

THE TWO RIVER TIMES™

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Kristen Gillette: Searching for a Cure

Kristen Gillette is a woman with a mission. Since 2006, the Oceanport resident has been channeling her grief over the death of her 9-year-old daughter, Kortney, into raising funds for research and awareness of pediatric brain tumors.

Her mission, she stresses, is to help others, find treatments and a cure for brain tumors in children and to ensure that the memory of her fun-loving, always ready-to-go-out-and-play daughter lives on.

Since its inception, The Kortney Rose Foundation has donated \$748,000 to pediatric brain tumor research being done at The Children's Hospital of Philadelphia (CHOP). The funds have been raised through many events, like the one coming up Saturday and Sunday, May 3-4, at Turning Point restaurants.

Gillette's mission is one that her husband Rich says Kortney may not have liked because Gillette has put all her energies into her foundation work and has very little time to go out and play. But, Kortney would have wholeheartedly approved of the idea of helping others. Her 50-year-old mother is driven by the goals of the foundation and is intent on its success.

Gillette, who grew up in Rumson, was no stranger to heartache when her daughter was diagnosed with an inoperable brain tumor. Her mother died suddenly from a heart attack when Gillette was just 21. "That kind of helped formulate my life, probably made me a little bit tougher and made me understand the importance of things earlier in life," she said.

Her mother's death was followed a few months later by the death of her cousin, "who was more like my brother." He died of a brain tumor.

"I experienced severe grief at such a young age. I knew what grief was but when I

lost Kortney, it was immeasurable," she said. She also knew that she was able to work her way out of her overwhelming grief after her mother died. Her aunt, who lost her son to a brainstem glioma, also was a role model. "I pulled from her greatly when I lost Kortney. Here was a woman who lost a child and went on to survive."

Looking back, Gillette sees another experience that helped her channel her energies when she set to work on The Kortney Rose Foundation. As a student at Susquehanna University, she was determined to start a soccer club at the school – and even wrote that in her college application. She did so in her sophomore year.

"That was my first taste of 'I want to do something. I set the things in motion. It gets accomplished.' I think that again, being brought up with an entrepreneurial spirit (that infused her family), helped shape me," she said.

After graduation, she worked in jobs that were pointing her toward a career in finance. She then married and started a family. Daughter Kasey was born in 1993, Kortney in 1996.

It was during a vacation visit to Gillette's father in North Carolina, when Kortney was 5, that the little girl was severely injured when a truck slammed into the rear of the stopped car in which they were traveling. Kortney "almost died. She had a skull fracture and traumatic brain injury and had to be airlifted to UNC (University of North Carolina Hospital) ... She was in ICU for nine days and was unconscious for many of them ... She had to go through physical therapy, speech therapy and occupational therapy for about seven months.

"It was a really traumatic experience," Gillette said.

While Kortney recovered significantly and headed to kindergarten that fall, she had some lingering issues, including weakness on her left side.

Three years later, Kortney was "weaker and having trouble holding her pencil correctly ... We figured it was from the car accident," Gillette said. "One day she just complained about headaches and came in from playing. This child never stopped playing ... She would come in and lay on the couch and say, 'I have a headache.' Ten minutes later she would go out again.

"A few days later, she was out playing in the snow before school ... I was looking at her from the front porch and I could see that her one eye had crossed, turned all the way in," she said.

Gillette set up an eye doctor appointment. The doctor then recommended that Kortney get an MRI.

It took two trips to hospitals to get the test taken. While Gillette was in the waiting room during the second trip, she was called to a nearby lobby phone.

"It's the eye doctor on the phone. She says, 'Kortney has a brain tumor. It's a brainstem glioma. You can't operate on it. The only thing you can do is radiation and chemo,'" Gillette said. "I am in front of all of these people, hysterically crying and she is saying, 'I know the doctor you should go to, I've seen this before.' I was in shock. *Over the phone*. I become inconsolable."

She was in such shock that she couldn't remember her husband's phone number when she tried to call him.

"The next day we went into New York to see a specialist," she said. "Dr. (Jeffrey) Allen – he's one of the best guys in the country –

good quality of life right up until the end. The last 21 days were the toughest. She had a really bad seizure at the end of March" and was transported to CHOP. She was heavily medicated to stop the seizures. Kristen and Rich Gillette slept in her room each night and didn't leave her side. "It was horrible," Gillette said.

It also was very hard on Kasey Gillette who turned 13 years old while her sister was in the hospital.

Diagnosed in December 2005, Kortney died April 27, 2006. "She would be 17 now and that just blows my mind," Gillette said. "When I see her friends I get so taken aback at how old they are."

While Kortney was ill, a group of Oceanport residents came together to create a foundation called Caring for Kortney. "It was amazing," Gillette said. "Caring for Kortney was the precursor to The Kortney Rose Foundation.

"I knew Kortney wasn't going to make it. From the day she was diagnosed, I started grieving for her so by the time we lost her, it was time to take action," Gillette said. "I immediately went to work on The Kortney Rose Foundation. She died in April; we had our first 2-mile walk in September.

"I put all my grief, every ounce, into it. It was my new mission in life ... I say, it saved my life. It was the only thing I could do and function," she said.

Gillette also found strength in caring for her daughter Kasey and showing her "life was going to be OK."

The organization began under the Caring for Kortney banner while The Kortney Rose Foundation was working to get its tax-exempt charity status. The first funds went toward purchasing new playground equipment at the Wolf Hill Elementary School in Oceanport where Kortney was a student. It was a fitting tribute to the child who loved to play. The space was renamed Kortney's Playground.

Kortney's illness offered the Gillettes a view of the lack of funding for brain tumors, particularly those that impact children. Fundraising then was aimed squarely at assisting researchers.

"I wanted to shout from the rooftops that we needed better treatments and cures," said Gillette, who also has been able to get May designated as Brain Tumor Awareness Month in New Jersey.

She met with doctors from CHOP who told her only 4 percent of funding goes to study childhood cancer.

Gillette said a recent tour of CHOP's facilities has let her know that "our money is being well spent" and will enable the hospital to go after grants to move the research along.

"In my wildest dreams ... I would love to find a cure for brainstem glioma," Gillette said. "But, ultimately, I just don't want to see these kids suffer anymore."

Gillette, who is "always looking forward," has had trouble seeing the difference she and the foundation have made. It has been her husband and friends who have made her see that there has been an impact.

She credits her husband's full support for being able to do what she has done. "He is the framework that keeps me going ... I couldn't do what I do without him."

The next fundraiser for the Kortney Rose Foundation will be 8 a.m. to 3 p.m. Saturday and Sunday, May 3-4, at Turning Point restaurants. Patrons who donate to the foundation will receive a gift card for use during their next visit. The event, called "Great Food for a Great Cause," raised about \$20,000 for research last year.

Additional information is available at www.thekortneyrosefoundation.org.

By Michele J. Kuhn



"I put all my grief, every ounce, into it. It was my new mission in life ... I say, it saved my life. It was the only thing I could do and function."
– Kristen Gillette

says there's no treatment for this. She has less than 5 percent chance of survival for two years and the only thing I can tell you to do is they have (clinical) trials you can try."

Kortney began six weeks of radiation at CHOP. After staying in Philadelphia for a few days for the short daily treatments, the family decided it was better to drive to CHOP from Oceanport at 5:30 a.m. each day for the hospital's first radiation appointment. After Kortney received her 20-minute treatment, they drove home and Kortney would be in school by lunchtime.

Kortney took it all in stride. When Allen initially told her the treatment would be that "they would shine bright lights on her, she said, 'I'm not afraid of bright lights ... The only thing I don't want is to have everyone look at me like the kid from the car accident again.'

"So, we knew the best course for her was to pretend everything was OK and let her play and do everything she wanted," Gillette said.

"She only survived for four months from the time she was diagnosed. She really had a