

Exceptional — Care For — Exceptional **KIDS**

**Children's Blood &
Cancer Center**

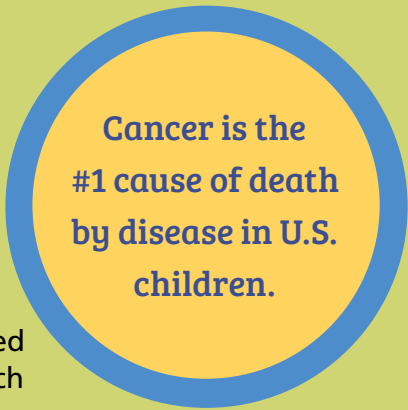


A member of the  **Seton** Family of Hospitals





Building a Better World of Care



**Cancer is the
#1 cause of death
by disease in U.S.
children.**

The Children's Blood & Cancer Center (CBCC) of Dell Children's Medical Center is a healing place for children and their families in need of highly advanced care for pediatric cancers and blood disorders. Each day we dedicate ourselves to caring for children with diagnoses ranging from the most common to the most complex and rare conditions. By providing the best care possible with the dignity and respect everyone deserves, we are healing children — one little human at a time. Welcome to Humancare.

The CBCC opened in 1988 and has been helping children return to healthy, productive lives while remaining close to home, surrounded by the love and support of family and friends.

The CBCC offers patients a wide array of treatment options designed by the international research collaborative Children's Oncology Group. These treatments can include chemotherapy, radiation therapy, surgery and immunotherapy.

Our mission is to cure and prevent childhood and adolescent cancer and blood disorders through individualized treatment, compassionate care and research. Our multidisciplinary team of specialists is devoted to treating the whole child, offering everything necessary to promote physical and emotional health and well-being today — and for years to come.

We Know Kids

The Children's Blood & Cancer Center is part of the nationally recognized Dell Children's Medical Center, a state-of-the-art facility providing care to sick and injured children and adolescents throughout the 46 counties that make up the Central Texas region. Dell Children's Medical Center was designed to address the unique healthcare needs of children, providing specialized care and treatment with a family-centered approach that keeps patients close to their loved ones at all times. The CBCC consists of the inpatient unit located at Dell Children's Medical Center and the outpatient ambulatory clinic located next door in the Strictly Pediatrics medical office building.

Children
with bleeding
disorders can live
full lives.

Treating the Whole Family

At the Children's Blood & Cancer Center we embrace a full-circle approach. From the moment a child is diagnosed with a serious cancer or blood disorder, his or her life can become consumed with the illness. Each of our programs has been specially designed to help children and their families successfully navigate this frightening and unfamiliar territory.

In addition to providing inpatient and outpatient medical treatment we take great care to address the child's entire spectrum of physical, emotional, social and spiritual needs with an experienced team of physicians, nurse practitioners, nurses, pharmacists, child life specialists, social workers, psychologists and dietitians.

Four out of five children diagnosed with cancer will survive.





Defying the Odds • PRINCESS GANT

Nichole Gant believes a small percentage of sickle cell patients can live bigger than the disease. She knows her nine-year-old daughter, Princess, is one of them.

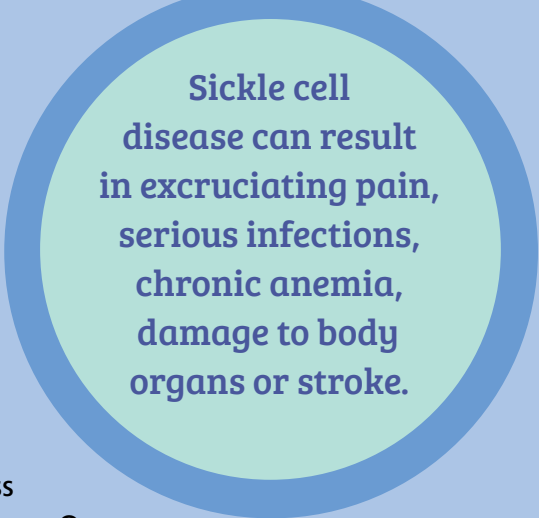
“As a baby, Princess’s doctors told me she’d never thrive. Sickle cell disease is stressful to her body. The more stress she’s under, the more pain, hospitalizations, medications and social deficits she’ll have that prevent her from participating in everyday activities. She has spent lots of time in the hospital and misses a significant amount of school. She missed three months of third grade.

I see Princess fight back. She has a strong will to live. I believe she's here to make a difference. She's happy to be at school, she learns, and she's in the top of her class. Despite her disease, she's a leader.

The Children's Blood & Cancer Center team has been a lifesaver for my family. They treat my whole family, which keeps us healthy enough to take care of Princess. Kids with sickle cell disease tend to get sick and stay sick. I believe Princess doesn't have to stay sick, and her healthcare team agrees with me. Our ultimate goal is to keep Princess healthy and participating in life.

I believe Dell Children's sets the standard for many other healthcare facilities across the country. Under their care Princess is going to defy the odds. She performs in musicals at Zachary Scott Theatre in Austin. She knows every move, every song. She works really hard, and I know she works through a lot of pain and fatigue. I am very proud of her."

Through Princess' eyes, her future looks bright. "Someday I'll get married and have at least four boys and three girls," she says. "I am awesome at singing and extremely awesome at dancing. I want to go to college and learn about music, art and dance. I want to be a superstar, have my own movie and live in a mansion!"



**Sickle cell
disease can result
in excruciating pain,
serious infections,
chronic anemia,
damage to body
organs or stroke.**



Driven to Find a Cure

Research through Clinical Trials

Most children diagnosed with cancer today will survive, thanks to years of medical research driven by the inquisitive minds of scientists and researchers. Much work remains to find treatments and cures for children's cancer, the leading cause of death by disease in children.

Dell Children's Medical Center is a teaching hospital and a member of the international Children's Oncology Group (COG), a prestigious research collaborative of approximately 2,000 physician researchers at more than 200 hospitals that is sponsored by the National Cancer Institute. COG is the world's largest organization devoted exclusively to childhood and adolescent cancer research.

Children's Blood & Cancer Center patients are offered opportunities to participate in COG studies — the most advanced clinical trials — so each child receives the highest quality of care. Studies show patients treated with COG protocols have significantly better disease-free survival rates than those who don't receive the same treatments.

CBCC is also a member of the Neuroblastoma and Medulloblastoma Translational Research Consortium, a network of 18 U.S. universities and children's hospitals. Patients with high-risk neuroblastoma and medulloblastoma cancers are given the chance to participate in clinical trials to improve their quality of life and odds of survival.

The Power of Love

LUIS DEJESUS

When Alfredo and Maria DeJesus learned their 11-year-old son Luis had leukemia, they prepared for a long battle. Luis would undergo chemotherapy treatment, followed by a bone marrow transplant.

“Luis told me, ‘Don’t cry. Promise me you won’t cry. I want to be strong,’” says Maria.

“It was hard for me, but he made me promise. I thought if he can do it, I can do it.”

The family found strength in their deep faith in God and through the love and support of each other and their close-knit circle of extended family and friends. Twenty-one people shaved their heads in



solidarity with Luis. The family prayed for a miracle and, seven months later, Luis was cancer free.

Maria describes Luis as her inspiration. “On those really difficult days, Luis reminded me not to cry,” she says. “He would say, ‘If you cry, I want to cry and I can’t. If you don’t cry, that’s my vitamin.’”

She watched as cancer transformed her son from an innocent, sensitive child into a strong, young man. She was grateful to be constantly surrounded with love. “We sometimes had 30 people in his hospital room,” she says. “Some families didn’t have anyone, so we would share our family. It was God’s plan for us.”

Today Luis is a survivor of childhood cancer and, in 2013, he was diagnosed with diabetes. He suffers late effects from chemotherapy, including sensitive skin and bone loss in his lower back and spine. He misses school due to illness and hospitalizations and struggles with memory problems, both negatively affecting his ability to learn.

Luis recently graduated from high school and looks to the future with confidence and hope. Having diabetes sparked his interest in a new passion — he has started a home bakery business, creating gluten-free special-occasion cakes for people who can’t eat sugar.

He plans to get college degrees in both business and culinary arts and dreams of owning a bakery franchise specializing in sugar-free items.

Maria believes Luis will achieve his dream. “Sometimes he’ll come home from school with a low grade. When he looks sad, I tell him, ‘No! Don’t cry! You can do it. Whatever it is you want, you can have it.’ He is determined to succeed, and I am really proud of him.”



Unlocking the Mysteries of Pediatric Cancer

Grant Supported Research

Supported by Dell Children's Medical Center, the commitment of the Children's Blood & Cancer Center to lead the fight against childhood cancer and blood disorders is stronger than ever.

We believe research lies at the heart of all medical progress. Our researchers collect clinical patient data through the health experiences of Dell Children's patients and collaborate with science laboratories throughout local and state academic institutions to study the data. These research projects help us understand why treatments work so that new solutions can be designed to bring better outcomes to patients.

Since Dell Children's opened in 2007 the CBCC has secured grant funding and has completed or is participating in a total of four research projects.

2007

Survivor Challenge began as a grant-supported pilot study at the Children's Blood & Cancer Center. The study evaluated the effects of organized physical activity on the health and well-being of adolescent cancer survivors. Survivor Challenge has become a successful training program for CBCC patients, ages 7 – 18, who are on or off treatment and their families. The Survivor Challenge program model has been replicated at the Children's Hospital of Wisconsin and the Ann & Robert E. Lurie Children's Hospital in Chicago.





2012

In collaboration with The University of Texas at Austin, the CBCC began a grant-supported two-year study to investigate the effects of cancer treatment on the child's ability to think, learn and behave, both during and after cancer treatment. Results of this study could have enormous implications for the prevention and treatment of negative late effects among childhood cancer survivors.

2012

The CBCC began a one-year grant-supported pilot study to evaluate the benefits of a designated neuro-oncology specialty clinic. The program focused on managing care for patients with tumors of the brain and spinal cord, as well as the neurological complications of cancer. By creating a dedicated neuro-oncology program, we can provide multidisciplinary care in one organized clinic visit so that families are happier, communications are strengthened, and medical care compliance is improved.

2013

In collaboration with the Dell Pediatric Research Institute (a research lab of The University of Texas at Austin), the CBCC began a grant-supported two-year study. Researchers are investigating molecular changes in cancer cell metabolism in response to medications, which could predict outcomes and allow for optimized care and personalized chemotherapy treatments. Results of this bench research will provide the first step toward the development of new strategies for cancer therapy design that could advance international change in pediatric cancer treatment and bring better outcomes to patients.

Caring for the Mind, Body and Spirit

Dealing with a life-threatening illness can cause enormous stress on children and families. At the Children's Blood & Cancer Center we believe that providing emotional support for a sick child is as essential as providing relief of physical symptoms.

We offer psychosocial support to help children cope with stress, including nontherapeutic interventions such as counseling and support groups. Members of the CBCC psychosocial team work together to support families in different ways to guide them through the cancer experience.



THE ROLE OF THE CHILD LIFE SPECIALIST

CBCC child life specialists provide developmental, emotional and social guidance to ease the stress that children and their families face during difficult diagnoses and treatments. They help patients understand their medical procedures and express their feelings in constructive ways.

In addition to working directly with patients and families in both the hospital and outpatient clinic settings, the CBCC child life team coordinates psychosocial services and special events.

- Annual educational events like **St. Baldrick's** and **Hematology Fair** connect patients and families to community resources so they can build strong support systems.
- **Hungry Bunch Teen Support Group** helps adolescent and teen patients build supportive friendships and a strong support system with other cancer and blood disorder patients.
- **Survivor Challenge Exercise Program** is a safe and structured physical activity training program to help patients feel better and make regular exercise an ongoing part of their lives.
- **School Services** help patients work through learning challenges caused by cancer and its treatments.
- **Camp Volente for Bereaved Siblings** supports children who've lost a brother or sister to cancer.
- **Art Therapy** is based on the idea that creative arts can heal and uses the creative process to help cancer patients cope with the stresses that come with battling life-threatening illnesses.

THE ROLE OF THE SOCIAL WORKER

Children's Blood & Cancer Center social workers provide services both in the medical setting and out in the community to ease the way for children with chronic illnesses and their caregivers. They interact with patients and families from diagnosis through cancer or blood disorder treatment and beyond to help them cope with stress, solve problems, make decisions and connect with supportive hospital and community programs.

Social workers oversee the distribution of emergency funds and financial assistance for many families facing hardship. A child's diagnosis of cancer or blood disorder can wreak financial havoc on any family, regardless of socioeconomic status.

Generous community support allows the CBCC to provide emergency funds to meet the special needs of these families. Emergency funds relieve incredible financial pressure felt by families and provide money for rent, mortgage or utility payments or to purchase food to feed their children. Often funds go toward providing transportation, purchasing wigs or shoes or paying for temporary living close to the hospital for out-of-town families.

Emergency funds have become an important safety net to lighten the load so families can focus their energies on loving and caring for their children.

Cancer's financial impact on families can be devastating. Many times one parent is forced to stop working. It could mean the loss of all income for single parents.



THE ROLE OF THE PSYCHOLOGIST

The Children's Blood & Cancer Center's Embedded Behavioral Clinic enables pediatric cancer and blood disorder patients to benefit from multidisciplinary healthcare, medical care and behavioral health treatment, all in one office visit. Psychologists from the Embedded Behavioral Clinic, located within the CBCC outpatient clinic, incorporate holistic psychosocial treatments to address all aspects of a child's life.

The traumatic experience of having cancer places children at significant risk for short- and long-term social, emotional, academic and behavioral difficulties.

ASSISTING THE CHILD

Psychologists provide therapy services to teach coping skills, problem solving and relaxation strategies that promote emotional well-being.

Patients undergo neuropsychological testing to identify learning problems encountered both during and following cancer treatments.

Psychologists refer patients for speech, occupational and physical therapy services, as well as psychotherapy and psychiatric services as needed.

STRENGTHENING THE FAMILY

Psychologists provide family therapy, parent training, marital counseling and sibling support services to ease the stress of diagnosis, treatments and late effects of pediatric cancer and blood disorders on patients and their entire families.

ADVOCATING AT SCHOOL

Psychologists help parents and educators understand the child's overall functioning, as well as weaknesses that can impede learning, and encourage extra educational support in the classroom for the child's special academic needs.

CONNECTING FAMILIES TO THE COMMUNITY

Psychologists refer families to outreach and support groups that unify patients, parents and siblings who are enduring similar hardships.

THE ROLE OF THE DIETITIAN

The CBCC dietitian helps cancer patients maintain adequate nutrition and health during treatment. Cancer and its treatments can negatively affect a child's appetite and tolerance of food, making it difficult to keep the body strong and growing.

The dietitian helps parents understand their child's specific nutritional needs and develops individual eating plans. Through the Food Fight for Life nutrition program, the dietitian educates families with scientific, evidence-based nutrition information and teaches fun, easy ways to prepare and incorporate cancer-fighting foods into everyday life. Food Fight for Life helps to empower children to explore new tastes and nutrients and build positive relationships with food.

Consuming the right foods can help a child achieve normal growth and development and manage treatment side effects that impact his or her ability to continue normal activities and thrive. Some cancer treatments work better when the patient is well nourished and may lead to a better prognosis and quality of life.

Support for the Long-Term

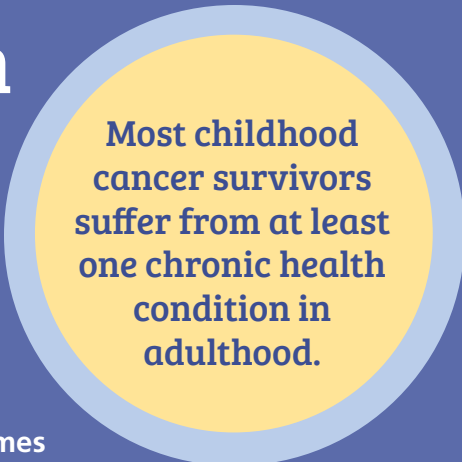
Cancer Survivorship

The Children's Blood & Cancer Center survivorship team supports patients so they can become happy, highly functioning members of society after the cancer experience.

The radiation, chemotherapy and surgery used to successfully treat childhood cancers may lead to what are called "late effects," sometimes many years after treatments end. Survivors of childhood cancer require lifelong follow-up care for the screening, prevention and treatment of late effects.

Once CBCC patients are two years post completion of treatment, they are closely monitored for delayed side effects and complications caused by previous cancer therapies. They will be seen by the survivorship team until they reach 18 years of age and/or have graduated high school. Each patient is provided with a treatment summary that includes all possible late effects that could occur based on their treatments. The treatment summary becomes part of the patient's permanent medical record that can be shared with all future healthcare professionals.

The CBCC survivorship team strives to increase patients' knowledge about their individual cancer treatments and manage any late effects they might have from treatment. Patients also learn the skills needed to maintain good health and lead happy, fulfilling lives.



Most childhood cancer survivors suffer from at least one chronic health condition in adulthood.



Common Late Effects after Treatment for Pediatric Cancer

- Slow or stunted growth
- Heart disease
- Delayed puberty, infertility or early menopause
- Thyroid dysfunction
- Secondary cancers
- Difficulty learning and succeeding in school, work and life

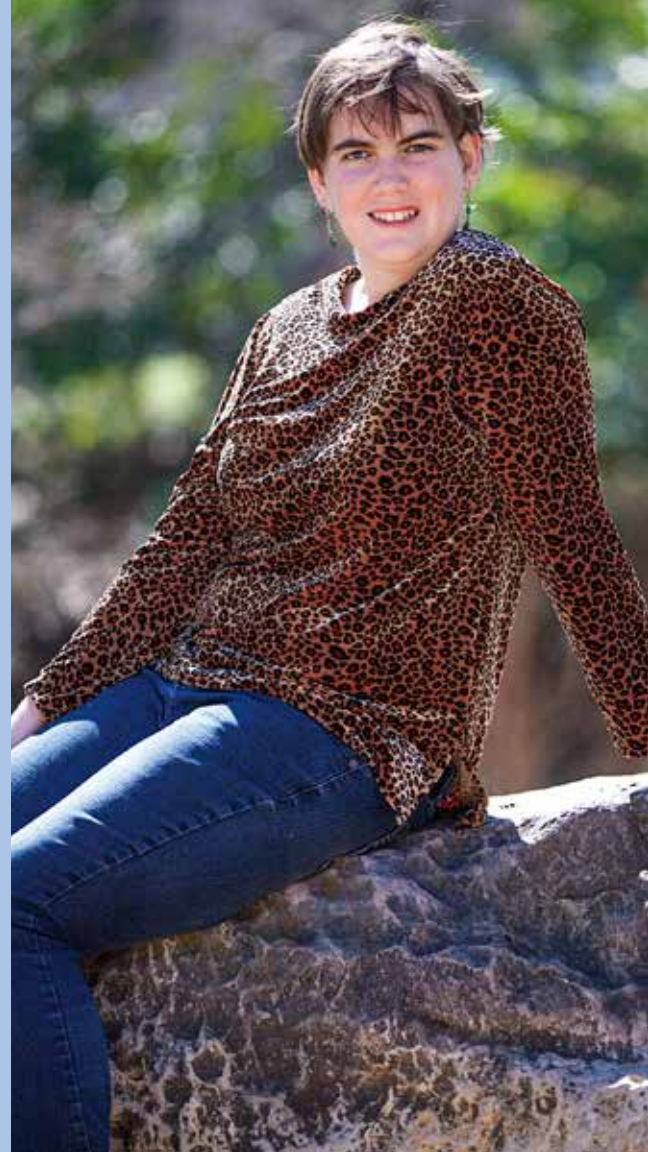
Life Beyond Cancer

LINDSEY SIMMER

“The awfulness of cancer doesn’t last forever,” says Lindsey Simmer, an adult survivor of childhood cancer. “One day life will be much better. In fact, it can be amazing.”

Lindsey was 2½ when she was diagnosed with a brain tumor at Children’s Hospital of Austin. Her cancer was managed without aggressive treatment until age 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. After nine months of chemo, her tumor disappeared.

Lindsey returned to school after treatment, but the tumor had compressed her optic nerve and impaired her vision. Her cancer treatments negatively affected her ability to learn. “I needed more time to finish my work than the other kids, and I couldn’t listen and write at the same time. I would lose my place looking



up at an overhead and then down to my paper. I couldn't track answers on Scantron tests because the dots moved around."

She remembers the most difficult part of cancer was trying to figure out how to get through school with her new way of learning. She and her family turned to her medical team for support, underwent neuropsychological testing to identify learning problems and requested support at school from teachers and note takers.

Having cancer taught Lindsey how to advocate for herself. Her desire to learn helped her persevere and overcome more challenges than many people face in a lifetime.

Now in her 20s, she says, "my life has moved to a happy place."

She graduated with an undergraduate degree in education from Texas State University in 2014 and works as a preschool teacher. She strengthens her mind and body through yoga. Each year she attends a national camp for young adult survivors of pediatric brain tumors where they discuss important survivor topics, including disability laws, medical insurance and fertility.

Camp is where Lindsey met Justin, the love of her life. They dream of marriage, raising a family and spending the rest of their lives together.

"There are things you'll dislike about what cancer has done to you," she says, "but take it day by day. If you're fortunate, you'll find a way to create a life for yourself that's really awesome. Just don't ever give up hope."



Contact Us

**Children's Blood & Cancer Center Outpatient Clinic (Suite 401)
and Cancer Survivorship Clinic (Suite 400)**

1301 Barbara Jordan Blvd. • Austin, TX 78723

Phone: [512-628-1900](tel:512-628-1900) • Fax: 512-628-1901

Children's Blood & Cancer Center Inpatient Unit at Dell Children's Medical Center, 4 North

4900 Mueller Blvd. • Austin, TX 78723

Phone: [512 324-0400](tel:512-324-0400) • Fax: 512-324-0620

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Website: dellchildrens.net/cancer

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