

“Your Child Has Cancer...”

No parent is prepared to hear those words. But it happens to dozens of families every day: There will be nearly 16,000 new cases of pediatric cancer this year. Read this inspiring story—and learn how you can help fight for more research to find a cure.

by ELIZABETH FOY LARSEN photographs by ANDREA VERDONE GORSEGNER

A month before her third birthday, a smattering of broken blood vessels began to appear, like pinpricks, around Natalie Gorsegner's eyes. She had a low-grade fever and just wanted to be held. Her father, Dan, took her to the doctor and was told she likely had a summer virus.

However, the following evening Natalie's mom, Andrea Verdone Gorsegner, returned home from work to discover that her daughter had a new symptom. “She had a broken blood vessel in the white of her eye,” recalls Andrea. The next morning, Natalie woke up with a tiny bruise at her hairline. Andrea decided she'd work a half day, then take Natalie back to the pediatrician. So she drove from her New Jersey home to Manhattan, where she was a photo editor. When she got to work, her phone was ringing; it was the pediatrician, returning her call. She patiently listened to Andrea's description of her daughter's symptoms.

“Bring Natalie in as soon as possible,” the doctor said calmly. Worried, Andrea quickly left her office, not knowing that she would never again return to work.

When they arrived at the doctor's office, Natalie had her blood drawn. But half an hour later, the pediatrician told Andrea that the machines in her practice weren't able to read the results and they needed to go to the emergency room. “We stared at each other for several moments, in silence,” recalls Andrea. “She didn't want to tell me what she thought it could be and scare me.”

But Andrea was scared. By the time she arrived at the E.R., Natalie's eye had swollen shut, and while they waited for test results, a slow stream of blood trickled from her eye and nose. “I was terrified,” says Andrea.

Then, a team of people gathered around Andrea and her dozing toddler. When one was introduced as a social worker, Andrea braced herself. The E.R. doctor who had examined Natalie had tears in her eyes.

“What's wrong with my baby?” Andrea asked.

The diagnosis was acute lymphoblastic leukemia (ALL), a cancer of the blood and bone marrow. Almost 2,500 children get ALL each year, making it the most common type of childhood cancer. Andrea called Dan, who was



Natalie Gorsegner, now 5, is in the maintenance phase of cancer treatment. Her mom, Andrea, took this picture and documented Natalie's two-year battle in photos seen on these pages: "Later in life I want Natalie to look back and remember this so she knows she can get through anything."

* A must-watch: Natalie's mom shares their journey in a special video at parents.com/cancer.



Andrea and Dan Gorsegner, with Natalie (left) and Hannah, at home on August 12, 2012. Natalie gets a nosebleed that day.



Two days later, Natalie, not yet 3 years old, is diagnosed with acute lymphoblastic leukemia.



In the next few months, Natalie will spike a fever and go to the E.R. so often that Dan and Andrea keep a hospital bag ready 24/7.

working on a job with his independent flooring business, to tell him the devastating news. “I kept saying, ‘Are they sure?’” he remembers. It would be almost an hour before Dan could get there to hug his wife and daughter.

The American Cancer Society estimates that 15,780 children and adolescents in the United States will be diagnosed with cancer in 2014. And among the 12 major types of childhood cancer, leukemias and cancers of the brain and central-nervous system account for more than half of all new cases.

Although the overall five-year survival rate has improved to 80 percent (from about 60 percent in the mid-1970s) pediatric cancer is still the leading cause of death in children after accidents. Approximately 1,960 children and teenagers in the U.S. will die of cancer this year. And that doesn’t include those who will die from secondary cancers or complications from their treatment.

In addition to these upsetting facts, Andrea was about to learn that there was another, deeply troubling truth about childhood cancer. At first, though, she was squarely focused on one thing: saving her daughter.

adjusting to a new life

Natalie’s cancer was diagnosed as “very high-risk” because of both her elevated white-blood-cell count and how her leukemia responded to therapy. Her treatment was often brutal. “Leukemia is different from other cancers because it’s a cancer of the blood and bone marrow, and not located in one organ as some other cancers are,” says Cindy Steele, M.D., Natalie’s primary oncologist at the Joseph M. Sanzari Children’s Hospital at HackensackUMC, in New Jersey. For the next month, Andrea and Dan felt as if Natalie had some type of drug pumped into her body every day. And since chemo compromises the immune system, Natalie often had to forgo normal activities. “We couldn’t have playdates, or take Natalie to family parties or the grocery store, or anywhere she could come into contact with a virus,” says Andrea. “We were basically at home or at the hospital for ten long months.”

Despite taking those precautions, Natalie had serious complications, such as the high fevers that indicate infection, an inevitable consequence for children with cancer. She made frequent visits to the E.R. One chemo

drug required a five-day stay in the hospital for every dose, to make sure it wasn’t damaging Natalie’s kidneys. Another medication made her so constipated that she spent all day sitting on the potty. “I’m tired of waiting. I’m never going to play again,” Natalie said, whimpering, as Andrea rubbed her back.

Because Natalie was only 3, Andrea and Dan had a hard time explaining to her what was happening. Says Andrea: “She was so young that we never sat down to tell her she had cancer.” Andrea and Dan took the fight day by day, explaining to Natalie that there were “yuckies” inside her. While children with cancer are often portrayed as brave, the reality of treatment was that it was painful and difficult. Andrea often had to help hold Natalie down for a procedure. “She’d yell out, ‘Why?’ I tried to explain that this medicine was going to make her feel better,” says Andrea. “But she just couldn’t understand how something that hurt would make her feel better.”

At the time of Natalie’s diagnosis, her big sister, Hannah, was a kindergartner, and the rhythm of her life was shattered too. “We went from



Natalie puts on a rainbow tutu she wore every day before she got sick. “We began referring to good days as ‘tutu days,’” says Andrea.



As Natalie’s hair starts to fall out that winter, Andrea reassures her, “I can see more of your sweet face!”



On days when Natalie’s too tired to walk, Dan gives her rides on her IV pole.

having a schedule to not being able to promise who was going to pick her up from child care,” says Andrea.

After six months, when Andrea ran out of vacation and personal-leave time from her job, it was clear she wouldn’t be returning to work, so her family lost her health benefits that helped pay Natalie’s medical bills. While Dan was in the process of upgrading his small company’s insurance policy, they went on COBRA for four months, at a cost of \$1,152 a month. As their bills mounted, they sold their home and moved to a less-expensive one. Friends and family pitched in with fund-raisers and donations. Andrea’s parents raised \$16,000 through yard sales. “Especially for young parents, cancer can wipe out a family’s savings,” says Dr. Steele.

becoming an advocate

Although he was wracked with worry about Natalie, Dan still had the daily routine of working. But Andrea’s whole world had changed dramatically overnight. Suddenly, she had no colleagues, no morning Starbucks run, no predictable pattern to her day. Her life was cancer now. She dealt with her anxiety by learning as much as she could from other “cancer moms” she

met on Facebook and by searching online for advances in treatments. At first, Andrea’s laser focus worried Dan. “She was living it all the time and I wanted to put Natalie’s cancer in the corner—it was just too hard for me to confront head-on,” he says.

Then one night, three months into Natalie’s treatment, Andrea was in bed with her iPad when she came across an award-winning documentary short film called *The Truth 365*. Suddenly, what had been intensely personal got political. As she watched stories of families like her own, Andrea was stunned by the main message: Research for pediatric cancers is severely underfunded in the United States. A little more than 4 percent of the National Cancer Institute’s annual budget goes toward childhood cancers. The Leukemia and Lymphoma Society allocates 8 percent of what’s donated to research for cures for kids. In the past ten years, there have been nine drug approvals specifically indicated for pediatric cancer, which is a fraction of the number of adult cancer-fighting drugs approved each year. Even though childhood cancers do account for less than 1 percent of all cancers annually, they remain the leading cause of

death by disease in children.

Until *The Truth 365*, Andrea had never thought of childhood cancers as diseases that required research and treatments that were different from those for adult cancers. “I was so angry I was crying,” she says. “How can the government get away with allocating so little funding for our kids?”

Certainly, developing drugs for childhood cancer isn’t easy. And because there are a smaller number of pediatric-cancer cases, it’s more complicated to do the clinical trials that are needed for most FDA approvals. Children also metabolize chemotherapy drugs differently than adults do. “They are not just miniature adults,” notes Dr. Steele. However, part of the problem has to do with profits. Almost 60 percent of medical research in the United States is funded by pharmaceutical companies, not by the government. Because children’s cancers impact far fewer patients than adult cancers do, the pharmaceutical industry doesn’t have a financial incentive to invest money in developing new chemotherapy drugs for children because there isn’t a way for it to get a return on the investment, says Peter Adamson, M.D., of The Children’s



The hospital oncology team likes to empower kids by encouraging them to help. Here, Natalie assists with drawing her blood.



Natalie, nearly seven months into treatment, on a double-tutu kind of day



Dan shaved his head to show Natalie he doesn't think hair's a big deal.

Hospital of Philadelphia, a leading hospital for pediatric-cancer research, and chair of the Children's Oncology Group, the world's largest organization devoted to childhood and adolescent cancer research.

That economic logic is cold comfort to parents whose children have lost their life to cancer. But the lack of research also enrages parents of children who survive, because kids often suffer from lifelong side effects. "Most of the treatments we use today rely on drugs that were discovered more than 40 years ago," explains Dr. Adamson. "We have a long way to go to find less-toxic therapies that will truly return children to full health."

In recent years, the government has passed several laws to persuade and sometimes force pharmaceutical companies to focus more attention on children: The Best Pharmaceuticals for Children Act provides incentive to drug companies to conduct pediatric studies; the Pediatric Research Equity Act requires them to study products (like adult cancer drugs) that might be used in children; and the Creating Hope Act of 2011 offers market incentives to develop medicines for

NEW HOPE FOR CHILDHOOD CANCER

Advances in science, including gene research, are more promising than they were even five years ago. "The pediatric-cancer community knows that making an investment will have a tremendous payout in terms of better therapies," says Dr. Peter Adamson, who emphasizes that research is essential to finding better treatments, such as a recent study from the Children's Oncology Group that found that children with a rare type of lymphoma could be put into remission using a single medicine. This is how you can make a difference:

BE INFORMED

Watch *The Truth 365*. Tell your friends about it and share it on Facebook and other social media.

GO GOLD

By wearing a gold ribbon (any time of the year, including during September, which is Childhood Cancer Awareness Month), you show your solidarity with the advocates who are working to raise awareness and money, and invite others to ask questions. You can explain that research for childhood cancer is severely underfunded.

ENLIST YOUR KIDS' HELP

There are a number of organizations (some started by children) that encourage kids to help raise money for both cancer research and treatment. You can:

- ✦ **Sell cookies.** Kids can organize a bake sale or sign up for a fun run. (Cookies for Kids' Cancer; cookiesforkidscancer.org)
- ✦ **Rally.** Children can "rally" to raise funds in multiple ways, from asking for donations in lieu of birthday gifts

to participating in a loose-change collection. (Rally Foundation; rallyfoundation.org)

✦ **Set up a lemonade stand. Empower kids to "mix, pour, find a cure!" (Alex's Lemonade Stand Foundation; alexlemonade.org)**

✦ **Shave your head! Learn how you can organize a head-shaving event in your community as a fund-raiser. (St. Baldrick's; stbaldricks.org)**



Natalie spends long hours on a spring day getting a blood transfusion.



Since Natalie's diagnosis, she loves to play doctor. Her doll gets every procedure Natalie does, including surgery to install a chest port.



Through two tough years of treatment, sister Hannah "always lights Natalie right up," says Andrea.

rare pediatric diseases. "For diseases like children's cancers, we need a real collaboration among academia, pharmaceutical companies, the government, and, very importantly, patient-advocacy groups," points out William Chin, M.D., executive vice president of science and regulatory affairs at the Pharmaceutical Researchers and Manufacturers of America. "With the progress in science that we can make, we should no longer have to live with the fact that 20 percent of kids who have cancer die. We want 100 percent of kids to survive cancer."

Andrea and Dan decided to join the campaign for more funding for pediatric-cancer research. They started a Facebook page called "Infinite Love for Natalie Grace" and a website encouraging visitors to donate any amount—even a dollar—for pediatric-cancer research, all of which goes to the nonprofit Arms Wide Open Childhood Cancer Foundation. (See "Help Fight Cancer With \$1" at right.) In five months they raised \$110,000. "I can't control what is happening in Natalie's body," says Andrea. "But this made me feel like I finally had a weapon in this fight."

looking to the future

Natalie, now 5, is scheduled to be finished with treatment this month. However, it will be five years before she's considered cured of cancer. She loves puzzles and animals, and playing with Hannah. She still has challenges related to her treatments, but Andrea and Dan agree that their family's battle



HELP FIGHT CANCER WITH \$1

If you wish to contribute to Andrea and Dan's cancer-fundraising efforts, you can donate at willyouendusadollar.com.

All proceeds will go directly to the Arms Wide Open Childhood Cancer Foundation, to fund therapies and treatments.

Or send a check made out to "Arms Wide Open/The Truth 365" to: Infinite Love for Natalie Grace
P.O. Box 4064
Middletown, NJ 07748

has made their bond stronger. "I appreciate my family and have a better perspective on the day-to-day stresses," says Dan. "How many people Andrea has impacted and what she's done—she's amazing."

While it surprises some to hear Andrea and Dan consider themselves fortunate, they know families who have suffered much more. Julianna Edel, a friend of Natalie's from their treatment clinic, died last year at the age of 12 from Ewing's sarcoma, a bone cancer that mainly affects children and teenagers. "People put their head in the sand about childhood cancer because it's too devastating to consider," says Julianna's mom, Tina.

One perception that frustrates parents like Tina and Andrea is the idea that pediatric cancer is rare. "Shark attacks are rare," says Andrea. "Tens of thousands of kids in treatment every year is not rare." But the National Institutes of Health considers any disease that affects fewer than 200,000 people to be rare. Says Andrea: "As a result, we can't get the funding we need."

It's the very thing that drives Andrea to continue to fight: "Every child with cancer should survive."