



Advocate Children's Hospital-(Park Ridge Campus)

Pediatric Oncology Long-Term Survivorship Program

Each year, over 12,000 American children are diagnosed with cancer. Remarkably, recent progress with pediatric cancer treatment and supportive care means that nearly 80% of these children will go on to become adult survivors. Today there are more than 300,000 survivors in the U.S. and that number is expected to keep rising. Survivors of childhood cancers can go on to live full and productive lives, but sometimes the mixture of treatments they've received and the cancer disease itself may put them at risk for medical problems down the road. Due to the growing needs of this unique population, Advocate Children's Hospital-Park Ridge Campus has invested in the future of our pediatric cancer patients to help them **"thrive after cancer."**

With funding from the Hyundai Hope on Wheels Program, we were able to begin the development of our Pediatric Oncology Long-Term Survivorship Program in late 2011. This funding allowed us to hire a Nurse Coordinator who, with support from the program's Medical Director, oversees the operations of the program. Funding from Hyundai Hope on Wheels will also support the time of a social worker as part of the program's multidisciplinary team over two years of the grant period. We are happy to report that our Pediatric Oncology Long-Term Survivorship Program is up and running as of September 2012, and has begun to see its first patients. However, there are additional program activities that we feel are essential to the program that are not supported by the Hyundai grant. We therefore plan to utilize funding from the Paul Seiwert Foundation to cover these additional expenses to ensure our staff is aware of cutting-edge research and best practices in the field, and that our patients and families are receiving the best care possible.

Our Mission/Vision

- Meet the complex needs of pediatric, adolescent and young adult survivors of childhood cancer
- Provide a comprehensive clinic where a patient/family's needs can be assessed and be addressed by a well-qualified multidisciplinary team
- Provide a complete cancer treatment summary or (survivorship care plan) to enable survivors and family members to play an active role in their health maintenance
- Through anticipatory guidance, advocacy and education help to improve the overall health and quality of life for survivors of childhood cancer
- Educate primary care physicians on late effects and how to most effectively, independently or co-manage these patients
- Develop collaborative research to improve outcomes/quality of life for survivors

Goals

- Establish of a multidisciplinary clinic where the needs of pediatric, adolescent and young adult survivors are addressed and interventions/plans to address those needs are

provided in a holistic manner

- Monitor for and provide early intervention for late effects
- Provide health education regarding diagnoses, past history, treatment effects, and risk factors utilizing the Children's Oncology Group (COG) Survivorship Guidelines
- Provide referrals to specialists and resources as needed
- Encourage healthy life style and wellness activities for survivors and their families
- Evaluate and provide intervention for the psychosocial needs of survivors and affected family members
- Help young adults survivors with ownership of their health by promoting self-care and help them navigate through the adult health-care system
- Ensure that patients and their families receive consistent communication in regards to their follow-up care and services needed.

Program Staffing

Dr. Goodell, the Medical Director of the survivorship clinic, has been a Hematology/Oncology physician within Advocate Health Care for over 20 years. He has seen the many twists and turns that cancer, treatments and late effects can cause on not only to a patient but to family members and siblings as well. He brings a wealth of knowledge and commitment to the long-term health of his patients to this new role in the Pediatric Oncology Long-Term Survivorship Program. The program's Nurse Coordinator brings 16 years experience as a pediatric oncology nurse, as well as her own personal experience as a cancer survivorship advocate and someone who has walked the cancer experience personally as a teenager and then again as a young adult. She knows how hard this experience was on her personally, but also on how difficult it was on her siblings and parents, as well as the anxiety, stress, fear and financial strain that a diagnosis of cancer brings. Having navigated this experience for over 20 years, the Nurse Coordinator can help guide the medical staff, along with the patients and families. As our clinic has recently started, we are in the building phase of our program, but we already have several plans for expansion and development in the coming year.

Over the next year our plan is to grow the program. We will do so by:

- Providing a means to find/track patients lost to follow up and bring them into the clinic
- Transitioning active patients once they meet survivorship criteria- 2 years off therapy and/or 5 years from diagnosis into the program
- Networking with referring pediatricians to inform them of our program and its purpose as well as educate and empower them to care for these patient in the community for routine pediatric/adolescent care needs
- Marketing materials to spread the word and purpose of the program within and outside Advocate Health Care

While the funding from Hyundai Hope on Wheels was the catalyst to create the Pediatric

Oncology Long-Term Survivorship Program, there are several elements of the program that require additional funding in the coming year. Specifically, we would like to utilize the generous gift of \$19,000 from the Paul Seiwert Foundation on the following program activities:

- **Conferences & Visits to Model Clinics:**

There are constant updates in the survivorship world-- new studies, results and findings, which direct the care of survivors of pediatric cancers, as these patients have very unique healthcare needs, and new discoveries are being made every day. Grant dollars will support the program's Medical Director and Nurse Coordinator's expenses to attend the **13th International Conference on the Long-term Complications of Treatment of Children and Adolescents will be held June 13-15, 2013** at the Peabody Hotel in Memphis, Tennessee. In addition to the research studies covered at this event, the networking, workshops, and learning opportunities this conference offers are invaluable. As we are in the building phase of our program, interacting with providers from other centers could help us lay a more solid platform and learn from other clinics' experiences. Please review last year's conference agenda, as an example of some of the content that will be shared.

Conference Fee-	2 attending	approx. \$450
Transportation/Flight-	2 attending	approx. \$300
Hotel-	2 attending	approx. \$200/night

In addition, we plan to make contacts with staff at other survivorship clinics around the country, so as to share best practices and learn from their experiences. Building upon this, we would like to visit one clinic in the coming year, and request funding to support these "field trips" Nurse Coordinator and Physician Director to travel and shadow clinics.

Transportation/Flight visit a year)	2 attending	\$200-\$300 (per visit x1
Hotel- visit a year)	2 attending	\$200/night (per visit x1

\$2,400 of the Paul Seiwert Foundation gift will cover conferences & visits to model clinics

- **Multidisciplinary Clinic Services:**

Survivorship care is so much more than just a physician and nurse. Some survivors may have unique needs based on their late effects requiring additional services. Some patients may need a nutritionist/dietician, physical therapist, therapist, social worker, child life specialist, neuropsychologist, endocrinologist, and/or cardiologist. Children that have received heavy steroids, antimetabolites and radiation therapy are at risk for bone loss, low vitamin d and calcium levels. Some patients may suffer from chronic high lipids/cholesterol, growth hormone deficiency to name a few. Some children treated with intrathecal chemotherapy, cranial radiation and/or

neuro surgery may have learning disabilities such as delayed processing, multi-tasking, math, reading and comprehension. These patients require additional services to aid in their survivorship care and help them succeed in life beyond cancer.

Specialists can provide screening, counseling and interventions to help these patient gain new normalcies after cancer. However, most of these services are an additional charge added to the routine follow up visit (often not covered by insurance) and can become a barrier to survivorship care.

Neuropsych Screening

Traditionally, neuropsych screening is done to assess the extent of skill impairment and to determine the area of the brain which may have been damaged following brain injury or neurological illness. Young children who received cranial radiation, high dose systemic MTX, and/or IT MTX can develop subtle learning disabilities; this is well documented in the scientific literature.

The most common problems are with handwriting, spelling, reading or reading comprehension, understanding math concepts, attention deficits, short term memory and information retrieval, planning and organizational skills, social maturity and social skills.

Some insurance will not cover screening or the interventions needed, however are extremely important to help these patients gain independence. The average cost for a neuropsych screening is \$2,800-3,500 for a child with no insurance, and we estimate that 8-10 patients would need these services in the coming year.

\$12,000 of the Paul Seiwert Foundation gift will cover approx. four neuropsych screenings for pediatric cancer survivors in the coming year.

Nutritional Assessments

Nutritional assessments can promote long-term survivorship by reducing the chance of recurrent disease, secondary prevention of cancer, and reducing the frequency and severity of late-complications of therapy and enhancing overall health and longevity. Pediatric oncology staff must continue to monitor survivors over longer periods of time, as long-term complications of treatments that are potential targets of dietary interventions are becoming clearer. For example, premature menopause may occur in some of our pediatric patients related to the high dose chemotherapy and radiation they were treated with, and this may contribute to accelerated osteoporosis—requiring alterations in dietary calcium and physical activity.

Survivorship caregivers should emphasize early interventions with dietary and exercise patterns that will maintain healthy blood cholesterol and triglyceride profiles. Incorporation of a dietitian's recommendations may aid in the care of survivors in our clinic. The average Cost for a nutritional screening is \$100-200, and we project 10-15 patients would benefit from these services in the coming year.

\$400 of the Paul Seiwert Foundation gift will cover 3-4 nutritional assessments for pediatric cancer survivors in the coming year.

- **Educational/Marketing Materials**

The Pediatric Oncology Long-Term Survivorship Program team has chosen a book to give to families with a child entering the clinic. The book, entitled, *Childhood Cancer Survivors: A Practical Guide to Your Future*, 3rd ed. by Nancy Keene, Wendy Hobbie, Kathy Ruccione, covers the issues of long-term survivorship, including medical late effects, relationships, overcoming employment or insurance discrimination, maximizing health, follow-up schedules. This book was written by a childhood cancer survivor's parent along with leading nursing experts in the field of survivorship. It is a valuable tool to connect parents and patients with accurate and up to date information and resources. The book costs about \$20 per book and we are targeting about 90 patients in the first 18 months. In addition, we would like to keep 10 copies on hand, so we would like to purchase 100 copies of the book, at a total cost of \$2,000.

In addition, we plan to develop marketing materials for patients and families, including handouts/pamphlets to give to families. We project the cost of these materials will be approx. \$1,500. We are also working with Advocate Health Care to develop a comprehensive website for our program, so that families can easily contact the program and access resources from home. The projected cost for website development is \$500 in the coming year.

\$4,000 of the Paul Seiwert Foundation gift will support educational and marketing materials for the program

- **Mailing Expenses for Pre-Clinic Questionnaires & Patient Feedback Surveys**

Mailing a pre-clinic questionnaire will allow families to share health history prior to visit to better help the Pediatric Oncology Long-Term Survivorship Program prepare for the patient visit. To aid with compliance, we would like to include a self-addressed envelope with postage to ensure these questionnaires are returned. In addition, family feedback is essential for the continued growth and improvement of any program. To continually provide excellent customer service-family feedback is crucial. Current AMG surveys are unable to filter out the Pediatric Oncology Long-Term Survivorship Programs' parent/patient feedback. Therefore, we would like to mail a survey post clinic with a self-addressed envelope with postage, along with a copy of the patient's comprehensive treatment summary. We hope to gain useful information about each patient's experience to better improve our program over time. Mailing costs are estimated \$0.65/ mailing, two per patient for goal of 90 patients, for a total of approximately \$200 in the coming year.

\$200 of the Paul Seiwert Foundation gift will support mailing expenses for the program in the coming year.

In Summary: With the new clinic up and running, our team is honored to be part of the Advocate Children's Hospital-(Park Ridge Campus) Pediatric Oncology Long-Term Survivorship Program, and excited for what the coming year brings for the survivors and families we serve. We are truly grateful for the gift from the Paul Seiwert Foundation Fund, and as this document shows, these funds will allow us to continue to develop our program so as to best meet the needs of the patients and families we will serve. We look forward to continuing to keep you updated on our progress in the coming year.