

The fight of their young lives



Sarah Grillo holds her daughter, Caitlyn, who is undergoing chemotherapy for neuroblastoma, a cancer of the nervous system.

First-time parents are determined to save infant daughter from a rare cancer

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It's a Wednesday in early February and 10-month-old Caitlyn Grillo is bobbing her head to the harmonic tones of "One, Two, Buckle My Shoe."

Sitting beside her parents in their Brockport home, Caitlyn looks like any other infant, playing with her nursery rhyme sing-along book. She can whine and moan with the best of them. She points and appears awestruck anytime a stranger enters the room. And she's practically hypnotized by a living room full of toys.

On this day, there's one item in particular that Caitlyn wants to play with. But her parents, Eric, 26, and Sarah, 25, are adamant that she not touch it.

Poking out from under Caitlyn's shirt is a plastic tube that leads to the central line in her chest where she receives chemotherapy once every three weeks.

On Nov. 4, 2008, Caitlyn was diagnosed with neuroblastoma, a cancer of the nervous system, putting Eric and Sarah in the midst of every parent's worst nightmare.

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Chemo has reduced the size of Caitlyn's tumor, and movement in her legs has improved.



BENEFIT FOR CAITLYN

WHEN: 2 p.m. Sunday, March 8

WHERE: The Jukebox, 5435 W. Ridge Road, Spencerport

WITH: The Spins, Big Eyed Phish and Ladder Theory.

COST: Donations welcome.

INFO: www.caringbridge.org/visit/caitlyngrillo

"You do everything you can to keep your child healthy, but you can't prevent cancer," Sarah says. "You feel so helpless. She goes through the testing and you see her scream and cry. I hate watching her go through all of this. She should be having a happy, healthy childhood, but instead she's in the hospital most of the time."

The situation has also affected friends and family, who have rallied to set up a benefit show for Caitlyn on March 8 at The Jukebox in Spencerport.

News of Caitlyn's illness came just four days after she had dressed up as a kitten for her first Halloween. Sarah and Eric took their daughter in for a routine checkup. The couple expressed concern over a lack of movement in Caitlyn's legs and that she wasn't urinating regularly. Caitlyn's doctor sent them to Strong Memorial Hospital immediately, where she underwent several days of testing. Results revealed a cancerous mass on her spine, which was determined to be neuroblastoma.

Though the disease is rare (about 650 new cases are reported in the United States each year), it is the most common cancer in infants and the third most common type of cancer in children, according

to the American Cancer Society.

Tests showed that Caitlyn's tumor — a Stage 3 (out of four) neuroblastoma — was wrapped around her spine and was pushing against her lungs to the point where one of them had nearly collapsed.

However, the cancer had not spread to any other part of her body. And because it hadn't advanced, doctors did not want to subject her to radiation. Surgery, meanwhile, carried the risk of paralysis, so her medical team determined that chemotherapy was the best option.

"I remember crying hysterically in the waiting room," Sarah says. "I just wanted to faint."

She and Eric took turns staying at Goli-sano Children's Hospital at Strong for two weeks, sleeping on a pullout chair, hoping and praying.

Before Caitlyn's diagnosis, the Grillos were living the life of a typical young, suburban family. Sarah and Eric met through friends while attending Monroe Community College. They'd been married almost three years, and around the time that Caitlyn's illness began to emerge, they'd just bought their Brockport home — their first.

Sarah was working at First Niagara Bank and Eric was a patrol officer for the Rochester Police Department.

However, now, because of Caitlyn's fre-



quent doctor's appointments and treatments, Sarah has taken a part-time role at the bank. And due to stress, Eric has taken an administrative desk job, temporarily, with the police department.

"It's difficult," Eric says. "You feel anger in the beginning, but after awhile you realize you can't feel sorry for yourself. You realize the only thing you can do is be strong and think positive."

The couple has set up a Web site in support of Caitlyn and to raise awareness of neuroblastoma (see info box). The site runs through Caring Bridge, a nonprofit Web service that connects family members and friends during a crisis. Caitlyn also has two MySpace pages; they were set up by Sarah, who jokes, "My daughter has more friends (on MySpace) than I do."

Donations made at the benefit show will help offset the costs of Caitlyn's in-home treatment and medication.

The show will feature performances by local bands The Spins, Big Eyed Phish and Ladder Theory.

"I wanted to help out any way I could," says David Inghima, 34, guitarist for The Spins who works with Caitlyn's aunt. "When I approached my band

about doing a benefit for Caitlyn, everyone was in a 'let's do it' mentality. The same went when asking the The Jukebox and the other two bands for their help."

In the meantime, Caitlyn's condition continues to improve. Her tumor has decreased in size after each chemotherapy session, and she is moving her legs more every day, which is evident in the way she gets around the house in her new walker.

Aside from a few empty patches of hair on her head from the chemotherapy, it's nearly impossible to discern that Caitlyn is sick.

Crouching down on the floor in the living room to engage Caitlyn in baby talk, Sarah sums up the new credo her family has adopted — mother to daughter.

"We're gonna kick cancer in the butt. Aren't we?" Sarah says to Caitlyn, before reaffirming — "Yes, we are!" ♦



Above, Caitlyn's dad, Eric Grillo, caresses his daughter as she plays. At left, Eric clears the central line in Caitlyn's chest, through which she receives chemo.