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UT Southwestern childhood-cancer survivor program celebrates 20 years

DALLAS – Nov. 3, 2009 – Alexandra Wilson was just 4 when she was diagnosed with acute lymphocytic leukemia, a cancer affecting blood and blood marrow. Eleven years after completing treatment at Children’s Medical Center Dallas she experienced heart abnormalities as a result of her chemotherapy. The sophomore at UT Dallas now receives her follow-up treatment at UT Southwestern Medical Center.

“My doctors expected me to have complications because of the chemotherapy,” said Ms. Wilson. “They were unsure, however, of when the symptoms would start to show. Luckily I was enrolled in the After the Cancer Experience program [ACE], which allowed for my heart to be monitored through the years. Consequently, when the symptoms did appear, I was placed on a new treatment plan and now receive adult care at UT Southwestern from physicians who are familiar with my medical background.”

The ACE program, established in 1989, was the first of its kind in North Texas to provide long-term monitoring for survivors of childhood cancer. Still the largest such program in the area, ACE is a member of the Childhood Cancer Survivors Study (CCSS), the leading consortium in late-effects research. Numerous studies from the CCSS have determined the frequency of late effects and identified risk factors for late effects in childhood-cancer survivors.

“One in every 640 young adults aged 20 to 39 years old is a cancer survivor, which means that there are now 270,000 childhood-cancer survivors in the U.S.,” said Dr. Daniel Bowers, associate professor of pediatrics at UT Southwestern who leads the ACE program. “Over the past two decades we’ve learned that cancer survivors have unique medical issues and may be at risk for severe side effects as a result of their cancer or its treatment. The ACE program was created to address these medical issues and to be on the forefront of medical research for childhood-cancer survivorship.”

Each childhood-cancer survivor enrolled in the ACE program receives a cancer treatment summary with a description of their diagnosis, detailed treatment information, complications encountered during treatment or any late effects and a plan for follow-up care.

When survivors turn 18, they transition from the ACE pediatric program at Children’s to the ACE Young Adult Program at UT Southwestern. This program component combines pediatric oncology experiences with adult medicine and focuses on the health needs of young adult survivors.

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Dr. Angela Orlino, assistant professor of internal medicine and director of the ACE Young Adult Program, says the Cancer Treatment Summary is an important tool for health care providers. ACE nurse practitioners coordinate annual follow-up visits with Dr. Orlino and other physicians, which will last throughout the survivors' lives.

"As survivors age, it is important to monitor their health and provide updates about potential ways to reduce the risks of late effects," Dr. Orlino said. "Many childhood-survivor programs do not have an adult-care component. Documenting the progress of our patients not only helps current childhood survivors; it also paves the way for future generations to receive improved treatments."

Ms. Wilson agrees, saying fighting cancer is one battle, while long-term survivorship is another.

"Cancer is a never-ending disease in that it affects people for the rest of their lives," she said. "Each checkup I never know whether to expect good or bad news. The ACE program lessens this scary reality. Having personal relationships with the doctors, nurses and staff makes each annual visit more comforting. I feel fortunate to be a part of ACE and my goal is to one day become a pediatric oncologist."

Visit www.utsouthwestern.org/cancercenter to learn more about UT Southwestern's clinical services in cancer treatment.

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