

LIFE GO



When a family learns their child has cancer, moving forward is not an easy task. They begin an emotional journey in search of answers. What kind of cancer is it? What treatments are recommended? Will our child live? What lies ahead for our family?

The good news is that 80 percent of children with cancer survive, but children pay the price for survival. Childhood cancers are treated aggressively, often with combinations of chemotherapy, radiation and surgery. Because young bodies are still growing and not fully developed, they become vulnerable to “late effects” from drugs and radiation. Late effects can include stunted growth; mild to severe learning disabilities; fertility issues including delayed puberty, infertility or early menopause; problems with thyroid function; increased risk of other cancers; and heart disease.

DESIGN

The LIVESTRONG® Survivorship Center

Central Texas children who have survived childhood cancers can move beyond cancer and maximize their lives through the LIVESTRONG Survivorship Center at Dell Children's, a clinic that begins seeing patients approximately two years after the end of cancer treatment. Dell Children's has established this unique, separate clinic that focuses on life after cancer because it recognizes the importance of providing its young patients with a continuum of care.

"I don't think a child is ever truly cured of cancer," says Virginia Harrod, M.D., medical director of the LIVESTRONG Survivorship Center. "Even if you are cured of cancer itself, the residual lingering deficits are always there. We take patients who've won—they've gotten past cancer—and provide a resource for them to be fully informed and receive optimal care. They are not alone, and we are here to help."

The Center, made possible by generous program and financial support from the Lance Armstrong Foundation and additional support from Dell Children's Medical Center, provides clinical care, patient education, research opportunities and social support services to young cancer survivors. The Center is run by a team of professionals who thoroughly screen, evaluate and educate survivors about their particular cancers and treatments and potential long term problems and teach them how to live healthier lives. "The goal for the Center is to be able to provide a resource for these patients to be fully informed and receive the best possible care on all levels—physical and psychological—so that they can live life to the fullest," says Harrod.

In its first year, the Center provided quality comprehensive patient care to more than 130 childhood cancer survivors and has implemented successful support groups, including a psycho-educational group called the Survive Strong Series; a physical activity group called the Survivor Challenge; and a Young Adult support/social group that helps meet the needs of survivors who are 18 to 30 years old.

You Can Help Create an Endowment to Support the LIVESTRONG Survivorship Center

The Children's Medical Center Foundation of Central Texas is raising funds to establish an endowment to help sustain the LIVESTRONG Survivorship Center at Dell Children's. Goals include long term sustainability, expanded community outreach and education, expanded services, and becoming a leader in research. For more information on giving opportunities for the LIVESTRONG Survivorship Center endowment, contact the Foundation at (512) 324-0170.

The External Advisory Committee of the LIVESTRONG Survivorship Center is a group of talented and committed volunteers from the Austin community. Each member brings a unique and invaluable expertise, providing guidance to the Center.

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LINDSEYSIMMER

Lindsey Simmer was diagnosed with an inoperable brain tumor when she was two. Her cancer was managed without aggressive treatment until she was 12, when she completed six weeks of cranial radiation therapy. Suddenly her tumor began to grow rapidly. Doctors hoped to slow down the tumor's growth with experimental chemotherapy, which Lindsey underwent for nine months. Her tumor disappeared.



Lindsey returned to school after treatment, but found it difficult to reconnect with friends. She looked different—her face was swollen from steroid drugs, and she had far less energy than the other kids. The tumor had compressed her optic nerve, impairing her vision. She was diagnosed with metabolic syndrome, caused by radiation and chemotherapy, which may cause future problems with high blood pressure, blood sugar problems and polycystic ovaries. She struggles with memory loss, weight gain, fatigue and joint pain.

Today 21-year-old Lindsey attends Austin Community College and is still tumor-free. She enjoys working with children and animals and looks forward to studying at a university. The LIVESTRONG Survivorship Center educates her about late effects of cancer treatment. She helps lead a physical activity group for cancer survivors called Survivor Challenge, which has improved her stamina and has been emotionally uplifting.

"Everyone who participates in Survivor Challenge seems to go home happier," says Lindsey. "I like to teach other kids how to solve their own problems. At the beginning of a session, many of the kids don't know anyone and they aren't confident in their physical abilities. But once they warm up and start making friends, they have fun and really start to push themselves."

When she was ten, Tierney Smith was diagnosed with acute lymphoblastic leukemia (ALL), a fast-growing cancer of the white blood cells. For the next 26 months, she underwent chemotherapy treatment at Children's Hospital of Austin. Her mom, Angus, says Tierney became tired and physically weak from her treatments, but was able to keep up with schoolwork. Through it all, her daughter remained emotionally strong. "Tierney never cried or complained about anything, even when she lost her hair," she says.

The medicines Tierney received during treatment have affected her memory. She is at risk for late effects including heart or lung problems, slowed or decreased growth and development, and fertility problems. The most serious side effects of ALL treatment are the risk of getting a second leukemia or developing non-Hodgkins lymphoma.

Tierney enjoyed appearing in a television commercial with Lance Armstrong and other young cancer survivors and has become a strong, supportive role model to two friends who have recently been diagnosed with cancer. The LIVESTRONG Survivorship Center has opened Tierney's eyes as to her risk of late effects from medications and treatment and the importance of nutrition and exercise. She works out almost daily, enjoys dancing, and tries to maintain a healthy diet. She's made new friends through a teen cancer survivor support group and attends special camps for cancer survivors.



Tierney is 17, graduated from high school in June and will begin classes at Austin Community College. She plans to continue her education at a four-year university. She discovered a strong ambition to work in the medical field through her cancer experience. "I want to become a pediatric nurse and help other children through their illnesses," she says.

TIERNEYSMITH

JUSTIN MENDOZA



When Justin Mendoza was 2 ½, his parents Lynn and Alfredo suspected a problem after he experienced persistent cold symptoms and his energy level steadily declined. At Children’s Hospital of Austin, Justin was diagnosed with acute lymphoblastic leukemia (ALL).

Boys with ALL experience a higher incidence of relapse than girls, so they require longer treatments. Justin spent the next 38 months undergoing chemotherapy. Lynn describes the first

few months of treatment as intense—he suffered from nausea, low energy and weakened muscles that left him uncoordinated and clumsy. As a toddler, physical confinement was especially difficult for him.

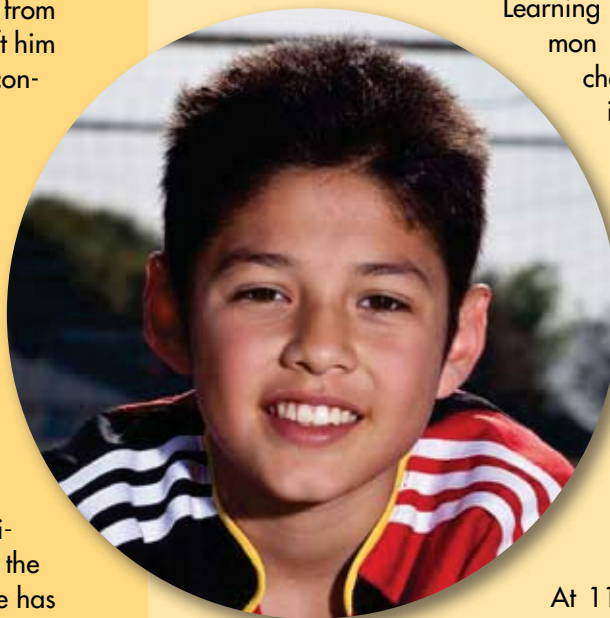
Fortunately Justin doesn’t have memories of cancer. Today the 13-year-old Georgetown teen is preparing to begin eighth grade in the fall and enjoys life like most kids his age. He especially enjoys theater classes and rocket club and dreams of becoming a paleontologist. The LIVESTRONG Survivorship Center has educated the family about the risk of late effects, including the fact that his cognitive abilities can fail at any time. He is also at risk for problems with behavior and coordination, calcium loss, periodontal disease and secondary cancers. Because the Center encourages him to stay physically active, he has played soccer and practiced Kuk Sool Won, a Korean martial art.

Justin is a regular participant in Survivor Challenge and has benefited from his interaction with other young cancer survivors. “Justin’s friends cannot relate to his cancer and oftentimes don’t know what to say,” says Lynn, “but when he’s with other survivors, they feel comfortable because of their similar experiences.”

Myrna and Jose Ibarra became concerned when their 4-year-old son, Jose, suffered from sore throats, swollen lymph nodes and labored breathing while sleeping. After his tonsils were removed, doctors discovered he had Burkitt’s lymphoma, cancer in his lymphatic system. Jose’s cancer was contained in lymph nodes in his neck, but he was in danger of the cancer spreading to his brain.

At that time, the family lived in Chicago, where Jose began five months of chemotherapy treatment. He became tired, moody, sad and easily agitated, but in the end, the family received good news – his cancer was in remission with a slim chance of recurrence.

The Ibarras moved to Round Rock in 2004 and were thrilled to find pediatric cancer specialists in Central Texas to continue Jose’s care. He’s been in remission for six years and makes regular visits to the LIVESTRONG Survivorship Center. “The Center provides a great support team for parents,” says Myrna. “They monitor his health and provide information about the importance of nutrition and physical activities.”



Learning disabilities are a common late effect from the chemotherapy drug used in Jose’s treatment, as well as heart problems, testicular dysfunction and secondary leukemias. The Center evaluates Jose’s school progress, working closely with school professionals, as he can be affected by late effects at any time.

At 11, he is an honor role student who begins sixth grade in the fall. Jose is in excellent health—and a soccer sensation. He dreams of playing professional soccer and becoming a soccer coach. His cancer, says Myrna, has brought her family closer. “As parents, we never think something like this will happen, especially to our children. We are thankful to have a medical center like Dell Children’s in Central Texas.”

JOSE IBARRA