medical Record #:**
MD/APN Contact Information:

RELAPSE(S) ☐ Yes ☐ No *If yes, provide information below*

Date: | **Site(s):** | **Laterality:** (Right/Left/NA) | **Date Therapy Completed:**

SUBSEQUENT MALIGNANT NEOPLASM(S) ☐ Yes ☐ No *If yes, provide information below*

Date: | **Type:** (see list #4)
Stage/Site(s): | **Date Therapy Completed:**

CANCER TREATMENT SUMMARY

PROTOCOL(S) ☐ Yes ☐ No *If yes, provide information below*

Acronym/Number	Title/Description	Initiated	Completed	On-Study

CHEMOTHERAPY ☐ Yes ☐ No *If yes, complete chart below*

Drug Name	Route	Additional Information†
(see list # 5)	(see list #6)	(see list #7)

† Anthracyclines: Include cumulative dose in mg/m^2 and age at first dose (see section 28 of Guidelines for isotoxic dose conversion); Carboplatin: Indicate if dose was myeloablative; IV Methotrexate and Cytarabine: Indicate if "high dose" (any single dose ≥1000 mg/m^2) or "standard dose" (all single doses <1000 mg/m^2);
Note: Cumulative doses, if known, should be recorded for all agents, particularly for alkylators and bleomycin.

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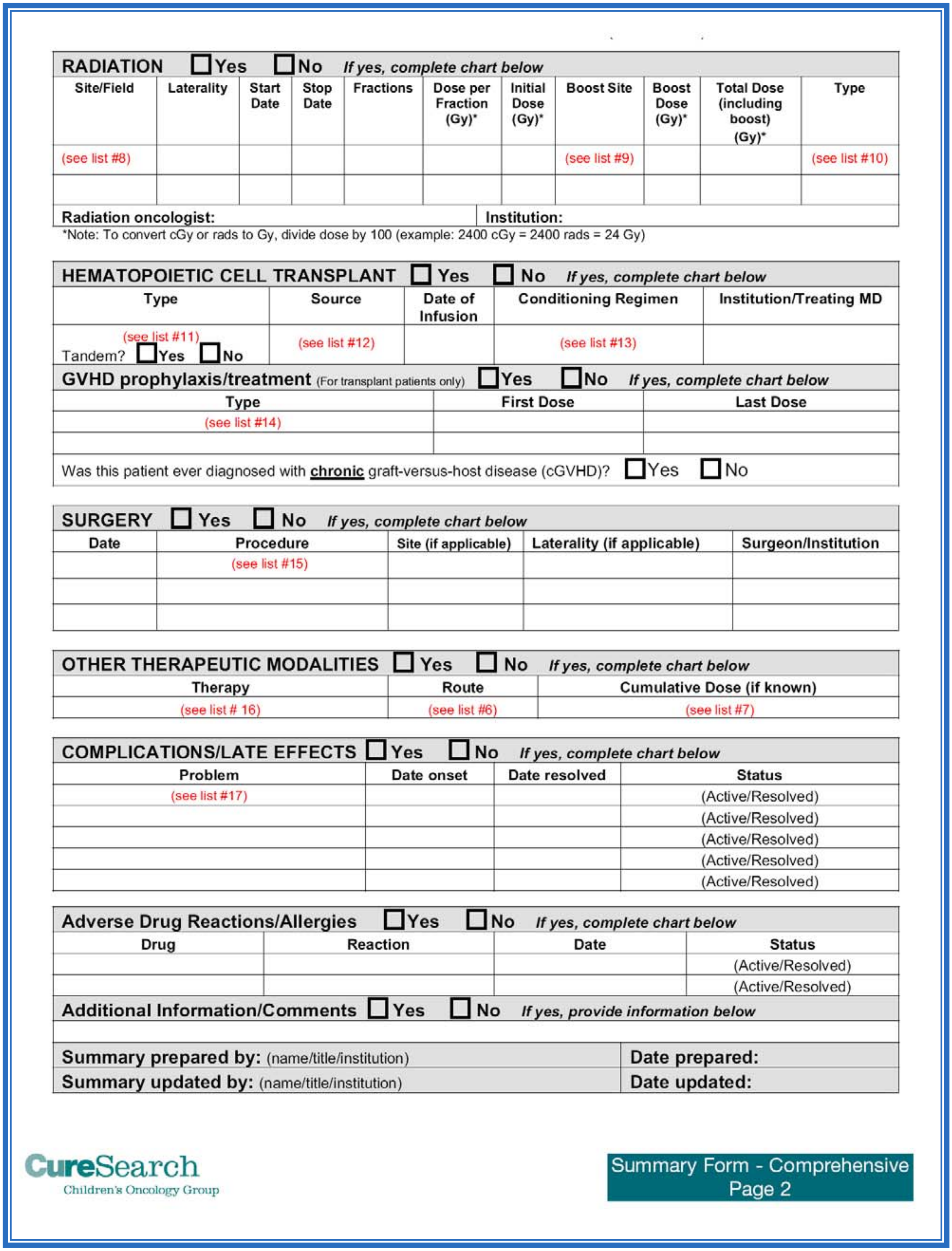
Summary Form - Comprehensive
Page 1

Figure 6: Comprehensive treatment summary (page 2)
(Summary form, instructions, and key for completion available at www.survivorshipguidelines.org)



RADIATION ☐ Yes ☐ No *If yes, complete chart below*

Site/Field	Laterality	Start Date	Stop Date	Fractions	Dose per Fraction (Gy)*	Initial Dose (Gy)*	Boost Site	Boost Dose (Gy)*	Total Dose (including boost) (Gy)*	Type
(see list #8)							(see list #9)			(see list #10)

Radiation oncologist:
Institution:

*Note: To convert cGy or rads to Gy, divide dose by 100 (example: 2400 cGy = 2400 rads = 24 Gy)

HEMATOPOIETIC CELL TRANSPLANT ☐ Yes ☐ No *If yes, complete chart below*

Type	Source	Date of Infusion	Conditioning Regimen	Institution/Treating MD
(see list #11) Tandem? ☐ Yes ☐ No	(see list #12)		(see list #13)	

GVHD prophylaxis/treatment (For transplant patients only) ☐ Yes ☐ No *If yes, complete chart below*

Type	First Dose	Last Dose
(see list #14)		

Was this patient ever diagnosed with **chronic** graft-versus-host disease (cGVHD)? ☐ Yes ☐ No

SURGERY ☐ Yes ☐ No *If yes, complete chart below*

Date	Procedure	Site (if applicable)	Laterality (if applicable)	Surgeon/Institution
	(see list #15)			

OTHER THERAPEUTIC MODALITIES ☐ Yes ☐ No *If yes, complete chart below*

Therapy	Route	Cumulative Dose (if known)
(see list # 16)	(see list #6)	(see list #7)

COMPLICATIONS/LATE EFFECTS ☐ Yes ☐ No *If yes, complete chart below*

Problem	Date onset	Date resolved	Status
(see list #17)			(Active/Resolved)
			(Active/Resolved)
			(Active/Resolved)
			(Active/Resolved)
			(Active/Resolved)

Adverse Drug Reactions/Allergies ☐ Yes ☐ No *If yes, complete chart below*

Drug	Reaction	Date	Status
			(Active/Resolved)
			(Active/Resolved)

Additional Information/Comments ☐ Yes ☐ No *If yes, provide information below*

Summary prepared by: (name/title/institution)
Date prepared:
Summary updated by: (name/title/institution)
Date updated:

CureSearch
Children's Oncology Group

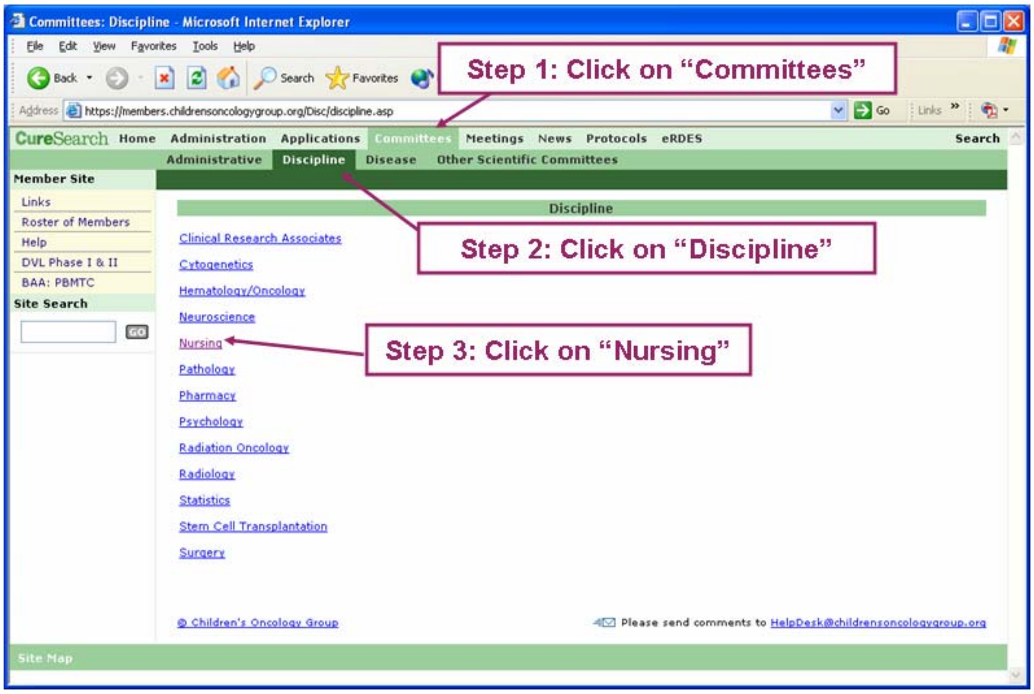
Summary Form - Comprehensive
Page 2

Late Effects Web Forum

The Late Effects Web Forum is an on-line discussion board where COG members can post and reply to questions regarding issues relating to late effects and long-term follow-up. Questions and replies remain accessible from the website as a resource for those seeking similar information. To reach the Late Effects Web Forum from the COG member home page, click on "Committees", then "Discipline", then "Nursing", and then click on "Late Effects Web Forum" from the menu on the left side of the page. Detailed instructions are provided below. Current COG membership and a valid web-access password are required for participation in the Late Effects Web Forum.

Figure 7: Late Effects Web Forum Instructions

To reach the Nursing Discipline Home Page from the COG Member Home Page:

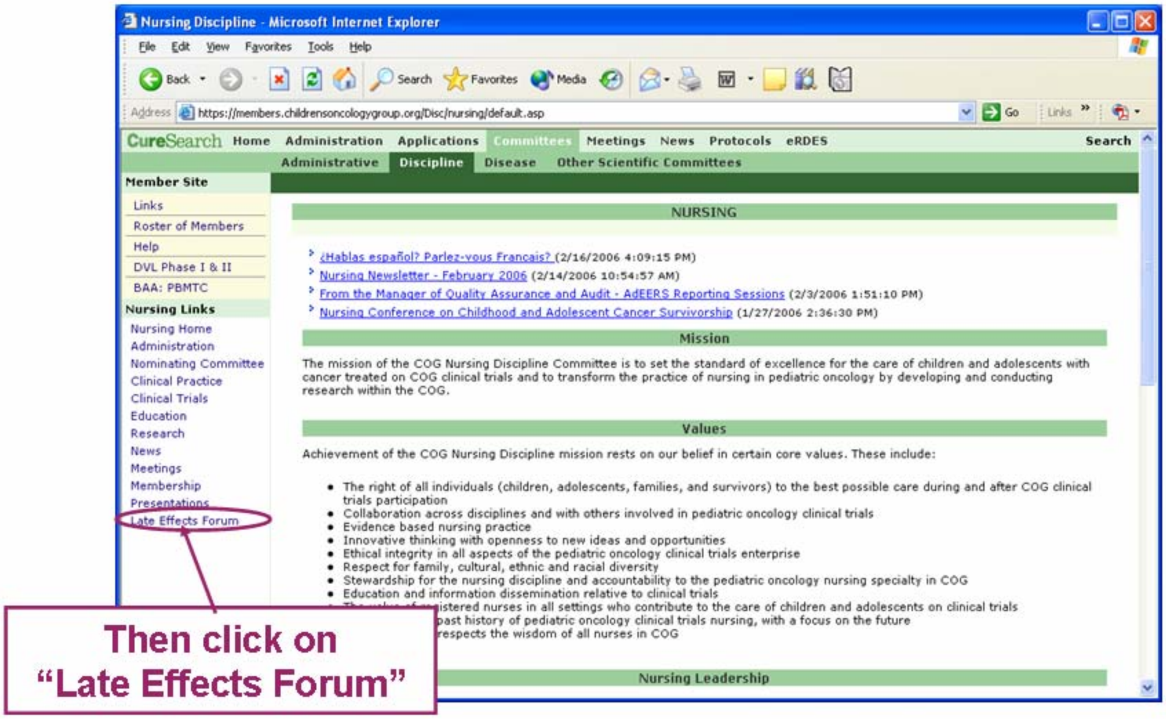


Step 1: Click on "Committees"

Step 2: Click on "Discipline"

Step 3: Click on "Nursing"

Figure 7: Late Effects Web Forum Instructions (continued)



NURSING

- ¿Hablas español? Parlez-vous Francais? (2/16/2006 4:09:15 PM)
- Nursing Newsletter - February 2006 (2/14/2006 10:54:57 AM)
- From the Manager of Quality Assurance and Audit - AdEERS Reporting Sessions (2/3/2006 1:51:10 PM)
- Nursing Conference on Childhood and Adolescent Cancer Survivorship (1/27/2006 2:36:30 PM)

Mission

The mission of the COG Nursing Discipline Committee is to set the standard of excellence for the care of children and adolescents with cancer treated on COG clinical trials and to transform the practice of nursing in pediatric oncology by developing and conducting research within the COG.

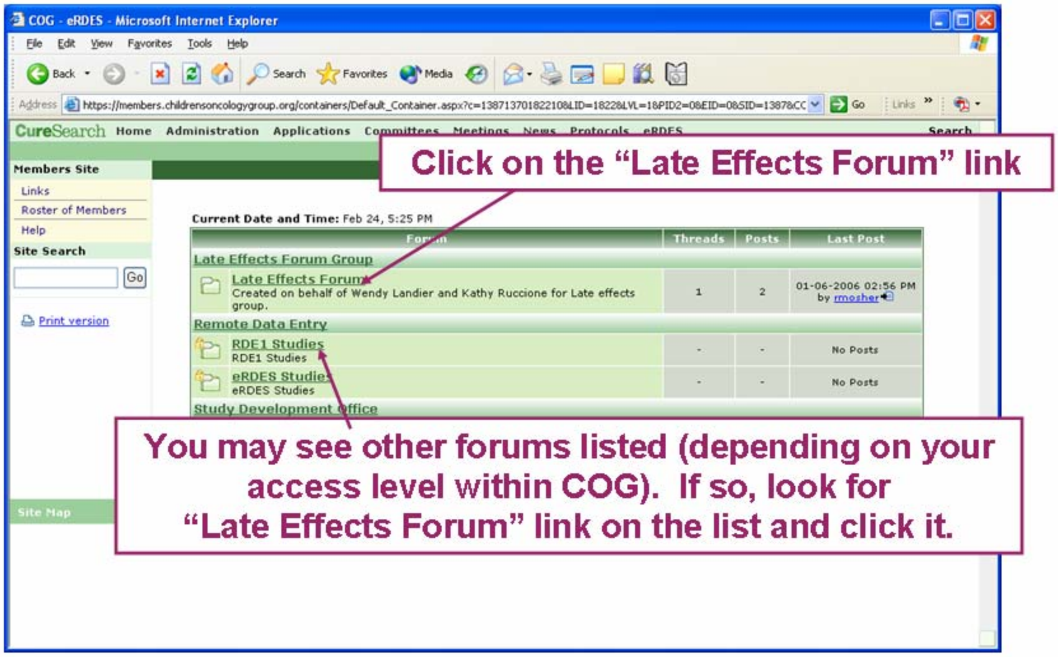
Values

Achievement of the COG Nursing Discipline mission rests on our belief in certain core values. These include:

- The right of all individuals (children, adolescents, families, and survivors) to the best possible care during and after COG clinical trials participation
- Collaboration across disciplines and with others involved in pediatric oncology clinical trials
- Evidence based nursing practice
- Innovative thinking with openness to new ideas and opportunities
- Ethical integrity in all aspects of the pediatric oncology clinical trials enterprise
- Respect for family, cultural, ethnic and racial diversity
- Stewardship for the nursing discipline and accountability to the pediatric oncology nursing specialty in COG
- Education and information dissemination relative to clinical trials
- The value of registered nurses in all settings who contribute to the care of children and adolescents on clinical trials
- past history of pediatric oncology clinical trials nursing, with a focus on the future
- respects the wisdom of all nurses in COG

Nursing Leadership

Then click on "Late Effects Forum"



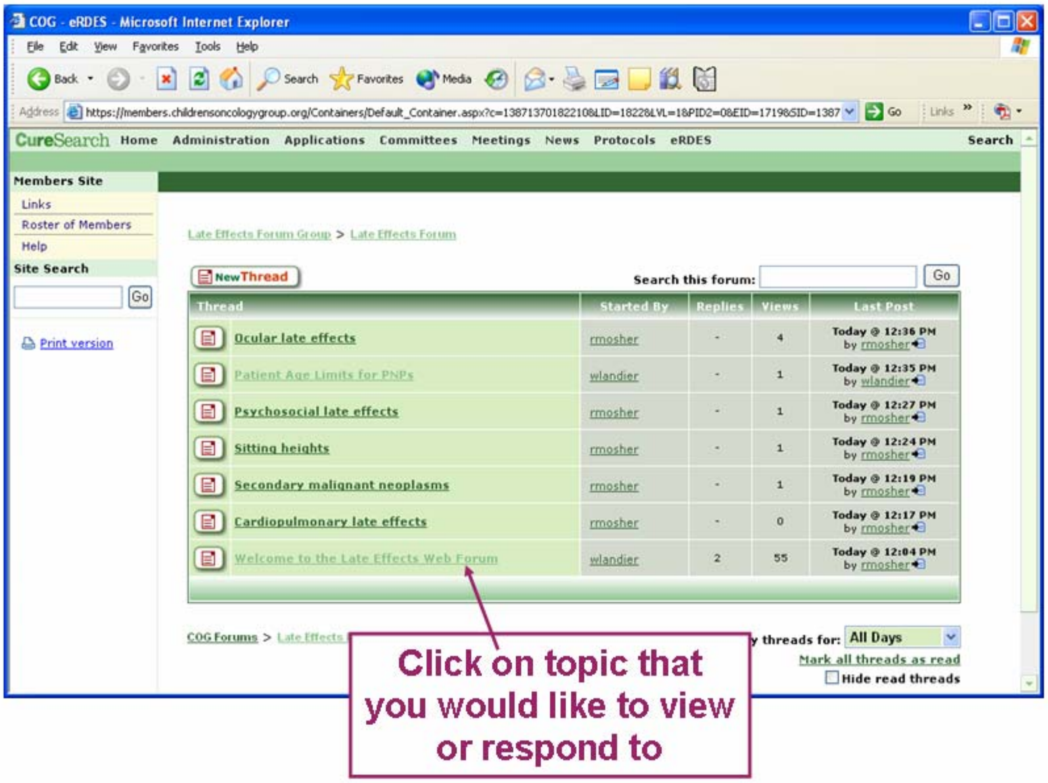
Click on the "Late Effects Forum" link

Current Date and Time: Feb 24, 5:25 PM

Forum	Threads	Posts	Last Post
Late Effects Forum Group			
Late Effects Forum Created on behalf of Wendy Landier and Kathy Ruccione for Late effects group.	1	2	01-06-2006 02:56 PM by rmosher
Remote Data Entry			
RDE1 Studies RDE1 Studies	-	-	No Posts
eRDES Studies eRDES Studies	-	-	No Posts
Study Development Office			

You may see other forums listed (depending on your access level within COG). If so, look for "Late Effects Forum" link on the list and click it.

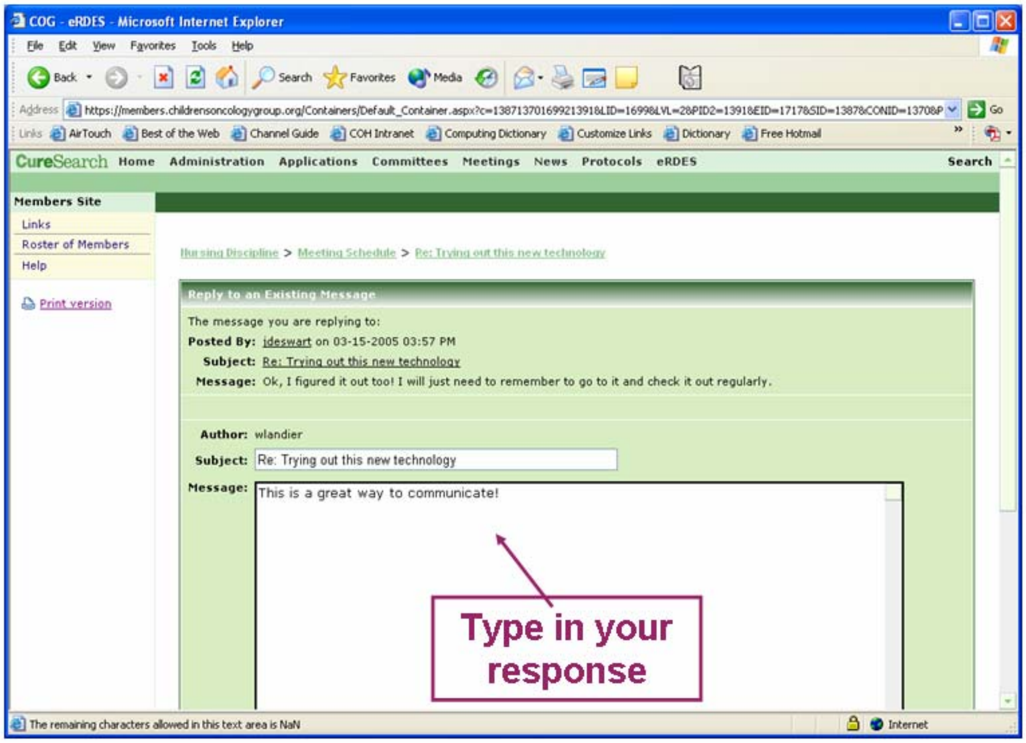
Figure 7: Late Effects Web Forum Instructions (continued)



Late Effects Forum Group > Late Effects Forum

Thread	Started By	Replies	Views	Last Post
Ocular late effects	rmosher	-	4	Today @ 12:36 PM by rmosher
Patient Age Limits for PNPs	wlandier	-	1	Today @ 12:35 PM by wlandier
Psychosocial late effects	rmosher	-	1	Today @ 12:27 PM by rmosher
Sitting heights	rmosher	-	1	Today @ 12:24 PM by rmosher
Secondary malignant neoplasms	rmosher	-	1	Today @ 12:19 PM by rmosher
Cardiopulmonary late effects	rmosher	-	0	Today @ 12:17 PM by rmosher
Welcome to the Late Effects Web Forum	wlandier	2	55	Today @ 12:04 PM by rmosher

Click on topic that you would like to view or respond to



Nursing Discipline > Meeting Schedule > Re: Trying out this new technology

Reply to an Existing Message

The message you are replying to:

Posted By: jdeswart on 03-15-2005 03:57 PM

Subject: Re: Trying out this new technology

Message: Ok, I figured it out too! I will just need to remember to go to it and check it out regularly.

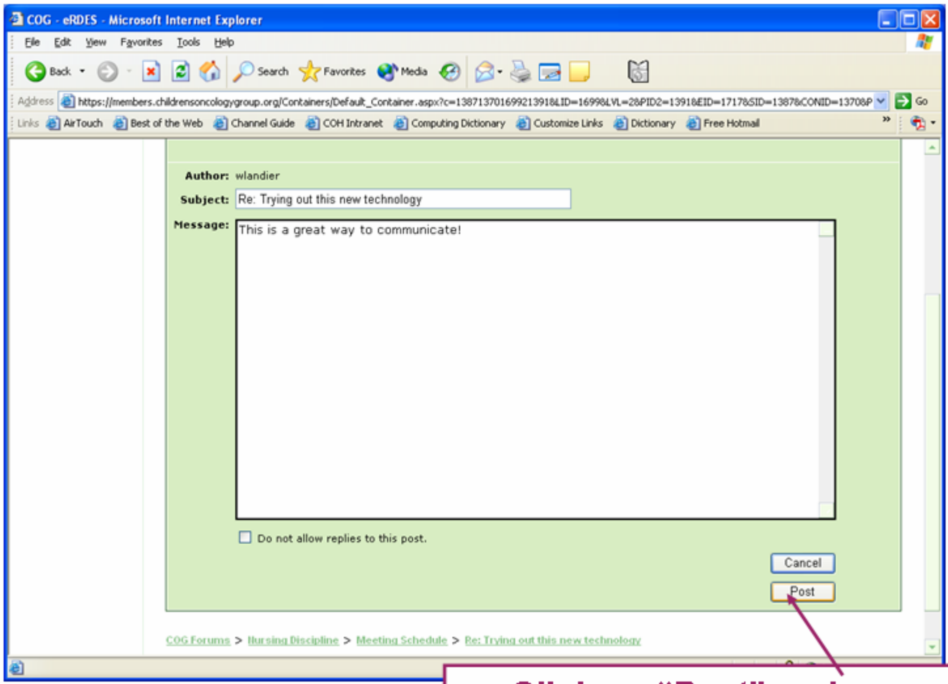
Author: wlandier

Subject: Re: Trying out this new technology

Message: This is a great way to communicate!

Type in your response

Figure 7: Late Effects Web Forum Instructions (continued)



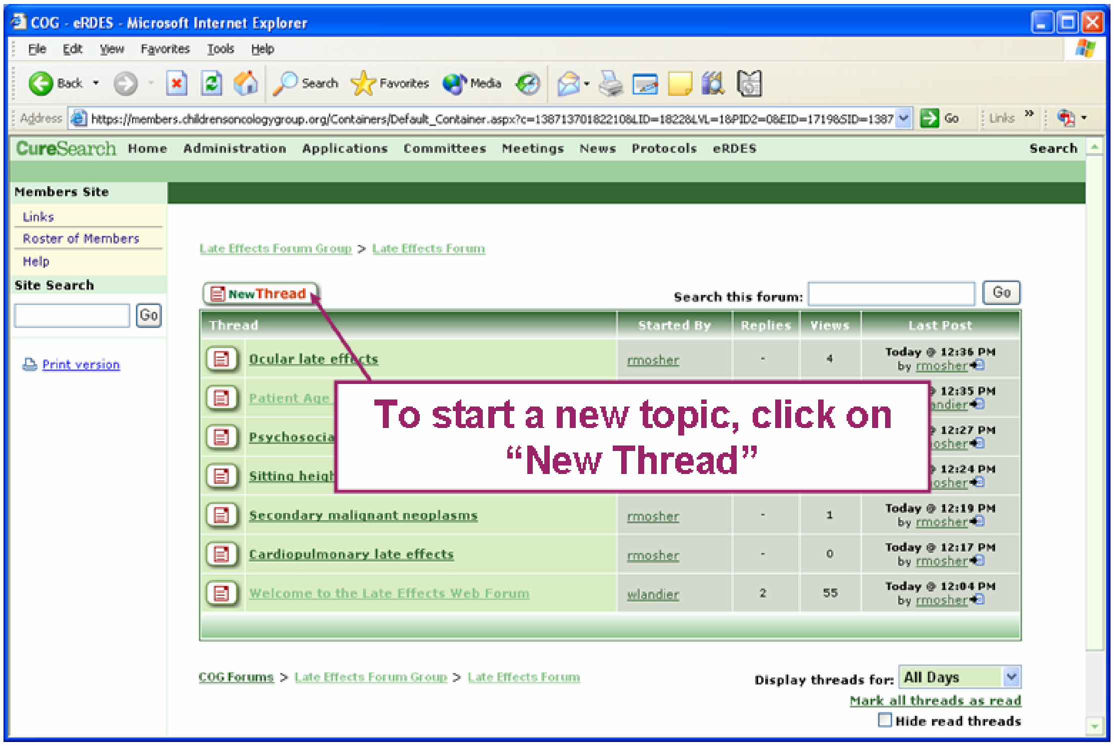
Author: wlandier

Subject: Re: Trying out this new technology

Message: This is a great way to communicate!

☐ Do not allow replies to this post.

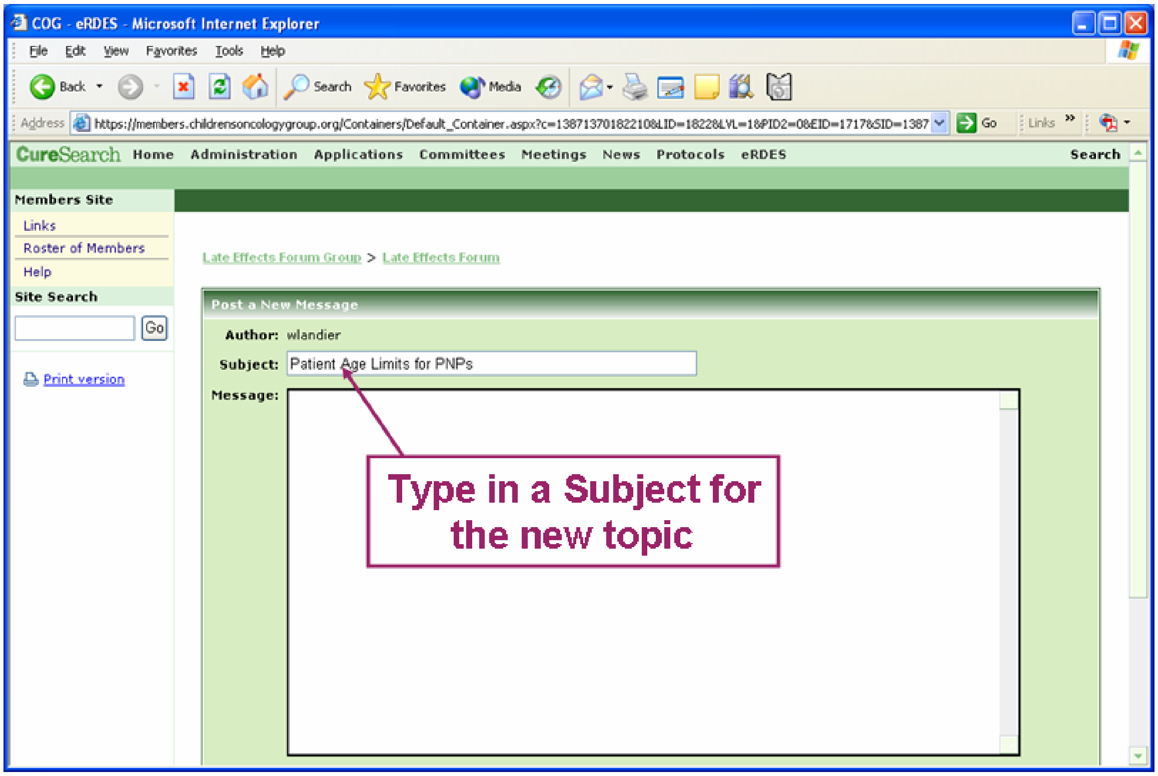
Click on “Post” and your response will be posted for all web forum members to read



Thread	Started By	Replies	Views	Last Post
Ocular late effects	rmosher	-	4	Today @ 12:36 PM by rmosher
Patient Age				12:35 PM ndier
Psychosocia				12:27 PM osher
Sitting heigh				12:24 PM osher
Secondary malignant neoplasms	rmosher	-	1	Today @ 12:19 PM by rmosher
Cardiopulmonary late effects	rmosher	-	0	Today @ 12:17 PM by rmosher
Welcome to the Late Effects Web Forum	wlandier	2	55	Today @ 12:04 PM by rmosher

To start a new topic, click on “New Thread”

Figure 7: Late Effects Web Forum Instructions (continued)

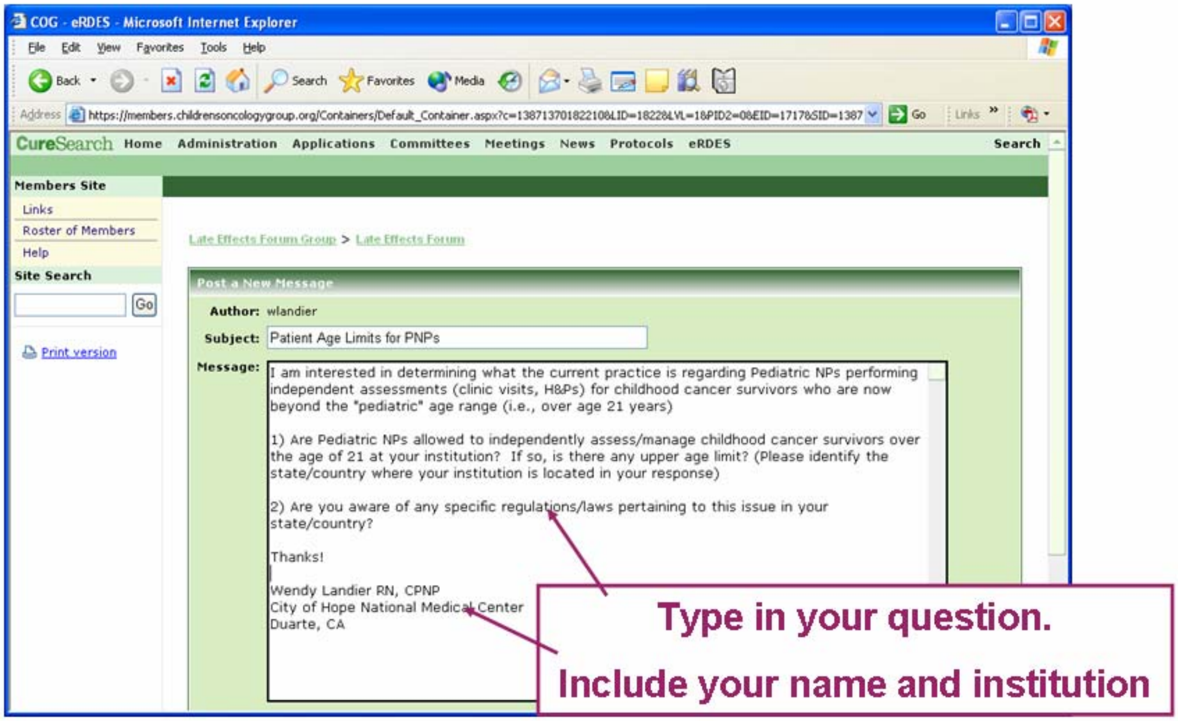


Author: wlandier

Subject: Patient Age Limits for PNPs

Message:

Type in a Subject for the new topic



Author: wlandier

Subject: Patient Age Limits for PNPs

Message:

I am interested in determining what the current practice is regarding Pediatric NPs performing independent assessments (clinic visits, H&Ps) for childhood cancer survivors who are now beyond the "pediatric" age range (i.e., over age 21 years)

1) Are Pediatric NPs allowed to independently assess/manage childhood cancer survivors over the age of 21 at your institution? If so, is there any upper age limit? (Please identify the state/country where your institution is located in your response)

2) Are you aware of any specific regulations/laws pertaining to this issue in your state/country?

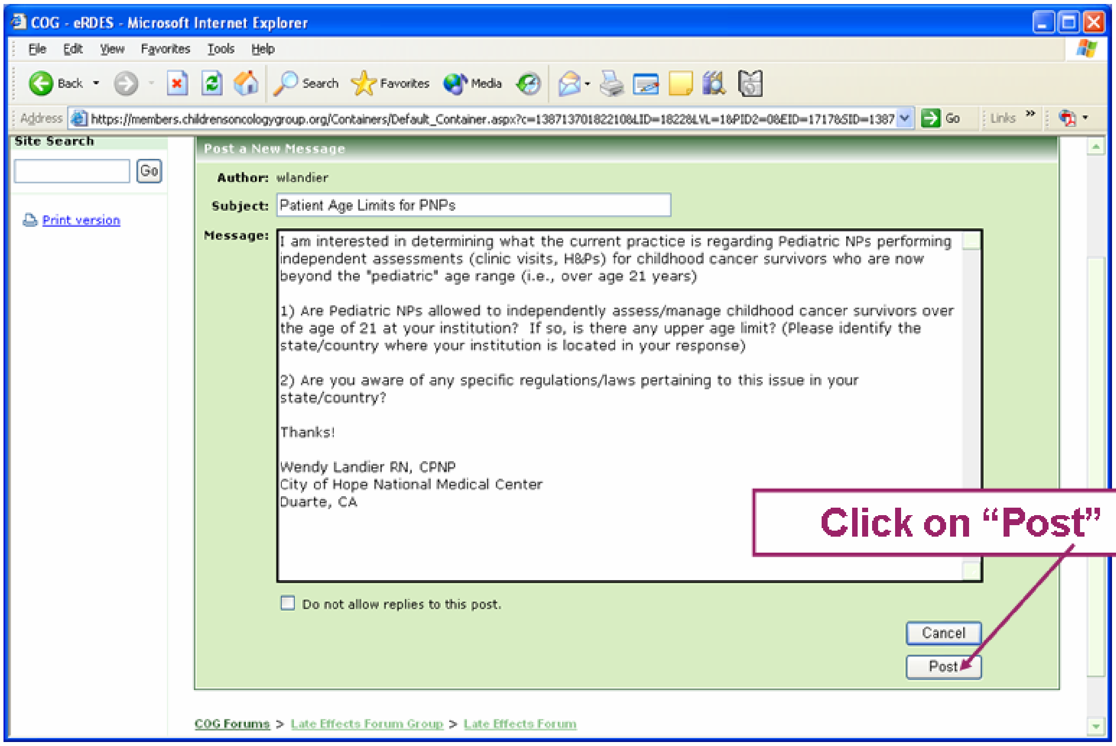
Thanks!

Wendy Landier RN, CPNP
City of Hope National Medical Center
Duarte, CA

Type in your question.

Include your name and institution

Figure 7: Late Effects Web Forum Instructions (continued)



Post a New Message

Author: wlandier

Subject: Patient Age Limits for PNPs

Message:

I am interested in determining what the current practice is regarding Pediatric NPs performing independent assessments (clinic visits, H&Ps) for childhood cancer survivors who are now beyond the "pediatric" age range (i.e., over age 21 years)

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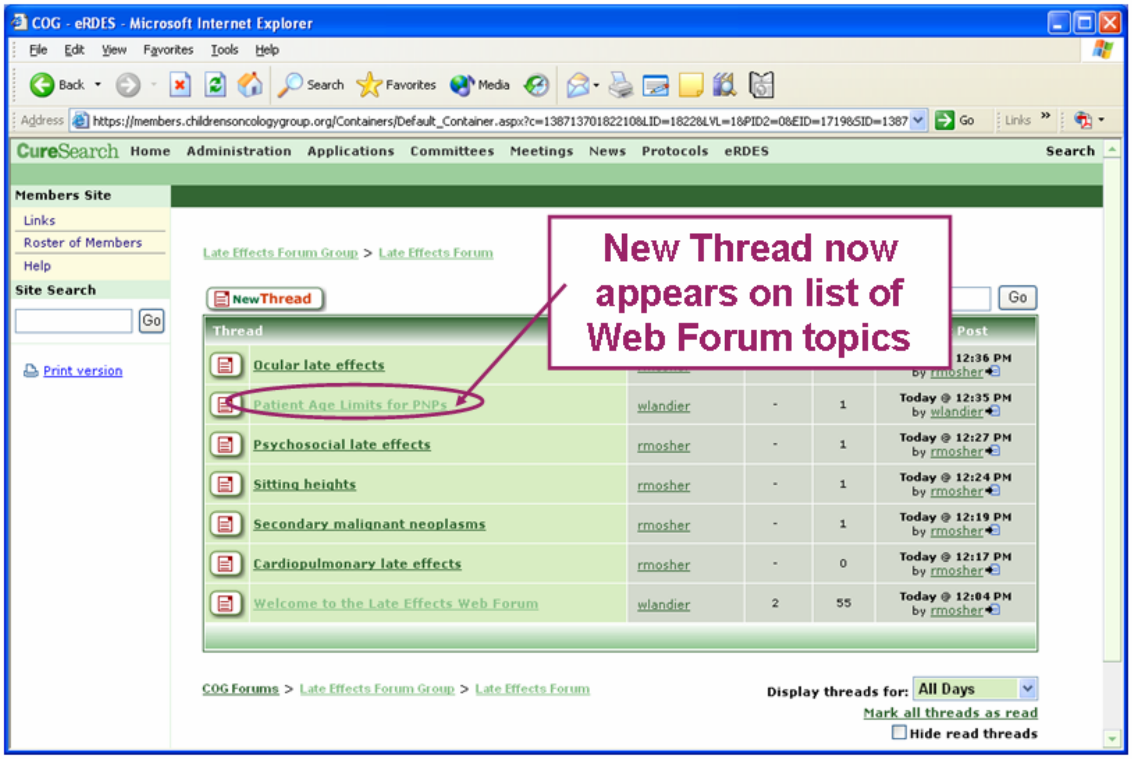
Thanks!

Wendy Landier RN, CPNP
City of Hope National Medical Center
Duarte, CA

☐ Do not allow replies to this post.

Click on "Post"



Thread				Post
Ocular late effects	[illegible]	[illegible]	[illegible]	12:36 PM by rmosher
Patient Age Limits for PNPs	wlandier	-	1	Today @ 12:35 PM by wlandier
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Welcome to the Late Effects Web Forum	wlandier	2	55	Today @ 12:04 PM by rmosher

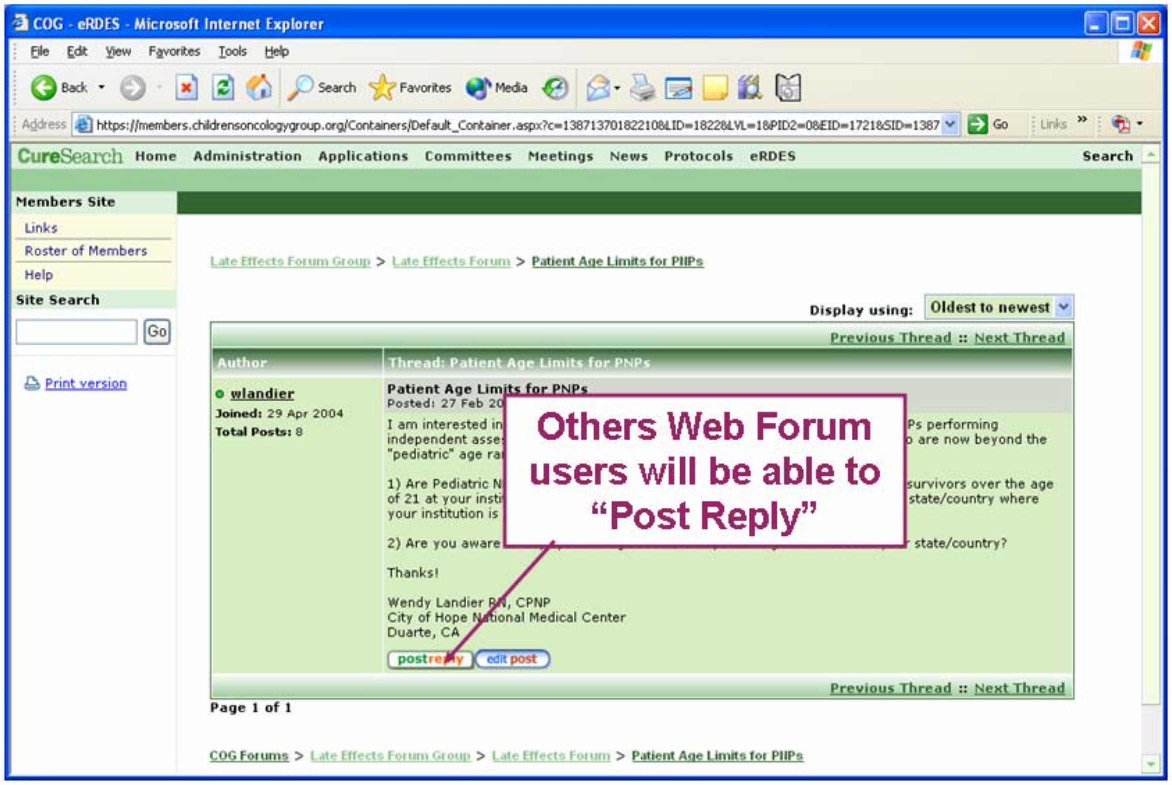
Display threads for: All Days

Mark all threads as read

☐ Hide read threads

New Thread now appears on list of Web Forum topics

Figure 7: Late Effects Web Forum Instructions (continued)



wlandier
Joined: 29 Apr 2004
Total Posts: 8

Patient Age Limits for PNPs
Posted: 27 Feb 20
I am interested in … Ps performing
independent asse… o are now beyond the
"pediatric" age ra…

1) Are Pediatric N… survivors over the age
of 21 at your insti… state/country where
your institution is …

2) Are you aware … state/country?

Thanks!

Wendy Landier RN, CPNP
City of Hope National Medical Center
Duarte, CA

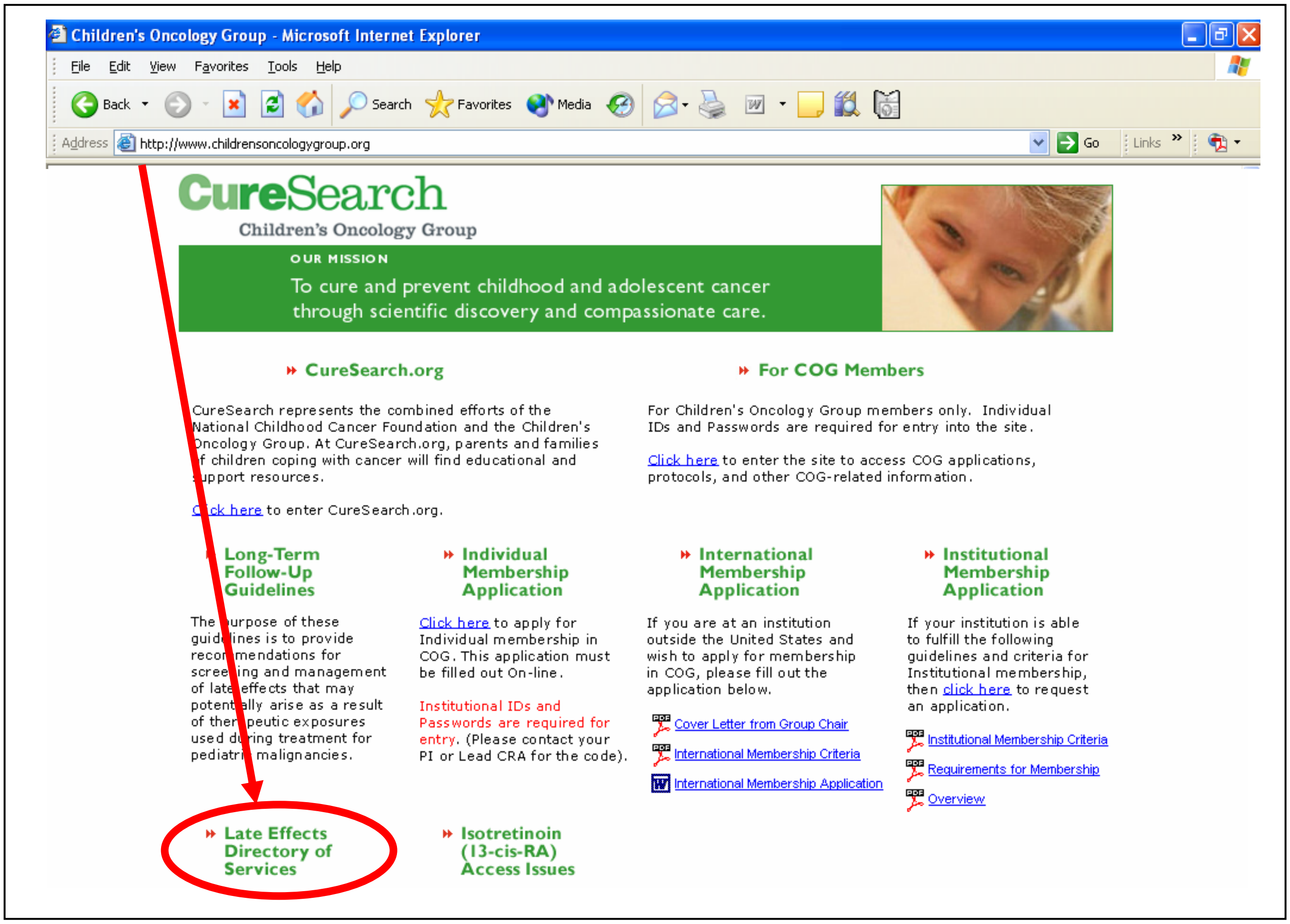
Others Web Forum users will be able to "Post Reply"

Late Effects Directory of Services

The Late Effects Directory of Services is an on-line database of LTFU programs at COG member institutions, created by Debra Eshelman, RN, MSN, CPNP, and Karen Kinahan, RN, MS, APRN. Available information includes types of patients followed, service providers, names and contact information for clinic coordinators and appointment scheduling.

The Directory of Services is available to the public from the COG public website at www.childrensoncologygroup.org (click on "Late Effects Directory of Services") [see Figure 8]. More detailed information from the database is accessible to COG Members from the member website by clicking on "Applications" and then "Late Effects Directory of Services" (listed under the "Miscellaneous" category). Instructions are provided in Figure 9.

Figure 8: Late Effects Directory of Services on Public Website www.childrensoncologygroup.org



To cure and prevent childhood and adolescent cancer through scientific discovery and compassionate care.

CureSearch.org

CureSearch represents the combined efforts of the National Childhood Cancer Foundation and the Children's Oncology Group. At CureSearch.org, parents and families of children coping with cancer will find educational and support resources.

Click here to enter CureSearch.org.

For COG Members

For Children's Oncology Group members only. Individual IDs and Passwords are required for entry into the site.

Click here to enter the site to access COG applications, protocols, and other COG-related information.

Long-Term Follow-Up Guidelines

The purpose of these guidelines is to provide recommendations for screening and management of late effects that may potentially arise as a result of therapeutic exposures used during treatment for pediatric malignancies.

Individual Membership Application

Click here to apply for Individual membership in COG. This application must be filled out On-line.

Institutional IDs and Passwords are required for entry. (Please contact your PI or Lead CRA for the code).

International Membership Application

If you are at an institution outside the United States and wish to apply for membership in COG, please fill out the application below.

- Cover Letter from Group Chair
- International Membership Criteria
- International Membership Application

Institutional Membership Application

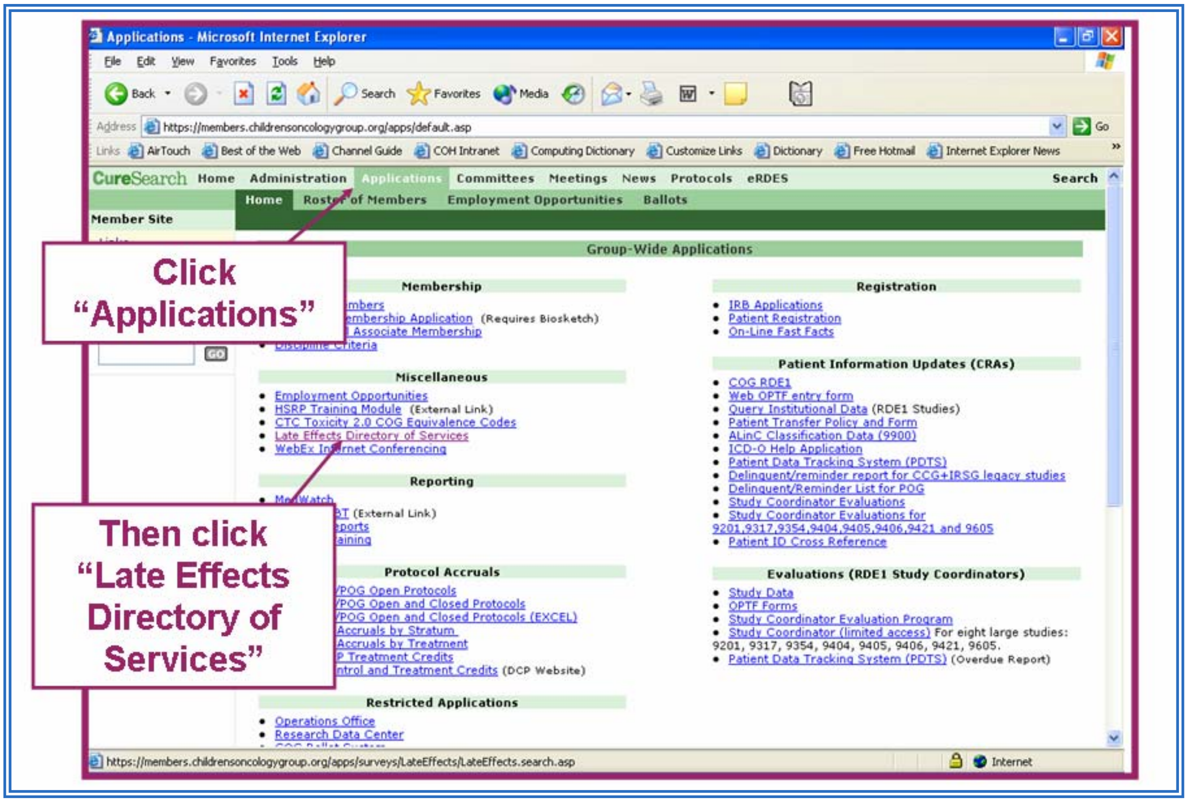
If your institution is able to fulfill the following guidelines and criteria for Institutional membership, then click here to request an application.

- Institutional Membership Criteria
- Requirements for Membership
- Overview

Late Effects Directory of Services

Isotretinoin (13-cis-RA) Access Issues

Figure 9: Instructions for Late Effects Directory of Services on COG Member Website



Click "Applications"

Then click "Late Effects Directory of Services"

https://members.childrensoncologygroup.org/apps/default.asp

Group-Wide Applications

Membership

- mbers
- embership Application (Requires Biosketch)
- Associate Membership
- Discipline Criteria

Miscellaneous

- Employment Opportunities
- HSRP Training Module (External Link)
- CTC Toxicity 2.0 COG Equivalence Codes
- Late Effects Directory of Services
- WebEx Internet Conferencing

Reporting

- MedWatch
- BT (External Link)
- eports
- aining

Protocol Accruals

- /POG Open Protocols
- /POG Open and Closed Protocols
- /POG Open and Closed Protocols (EXCEL)
- Accruals by Stratum
- Accruals by Treatment
- P Treatment Credits
- ntrol and Treatment Credits (DCP Website)

Restricted Applications

- Operations Office
- Research Data Center

Registration

- IRB Applications
- Patient Registration
- On-Line Fast Facts

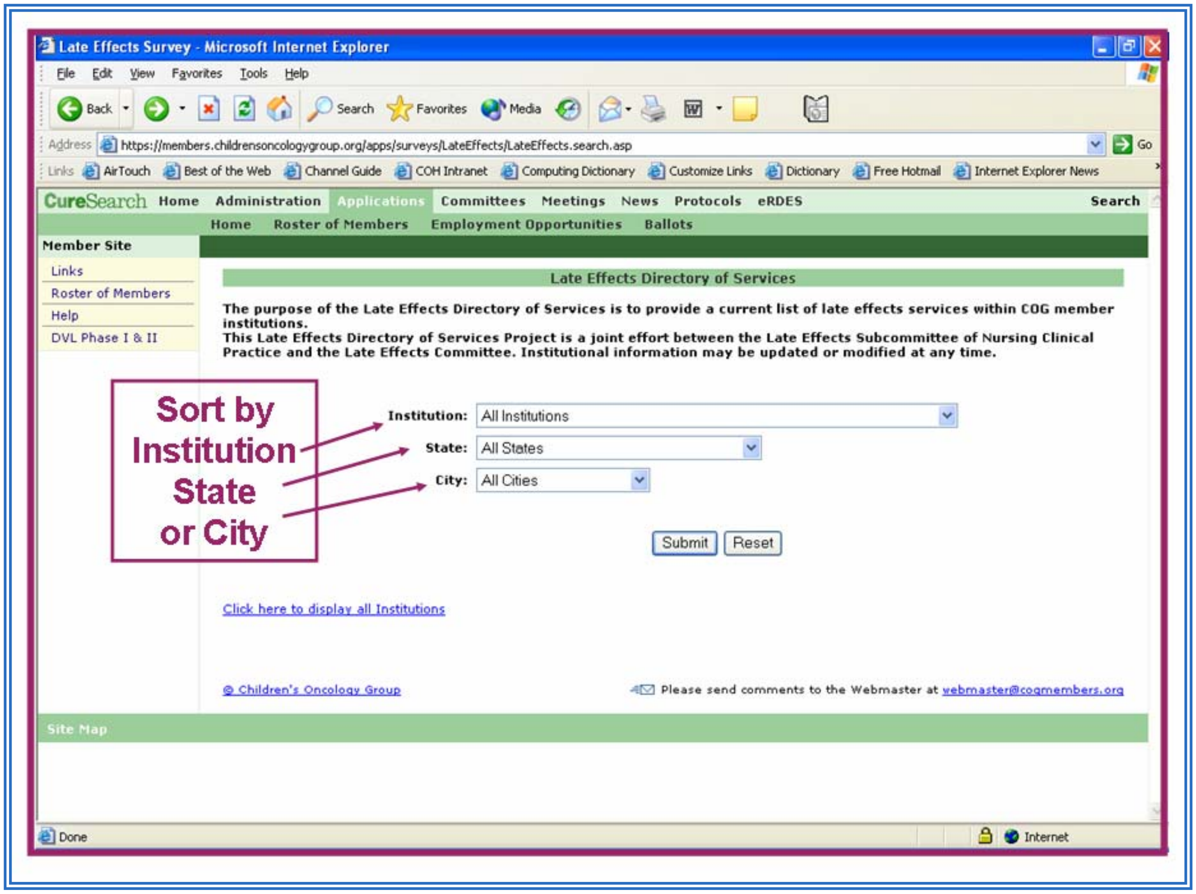
Patient Information Updates (CRAs)

- COG RDE1
- Web OPTF entry form
- Query Institutional Data (RDE1 Studies)
- Patient Transfer Policy and Form
- ALinC Classification Data (9900)
- ICD-O Help Application
- Patient Data Tracking System (PDTS)
- Delinquent/reminder report for CCG+IRSG legacy studies
- Delinquent/Reminder List for POG
- Study Coordinator Evaluations
- Study Coordinator Evaluations for 9201,9317,9354,9404,9405,9406,9421 and 9605
- Patient ID Cross Reference

Evaluations (RDE1 Study Coordinators)

- Study Data
- OPTF Forms
- Study Coordinator Evaluation Program
- Study Coordinator (limited access) For eight large studies: 9201, 9317, 9354, 9404, 9405, 9406, 9421, 9605.
- Patient Data Tracking System (PDTS) (Overdue Report)

https://members.childrensoncologygroup.org/apps/surveys/LateEffects/LateEffects.search.asp



https://members.childrensoncologygroup.org/apps/surveys/LateEffects/LateEffects.search.asp

Late Effects Directory of Services

The purpose of the Late Effects Directory of Services is to provide a current list of late effects services within COG member institutions.
This Late Effects Directory of Services Project is a joint effort between the Late Effects Subcommittee of Nursing Clinical Practice and the Late Effects Committee. Institutional information may be updated or modified at any time.

Sort by Institution State or City

Institution: All Institutions

State: All States

City: All Cities

Click here to display all Institutions

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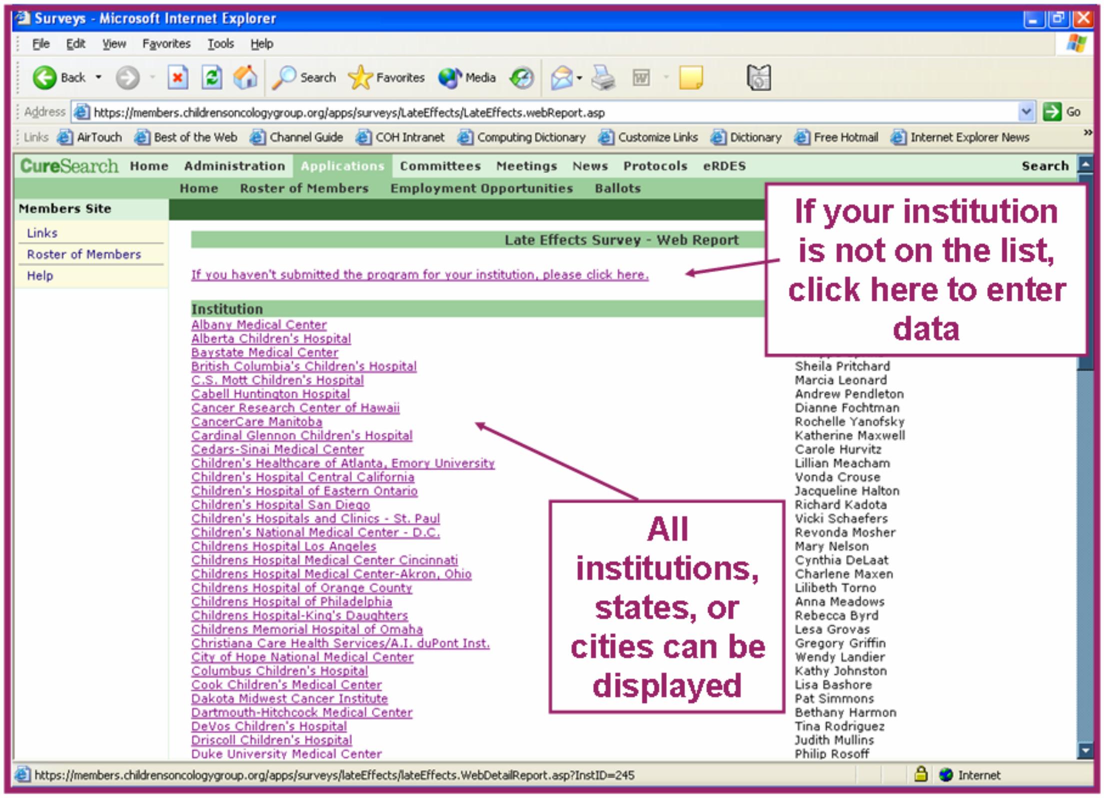
Please send comments to the Webmaster at webmaster@cogmembers.org

Figure 9: Instructions for Late Effects Directory of Services on COG Member Website



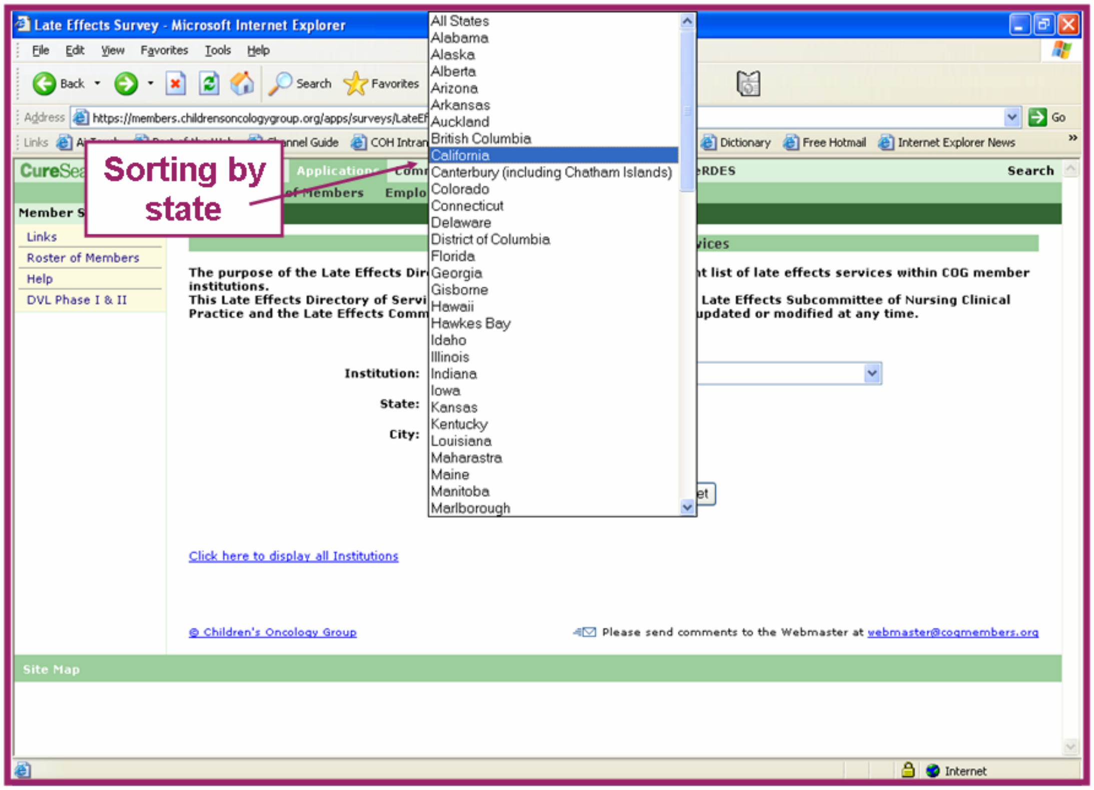
Late Effects Survey - Web Report

If you haven't submitted the program for your institution, please click here.

Institution	
Albany Medical Center	
Alberta Children's Hospital	
Baystate Medical Center	
British Columbia's Children's Hospital	Sheila Pritchard
C.S. Mott Children's Hospital	Marcia Leonard
Cabell Huntington Hospital	Andrew Pendleton
Cancer Research Center of Hawaii	Dianne Fochtman
CancerCare Manitoba	Rochelle Yanofsky
Cardinal Glennon Children's Hospital	Katherine Maxwell
Cedars-Sinai Medical Center	Carole Hurvitz
Children's Healthcare of Atlanta, Emory University	Lillian Meacham
Children's Hospital Central California	Vonda Crouse
Children's Hospital of Eastern Ontario	Jacqueline Halton
Children's Hospital San Diego	Richard Kadota
Children's Hospitals and Clinics - St. Paul	Vicki Schaefers
Children's National Medical Center - D.C.	Revonda Mosher
Childrens Hospital Los Angeles	Mary Nelson
Childrens Hospital Medical Center Cincinnati	Cynthia DeLaat
Childrens Hospital Medical Center-Akron, Ohio	Charlene Maxen
Childrens Hospital of Orange County	Lilibeth Torno
Childrens Hospital of Philadelphia	Anna Meadows
Childrens Hospital-King's Daughters	Rebecca Byrd
Childrens Memorial Hospital of Omaha	Lesa Grovas
Christiana Care Health Services/A.I. duPont Inst.	Gregory Griffin
City of Hope National Medical Center	Wendy Landier
Columbus Children's Hospital	Kathy Johnston
Cook Children's Medical Center	Lisa Bashore
Dakota Midwest Cancer Institute	Pat Simmons
Dartmouth-Hitchcock Medical Center	Bethany Harmon
DeVos Children's Hospital	Tina Rodriguez
Driscoll Children's Hospital	Judith Mullins
Duke University Medical Center	Philip Rosoff

If your institution is not on the list, click here to enter data

All institutions, states, or cities can be displayed



The purpose of the Late Effects Dir... ...t list of late effects services within COG member institutions.
This Late Effects Directory of Servi... ...Late Effects Subcommittee of Nursing Clinical Practice and the Late Effects Comm... ...updated or modified at any time.

Institution:
State:
City:

- All States
- Alabama
- Alaska
- Alberta
- Arizona
- Arkansas
- Auckland
- British Columbia
- California
- Canterbury (including Chatham Islands)
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Gisborne
- Hawaii
- Hawkes Bay
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maharastra
- Maine
- Manitoba
- Marlborough

Click here to display all Institutions

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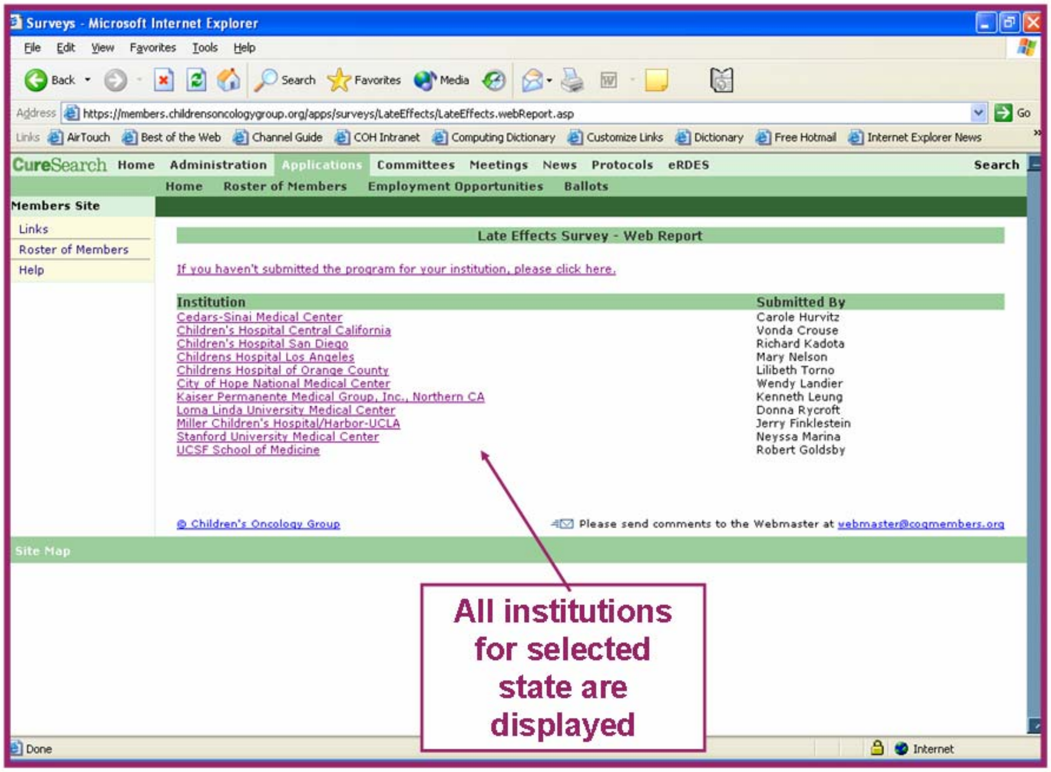
Please send comments to the Webmaster at webmaster@cogmembers.org

Sorting by state

Figure 9: Instructions for Late Effects Directory of Services on COG Member Website



Late Effects Survey - Web Report

If you haven't submitted the program for your institution, please click here.

Institution	Submitted By
Cedars-Sinai Medical Center	Carole Hurvitz
Children's Hospital Central California	Vonda Crouse
Children's Hospital San Diego	Richard Kadota
Childrens Hospital Los Angeles	Mary Nelson
Childrens Hospital of Orange County	Lilibeth Torno
City of Hope National Medical Center	Wendy Landier
Kaiser Permanente Medical Group, Inc., Northern CA	Kenneth Leung
Loma Linda University Medical Center	Donna Rycroft
Miller Children's Hospital/Harbor-UCLA	Jerry Finklestein
Stanford University Medical Center	Neyssa Marina
UCSF School of Medicine	Robert Goldsby

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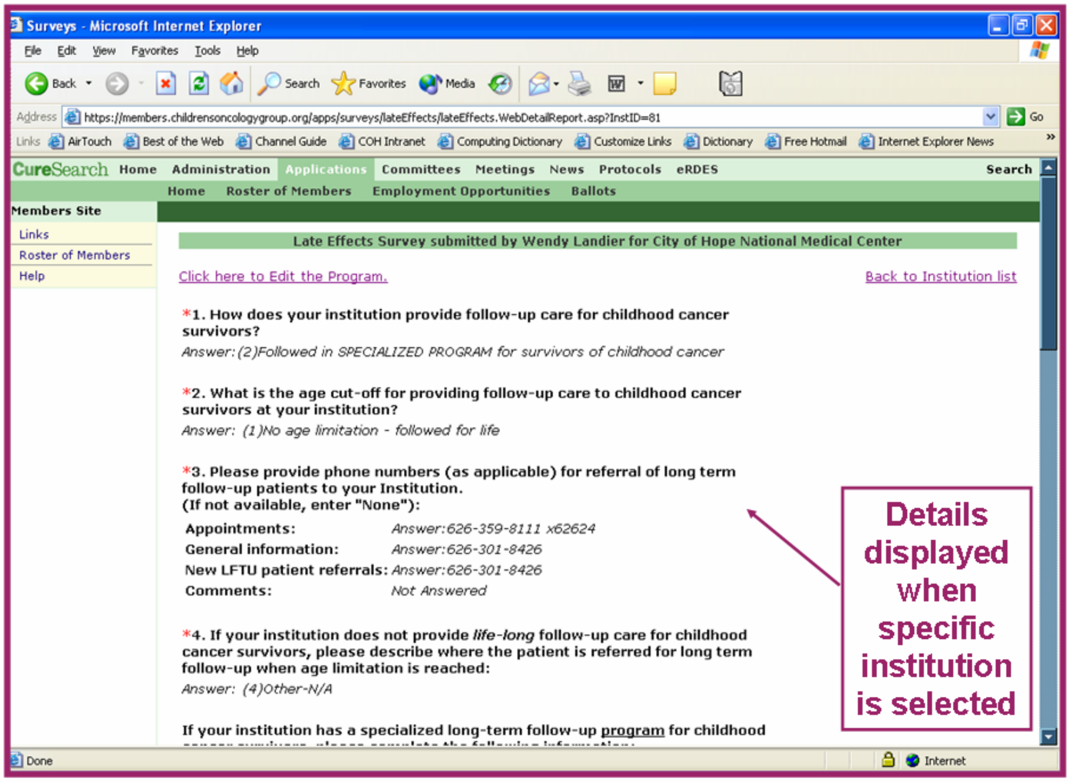
Please send comments to the Webmaster at webmaster@cogmembers.org

All institutions for selected state are displayed



Late Effects Survey submitted by Wendy Landier for City of Hope National Medical Center

Click here to Edit the Program.

Back to Institution list

***1. How does your institution provide follow-up care for childhood cancer survivors?**

Answer: (2)Followed in SPECIALIZED PROGRAM for survivors of childhood cancer

***2. What is the age cut-off for providing follow-up care to childhood cancer survivors at your institution?**

Answer: (1)No age limitation - followed for life

***3. Please provide phone numbers (as applicable) for referral of long term follow-up patients to your Institution.**
(If not available, enter "None"):

Appointments:	*Answer:626-359-8111 x62624*
General information:	*Answer:626-301-8426*
New LFTU patient referrals:	*Answer:626-301-8426*
Comments:	*Not Answered*

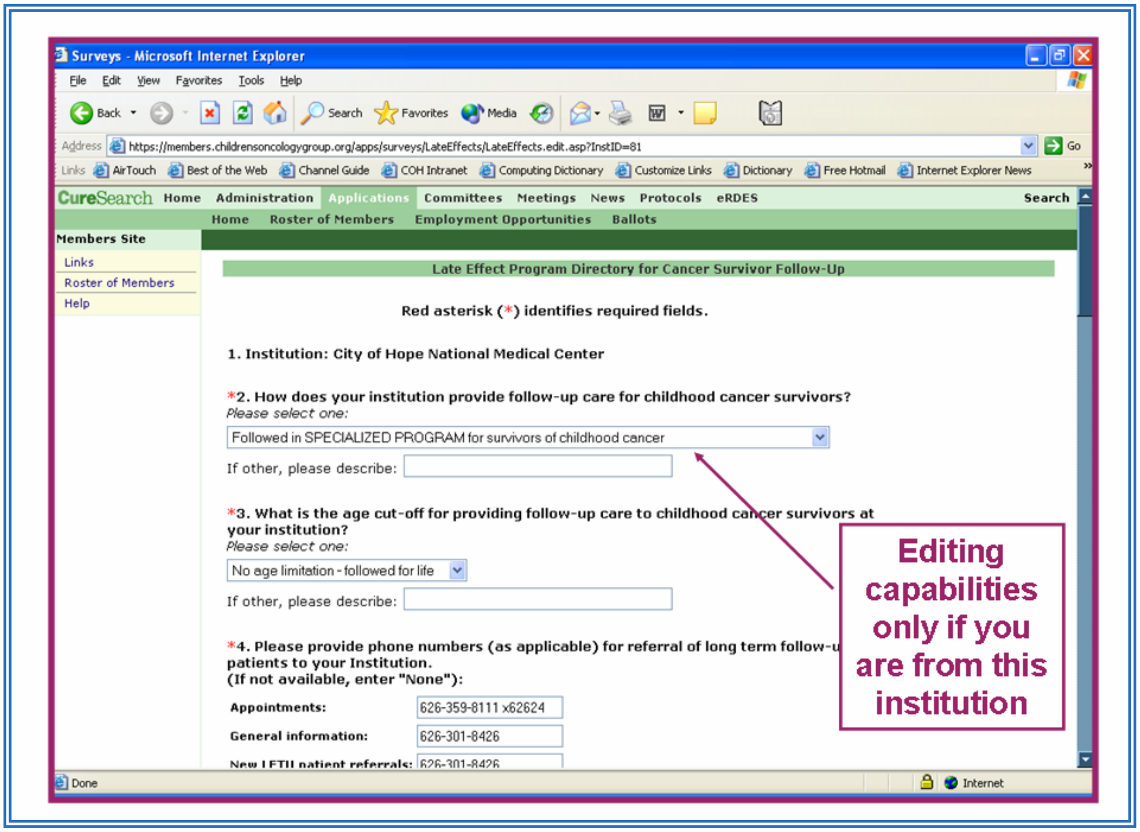
***4. If your institution does not provide *life-long* follow-up care for childhood cancer survivors, please describe where the patient is referred for long term follow-up when age limitation is reached:**

Answer: (4)Other-N/A

If your institution has a specialized long-term follow-up program for childhood

Details displayed when specific institution is selected

Figure 9: Instructions for Late Effects Directory of Services on COG Member Website



https://members.childrensoncologygroup.org/apps/surveys/LateEffects/LateEffects.edit.asp?InstID=81

Late Effect Program Directory for Cancer Survivor Follow-Up

Red asterisk (*) identifies required fields.

1. Institution: City of Hope National Medical Center

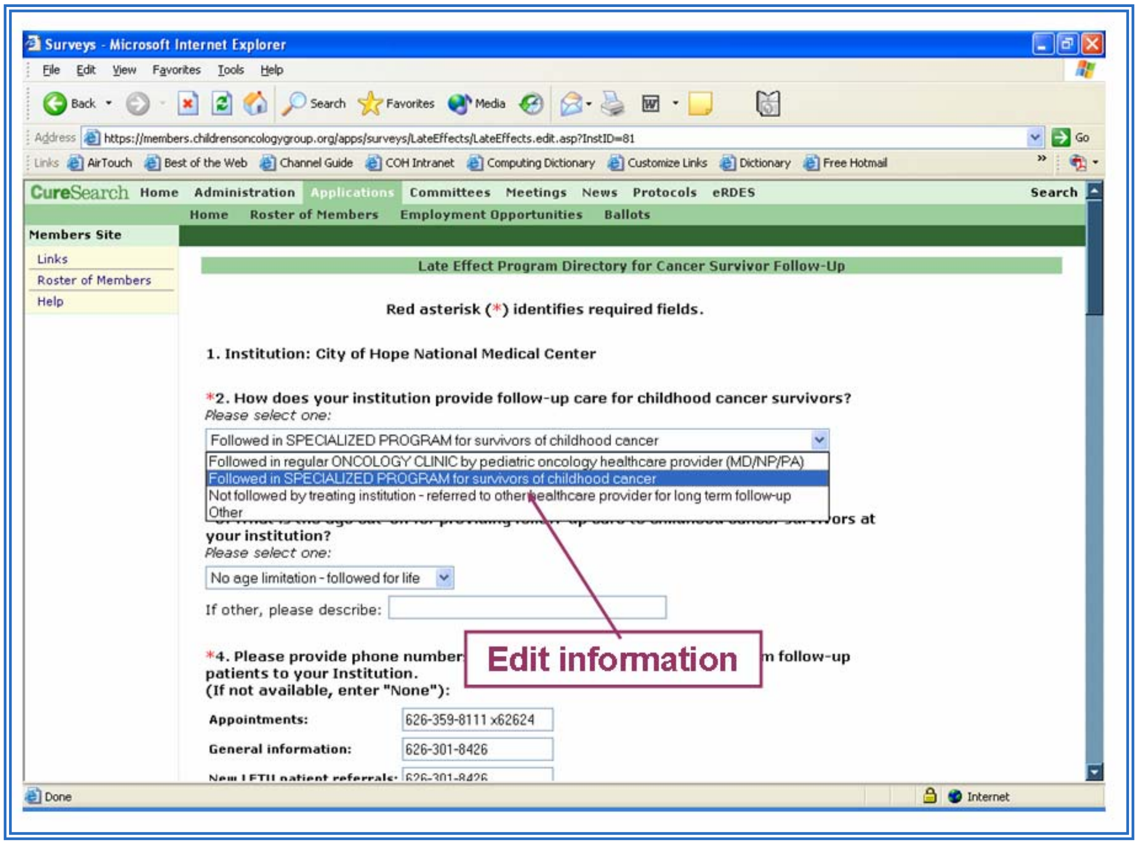
*2. How does your institution provide follow-up care for childhood cancer survivors?
Please select one:
Followed in SPECIALIZED PROGRAM for survivors of childhood cancer
If other, please describe:

*3. What is the age cut-off for providing follow-up care to childhood cancer survivors at your institution?
Please select one:
No age limitation - followed for life
If other, please describe:

*4. Please provide phone numbers (as applicable) for referral of long term follow-u
patients to your Institution.
(If not available, enter "None"):

Appointments: 626-359-8111 x62624
General information: 626-301-8426
New LTFU patient referrals: 626-301-8426

Editing capabilities only if you are from this institution



https://members.childrensoncologygroup.org/apps/surveys/LateEffects/LateEffects.edit.asp?InstID=81

Late Effect Program Directory for Cancer Survivor Follow-Up

Red asterisk (*) identifies required fields.

1. Institution: City of Hope National Medical Center

*2. How does your institution provide follow-up care for childhood cancer survivors?
Please select one:
Followed in SPECIALIZED PROGRAM for survivors of childhood cancer
- Followed in regular ONCOLOGY CLINIC by pediatric oncology healthcare provider (MD/NP/PA)
- Followed in SPECIALIZED PROGRAM for survivors of childhood cancer
- Not followed by treating institution - referred to other healthcare provider for long term follow-up
- Other

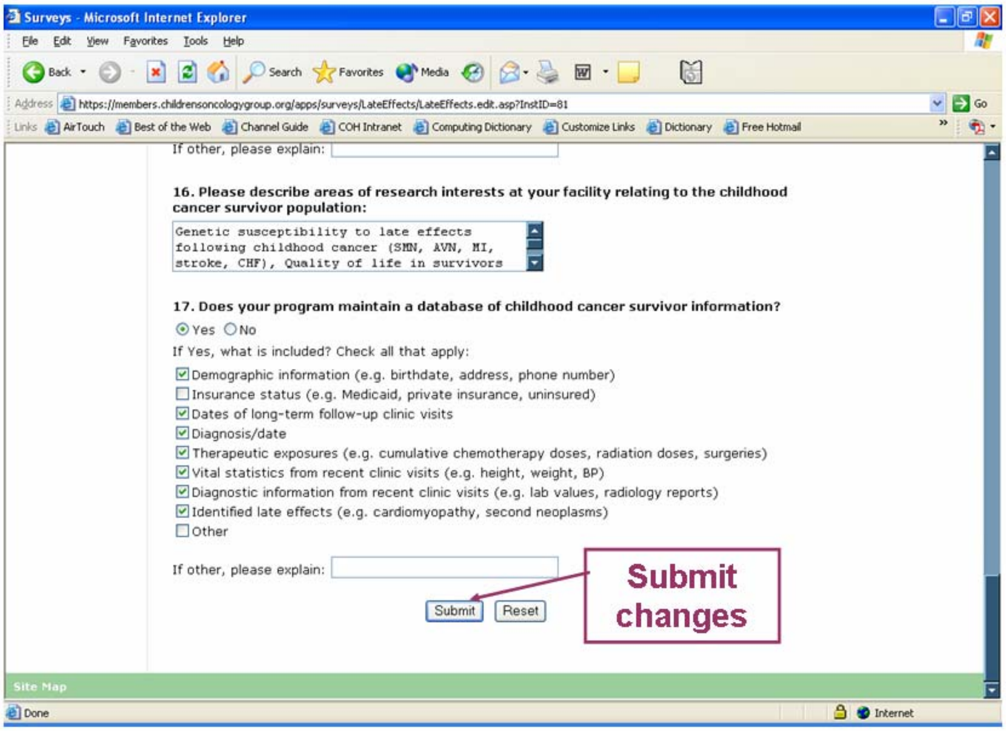
ors at
your institution?
Please select one:
No age limitation - followed for life
If other, please describe:

*4. Please provide number m follow-up
patients to your Institution.
(If not available, enter "None"):

Appointments: 626-359-8111 x62624
General information: 626-301-8426
New LTFU patient referrals: 626-301-8426

Edit information

Figure 9: Instructions for Late Effects Directory of Services on COG Member Website



If other, please explain:

16. Please describe areas of research interests at your facility relating to the childhood cancer survivor population:

Genetic susceptibility to late effects following childhood cancer (SMN, AVN, MI, stroke, CHF), Quality of life in survivors

17. Does your program maintain a database of childhood cancer survivor information?

● Yes ○ No

If Yes, what is included? Check all that apply:

- ☑ Demographic information (e.g. birthdate, address, phone number)
- ☐ Insurance status (e.g. Medicaid, private insurance, uninsured)
- ☑ Dates of long-term follow-up clinic visits
- ☑ Diagnosis/date
- ☑ Therapeutic exposures (e.g. cumulative chemotherapy doses, radiation doses, surgeries)
- ☑ Vital statistics from recent clinic visits (e.g. height, weight, BP)
- ☑ Diagnostic information from recent clinic visits (e.g. lab values, radiology reports)
- ☑ Identified late effects (e.g. cardiomyopathy, second neoplasms)
- ☐ Other

If other, please explain:

Submit Reset

Submit changes

APPENDIX 2:
Institute of Medicine Recommendations

With commentary by John Gates, MD

Children's Hospital Central California

Madera, California

RECOMMENDATIONS FROM THE INSTITUTE OF MEDICINE *WITH COMMENTARY*

The task of educating and providing services for childhood cancer survivors prompted the Institute of Medicine (IOM) to issue a report[5] detailing steps for improving care and quality of life for survivors of childhood cancer. Listed below are the IOM recommendations, along with comments regarding progress that has been made since the report's release in 2003, as well as ongoing challenges in survivorship care.

RECOMMENDATION 1: *Develop evidence-based clinical practice guidelines for the care of survivors of childhood cancer.*

Commentary: The Children's Oncology Group (COG) established a task force to accomplish this goal, and as a result has developed a set of evidence-based LTFU guidelines known as the *Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*, available at www.survivorshipguidelines.org. These guidelines identify health risks related to specific therapeutic exposures used during treatment of childhood cancer and provide recommendations for screening and management of late effects in childhood cancer survivors.

In addition to having a plan for medical follow-up, it is also important to design a healthcare system responsive to the full range of survivors' healthcare needs. The IOM report recommends development of comprehensive multidisciplinary follow-up programs for childhood cancer survivors that include the following:

- Psychological services to address psychological implications of cancer for survivors and their families
- Educational support through school transition programs
- Personnel to assist with insurance and employment issues
- A transition plan to facilitate the transfer of survivors into adult systems of care as they reach young adulthood

Although many COG institutions provide medical follow-up care for childhood cancer survivors, not all institutions currently provide multidisciplinary programs addressing this full range of survivor care.

RECOMMENDATION 2: *Define a minimum set of standards for systems of comprehensive, multidisciplinary follow-up care that link specialty and primary care providers (PCPs), ensure the presence of such a system within institutions treating children with cancer, and evaluate alternate models of delivery of survivorship care.*

Commentary: Providing a network of specialty and primary care providers to manage the multiple aspects of care required by childhood cancer survivors is often complicated by multiple factors, including time, distance, and insurance-related issues. A survivor may need coordination of care involving multiple specialists, such as a cardiologist, neurologist, endocrinologist, surgeon, ophthalmologist, physical therapist, neuropsychologist and oncologist, as well as continue to require vaccines, check-ups, dental care, specialized educational services and/or vocational counseling and community support. Obtaining access to any one of these requires time, financial resources, effort, the correct referrals, and persistence. Survivors may require many or all of these services, and often face the challenge of navigating complex healthcare systems with variable results.

RECOMMENDATION 3: ***Improve awareness of late effects and their implications for long-term health among childhood cancer survivors and their families.***

Commentary: Inadequate knowledge regarding diagnosis and treatment among childhood cancer survivors has been documented, and many survivors are also unaware of their risk for late effects. Although wellness education and care summaries are provided through many LTFU programs, a recent report from the Childhood Cancer Survivor Study revealed that the likelihood of a survivor undergoing a general physical exam or cancer-related visit within a two-year period decreased substantially as the survivor aged or as the time interval from diagnosis increased, and that only a minority of adult survivors of childhood cancer received risk-based healthcare (Oeffinger et al., 2004). Many survivor programs use multidisciplinary teams to provide education and resources regarding late effects - including psychosocial and wellness issues - using an array of formats (e.g., booklets, handouts, workshops). However, these programs are often geographically distant from survivors and may not serve patients who are beyond the pediatric age range.

RECOMMENDATION 4: ***Improve professional education and training regarding late effects and their management for both specialty and PCPs.***

Commentary: Many times the PCP is the one responsible for ongoing health management of childhood cancer survivors. PCPs may lack adequate information and resources in order to: 1) verify health risk factors of survivors; 2) stay up-to-date with research and developments in the area of late effects; 3) become familiar with the support and educational resources available; and 4) effectively provide quality long-term survivor services. Emphasis on survivorship issues in the curricula of both primary and specialty training programs will help with this process, but ongoing education to physicians and multidisciplinary specialty providers who may encounter childhood cancer survivors in their practices is also essential.

RECOMMENDATION 5: ***The Health Resources and Services Administration's Maternal and Child Health Bureau and its partners should be fully supported in implementing the "Healthy People 2010" goals for children with special healthcare needs. These efforts include a national communication strategy, efforts at capacity building, setting standards, and establishing accountability.***

Commentary: Although many childhood cancer survivors attain a high quality of life following completion of treatment, a significant number are faced with late effects and medical problems similar to individuals with other chronic illnesses and disabling conditions. Strengthening public programs serving children and adults with special needs and ensuring childhood cancer survivors have appropriate access to services is a priority.

RECOMMENDATION 6: ***Federal, state, and private efforts are needed to optimize childhood cancer survivors' access to appropriate resources and delivery systems through both health insurance reforms and support of safety net programs such as Health Resources and Services Administration's community and migrant health centers.***

Commentary: Ideally everyone, regardless of medical history or employment status, should have health insurance coverage and access to affordable healthcare. In lieu of national healthcare reform in the United States, support for childhood cancer survivors may be provided by state legislation targeting their specific issues. Such changes may allow survivors access to affordable healthcare services and prevent them from being excluded from receiving healthcare when they need it most.

RECOMMENDATION 7: ***Public and private research organizations (e.g., the National Cancer Institute, the National Institute for Nursing Research, the American Cancer Society) must increase support for research to prevent or ameliorate the long-term consequences of childhood cancer. Priority areas of research include assessing the prevalence and etiology of late effects; testing methods that may reduce late effects during treatment; developing interventions to prevent or reduce late effects after treatment; and furthering improvements in quality of care to ameliorate the consequences of late effects on individuals and families.***

Commentary: Understanding and preventing or adequately treating the complications associated with surviving childhood cancer will allow this population to achieve the best health status possible. Only when this is achieved can we truly say that we have conquered childhood cancer.

APPENDIX 3:
Sample Forms and Letters
for use in Long-Term Follow-Up Clinics

APPENDIX 3

PROCEDURES

CLINICAL FORMS

QUESTIONNAIRES

LETTERS

PROCEDURES

PROCEDURE:
PREPARATION FOR CLINIC

UCSF
San Francisco, CA

UCSF Survivors of Childhood Cancer Program
Preparing for Long-Term Follow-Up Clinic

Pre-Clinic

1.) **Gather patient data, via an extensive medical record review**
   - a. Gather data from medical records, FoxPro and STOR records (if seen at UCSF)
     - i. Demographic Data (Name, Gender, Date of Birth, Contact Info)
     - ii. Diagnosis
       - 1. Include site, stage, date, relapses, metastases, etc.
     - iii. Protocol(s) treated on
       - 1. Start/End Dates, Note if treated on or off study
     - iv. Chemotherapies (Agents, doses, cumulative doses)
       - 1. Critical information by agent:
         - a. Methotrexate and Cytarabine
           - i. High dose = any single dose $\geq$ 1000 mg/m^2
         - b. Carboplatin
           - i. Myeloablative Dose = conditioning dose for HCT (BMT)
         - c. Daunorubicin, Doxorubicin, Epirubicin, Idarubicin, Mitoxantrone
           - i. Note age at first dose
           - ii. Cumulative Dosages critical
     - v. Radiation Therapy Summary
       - 1. Type of radiation therapy (external beam, IMRT, etc), Fields involved, start/stop dates, # of fractions, dose per fraction, total dose in cGy
       - 2. Note age at time of XRT for the following fields of radiation
         - a. Thoracic Spine, Mantle, Mediastinal, Chest/Thorax, Axilla, Whole Abdomen, or any Abdomen field
     - vi. HCT Data (Bone Marrow Transplant/Hematopoetic Cell Transplant)
       - 1. Type of transplant, source of cells, cell donor, conditioning regimen, GVHD prophylaxis and treatment
       - *2. These records are not always included in the general medical record, but are available from the UCSF BMT Department (if treated at UCSF).*
       - 3. Take note if patient experienced chronic GVHD.
     - vii. Surgical Procedure Summary
       - 1. Type of surgery, date, site, surgeon
     - viii. Other therapeutic modalities
       - 1. MIBG, I-131, Bioimmunotherapy (G/GM-CSF, etc.)
     - ix. Significant complications during/after treatment
       - 1. Any significant interval history since treatment
       - 2. Past medical problems
       - 3. Adverse drug reactions/allergies
   - b. Enter all gathered data into database

2.) **Print Pre-Appointment Form**
   - a. This summarizes the treatment information for the patient.

3.) **Find patient-specific guidelines**
   - a. Using the "Patient-Specific Guideline Identification Tool", check off and fill in information appropriate to patients.
     - i. Find the applicable guideline sections in the Long Term Follow-Up Guidelines
     - ii. Fill in appropriate Baseline Examinations and Recommended Follow-Up Examinations in the database

4.) **Make Dictation**
   a. Output a dictation template from the database
   b. Open the Dictation Template file in the "Clinic Preparation Templates" folder.
      i. Save template for the current patient in the "Patient Information" folder, under "Dictations"
         1. Name the file with the patient's name (Last, First, Medical Record #)
      ii. Customize template for the patient's information
         1. Fill in patient's name where necessary, and customize paragraphs to match patient data (change his/her to gender-specific identifier)
         2. Paste in Cancer information, Protocol, Chemotherapy, Surgery, Radiation, Past Medical Problems, Baseline Examinations, and Recommended Follow-Up from database-outputted document.
         3. Customize the "Assessment and Long-Term Follow-Up Recommendations" section to the patient, removing non-pertinent sections based on which drugs the patient was treated with.

5.) **Create a "Patient Follow-Up Letter", and print HealthLinks**
   a. Customize for the patient, indicating which baseline examinations need to be completed.
   b. Print out patient-specific HealthLinks from www.survivorshipguidelines.org, when indicated by the LTFU Guidelines

6.) **Create Lab Requisitions**
   a. Based on patient's recommended baseline examinations, in accordance to the follow-up letter, create appropriate lab requisitions.

7.) **Assemble Patient Chart**
   a. Label chart with patient name and MRN
   b. Place all history and roadmaps in the first section, left side
   c. Place the "Pre-Appointment Form" in the first section, right side.
   d. Place Dictation Template in second section, left side.
   e. Place a "patient intake form" and growth chart in second section, right side
   f. Print out a copy of the "Patient Questionnaire" and place in the third section, left side.
   g. Print out and place social work packet in third section, right side.
   h. Clip all HealthLinks together, placing the "Patient Follow-Up Letter" on top, and lab requisitions on bottom, and place loose in third section.

<u>During Clinic</u>

1.) **Greet patient, and introduce questionnaire**
2.) **Following patient's visit, update database with any new information provided by the questionnaire.**
   a. If the patient's current outside doctor has changed from what is currently listed on the dictation template, change to reflect patient's current doctor.
   b. Add patient's address to carbon copy section if patient opted to receive letter.
3.) **Ensure that doctor has made or will make a STOR dictation, so that the letter can be pasted in ASAP.**

After Clinic

1.) **Assist MDs in completing dictations when appropriate.**
2.) **E-Mail to Karon once all dictations are complete, indicating that they can be sent.**
    a. If passport requires any corrections:
        i. Update and re-print passport, and send to patient along with dictation.
3.) **Follow up with patients regarding labs, etc.**
4.) **Return charts to Medical Records**
    a. Place all medical records ready for return into a box, and put in right side corner of conference room
    b. E-Mail to Jackie indicating which boxes are ready to be returned to Medical Records
        i. Assist her if necessary

CLINICAL FORMS

CLINICAL SUMMARY FORM

Carolinas Medical Center
Charlotte, NC

PATIENT SUMMARY FORM

Letterhead

Summary

Disease, Treatment and Follow-up

(patient name):

This is your pediatric oncology, long-term follow-up summary, which should be shared with your doctor(s) and kept in your personal files.

Medical Record Number:

Diagnosis:

Date of Diagnosis: **Age at Diagnosis:**

Summary of presentation:

Treatment Summary:

1) **Surgery:**
2) **Chemotherapy:**
3) **Radiation Therapy:**
4) **Complications:** **Protocol # ________**

Date off Treatment:

Potential Problem: **Recommendation:**

These are the specific risks and recommendations for your medical follow-up based upon your disease and treatment.
1)
2)
3)…..

General recommendations for all cancer survivors include:
1) yearly physical exams with primary care provider
2) yearly dental exams
3) yearly ophthalmology ….

CLINICAL SUMMARY FORM

Northwestern University (STAR Program)
Chicago, IL

Survivors
Taking
Action &
Responsibility
PROGRAM
Comprehensive Care for Childhood Cancer Survivors

Clinical Summary

Name: **SS#:** **Date of Appointment:**

DOB: **Sex:** **Race:** **NMFF MR#**

Diagnosis:

Date of Diagnosis:

Age at Diagnosis:

Date First Referred to Heme/Onc:

Presenting Symptoms & Findings (PE and/or Labs):

Prognostic Factors:	**<u>For Leukemia</u>**	**<u>For Solid Tumors</u>**
	Age:	**Stage:**
	WBC:	**Site(s) of Involvement:**
	Risk Group:	
	Lineage:	**Other:**
	CNS Status:	
	Cytogen/Other:	

PMH:

FH:

Treatment:

Protocol:
Date Initiated:
Date Completed:
Chemotherapy:
Radiation:
Transfusions:

Procedures:

Acute Complications:

Name:

Primary Therapy

Chemotherapy Drugs:

	Induction	*Consolidation*	*Re-Intensification*	*Interim Maintenance*	*Delayed Intensification*	*Maintenance*	*Relapse Y or N?If yes, See page 2A*	*BMT-Y or N? If yes,see page 2A*

***Total Anthracycline Dose: mg/m2**

Other:

Radiation:

Date (From – To)	**Site**	**Dose/Schedule**	**Shielding**

Name:

Cardiac Studies:

Type	Date	Results

Endocrine Studies:

Type	Date	Results

Other Studies:

Type	Date	Results

Name:

Psychosocial/Neurocognitive:
Marital Status:
Pregnancies:
Viable Offspring:
Employed:
Occupation:
Insurance:
Education – Highest Level:
Special Education:

Past Medical Concerns:

Known Late Effects:
( )Growth
( )Obesity/FTT
( )Immunologic
( )a/c GVHD
( )ENT
( )Ophthal
( )Dental
( )Cognitive
( )Psychological
( )Endocrine
( )Malig-1st Rel
( )Cardio-vasc
( )Pulmonary
( )GI
( )Hepatic
( )Renal
( )Neurologic
( )Muscular
( )Dermatologic
( )2nd Malig
( )Malig-2nd Rel
( )Ortho

Dx:
Onset:
Status:

Dx:
Onset:
Status:

Dx:
Onset:
Status:

Dx:
Onset:
Status:

New Concerns/Plan:

Labs Needed:

LTFU Visit Dates:

Date Form Completed:

Name:

ADDENDUM – Recurrence / Progressive Disease

Date:

Presentation:
Significant Findings:

Site:

<u>Relapse Chemotherapy:</u>

TREATMENT

	Induction	*Consolidation*	*Re-Intensification*	*Interim Maintenance*	*Delayed Intensification*	*Maintenance*	*If additional treatment given, see page 2B*

Date off Therapy:

Surgery / Major Procedures (incl. Diagnostic) / Significant Complications:

Name:

-2B-

COMBINED CLINICAL SUMMARY AND H&P FORM
INITIAL VISIT / NON-TRANSPLANT PATIENT

University of Michigan
Ann Arbor, MI

Long-Term Follow-Up Clinical Summary

Name: *Sex*:

CPI #: *Race*:

DOB: *Date of Dx*:

Allergies: *Age at Dx*:

Past medical history: Family history: Cancer in first degree relative: Yes No

Cancer in second degree relative: Yes No

Presenting symptoms and physical exam:

Diagnosis:
Histology/morphology:

Stage: Marker Studies:

Metastatic Sites: Chromosomes: Done?

Initial workup:

CBC:	WBC	Hgb	PLT	ESR	DIFF
Chem:	Creat	Alk Phos	LDH	AST	Ca

CSF:

BM:

Radiologic tests done:

Surgery history:

1.

2.

3.

Treatment:

First Protocol:

Patient ID#

Second Protocol:

Patient ID#

Cumulative Drug Doses:

Actinomycin
Adriamycin
Ara-C
(IT) Ara-C
Bleomycin
CCNU/BCNU
Carboplatin
Cisplatin
Cyclophosphamide
Daunomycin
Decadron
DTIC
Etoposide
5 FU

Ifosfamide
L'Asparaginase
Methotrexate
(IT) Methotrexate
Nitrogen mustard
*Other anthracycline
Prednisone
Procarbazine
6-MP
6-TG
Thiotepa
Vinblastine
Vincristine
VM-26

Transfusions:
Yes:
No:

Radiation therapy:

Site:
Dose:

Complications:

Neurologic?
Cardiac?
Pulmonary?
Endocrine?
Dental?

GI Tract?
Hepatic?
Renal?
Growth?
EENT?

Infectious (not F&N)?
Bone?
Muscle?
2nd Malignancy?
Skin?

Date off therapy:

Number of hospitalizations off therapy:

Problems off therapy:

Most recent diagnostic studies:

Echo:	EKG:	PFT's:	HIV Status:
Scans:	Holter:	CXR:	HepC Status:
Mammogram:	Semen Analysis:	Audiogram:	

Current medications and doses: *Immunization Status:*

Current MD's Name & Address:

Current interval history/concerns:

Physical Exam: *Date:*_______________

Ht_____%_____ Wt_____%_____ BMI _____ BP_____ HR_____

PRIMARY TUMOR SITE:

HEENT:

TANNER STAGE:

OPTHOMALOGY:
Cataracts: Yes No

FEMALE:
Menarche: Y N Age: _____

EXAM OF TEETH:

Regular:_____ Irregular: _____

SKIN:

Use of OCP's: ______

CVS:

RESP:

THYROID:

BREAST EXAM (F):

ABD:

MSK:

NEURO:

	YES	NO
Tobacco:	_____	_____
Alcohol:	_____	_____
Seat Belt:	_____	_____
Bike Helmet:	_____	_____
Sunscreen	_____	_____

Psychosocial:

Marital Status:	Special education:
Pregnancies/ Offspring:	Highest Level Education:
Insurance Status:	GPA:
Health:	Employed/Occupation:
Life:	

Psychosocial Functioning:

Problem List:

1.

2.

3.

4.

5.

Recommendations:

1.

2.

3.

4.

5.

*Signature:*_____________________________________ *Date:* ___________________

COMBINED CLINICAL SUMMARY AND H&P FORM INITIAL VISIT / TRANSPLANT PATIENT

University of Michigan
Ann Arbor, MI

Long-Term Follow-Up Clinical Summary

Name:	*Sex*:
CPI #:	*Race*:
DOB:	*Date of Dx*:
Allergies:	*Age at Dx*:

Past medical history: Family history:

Cancer in first degree relative:	Yes	No
Cancer in second degree relative:	Yes	No

Presenting symptoms and physical exam:

Diagnosis:
Histology/morphology:

Stage:	Marker Studies:
Metastatic Sites:	Chromosomes: Done?

Initial workup:

CBC:	WBC	Hgb	PLT	ESR	DIFF
Chem:	Creat	Alk Phos	LDH	AST	Ca

CSF:

BM:

Radiologic tests done:

Surgery history:

1.

2.

3.

Treatment:

First Protocol:

Patient ID#

Second Protocol:

Patient ID#

Cumulative Drug Doses:

Actinomycin
Adriamycin
Ara-C
(IT) Ara-C
Bleomycin
CCNU/BCNU
Carboplatin
Cisplatin
Cyclophosphamide
Daunomycin
Decadron
DTIC
Etoposide
5 FU

Ifosfamide
L'Asparaginase
Methotrexate
(IT) Methotrexate
Nitrogen mustard
*Other anthracycline
Prednisone
Procarbazine
6-MP
6-TG
Thiotepa
Vinblastine
Vincristine
VM-26

Transfusions:
Yes:
No*:*

Radiation therapy:

Site:
Dose:

Complications:

Neurologic?
Cardiac?
Pulmonary?
Endocrine?
Dental?

GI Tract?
Hepatic?
Renal?
Growth?
EENT?

Infectious (not F&N)?
Bone?
Muscle?
2nd Malignancy?
Skin?

Date of transplant:

Date off all immunosuppressants:
Post transplant complications:

Hospitalizations post transplant:

Most recent diagnostic studies:

Echo:	EKG:	PFT’s:	HIV Status:
Scans:	Holter:	CXR:	HepC Status:
Mammogram:	Semen Analysis:	Audiogram:	

Current medications and doses: *Immunization Status:*

Current MD’s Name & Address:
Current interval history/concerns:

Physical Exam: *Date:*________________

Ht_____%_____ Wt_____%_____ BMI _____ BP_____ HR_____

PRIMARY TUMOR SITE:
GVHD symptoms:

HEENT:

TANNER STAGE:

OPTHOMALOGY:
Cataracts: Yes No

FEMALE:
Menarche: Y N Age: _____
Regular:_____ Irregular: ______
Use of OCP’s: ______

EXAM OF TEETH:

SKIN:

CVS:

RESP:

THYROID:

BREAST EXAM (F):

ABD:

MSK:

NEURO:

	YES	NO
Tobacco:	_____	_____
Alcohol:	_____	_____
Seat Belt:	_____	_____
Bike Helmet:	_____	_____
Sunscreen	_____	_____

Psychosocial:

Marital Status:	Special education:
Pregnancies/ Offspring:	Highest Level Education:
Insurance Status:	GPA:
Health:	Employed/Occupation:
Life:	

Psychosocial Functioning:

GVHD: antibiotic prophylaxis Y N

Annual:

1. Opthy exam
2. Dental exam
3. Respiratory function
4. Gonadal function
5. Vaginal exam for females
6. Immunizations
7. DexaScan

Problem List:

1.

2.

3.

4.

5.

Recommendations:

1.

2.

3.

4.

5.

*Signature:*____ *Date:* ___________________

COMBINED H&P / PATIENT EDUCATION FORM SUBSEQUENT VISIT

University of Michigan
Ann Arbor, MI

Subsequent Visit - Long-Term Follow-Up Clinic

Name: *Age:*
CPI#: *Date:*

Past Cancer History:

Problems/Issues from last year's visit:

Current interval history/concerns:

Current medications and doses: Immunization Status:

Current MD's Name & Address:
Physical Exam: *Date:*

Ht_____%_____ Wt_____%_____ BMI: ________ BP_____HR_____

Primary Tumor Site:

HEENT: TANNER STAGE:

Cataracts: Yes No

SKIN: FEMALES

Menarche: ________

Age: ________

CVS: Regular: ______ Irregular______

RESP: Length of cycle:_______
Day of cycle: _________

EXAM OF TEETH: Use of OCP's: Yes NO

	YES	NO

THYROID:

BREAST EXAM (f): Tobacco: _____ _____

ABD: Alcohol: _____ _____

MSK:

SCOLIOSIS EXAM: NL____ ABNL_____

NEURO:

Seat Belt:	_____	_____
Bike Helmet:	_____	_____
Sunscreen	_____	_____

Most recent diagnostic studies:

- Echo:
- EKG:
- Holter:
- PFT's:
- HepC Status:
- HIV Status:
- CXR:
- *Mammogram:*
- *Audiogram:*

Psychosocial:

Marital Status:

Pregnancies/Viable Offspring:

Insurance Status:

Health: Y N

Life: Y N

Highest Level Education:

IEP:

Special education

GPA:

Employed/Occupation:

Psychosocial functioning:

Current Problems/ Issues:

1.

Plan:

1.
2.
3.
4.
5.

*Signature:*___________________________________ *Date:* _______________

PATIENT EDUCATION MATERIALS

- ☐ *Introduction to Long-Term Follow Up Care*
- ☐ Childhood Cancer Survivors Book

- ☐ *Avascular necrosis*
- ☐ *Bleomycin Alert*
- ☐ *Bone Health*
- ☐ *Breast Cancer*
- ☐ *Central Adrenal Insufficiency*
- ☐ *Dental Health*
- ☐ *Emotional Issues after Childhood Cancer*
- ☐ *Eye Problems*
- ☐ *Female Health Issues*
- ☐ *Finding Appropriate Healthcare*
- ☐ *Growth Hormone Deficiency*
- ☐ *Health Promotion through Diet and Exercise*
- ☐ *Hearing Problems*
- ☐ *Heart and Anthracyclines*
- ☐ *Heart and Radiation*
- ☐ *Hepatitis*
- ☐ *Hyperprolactinemia*
- ☐ *Hypopituitarism*
- ☐ *Kidney Health*
- ☐ *Limb Salvage*
- ☐ *Liver Health*
- ☐ *Male Health Issues*
- ☐ *Peripheral Neuropathy*
- ☐ *Precocious Puberty*
- ☐ *Pulmonary Health*
- ☐ *Raynaud's Phenomenon*
- ☐ *Reducing the Risk of Second Cancers*
- ☐ *School and Learning Issues*
- ☐ *Scoliosis and Kyphosis*
- ☐ *Single Kidney Precautions*
- ☐ *Skin Health*
- ☐ *Spleen Precautions*
- ☐ *Thyroid Problems*

- ☐ *Camp materials*
- ☐ *Scholarship Material*
- ☐ *Osteoporosis Guidelines*
- ☐ *Nutritional Resources*
  - ☐ _____________
  - ☐ ____________
  - ☐ ______________
  - ☐ _______________

COMBINED CLINICAL SUMMARY AND OFF-THERAPY EVALUATION TRACKING FORM

Children’s Hospital of Philadelphia
Philadelphia, PA

Cancer Survivorship Clinic - Clinical Summary

Demographics

Name:
DOB:
MR#:
Sex:
Race:

Address:

Phone:

Parents Names:

Diagnosis

Diagnosis:
Date of Dx:
Age at Dx:

Date off Tx:
Age off Tx:

Histology/Pathology:
Stage/Class:
Metastatic Sites:

Cytogenetics:
Presenting Sx:

Family History of Cancer:

Medical Team

Primary Oncologist:

Primary Physician:

Surgeon:

Sub-specialists:

Chemotherapy History

Initial BSA:

Protocol	**Reason**	**List of Drugs**	**Start Date**	**Stop Date**
#1				
#2				
#3				

Drug	**Cumulative Dose**	**Drug**	**Cumulative Dose**	**Drug**	**Cumulative Dose**
Adriamycin	**mg/m2**	**Cyclophosphamide**	**g/m2**	**Procarbazine**	**g/m2**
Idarubicin	**mg/m2**	**Ifosfamide**	**g/m2**	**Bleomycin**	**u/m2**
Daunomycin	**mg/m2**	**Cisplatin**	**mg/m2**	**HD MTX (>1g/m2)**	**g/m2**
VP-16	**g/m2**	**Carboplatin**	**mg/m2**		

Surgical History

Date	**Surgery**	**Surgeon**

Radiation History

Date	**Site**	**Dose**

Bone Marrow Transplant

Date:	**Acute GVHD:**
Type:	**Chronic GVHD:**
Prep Regime:	

Agent	Cumulative Dose	Agent	Cumulative Dose
Melphalan	**Mg/m2 or kg**		**Mg/m2 or kg**
Cyclophosphamide	**Mg/m2 or kg**		**Mg/m2 or kg**
Busulfan	**Mg/m2 or kg**		**Mg/m2 or kg**

Complications on Therapy

Neuropsych: Y/N	**Renal: Y/N**	**Endocrine: Y/N**	**Dental: Y/N**
Neurology: Y/N	**GI/GU: Y/N**	**Growth: Y/N**	**Infections: Y/N**
Pulmonary: Y/N	**Hepatic: Y/N**	**Skin: Y/N**	**Nutrition: Y/N**
Cardiac: Y/N	**GYN: Y/N**	**Muscle/Bone: Y/N**	**SMN: Y/N**
Vascular: Y/N	**EENT: Y/N**	**Orthopedic: Y/N**	

Complications off Therapy

Neuropsych: Y/N	**Renal: Y/N**	**Endocrine: Y/N**	**Dental: Y/N**
Neurology: Y/N	**GI/GU: Y/N**	**Growth: Y/N**	**Infections: Y/N**
Pulmonary: Y/N	**Hepatic: Y/N**	**Skin: Y/N**	**Nutrition: Y/N**
Cardiac: Y/N	**GYN: Y/N**	**Muscle/Bone: Y/N**	**SMN: Y/N**
Vascular: Y/N	**EENT: Y/N**	**Orthopedic: Y/N**	

Education/Vocation/Career/Psychosocial Information

Education: **Grade Level:** **Special Ed:** **Resource:**	**OVR: Y/N** **Employment: Y/N** **Occupation:**	**Marital Status:** **Pregnancies:** **Offspring:**
	Neuropsychology Testing:	
Date/Results	**Date/Results**	**Date/Results**

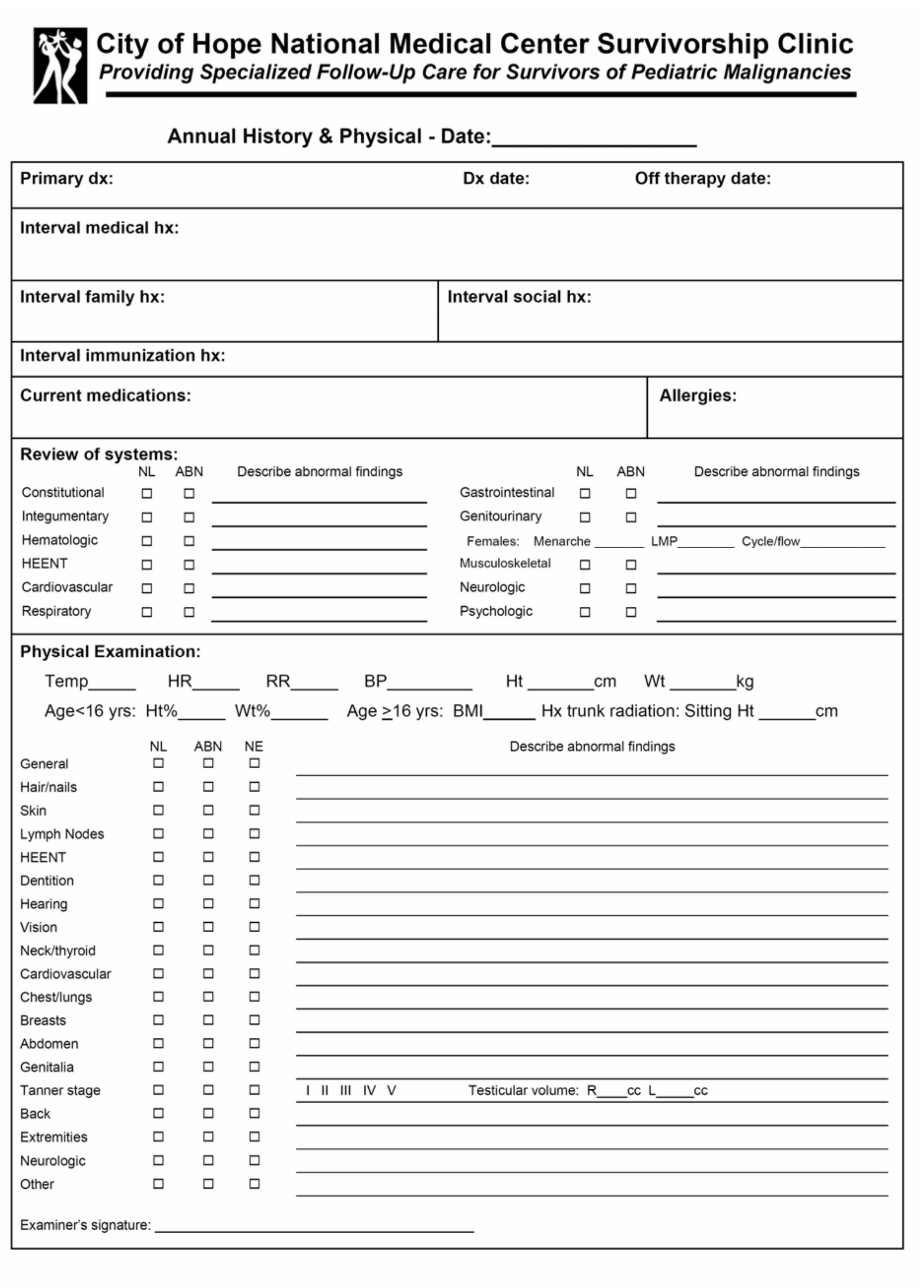
Problem	**Date of Evaluation/ Who?**	**Intervention**	**Last Follow-up**

Review of Off-Therapy Evaluations

System	**Test**	**Date**	**Date**	**Date**	**Date**	**Date**	**Date**	**Date**	**Date**
Hearing/ Vision	Audio								
	Optho								
Endo	T4/TSH								
	Somato-C								
	IGF-BP3								
	FSH/LH								
	Estro/ Testost								
	Bone Age								
Pulm	PFT's								
Cardiac	Echo								
	EKG								
	Holter								
	Exc Stress								
	Lipids								
Renal	BUN/ Cr								
	CrCl								
	BP								
Heme	CBC								
	ESR								
Chemisty									
ID	Hep C								
	HIV								
	Flu Vaccine								
	Pneumovax								
	Meningovax								
	HIB								
	PCN Prophyl								
Radiology	CXR								
	CT/MR/ US								
	DEXA/ PQCT								

H & P FORM

City of Hope
Duarte, CA



City of Hope National Medical Center Survivorship Clinic

Providing Specialized Follow-Up Care for Survivors of Pediatric Malignancies

Annual History & Physical - Date:__________________

Primary dx: **Dx date:** **Off therapy date:**

Interval medical hx:

Interval family hx: **Interval social hx:**

Interval immunization hx:

Current medications: **Allergies:**

Review of systems:

	NL	ABN	Describe abnormal findings		NL	ABN	Describe abnormal findings
Constitutional	☐	☐	____________________	Gastrointestinal	☐	☐	____________________
Integumentary	☐	☐	____________________	Genitourinary	☐	☐	____________________
Hematologic	☐	☐	____________________	Females: Menarche _______ LMP________ Cycle/flow____________			
HEENT	☐	☐	____________________	Musculoskeletal	☐	☐	____________________
Cardiovascular	☐	☐	____________________	Neurologic	☐	☐	____________________
Respiratory	☐	☐	____________________	Psychologic	☐	☐	____________________

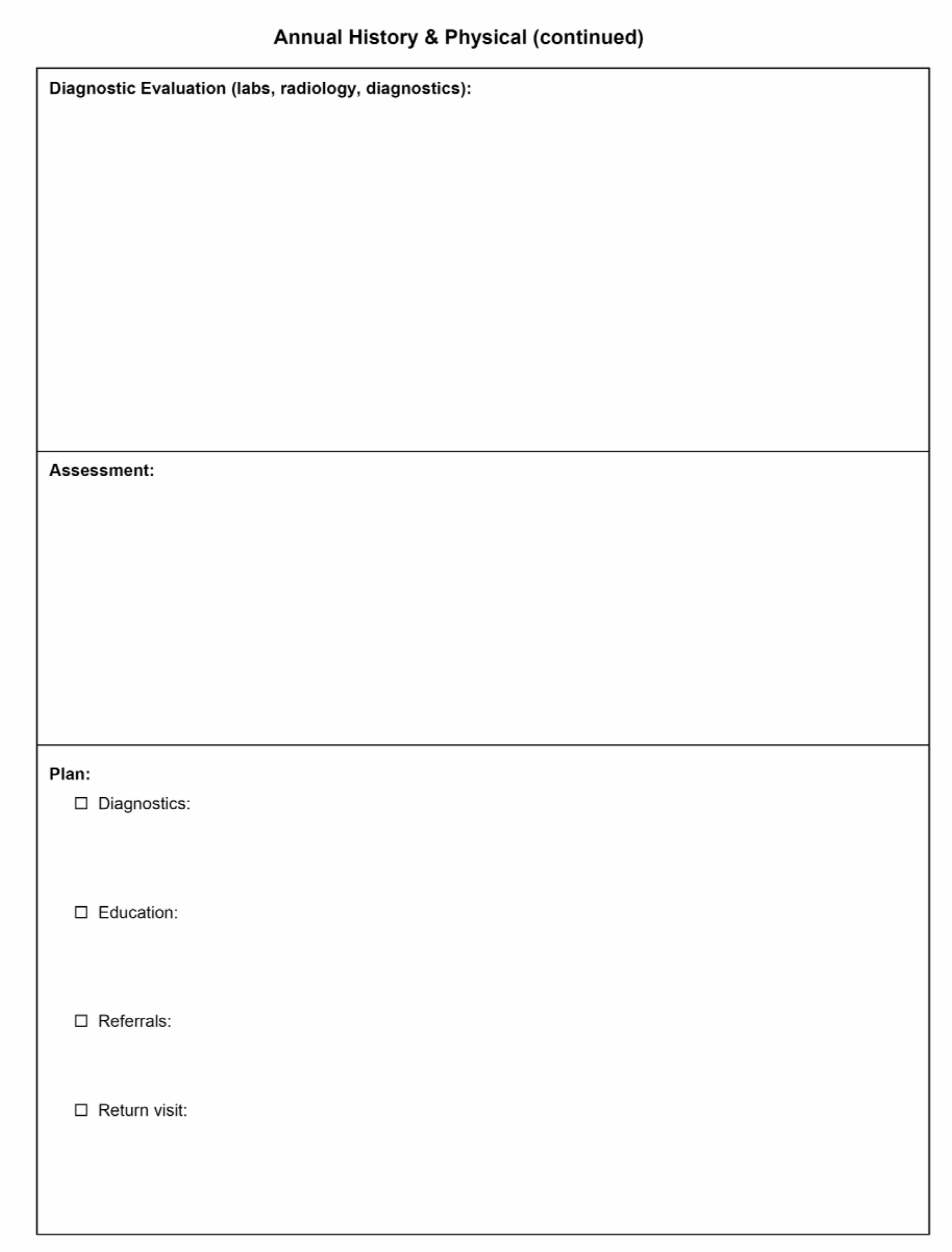
Physical Examination:

Temp_____ HR_____ RR_____ BP__________ Ht _______cm Wt _______kg

Age<16 yrs: Ht%_____ Wt%______ Age ≥16 yrs: BMI______ Hx trunk radiation: Sitting Ht ______cm

	NL	ABN	NE	Describe abnormal findings
General	☐	☐	☐	________________________________
Hair/nails	☐	☐	☐	________________________________
Skin	☐	☐	☐	________________________________
Lymph Nodes	☐	☐	☐	________________________________
HEENT	☐	☐	☐	________________________________
Dentition	☐	☐	☐	________________________________
Hearing	☐	☐	☐	________________________________
Vision	☐	☐	☐	________________________________
Neck/thyroid	☐	☐	☐	________________________________
Cardiovascular	☐	☐	☐	________________________________
Chest/lungs	☐	☐	☐	________________________________
Breasts	☐	☐	☐	________________________________
Abdomen	☐	☐	☐	________________________________
Genitalia	☐	☐	☐	________________________________
Tanner stage	☐	☐	☐	I II III IV V Testicular volume: R____cc L_____cc
Back	☐	☐	☐	________________________________
Extremities	☐	☐	☐	________________________________
Neurologic	☐	☐	☐	________________________________
Other	☐	☐	☐	________________________________

Examiner's signature: ______________________________________



Annual History & Physical (continued)

Diagnostic Evaluation (labs, radiology, diagnostics):

Assessment:

Plan:

- ☐ Diagnostics:
- ☐ Education:
- ☐ Referrals:
- ☐ Return visit:

H & P FORM - TRANSPLANT

Helen DeVos Children's Hospital
Grand Rapids, MI

PEDIATRIC BLOOD & BONE MARROW TRANSPLANTATION
AFTER-CARE AND TRANSITION (ACT) CLINIC

DeVos Children's Hospital

Patient: ____________________ MR#: ______________ DOT: ____________

Vital Signs: B/P: ______ HR: _____ RR: ______ T: __________

Hgt: ______ cm/in Wgt: ______ kg/lbs O_2 Sats: ________%

General Health:
☐ Recent PCP office visits? ____________________
☐ Recent subspecialty office visits? ____________________
  ☐ Dental? ____________________
  ☐ Ophthalmology? ____________________

Flu Vaccination: ☐ yes ________ year ☐ no

Medications: ____________________
____
____
____
____

Recent Family History: ____________________
(malignancies, deceased, etc)
____
____

Psychosocial: School: ____________________

grade: ______ grades: ________ Resource help? IEP? __________
time spent on TV/media/video games: ____________________

Extracurricular activities: ____________________
____
____
____

Hobbies: ____________________
Living conditions: ____________________

Parents: ☐ married ☐ divorced ☐ separated
Sibs: ___________ (full ____, half ____, step ____)

REVIEW OF SYSTEMS:		*yes*	*no*	*other*
General	excessive weight gain/loss			
	fatigue			
	malaise			
	sleeping pattern			
Skin	rash			
	dry skin			
	bruises			
	new moles or changes in mole size/color			
	central line history			

REVIEW OF SYSTEMS (con't):		*yes*	*no*	*other*
Head	chronic headaches, migraines, etc.			
	thin hair growth			
	alopecia			
Eyes	blurred/double vision			
	glasses			
	dry eyes			
Ears	tinnitus			
	loss of hearing			
	chronic otitis media			
Nose	epistaxis			
	chronic rhinorrhea			
	chronic congestion			
Mouth/Throat	excessive dental caries			
	gum bleeding			
	mucosal ulcers			
	dry mouth			
	sore throat			
	odynophagia			
	other:			
Neck	swelling			
	stiffness			
Lungs	cough			
	exercise-induced cough			
	resting shortness of breath			
	dyspnea w/ exertion			
	orthopnea			
	hemoptysis			
	other:			
Cardiovascular	chest pain			
	exercise stamina			
	extremity swelling			
	extremity cyanosis			
Abdomen	appetite			
	nutrition			
	nausea/emesis			
	bloating			
	cramping			
	diarrhea			
G/U	rectal bleeding			
♂	testicular/scrotal swelling			
	testicular self exam			
	early a.m. erection			
	sexual arousal			
	sexually active			
♀	SBE			
	menses			
	sexually active			
	prophylaxis			
Musculoskeletal	joint pain			
	decreased ROM			
	myalgias			
	paresis			
Neurological	dizzy			
	syncope			
	falls			
	paresthesia			

PSYCHOSOCIAL ASSESSMENT FORM (SOCIAL WORK)

University of Michigan
Ann Arbor, MI

Medical Social Work Psychosocial Assessment

Identifying Information/Presenting Problem:

Patient History:

Abuse/Violence:

Substance Use/Abuse:

Family/Social Support:

Family genogram:

Family functioning/sibling relationships:

Memory/meaning of treatment (patient/parent):

Meaning/significance of cancer/survivorship:

Emotional coping/treatment, if any:

Spiritual/faith support:

School/academic functioning:

Special Ed services:

Extracurricular activities/sports:

Relationships: friends/significant others:

Recreational pursuits:

Awareness/concern with Late Effects:

FINANCIAL/INSURANCE:

Clinical Assessment:

Intervention/Education:

Discharge Plan/Treatment plan:

NUTRITION ASSESSMENT FORM

University of Michigan
Ann Arbor, MI

Nutrition Assessment
Pediatric Oncology/Long Term Follow UP Clinic

Name: ___________________________________ **Date**:_____________

CPI# ____________________________________

Diagnosis: _______________________________Date of diagnosis: __________

Treatment: ____

Medications: ____

Supplements: ____

Anthropometrics
Weight: _______kg _______# ______%ile
Usual Body Weight _______ ______%UBW
Ideal Body Weight _______ ______%IBW
Height: _________cm ______%ile
BMI: _________
Weight/height /growth: ____

Food Intake Information/Diet History

Appetite (circle one): poor fair good excellent

Food Allergies/Intolerances? Yes ____
No

Lifestyle Factors:
Exercise? Yes ____ No
Smoking? Yes ____ No
Alcohol? Yes ____ No

Social History:

Patient/Family Nutrition Concerns:____________________________________

Diet History:

Breakfast Lunch Dinner

Snack Snack Snack

Assessment

Patient is: (circle one) maintaining, decreasing, gaining weight.
Patient is: (circle one) maintaining, growing in height.
Current diet appears:

Well balanced
Lacking in: calcium calories protein fat fiber iron
Excessive in: calories fat sugar salt fast food

Written patient education provided:

1. ____
2. ____
3. ____
4. ____

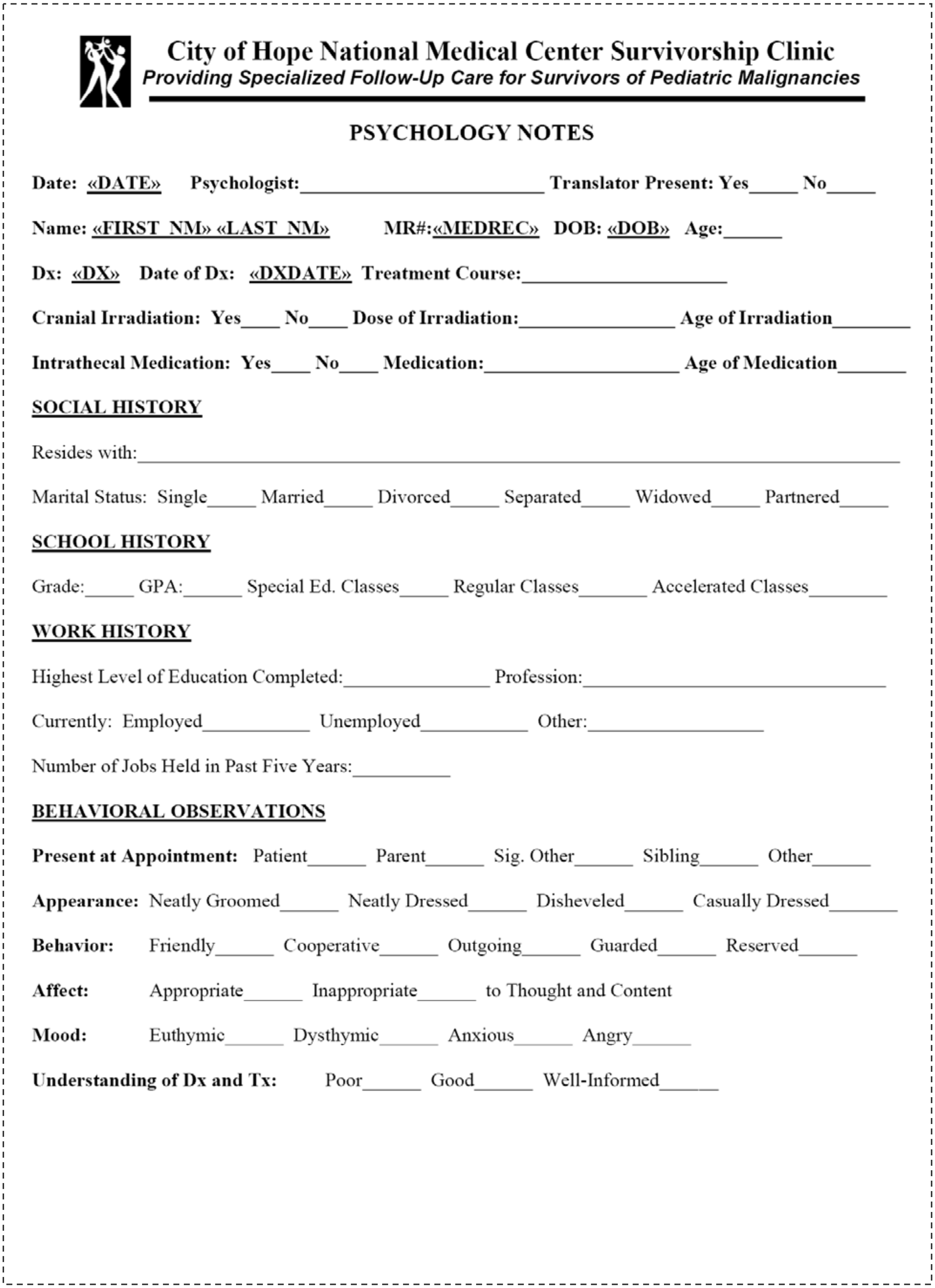
Recommendations:

1. ____
   ____
2. ____

___________________________**Pediatric Oncology Registered Dietitian**

PSYCHOLOGY ASSESSMENT FORM

City of Hope
Duarte, CA



City of Hope National Medical Center Survivorship Clinic

Providing Specialized Follow-Up Care for Survivors of Pediatric Malignancies

PSYCHOLOGY NOTES

Date: «DATE» **Psychologist:**_________________________ **Translator Present: Yes**_____ **No**_____

Name: «FIRST_NM» «LAST_NM» **MR#:«MEDREC»** **DOB: «DOB»** **Age:**______

Dx: «DX» **Date of Dx: «DXDATE»** **Treatment Course:**_____________________

Cranial Irradiation: Yes____ **No**____ **Dose of Irradiation:**________________ **Age of Irradiation**________

Intrathecal Medication: Yes____ **No**____ **Medication:**____________________ **Age of Medication**_______

SOCIAL HISTORY

Resides with:____

Marital Status: Single_____ Married_____ Divorced_____ Separated_____ Widowed_____ Partnered_____

SCHOOL HISTORY

Grade:_____ GPA:______ Special Ed. Classes_____ Regular Classes_______ Accelerated Classes________

WORK HISTORY

Highest Level of Education Completed:_______________ Profession:_______________________________

Currently: Employed___________ Unemployed___________ Other:__________________

Number of Jobs Held in Past Five Years:__________

BEHAVIORAL OBSERVATIONS

Present at Appointment: Patient______ Parent______ Sig. Other______ Sibling______ Other______

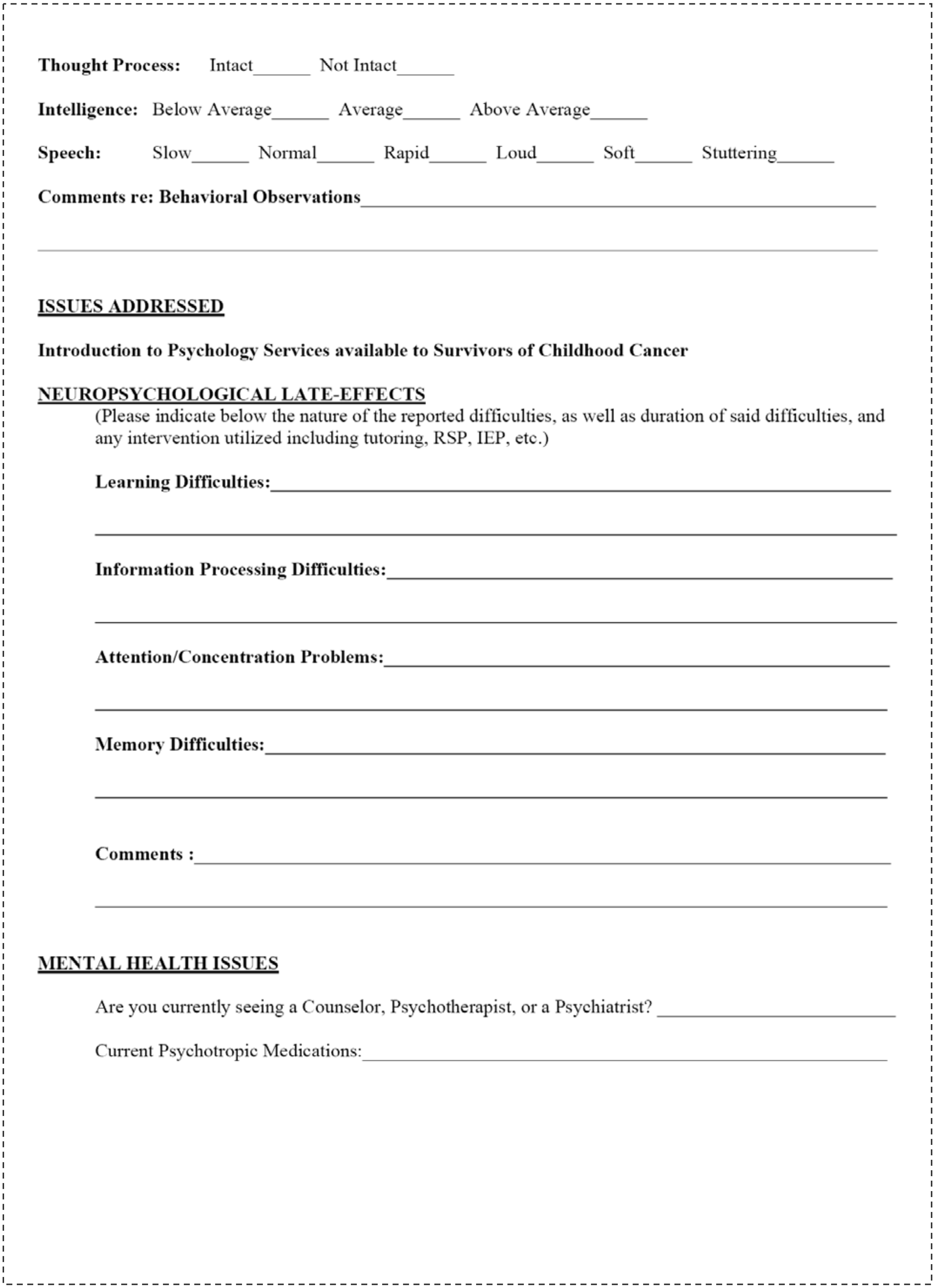
Appearance: Neatly Groomed______ Neatly Dressed______ Disheveled______ Casually Dressed_______

Behavior: Friendly______ Cooperative______ Outgoing______ Guarded______ Reserved______

Affect: Appropriate______ Inappropriate______ to Thought and Content

Mood: Euthymic______ Dysthymic______ Anxious______ Angry______

Understanding of Dx and Tx: Poor______ Good______ Well-Informed______



Thought Process: Intact______ Not Intact______

Intelligence: Below Average______ Average______ Above Average______

Speech: Slow______ Normal______ Rapid______ Loud______ Soft______ Stuttering______

Comments re: Behavioral Observations____

____

ISSUES ADDRESSED

Introduction to Psychology Services available to Survivors of Childhood Cancer

NEUROPSYCHOLOGICAL LATE-EFFECTS

(Please indicate below the nature of the reported difficulties, as well as duration of said difficulties, and any intervention utilized including tutoring, RSP, IEP, etc.)

Learning Difficulties:____

____

Information Processing Difficulties:________________________________

____

Attention/Concentration Problems:_________________________________

____

Memory Difficulties:____

____

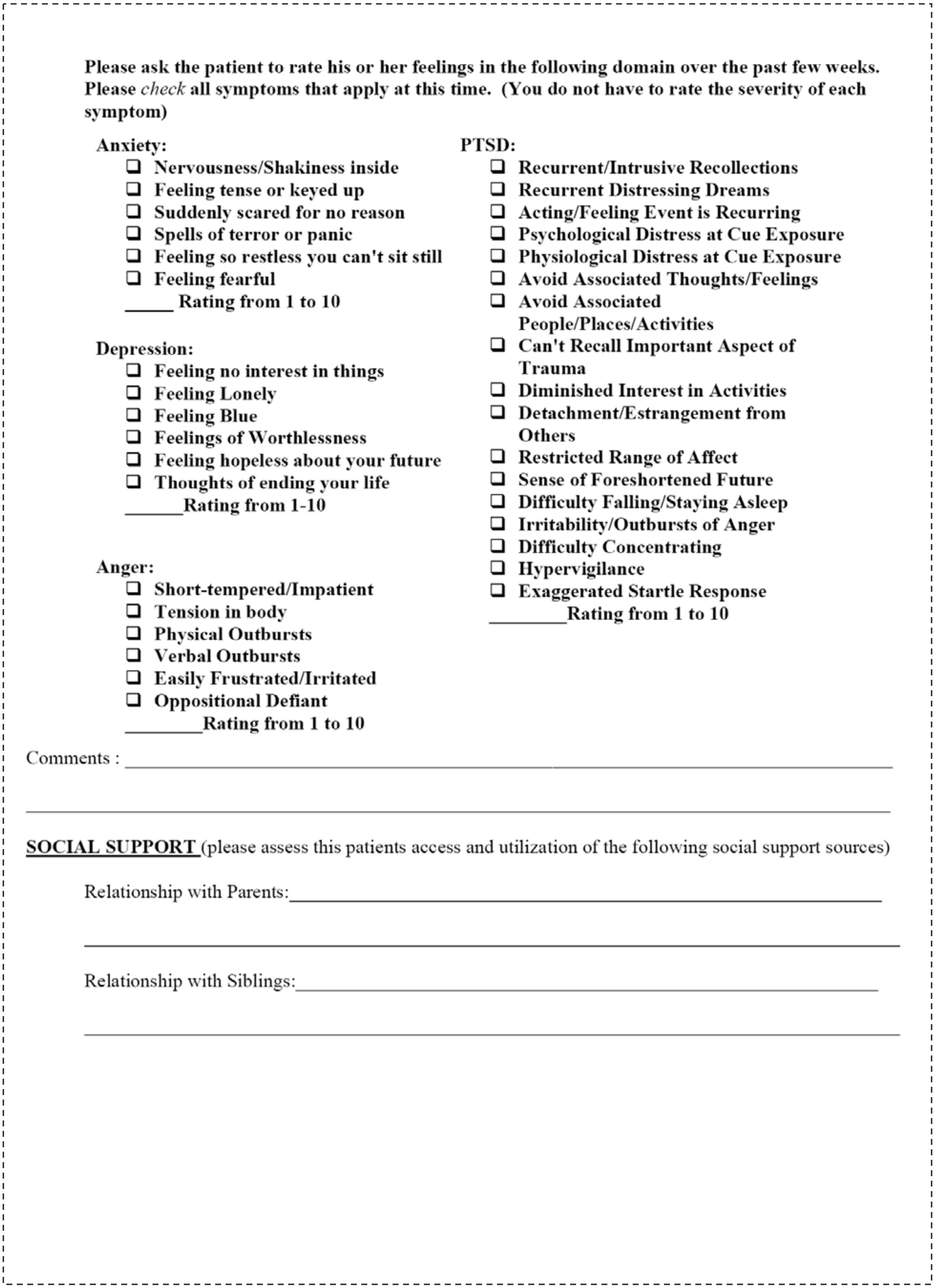
Comments :____

____

MENTAL HEALTH ISSUES

Are you currently seeing a Counselor, Psychotherapist, or a Psychiatrist? ____________________

Current Psychotropic Medications:______________________________________



Please ask the patient to rate his or her feelings in the following domain over the past few weeks. Please *check* all symptoms that apply at this time. (You do not have to rate the severity of each symptom)

Anxiety:

- ☐ **Nervousness/Shakiness inside**
- ☐ **Feeling tense or keyed up**
- ☐ **Suddenly scared for no reason**
- ☐ **Spells of terror or panic**
- ☐ **Feeling so restless you can't sit still**
- ☐ **Feeling fearful**

_____ Rating from 1 to 10

Depression:

- ☐ **Feeling no interest in things**
- ☐ **Feeling Lonely**
- ☐ **Feeling Blue**
- ☐ **Feelings of Worthlessness**
- ☐ **Feeling hopeless about your future**
- ☐ **Thoughts of ending your life**

______Rating from 1-10

Anger:

- ☐ **Short-tempered/Impatient**
- ☐ **Tension in body**
- ☐ **Physical Outbursts**
- ☐ **Verbal Outbursts**
- ☐ **Easily Frustrated/Irritated**
- ☐ **Oppositional Defiant**

________Rating from 1 to 10

PTSD:

- ☐ **Recurrent/Intrusive Recollections**
- ☐ **Recurrent Distressing Dreams**
- ☐ **Acting/Feeling Event is Recurring**
- ☐ **Psychological Distress at Cue Exposure**
- ☐ **Physiological Distress at Cue Exposure**
- ☐ **Avoid Associated Thoughts/Feelings**
- ☐ **Avoid Associated People/Places/Activities**
- ☐ **Can't Recall Important Aspect of Trauma**
- ☐ **Diminished Interest in Activities**
- ☐ **Detachment/Estrangement from Others**
- ☐ **Restricted Range of Affect**
- ☐ **Sense of Foreshortened Future**
- ☐ **Difficulty Falling/Staying Asleep**
- ☐ **Irritability/Outbursts of Anger**
- ☐ **Difficulty Concentrating**
- ☐ **Hypervigilance**
- ☐ **Exaggerated Startle Response**

________Rating from 1 to 10

Comments : ____

____

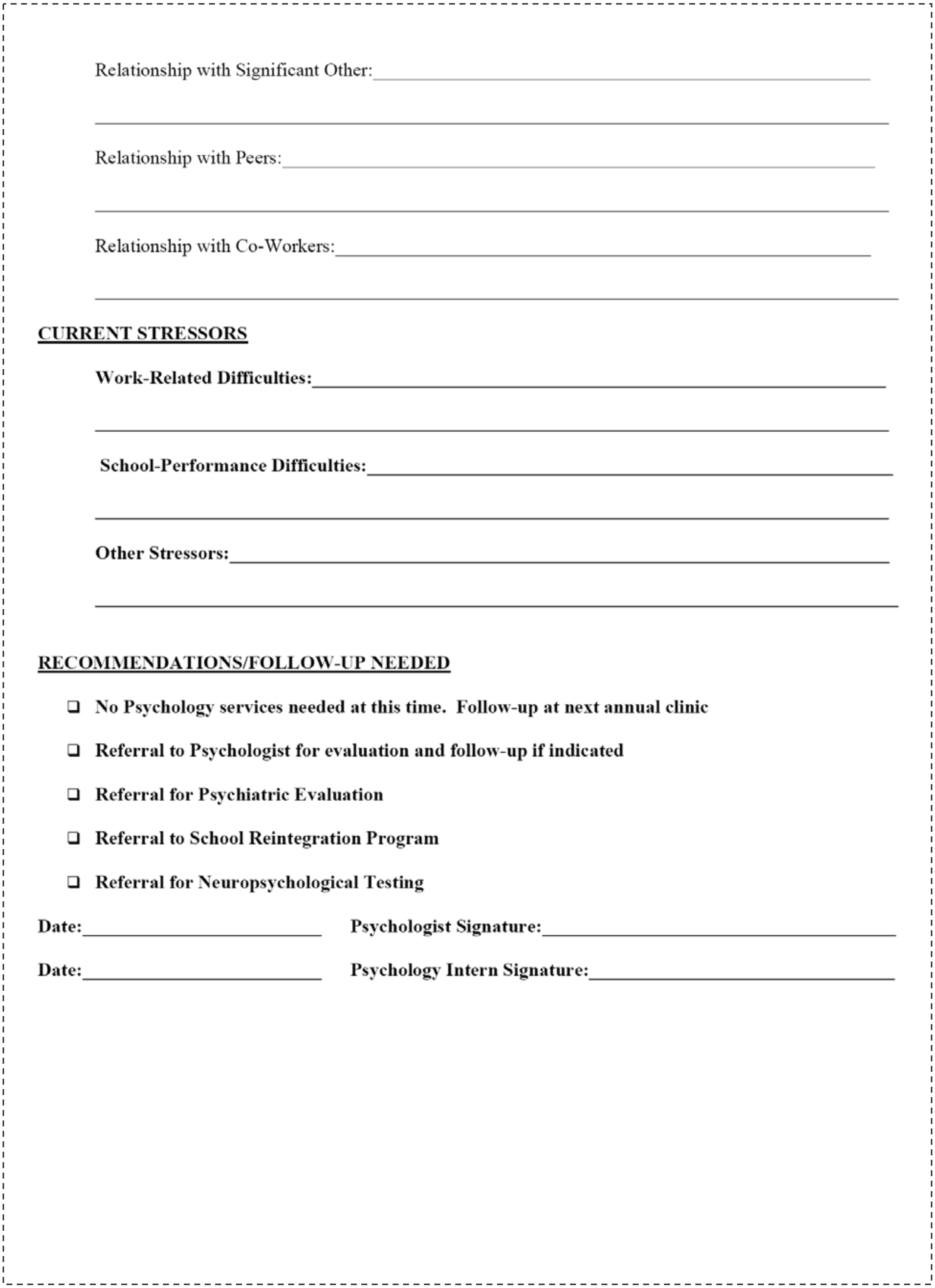
<u>SOCIAL SUPPORT</u> (please assess this patients access and utilization of the following social support sources)

Relationship with Parents:____

____

Relationship with Siblings:____

____



Relationship with Significant Other:____

____

Relationship with Peers:____

____

Relationship with Co-Workers:____

____

CURRENT STRESSORS

Work-Related Difficulties:____

____

School-Performance Difficulties:____

____

Other Stressors:____

____

RECOMMENDATIONS/FOLLOW-UP NEEDED

- ☐ **No Psychology services needed at this time. Follow-up at next annual clinic**
- ☐ **Referral to Psychologist for evaluation and follow-up if indicated**
- ☐ **Referral for Psychiatric Evaluation**
- ☐ **Referral to School Reintegration Program**
- ☐ **Referral for Neuropsychological Testing**

Date:____________________ **Psychologist Signature:**______________________________

Date:____________________ **Psychology Intern Signature:**_________________________

PATIENT EDUCATION/HEALTH LINKS FORM

Carolinas Medical Center
Charlotte, NC

PATIENT EDUCATION/HEALTH LINKS FORM

Documentation of Educational Information

Health Link Brochures	***Date Reviewed and given to patient***
Avascular Necrosis	
Bladder Health	
Bleomycin Alert	
Bone Health	
Breast Cancer	
Breast Cancer: Are you at Risk?	
Central Adrenal Insufficiency	
Colorectal Cancer	
Dental Health	
Emotional Issues	
Eye Problems	
Female Health Issues	
GI Health	
Growth hormone deficiency	
Health Promotion	
Hearing Problems	
Heart and Anthracyclines	
Heart and Radiation	
Hepatitis	
Hepatitis	
Hyperprolactinemia	
Hypopituitarism	
Intro. To LTFU after Treatment	
Kidney Health	
Limb Salvage	
Liver Health	
Male Health Issues	
Pain	
Peripheral Neuropathy	
Precocious Puberty	
Pulmonary Health	
Raynaud’s Phenomena	
Reducing Risk of Secondary Ca	
School and Learning Issues	
Scoliosis	
Single Kidney	
Skin Health	
Spleen	
Splenic Precautions	
Thyroid Problems	

Other Educational Information

Cancer Survivor Summary ____________________
Self-Breast Exam ____________________
Sun Safety ____________________
Testicular Self exam ____________________
Tobacco Education/Cessation ____________________

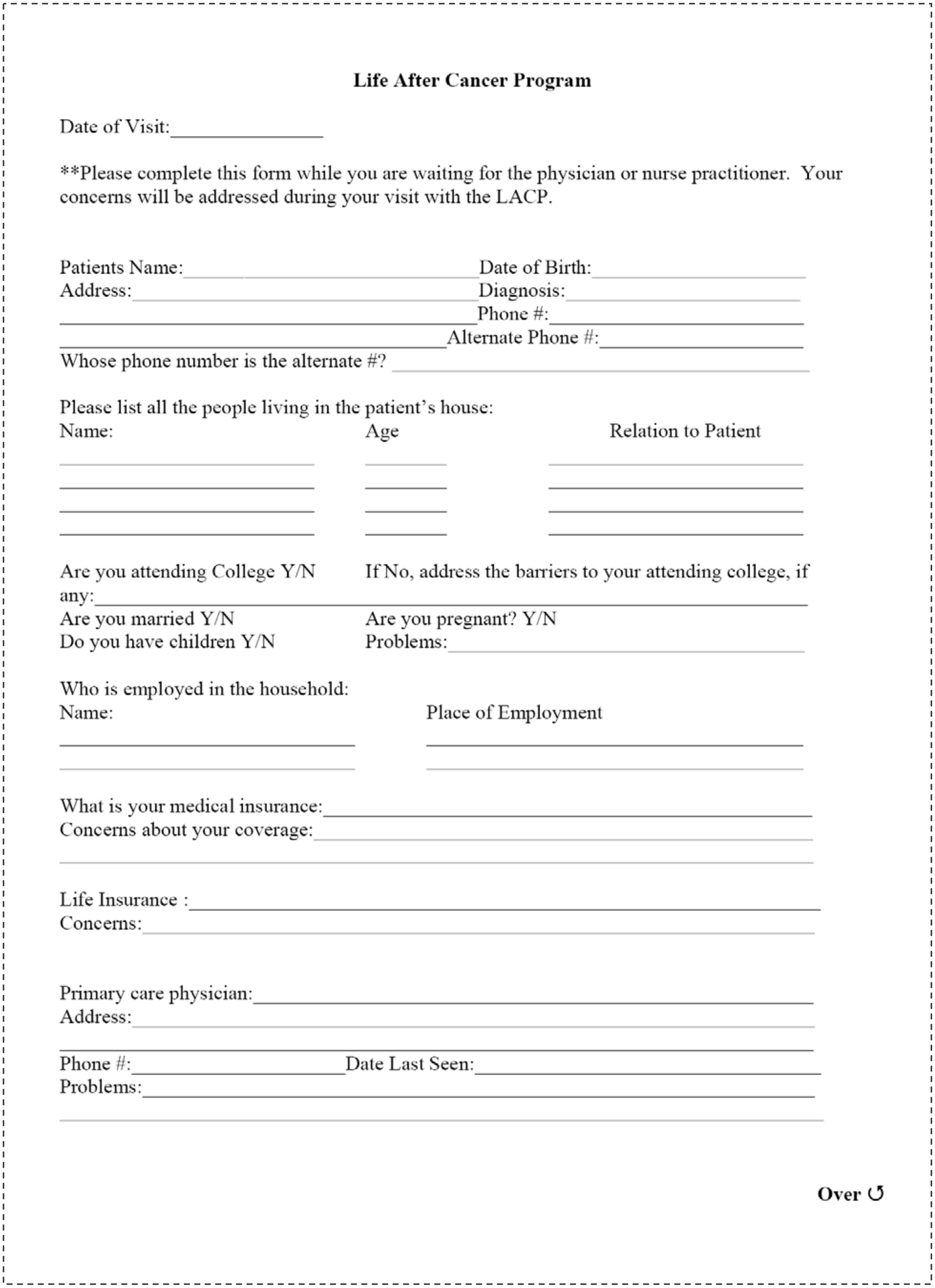
Letters

To patient ____________________
To PCP ____________________
To other specialist ____________________
____
____

QUESTIONNAIRES

BASELINE QUESTIONNAIRE (ENGLISH AND SPANISH)

Cook Children's Hospital
Fort Worth, TX



Life After Cancer Program

Date of Visit:________________

**Please complete this form while you are waiting for the physician or nurse practitioner. Your concerns will be addressed during your visit with the LACP.

Patients Name:______________________________ Date of Birth:____________________

Address:__________________________________ Diagnosis:____________________

____ Phone #:____________________

____ Alternate Phone #:____________________

Whose phone number is the alternate #? ______________________________

Please list all the people living in the patient's house:

Name:	Age	Relation to Patient

Are you attending College Y/N   If No, address the barriers to your attending college, if any:____

Are you married Y/N   Are you pregnant? Y/N

Do you have children Y/N   Problems:______________________________

Who is employed in the household:

Name:	Place of Employment

What is your medical insurance:____

Concerns about your coverage:____

____

Life Insurance :____

Concerns:____

Primary care physician:____

Address:____

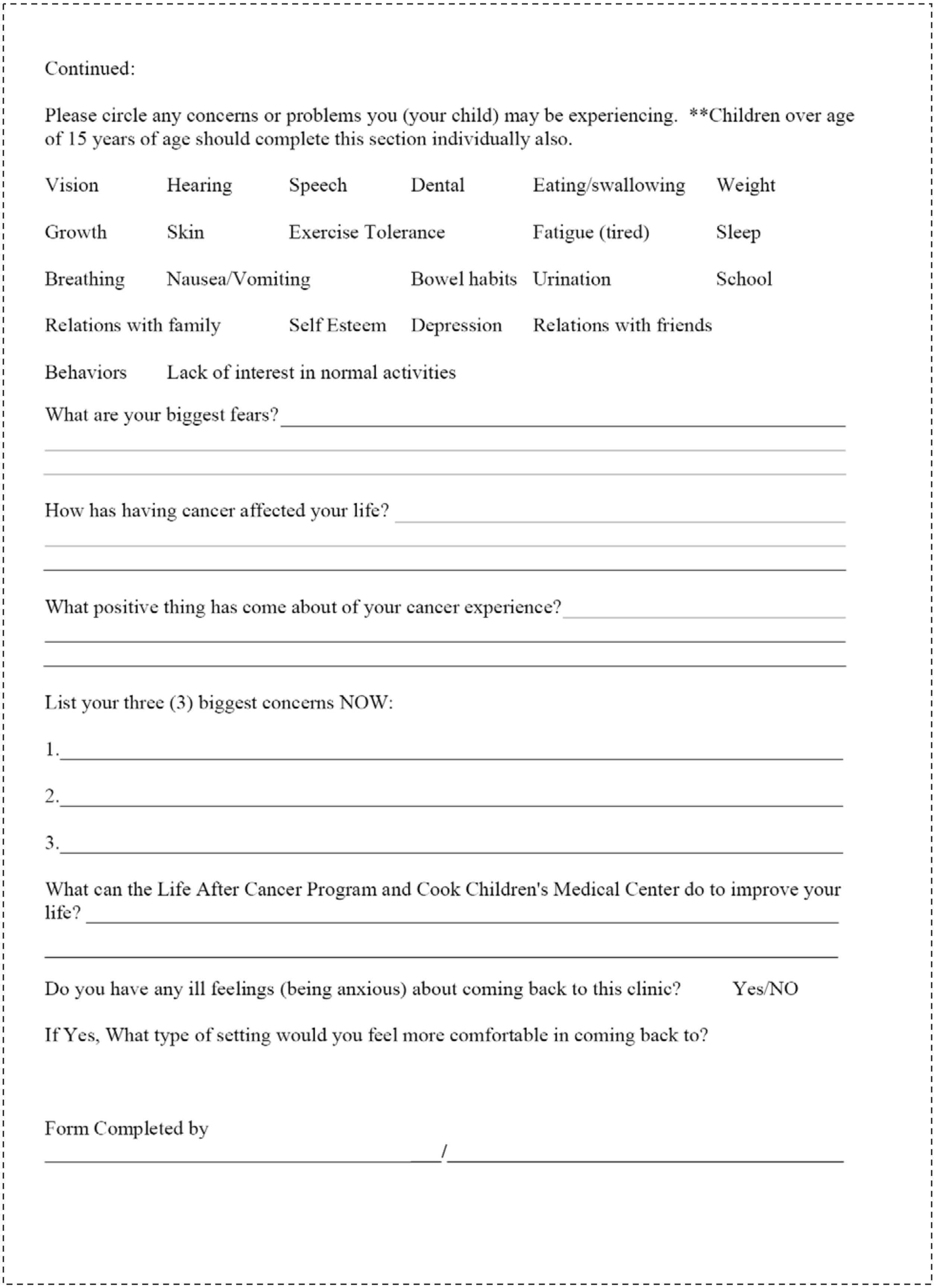
____

Phone #:______________________Date Last Seen:______________________________

Problems:____

____

Over ↺



Continued:

Please circle any concerns or problems you (your child) may be experiencing. **Children over age of 15 years of age should complete this section individually also.

Vision Hearing Speech Dental Eating/swallowing Weight

Growth Skin Exercise Tolerance Fatigue (tired) Sleep

Breathing Nausea/Vomiting Bowel habits Urination School

Relations with family Self Esteem Depression Relations with friends

Behaviors Lack of interest in normal activities

What are your biggest fears?______________________________

How has having cancer affected your life? ______________________________

What positive thing has come about of your cancer experience?____________________

List your three (3) biggest concerns NOW:

1.____

2.____

3.____

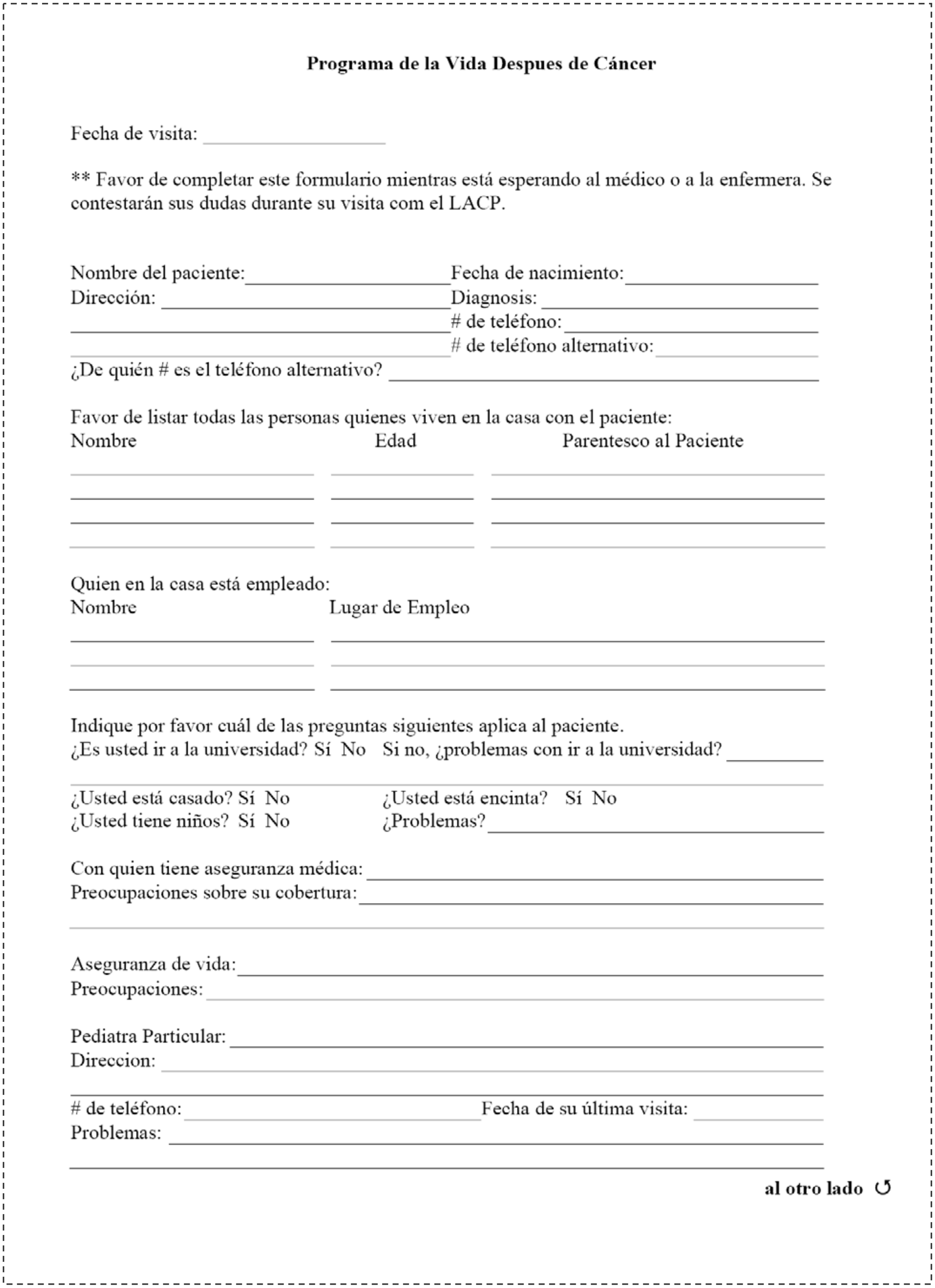
What can the Life After Cancer Program and Cook Children's Medical Center do to improve your life? ______________________________

Do you have any ill feelings (being anxious) about coming back to this clinic? Yes/NO

If Yes, What type of setting would you feel more comfortable in coming back to?

Form Completed by

________________________/________________________



Programa de la Vida Despues de Cáncer

Fecha de visita: ____________________

** Favor de completar este formulario mientras está esperando al médico o a la enfermera. Se contestarán sus dudas durante su visita com el LACP.

Nombre del paciente: ____________________ Fecha de nacimiento: ____________________
Dirección: ____________________ Diagnosis: ____________________
____________________ # de teléfono: ____________________
____________________ # de teléfono alternativo: ____________________
¿De quién # es el teléfono alternativo? ____________________

Favor de listar todas las personas quienes viven en la casa con el paciente:

Nombre	Edad	Parentesco al Paciente

Quien en la casa está empleado:

Nombre	Lugar de Empleo

Indique por favor cuál de las preguntas siguientes aplica al paciente.
¿Es usted ir a la universidad? Sí No Si no, ¿problemas con ir a la universidad? ____________________
____
¿Usted está casado? Sí No ¿Usted está encinta? Sí No
¿Usted tiene niños? Sí No ¿Problemas? ____________________

Con quien tiene aseguranza médica: ____________________
Preocupaciones sobre su cobertura: ____________________
____

Aseguranza de vida: ____________________
Preocupaciones: ____________________

Pediatra Particular: ____________________
Direccion: ____________________
____
de teléfono: ____________________ Fecha de su última visita: ____________________
Problemas: ____________________
____

al otro lado ↺

Favor de hacer un círculo alrededor de las dudas o preblemas que ested o su hijo está experienciado.
** Ninos mayores de 15 anos deben completar esta sección indiviualmente también.

Visión   Sentido de Oir   Habla   Dental   Comer/Tragar   Peso

Crecimiento   Piel   Tolera bien ejercicio   Fatiga (muy cansado)   Dormir

Respirar   Nausea/Vómitos   Habitos de Ecrementos   Orinación   Escuela

Rlaciones Familiares   Self Esteem   Depresión   Relaciones con amigos

Comportamiento   Falta de interés en actividades normales

Cuelas son sus mayores terrores? ____

____

____

Como le ha afectao su vida el tener cáncer? _________________________________

____

____

Que cosa positiva ha salido de su experiencia con cáncer? ______________________

____

____

Liste sus preocupaciones más grandes AHORA:
1. ____
2. ____
3. ____

Que pueden hacer el Life After Cancer Program y Cook Chilren's Medical Center para mejorar su vida?

____

____

____

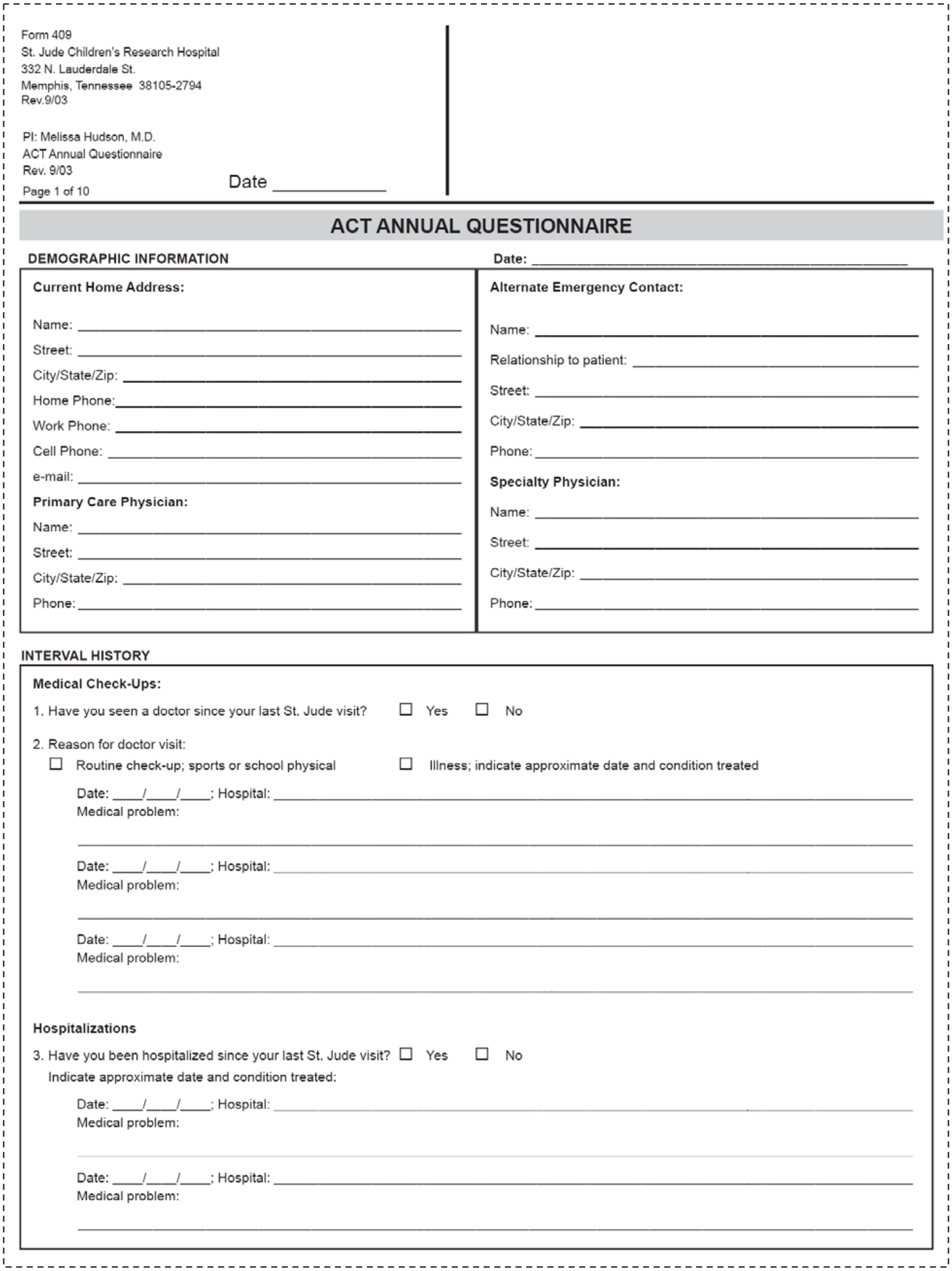
____

Formulario Completado por

____________________________________/____________________________

COMBINED ANNUAL QUESTIONNAIRE WITH H&P, PATIENT EDUCATION, AND FAMILY/PREGNANCY HISTORY FORMS

St. Jude Children's Research Hospital
Memphis, TN



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ACT ANNUAL QUESTIONNAIRE

DEMOGRAPHIC INFORMATION

Date: ____

Current Home Address:

Name: ____
Street: ____
City/State/Zip: ____________________________________
Home Phone: ______________________________________
Work Phone: ______________________________________
Cell Phone: _______________________________________
e-mail: ____

Primary Care Physician:

Name: ____
Street: ____
City/State/Zip: ____________________________________
Phone: ____

Alternate Emergency Contact:

Name: ____
Relationship to patient: ____________________________
Street: ____
City/State/Zip: ____________________________________
Phone: ____

Specialty Physician:

Name: ____
Street: ____
City/State/Zip: ____________________________________
Phone: ____

INTERVAL HISTORY

Medical Check-Ups:

1. Have you seen a doctor since your last St. Jude visit? ☐ Yes ☐ No

2. Reason for doctor visit:
☐ Routine check-up; sports or school physical ☐ Illness; indicate approximate date and condition treated

Date: ____/____/____; Hospital: ______________________________
Medical problem:
____

Date: ____/____/____; Hospital: ______________________________
Medical problem:
____

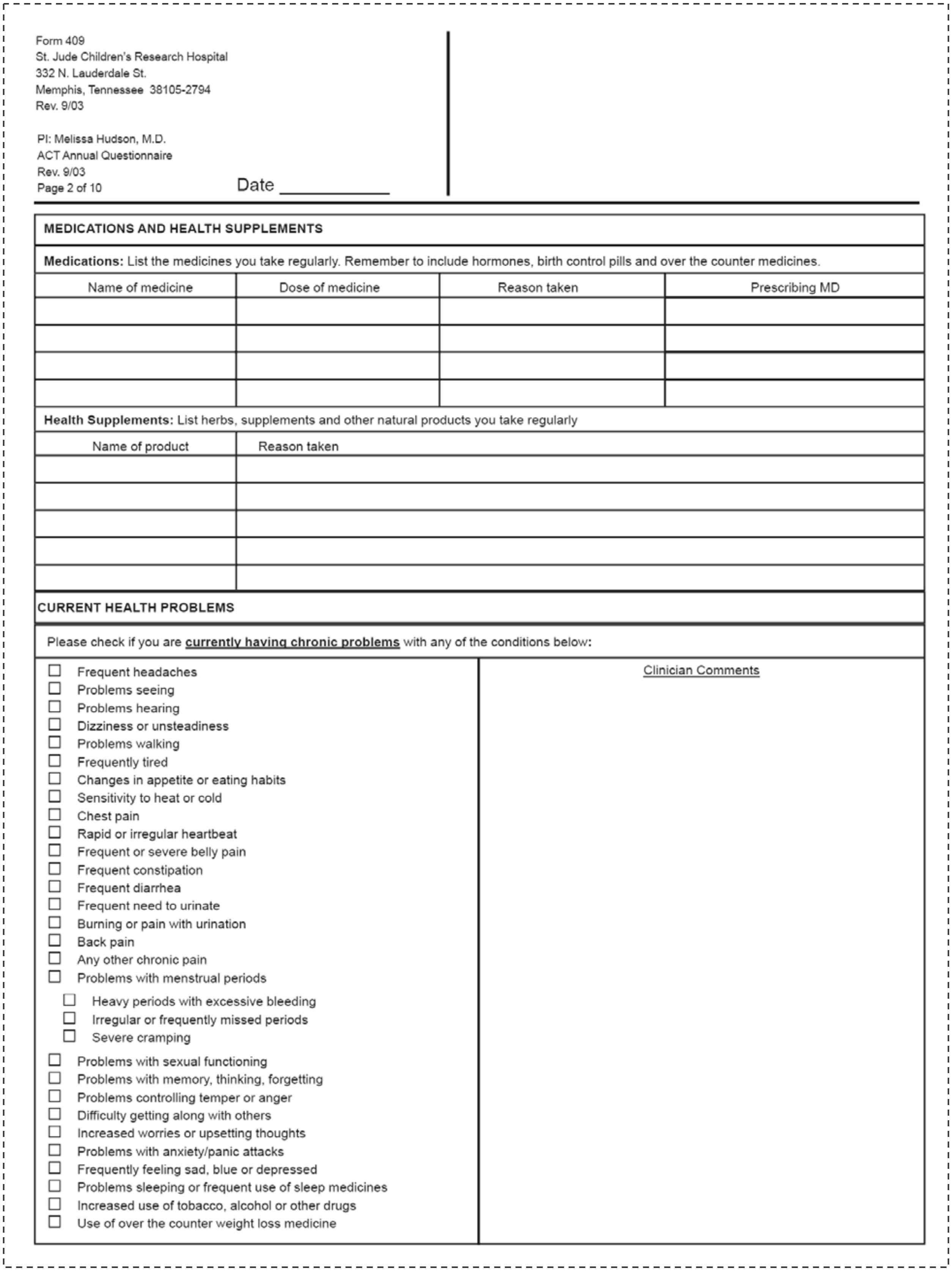
Date: ____/____/____; Hospital: ______________________________
Medical problem:
____

Hospitalizations

3. Have you been hospitalized since your last St. Jude visit? ☐ Yes ☐ No
Indicate approximate date and condition treated:

Date: ____/____/____; Hospital: ______________________________
Medical problem:
____

Date: ____/____/____; Hospital: ______________________________
Medical problem:
____



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MEDICATIONS AND HEALTH SUPPLEMENTS

Medications: List the medicines you take regularly. Remember to include hormones, birth control pills and over the counter medicines.

Name of medicine	Dose of medicine	Reason taken	Prescribing MD

Health Supplements: List herbs, supplements and other natural products you take regularly

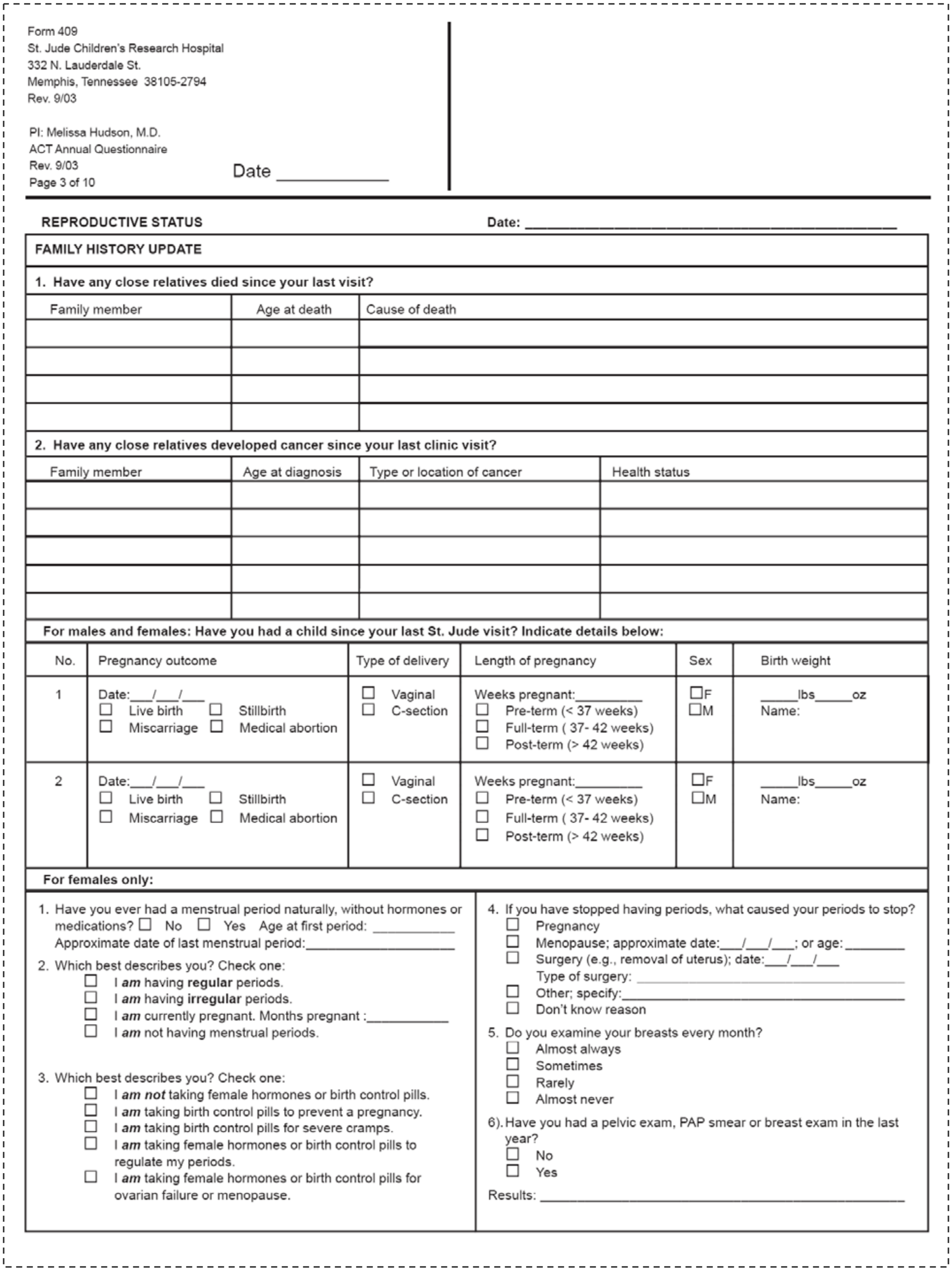
Name of product	Reason taken

CURRENT HEALTH PROBLEMS

Please check if you are **currently having chronic problems** with any of the conditions below:

- ☐ Frequent headaches
- ☐ Problems seeing
- ☐ Problems hearing
- ☐ Dizziness or unsteadiness
- ☐ Problems walking
- ☐ Frequently tired
- ☐ Changes in appetite or eating habits
- ☐ Sensitivity to heat or cold
- ☐ Chest pain
- ☐ Rapid or irregular heartbeat
- ☐ Frequent or severe belly pain
- ☐ Frequent constipation
- ☐ Frequent diarrhea
- ☐ Frequent need to urinate
- ☐ Burning or pain with urination
- ☐ Back pain
- ☐ Any other chronic pain
- ☐ Problems with menstrual periods
  - ☐ Heavy periods with excessive bleeding
  - ☐ Irregular or frequently missed periods
  - ☐ Severe cramping
- ☐ Problems with sexual functioning
- ☐ Problems with memory, thinking, forgetting
- ☐ Problems controlling temper or anger
- ☐ Difficulty getting along with others
- ☐ Increased worries or upsetting thoughts
- ☐ Problems with anxiety/panic attacks
- ☐ Frequently feeling sad, blue or depressed
- ☐ Problems sleeping or frequent use of sleep medicines
- ☐ Increased use of tobacco, alcohol or other drugs
- ☐ Use of over the counter weight loss medicine

Clinician Comments



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REPRODUCTIVE STATUS **Date:** ____

FAMILY HISTORY UPDATE

1. Have any close relatives died since your last visit?

Family member	Age at death	Cause of death

2. Have any close relatives developed cancer since your last clinic visit?

Family member	Age at diagnosis	Type or location of cancer	Health status

For males and females: Have you had a child since your last St. Jude visit? Indicate details below:

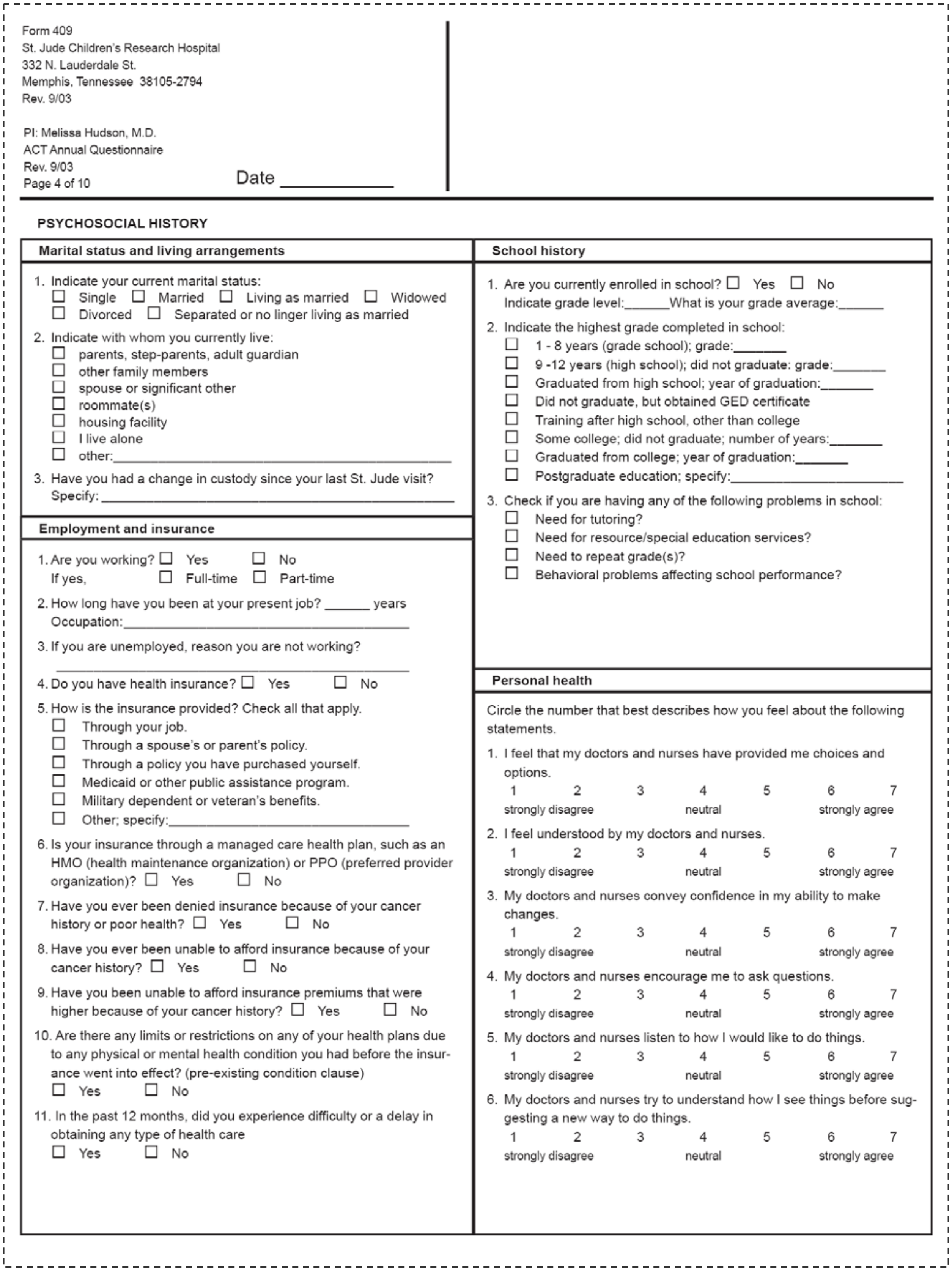
No.	Pregnancy outcome	Type of delivery	Length of pregnancy	Sex	Birth weight
1	Date:___/___/___ ☐ Live birth ☐ Stillbirth ☐ Miscarriage ☐ Medical abortion	☐ Vaginal ☐ C-section	Weeks pregnant:_________ ☐ Pre-term (< 37 weeks) ☐ Full-term (37- 42 weeks) ☐ Post-term (> 42 weeks)	☐F ☐M	_____lbs_____oz Name:
2	Date:___/___/___ ☐ Live birth ☐ Stillbirth ☐ Miscarriage ☐ Medical abortion	☐ Vaginal ☐ C-section	Weeks pregnant:_________ ☐ Pre-term (< 37 weeks) ☐ Full-term (37- 42 weeks) ☐ Post-term (> 42 weeks)	☐F ☐M	_____lbs_____oz Name:

For females only:

1. Have you ever had a menstrual period naturally, without hormones or medications? ☐ No ☐ Yes Age at first period: ___________
   Approximate date of last menstrual period:_____________________
2. Which best describes you? Check one:
   - ☐ I ***am*** having **regular** periods.
   - ☐ I ***am*** having **irregular** periods.
   - ☐ I ***am*** currently pregnant. Months pregnant :___________
   - ☐ I ***am*** not having menstrual periods.
3. Which best describes you? Check one:
   - ☐ I ***am not*** taking female hormones or birth control pills.
   - ☐ I ***am*** taking birth control pills to prevent a pregnancy.
   - ☐ I ***am*** taking birth control pills for severe cramps.
   - ☐ I ***am*** taking female hormones or birth control pills to regulate my periods.
   - ☐ I ***am*** taking female hormones or birth control pills for ovarian failure or menopause.
4. If you have stopped having periods, what caused your periods to stop?
   - ☐ Pregnancy
   - ☐ Menopause; approximate date:___/___/___; or age: ________
   - ☐ Surgery (e.g., removal of uterus); date:___/___/___
     Type of surgery: ___________________________________
   - ☐ Other; specify:_____________________________________
   - ☐ Don't know reason
5. Do you examine your breasts every month?
   - ☐ Almost always
   - ☐ Sometimes
   - ☐ Rarely
   - ☐ Almost never

6). Have you had a pelvic exam, PAP smear or breast exam in the last year?
- ☐ No
- ☐ Yes

Results: ____



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PSYCHOSOCIAL HISTORY

Marital status and living arrangements

1. Indicate your current marital status:
   ☐ Single ☐ Married ☐ Living as married ☐ Widowed
   ☐ Divorced ☐ Separated or no linger living as married
2. Indicate with whom you currently live:
   ☐ parents, step-parents, adult guardian
   ☐ other family members
   ☐ spouse or significant other
   ☐ roommate(s)
   ☐ housing facility
   ☐ I live alone
   ☐ other:____
3. Have you had a change in custody since your last St. Jude visit?
   Specify: ____

Employment and insurance

1. Are you working? ☐ Yes ☐ No
   If yes, ☐ Full-time ☐ Part-time
2. How long have you been at your present job? ______ years
   Occupation:____________________________________
3. If you are unemployed, reason you are not working?
   ____
4. Do you have health insurance? ☐ Yes ☐ No
5. How is the insurance provided? Check all that apply.
   ☐ Through your job.
   ☐ Through a spouse's or parent's policy.
   ☐ Through a policy you have purchased yourself.
   ☐ Medicaid or other public assistance program.
   ☐ Military dependent or veteran's benefits.
   ☐ Other; specify:______________________________
6. Is your insurance through a managed care health plan, such as an HMO (health maintenance organization) or PPO (preferred provider organization)? ☐ Yes ☐ No
7. Have you ever been denied insurance because of your cancer history or poor health? ☐ Yes ☐ No
8. Have you ever been unable to afford insurance because of your cancer history? ☐ Yes ☐ No
9. Have you been unable to afford insurance premiums that were higher because of your cancer history? ☐ Yes ☐ No
10. Are there any limits or restrictions on any of your health plans due to any physical or mental health condition you had before the insurance went into effect? (pre-existing condition clause)
    ☐ Yes ☐ No
11. In the past 12 months, did you experience difficulty or a delay in obtaining any type of health care
    ☐ Yes ☐ No

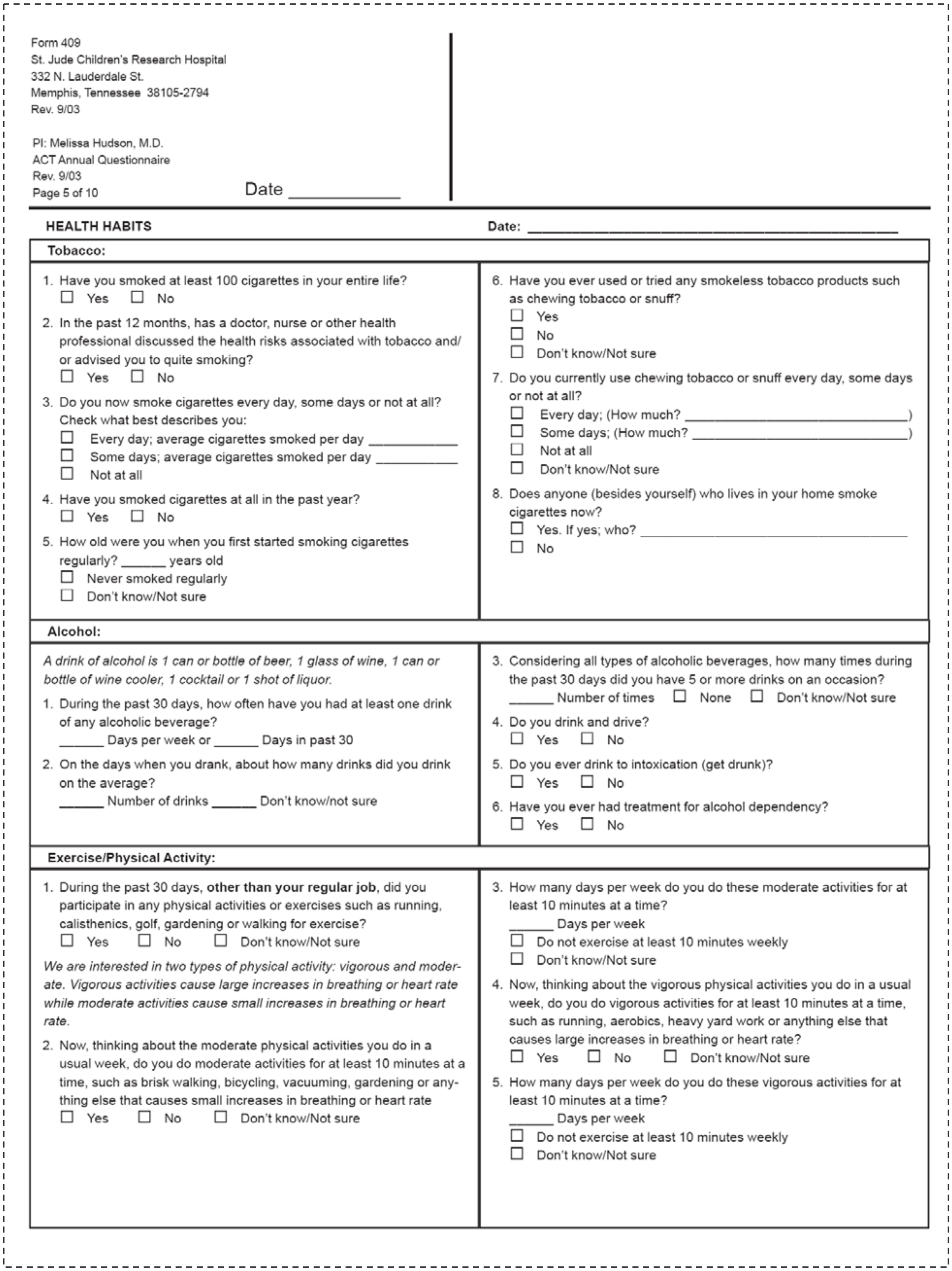
School history

1. Are you currently enrolled in school? ☐ Yes ☐ No
   Indicate grade level:______What is your grade average:______
2. Indicate the highest grade completed in school:
   ☐ 1 - 8 years (grade school); grade:_______
   ☐ 9 -12 years (high school); did not graduate: grade:_______
   ☐ Graduated from high school; year of graduation:_______
   ☐ Did not graduate, but obtained GED certificate
   ☐ Training after high school, other than college
   ☐ Some college; did not graduate; number of years:_______
   ☐ Graduated from college; year of graduation:_______
   ☐ Postgraduate education; specify:______________________
3. Check if you are having any of the following problems in school:
   ☐ Need for tutoring?
   ☐ Need for resource/special education services?
   ☐ Need to repeat grade(s)?
   ☐ Behavioral problems affecting school performance?

Personal health

Circle the number that best describes how you feel about the following statements.

1. I feel that my doctors and nurses have provided me choices and options.
   1 2 3 4 5 6 7
   strongly disagree neutral strongly agree
2. I feel understood by my doctors and nurses.
   1 2 3 4 5 6 7
   strongly disagree neutral strongly agree
3. My doctors and nurses convey confidence in my ability to make changes.
   1 2 3 4 5 6 7
   strongly disagree neutral strongly agree
4. My doctors and nurses encourage me to ask questions.
   1 2 3 4 5 6 7
   strongly disagree neutral strongly agree
5. My doctors and nurses listen to how I would like to do things.
   1 2 3 4 5 6 7
   strongly disagree neutral strongly agree
6. My doctors and nurses try to understand how I see things before suggesting a new way to do things.
   1 2 3 4 5 6 7
   strongly disagree neutral strongly agree



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HEALTH HABITS **Date:** ____

Tobacco:

1. Have you smoked at least 100 cigarettes in your entire life?
   ☐ Yes ☐ No
2. In the past 12 months, has a doctor, nurse or other health professional discussed the health risks associated with tobacco and/or advised you to quite smoking?
   ☐ Yes ☐ No
3. Do you now smoke cigarettes every day, some days or not at all? Check what best describes you:
   ☐ Every day; average cigarettes smoked per day ____________
   ☐ Some days; average cigarettes smoked per day ___________
   ☐ Not at all
4. Have you smoked cigarettes at all in the past year?
   ☐ Yes ☐ No
5. How old were you when you first started smoking cigarettes regularly? ______ years old
   ☐ Never smoked regularly
   ☐ Don't know/Not sure
6. Have you ever used or tried any smokeless tobacco products such as chewing tobacco or snuff?
   ☐ Yes
   ☐ No
   ☐ Don't know/Not sure
7. Do you currently use chewing tobacco or snuff every day, some days or not at all?
   ☐ Every day; (How much? ______________________________)
   ☐ Some days; (How much? _____________________________)
   ☐ Not at all
   ☐ Don't know/Not sure
8. Does anyone (besides yourself) who lives in your home smoke cigarettes now?
   ☐ Yes. If yes; who? ___________________________________
   ☐ No

Alcohol:

A drink of alcohol is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail or 1 shot of liquor.

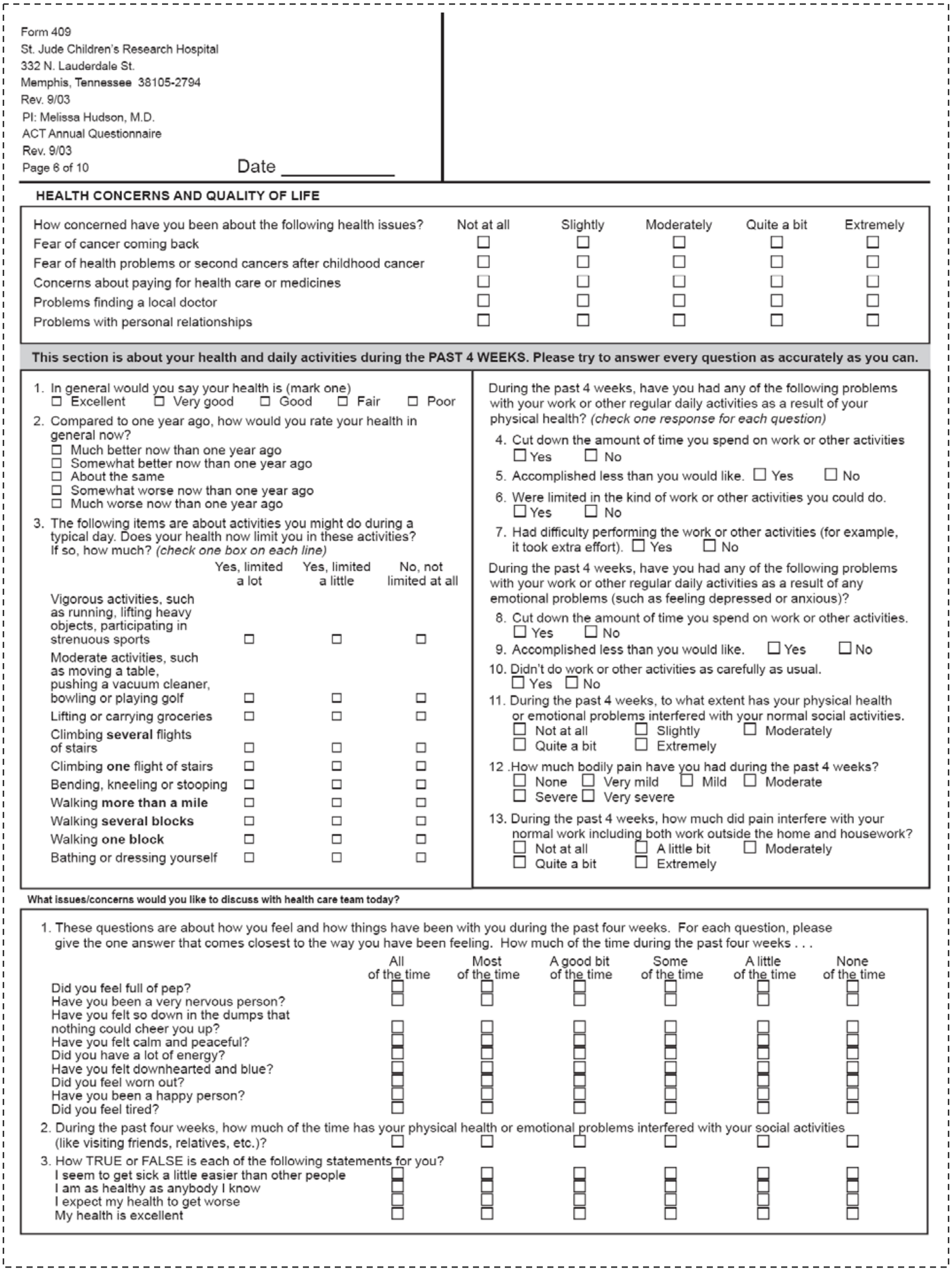
1. During the past 30 days, how often have you had at least one drink of any alcoholic beverage?
   ______ Days per week or ______ Days in past 30
2. On the days when you drank, about how many drinks did you drink on the average?
   ______ Number of drinks ______ Don't know/not sure
3. Considering all types of alcoholic beverages, how many times during the past 30 days did you have 5 or more drinks on an occasion?
   ______ Number of times ☐ None ☐ Don't know/Not sure
4. Do you drink and drive?
   ☐ Yes ☐ No
5. Do you ever drink to intoxication (get drunk)?
   ☐ Yes ☐ No
6. Have you ever had treatment for alcohol dependency?
   ☐ Yes ☐ No

Exercise/Physical Activity:

1. During the past 30 days, **other than your regular job**, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening or walking for exercise?
   ☐ Yes ☐ No ☐ Don't know/Not sure

We are interested in two types of physical activity: vigorous and moderate. Vigorous activities cause large increases in breathing or heart rate while moderate activities cause small increases in breathing or heart rate.

2. Now, thinking about the moderate physical activities you do in a usual week, do you do moderate activities for at least 10 minutes at a time, such as brisk walking, bicycling, vacuuming, gardening or anything else that causes small increases in breathing or heart rate
   ☐ Yes ☐ No ☐ Don't know/Not sure
3. How many days per week do you do these moderate activities for at least 10 minutes at a time?
   ______ Days per week
   ☐ Do not exercise at least 10 minutes weekly
   ☐ Don't know/Not sure
4. Now, thinking about the vigorous physical activities you do in a usual week, do you do vigorous activities for at least 10 minutes at a time, such as running, aerobics, heavy yard work or anything else that causes large increases in breathing or heart rate?
   ☐ Yes ☐ No ☐ Don't know/Not sure
5. How many days per week do you do these vigorous activities for at least 10 minutes at a time?
   ______ Days per week
   ☐ Do not exercise at least 10 minutes weekly
   ☐ Don't know/Not sure



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HEALTH CONCERNS AND QUALITY OF LIFE

How concerned have you been about the following health issues?	Not at all	Slightly	Moderately	Quite a bit	Extremely
Fear of cancer coming back	☐	☐	☐	☐	☐
Fear of health problems or second cancers after childhood cancer	☐	☐	☐	☐	☐
Concerns about paying for health care or medicines	☐	☐	☐	☐	☐
Problems finding a local doctor	☐	☐	☐	☐	☐
Problems with personal relationships	☐	☐	☐	☐	☐

This section is about your health and daily activities during the PAST 4 WEEKS. Please try to answer every question as accurately as you can.

1. In general would you say your health is (mark one)
   ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor
2. Compared to one year ago, how would you rate your health in general now?
   ☐ Much better now than one year ago
   ☐ Somewhat better now than one year ago
   ☐ About the same
   ☐ Somewhat worse now than one year ago
   ☐ Much worse now than one year ago
3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *(check one box on each line)*

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
Lifting or carrying groceries	☐	☐	☐
Climbing **several** flights of stairs	☐	☐	☐
Climbing **one** flight of stairs	☐	☐	☐
Bending, kneeling or stooping	☐	☐	☐
Walking **more than a mile**	☐	☐	☐
Walking **several blocks**	☐	☐	☐
Walking **one block**	☐	☐	☐
Bathing or dressing yourself	☐	☐	☐

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? *(check one response for each question)*

4. Cut down the amount of time you spend on work or other activities
   ☐ Yes ☐ No
5. Accomplished less than you would like. ☐ Yes ☐ No
6. Were limited in the kind of work or other activities you could do.
   ☐ Yes ☐ No
7. Had difficulty performing the work or other activities (for example, it took extra effort). ☐ Yes ☐ No

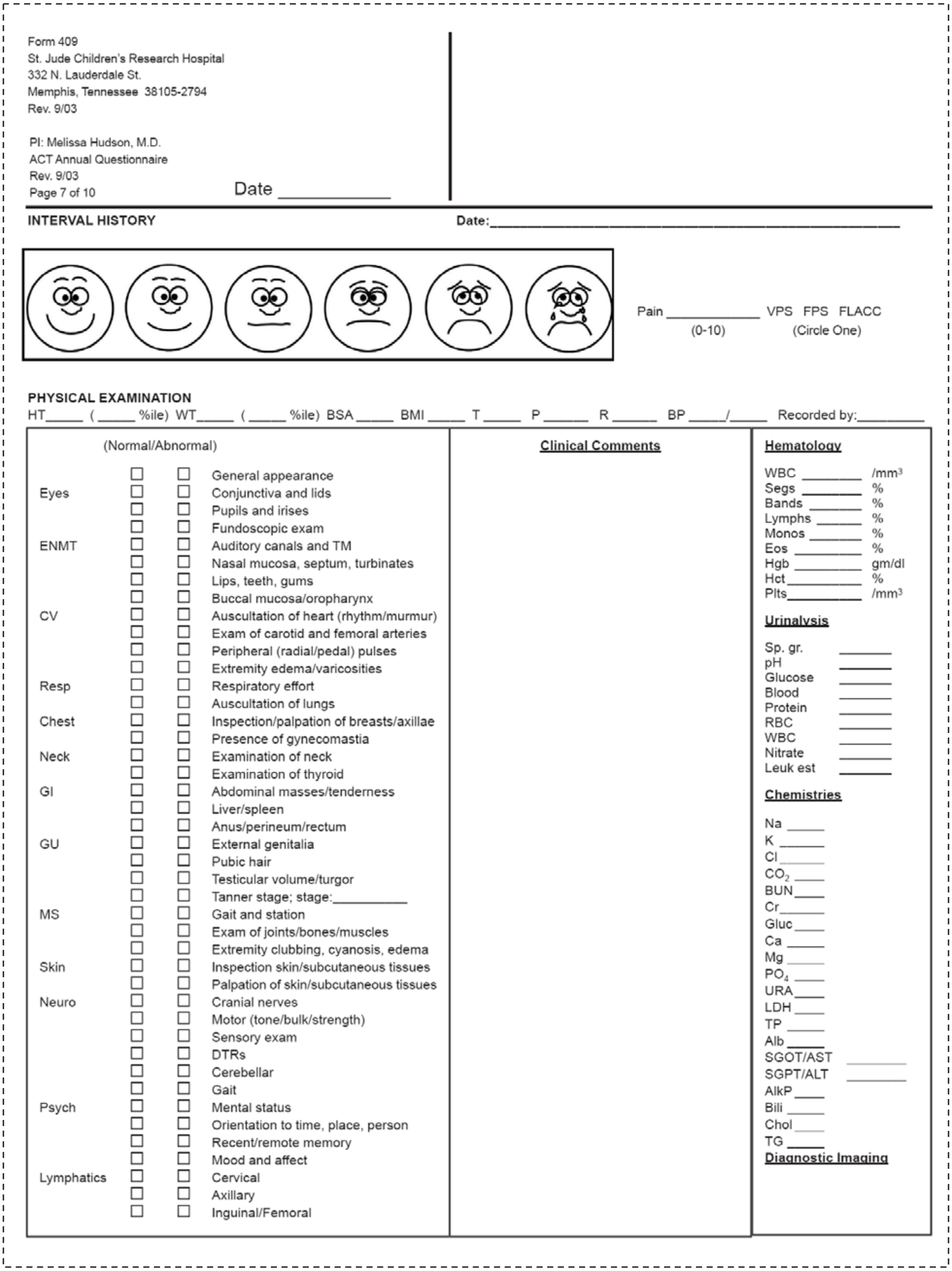
During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

8. Cut down the amount of time you spend on work or other activities.
   ☐ Yes ☐ No
9. Accomplished less than you would like. ☐ Yes ☐ No
10. Didn't do work or other activities as carefully as usual.
    ☐ Yes ☐ No
11. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities.
    ☐ Not at all ☐ Slightly ☐ Moderately
    ☐ Quite a bit ☐ Extremely
12 .How much bodily pain have you had during the past 4 weeks?
    ☐ None ☐ Very mild ☐ Mild ☐ Moderate
    ☐ Severe ☐ Very severe
13. During the past 4 weeks, how much did pain interfere with your normal work including both work outside the home and housework?
    ☐ Not at all ☐ A little bit ☐ Moderately
    ☐ Quite a bit ☐ Extremely

What issues/concerns would you like to discuss with health care team today?

1. These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks . . .

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of pep?	☐	☐	☐	☐	☐	☐
Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐
Did you feel worn out?	☐	☐	☐	☐	☐	☐
Have you been a happy person?	☐	☐	☐	☐	☐	☐
Did you feel tired?	☐	☐	☐	☐	☐	☐
2. During the past four weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?	☐	☐	☐	☐	☐	☐
3. How TRUE or FALSE is each of the following statements for you?						
I seem to get sick a little easier than other people	☐	☐	☐	☐	☐	☐
I am as healthy as anybody I know	☐	☐	☐	☐	☐	☐
I expect my health to get worse	☐	☐	☐	☐	☐	☐
My health is excellent	☐	☐	☐	☐	☐	☐



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INTERVAL HISTORY

Date:____

Pain ____________ VPS FPS FLACC
(0-10) (Circle One)

PHYSICAL EXAMINATION

HT_____ (_____ %ile) WT_____ (_____ %ile) BSA _____ BMI _____ T _____ P _____ R _____ BP _____/_____ Recorded by:_________

	(Normal/Abnormal)			**Clinical Comments**
	☐	☐	General appearance	
Eyes	☐	☐	Conjunctiva and lids	
	☐	☐	Pupils and irises	
	☐	☐	Fundoscopic exam	
ENMT	☐	☐	Auditory canals and TM	
	☐	☐	Nasal mucosa, septum, turbinates	
	☐	☐	Lips, teeth, gums	
	☐	☐	Buccal mucosa/oropharynx	
CV	☐	☐	Auscultation of heart (rhythm/murmur)	
	☐	☐	Exam of carotid and femoral arteries	
	☐	☐	Peripheral (radial/pedal) pulses	
	☐	☐	Extremity edema/varicosities	
Resp	☐	☐	Respiratory effort	
	☐	☐	Auscultation of lungs	
Chest	☐	☐	Inspection/palpation of breasts/axillae	
	☐	☐	Presence of gynecomastia	
Neck	☐	☐	Examination of neck	
	☐	☐	Examination of thyroid	
GI	☐	☐	Abdominal masses/tenderness	
	☐	☐	Liver/spleen	
	☐	☐	Anus/perineum/rectum	
GU	☐	☐	External genitalia	
	☐	☐	Pubic hair	
	☐	☐	Testicular volume/turgor	
	☐	☐	Tanner stage; stage:__________	
MS	☐	☐	Gait and station	
	☐	☐	Exam of joints/bones/muscles	
	☐	☐	Extremity clubbing, cyanosis, edema	
Skin	☐	☐	Inspection skin/subcutaneous tissues	
	☐	☐	Palpation of skin/subcutaneous tissues	
Neuro	☐	☐	Cranial nerves	
	☐	☐	Motor (tone/bulk/strength)	
	☐	☐	Sensory exam	
	☐	☐	DTRs	
	☐	☐	Cerebellar	
	☐	☐	Gait	
Psych	☐	☐	Mental status	
	☐	☐	Orientation to time, place, person	
	☐	☐	Recent/remote memory	
	☐	☐	Mood and affect	
Lymphatics	☐	☐	Cervical	
	☐	☐	Axillary	
	☐	☐	Inguinal/Femoral	

Hematology

WBC ________ /mm^3
Segs ________ %
Bands _______ %
Lymphs ______ %
Monos _______ %
Eos _________ %
Hgb _________ gm/dl
Hct _________ %
Plts__________ /mm^3

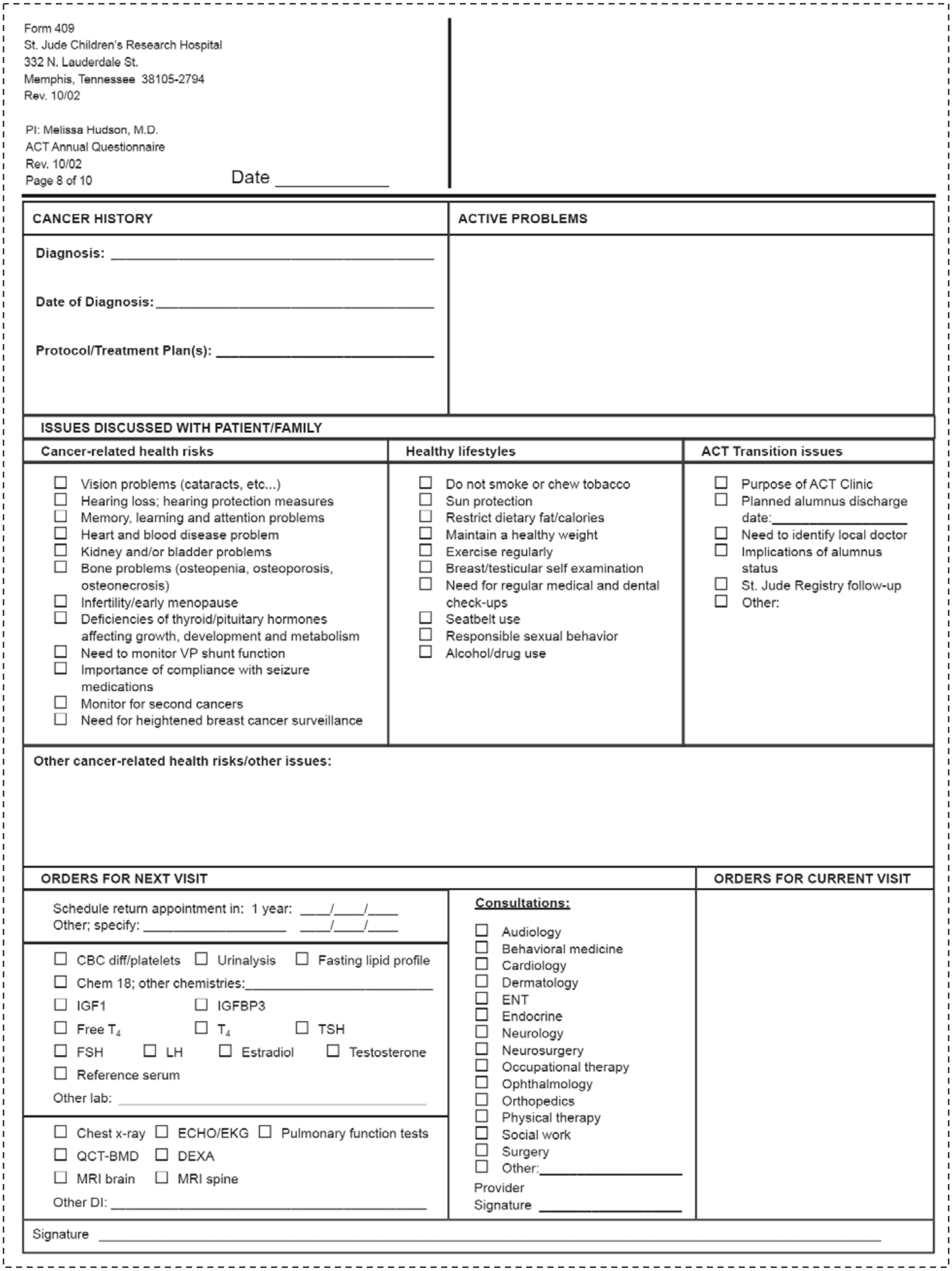
Urinalysis

Sp. gr. _______
pH _______
Glucose _______
Blood _______
Protein _______
RBC _______
WBC _______
Nitrate _______
Leuk est _______

Chemistries

Na _____
K _____
Cl _____
CO_2 ____
BUN ____
Cr _____
Gluc ____
Ca _____
Mg _____
PO_4 ____
URA ____
LDH ____
TP _____
Alb _____
SGOT/AST ________
SGPT/ALT ________
AlkP ____
Bili _____
Chol ____
TG _____

Diagnostic Imaging



Form 409
St. Jude Children's Research Hospital
332 N. Lauderdale St.
Memphis, Tennessee 38105-2794
Rev. 10/02

PI: Melissa Hudson, M.D.
ACT Annual Questionnaire
Rev. 10/02
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Date ____________

CANCER HISTORY	**ACTIVE PROBLEMS**
Diagnosis: ________________________________ **Date of Diagnosis:** ____________________________ **Protocol/Treatment Plan(s):** ______________________	

ISSUES DISCUSSED WITH PATIENT/FAMILY

Cancer-related health risks

- ☐ Vision problems (cataracts, etc...)
- ☐ Hearing loss; hearing protection measures
- ☐ Memory, learning and attention problems
- ☐ Heart and blood disease problem
- ☐ Kidney and/or bladder problems
- ☐ Bone problems (osteopenia, osteoporosis, osteonecrosis)
- ☐ Infertility/early menopause
- ☐ Deficiencies of thyroid/pituitary hormones affecting growth, development and metabolism
- ☐ Need to monitor VP shunt function
- ☐ Importance of compliance with seizure medications
- ☐ Monitor for second cancers
- ☐ Need for heightened breast cancer surveillance

Healthy lifestyles

- ☐ Do not smoke or chew tobacco
- ☐ Sun protection
- ☐ Restrict dietary fat/calories
- ☐ Maintain a healthy weight
- ☐ Exercise regularly
- ☐ Breast/testicular self examination
- ☐ Need for regular medical and dental check-ups
- ☐ Seatbelt use
- ☐ Responsible sexual behavior
- ☐ Alcohol/drug use

ACT Transition issues

- ☐ Purpose of ACT Clinic
- ☐ Planned alumnus discharge date:_______________
- ☐ Need to identify local doctor
- ☐ Implications of alumnus status
- ☐ St. Jude Registry follow-up
- ☐ Other:

Other cancer-related health risks/other issues:

ORDERS FOR NEXT VISIT

Schedule return appointment in: 1 year: ____/____/____
Other; specify: ________________ ____/____/____

☐ CBC diff/platelets ☐ Urinalysis ☐ Fasting lipid profile
☐ Chem 18; other chemistries:____________________
☐ IGF1 ☐ IGFBP3
☐ Free T_4 ☐ T_4 ☐ TSH
☐ FSH ☐ LH ☐ Estradiol ☐ Testosterone
☐ Reference serum
Other lab: ________________________________

☐ Chest x-ray ☐ ECHO/EKG ☐ Pulmonary function tests
☐ QCT-BMD ☐ DEXA
☐ MRI brain ☐ MRI spine
Other DI: ________________________________

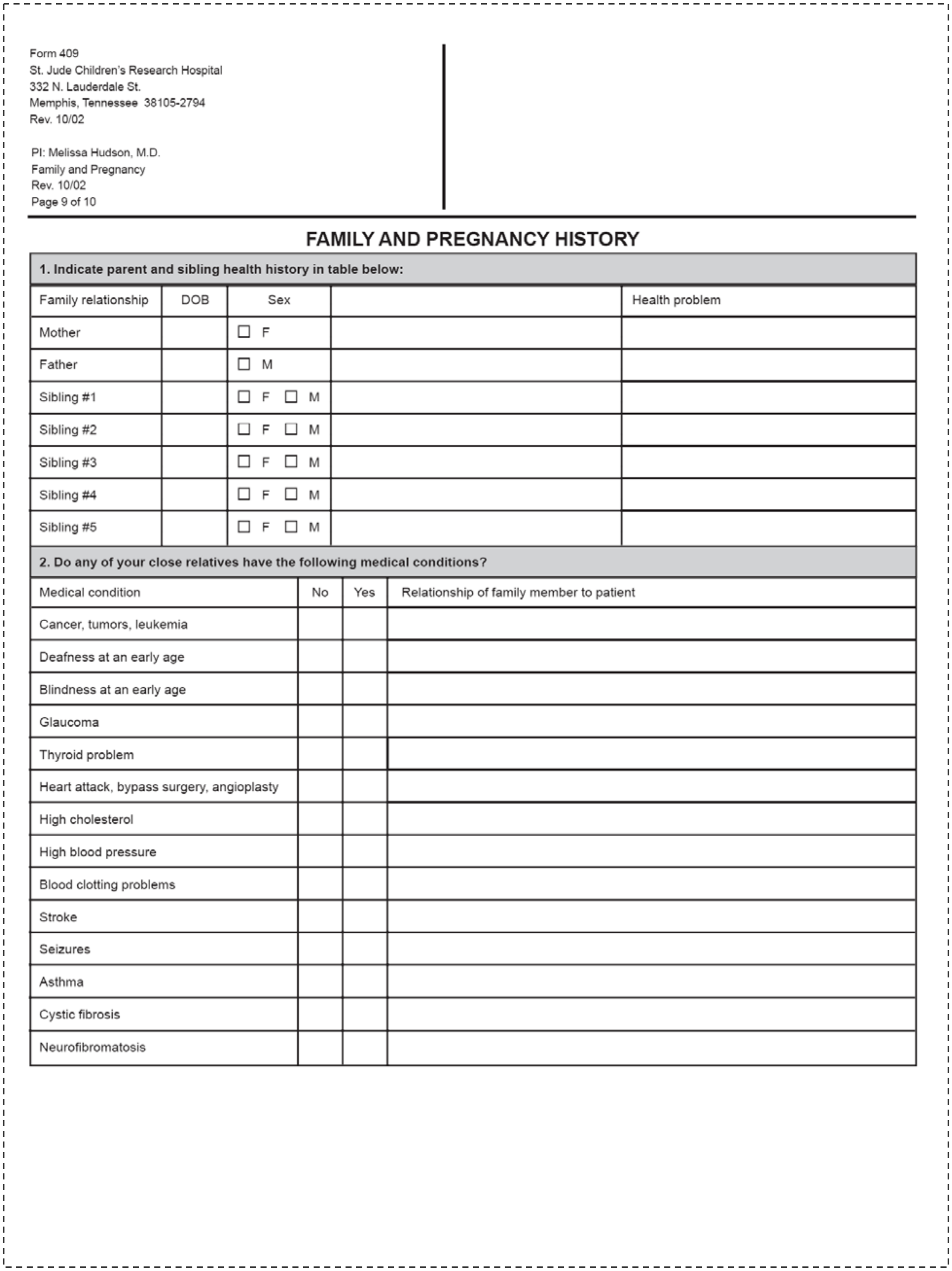
Consultations:

- ☐ Audiology
- ☐ Behavioral medicine
- ☐ Cardiology
- ☐ Dermatology
- ☐ ENT
- ☐ Endocrine
- ☐ Neurology
- ☐ Neurosurgery
- ☐ Occupational therapy
- ☐ Ophthalmology
- ☐ Orthopedics
- ☐ Physical therapy
- ☐ Social work
- ☐ Surgery
- ☐ Other:______________

Provider
Signature ______________

ORDERS FOR CURRENT VISIT

Signature ____



Form 409
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Family and Pregnancy
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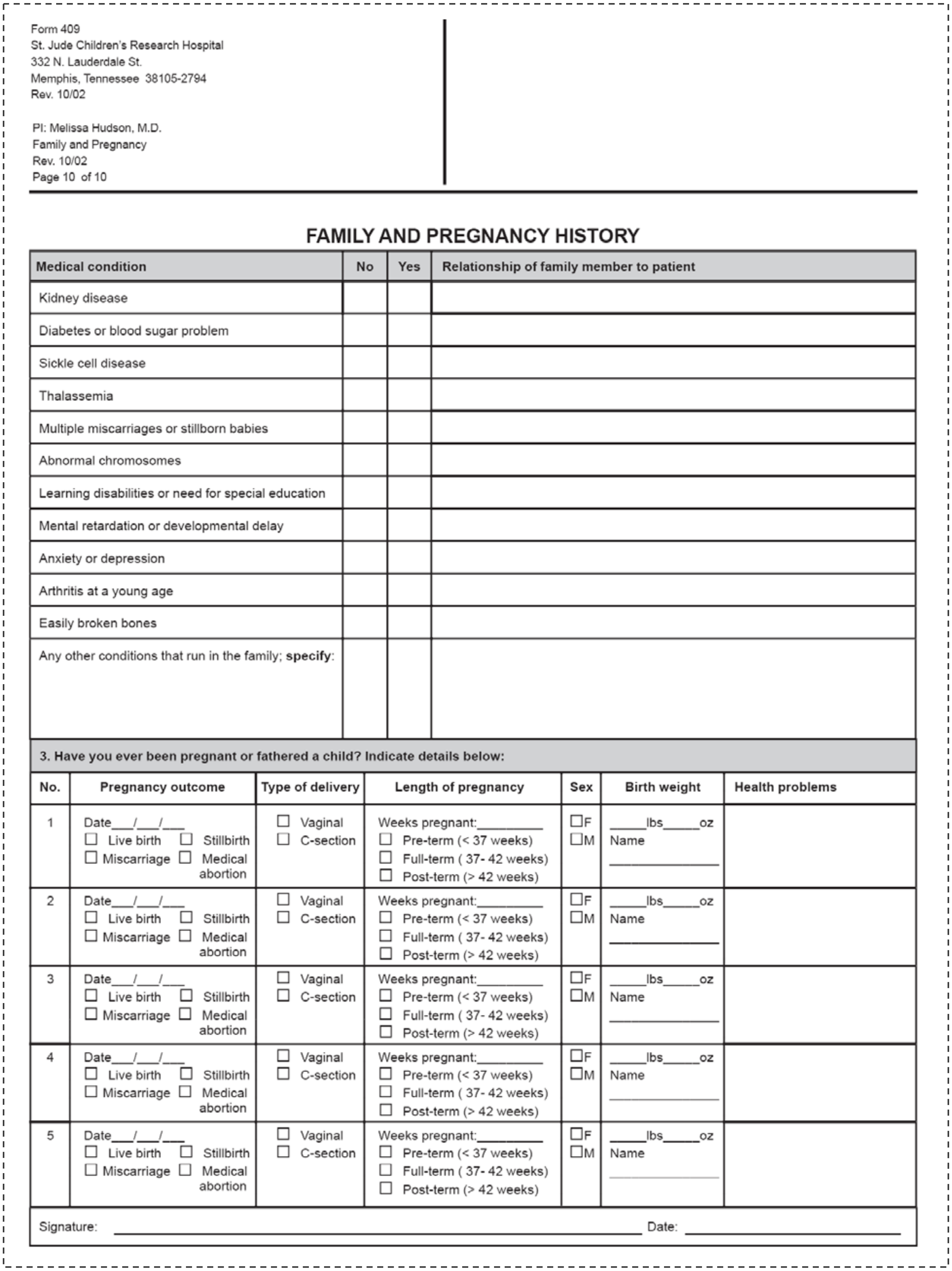
FAMILY AND PREGNANCY HISTORY

1. Indicate parent and sibling health history in table below:

Family relationship	DOB	Sex		Health problem
Mother		☐ F		
Father		☐ M		
Sibling #1		☐ F ☐ M		
Sibling #2		☐ F ☐ M		
Sibling #3		☐ F ☐ M		
Sibling #4		☐ F ☐ M		
Sibling #5		☐ F ☐ M		

2. Do any of your close relatives have the following medical conditions?

Medical condition	No	Yes	Relationship of family member to patient
Cancer, tumors, leukemia			
Deafness at an early age			
Blindness at an early age			
Glaucoma			
Thyroid problem			
Heart attack, bypass surgery, angioplasty			
High cholesterol			
High blood pressure			
Blood clotting problems			
Stroke			
Seizures			
Asthma			
Cystic fibrosis			
Neurofibromatosis			



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Family and Pregnancy
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FAMILY AND PREGNANCY HISTORY

Medical condition	No	Yes	Relationship of family member to patient
Kidney disease			
Diabetes or blood sugar problem			
Sickle cell disease			
Thalassemia			
Multiple miscarriages or stillborn babies			
Abnormal chromosomes			
Learning disabilities or need for special education			
Mental retardation or developmental delay			
Anxiety or depression			
Arthritis at a young age			
Easily broken bones			
Any other conditions that run in the family; **specify**:			

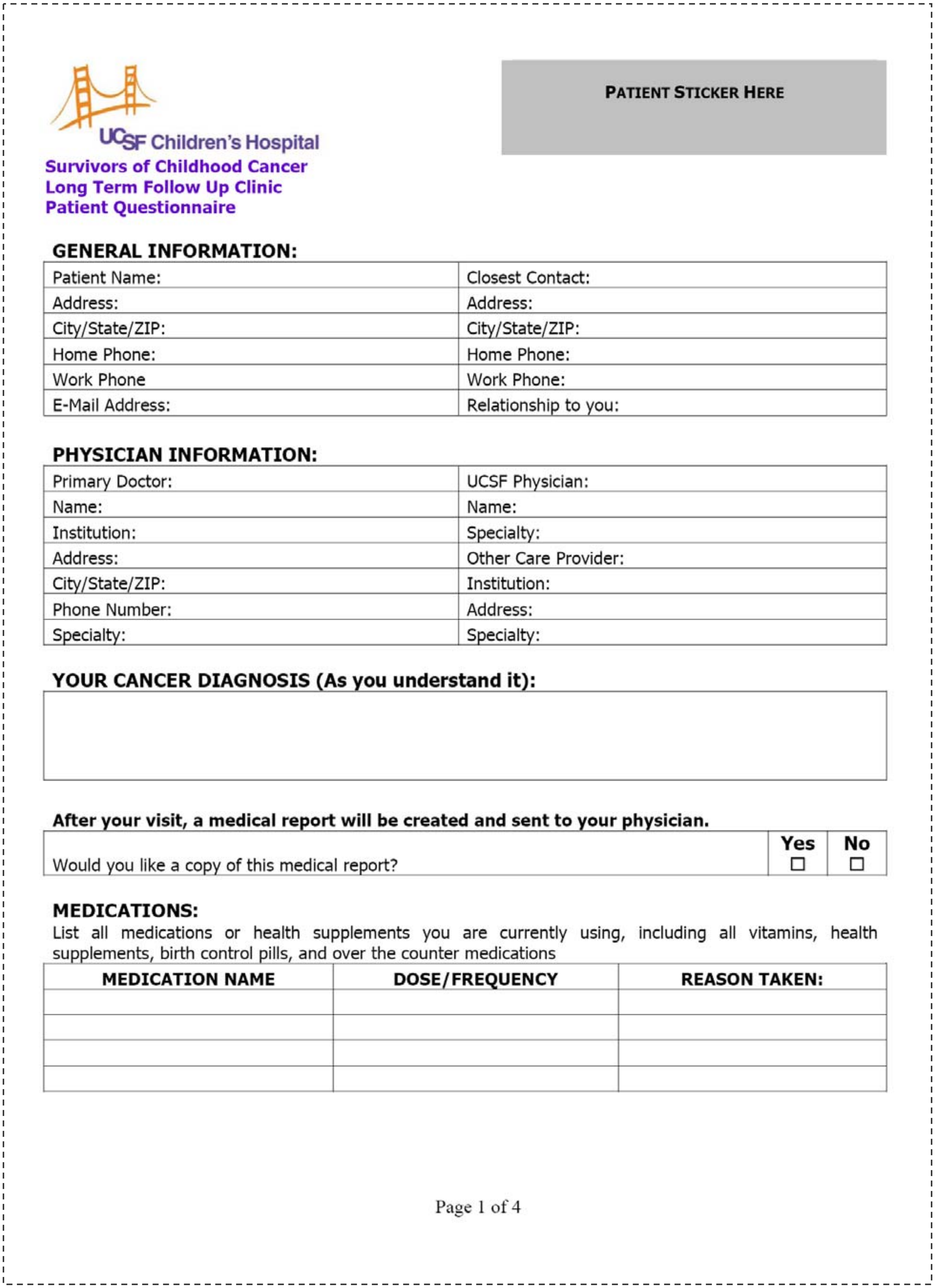
3. Have you ever been pregnant or fathered a child? Indicate details below:

No.	Pregnancy outcome	Type of delivery	Length of pregnancy	Sex	Birth weight	Health problems
1	Date___/___/___ ☐ Live birth ☐ Stillbirth ☐ Miscarriage ☐ Medical abortion	☐ Vaginal ☐ C-section	Weeks pregnant:__________ ☐ Pre-term (< 37 weeks) ☐ Full-term (37- 42 weeks) ☐ Post-term (> 42 weeks)	☐F ☐M	_____lbs_____oz Name _______________	
2	Date___/___/___ ☐ Live birth ☐ Stillbirth ☐ Miscarriage ☐ Medical abortion	☐ Vaginal ☐ C-section	Weeks pregnant:__________ ☐ Pre-term (< 37 weeks) ☐ Full-term (37- 42 weeks) ☐ Post-term (> 42 weeks)	☐F ☐M	_____lbs_____oz Name _______________	
3	Date___/___/___ ☐ Live birth ☐ Stillbirth ☐ Miscarriage ☐ Medical abortion	☐ Vaginal ☐ C-section	Weeks pregnant:__________ ☐ Pre-term (< 37 weeks) ☐ Full-term (37- 42 weeks) ☐ Post-term (> 42 weeks)	☐F ☐M	_____lbs_____oz Name _______________	
4	Date___/___/___ ☐ Live birth ☐ Stillbirth ☐ Miscarriage ☐ Medical abortion	☐ Vaginal ☐ C-section	Weeks pregnant:__________ ☐ Pre-term (< 37 weeks) ☐ Full-term (37- 42 weeks) ☐ Post-term (> 42 weeks)	☐F ☐M	_____lbs_____oz Name _______________	
5	Date___/___/___ ☐ Live birth ☐ Stillbirth ☐ Miscarriage ☐ Medical abortion	☐ Vaginal ☐ C-section	Weeks pregnant:__________ ☐ Pre-term (< 37 weeks) ☐ Full-term (37- 42 weeks) ☐ Post-term (> 42 weeks)	☐F ☐M	_____lbs_____oz Name _______________	

Signature: ____ Date: ____________________

ANNUAL QUESTIONNAIRE

UCSF
San Francisco, CA



UCSF Children's Hospital

Survivors of Childhood Cancer
Long Term Follow Up Clinic
Patient Questionnaire

PATIENT STICKER HERE

GENERAL INFORMATION:

Patient Name:	Closest Contact:
Address:	Address:
City/State/ZIP:	City/State/ZIP:
Home Phone:	Home Phone:
Work Phone	Work Phone:
E-Mail Address:	Relationship to you:

PHYSICIAN INFORMATION:

Primary Doctor:	UCSF Physician:
Name:	Name:
Institution:	Specialty:
Address:	Other Care Provider:
City/State/ZIP:	Institution:
Phone Number:	Address:
Specialty:	Specialty:

YOUR CANCER DIAGNOSIS (As you understand it):

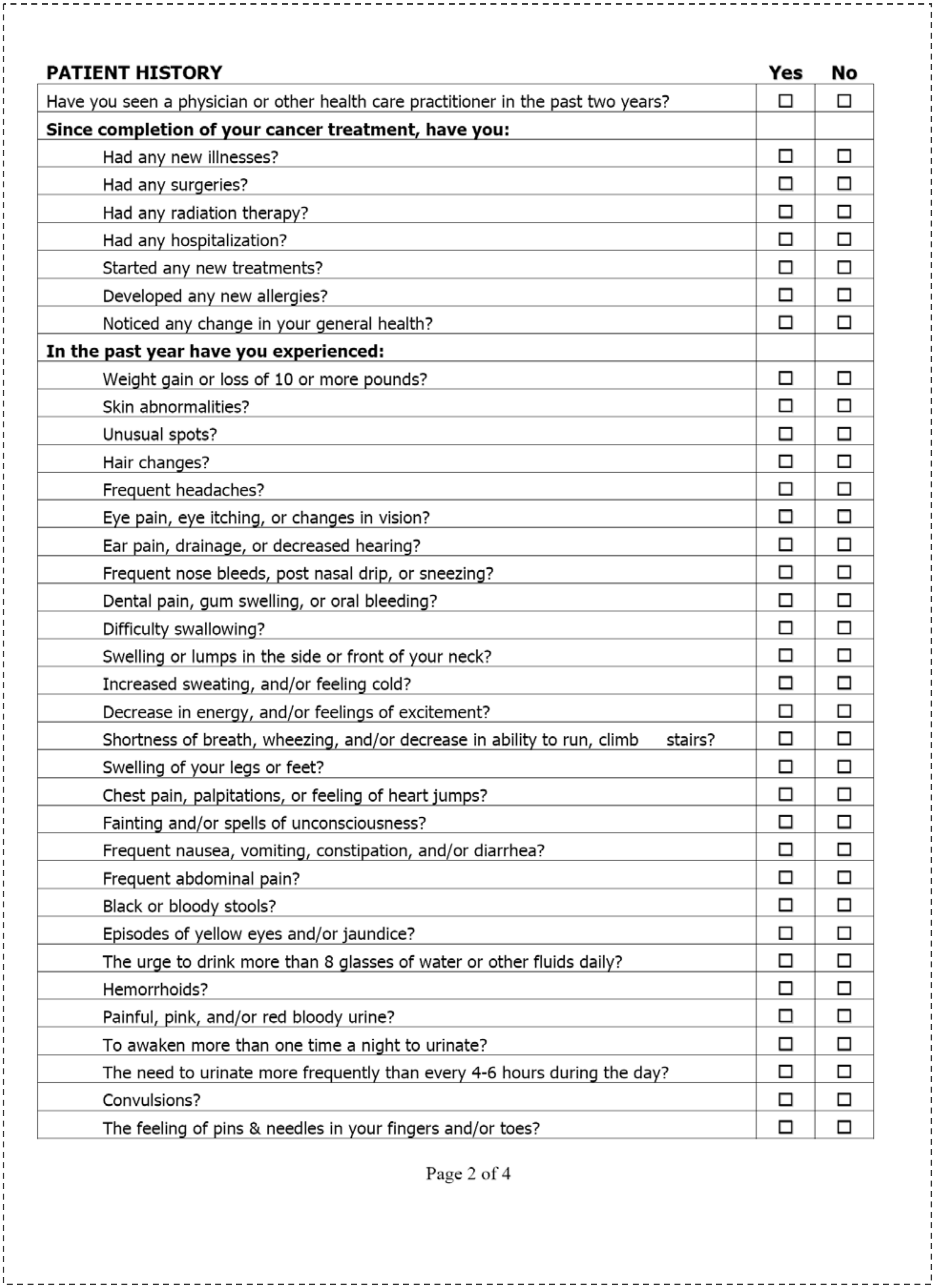
After your visit, a medical report will be created and sent to your physician.

	Yes	**No**
Would you like a copy of this medical report?	☐	☐

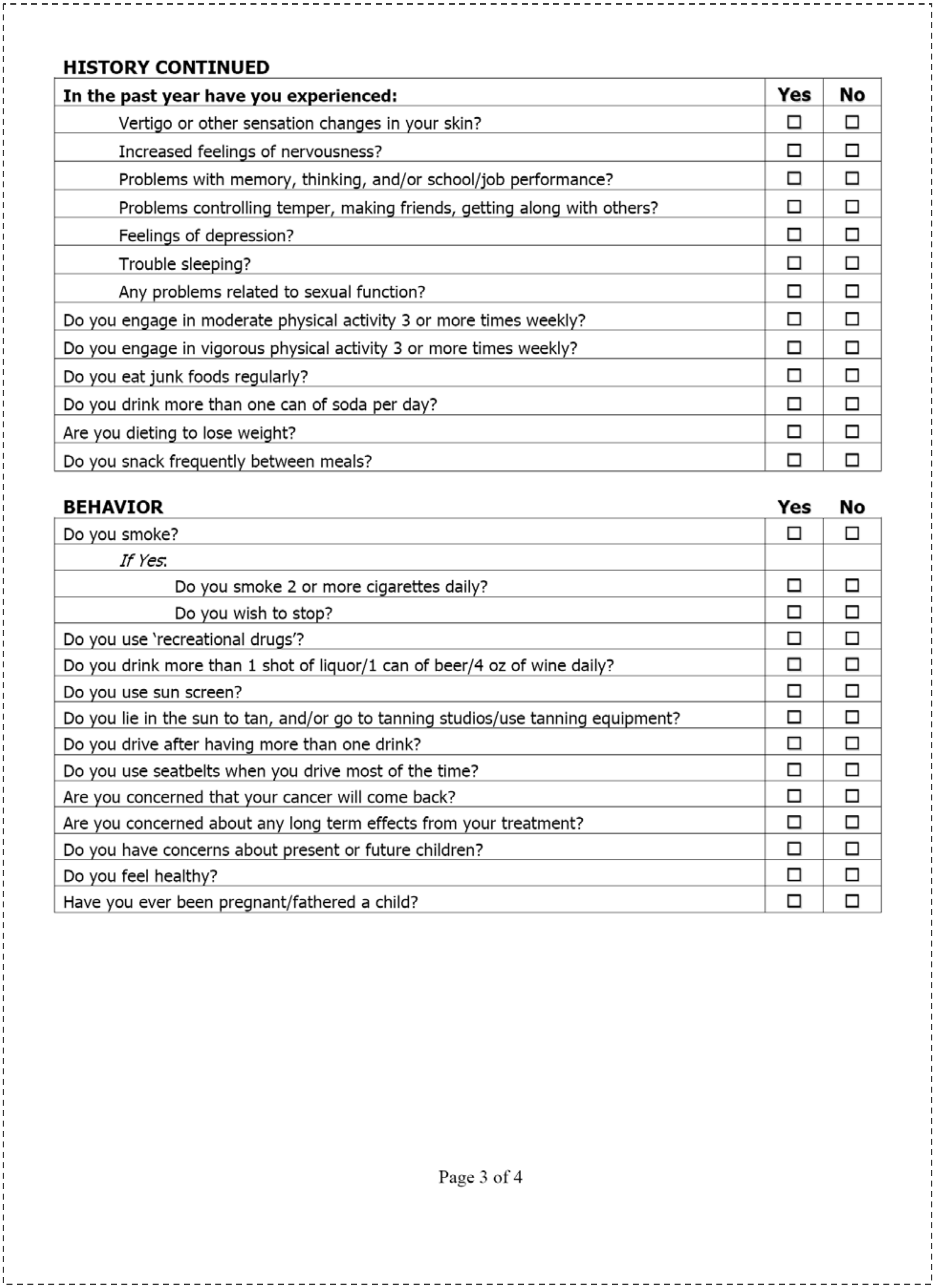
MEDICATIONS:

List all medications or health supplements you are currently using, including all vitamins, health supplements, birth control pills, and over the counter medications

MEDICATION NAME	**DOSE/FREQUENCY**	**REASON TAKEN:**



PATIENT HISTORY	**Yes**	**No**
Have you seen a physician or other health care practitioner in the past two years?	☐	☐
Since completion of your cancer treatment, have you:		
Had any new illnesses?	☐	☐
Had any surgeries?	☐	☐
Had any radiation therapy?	☐	☐
Had any hospitalization?	☐	☐
Started any new treatments?	☐	☐
Developed any new allergies?	☐	☐
Noticed any change in your general health?	☐	☐
In the past year have you experienced:		
Weight gain or loss of 10 or more pounds?	☐	☐
Skin abnormalities?	☐	☐
Unusual spots?	☐	☐
Hair changes?	☐	☐
Frequent headaches?	☐	☐
Eye pain, eye itching, or changes in vision?	☐	☐
Ear pain, drainage, or decreased hearing?	☐	☐
Frequent nose bleeds, post nasal drip, or sneezing?	☐	☐
Dental pain, gum swelling, or oral bleeding?	☐	☐
Difficulty swallowing?	☐	☐
Swelling or lumps in the side or front of your neck?	☐	☐
Increased sweating, and/or feeling cold?	☐	☐
Decrease in energy, and/or feelings of excitement?	☐	☐
Shortness of breath, wheezing, and/or decrease in ability to run, climb stairs?	☐	☐
Swelling of your legs or feet?	☐	☐
Chest pain, palpitations, or feeling of heart jumps?	☐	☐
Fainting and/or spells of unconsciousness?	☐	☐
Frequent nausea, vomiting, constipation, and/or diarrhea?	☐	☐
Frequent abdominal pain?	☐	☐
Black or bloody stools?	☐	☐
Episodes of yellow eyes and/or jaundice?	☐	☐
The urge to drink more than 8 glasses of water or other fluids daily?	☐	☐
Hemorrhoids?	☐	☐
Painful, pink, and/or red bloody urine?	☐	☐
To awaken more than one time a night to urinate?	☐	☐
The need to urinate more frequently than every 4-6 hours during the day?	☐	☐
Convulsions?	☐	☐
The feeling of pins & needles in your fingers and/or toes?	☐	☐



HISTORY CONTINUED

In the past year have you experienced:	Yes	No
Vertigo or other sensation changes in your skin?	☐	☐
Increased feelings of nervousness?	☐	☐
Problems with memory, thinking, and/or school/job performance?	☐	☐
Problems controlling temper, making friends, getting along with others?	☐	☐
Feelings of depression?	☐	☐
Trouble sleeping?	☐	☐
Any problems related to sexual function?	☐	☐
Do you engage in moderate physical activity 3 or more times weekly?	☐	☐
Do you engage in vigorous physical activity 3 or more times weekly?	☐	☐
Do you eat junk foods regularly?	☐	☐
Do you drink more than one can of soda per day?	☐	☐
Are you dieting to lose weight?	☐	☐
Do you snack frequently between meals?	☐	☐

BEHAVIOR	Yes	No
Do you smoke?	☐	☐
If Yes:		
Do you smoke 2 or more cigarettes daily?	☐	☐
Do you wish to stop?	☐	☐
Do you use 'recreational drugs'?	☐	☐
Do you drink more than 1 shot of liquor/1 can of beer/4 oz of wine daily?	☐	☐
Do you use sun screen?	☐	☐
Do you lie in the sun to tan, and/or go to tanning studios/use tanning equipment?	☐	☐
Do you drive after having more than one drink?	☐	☐
Do you use seatbelts when you drive most of the time?	☐	☐
Are you concerned that your cancer will come back?	☐	☐
Are you concerned about any long term effects from your treatment?	☐	☐
Do you have concerns about present or future children?	☐	☐
Do you feel healthy?	☐	☐
Have you ever been pregnant/fathered a child?	☐	☐

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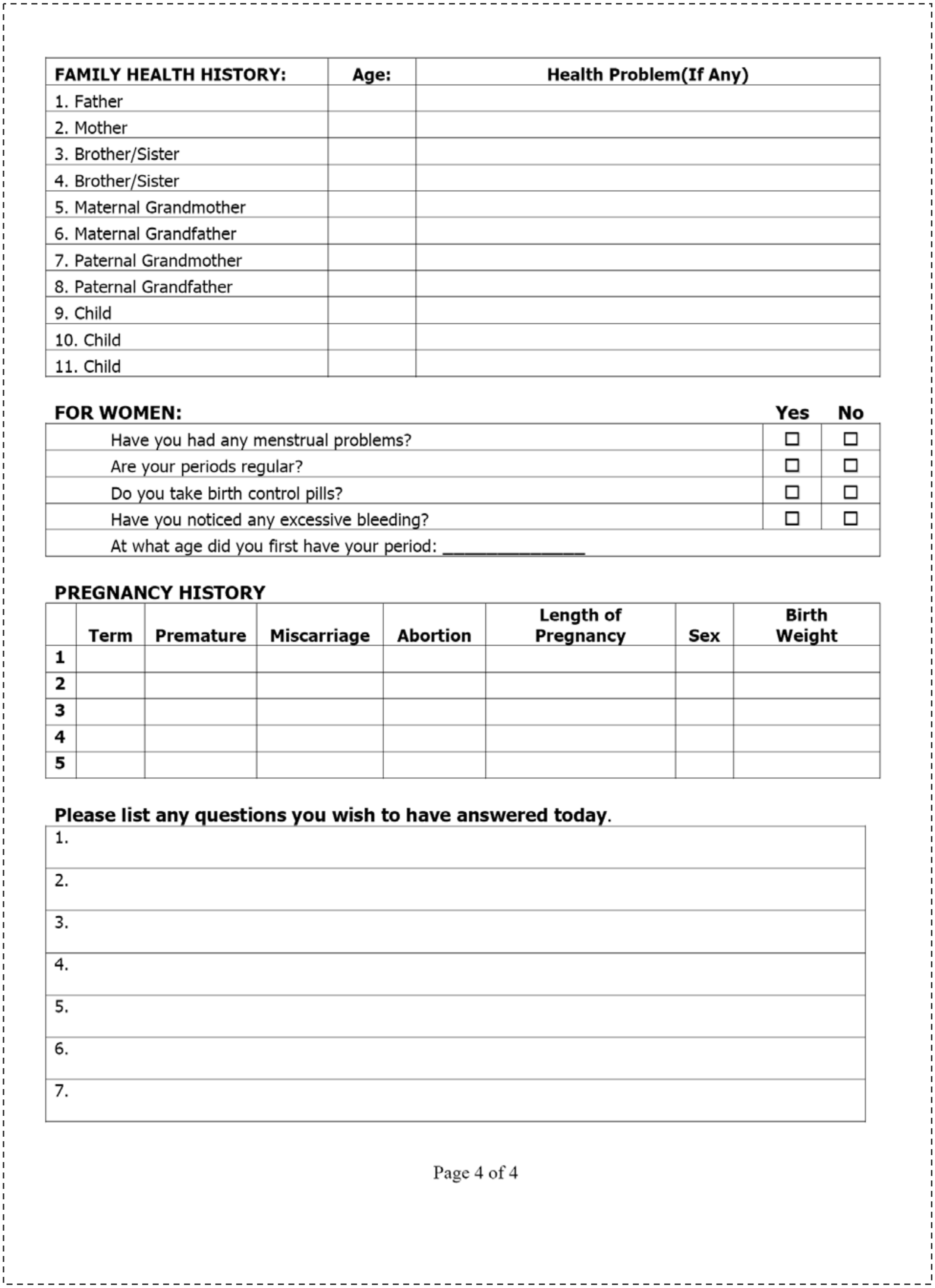

FAMILY HEALTH HISTORY:	**Age:**	**Health Problem(If Any)**
1. Father		
2. Mother		
3. Brother/Sister		
4. Brother/Sister		
5. Maternal Grandmother		
6. Maternal Grandfather		
7. Paternal Grandmother		
8. Paternal Grandfather		
9. Child		
10. Child		
11. Child		

FOR WOMEN:	**Yes**	**No**
Have you had any menstrual problems?	☐	☐
Are your periods regular?	☐	☐
Do you take birth control pills?	☐	☐
Have you noticed any excessive bleeding?	☐	☐
At what age did you first have your period: _______________		

PREGNANCY HISTORY

	Term	**Premature**	**Miscarriage**	**Abortion**	**Length of Pregnancy**	**Sex**	**Birth Weight**
1							
2							
3							
4							
5							

Please list any questions you wish to have answered today.

1.

2.

3.

4.

5.

6.

7.

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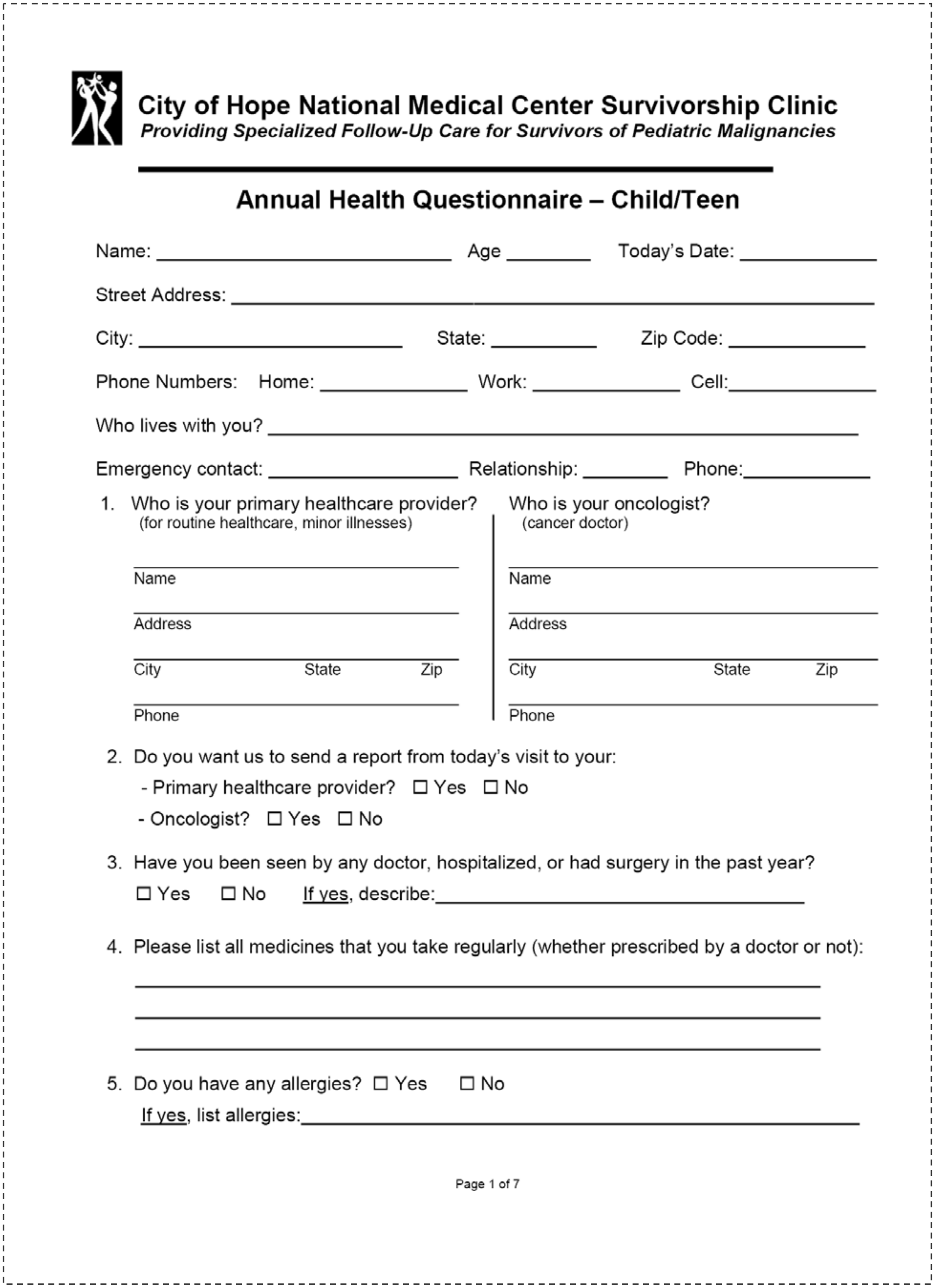
ANNUAL QUESTIONNAIRE: CHILD/TEEN (ENGLISH & SPANISH)

City of Hope
Duarte, CA



City of Hope National Medical Center Survivorship Clinic

Providing Specialized Follow-Up Care for Survivors of Pediatric Malignancies

Annual Health Questionnaire – Child/Teen

Name: ____________________ Age ________ Today's Date: ____________

Street Address: ____

City: ____________________ State: __________ Zip Code: ____________

Phone Numbers: Home: ____________ Work: ____________ Cell:____________

Who lives with you? ____

Emergency contact: ______________ Relationship: ________ Phone:____________

1. Who is your primary healthcare provider? (for routine healthcare, minor illnesses) | Who is your oncologist? (cancer doctor)

Who is your primary healthcare provider? (for routine healthcare, minor illnesses)	Who is your oncologist? (cancer doctor)
Name	Name
Address	Address
City State Zip	City State Zip
Phone	Phone

2. Do you want us to send a report from today's visit to your:
   - Primary healthcare provider? ☐ Yes ☐ No
   - Oncologist? ☐ Yes ☐ No

3. Have you been seen by any doctor, hospitalized, or had surgery in the past year?
   ☐ Yes ☐ No <u>If yes</u>, describe:______________________________

4. Please list all medicines that you take regularly (whether prescribed by a doctor or not):
   ____
   ____
   ____

5. Do you have any allergies? ☐ Yes ☐ No
   <u>If yes</u>, list allergies:______________________________

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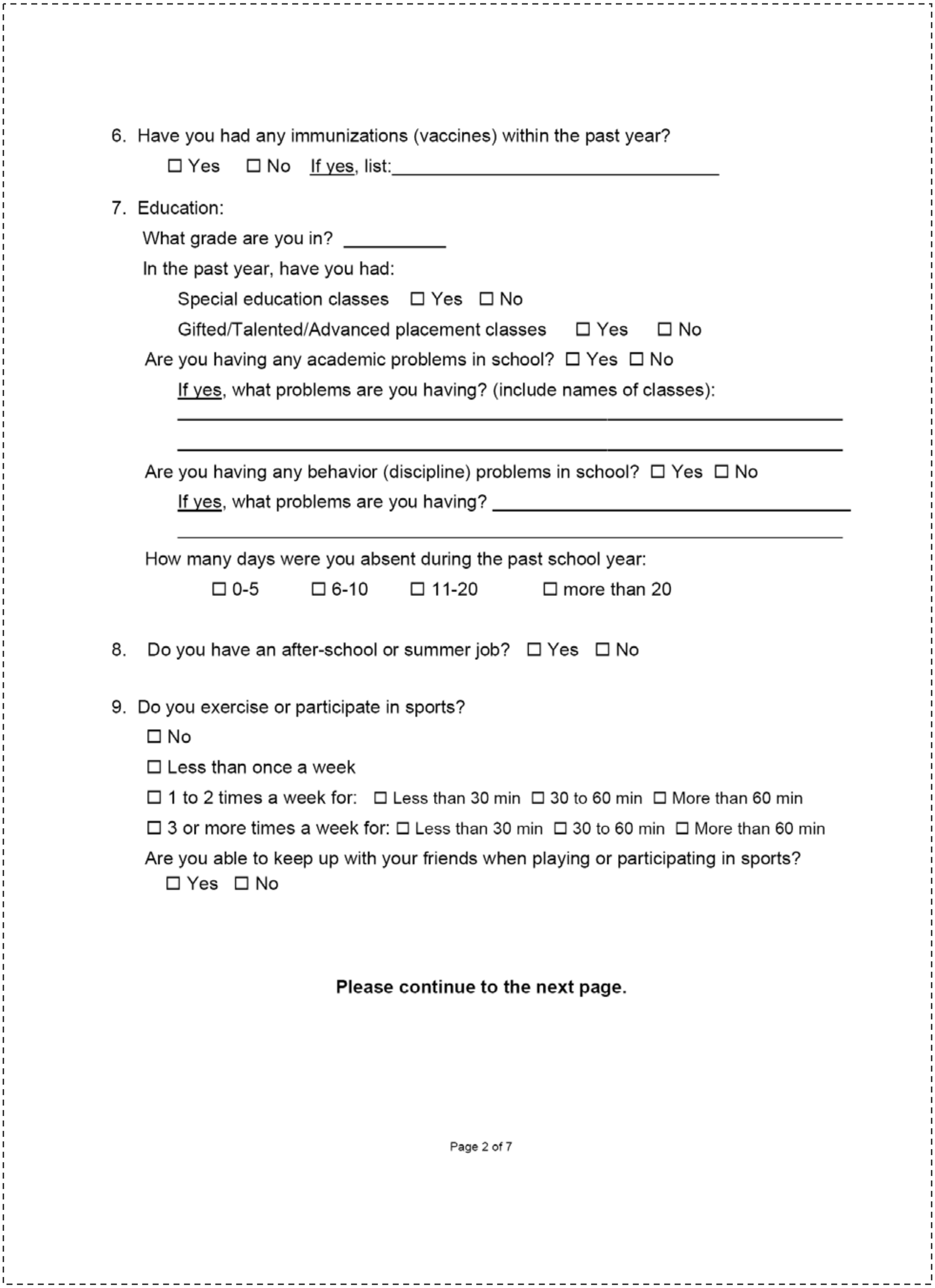

6. Have you had any immunizations (vaccines) within the past year?

   ☐ Yes ☐ No If yes, list:______________________________

7. Education:

   What grade are you in? __________

   In the past year, have you had:

   Special education classes ☐ Yes ☐ No

   Gifted/Talented/Advanced placement classes ☐ Yes ☐ No

   Are you having any academic problems in school? ☐ Yes ☐ No

   If yes, what problems are you having? (include names of classes):

   ____

   ____

   Are you having any behavior (discipline) problems in school? ☐ Yes ☐ No

   If yes, what problems are you having? ______________________________

   ____

   How many days were you absent during the past school year:

   ☐ 0-5 ☐ 6-10 ☐ 11-20 ☐ more than 20

8. Do you have an after-school or summer job? ☐ Yes ☐ No

9. Do you exercise or participate in sports?

   ☐ No

   ☐ Less than once a week

   ☐ 1 to 2 times a week for: ☐ Less than 30 min ☐ 30 to 60 min ☐ More than 60 min

   ☐ 3 or more times a week for: ☐ Less than 30 min ☐ 30 to 60 min ☐ More than 60 min

   Are you able to keep up with your friends when playing or participating in sports?

   ☐ Yes ☐ No

Please continue to the next page.

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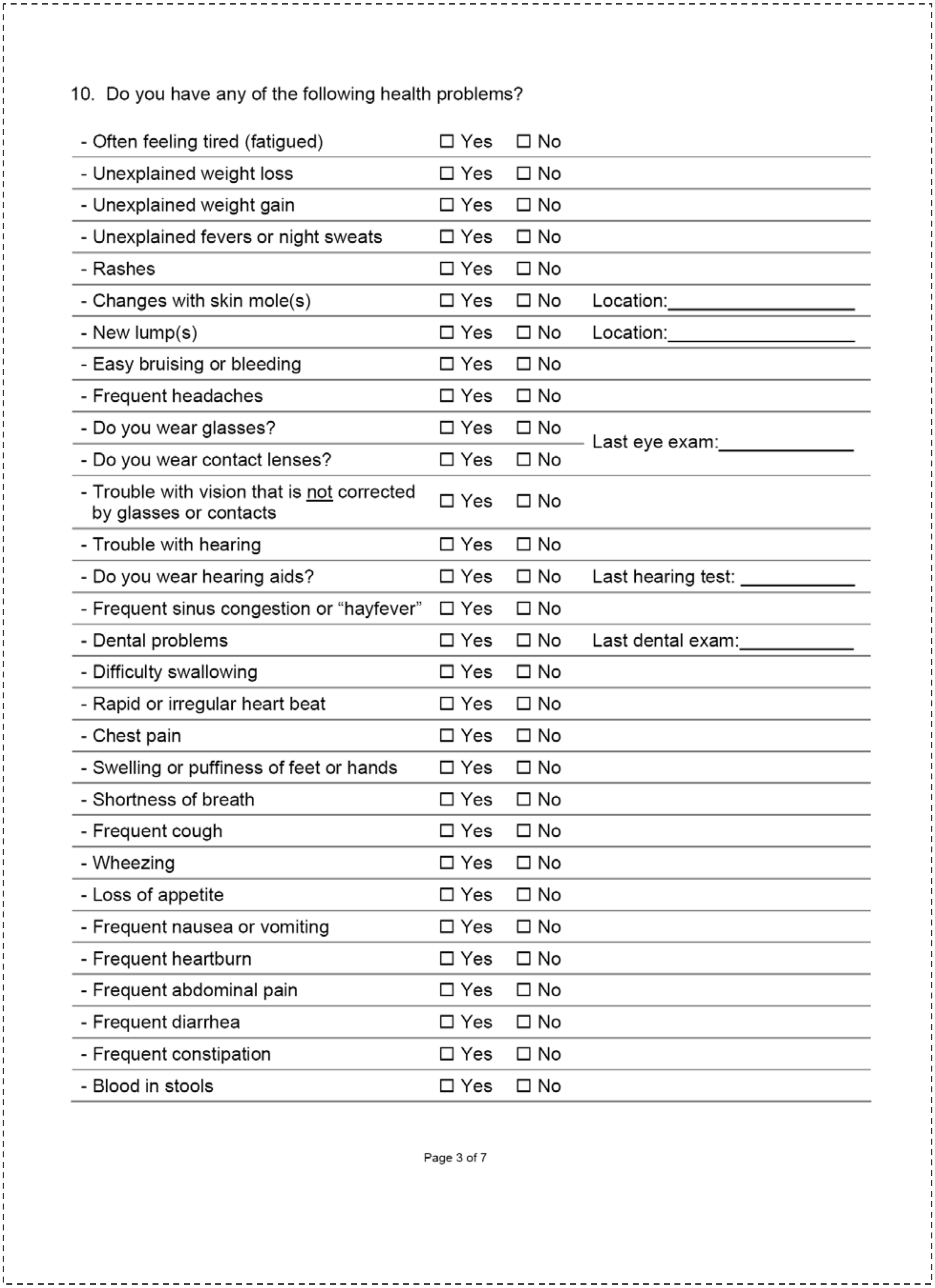
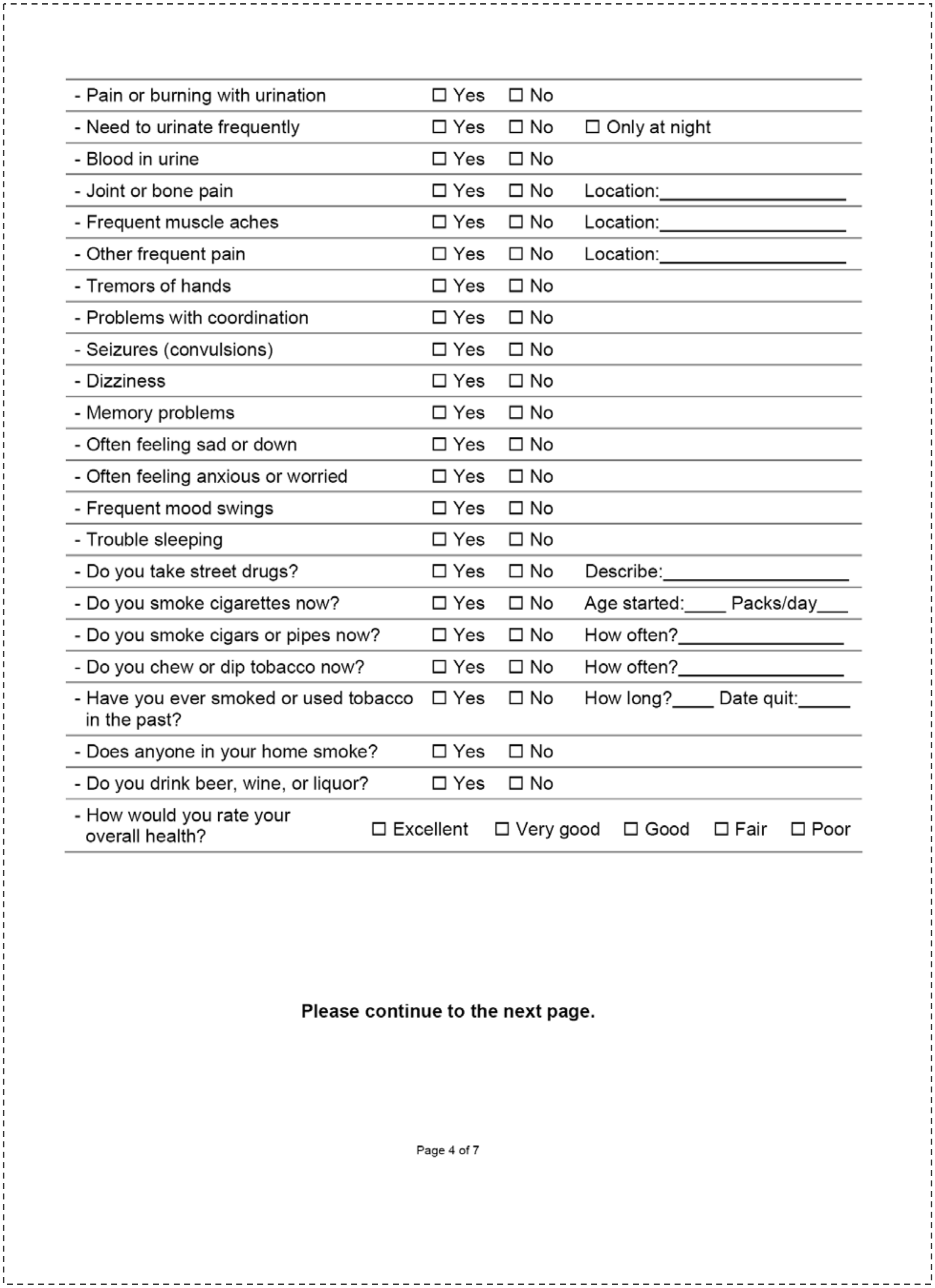


10. Do you have any of the following health problems?

- Often feeling tired (fatigued)	☐ Yes	☐ No	
- Unexplained weight loss	☐ Yes	☐ No	
- Unexplained weight gain	☐ Yes	☐ No	
- Unexplained fevers or night sweats	☐ Yes	☐ No	
- Rashes	☐ Yes	☐ No	
- Changes with skin mole(s)	☐ Yes	☐ No	Location:____________________
- New lump(s)	☐ Yes	☐ No	Location:____________________
- Easy bruising or bleeding	☐ Yes	☐ No	
- Frequent headaches	☐ Yes	☐ No	
- Do you wear glasses?	☐ Yes	☐ No	Last eye exam:______________
- Do you wear contact lenses?	☐ Yes	☐ No	
- Trouble with vision that is <u>not</u> corrected by glasses or contacts	☐ Yes	☐ No	
- Trouble with hearing	☐ Yes	☐ No	
- Do you wear hearing aids?	☐ Yes	☐ No	Last hearing test: ____________
- Frequent sinus congestion or "hayfever"	☐ Yes	☐ No	
- Dental problems	☐ Yes	☐ No	Last dental exam:____________
- Difficulty swallowing	☐ Yes	☐ No	
- Rapid or irregular heart beat	☐ Yes	☐ No	
- Chest pain	☐ Yes	☐ No	
- Swelling or puffiness of feet or hands	☐ Yes	☐ No	
- Shortness of breath	☐ Yes	☐ No	
- Frequent cough	☐ Yes	☐ No	
- Wheezing	☐ Yes	☐ No	
- Loss of appetite	☐ Yes	☐ No	
- Frequent nausea or vomiting	☐ Yes	☐ No	
- Frequent heartburn	☐ Yes	☐ No	
- Frequent abdominal pain	☐ Yes	☐ No	
- Frequent diarrhea	☐ Yes	☐ No	
- Frequent constipation	☐ Yes	☐ No	
- Blood in stools	☐ Yes	☐ No	



- Pain or burning with urination	☐ Yes	☐ No	
- Need to urinate frequently	☐ Yes	☐ No	☐ Only at night
- Blood in urine	☐ Yes	☐ No	
- Joint or bone pain	☐ Yes	☐ No	Location:___________________
- Frequent muscle aches	☐ Yes	☐ No	Location:___________________
- Other frequent pain	☐ Yes	☐ No	Location:___________________
- Tremors of hands	☐ Yes	☐ No	
- Problems with coordination	☐ Yes	☐ No	
- Seizures (convulsions)	☐ Yes	☐ No	
- Dizziness	☐ Yes	☐ No	
- Memory problems	☐ Yes	☐ No	
- Often feeling sad or down	☐ Yes	☐ No	
- Often feeling anxious or worried	☐ Yes	☐ No	
- Frequent mood swings	☐ Yes	☐ No	
- Trouble sleeping	☐ Yes	☐ No	
- Do you take street drugs?	☐ Yes	☐ No	Describe:___________________
- Do you smoke cigarettes now?	☐ Yes	☐ No	Age started:____ Packs/day___
- Do you smoke cigars or pipes now?	☐ Yes	☐ No	How often?_________________
- Do you chew or dip tobacco now?	☐ Yes	☐ No	How often?_________________
- Have you ever smoked or used tobacco in the past?	☐ Yes	☐ No	How long?____ Date quit:_____
- Does anyone in your home smoke?	☐ Yes	☐ No	
- Do you drink beer, wine, or liquor?	☐ Yes	☐ No	
- How would you rate your overall health?	☐ Excellent ☐ Very good	☐ Good ☐ Fair	☐ Poor

Please continue to the next page.

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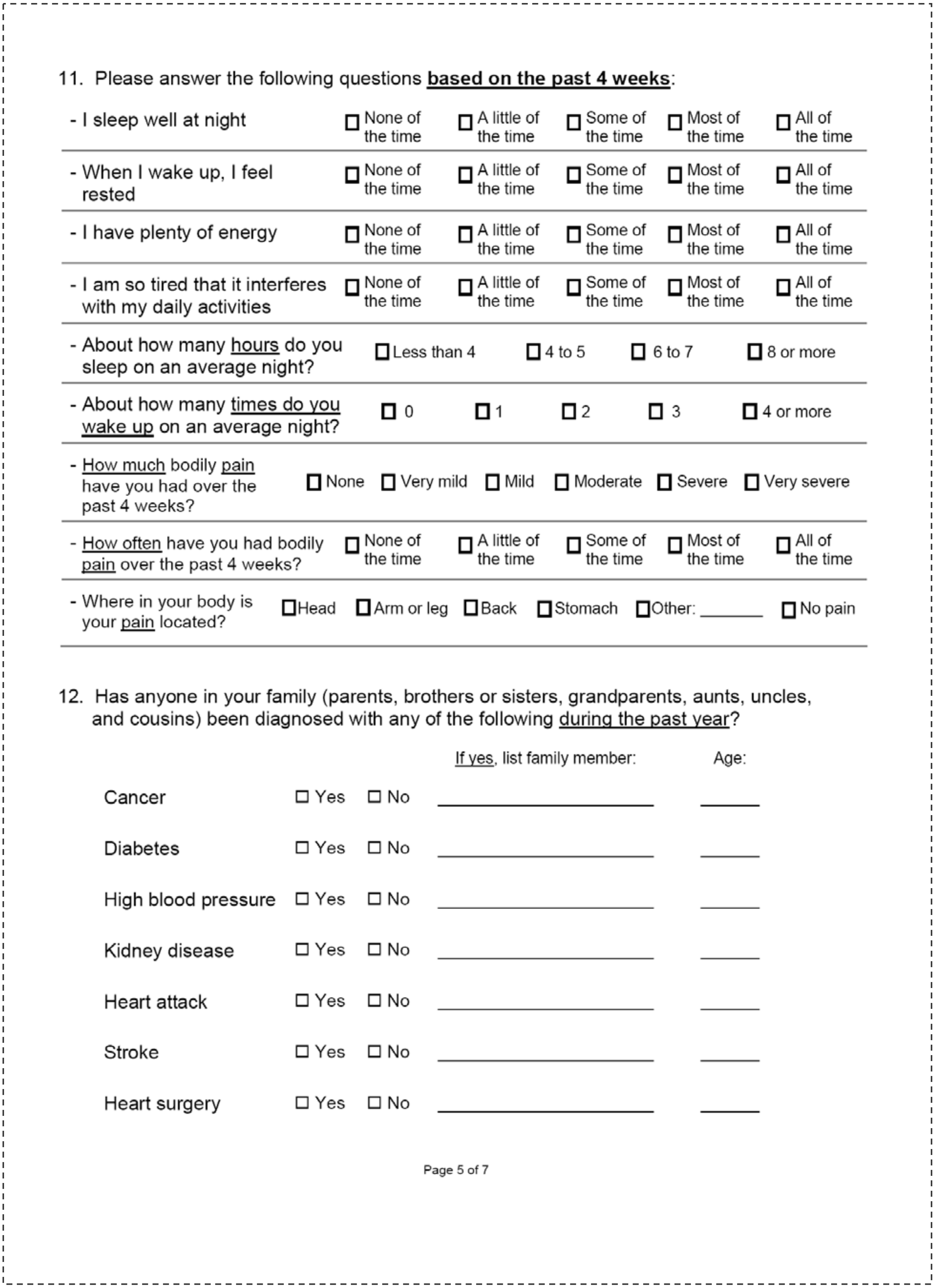


11. Please answer the following questions **based on the past 4 weeks**:

- I sleep well at night	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- When I wake up, I feel rested	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- I have plenty of energy	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- I am so tired that it interferes with my daily activities	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- About how many hours do you sleep on an average night?	☐ Less than 4	☐ 4 to 5	☐ 6 to 7	☐ 8 or more		
- About how many times do you wake up on an average night?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4 or more	
- How much bodily pain have you had over the past 4 weeks?	☐ None	☐ Very mild	☐ Mild	☐ Moderate	☐ Severe	☐ Very severe
- How often have you had bodily pain over the past 4 weeks?	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- Where in your body is your pain located?	☐ Head	☐ Arm or leg	☐ Back	☐ Stomach	☐ Other: _______	☐ No pain

12. Has anyone in your family (parents, brothers or sisters, grandparents, aunts, uncles, and cousins) been diagnosed with any of the following during the past year?

			If yes, list family member:	Age:
Cancer	☐ Yes	☐ No	______________________	______
Diabetes	☐ Yes	☐ No	______________________	______
High blood pressure	☐ Yes	☐ No	______________________	______
Kidney disease	☐ Yes	☐ No	______________________	______
Heart attack	☐ Yes	☐ No	______________________	______
Stroke	☐ Yes	☐ No	______________________	______
Heart surgery	☐ Yes	☐ No	______________________	______

13. Do you have health insurance? ☐ Yes ☐ No

If yes, please indicate how you obtain your health insurance:

___ Through my parent's job	___Through my job
___ Through a policy my parents (or someone else) bought for me	___ Medi-Cal or other government assistance
___ Through my school	___ Don't know

___ Other: ____

14. During the past year, have you been denied health insurance because of your health history?

☐ Yes ☐ No ☐ Don't know

15. Do you have any other health problems or concerns that have not been addressed in this questionnaire?

☐ Yes ☐ No If yes, please describe: ______________________________

____

____

16. Is there anything else about your health status that you are worried about or that you would like us to know about?

☐ Yes ☐ No If yes, please describe: ______________________________

____

____

17. Who completed this questionnaire?

☐ Self (patient)

☐ Mother

☐ Father

☐ Other (describe): ________________________

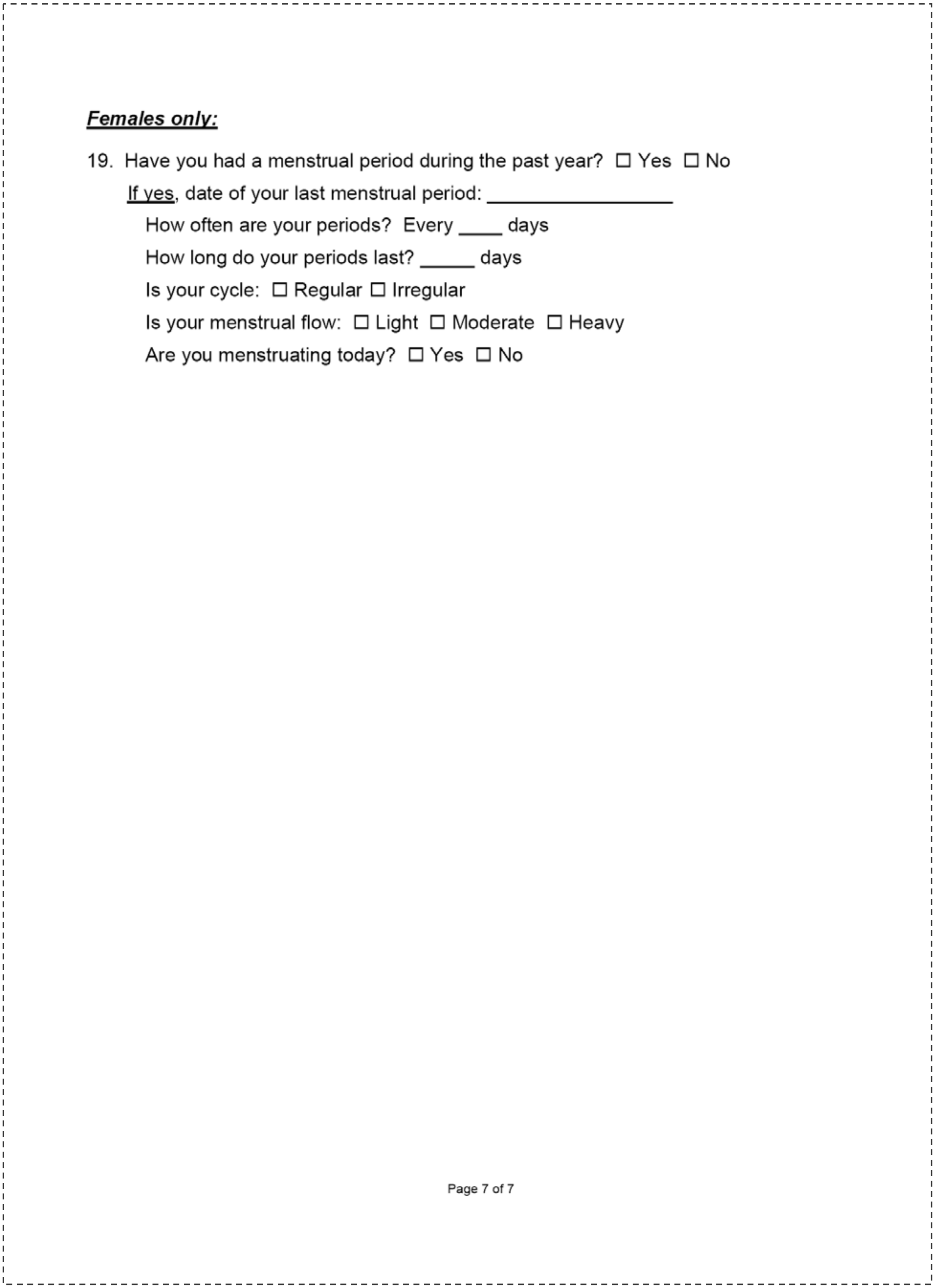
18. What is the primary language of the person completing this questionnaire?

☐ English

☐ Spanish

☐ Other (describe): ________________________

For female patients only: ***Please continue to the next page.***



Females only:

19. Have you had a menstrual period during the past year? ☐ Yes ☐ No

If yes, date of your last menstrual period: ___________________

How often are your periods? Every _____ days

How long do your periods last? ______ days

Is your cycle: ☐ Regular ☐ Irregular

Is your menstrual flow: ☐ Light ☐ Moderate ☐ Heavy

Are you menstruating today? ☐ Yes ☐ No

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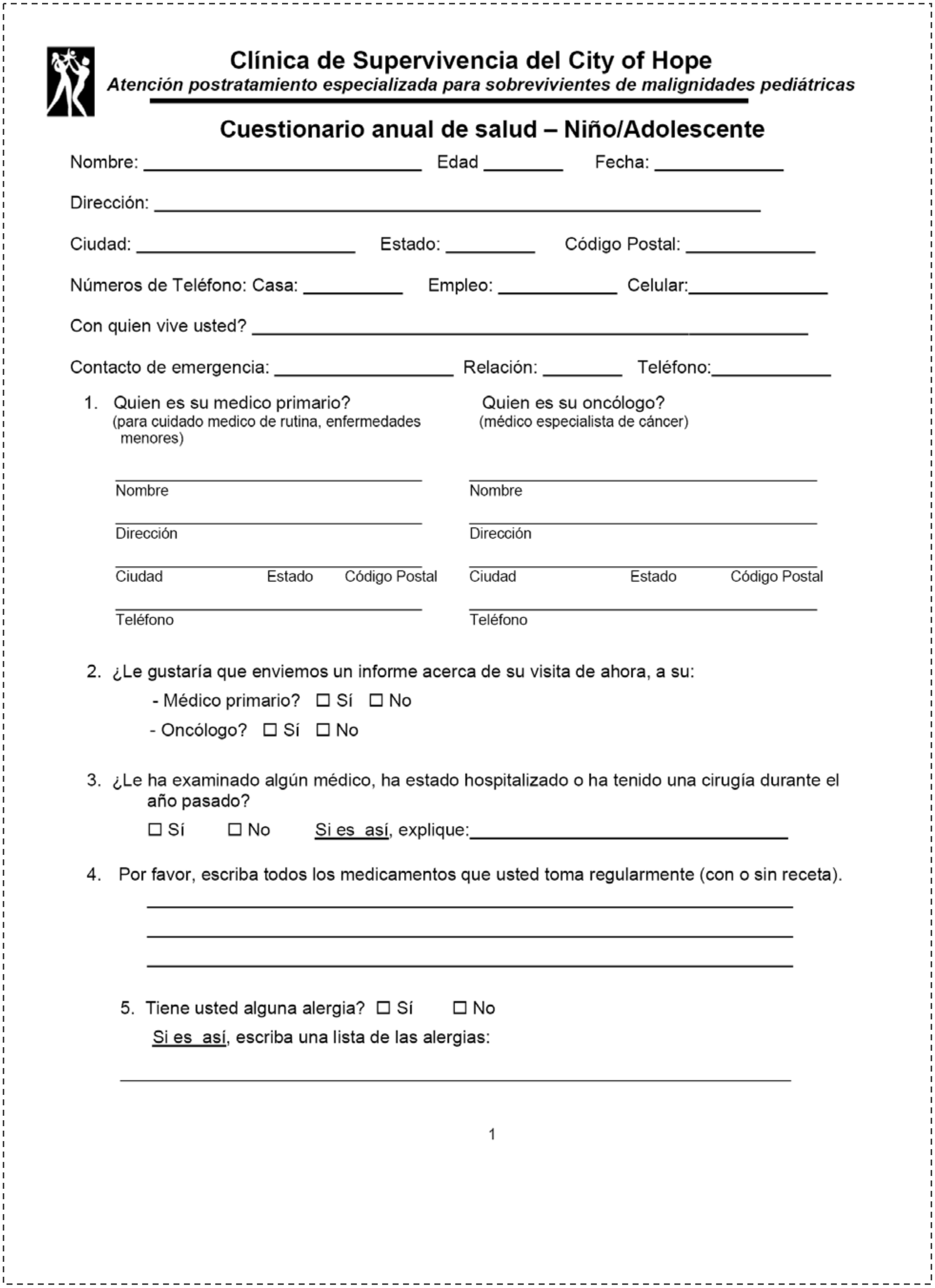


Clínica de Supervivencia del City of Hope

Atención postratamiento especializada para sobrevivientes de malignidades pediátricas

Cuestionario anual de salud – Niño/Adolescente

Nombre: ______________________________ Edad ________ Fecha: ______________

Dirección: ____

Ciudad: _______________________ Estado: _________ Código Postal: ______________

Números de Teléfono: Casa: __________ Empleo: ____________ Celular:______________

Con quien vive usted? ____

Contacto de emergencia: ___________________ Relación: ________ Teléfono:____________

1. Quien es su medico primario?
(para cuidado medico de rutina, enfermedades menores)

____
Nombre

____
Dirección

____
Ciudad Estado Código Postal

____
Teléfono

Quien es su oncólogo?
(médico especialista de cáncer)

____
Nombre

____
Dirección

____
Ciudad Estado Código Postal

____
Teléfono

2. ¿Le gustaría que enviemos un informe acerca de su visita de ahora, a su:
   - Médico primario? ☐ Sí ☐ No
   - Oncólogo? ☐ Sí ☐ No

3. ¿Le ha examinado algún médico, ha estado hospitalizado o ha tenido una cirugía durante el año pasado?
   ☐ Sí ☐ No <u>Si es así</u>, explique:__________________________________

4. Por favor, escriba todos los medicamentos que usted toma regularmente (con o sin receta).
   ____
   ____
   ____

5. Tiene usted alguna alergia? ☐ Sí ☐ No
   <u>Si es así</u>, escriba una lista de las alergias:
   ____

1

6. ¿Ha tenido usted alguna vacunación dentro del año pasado?

☐ Sí ☐ No Si es así, haga una lista de las vacunaciones:

____

7. Educación:

¿En que grado está usted? __________

Durante el año pasado, ha asistido:

Clases de educación especial ☐ Sí ☐ No

Clases para niños superdotados/talentosos/clases avanzadas ☐ Sí ☐ No

¿Tiene usted algún problema académico? ☐ Sí ☐ No

Si es así, especifique (incluya los nombres de las clases)

____

____

¿Tiene usted algún problema de comportamiento (disciplina) en la escuela? ☐ Sí ☐ No

Si es así, especifique:

____

____

¿Cuántos días era usted ausente durante el año escolar pasado?

☐ 0-5 ☐ 6-10 ☐ 11-20 ☐ más de 20

8. ¿Tiene usted un trabajo luego de la escuela o de verano? ☐ Sí ☐ No

9. ¿Hace ejercicio o practica deportes?

☐ No

☐ Rara vez

☐ De 1 a 2 veces a la semana por: ☐ menos de 30 min. ☐ 30 a 60 min. ☐ más de 60 min.

☐ 3 o más veces a la semana por: ☐ menos de 30 min. ☐ 30 a 60 min. ☐ más de 60 min.

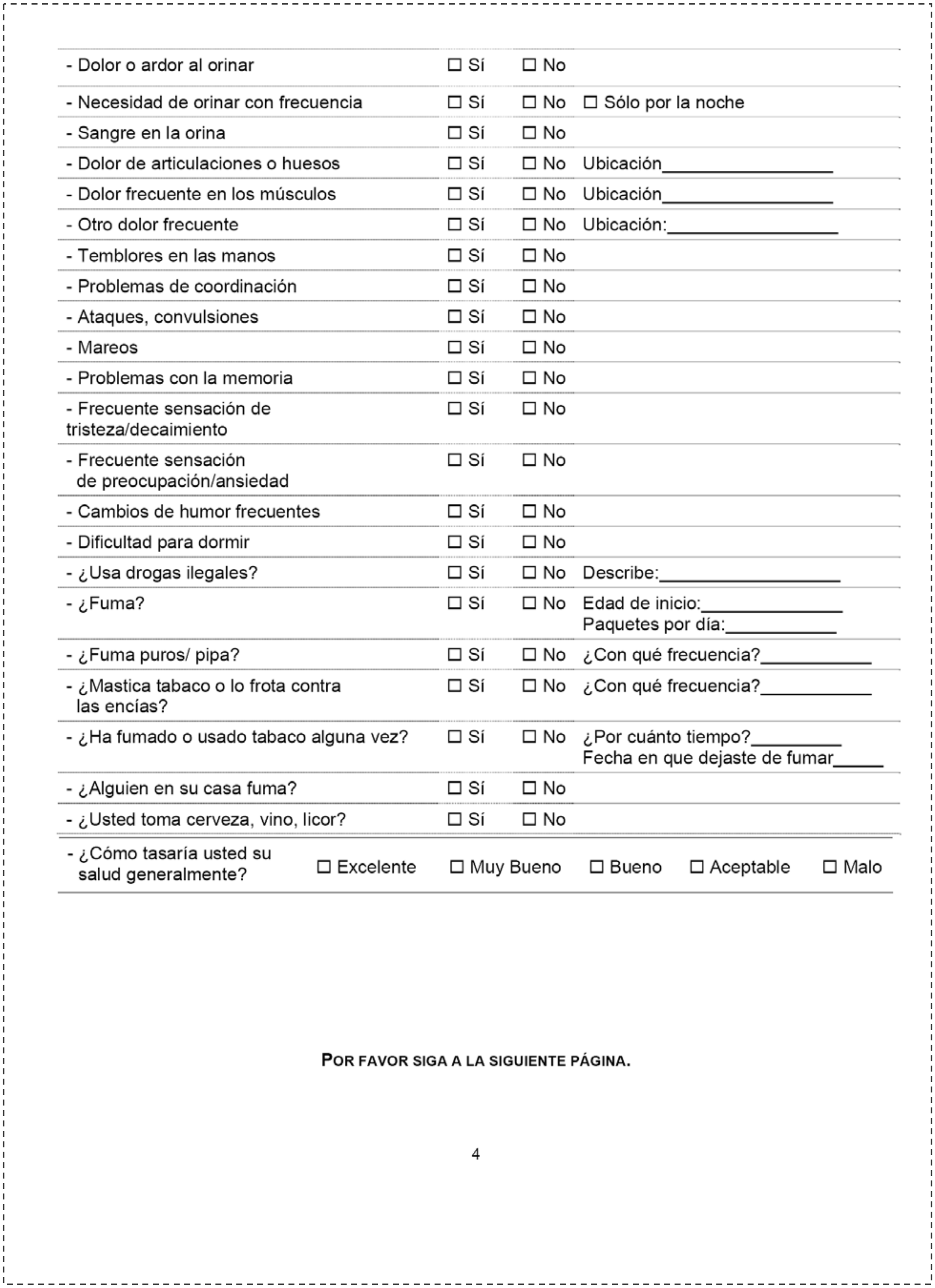
¿Puede mantener el mismo ritmo que sus amigos cuando juegas o practicas deportes?

☐ Sí ☐ No

POR FAVOR SIGA A LA SIGUIENTE PÁGINA.

10. ¿Tiene usted alguno de los siguientes problemas?

- Sensación frecuente de cansancio/fatiga	☐ Sí	☐ No	
- Pérdida de peso inexplicable	☐ Sí	☐ No	
- Aumento de peso inexplicable	☐ Sí	☐ No	
- Fiebre inexplicable o sudor nocturno	☐ Sí	☐ No	
- Sarpullido o cambios en la piel	☐ Sí	☐ No	
- Cambios en lunar(es)	☐ Sí	☐ No	Ubicación:__________________
- Algún nuevo bulto, chichón, alguna nueva inflamación	☐ Sí	☐ No	Ubicación:__________________
- Aparecen moretones con facilidad	☐ Sí	☐ No	
- Dolores de cabeza frecuentes	☐ Sí	☐ No	
- ¿Usa anteojos?	☐ Sí	☐ No	Último examen de la vista:__________________
- ¿Usa lentes de contacto?	☐ Sí	☐ No	
- Problema de la visión que no se corrige con los anteojos o los lentes de contacto	☐ Sí	☐ No	
- Problema de audición	☐ Sí	☐ No	
- ¿Usa aparato para oír?	☐ Sí	☐ No	Último examen de la audición: ______________
- Frecuente congestión de los senos nasales, fiebre de heno o “alergia”	☐ Sí	☐ No	
- Problemas dentales	☐ Sí	☐ No	Último examen dental:_________
- Dificultad para tragar	☐ Sí	☐ No	
- Latidos del corazón rápidos o irregulares	☐ Sí	☐ No	
- Dolor en el pecho	☐ Sí	☐ No	
- Inflamación o hinchazón de los pies o las manos	☐ Sí	☐ No	
- Dificultad para respirar	☐ Sí	☐ No	
- Tos frecuente	☐ Sí	☐ No	
- Silbido al respirar (jadeo)	☐ Sí	☐ No	
- Pérdida del apetito	☐ Sí	☐ No	
- Náuseas o vómitos frecuentes	☐ Sí	☐ No	
- Acidez estomacal frecuente	☐ Sí	☐ No	
- Dolor abdominal frecuente o intenso	☐ Sí	☐ No	
- Diarrea frecuente	☐ Sí	☐ No	
- Estreñimiento frecuente	☐ Sí	☐ No	
- Sangre en las heces	☐ Sí	☐ No	



- Dolor o ardor al orinar	☐ Sí	☐ No	
- Necesidad de orinar con frecuencia	☐ Sí	☐ No	☐ Sólo por la noche
- Sangre en la orina	☐ Sí	☐ No	
- Dolor de articulaciones o huesos	☐ Sí	☐ No	Ubicación__________________
- Dolor frecuente en los músculos	☐ Sí	☐ No	Ubicación__________________
- Otro dolor frecuente	☐ Sí	☐ No	Ubicación:__________________
- Temblores en las manos	☐ Sí	☐ No	
- Problemas de coordinación	☐ Sí	☐ No	
- Ataques, convulsiones	☐ Sí	☐ No	
- Mareos	☐ Sí	☐ No	
- Problemas con la memoria	☐ Sí	☐ No	
- Frecuente sensación de tristeza/decaimiento	☐ Sí	☐ No	
- Frecuente sensación de preocupación/ansiedad	☐ Sí	☐ No	
- Cambios de humor frecuentes	☐ Sí	☐ No	
- Dificultad para dormir	☐ Sí	☐ No	
- ¿Usa drogas ilegales?	☐ Sí	☐ No	Describe:___________________
- ¿Fuma?	☐ Sí	☐ No	Edad de inicio:_______________ Paquetes por día:____________
- ¿Fuma puros/ pipa?	☐ Sí	☐ No	¿Con qué frecuencia?____________
- ¿Mastica tabaco o lo frota contra las encías?	☐ Sí	☐ No	¿Con qué frecuencia?____________
- ¿Ha fumado o usado tabaco alguna vez?	☐ Sí	☐ No	¿Por cuánto tiempo?__________ Fecha en que dejaste de fumar_____
- ¿Alguien en su casa fuma?	☐ Sí	☐ No	
- ¿Usted toma cerveza, vino, licor?	☐ Sí	☐ No	

- ¿Cómo tasaría usted su salud generalmente?	☐ Excelente	☐ Muy Bueno	☐ Bueno	☐ Aceptable	☐ Malo

POR FAVOR SIGA A LA SIGUIENTE PÁGINA.

4

11. Durante las **cuartas semanas pasadas**:

- Duermo bien por la noche	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
- Cuando me despierto, me siento descansado	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
- Tengo suficiente energía	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
- Mi fatiga interfiere con mis actividades diarias	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
- ¿Cuántas horas duerme usted durante una noche media?	☐ Menos de 4	☐ De 4 a 5	☐ De 6 a 7	☐ 8 o más		
- ¿Cuántas veces se despierta durante una noche media?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4 o más	
- Durante las cuarto semanas pasadas, su dolor corporal era:	☐ Nada	☐ Muy suave	☐ Suave	☐ Moderado	☐ Severo	☐ Severísimo
- ¿En las 4 semanas pasadas, con qué frecuencia ha tenido dolor corporal?	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	

12. ¿Durante el año pasado, alguien en su familia (padres, hermanos/hermanas, abuelos, tías, tíos, y primos) ha sido diagnosticado con cualquiera de los siguientes?

			Si es así, cual miembro de su familia:	Edad:
Cáncer	☐ Sí	☐ No	______________________	______
Diabetes	☐ Sí	☐ No	______________________	______
Alta Presión	☐ Sí	☐ No	______________________	______
Enfermedad Renal	☐ Sí	☐ No	______________________	______
Ataque de Corazón	☐ Sí	☐ No	______________________	______
Embolia	☐ Sí	☐ No	______________________	______
Cirugía Cardiaca	☐ Sí	☐ No	______________________	______

13. ¿Tiene algún otro problema médico o preocupación de su salud que no se presenta en este cuestionario?

☐ Sí ☐ No <u>Si es así</u>, especifique: ________________________________

____

____

14. ¿Hay algún otro aspecto de su estado de salud que le preocupa o sobre el que desearía que supiéramos?

☐ Sí ☐ No <u>Si es así</u>, especifique: ____________________________________

____

____

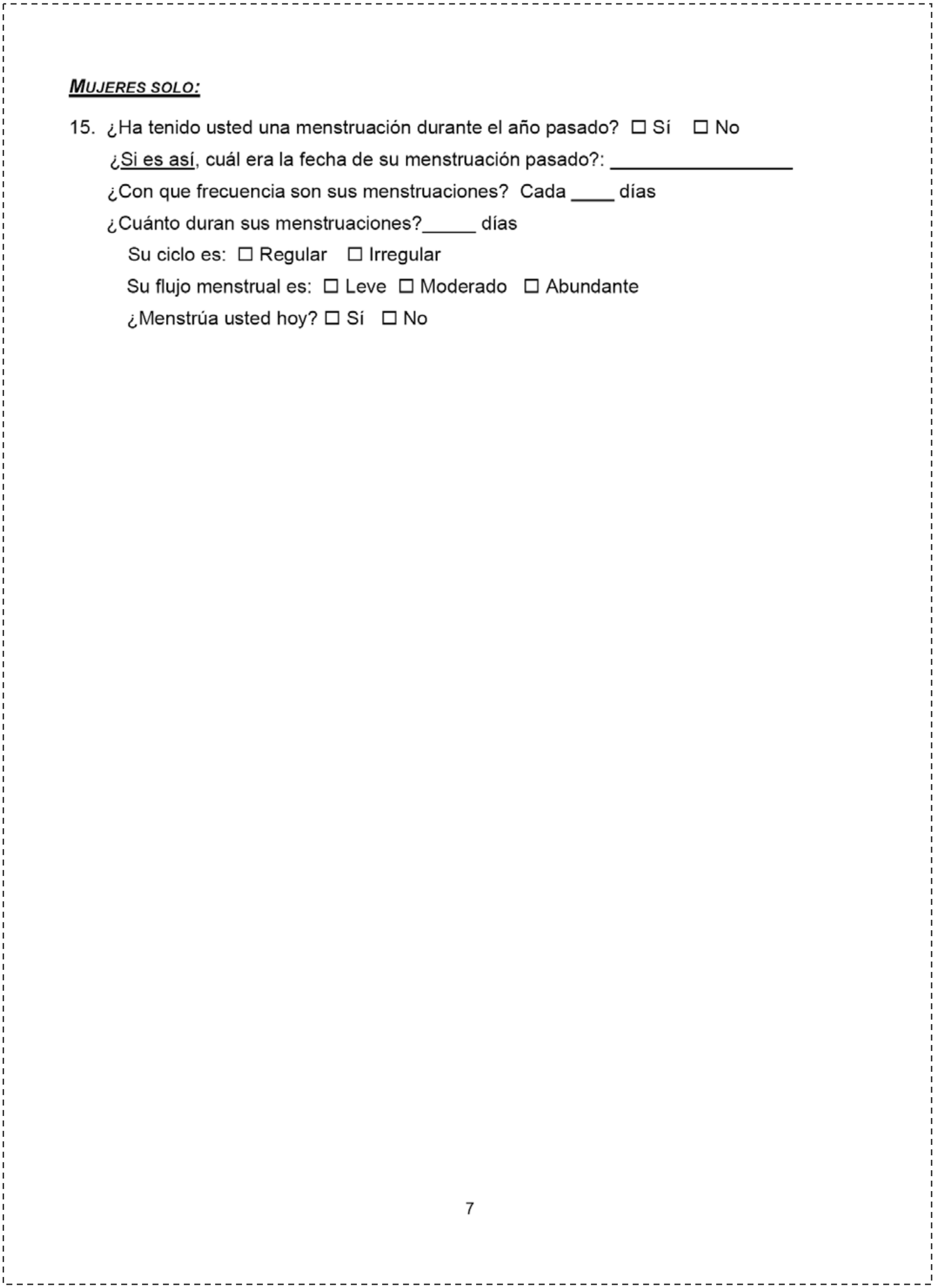
15. ¿Quién completó este cuestionario?

☐ Usted (paciente)
☐ Madre
☐ Padre
☐ Otro (especifique):_______________________________

16. ¿Cuál es la lengua primaria de la persona que completa este cuestionario?

☐ Ingles
☐ Español
☐ Otra (especifique): __________________________

PARA PACIENTES <u>FEMENINOS</u> SÓLO: *POR FAVOR SIGA A LA PÁGINA SIGUIENTE.*



MUJERES SOLO:

15. ¿Ha tenido usted una menstruación durante el año pasado? ☐ Sí ☐ No

¿Si es así, cuál era la fecha de su menstruación pasado?: ____________________

¿Con que frecuencia son sus menstruaciones? Cada ____ días

¿Cuánto duran sus menstruaciones?_____ días

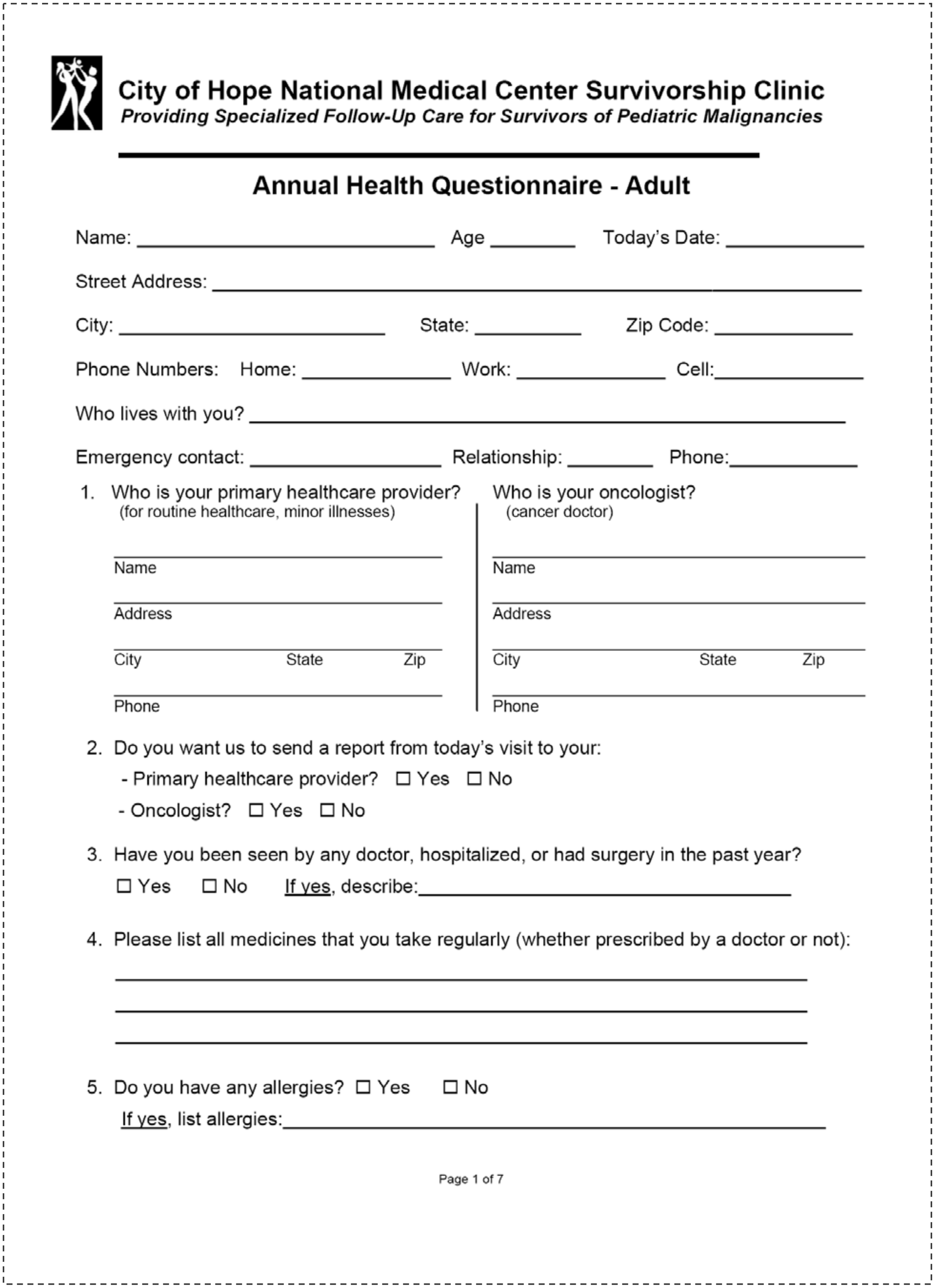
Su ciclo es: ☐ Regular ☐ Irregular

Su flujo menstrual es: ☐ Leve ☐ Moderado ☐ Abundante

¿Menstrúa usted hoy? ☐ Sí ☐ No

ANNUAL QUESTIONNAIRE: ADULT (ENGLISH & SPANISH)

City of Hope
Duarte, CA



City of Hope National Medical Center Survivorship Clinic
Providing Specialized Follow-Up Care for Survivors of Pediatric Malignancies

Annual Health Questionnaire - Adult

Name: ______________________ Age ________ Today's Date: ____________

Street Address: ____

City: ____________________ State: __________ Zip Code: ____________

Phone Numbers: Home: ____________ Work: ____________ Cell: ____________

Who lives with you? ____

Emergency contact: ______________ Relationship: ________ Phone: ____________

1. Who is your primary healthcare provider? (for routine healthcare, minor illnesses)	Who is your oncologist? (cancer doctor)
Name	Name
Address	Address
City State Zip	City State Zip
Phone	Phone

2. Do you want us to send a report from today's visit to your:
   - Primary healthcare provider? ☐ Yes ☐ No
   - Oncologist? ☐ Yes ☐ No

3. Have you been seen by any doctor, hospitalized, or had surgery in the past year?
   ☐ Yes ☐ No <u>If yes</u>, describe: ______________________________

4. Please list all medicines that you take regularly (whether prescribed by a doctor or not):
   ____
   ____
   ____

5. Do you have any allergies? ☐ Yes ☐ No
   <u>If yes</u>, list allergies: ______________________________________

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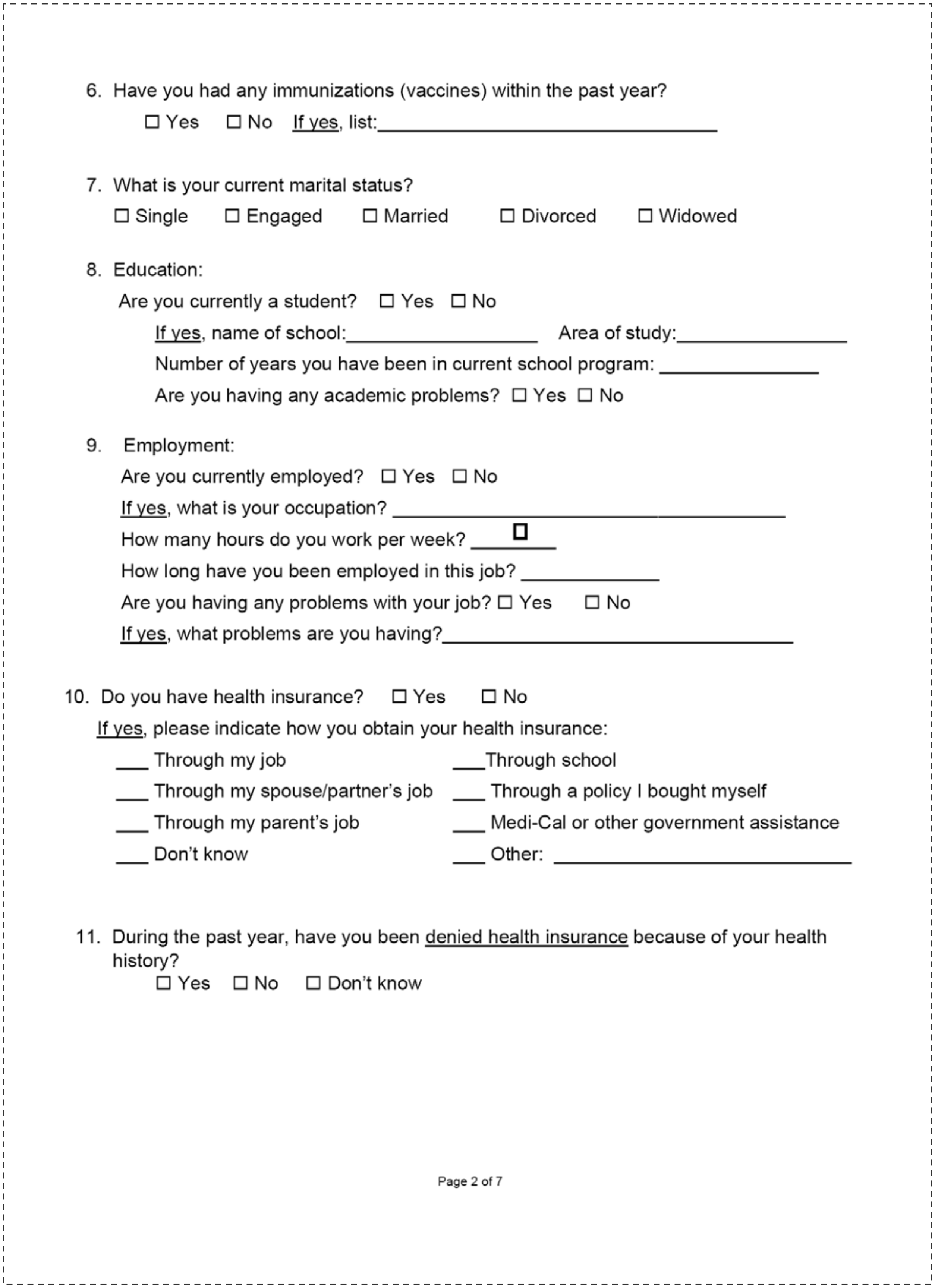

6. Have you had any immunizations (vaccines) within the past year?

   ☐ Yes ☐ No <u>If yes</u>, list:________________________________

7. What is your current marital status?

   ☐ Single ☐ Engaged ☐ Married ☐ Divorced ☐ Widowed

8. Education:

   Are you currently a student? ☐ Yes ☐ No

   <u>If yes</u>, name of school:__________________ Area of study:________________

   Number of years you have been in current school program: _______________

   Are you having any academic problems? ☐ Yes ☐ No

9. Employment:

   Are you currently employed? ☐ Yes ☐ No

   <u>If yes</u>, what is your occupation? _____________________________________

   How many hours do you work per week? ________ ☐

   How long have you been employed in this job? _____________

   Are you having any problems with your job? ☐ Yes ☐ No

   <u>If yes</u>, what problems are you having?_________________________________

10. Do you have health insurance? ☐ Yes ☐ No

    <u>If yes</u>, please indicate how you obtain your health insurance:

    ___ Through my job

    ___ Through my spouse/partner's job

    ___ Through my parent's job

    ___ Don't know

    ___Through school

    ___ Through a policy I bought myself

    ___ Medi-Cal or other government assistance

    ___ Other: ____________________________

11. During the past year, have you been <u>denied health insurance</u> because of your health history?

    ☐ Yes ☐ No ☐ Don't know

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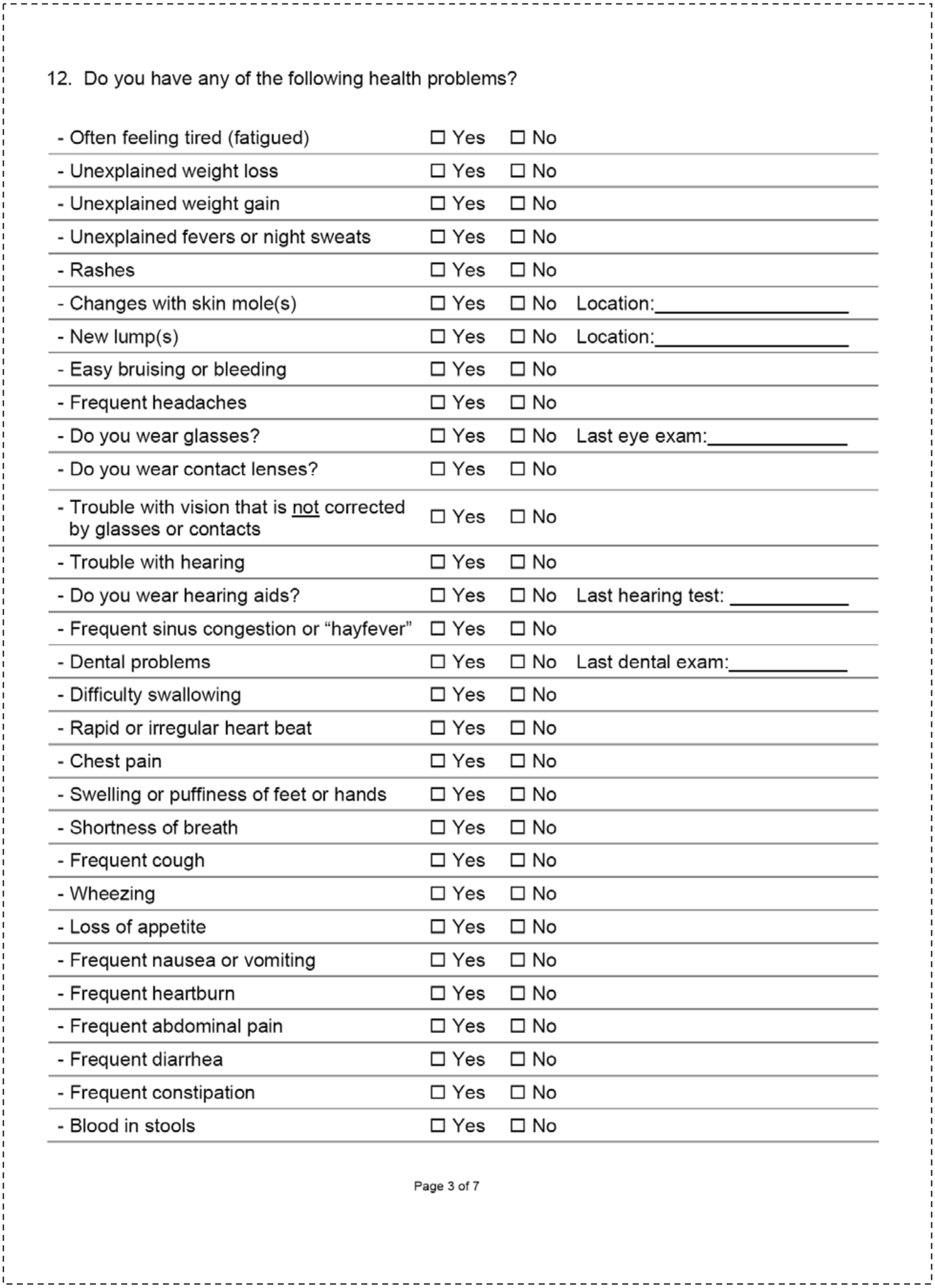

12. Do you have any of the following health problems?

- Often feeling tired (fatigued)	☐ Yes	☐ No	
- Unexplained weight loss	☐ Yes	☐ No	
- Unexplained weight gain	☐ Yes	☐ No	
- Unexplained fevers or night sweats	☐ Yes	☐ No	
- Rashes	☐ Yes	☐ No	
- Changes with skin mole(s)	☐ Yes	☐ No	Location:____________________
- New lump(s)	☐ Yes	☐ No	Location:____________________
- Easy bruising or bleeding	☐ Yes	☐ No	
- Frequent headaches	☐ Yes	☐ No	
- Do you wear glasses?	☐ Yes	☐ No	Last eye exam:______________
- Do you wear contact lenses?	☐ Yes	☐ No	
- Trouble with vision that is <u>not</u> corrected by glasses or contacts	☐ Yes	☐ No	
- Trouble with hearing	☐ Yes	☐ No	
- Do you wear hearing aids?	☐ Yes	☐ No	Last hearing test: ____________
- Frequent sinus congestion or “hayfever”	☐ Yes	☐ No	
- Dental problems	☐ Yes	☐ No	Last dental exam:____________
- Difficulty swallowing	☐ Yes	☐ No	
- Rapid or irregular heart beat	☐ Yes	☐ No	
- Chest pain	☐ Yes	☐ No	
- Swelling or puffiness of feet or hands	☐ Yes	☐ No	
- Shortness of breath	☐ Yes	☐ No	
- Frequent cough	☐ Yes	☐ No	
- Wheezing	☐ Yes	☐ No	
- Loss of appetite	☐ Yes	☐ No	
- Frequent nausea or vomiting	☐ Yes	☐ No	
- Frequent heartburn	☐ Yes	☐ No	
- Frequent abdominal pain	☐ Yes	☐ No	
- Frequent diarrhea	☐ Yes	☐ No	
- Frequent constipation	☐ Yes	☐ No	
- Blood in stools	☐ Yes	☐ No	

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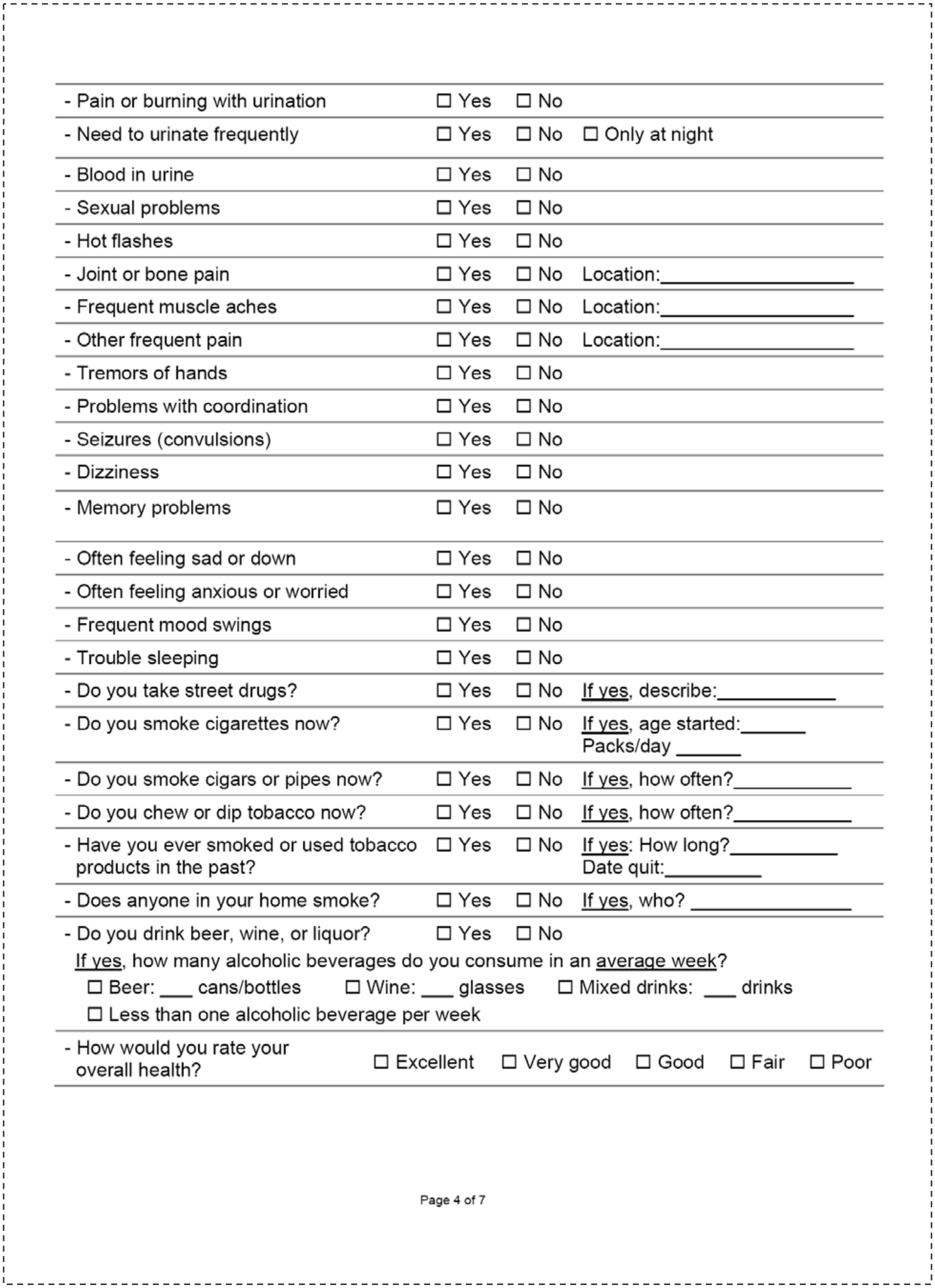

- Pain or burning with urination	☐ Yes	☐ No	
- Need to urinate frequently	☐ Yes	☐ No	☐ Only at night
- Blood in urine	☐ Yes	☐ No	
- Sexual problems	☐ Yes	☐ No	
- Hot flashes	☐ Yes	☐ No	
- Joint or bone pain	☐ Yes	☐ No	Location:___________________
- Frequent muscle aches	☐ Yes	☐ No	Location:___________________
- Other frequent pain	☐ Yes	☐ No	Location:___________________
- Tremors of hands	☐ Yes	☐ No	
- Problems with coordination	☐ Yes	☐ No	
- Seizures (convulsions)	☐ Yes	☐ No	
- Dizziness	☐ Yes	☐ No	
- Memory problems	☐ Yes	☐ No	
- Often feeling sad or down	☐ Yes	☐ No	
- Often feeling anxious or worried	☐ Yes	☐ No	
- Frequent mood swings	☐ Yes	☐ No	
- Trouble sleeping	☐ Yes	☐ No	
- Do you take street drugs?	☐ Yes	☐ No	If yes, describe:____________
- Do you smoke cigarettes now?	☐ Yes	☐ No	If yes, age started:______ Packs/day ______
- Do you smoke cigars or pipes now?	☐ Yes	☐ No	If yes, how often?____________
- Do you chew or dip tobacco now?	☐ Yes	☐ No	If yes, how often?____________
- Have you ever smoked or used tobacco products in the past?	☐ Yes	☐ No	If yes: How long?___________ Date quit:__________
- Does anyone in your home smoke?	☐ Yes	☐ No	If yes, who? _________________
- Do you drink beer, wine, or liquor?	☐ Yes	☐ No	

If yes, how many alcoholic beverages do you consume in an average week?

☐ Beer: ___ cans/bottles ☐ Wine: ___ glasses ☐ Mixed drinks: ___ drinks

☐ Less than one alcoholic beverage per week

- How would you rate your overall health? ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

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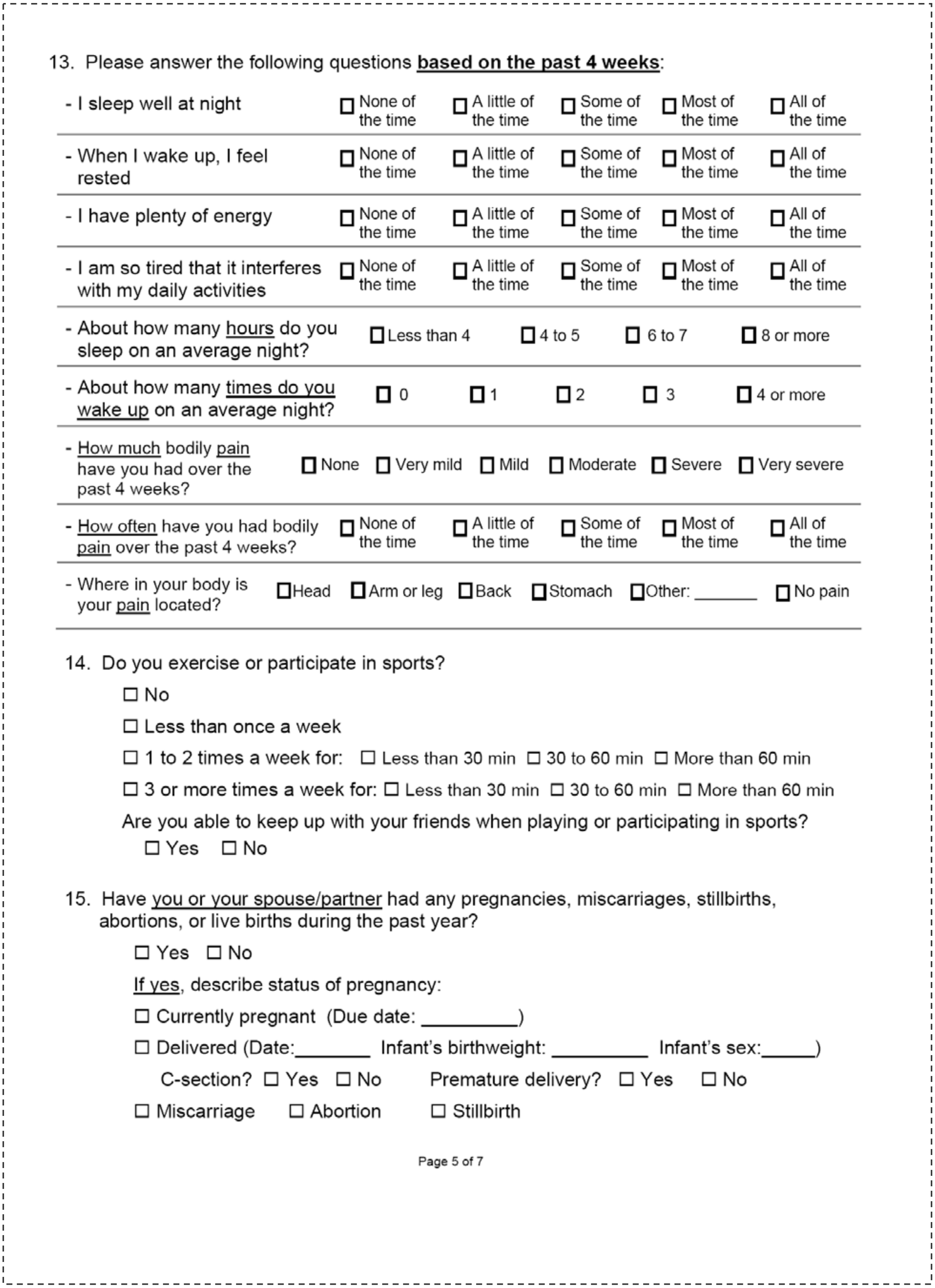


13. Please answer the following questions **based on the past 4 weeks**:

- I sleep well at night	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- When I wake up, I feel rested	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- I have plenty of energy	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- I am so tired that it interferes with my daily activities	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- About how many <u>hours</u> do you sleep on an average night?	☐ Less than 4	☐ 4 to 5	☐ 6 to 7	☐ 8 or more		
- About how many <u>times do you wake up</u> on an average night?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4 or more	
- <u>How much</u> bodily <u>pain</u> have you had over the past 4 weeks?	☐ None	☐ Very mild	☐ Mild	☐ Moderate	☐ Severe	☐ Very severe
- <u>How often</u> have you had bodily <u>pain</u> over the past 4 weeks?	☐ None of the time	☐ A little of the time	☐ Some of the time	☐ Most of the time	☐ All of the time	
- Where in your body is your <u>pain</u> located?	☐ Head	☐ Arm or leg	☐ Back	☐ Stomach	☐ Other: _______	☐ No pain

14. Do you exercise or participate in sports?

☐ No

☐ Less than once a week

☐ 1 to 2 times a week for: ☐ Less than 30 min ☐ 30 to 60 min ☐ More than 60 min

☐ 3 or more times a week for: ☐ Less than 30 min ☐ 30 to 60 min ☐ More than 60 min

Are you able to keep up with your friends when playing or participating in sports?

☐ Yes ☐ No

15. Have <u>you or your spouse/partner</u> had any pregnancies, miscarriages, stillbirths, abortions, or live births during the past year?

☐ Yes ☐ No

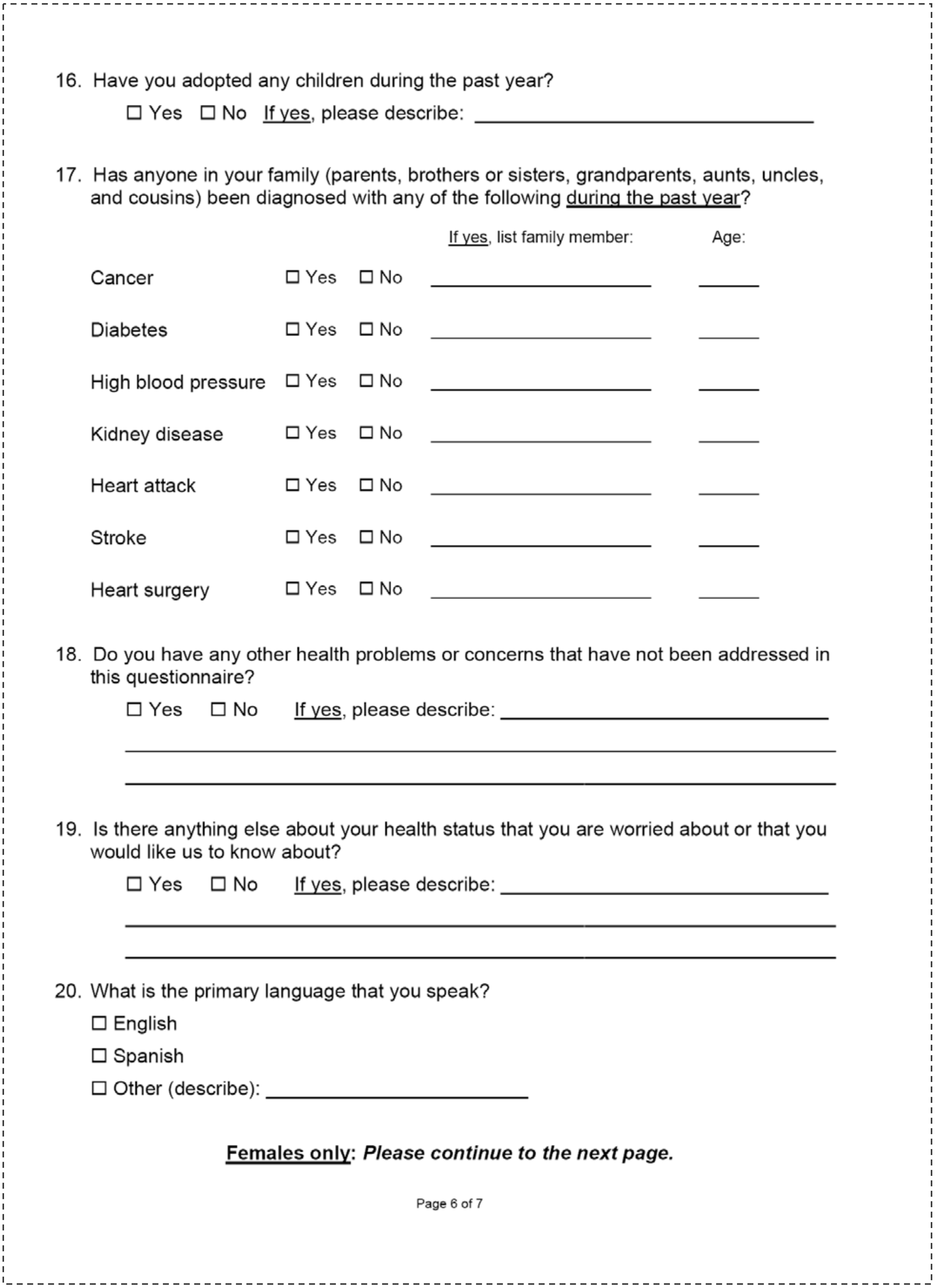
<u>If yes</u>, describe status of pregnancy:

☐ Currently pregnant (Due date: __________)

☐ Delivered (Date:________ Infant's birthweight: __________ Infant's sex:_____)

C-section? ☐ Yes ☐ No Premature delivery? ☐ Yes ☐ No

☐ Miscarriage ☐ Abortion ☐ Stillbirth



16. Have you adopted any children during the past year?

☐ Yes ☐ No <u>If yes</u>, please describe: ________________________________

17. Has anyone in your family (parents, brothers or sisters, grandparents, aunts, uncles, and cousins) been diagnosed with any of the following <u>during the past year</u>?

			<u>If yes</u>, list family member:	Age:
Cancer	☐ Yes	☐ No	____________________	______
Diabetes	☐ Yes	☐ No	____________________	______
High blood pressure	☐ Yes	☐ No	____________________	______
Kidney disease	☐ Yes	☐ No	____________________	______
Heart attack	☐ Yes	☐ No	____________________	______
Stroke	☐ Yes	☐ No	____________________	______
Heart surgery	☐ Yes	☐ No	____________________	______

18. Do you have any other health problems or concerns that have not been addressed in this questionnaire?

☐ Yes ☐ No <u>If yes</u>, please describe: ________________________________

____

____

19. Is there anything else about your health status that you are worried about or that you would like us to know about?

☐ Yes ☐ No <u>If yes</u>, please describe: ________________________________

____

____

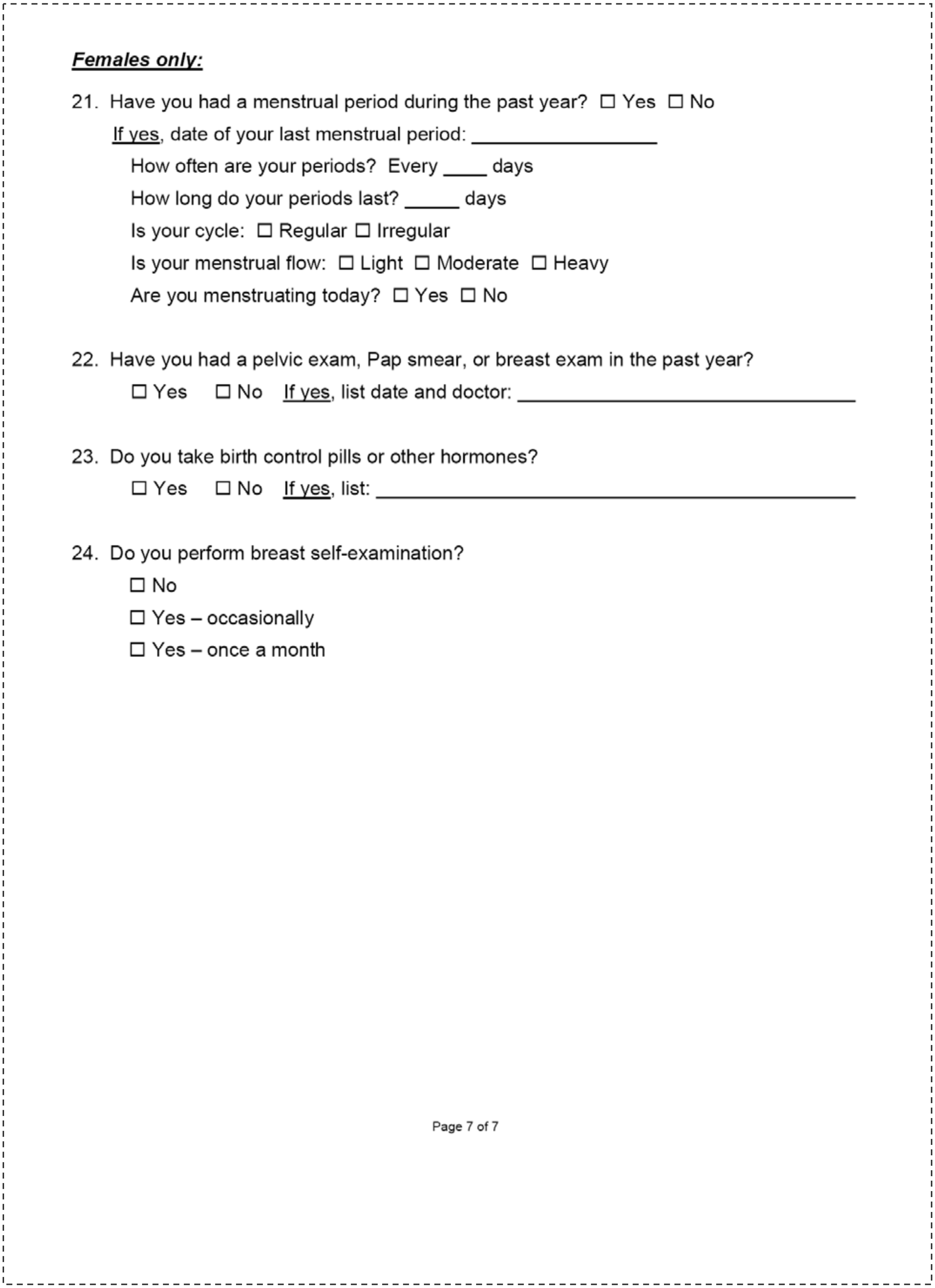
20. What is the primary language that you speak?

☐ English

☐ Spanish

☐ Other (describe): ________________________

<u>Females only</u>: ***Please continue to the next page.***



Females only:

21. Have you had a menstrual period during the past year? ☐ Yes ☐ No

If yes, date of your last menstrual period: ____________________

How often are your periods? Every _____ days

How long do your periods last? ______ days

Is your cycle: ☐ Regular ☐ Irregular

Is your menstrual flow: ☐ Light ☐ Moderate ☐ Heavy

Are you menstruating today? ☐ Yes ☐ No

22. Have you had a pelvic exam, Pap smear, or breast exam in the past year?

☐ Yes ☐ No If yes, list date and doctor: ____________________________________

23. Do you take birth control pills or other hormones?

☐ Yes ☐ No If yes, list: ____

24. Do you perform breast self-examination?

☐ No
☐ Yes – occasionally
☐ Yes – once a month

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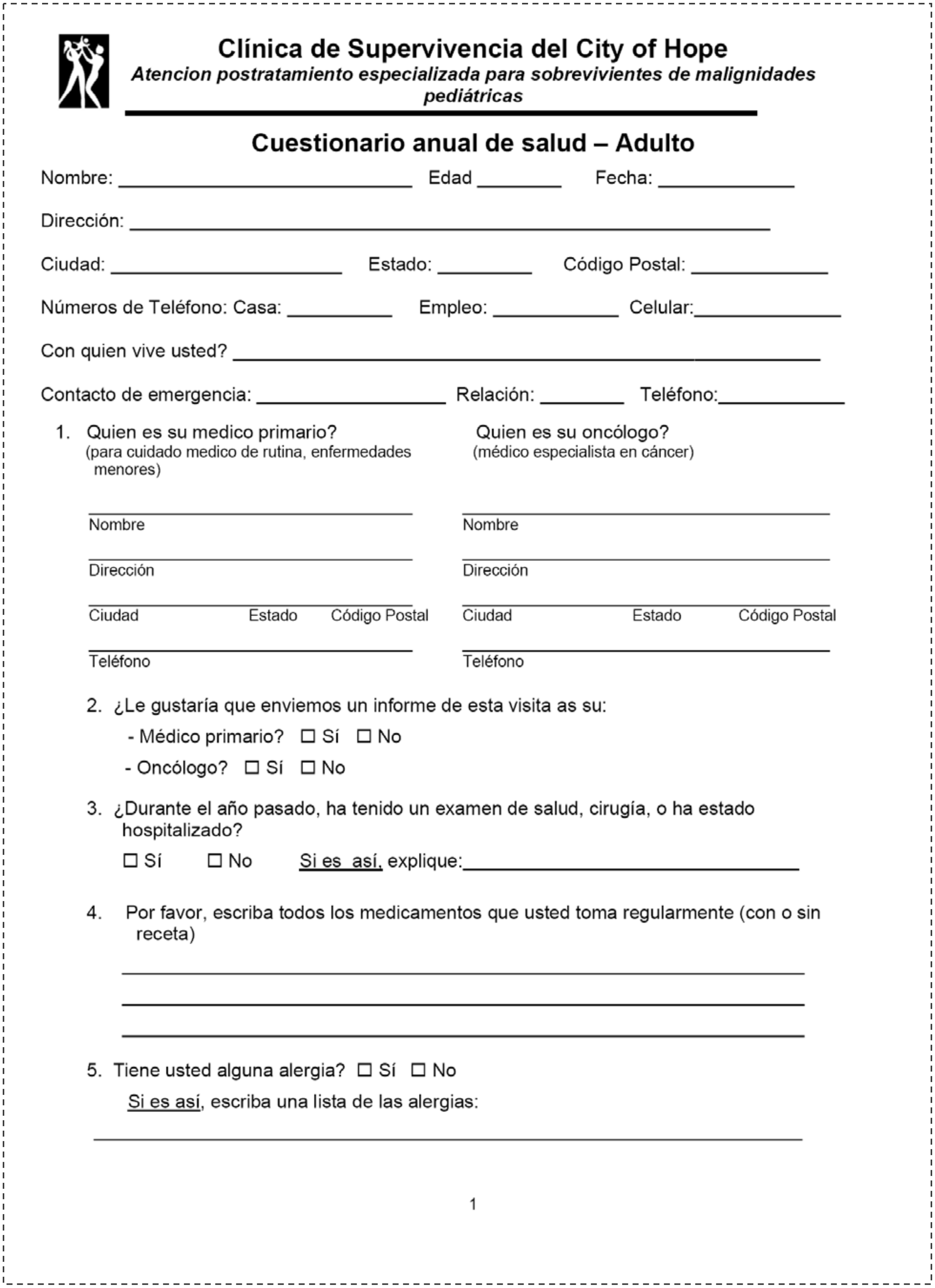


Clínica de Supervivencia del City of Hope

Atencion postratamiento especializada para sobrevivientes de malignidades pediátricas

Cuestionario anual de salud – Adulto

Nombre: ______________________________ Edad ________ Fecha: _____________

Dirección: ____

Ciudad: ________________________ Estado: _________ Código Postal: _____________

Números de Teléfono: Casa: __________ Empleo: ____________ Celular:______________

Con quien vive usted? ____

Contacto de emergencia: ___________________ Relación: ________ Teléfono:____________

1. Quien es su medico primario? (para cuidado medico de rutina, enfermedades menores)	Quien es su oncólogo? (médico especialista en cáncer)
______________________________ Nombre	______________________________ Nombre
______________________________ Dirección	______________________________ Dirección
______________________________ Ciudad Estado Código Postal	______________________________ Ciudad Estado Código Postal
______________________________ Teléfono	______________________________ Teléfono

2. ¿Le gustaría que enviemos un informe de esta visita as su:

   - Médico primario? ☐ Sí ☐ No

   - Oncólogo? ☐ Sí ☐ No

3. ¿Durante el año pasado, ha tenido un examen de salud, cirugía, o ha estado hospitalizado?

   ☐ Sí ☐ No <u>Si es así,</u> explique:_________________________________

4. Por favor, escriba todos los medicamentos que usted toma regularmente (con o sin receta)

   ____

   ____

   ____

5. Tiene usted alguna alergia? ☐ Sí ☐ No

   <u>Si es así</u>, escriba una lista de las alergias:

   ____

6. ¿Ha tenido usted alguna inmunización (vacuna) dentro del año pasado?

☐ Sí ☐ No Si es así, haga una lista de las vacunas:

____

7. ¿Cuál es su estado civil?

☐ Soltero/a ☐ Comprometido/a ☐ Casado/a ☐ Divorciado/a ☐ Viudo/a

8. Educación:

¿Asiste usted la escuela? ☐ Sí ☐ No

Si es así, ¿Cuál es el nombre de la escuela?:______________________________

¿Cuál es su área de estudio?:______________

Número de años usted ha estado en el programa escolar corriente: ____________

¿Tiene usted algún problema académico? ☐ Sí ☐ No

9. Empleo:

¿Es empleado actualmente usted? ☐ Sí ☐ No

Si es así, ¿cuál es su ocupación? ___________☐___________

¿Cuántas horas semanales trabaja? ____________

¿Cuánto hace que tiene este trabajo?____________

¿Tiene usted algún problema con su trabajo? ☐ Sí ☐ No

Si es así, ¿Qué problemas tiene?____

10. Tiene usted algún seguro médico? ☐ Sí ☐ No

Si es así, por favor indique como usted obtiene su seguro médico:

___ Por mi trabajo

___ Por el trabajo de mi esposo/a o compañero/a

___ Por el trabajo de mis padres

___ De otra manera: ____

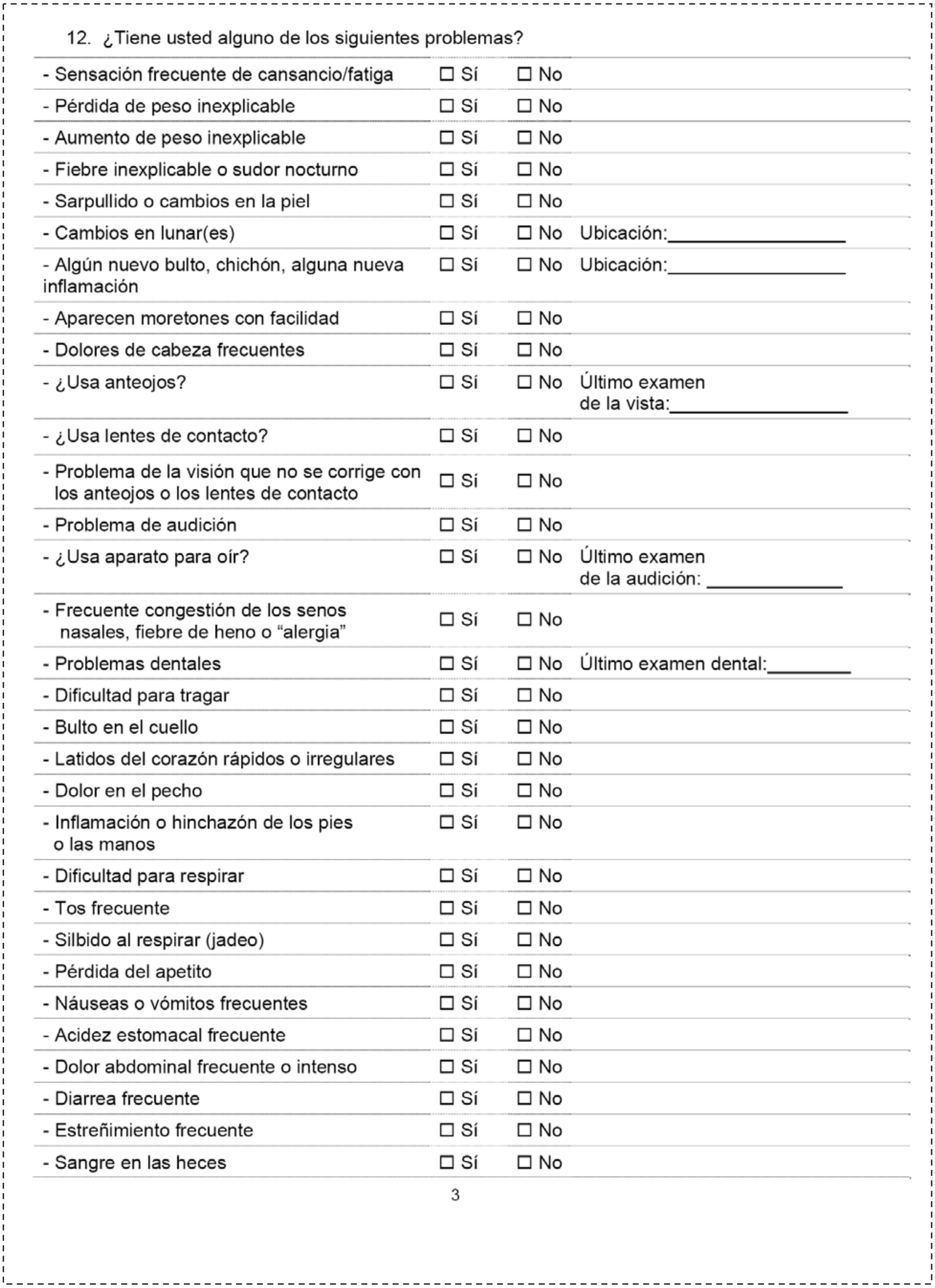
___Por la escuela

___ Por una política que compré

___ Medi-Cal o otra ayuda gubernamental

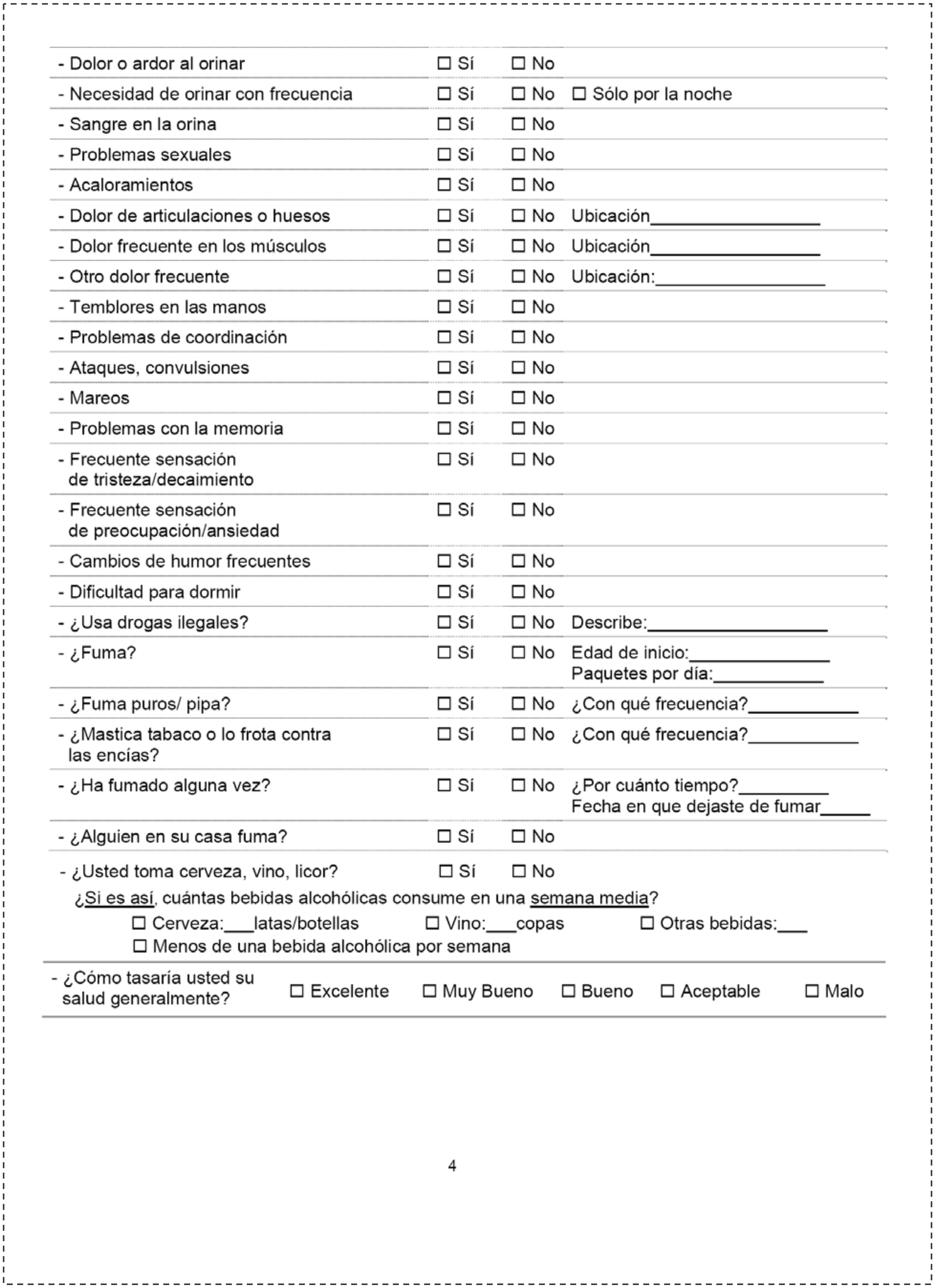
11. Durante el año pasado ha sido negado usted seguro médico por tu historia de salud?

☐ Sí ☐ No ☐ No lo sé



12. ¿Tiene usted alguno de los siguientes problemas?

- Sensación frecuente de cansancio/fatiga	☐ Sí	☐ No	
- Pérdida de peso inexplicable	☐ Sí	☐ No	
- Aumento de peso inexplicable	☐ Sí	☐ No	
- Fiebre inexplicable o sudor nocturno	☐ Sí	☐ No	
- Sarpullido o cambios en la piel	☐ Sí	☐ No	
- Cambios en lunar(es)	☐ Sí	☐ No	Ubicación:___________________
- Algún nuevo bulto, chichón, alguna nueva inflamación	☐ Sí	☐ No	Ubicación:___________________
- Aparecen moretones con facilidad	☐ Sí	☐ No	
- Dolores de cabeza frecuentes	☐ Sí	☐ No	
- ¿Usa anteojos?	☐ Sí	☐ No	Último examen de la vista:___________________
- ¿Usa lentes de contacto?	☐ Sí	☐ No	
- Problema de la visión que no se corrige con los anteojos o los lentes de contacto	☐ Sí	☐ No	
- Problema de audición	☐ Sí	☐ No	
- ¿Usa aparato para oír?	☐ Sí	☐ No	Último examen de la audición: _______________
- Frecuente congestión de los senos nasales, fiebre de heno o “alergia”	☐ Sí	☐ No	
- Problemas dentales	☐ Sí	☐ No	Último examen dental:_________
- Dificultad para tragar	☐ Sí	☐ No	
- Bulto en el cuello	☐ Sí	☐ No	
- Latidos del corazón rápidos o irregulares	☐ Sí	☐ No	
- Dolor en el pecho	☐ Sí	☐ No	
- Inflamación o hinchazón de los pies o las manos	☐ Sí	☐ No	
- Dificultad para respirar	☐ Sí	☐ No	
- Tos frecuente	☐ Sí	☐ No	
- Silbido al respirar (jadeo)	☐ Sí	☐ No	
- Pérdida del apetito	☐ Sí	☐ No	
- Náuseas o vómitos frecuentes	☐ Sí	☐ No	
- Acidez estomacal frecuente	☐ Sí	☐ No	
- Dolor abdominal frecuente o intenso	☐ Sí	☐ No	
- Diarrea frecuente	☐ Sí	☐ No	
- Estreñimiento frecuente	☐ Sí	☐ No	
- Sangre en las heces	☐ Sí	☐ No	

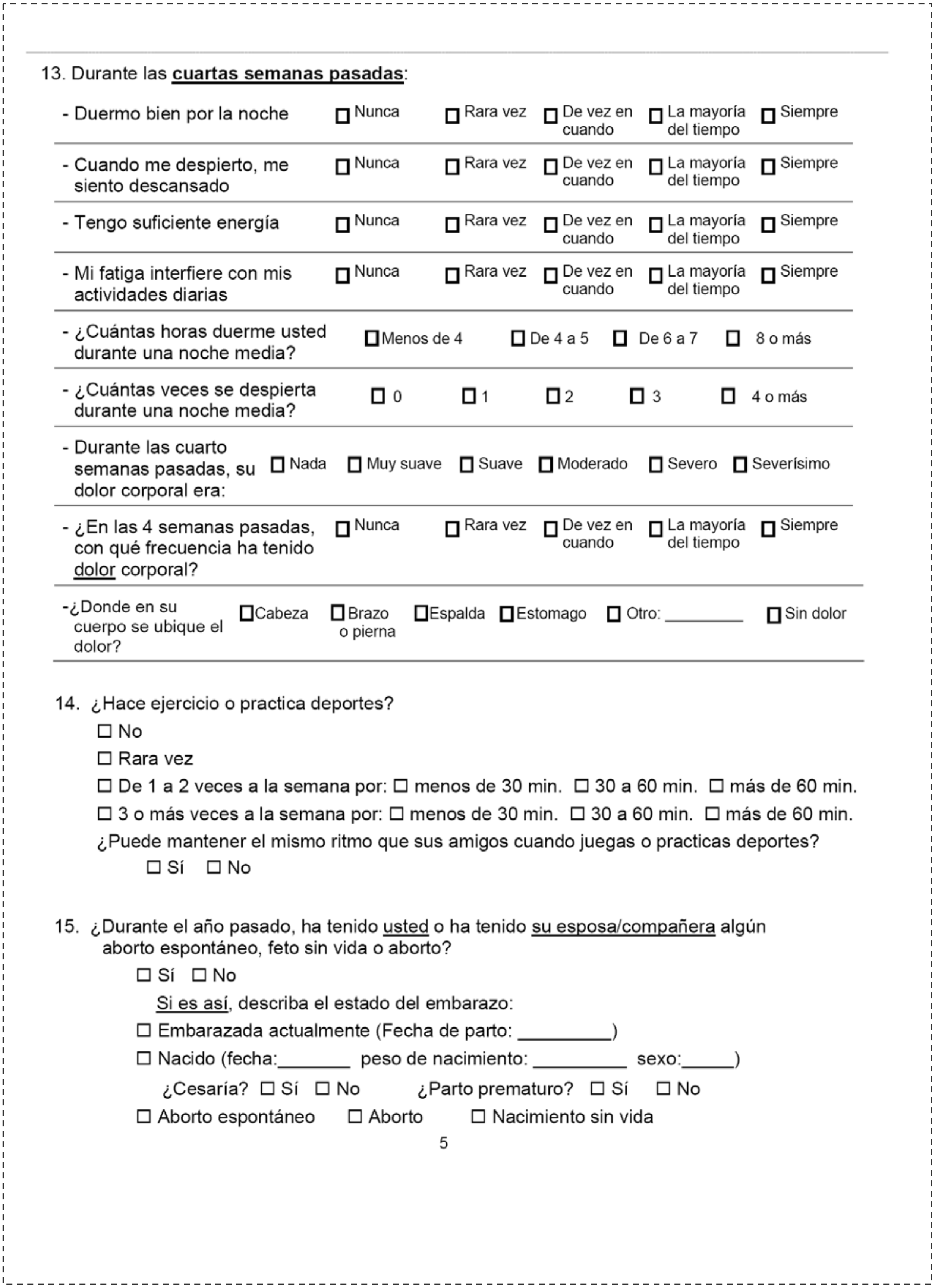


- Dolor o ardor al orinar	☐ Sí	☐ No	
- Necesidad de orinar con frecuencia	☐ Sí	☐ No	☐ Sólo por la noche
- Sangre en la orina	☐ Sí	☐ No	
- Problemas sexuales	☐ Sí	☐ No	
- Acaloramientos	☐ Sí	☐ No	
- Dolor de articulaciones o huesos	☐ Sí	☐ No	Ubicación__________________
- Dolor frecuente en los músculos	☐ Sí	☐ No	Ubicación__________________
- Otro dolor frecuente	☐ Sí	☐ No	Ubicación:__________________
- Temblores en las manos	☐ Sí	☐ No	
- Problemas de coordinación	☐ Sí	☐ No	
- Ataques, convulsiones	☐ Sí	☐ No	
- Mareos	☐ Sí	☐ No	
- Problemas con la memoria	☐ Sí	☐ No	
- Frecuente sensación de tristeza/decaimiento	☐ Sí	☐ No	
- Frecuente sensación de preocupación/ansiedad	☐ Sí	☐ No	
- Cambios de humor frecuentes	☐ Sí	☐ No	
- Dificultad para dormir	☐ Sí	☐ No	
- ¿Usa drogas ilegales?	☐ Sí	☐ No	Describe:___________________
- ¿Fuma?	☐ Sí	☐ No	Edad de inicio:_______________ Paquetes por día:____________
- ¿Fuma puros/ pipa?	☐ Sí	☐ No	¿Con qué frecuencia?____________
- ¿Mastica tabaco o lo frota contra las encías?	☐ Sí	☐ No	¿Con qué frecuencia?____________
- ¿Ha fumado alguna vez?	☐ Sí	☐ No	¿Por cuánto tiempo?_________ Fecha en que dejaste de fumar_____
- ¿Alguien en su casa fuma?	☐ Sí	☐ No	
- ¿Usted toma cerveza, vino, licor?	☐ Sí	☐ No	

¿Si es así, cuántas bebidas alcohólicas consume en una semana media?
☐ Cerveza:___latas/botellas ☐ Vino:___copas ☐ Otras bebidas:___
☐ Menos de una bebida alcohólica por semana

- ¿Cómo tasaría usted su salud generalmente? ☐ Excelente ☐ Muy Bueno ☐ Bueno ☐ Aceptable ☐ Malo

4



13. Durante las **cuartas semanas pasadas**:

- Duermo bien por la noche	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
- Cuando me despierto, me siento descansado	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
- Tengo suficiente energía	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
- Mi fatiga interfiere con mis actividades diarias	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
- ¿Cuántas horas duerme usted durante una noche media?	☐ Menos de 4	☐ De 4 a 5	☐ De 6 a 7	☐ 8 o más		
- ¿Cuántas veces se despierta durante una noche media?	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4 o más	
- Durante las cuarto semanas pasadas, su dolor corporal era:	☐ Nada	☐ Muy suave	☐ Suave	☐ Moderado	☐ Severo	☐ Severísimo
- ¿En las 4 semanas pasadas, con qué frecuencia ha tenido <u>dolor</u> corporal?	☐ Nunca	☐ Rara vez	☐ De vez en cuando	☐ La mayoría del tiempo	☐ Siempre	
-¿Donde en su cuerpo se ubique el dolor?	☐ Cabeza	☐ Brazo o pierna	☐ Espalda	☐ Estomago	☐ Otro: _________	☐ Sin dolor

14. ¿Hace ejercicio o practica deportes?

☐ No

☐ Rara vez

☐ De 1 a 2 veces a la semana por: ☐ menos de 30 min. ☐ 30 a 60 min. ☐ más de 60 min.

☐ 3 o más veces a la semana por: ☐ menos de 30 min. ☐ 30 a 60 min. ☐ más de 60 min.

¿Puede mantener el mismo ritmo que sus amigos cuando juegas o practicas deportes?

☐ Sí ☐ No

15. ¿Durante el año pasado, ha tenido <u>usted</u> o ha tenido <u>su esposa/compañera</u> algún aborto espontáneo, feto sin vida o aborto?

☐ Sí ☐ No

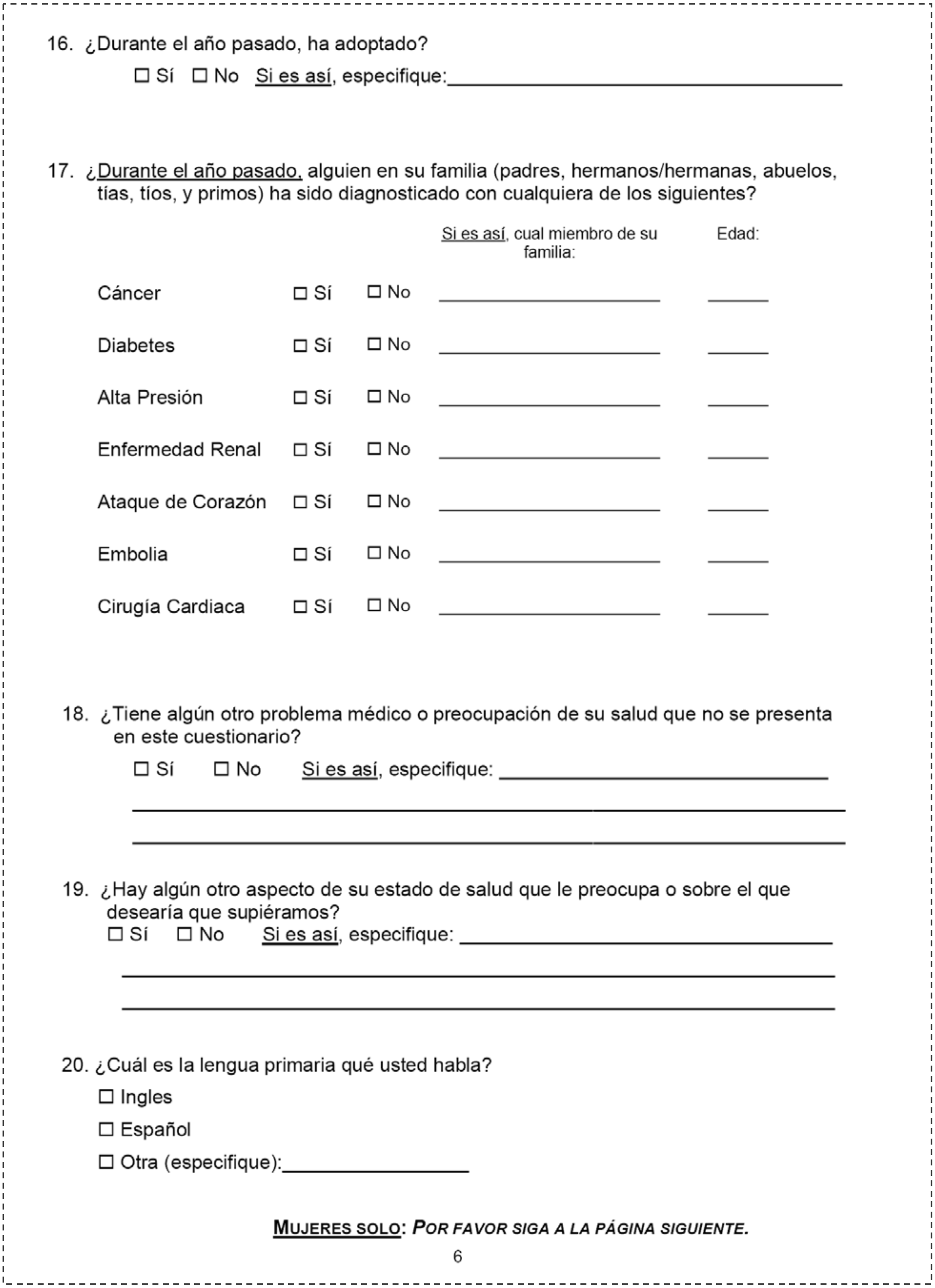
<u>Si es así</u>, describa el estado del embarazo:

☐ Embarazada actualmente (Fecha de parto: __________)

☐ Nacido (fecha:________ peso de nacimiento: __________ sexo:_____)

¿Cesaría? ☐ Sí ☐ No ¿Parto prematuro? ☐ Sí ☐ No

☐ Aborto espontáneo ☐ Aborto ☐ Nacimiento sin vida



16. ¿Durante el año pasado, ha adoptado?

☐ Sí ☐ No Si es así, especifique:____

17. ¿Durante el año pasado, alguien en su familia (padres, hermanos/hermanas, abuelos, tías, tíos, y primos) ha sido diagnosticado con cualquiera de los siguientes?

			Si es así, cual miembro de su familia:	Edad:
Cáncer	☐ Sí	☐ No	____________________	______
Diabetes	☐ Sí	☐ No	____________________	______
Alta Presión	☐ Sí	☐ No	____________________	______
Enfermedad Renal	☐ Sí	☐ No	____________________	______
Ataque de Corazón	☐ Sí	☐ No	____________________	______
Embolia	☐ Sí	☐ No	____________________	______
Cirugía Cardiaca	☐ Sí	☐ No	____________________	______

18. ¿Tiene algún otro problema médico o preocupación de su salud que no se presenta en este cuestionario?

☐ Sí ☐ No Si es así, especifique: __________________________________

____

____

19. ¿Hay algún otro aspecto de su estado de salud que le preocupa o sobre el que desearía que supiéramos?

☐ Sí ☐ No Si es así, especifique: ______________________________________

____

____

20. ¿Cuál es la lengua primaria qué usted habla?

☐ Ingles
☐ Español
☐ Otra (especifique):___________________

MUJERES SOLO: ***POR FAVOR SIGA A LA PÁGINA SIGUIENTE.***

MUJERES SOLO:

21. ¿Ha tenido usted una menstruación durante el año pasado? ☐ Sí ☐ No

¿Si es así, cuál era la fecha de su menstruación pasado?: ____________________

¿Con que frecuencia son sus menstruaciones? Cada ____ días

¿Cuánto duran sus menstruaciones?_____ días

Su ciclo es: ☐ Regular ☐ Irregular

Su flujo menstrual es: ☐ Leve ☐ Moderado ☐ Abundante

¿Menstrúa usted hoy? ☐ Sí ☐ No

22. ¿Le ha hecho un examen pélvico, Papanicolaou o un examen de senos en el último año?

☐ Sí ☐ No Si es así, marque la fecha y el doctor:__________________________

23. ¿Toma usted píldoras contraceptivas o otras hormonas?

☐ Sí ☐ No Si es así, especifique: ______________________________________

24. ¿Hace usted el auto-examen de senos?

☐ No

☐ Sí – de vez en cuando

☐ Sí – una vez al mes

LETTERS

APPOINTMENT LETTER

Helen DeVos Children's Hospital
Grand Rapids, MI

After-Care and Transition Program
Division of Pediatric Hematology/Oncology
Blood & Bone Marrow Transplantation
(616) 391-2238

«FirstName» «LastName»
«Address1»
«City» «State» «PostalCode»

Dear «FirstName»,

Welcome to the After-Care and Transition (ACT) clinic. Staffed by a team of specialists consisting of a physician, physician assistant or nurse practitioner, nurse, medical social worker and child psychologist, our clinic is dedicated to the care of long-term survivors of childhood cancer. An appointment in the ACT Clinic signifies that you have reached an important milestone.

Your child has an appointment scheduled for:

«Appointment»

«DiagTesting»

«DiagTesting2»

«DiagTesting3»

Where Do I Go?
Patients are seen in Suite #203 of the Women's & Children's Center at 330 Barclay, across the street from the spectrum Health-Butterworth Emergency Room. Parking is available free of charge. Please stop at the laboratory located on the first floor of our building for any necessary blood work, and take the elevator to the second floor for your appointment wit our ACT Clinic staff.

What is the ACT Clinic?
The ACT Clinic provides a comprehensive assessment, education resources, and a treatment summary specific to the individual survivor. We will review your individual medical history, previous treatment, and current state of health. Following completion of the clinical assessment and receipt of available test results from the day, the physician and nurse practitioner/physician assistant will have an in-depth discussion with you and your family to discuss current and /or potential health concerns. Recommendations are made regarding continued follow-up care and at what point transition to an adult primary care provider will occur. Wellness education is a key part of this discussion. A folder containing general and individualized educational material will be given to you on the day of your clinic appointment. A complete treatment summary letter including a problem list and plan is sent to the primary doctor, all consultants, and to you/your family for your personal records.

What Else Should I Know?
We are dedicated to providing the best care for each of our patients. This specialty clinic is held only one day each month, and every patient receives an extensive comprehensive visit. *It is very difficult to reschedule patients because of the limited number of available appointments, so please make every effort to keep your appointment.* If you have questions regarding this, please call Colleen Gardner at the number listed below.

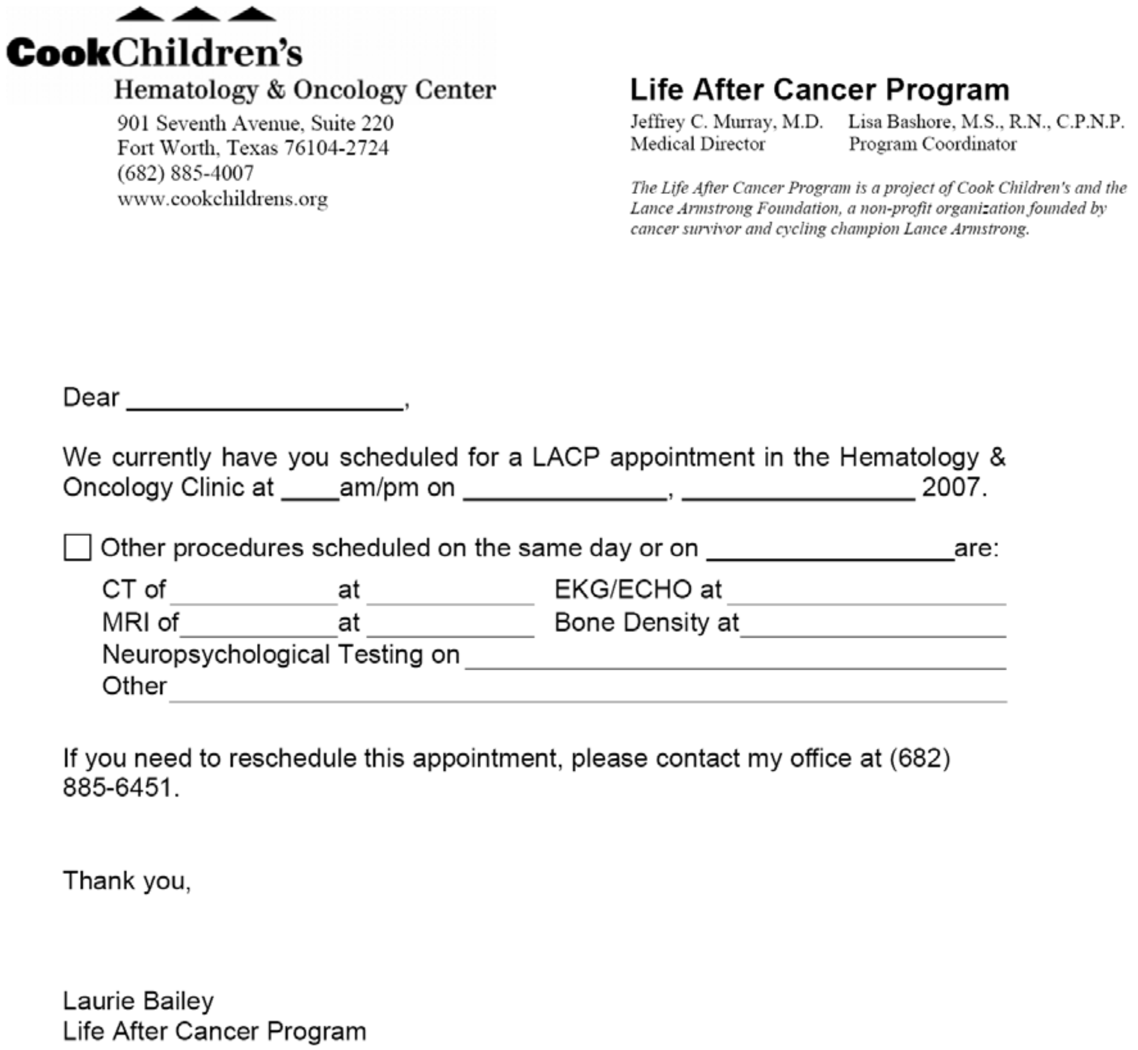
Please call (616) 391-2238 or send an email to colleen.gardner@spectrum-health.org as soon as possible **to confirm your appointment**.

We look forward to seeing you!

The ACT Program Staff
David R. Freyer, D.O.
Michele VanSoelen, RN, BSN
Colleen Gardner, RN
Scott Hawkins, MSW
Steve Pastyrnak, PhD

APPOINTMENT LETTER

Cook Children's Hospital
Fort Worth, TX



CookChildren's
Hematology & Oncology Center
901 Seventh Avenue, Suite 220
Fort Worth, Texas 76104-2724
(682) 885-4007
www.cookchildrens.org

Life After Cancer Program
Jeffrey C. Murray, M.D. Medical Director
Lisa Bashore, M.S., R.N., C.P.N.P. Program Coordinator

The Life After Cancer Program is a project of Cook Children's and the Lance Armstrong Foundation, a non-profit organization founded by cancer survivor and cycling champion Lance Armstrong.

Dear ____________________,

We currently have you scheduled for a LACP appointment in the Hematology & Oncology Clinic at ____am/pm on _______________, _________________ 2007.

☐ Other procedures scheduled on the same day or on __________________are:

CT of____________ at ____________ EKG/ECHO at ____________________
MRI of____________ at ____________ Bone Density at___________________
Neuropsychological Testing on ___________________________________
Other ____

If you need to reschedule this appointment, please contact my office at (682) 885-6451.

Thank you,

Laurie Bailey
Life After Cancer Program

APPOINTMENT REMINDER LETTER (ENGLISH & SPANISH)

Cook Children's Hospital
Fort Worth, TX

CookChildren's
Hematology & Oncology Center
901 Seventh Avenue, Suite 220
Fort Worth, Texas 76104-2724
(682) 885-4007
www.cookchildrens.org

Life After Cancer Program
Jeffrey C. Murray, M.D.
Medical Director
Lisa Bashore, M.S., R.N., C.P.N.P.
Program Coordinator

The Life After Cancer Program is a project of Cook Children's and the Lance Armstrong Foundation, a non-profit organization founded by cancer survivor and cycling champion Lance Armstrong.

Dear ____________________,

We just wanted to remind you of your appointment in the Hematology & Oncology Clinic at ______am/pm on ______________, _________________ 2006.

Other procedures scheduled on the same day or on _____________________are:

CT of ____________ at ____________ EKG/ECHO at _______________________
MRI of ___________ at ____________ Bone Density at _____________________
Neuropsychological Testing on ____
Other ____

A nurse from that office should call you if any preparations are necessary. Other special instructions: ____

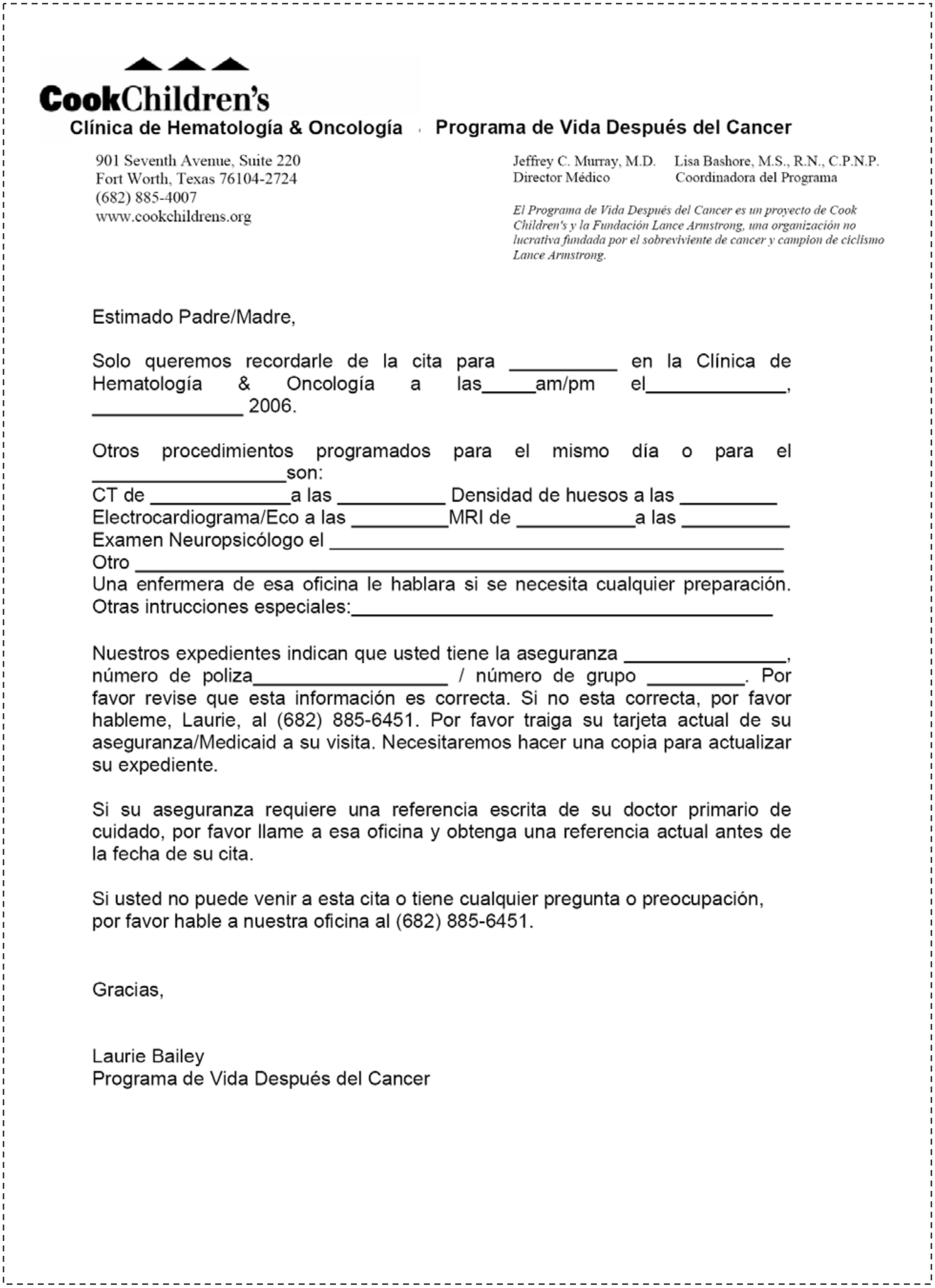
Our records indicate you have ______________________________ insurance, policy number ___________________ / group number __________. Please verify that this information is correct. If it is incorrect, please contact me, Laurie, at (682) 885-6451. Please bring your current insurance/Medicaid card to your visit. We will need to make a copy to update the chart.

If your insurance requires a written referral from your primary care physician, please call that office and obtain a current referral before your scheduled appointment date.

If you are unable to make this appointment or you have any questions or concerns, please contact our office at (682) 885-6451.

Thank you,

Laurie Bailey
Life After Cancer Program



CookChildren's
Clínica de Hematología & Oncología · Programa de Vida Después del Cancer

901 Seventh Avenue, Suite 220
Fort Worth, Texas 76104-2724
(682) 885-4007
www.cookchildrens.org

Jeffrey C. Murray, M.D.
Director Médico

Lisa Bashore, M.S., R.N., C.P.N.P.
Coordinadora del Programa

El Programa de Vida Después del Cancer es un proyecto de Cook Children's y la Fundación Lance Armstrong, una organización no lucrativa fundada por el sobreviviente de cancer y campion de ciclismo Lance Armstrong.

Estimado Padre/Madre,

Solo queremos recordarle de la cita para ___________ en la Clínica de Hematología & Oncología a las_____am/pm el______________, _______________ 2006.

Otros procedimientos programados para el mismo día o para el ___________________son:
CT de ______________a las ___________ Densidad de huesos a las _________
Electrocardiograma/Eco a las _________MRI de ____________a las ___________
Examen Neuropsicólogo el ____
Otro ____
Una enfermera de esa oficina le hablara si se necesita cualquier preparación.
Otras intrucciones especiales:____

Nuestros expedientes indican que usted tiene la aseguranza ________________, número de poliza___________________ / número de grupo _________. Por favor revise que esta información es correcta. Si no esta correcta, por favor hableme, Laurie, al (682) 885-6451. Por favor traiga su tarjeta actual de su aseguranza/Medicaid a su visita. Necesitaremos hacer una copia para actualizar su expediente.

Si su aseguranza requiere una referencia escrita de su doctor primario de cuidado, por favor llame a esa oficina y obtenga una referencia actual antes de la fecha de su cita.

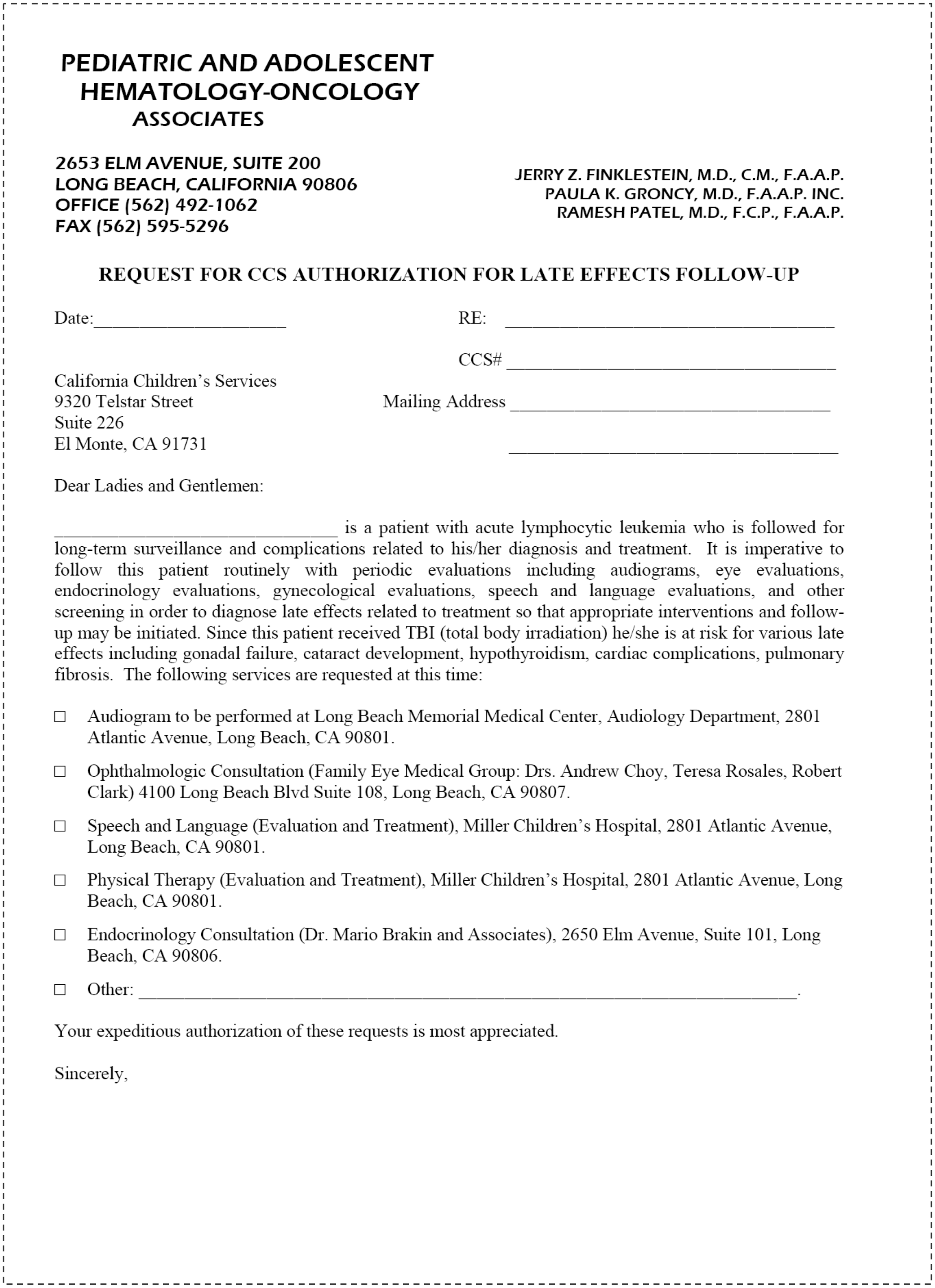
Si usted no puede venir a esta cita o tiene cualquier pregunta o preocupación, por favor hable a nuestra oficina al (682) 885-6451.

Gracias,

Laurie Bailey
Programa de Vida Después del Cancer

AUTHORIZATION LETTERS (STATE FUNDED PROGRAM)

Pediatric and Adolescent Hematology-Oncology Associates/Miller Children's Hospital
Long Beach, CA



PEDIATRIC AND ADOLESCENT
HEMATOLOGY-ONCOLOGY
ASSOCIATES

2653 ELM AVENUE, SUITE 200
LONG BEACH, CALIFORNIA 90806
OFFICE (562) 492-1062
FAX (562) 595-5296

JERRY Z. FINKLESTEIN, M.D., C.M., F.A.A.P.
PAULA K. GRONCY, M.D., F.A.A.P. INC.
RAMESH PATEL, M.D., F.C.P., F.A.A.P.

REQUEST FOR CCS AUTHORIZATION FOR LATE EFFECTS FOLLOW-UP

Date:______________________

RE: ______________________________________

CCS# ______________________________________

California Children's Services
9320 Telstar Street
Suite 226
El Monte, CA 91731

Mailing Address ______________________________________
____

Dear Ladies and Gentlemen:

________________________________ is a patient with acute lymphocytic leukemia who is followed for long-term surveillance and complications related to his/her diagnosis and treatment. It is imperative to follow this patient routinely with periodic evaluations including audiograms, eye evaluations, endocrinology evaluations, gynecological evaluations, speech and language evaluations, and other screening in order to diagnose late effects related to treatment so that appropriate interventions and follow-up may be initiated. Since this patient received TBI (total body irradiation) he/she is at risk for various late effects including gonadal failure, cataract development, hypothyroidism, cardiac complications, pulmonary fibrosis. The following services are requested at this time:

☐ Audiogram to be performed at Long Beach Memorial Medical Center, Audiology Department, 2801 Atlantic Avenue, Long Beach, CA 90801.

☐ Ophthalmologic Consultation (Family Eye Medical Group: Drs. Andrew Choy, Teresa Rosales, Robert Clark) 4100 Long Beach Blvd Suite 108, Long Beach, CA 90807.

☐ Speech and Language (Evaluation and Treatment), Miller Children's Hospital, 2801 Atlantic Avenue, Long Beach, CA 90801.

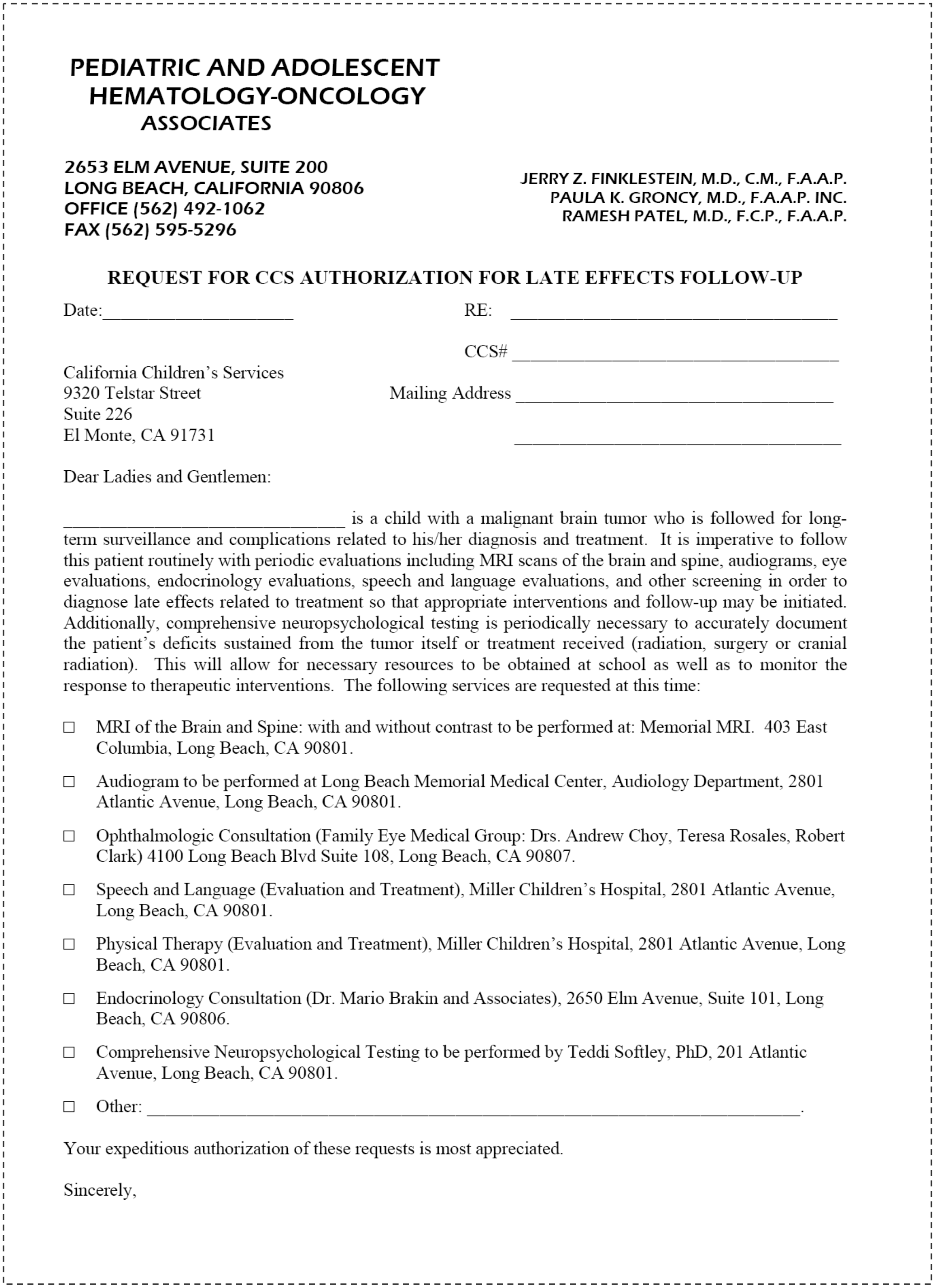
☐ Physical Therapy (Evaluation and Treatment), Miller Children's Hospital, 2801 Atlantic Avenue, Long Beach, CA 90801.

☐ Endocrinology Consultation (Dr. Mario Brakin and Associates), 2650 Elm Avenue, Suite 101, Long Beach, CA 90806.

☐ Other: ____.

Your expeditious authorization of these requests is most appreciated.

Sincerely,



**PEDIATRIC AND ADOLESCENT
HEMATOLOGY-ONCOLOGY
ASSOCIATES**

**2653 ELM AVENUE, SUITE 200
LONG BEACH, CALIFORNIA 90806
OFFICE (562) 492-1062
FAX (562) 595-5296**

**JERRY Z. FINKLESTEIN, M.D., C.M., F.A.A.P.
PAULA K. GRONCY, M.D., F.A.A.P. INC.
RAMESH PATEL, M.D., F.C.P., F.A.A.P.**

REQUEST FOR CCS AUTHORIZATION FOR LATE EFFECTS FOLLOW-UP

Date:_____________________

RE: ___________________________________

CCS# ___________________________________

Mailing Address ___________________________________

____

California Children's Services
9320 Telstar Street
Suite 226
El Monte, CA 91731

Dear Ladies and Gentlemen:

______________________________ is a child with a malignant brain tumor who is followed for long-term surveillance and complications related to his/her diagnosis and treatment. It is imperative to follow this patient routinely with periodic evaluations including MRI scans of the brain and spine, audiograms, eye evaluations, endocrinology evaluations, speech and language evaluations, and other screening in order to diagnose late effects related to treatment so that appropriate interventions and follow-up may be initiated. Additionally, comprehensive neuropsychological testing is periodically necessary to accurately document the patient's deficits sustained from the tumor itself or treatment received (radiation, surgery or cranial radiation). This will allow for necessary resources to be obtained at school as well as to monitor the response to therapeutic interventions. The following services are requested at this time:

☐ MRI of the Brain and Spine: with and without contrast to be performed at: Memorial MRI. 403 East Columbia, Long Beach, CA 90801.

☐ Audiogram to be performed at Long Beach Memorial Medical Center, Audiology Department, 2801 Atlantic Avenue, Long Beach, CA 90801.

☐ Ophthalmologic Consultation (Family Eye Medical Group: Drs. Andrew Choy, Teresa Rosales, Robert Clark) 4100 Long Beach Blvd Suite 108, Long Beach, CA 90807.

☐ Speech and Language (Evaluation and Treatment), Miller Children's Hospital, 2801 Atlantic Avenue, Long Beach, CA 90801.

☐ Physical Therapy (Evaluation and Treatment), Miller Children's Hospital, 2801 Atlantic Avenue, Long Beach, CA 90801.

☐ Endocrinology Consultation (Dr. Mario Brakin and Associates), 2650 Elm Avenue, Suite 101, Long Beach, CA 90806.

☐ Comprehensive Neuropsychological Testing to be performed by Teddi Softley, PhD, 201 Atlantic Avenue, Long Beach, CA 90801.

☐ Other: ____.

Your expeditious authorization of these requests is most appreciated.

Sincerely,

POST-CLINIC LETTER TO PATIENT

Carolinas Medical Center
Charlotte, NC

POST CLINIC LETTER TO PATIENT

Date

Dear *(patient)*

It was a pleasure seeing you in the *Children's Specialty Center* for our Long-term Follow-up clinic. We hope you found this visit useful and had the opportunity to ask questions related to your disease and treatment.

Your lab work showed ___________
Your echocardiogram showed_________
(*List all other pertinent tests results)*

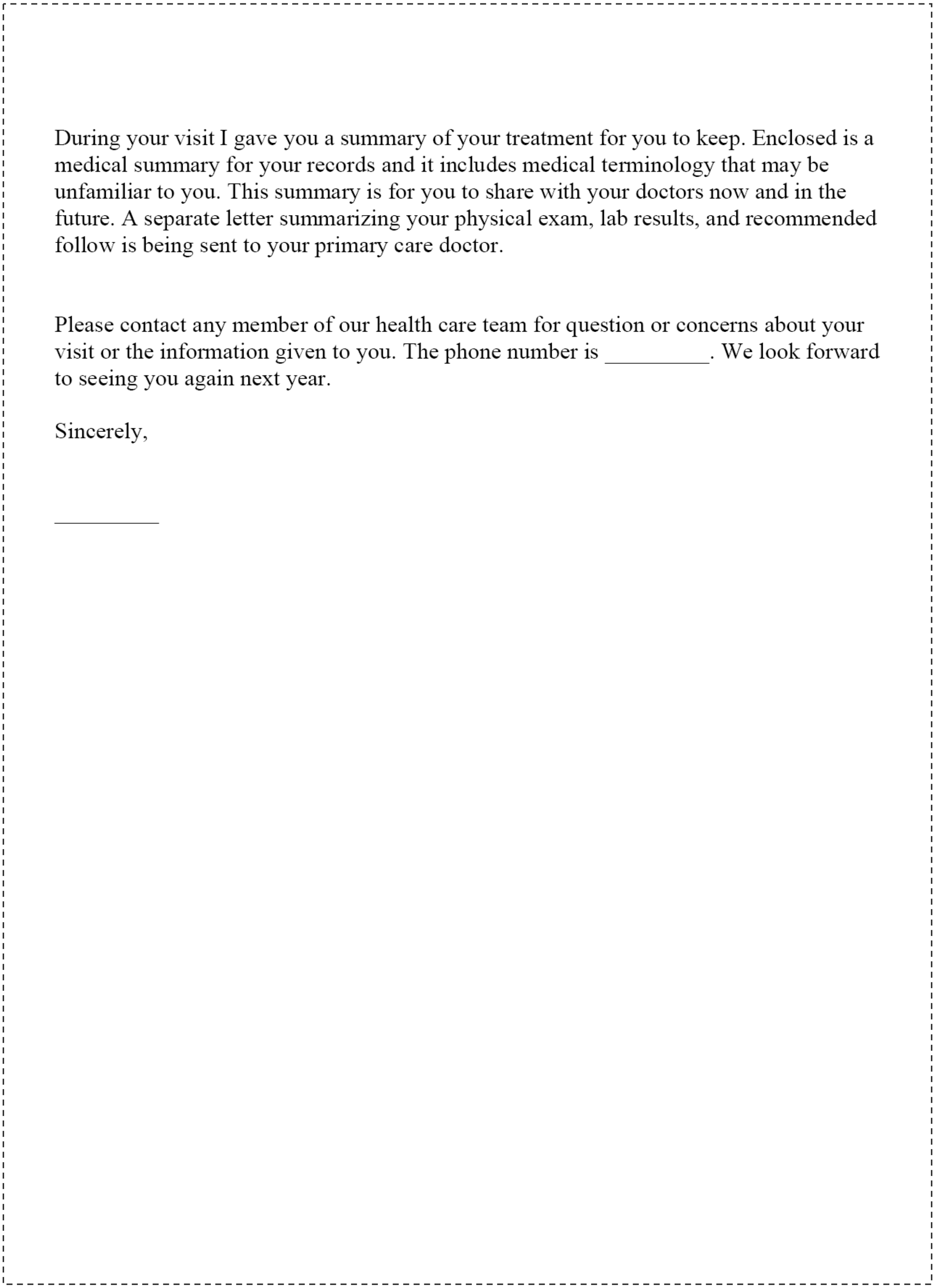
The healthcare providers who met with you have discussed your case and have made suggestions concerning your healthcare. These are as follows:

We get this info, from own knowledge, experience, standards, and the COG guidelines for late effects . The following example is for a patient seen with Hodgkin's Disease

- Report to us any chest pain, shortness of breath, swelling of feet and ankles, increasing fatigue. We recommend an EKG/Echocardiogram every 2 years or sooner if symptoms indicate.
- Report frequent coughing or wheezing, frequent lung infections such as bronchitis or pneumonia, or if you become easily fatigued or short of breath during mild exercise.
- **Notify your doctor of Bleomycin therapy prior to any general anesthesia**
- If you have any concerns about complications after cancer treatment that may be causing feelings of anxiety or depression, please share these concerns with us or your primary care physician.
- Continue Synthroid at 125 mcg. Notify us for symptoms of low thyroid (see handout given to you on day of visit)

Frequency of echos, PFT, etc
List name and contact of any community referrals

Your continued health is important to us! Therefore, in an effort to minimize the potential complications of your disease and treatment, we recommend a return visit to *(name of our clinic)* on *(date of return visit)*.



During your visit I gave you a summary of your treatment for you to keep. Enclosed is a medical summary for your records and it includes medical terminology that may be unfamiliar to you. This summary is for you to share with your doctors now and in the future. A separate letter summarizing your physical exam, lab results, and recommended follow is being sent to your primary care doctor.

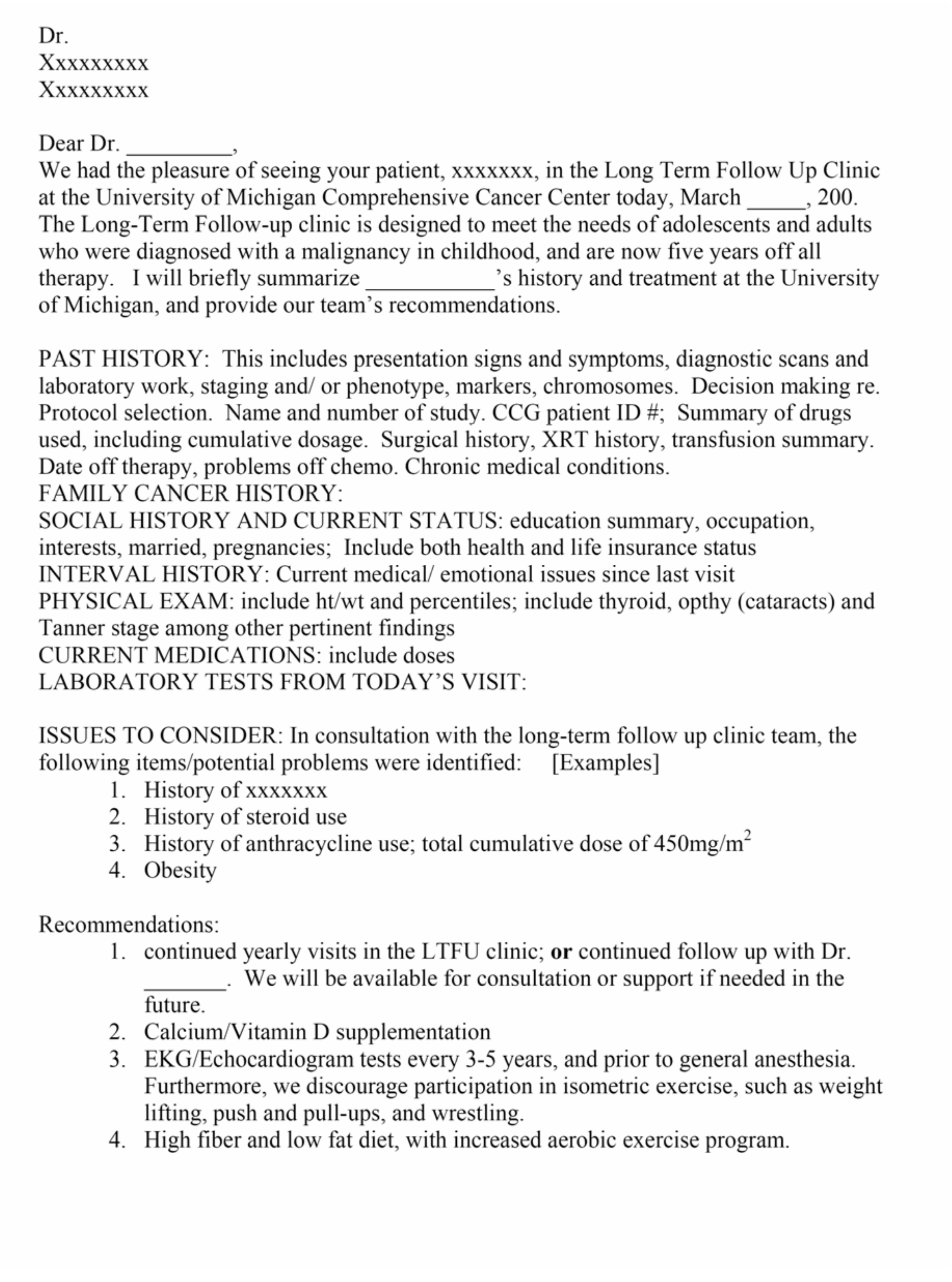
Please contact any member of our health care team for question or concerns about your visit or the information given to you. The phone number is __________. We look forward to seeing you again next year.

Sincerely,

____

POST-CLINIC LETTER TO PHYSICIAN

University of Michigan
Ann Arbor, MI



Dr.
Xxxxxxxxx
Xxxxxxxxx

Dear Dr. _________,
We had the pleasure of seeing your patient, xxxxxxx, in the Long Term Follow Up Clinic at the University of Michigan Comprehensive Cancer Center today, March _____, 200. The Long-Term Follow-up clinic is designed to meet the needs of adolescents and adults who were diagnosed with a malignancy in childhood, and are now five years off all therapy. I will briefly summarize ___________'s history and treatment at the University of Michigan, and provide our team's recommendations.

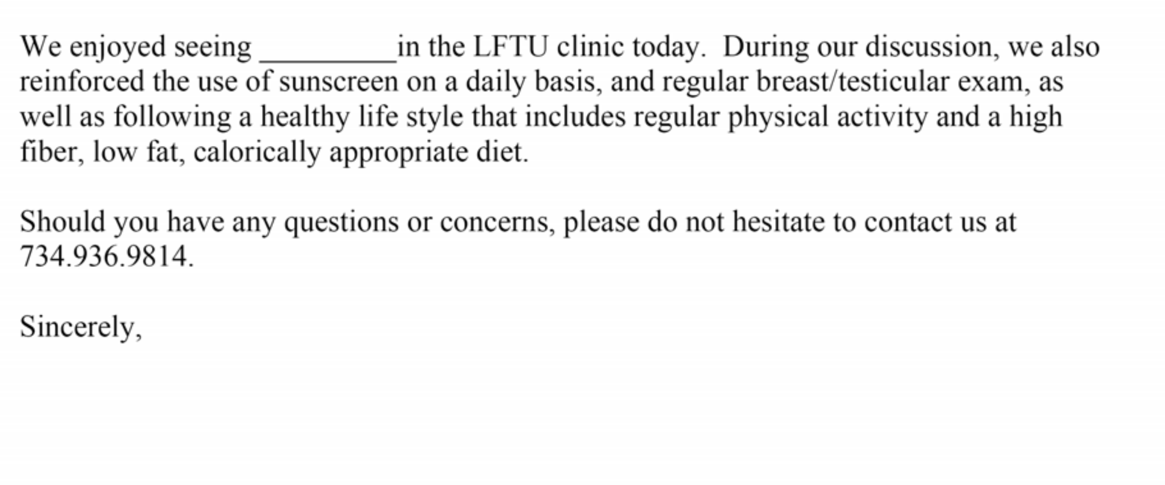
PAST HISTORY: This includes presentation signs and symptoms, diagnostic scans and laboratory work, staging and/ or phenotype, markers, chromosomes. Decision making re. Protocol selection. Name and number of study. CCG patient ID #; Summary of drugs used, including cumulative dosage. Surgical history, XRT history, transfusion summary. Date off therapy, problems off chemo. Chronic medical conditions.
FAMILY CANCER HISTORY:
SOCIAL HISTORY AND CURRENT STATUS: education summary, occupation, interests, married, pregnancies; Include both health and life insurance status
INTERVAL HISTORY: Current medical/ emotional issues since last visit
PHYSICAL EXAM: include ht/wt and percentiles; include thyroid, opthy (cataracts) and Tanner stage among other pertinent findings
CURRENT MEDICATIONS: include doses
LABORATORY TESTS FROM TODAY'S VISIT:

ISSUES TO CONSIDER: In consultation with the long-term follow up clinic team, the following items/potential problems were identified: [Examples]

1. History of xxxxxxx
2. History of steroid use
3. History of anthracycline use; total cumulative dose of 450mg/m^2
4. Obesity

Recommendations:

1. continued yearly visits in the LTFU clinic; **or** continued follow up with Dr. _______. We will be available for consultation or support if needed in the future.
2. Calcium/Vitamin D supplementation
3. EKG/Echocardiogram tests every 3-5 years, and prior to general anesthesia. Furthermore, we discourage participation in isometric exercise, such as weight lifting, push and pull-ups, and wrestling.
4. High fiber and low fat diet, with increased aerobic exercise program.



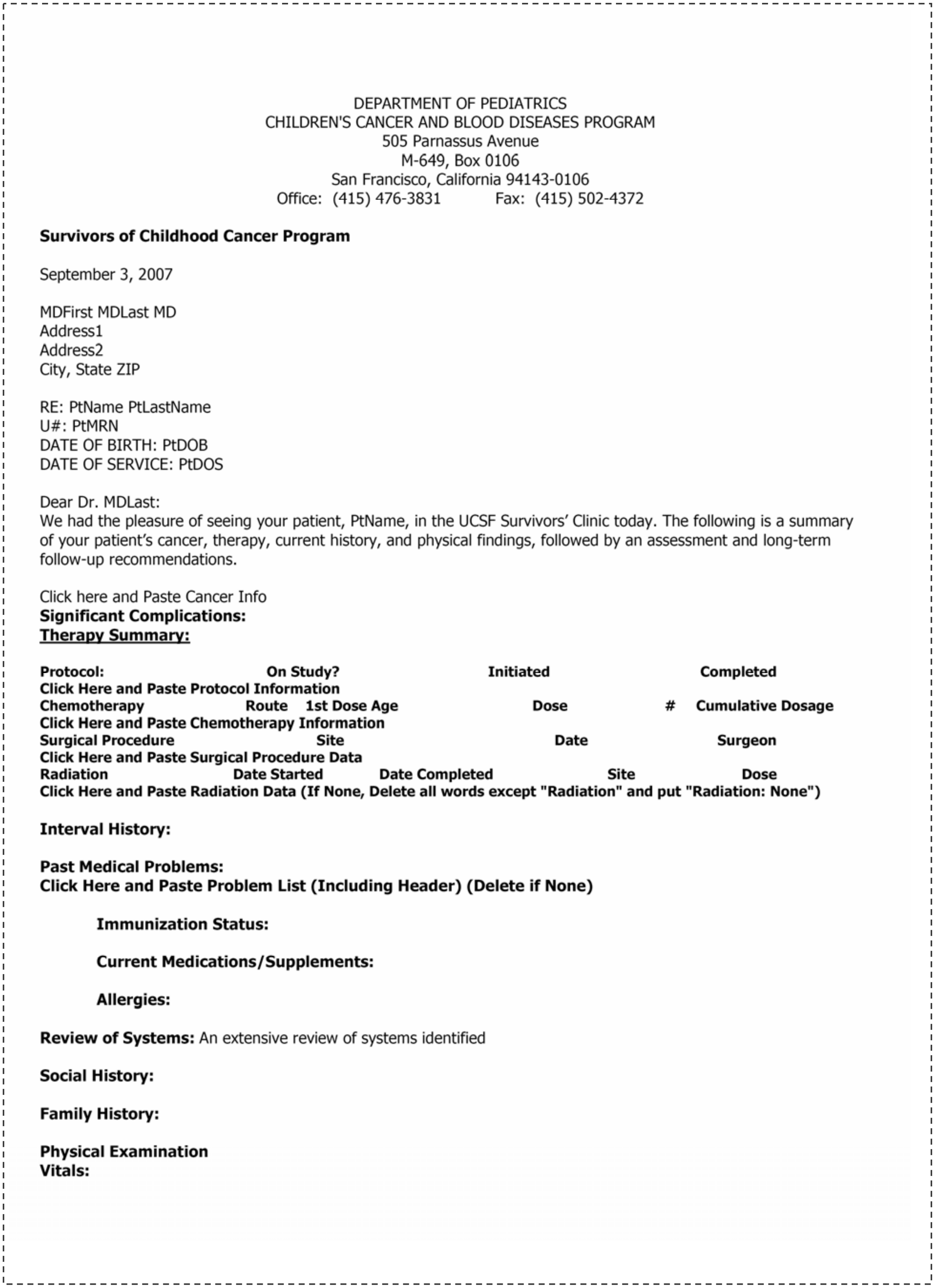
We enjoyed seeing _________in the LFTU clinic today. During our discussion, we also reinforced the use of sunscreen on a daily basis, and regular breast/testicular exam, as well as following a healthy life style that includes regular physical activity and a high fiber, low fat, calorically appropriate diet.

Should you have any questions or concerns, please do not hesitate to contact us at 734.936.9814.

Sincerely,

POST-CLINIC LETTER TO PHYSICIAN

UCSF
San Francisco, CA



DEPARTMENT OF PEDIATRICS
CHILDREN'S CANCER AND BLOOD DISEASES PROGRAM
505 Parnassus Avenue
M-649, Box 0106
San Francisco, California 94143-0106
Office: (415) 476-3831 Fax: (415) 502-4372

Survivors of Childhood Cancer Program

September 3, 2007

MDFirst MDLast MD
Address1
Address2
City, State ZIP

RE: PtName PtLastName
U#: PtMRN
DATE OF BIRTH: PtDOB
DATE OF SERVICE: PtDOS

Dear Dr. MDLast:
We had the pleasure of seeing your patient, PtName, in the UCSF Survivors' Clinic today. The following is a summary of your patient's cancer, therapy, current history, and physical findings, followed by an assessment and long-term follow-up recommendations.

Click here and Paste Cancer Info
Significant Complications:
<u>Therapy Summary:</u>

Protocol: On Study? Initiated Completed
Click Here and Paste Protocol Information
Chemotherapy Route 1st Dose Age Dose # Cumulative Dosage
Click Here and Paste Chemotherapy Information
Surgical Procedure Site Date Surgeon
Click Here and Paste Surgical Procedure Data
Radiation Date Started Date Completed Site Dose
Click Here and Paste Radiation Data (If None, Delete all words except "Radiation" and put "Radiation: None")

Interval History:

Past Medical Problems:
Click Here and Paste Problem List (Including Header) (Delete if None)

Immunization Status:

Current Medications/Supplements:

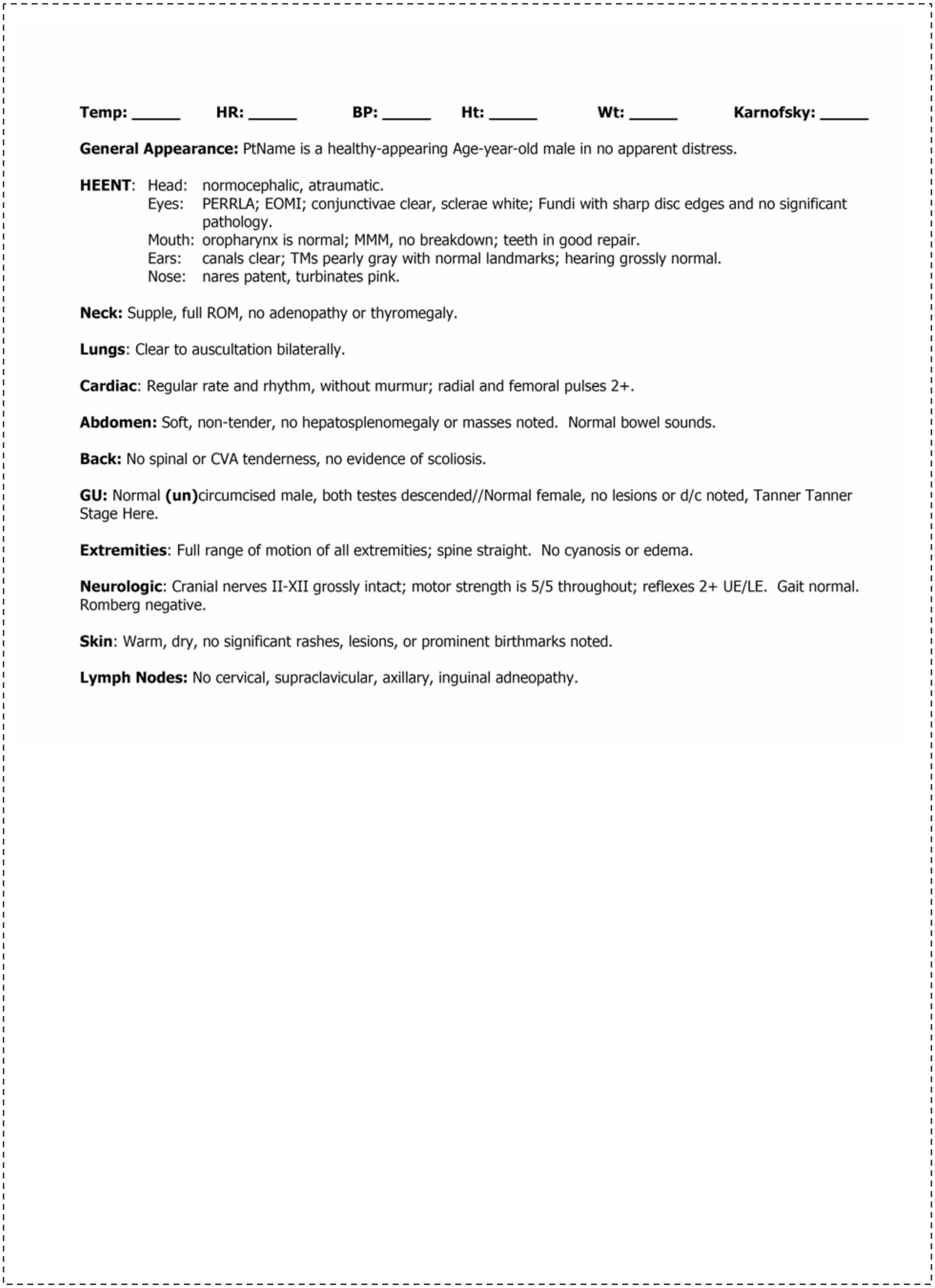
Allergies:

Review of Systems: An extensive review of systems identified

Social History:

Family History:

Physical Examination
Vitals:



Temp: ______ **HR:** ______ **BP:** ______ **Ht:** ______ **Wt:** ______ **Karnofsky:** ______

General Appearance: PtName is a healthy-appearing Age-year-old male in no apparent distress.

HEENT: Head: normocephalic, atraumatic.
Eyes: PERRLA; EOMI; conjunctivae clear, sclerae white; Fundi with sharp disc edges and no significant pathology.
Mouth: oropharynx is normal; MMM, no breakdown; teeth in good repair.
Ears: canals clear; TMs pearly gray with normal landmarks; hearing grossly normal.
Nose: nares patent, turbinates pink.

Neck: Supple, full ROM, no adenopathy or thyromegaly.

Lungs: Clear to auscultation bilaterally.

Cardiac: Regular rate and rhythm, without murmur; radial and femoral pulses 2+.

Abdomen: Soft, non-tender, no hepatosplenomegaly or masses noted. Normal bowel sounds.

Back: No spinal or CVA tenderness, no evidence of scoliosis.

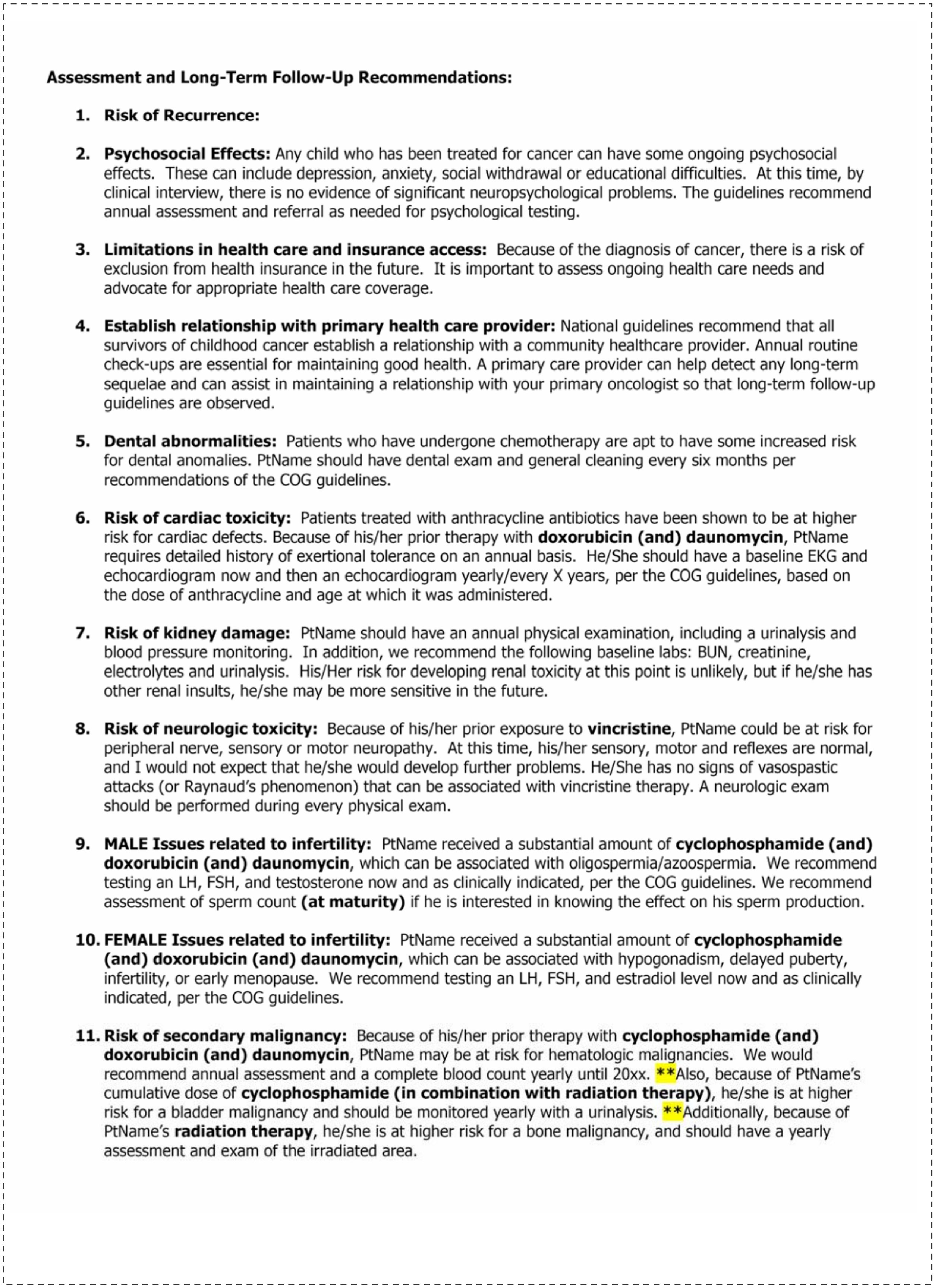
GU: Normal **(un)**circumcised male, both testes descended//Normal female, no lesions or d/c noted, Tanner Tanner Stage Here.

Extremities: Full range of motion of all extremities; spine straight. No cyanosis or edema.

Neurologic: Cranial nerves II-XII grossly intact; motor strength is 5/5 throughout; reflexes 2+ UE/LE. Gait normal. Romberg negative.

Skin: Warm, dry, no significant rashes, lesions, or prominent birthmarks noted.

Lymph Nodes: No cervical, supraclavicular, axillary, inguinal adneopathy.



Assessment and Long-Term Follow-Up Recommendations:

1. **Risk of Recurrence:**

2. **Psychosocial Effects:** Any child who has been treated for cancer can have some ongoing psychosocial effects. These can include depression, anxiety, social withdrawal or educational difficulties. At this time, by clinical interview, there is no evidence of significant neuropsychological problems. The guidelines recommend annual assessment and referral as needed for psychological testing.

3. **Limitations in health care and insurance access:** Because of the diagnosis of cancer, there is a risk of exclusion from health insurance in the future. It is important to assess ongoing health care needs and advocate for appropriate health care coverage.

4. **Establish relationship with primary health care provider:** National guidelines recommend that all survivors of childhood cancer establish a relationship with a community healthcare provider. Annual routine check-ups are essential for maintaining good health. A primary care provider can help detect any long-term sequelae and can assist in maintaining a relationship with your primary oncologist so that long-term follow-up guidelines are observed.

5. **Dental abnormalities:** Patients who have undergone chemotherapy are apt to have some increased risk for dental anomalies. PtName should have dental exam and general cleaning every six months per recommendations of the COG guidelines.

6. **Risk of cardiac toxicity:** Patients treated with anthracycline antibiotics have been shown to be at higher risk for cardiac defects. Because of his/her prior therapy with **doxorubicin (and) daunomycin**, PtName requires detailed history of exertional tolerance on an annual basis. He/She should have a baseline EKG and echocardiogram now and then an echocardiogram yearly/every X years, per the COG guidelines, based on the dose of anthracycline and age at which it was administered.

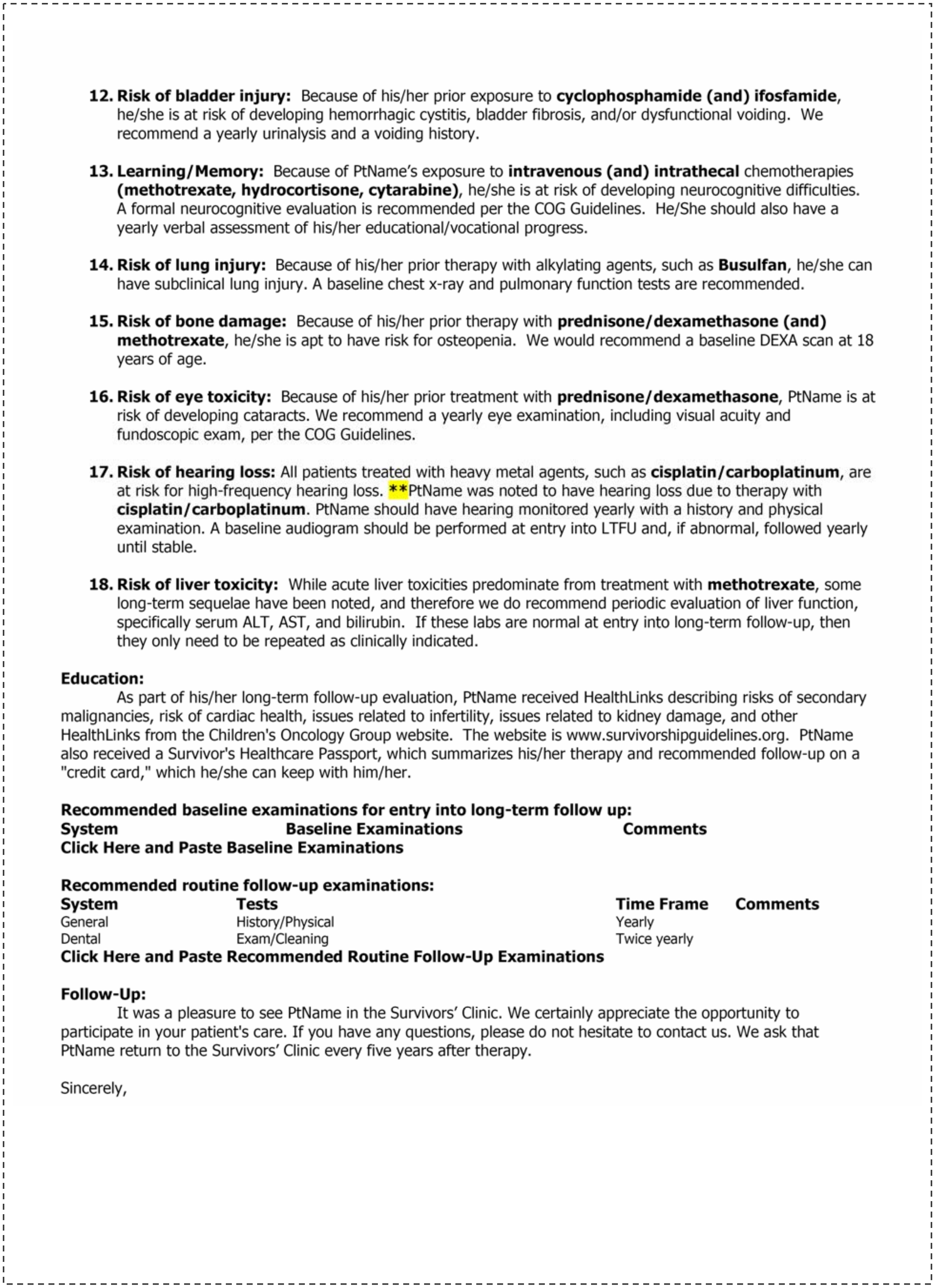
7. **Risk of kidney damage:** PtName should have an annual physical examination, including a urinalysis and blood pressure monitoring. In addition, we recommend the following baseline labs: BUN, creatinine, electrolytes and urinalysis. His/Her risk for developing renal toxicity at this point is unlikely, but if he/she has other renal insults, he/she may be more sensitive in the future.

8. **Risk of neurologic toxicity:** Because of his/her prior exposure to **vincristine**, PtName could be at risk for peripheral nerve, sensory or motor neuropathy. At this time, his/her sensory, motor and reflexes are normal, and I would not expect that he/she would develop further problems. He/She has no signs of vasospastic attacks (or Raynaud’s phenomenon) that can be associated with vincristine therapy. A neurologic exam should be performed during every physical exam.

9. **MALE Issues related to infertility:** PtName received a substantial amount of **cyclophosphamide (and) doxorubicin (and) daunomycin**, which can be associated with oligospermia/azoospermia. We recommend testing an LH, FSH, and testosterone now and as clinically indicated, per the COG guidelines. We recommend assessment of sperm count **(at maturity)** if he is interested in knowing the effect on his sperm production.

10. **FEMALE Issues related to infertility:** PtName received a substantial amount of **cyclophosphamide (and) doxorubicin (and) daunomycin**, which can be associated with hypogonadism, delayed puberty, infertility, or early menopause. We recommend testing an LH, FSH, and estradiol level now and as clinically indicated, per the COG guidelines.

11. **Risk of secondary malignancy:** Because of his/her prior therapy with **cyclophosphamide (and) doxorubicin (and) daunomycin**, PtName may be at risk for hematologic malignancies. We would recommend annual assessment and a complete blood count yearly until 20xx. ******Also, because of PtName’s cumulative dose of **cyclophosphamide (in combination with radiation therapy)**, he/she is at higher risk for a bladder malignancy and should be monitored yearly with a urinalysis. ******Additionally, because of PtName’s **radiation therapy**, he/she is at higher risk for a bone malignancy, and should have a yearly assessment and exam of the irradiated area.



12. **Risk of bladder injury:** Because of his/her prior exposure to **cyclophosphamide (and) ifosfamide**, he/she is at risk of developing hemorrhagic cystitis, bladder fibrosis, and/or dysfunctional voiding. We recommend a yearly urinalysis and a voiding history.

13. **Learning/Memory:** Because of PtName's exposure to **intravenous (and) intrathecal** chemotherapies **(methotrexate, hydrocortisone, cytarabine)**, he/she is at risk of developing neurocognitive difficulties. A formal neurocognitive evaluation is recommended per the COG Guidelines. He/She should also have a yearly verbal assessment of his/her educational/vocational progress.

14. **Risk of lung injury:** Because of his/her prior therapy with alkylating agents, such as **Busulfan**, he/she can have subclinical lung injury. A baseline chest x-ray and pulmonary function tests are recommended.

15. **Risk of bone damage:** Because of his/her prior therapy with **prednisone/dexamethasone (and) methotrexate**, he/she is apt to have risk for osteopenia. We would recommend a baseline DEXA scan at 18 years of age.

16. **Risk of eye toxicity:** Because of his/her prior treatment with **prednisone/dexamethasone**, PtName is at risk of developing cataracts. We recommend a yearly eye examination, including visual acuity and fundoscopic exam, per the COG Guidelines.

17. **Risk of hearing loss:** All patients treated with heavy metal agents, such as **cisplatin/carboplatinum**, are at risk for high-frequency hearing loss. ******PtName was noted to have hearing loss due to therapy with **cisplatin/carboplatinum**. PtName should have hearing monitored yearly with a history and physical examination. A baseline audiogram should be performed at entry into LTFU and, if abnormal, followed yearly until stable.

18. **Risk of liver toxicity:** While acute liver toxicities predominate from treatment with **methotrexate**, some long-term sequelae have been noted, and therefore we do recommend periodic evaluation of liver function, specifically serum ALT, AST, and bilirubin. If these labs are normal at entry into long-term follow-up, then they only need to be repeated as clinically indicated.

Education:

As part of his/her long-term follow-up evaluation, PtName received HealthLinks describing risks of secondary malignancies, risk of cardiac health, issues related to infertility, issues related to kidney damage, and other HealthLinks from the Children's Oncology Group website. The website is www.survivorshipguidelines.org. PtName also received a Survivor's Healthcare Passport, which summarizes his/her therapy and recommended follow-up on a "credit card," which he/she can keep with him/her.

Recommended baseline examinations for entry into long-term follow up:

System	**Baseline Examinations**	**Comments**

Click Here and Paste Baseline Examinations

Recommended routine follow-up examinations:

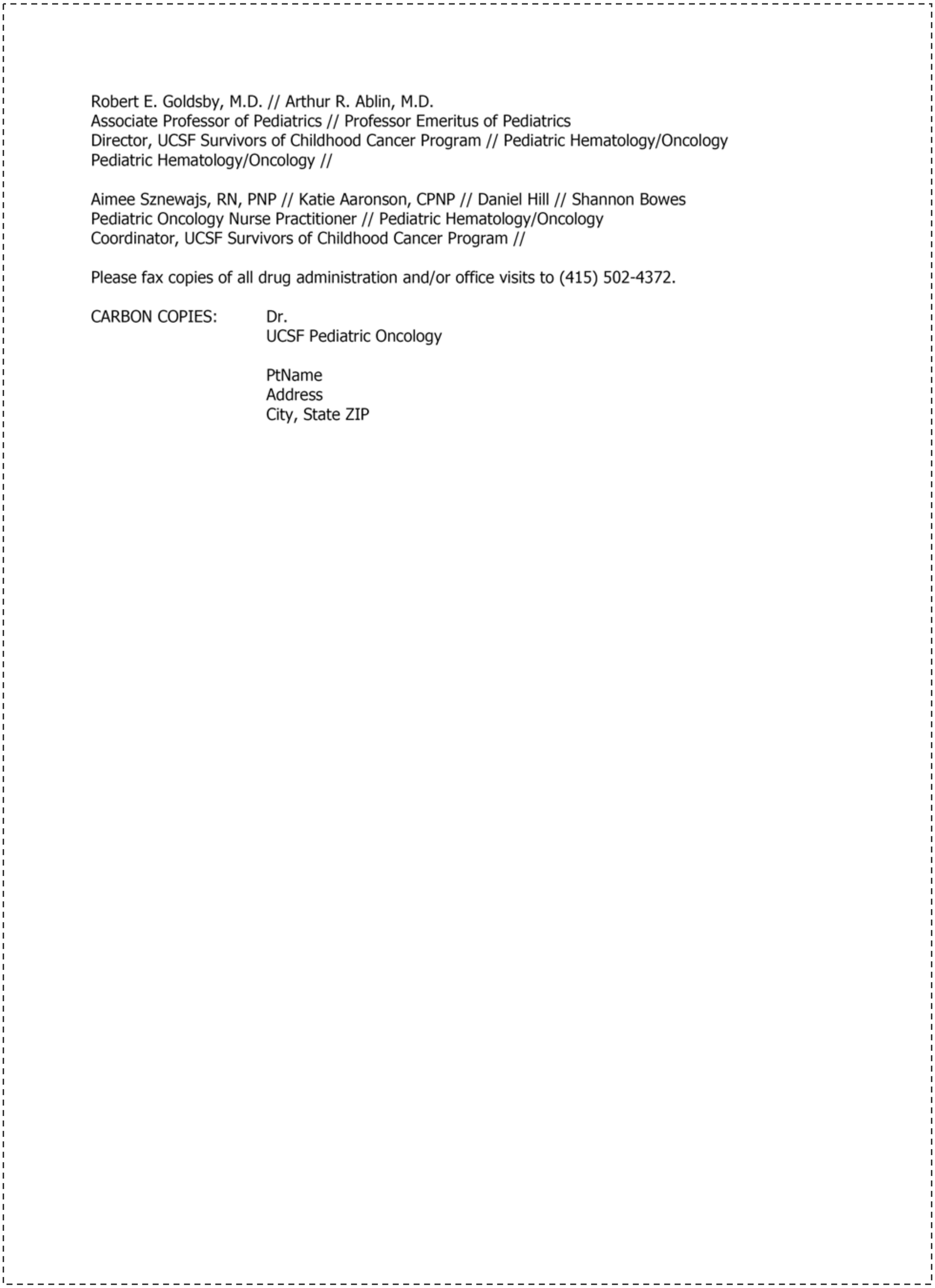
System	**Tests**	**Time Frame**	**Comments**
General	History/Physical	Yearly	
Dental	Exam/Cleaning	Twice yearly	

Click Here and Paste Recommended Routine Follow-Up Examinations

Follow-Up:

It was a pleasure to see PtName in the Survivors' Clinic. We certainly appreciate the opportunity to participate in your patient's care. If you have any questions, please do not hesitate to contact us. We ask that PtName return to the Survivors' Clinic every five years after therapy.

Sincerely,



Robert E. Goldsby, M.D. // Arthur R. Ablin, M.D.
Associate Professor of Pediatrics // Professor Emeritus of Pediatrics
Director, UCSF Survivors of Childhood Cancer Program // Pediatric Hematology/Oncology
Pediatric Hematology/Oncology //

Aimee Sznewajs, RN, PNP // Katie Aaronson, CPNP // Daniel Hill // Shannon Bowes
Pediatric Oncology Nurse Practitioner // Pediatric Hematology/Oncology
Coordinator, UCSF Survivors of Childhood Cancer Program //

Please fax copies of all drug administration and/or office visits to (415) 502-4372.

CARBON COPIES: Dr.
UCSF Pediatric Oncology

PtName
Address
City, State ZIP

LONG-TERM FOLLOW-UP PROGRAM

RESOURCE GUIDE

CureSearch

Children's Oncology Group