



EVERYDAY HEROES



When these parents heard the unimaginable words “your child has cancer,” they grieved—then got to work to help find a cure

The Fight Of Their Lives

BY KIMBERLY HISS

ON A MONDAY afternoon in February 2007, Gretchen Holt-Witt took Liam, her 2½-year-old son, to his pediatrician because of some new habits—longer naps, pickier eating. After subsequent tests, the doctor called with impossible news: The ultrasound had found a large mass in Liam’s abdomen. After more testing at the hospital, Gretchen



From left: Barbara Canales, Nancy Goodman, Gretchen Holt-Witt, Frank Kalman, and Lisa Tichenor

learned that her son had neuroblastoma, a ruthless cancer that affects nerve cells.

Liam began three rounds of high-dose chemotherapy, then later underwent a 12½-hour surgery that left him on a ventilator. He faced more high-dose chemotherapy, multiple rounds of radiation therapy, retinoid therapy, and an antibody therapy so painful that it's given with an addictive, morphine-like drug. Meanwhile, Gretchen grappled with a startling fact that she discovered the first week Liam was in the hospital: Among diseases, cancer is the number-one killer of

children in the United States. "I asked Liam's oncologist how it was possible that I'd never heard that," says Gretchen, a 50-year-old public relations consultant from Califon, New Jersey. She recalls that the doctor told her that people don't care enough about kids who get cancer. They don't make headlines; their diseases don't get funding.

After Liam was declared disease free a few months later, his parents were overwhelmed with the impulse to give back. "Pediatric cancer is just so frightening," says Gretchen. To ask for help without scaring people off,

she decided to bake cookies—96,000 of them, over a few weeks—in exchange for donations. She and her husband enlisted friends to help, found a certified kitchen in Brooklyn, and launched a website to sell the cookies, which she packaged with a note to raise awareness about pedi-

atric cancer. As local news stations picked up the story, the batches quickly sold out.

"Everyone said, 'I had no idea cancer was the number-one disease killer of children. How can I help?'" Gretchen says. "I knew it wasn't that 'nobody cares.' They just didn't know."

After the ovens had cooled, Gretchen and her husband developed

a plan to help other people hold bake sales, assembled a medical advisory board, and began investigating the best research groups to support. In September 2008, they launched the nonprofit Cookies for Kids' Cancer, to raise research dollars for five powerhouse pediatric cancer centers. Bake sales and other fund-raising events began to spring up, eventually in all 50 states as well as overseas. Cookies for Kids' Cancer has since raised more than \$7 million for pediatric cancer research and has helped fund six new treatments for kids.

But as fund-raisers flourished,

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"How could I look Liam in the face if I couldn't say I had done everything I could?" says Gretchen.

Liam's disease recurred. He endured more surgeries, chemotherapy, radiation, and antibody treatments before his brave battle ended on a January afternoon in 2011.

"People ask me, 'Why do you keep doing this even though you lost?'" says Gretchen, also mom to Ella, eight. "One day, I'll see Liam again. I know he's going to ask, 'Mommy, did you make it better for other people?' How could I look him in the face if I couldn't say I had done everything I could? That meeting keeps me moving forward. And I can't wait to see him again."

To make a donation, visit cookiesforkidscancer.org.

THE ULTIMATE WIN

First-grader Jackie Canales was playing hide-and-seek at recess in 2006 when she ran into an oak tree. Fearing the girl had a concussion, the school nurse suggested Jackie get checked out. That night, Jackie's mother, Barbara Canales, a divorced mother of five and an attorney from Corpus Christi, Texas, found herself sitting across from a doctor who explained that a large tumor was pressing against her daughter's brain stem, spread like a star over the entire left cerebellum.

Barbara, 47, moved her daughter to Texas Children's Cancer Center in Houston and sent the scans to eight neuro-oncologists across the country. An initial surgery revealed that

the tumor was a devastating grade 3 anaplastic astrocytoma, and Jackie needed another crucial operation to remove all of it. Afterward, she had to relearn how to crawl and then walk. "I asked our oncologist if he knew anyone with Jackie's diagnosis who had lived, and he said he knew one," Barbara says. "I told him Jackie would be two."

The next year and a half was consumed with radiation treatments at the highest allowable dose and a blitz of chemotherapy. "To see your child taken into a chamber where she has to wear a mask and be strapped to a table is an unbelievable thing," says Barbara. "And Jackie did it 33 times. That can't possibly be the best we can do."

Barbara requested a meeting with the director of the Texas Children's Cancer Center to see how she could help. "They said, 'We need money. Period,'" Barbara says. With Jackie finally feeling better, Barbara committed herself to fund-raising.

In 2007, Barbara established the Ready or Not Foundation, named for the game that saved her daughter's life. (Now 14 years old, Jackie is cancer free.) Through car washes, barbecue cook-offs, casino nights, and fashion shows, Ready or Not has so far raised \$2.2 million for the Glioma Research Program at Texas Children's Cancer Center. Projects include developing nanotechnologies that deliver immune-based therapies directly to

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tumor cells and establishing a genomic database that researchers can use to identify new treatments.

To make a donation, visit readyornotfoundation.org.

A LIFESAVING LAW

In 2007, a pediatric brain cancer called medulloblastoma transformed Nancy Goodman's eight-year-old son, Jacob, from a boy passionate about sports and music to a wheelchair-bound patient running out of options. After Goodman, a Washington, DC, lawyer, contacted 36 teams of doctors and researchers across the globe, she realized that their underfunding was so profound, there was no help to be had.

"Jacob died on a Friday night in 2009," Nancy says. "On Saturday morning, I put my laptop on the dining room table to figure out how to make research more productive for children's cancers." That was the start of Kids v Cancer.

The first project grew from the decision that Nancy, 50, had made in her son's final days to donate his autopsy tumor tissue. Researchers used that precious gift to make significant advances. (One scientist discovered that primary and metastatic tumor tissues are genetically different, which affects treatment.) Nancy learned that many families would like to donate tissue as a "last stand against cancer," but doctors are reluctant to make such a sensi-

tive suggestion. So Kids v Cancer launched a program that facilitates donations at families' requests.

At the same time, Nancy knew that massive changes were needed in the landscape of drug development for rare childhood diseases. She enlisted help to draft a bill called the Creating Hope Act, then headed to Capitol Hill for the first time. She visited hundreds of members of Congress and staffers with fellow lobbyists, including Jacob's friends and his little brother, Ben, now 11. "Ben would talk about losing his brother and what he understood about the need for new drugs. He could make a senator cry," says Nancy, who also has a daughter, Sarah, three. After the bill secured 172 cosponsors, it passed into law on July 9, 2012.

Under the law, if the FDA approves a company's drug for pediatric cancer or other diseases, that company receives a priority review voucher (Nancy calls it a golden ticket) that can be applied to any other medication—such as a lucrative adult drug—to get it reviewed faster by the FDA. "We've given companies a way to do well by doing good," Nancy says.

To make a donation or to help write to members of Congress about pediatric cancer, visit kidsvcancer.org.

AN UNBREAKABLE BOND

When it became apparent that Lisa and Mac Tichenor's 19-year-old son, Willie, would not survive the

osteosarcoma he'd been battling for three years, they asked him on a February afternoon in 2006 what he wanted them to do after he'd passed away. His two answers: "Find new treatments for patients like me" and "Take care of my friends."

So the Dallas couple founded What Would Willie Want, the QuadW Foundation, an organization committed to advancing sarcoma research. They asked his brother, Taylor, now 29, and eight of Willie's friends who had been at his side throughout his treatments to serve as the board of directors.

They hosted an exploratory meeting with scientists from institutions across the country to better understand the research field. As the researchers talked about obstacles they'd all experienced, a common denominator emerged: The osteosarcoma tissue bank maintained by the Children's Oncology Group, which houses the samples investigators use for experiments, wasn't fully annotated, which meant researchers couldn't analyze all the samples.

QuadW funded the staff so they could gather the necessary information. "That has led to some terrific developments for research," says Lisa, 57. QuadW's other projects include sponsoring the next generation of sarcoma researchers by helping fund the Young Investigator Award. Today, the QuadW board has conference calls every month and in-person

meetings every six. Each member attends at least one medical conference a year to identify the foundation's next projects.

"These kids miss Willie like we do," says Lisa. "They're carrying out his wishes by coming up with so many great ideas for our grants. They tell me they feel like nothing is impossible."

To make a donation, visit quadw.org.

A DAD'S DEVOTION

After a CT scan in 2001 to investigate a lump on the side of Calli Kalman's torso had led to middle-of-the-night surgery, doctors determined the ten-year-old's mass was a malignant neuroblastoma. Though they removed it, the tumor came back the next year, requiring another surgery, and the year after, when it had become horribly tangled with the blood vessels between Calli's spine and kidneys. The risky but successful surgery that followed rendered Calli disease free for four years. But in 2007, the cancer recurred in Calli's leg, which led to radiation, more chemotherapy, a 20 percent drop in body weight, and the realization that none of this was working.

Calli's mother, Terry, became the breadwinner, and her father, Frank, 57, devoted himself to finding new therapies. (The Kalmans, from San Luis Obispo, California, also have twin daughters, Taylor and Taryn, who are three years younger than Calli.) Fearful of high-toxicity chemotherapy and radiation, Frank focused

on enrolling Calli in clinical trials for biological therapies, which train the body's immune system to fight off cancer. Finally, in 2010, Calli's doctors at Memorial Sloan-Kettering in New York City tried more drugs, including one called Revlimid, which has the potential to enhance immune function—and Calli has had no evidence of disease since.

Frank had been wondering how he could help others, and one day his mind was made up for him. "One Friday, three kids in a blog community I'm involved with earned their angel wings [passed away]—and that knocked me to my knees," Frank recalls. He decided to launch the Kids Cancer Research Foundation (KCRF), which raises money from private donors and works with medical advisers to fund research advances. "We pounded the pavement to find the most promising projects, just like I did when searching for treatments

for Calli. I go to conferences, monitor clinical trials, and network with doctors." KCRF's first grant helped an immunotherapy trial called CAR T-Cell therapy—an improved version of a therapy that Calli had once tried.

The foundation has started to make a difference in the lives of desperate families nationwide, and Calli's future is looking bright as well. In 2012, not only did the 23-year-old graduate from California Polytechnic State University, but Frank had the great joy of walking her down the aisle. "This is the happiest I've ever seen her. Thank God," he says. **R**

To make a donation or download Steps to Hope, a booklet about navigating your child's cancer, visit endkidscancer.org.

📖 *Download the Reader's Digest app for videos about these families' amazing stories, or watch them at rd.com/march.*

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THE SECRET LIVES OF FAMOUS FILMS

To ward off unwanted publicity, many Hollywood movies adopt a working title during production. What three flicks were once called:

WORKING TITLE	ACTUAL TITLE
<i>Planet Ice</i>	<i>Titanic</i>
<i>Group Hug</i>	<i>The Avengers</i>
<i>Everybody Comes to Rick's</i>	<i>Casablanca</i>

FROM MENTAL FLOSS