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'It turns your life upside down'

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Young boy treated in New York monthly for rare cancer



Nick Lovejoy

Ty Murray, 3, held his arms out like Buzz Lightyear from the "Toy Story" series as he did the character's famous line, "To infinity and beyond." He jumped on his dad's back and giggled when his mom hugged him. His dark eyes lit up as he handed plates of plastic food to guests at his grandparents' house on Line Street, where they watch him a couple days a week while his parents work.

Ty's parents, though, kept a close eye on the little boy who has been in and out of hospitals since he was 16 months old. He was diagnosed with Stage 4 neuroblastoma. The illness is a rare type of childhood cancer that is mostly diagnosed in toddlers. Around 650 children are diagnosed with neuroblastoma each year, according to the American Cancer Society.

"He's thriving and running around," said Carmen Hernandez Murray, Ty's mother. "To look at him, you wouldn't know he had cancer. He's a normal 3-year-old who likes to play, but he is so used to the hospital."

'It turns your life upside down'

Ty Murray, 3, suffers from a rare form of cancer called neuroblastoma. His parents Scott and Carmen travel with him to New York once a month for treatment in a clinical trial. Here, he plays in the front yard of his grandparents' Hollister home, where they babysit him a couple times a week.

A rare and aggressive illness

Ty's doctors pronounced that there was no evidence of cancer in April, but his parents are still hopefully cautious.

"One of the other kids just relapsed after 20 months," Carmen said. "We saw him two weeks before and he was fine. You couldn't tell."

Carmen mentioned another boy who went through the stem-cell transplant with Ty who had no evidence of the disease who died in July.

"We've met so many families. We know so many kids who have died," she said. "We don't want to read that we have no more options."

Carmen and Scott Murray, Ty's father, share the same story of how they were blindsided by his serious diagnosis.

"He had no symptoms, just low-grade fevers," Carmen said. "He was fussy, but I was a new mom. I took him to the pediatrician and they said he is just colicky."

Scott added that the doctors thought the fever was related to teething. He took his son to the doctor for the second time in a week when the little boy would only lay on his dad's chest and didn't want to play.

"The doctor did notice his stomach was distended," Scott said.

The doctor sent the family for an x-ray and then to the emergency room because they thought he had an enlarged liver.



"Later on, they said he had a tumor, Wilms'," Scott said. "They showed us it had a 90-percent survival rate, and that was devastating."

With further testing, the doctors discovered Ty had neuroblastoma, a type of cancer of the sympathetic nervous system.

"Research tells you there is a 20- to 30-percent survival rate," Scott said. "It turns your life upside down. The only important thing is to get him healthy."

Carmen remembers vividly getting the news of her son's diagnosis at Stanford Hospital.

"They said no, he has neuroblastoma. It's a poor prognosis, stage 4," she said. "I remember all these words and just saying neuroblastoma. It was heart breaking. You would never think cancer."

Long-distance treatment

Since the diagnosis, Ty has undergone an aggressive treatment plan. He has endured radiation, high-dose chemotherapy, a stem-cell transplant and is now part of a clinical trial at Memorial Sloan-Kettering Cancer Center in New York.

When he was first diagnosed he had a port put in with two plastic lines hanging out of his chest where doctors drew blood and administered his chemo treatments. Carmen and Scott found themselves overwhelmed with all the medical terms and procedures. Scott said despite Carmen's bachelor's and his master's degree, they would need a degree in biology to understand everything. They had to learn how to keep Ty's port clean and to keep it from getting infected. Before every bath, they had to wrap it up in Saran wrap. He now has a different port installed under the skin, so he can swim and bath without all the preparation.

The first year of treatment was especially hard.

"We had to keep him isolated the first year because he was going through chemo every month, so his immune system was down," Carmen said.

Looking at Ty now, Scott recalled that same time.

"There was a month period where he didn't want to acknowledge or look at anyone," Scott said. "He was just miserable."

Scott added that the doctors said most adults could not survive the treatment.

"Throughout this whole process, he's handled things well," Scott said, describing how Ty knows to lift his arm for nurses to have his temperature taken. "He knows the routines. The nurses say he is the best patient because he knows the routines, but that is kind of sad that most of his life has been in and out of the hospital."

His latest treatment, an anti-body that attacks the neuroblastoma cells, brings the family to New York once a month for a week. The trial continues through May 2011.

"It's just something you have to do," Carmen said. "It's not even a question. We are going and we will do whatever it takes to get him there. We are pros at flying with a toddler."

Carmen said Ty looks forward to the trips to New York, despite his time in the hospital. He likes seeing friends he's made at the hospital. He dons a blue New York Yankees cap, shading his dark brown eyes and covering his short, dark hair. His dad said he likes New York-style pizza.

Support from many sources

Carmen and Scott both work for the Santa Clara County probation department where their employers have been flexible about their time off. Carmen took a year off when Ty was first diagnosed and now works part time so she can get Ty to local appointments. Through a program at the county, other co-workers were able to donate sick leave to the couple.

"We've been 10 times since February or March (2009)," Scott said, of traveling to New York. "It's never been a problem. They've been really understanding."

Scott used up 600 hours of vacation time and sick leave, then had 1,100 donated to him.

"Some folks gave money or gift cards to [restaurants] in Palo Alto, by Stanford," he said.

Their family has also been supportive. Scott's father, who lives in Northern California, stays at their Gilroy residence when the family goes to New York. His mother and brother, who live in the Bay Area, come down to visit. Carmen's family watches Ty when they have to work and she said her siblings have offered emotional support for her.

Carmen started an online journal when they first started going to New York.

"I wish I would have started right when he was diagnosed," she said. "Initially, we thought we were going to be there for at least four months straight."

The doctors kept Ty in New York for two months, and then said he could come back and forth.

"We wanted to let family and friends know what was going on as opposed to calling everyone," Carmen said. "I like it. It's a good outlet for me ... when you get hit with a lot of bad news and don't want to deal with it (it's hard to maintain), but then again I think about it and it's a good outlet for me to let it out there."

Some of the other patients and their families, some from other countries, have been in New York for years. Many of the parents have bonded

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through the Band of Parents Foundation, which raises money and awareness of neuroblastoma. Carmen is planning a fundraiser for the group in September (see sidebar above for details.)

"We are very fortunate we live here," Carmen said. "It's a burden, but at least we are close enough we can come home."

The time away from Sloan Kettering allows the family to get back into some semblance of normal life, Scott said.

"We stayed at the Ronald McDonald House," Carmen said. "You meet a lot of families and a lot of sick kids. It's the same at the hospital. You hear stories that so-and-so had to go home on hospice. It's a constant kind of bad news. It makes it more depressing."

The family does have travel plans to somewhere other than New York. In October, Ty has been granted a trip to Disney World from the Make a Wish Foundation.

"We'll probably go to Sea World then, too, Carmen said.

When asked what keeps them optimistic, the couple has a long list.

"I can't imagine doing it without the support," Scott said.

"We joke about things still," Carmen added. "You have to have a sense of humor. My faith in God has strengthened, if you can believe that. It's like I'm looking for direction."

As for Ty, he seemed oblivious that anything is wrong as he jumped around the front lawn of his grandparents' house, in his Yankees cap and a blue T-shirt with the words "Beat Cancer" on it.

Team Ty's 'Help Us Find a Cure for Neuroblastoma'

Carmen Hernandez Murray is organizing a fundraiser for neuroblastoma research through a group called the Band of Parents Foundation. The money raised goes straight to doctors at Memorial Sloan-Kettering Cancer Center for research into treatment of neuroblastoma.

Team Ty's "Help Us Find a Cure for Neuroblastoma" dinner and gala is Sept. 24, from 6:30 p.m. to midnight at the Wyndham Hotel, in San Jose, 1350 North First St. Tickets are \$80 and include a salad, entree, wine, dessert, music, raffle prizes and a silent auction. The family chose September for the event because it is Childhood Cancer Awareness Month.

Some of the prizes include two tickets to the World Series, two round-trip tickets to anywhere JetBlue flies, a week stay in Mazatlan, Mexico and gift certificates for Santana Row.

Murray has four people helping her with the fundraiser, but it has been a lot of work.

"I didn't realize how much there is to do," she said. "Coming up we may go to New York next weekend so I will lose a week."

But Murray said she is dedicated to the cause.

"Band of Parents have raised so much money," she said. "That's why we wanted to do the fundraiser. We don't want to be in that predicament of hearing, 'Sorry, we can't help you.'"

According to a study from the National Cancer Institute, less than 3 percent of funding goes to childhood cancers.

"There really isn't any funding," Murray said. "It's up to the parents."

For more information or to purchase tickets, visit www.team-ty.org or call Murray at 408-396-8112.

What is neuroblastoma?

Information courtesy of the American Cancer Society

Neuroblastoma is a form of cancer that starts in some types of primitive nerve cells found in embryos and fetuses. The tumors start in the sympathetic nervous system, which includes nerve fibers that run along the spinal cord, clusters of nerves called ganglia and nerve-like cells found in the adrenal glands.

Neuroblasts are a normal part of the sympathetic nervous system, but sometimes the cells do not mature fully before a baby is born. In most cases, the cells will continue to grow and mature into nerve cells or disappear. But in some children, the cells continue to divide and grow into neuroblastoma due to a DNA mutation acquired early in the child's development.

The average age of children who are diagnosed with neuroblastoma is 1 to 2 years of age. Nearly 90 percent of cases are diagnosed by age 5.

It accounts for about 7 percent of all cancer in children, and about 650 new cases are diagnosed in the United States each year.

In 2 out of 3 cases, the disease has already spread to other parts of the body when it is diagnosed, resulting in a poorer prognosis and the need for more aggressive treatment.

Researchers have not identified any risk factors for neuroblastoma, though in 1 to 2 percent of cases there is a heredity link.

Neuroblastoma can be hard to diagnose because outward symptoms often do not show up until the disease has advanced.

The most common symptom is an unusual lump or mass, usually found in a child's abdomen. The child may not want to eat or complain of feeling full or having pain, but the lump itself is not usually tender to the touch.

Other symptoms caused by the hormones secreted by the tumor include fever, in 1 out of 4 children; constant diarrhea; high blood pressure;



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rapid heartbeat; reddening of the skin and sweating.

The tumor can cause swelling in other parts of the body, such as the legs, or the scrotum in males.

If the tumor has spread to other parts of the body, some signs may include bone pain, blue or purple bumps that look like small blueberries on the skin, or tiredness, irritability, weakness, frequent infections and excessive bleeding from small cuts or scrapes, due to low blood cell counts.

The five-year survival rate for cases diagnosed at an advanced stage is 20 to 40 percent.

For more information on neuroblastoma or other types of cancer, visit www.acs.org.

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Melissa Flores City Editor



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