

because kids can't fight cancer alone





## The American Cancer Society announced staggering statistics:

- 1 in 285 U.S. children will be diagnosed with cancer before the age of 20.
- Cancer is the #1 disease killer of children in the U.S.
- Cancer in children is on the rise





Our mission is two fold:

- · Encourage teens in the battle
- · Fund childhood cancer research

Let's start with the encouragement part. A cancer diagnosis is difficult at any age, but it seems especially complicated for teens.

There's a growing awareness across the country to encourage teens in the battle and the Carson Leslie Foundation is smack dab in the middle of it, offering teens a bit of normalcy while fighting for life.

- We built Carson's Corner, the teen room at Children's Medical Center of Dallas.
- Four times a year, in first class fashion, we take teen cancer patients out and about in the city of Big D!
- We provide newly diagnosed teens Under Armour backpacks full of items they may need for their cancer battle.

Everyone needs a little encouragement along the way, so here at the Carson Leslie Foundation, we encourage teens in their valiant fight for life on a regular basis.

### Carson's Corner, the Teen Room...

"Carson was a giver at heart," said his mom, Annette Leslie. "He insisted that his cancer-filled brain be studied with the hope of helping the next kid diagnosed with cancer. He also kept a journal, in which he wrote: 'I feel deserted and lonely... I am not looking for some meaningful deep conversation; I am just looking for a conversation. The weather will work.""

So, CLF and Friends built Carson's Corner, a teen room on the cancer floor at Children's Medical Center of Dallas. It's a little corner of the hospital where cancer-fighting teens can go and *talk about the weather* and just chat with friends about music, movies - all the regular stuff teens talk about.

We established a \$100,000 Endowment at Children's Medical Center of Dallas to keep Carson's Corner updated.



"I couldn't help but think about Carson and how happy he would have been in there and how his life inspires us. He is continuing to impact people with his legacy and is making life better for these teens."

 Melinda Goff, Director of Childlife, Oncology at Children's Health of Dallas







## Once a Cowboy, always a Cowboy...

Jerry Jones signed Carson to The Dallas Cowboys then looked at Carson and said "Once a Cowboy, always a Cowboy!" So we take limos full of cancer-fighting-teens to the Dallas Cowboy games in first-class fashion.

"At the Cowboy game, there were two girls who were initially reluctant to attend because they were nervous to spend an evening with people they did not know well. By the end of the night, the girls were friends, now text one another and have stayed friends. They are a support to one another and truly can understand the fear, burdens and moments of joy within hospitalization and treatment.

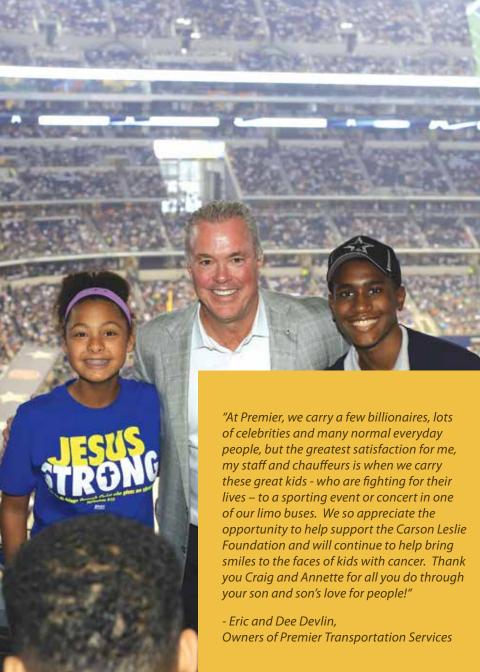
Another teen who went to the game is a young man who had received his prosthetic leg the day before the event and walked though the stadium, surrounded by the group and felt comfortable and confident to walk in public. Can you imagine how powerful the event was for him, the friendships, laughter, feelings of hope and acceptance.

There was another young man who lost his battle with cancer shortly after attending the event. He was a huge Cowboy fan and the evening was a dream come true for him.



Not a teen who attended that evening who would have been able to attend a game, experience a suite and feel so special without your foundations support."

-Melinda Goff, Director of Childlife, Oncology at Children's Health of Dallas



## "I love sports, babies and Mexican food..."

In Carson's book, <u>Carry Me</u>, he wrote: "Baseball is deep in my soul. I loved putting on the jersey, the long socks, the pants; the whole uniform. I loved sliding in the dirt, the smell of my glove and the anticipation of playing the game. I loved going up to the plate holding the bat in my hands and swinging it around before I actually took my stance. I was always first to bat."

To honor Carson's love of the game we celebrate his July birthday at the ballpark in Arlington.





The Dallas Mavericks was always one of Carson's loves and the Mavs annually roll out the red carpet when we bring a limo full of cancer fighting teens to a game! We go into the locker room and onto the practice court!

"The Maverick outing was truly a night the teens will never forget! One 13 year boy stated that it was the best day of his life. Another described the night as "the coolest thing I have ever done in my life". The Carson Leslie Foundation gives teens battling cancer a chance to set aside the angst of cancer treatment giving our patients a night to simply feel like a teen." - Melinda Goff, Director of Childlife, Oncology at Children's Health of Dallas







Annette Leslie is part of CPRIT's Advisory Council on Childhood Cancer, and the two organizations have established a close relationship to help pediatric cancer patients. One of the most recent initiatives was awarding \$3,200,000 grants funding research for less toxic childhood brain cancer treatments.

- Wayne Roberts, CEO CPRIT





#### Fund Childhood Cancer Research

The Carson Leslie Foundation believes in collaboration, working together and directing funds!

- In 2010, a few months after Carson's death, Congressman Michael McCaul invited Annette to speak at the Inaugural Congressional Childhood Cancer Caucus in Washington, D.C.
- CLF continues a strong presence in D.C. with an annual trek during childhood cancer awareness month. Our visits to D.C. are full of late night dinners, receptions, galas, roundtable discussions, speaking engagements, lobbying, invitations to The White House and Chairing Congressional toasts!
- CLF has a unique relationship with the Cancer Prevention and Research Institute of Texas (CPRIT). Annette has served on CPRIT's Advisory Council for Childhood Cancer since 2010.

## The Cancer Prevention and Research Institute of Texas

In the William B. Travis Building in Austin Texas, The Cancer Prevention and Research Institute of Texas (CPRIT), a \$3 billion cancer institute, named their conference room in honor of an extraordinary boy who lived LARGE while he was able.

This plaque hangs in that room!

#### CARSON ROBERT LESLIE

July 6, 1992 - January 12, 2010

"I can either go around mad and sad, or go around living with the strength and courage that comes from God and from the people he puts around me." ~ Carson Leslie

Carson was diagnosed with medulloblastoma, a brain tumor at the age of 14 in 2006. He shared his fight against cancer in his book, Carry Me, which Carson hoped would offer encouragement and strength to other young cancer patients. He asked his family to make sure that researchers study the tumors in his brain,

"because if those tumors can help some kid not die from cancer like I am, I'd like that, it's hard to have cancer." The Carson Leslie Foundation was established in his memory.

IN NAMING THIS ROOM FOR CARSON,
CPRIT HONORS ALL TEXANS AND THEIR FAMILIES
AND FRIENDS WHO HAVE BEEN AFFECTED BY CANCER.



This photo hangs in that room #TexasProud

"We named CPRIT's conference room after Carson to honor his memory and to inspire us with a tangible reminder of the courage, strength and hopefulness he showed in his fiaht against cancer. CPRIT has made childhood cancer a priority, funding 63 grants totaling almost \$69 million. Our increased grant support is intended to accelerate progress for prevention and research of pediatric and adolescent cancers, and to help Texas become a global leader in childhood cancer research."

- Wayne Roberts, CPRIT-CEO

When Annette was invited to serve on CPRIT's Advisory Council for Childhood Cancer it quickly became apparent their sympathies line up in regard to the necessity of childhood cancer research. So, the Carson Leslie Awards for Pediatric Brain Cancer Research were established resulting in a \$3.2 million collaboration between CPRIT and CLF.

#### The Carson Leslie Awards for Pediatric Brain Cancer Research

Nearly 200,000 children undergo treatment for childhood brain tumors annually. Cancer is the #1 disease killer of American children and brain cancer in children is the deadliest.

The "lucky ones" who survive face a lifetime of challenges because of the harsh toxicity of current treatment.

The Carson Leslie Research Grants (a CLF + CPRIT \$3,200,000 collaboration) early findings are explained here in layman's terms!



#### The University of Texas Southwestern Medical Center

Genotype and Metabolic Phenotype in Pediatric Brain cancer "The team at UT Southwestern Medical Center is investigating the metabolic processes that drive the growth of gliomas and medulloblastomas. Although sugar is an important fuel, the team has found there are other sources such as acetate, which appear to be important for glioma growth. Using multiple different methods, the team is looking for new ways to cut off the fuel supply. The Carson Leslie Foundation is a key partner in this work in terms of funding the experiments and funding the scientists." - Dr. Elizabeth Maher

#### **Texas Tech University Health Science Center**

(using tumors from Carson) - Dr. Srivenugopal's grant focus is improving the chemotherapy for medulloblastoma and glioblastoma patients to curtail the activity of a DNA repair protein called MGMT, which is present abundantly in brain tumors. MGMT makes therapy ineffective by removing the DNA damage induced by temozolomide. Currently available MGMT inhibitors cause profound bone marrow suppression and have not been useful. Drug discovery is a lengthy expensive process, there has been much interest in repurposing drugs used for other diseases. With the help from the Carson Leslie Foundation, Dr. Srivenugopal has repurposed inhibitors for MGMT such as the disulfiram and is working with Neuro-Oncologists to test the drugs in high risk brain tumor patients.- Dr. Kalkunte Srivenugopal

#### **Baylor College of Medicine**

Proton Beam Radiation vs. Conventional Beam Radiation "This study is extended across 6 institutions in Texas and will gain a better understanding of the short-term side-effects due to radiation. The study promises to inform the development of future therapy approaches that will decrease the negative effects and enhance the functioning and quality of life for survivors." - Dr. Douglas Ris

### A Golden Toast and Storming the Hill...

Carson Leslie Foundation chairs and hosts "a golden toast" honoring and thanking the Congressmen for their tireless efforts in championing the bipartisan Congressional Childhood cancer Caucus which gives the childhood cancer community a powerful soapbox from which to shout! The room is full of dignitaries, Congressmen and leaders in the childhood cancer community.



Congressman McCaul stated, "Serving as co-chair of the childhood cancer caucus is one of the great honors of my time in Congress. The privilege of working together to help improve and save the lives of childhood cancer patients is unparalleled. I could not be more proud of the efforts of the caucus and its members as well as the advocates, families, and the medical community who make this possible."

"Dear Annette, Your advocacy on behalf of pediatric cancer patients is making a difference. By bringing advocates, researchers and policy makers together you are playing a leading role in the fight to one day eradicate pediatric cancer as a threat to children. We look forward to continuing work with you to support pediatric cancer research, greater access to treatments, and high quality care for patients and survivors."

- Congressman Michael McCaul & Congressman Chris Van Hollen



#### The Texas Resolution...

# Carson Leslie Foundation received an Honor and Recognition of High Regard from **The State of Texas House of Representatives**





#### RESOLUTION

WHEREAS, The Carson Leslie Foundation is making a positive impact through its efforts in behalf of children battling cancer; and

WHEREAS, In 2010, the foundation was established by Annette Leslie just a few months following the untimely death of her 17-year-old son, Carson; the organization is dedicated to raising funds for pediatric cancer and enriching the lives of teenage cancer patients; and

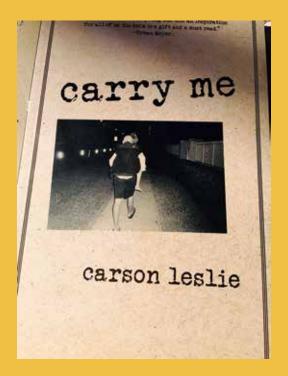
WHEREAS, The American Cancer Society reports that cancer is the leading cause of death by disease in children under the age of 15; one in every 285 Americans develops cancer before the age of 20, and the incidence of invasive pediatric cancers has gone up 29 percent in the past 20 years; some pediatric brain cancers are terminal upon diagnosis, and no new protocols have been developed in three decades; and

WHEREAS, Since its inception, the Carson Leslie Foundation has sponsored a variety of fund-raising events; it secured a \$3.2 million partnership with the Cancer Prevention and Research Institute of Texas, and grants from the Carson Leslie Awards for Pediatric Brain Cancers are now supporting research at The University of Texas Southwestern Medical Center, Baylor College of Medicine, and the Texas Tech University Health Sciences Center; and

WHEREAS, The medical community has long recognized the need to expand research in pediatric brain cancer, and the Carson Leslie Foundation is playing a vital role through its commitment to increasing funding for these vital endeavors; now, therefore, be it

RESOLVED, That the House of Representatives of the 84th Texas Legislature hereby honor the Carson Leslie Foundation for raising funds to combat pediatric cancer and extend to all those associated with the organization sincere best wishes for continued success in their important work; and, be it further

RESOLVED, That an official copy of this resolution be prepared for the foundation as an expression of high regard by the Texas House of Representatives.



Carson kept a journal during his valiant fight for life. And when those tumors in his brain were relentless, he asked that his journal be published in hopes of giving a voice to the children too small to share what it's like to have cancer. 6 days before he died, *Carry Me* was published. We've sold thousands, it's in The Library of Congress and proceeds go to childhood cancer research.

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