



Hyundai Hope on Wheels Hyundai Scholar Research

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Almost 80% of all children and adolescents diagnosed with cancer are long term survivors, and the majority are considered cured. This success has largely been due to the use of more intensive therapy using a combination of different chemotherapeutic agents, surgery, and radiation. However, no treatment is without cost! As childhood cancer survivors become adolescents and young adults, some of them are at risk of developing complications related to the very treatment that saved their lives. No longer can pediatric oncologists walk away from the responsibility of monitoring these survivors for late effects of treatment, most of which appear years after completion of treatment, and range from physical to educational to psychological issues.

The Late Effects Clinic was established six years ago as part of the general pediatric oncology program at Lombardi, and was initially staffed by just one pediatric oncologist. In addition to addressing specific issues related to late effects, we started putting together comprehensive “Off-Therapy” summaries for all patients who finished treatment in our program, as it was evident that this was the most important piece of information we needed to provide patients and their primary care providers. As the clinic became established, our patients’ families came forward and started helping with funding of staff and research projects. In 2005, a generous grant from the Hyundai Motor Corporation helped us to hire a nurse practitioner and to expand the clinic into a Cancer Survivorship Program. This funding has continued over the last four years and allowed us to grow as a program to provide better care for childhood cancer survivors, not just patients from Georgetown, but from the Greater Washington area and beyond. It has also allowed us to initiate research in childhood cancer survivorship.

The program has three goals: (1) to provide services, including education and follow-up care, for pediatric cancer survivors in the Washington, DC metropolitan area; (2) to establish a “Transition Clinic” to reach out to young adults treated by Lombardi’s adult cancer programs, as they have many cancer survivorship issues in common with the pediatric population; and (3) to continue to focus on clinical research in cancer survivorship.

Specific objectives to accomplish the above goals include: (1) screen patients for various types of medical and psychosocial late effects; (2) assess financial/occupational difficulties and identify appropriate resources; (3) provide or arrange neuropsychological testing for evaluation of emotional and learning ability concerns; (4) educate families and/or patients about previous diagnosis, treatment and potential cancer survivorship issues for early detection and intervention; (5) develop a database to facilitate longitudinal research on survivors of childhood cancer.

The program is led by Dr. Aziza Shad. Additional staff appointments, including Ms. Karen Hennessey, PNP, nurse practitioner; Ms. Leslie Nelson, social worker; and Ms. Tracy Council, art therapist, completed staffing of this program in 2008. These staff additions enabled us to expand our patient population, which includes children from as far away as North Carolina, Tennessee and several countries in the Middle East and Latin America. In addition, the program now has a collaborative relationship with several pediatric and adult sub-specialties such as cardiology, pulmonology, endocrinology, and gynecology, so that late effects issues in our patients can be addressed promptly.

In July, 2009, we will be adding an adult internist to our program, so that we can expand the program to include young adult cancer survivors from Lombardi and, at the same time, provide better care to childhood cancer survivors who are becoming adults.

Lombardi's Cancer Survivorship Program is now recognized as a distinguished program for cancer survivors nationally, and as a premier program locally. In fact, Georgetown University held the first comprehensive conference for pediatric cancer survivors here in Washington, DC in 2006, which was supported by Hyundai. Its success led to a subsequent conference in 2008; "Rise to Action", in partnership with the Children's Cause for Cancer Advocacy and Special Love.

The expansion of our patient population provides us with the opportunity to engage in cancer survivorship research. Currently, our research is focused on psychosocial issues, post-traumatic stress syndrome, growth, fertility and organ function. One recent study explored the use of cigarettes, sunscreen, and the lack of physical activity in adolescent cancer survivors. The researchers found that 15 percent of the patients had a history of cigarette use, 20 percent engaged in insufficient physical activity, and 37 percent did not use sun protection, as recommended. Some of these youths may be especially "stress prone," and thus more likely to have difficulty protecting their health. These results suggest that because stress may mediate or moderate the health promotion behaviors in this special population, interventions to address personal and family stress levels are warranted.

One of the program's greatest achievements in 2008 was the publication of *The Next Step...Crossing the Bridge to Survivorship*, by Dr. Aziza Shad and Karen Hennessey. Written for cancer patients and their families, the book is customized to include individualized information for each patient. When treatment is complete, each patient receives an off-therapy summary that is inserted into their book. Laminated wallet cards with a brief medical history and treatment summary are also provided. Other features include information about the patient's tumor, the treatment and dosage they received, potential late effects for their particular therapy, and recommended long-term follow-up. A primary focus of the book is to reinforce lifelong follow-up and the importance of health maintenance, including lifestyle recommendations and cancer screening. It is also our goal that patients and their families continue to feel supported and understand that they are not alone in adjusting to life after cancer. To date, 500 copies have been provided to families free of charge.

In 2009, the Hyundai Scholars grant will be used to further advance cancer survivorship research. New research protocols focused on post-traumatic stress syndrome and growth and fertility will be established. We also look forward to initiating research for a second book targeted toward primary care physicians such as internists, obstetricians, gynecologists, and nurse practitioners, who see former cancer patients after their treatment is discontinued. Finally, we would like to establish a database to collect patient information to enhance our research efforts.