



# HEALTHY LIVING

THE WEEK OF JUNE 3 - 10, 2011

## Remembering Kortney Rose

### A mother's loss sparks an effort to find a cure for childhood brain cancer

By Marion Lynch

**A**T A GRADUATION ceremony coming up this month at Wolf Hill Elementary School in Oceanport, some of the graduates and their teachers will be wearing rose ribbons to honor the memory of their classmate who didn't live to share in one of childhood's joyous milestones.

Kortney Rose Gillette was an active, healthy child when she celebrated her ninth birthday on November 27, 2005. A third grader at Wolf Hill, she played soccer and basketball, and enjoyed spending playing with her many friends.

Weeks after her party at Fun Time America, Kortney's parents, Kristen and Rich Gillette, noticed that she would come in from playing outside to lie down on the couch. She said that her head hurt, but minutes later she would head back outside to play.

When Kortney came in from playing in the snow, Kristen noticed that her daughter's left eye turned inward. She brought her to an optometrist who ordered an MRI.

A look inside Kortney's brain revealed the tragic news that became the Gillette family's worst nightmare. A brainstem glioma, a rare but deadly tumor was growing deep inside her brain.

A neuro-oncologist told the Gillettes that little could be done to stop the tumor's deadly assault on their daughter's brain. The tumor was inoperable because of its location. Radiation could buy Kortney some time, but not much.

"Brainstem gliomas very rare; only about 100 kids a year get them and none of them live," says Kristen. "It cannot be operated on. (The brain stem) controls breathing and heart rate - they can't touch that area."

Because the area cannot be biopsied, doctors cannot design chemotherapies specific to the cancer cells. "Because they can't get the cells, they just throw things at it to see what works," she says.

The next stop for Kortney was Children's Hospital of Philadelphia (CHOP), where she was placed under the care of Dr. Jean Belasco, who treated her with radiation and a drug called Iressa, which was in clinical trials. The radiation would

slow the tumor's destructive growth help give Kortney the best quality of life possible.

For two weeks that January the Gillettes stayed in Philadelphia while Kortney underwent radiation. But Kortney missed school and her friends, so the family went home to Oceanport and began a grueling daily routine. They woke at five and drove to CHOP for Kortney's radiation treatments. When she was done, it was back in the car to Oceanport so that Kortney could attend school, in time for lunch and her afternoon class.

"Thankfully she had a really good quality of life," says Kristen. "She was amazing. She would sleep on the way up and sleep on the way back. She loved school and she wasn't missing it."

Radiation ended and a mid-March MRI showed that Kortney's tumor had shrunk. Even though the news was good, the Gillettes knew that Kortney's tumor would likely grow again.

Time was not on Kortney's side. On April 6, while the family was preparing for a trip to the Atlantis resort with the Make A Wish Foundation, Kortney woke up screaming in pain. She was transported to CHOP by helicopter, where several days later the bad news was confirmed: Kortney's tumor had spread.

What followed was what Kristen describes as "21 days of

hell." Kortney was in tremendous pain and had seizures. All that the doctors could do was medicate her to alleviate the pain. All that Kortney's parents could do was wait for the inevitable.

Kortney died on the night of April 27, 2006, just five months after she celebrated her ninth birthday.

What do you do when your youngest daughter's life is tragically cut short? The Gillettes turned their grief into action. The

*Continued on Page 19*



Team Kortney at the Today Show promoting Brain Tumor Awareness Month.

COURTESY KRISTEN GILLETTE



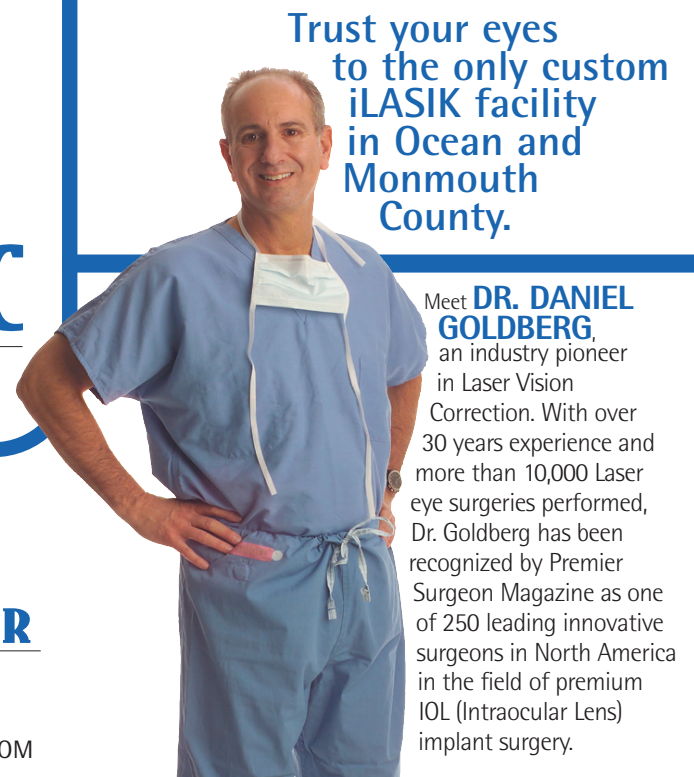
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HEALTHY LIVING

Kortney Rose

Continued from Page 15

Kortney Rose Foundation was established not only to preserve Kortney's memory, but to help find a cure for childhood brain tumors, the number one cancer-related cause of death in children.

Kristen Gillette serves as the foundation's president, and she has made it her life's work to help researchers find a cure. She is armed with facts, such as:

- For every dollar spent on prostate cancer, less than 20 cents is spent on childhood cancers.
- Only three percent of the National Cancer Institute's research funding is spent on pediatric cancers. Only .5 percent of that is spent on pediatric brain tumors.
- Funding for pediatric cancer clinical trials has dropped every year since 2003.

Approximately 17,000 malignant tumors of the brain or spinal cord are diagnosed each year in the U.S., of which about 3,500 are in children. Brain tumors can occur at any age, but they occur most often in children age 3 – 12 and adults 40 – 70.

Kristen knows that the only hope for saving young lives is money. Without money there is no research and without research there is no cure. And she knows that research on brain tumors is more difficult than other cancers.

"It's a really tough research area," she says. "It's not like breast cancer or leukemia." Brain tumors are different from other cancers because the blood-brain barrier that protects the brain also prevents chemotherapy from attacking tumors. In addition, there are fewer brain tumor tissue samples to biopsy than other cancers, so researchers have less to work with.

Kristen often feels like a voice crying in the wilderness as she tries to raise awareness and funds for brain cancer research. Even though brain cancer kills more children than leukemia, brain cancer seems to remain off the radar when it comes to funding. She knows that the key to getting more money for brain cancer research is raising awareness about the disease and the devastating toll it takes on young lives.

"There are so many little foundations like mine, but there's no unifying voice," she says.

"The Leukemia Society has done a great job; when you think of kid's cancer you automatically think of leukemia, you don't think of brain tumors. Yet brain tumors kill more kids than leukemia. We have to get this out.

"Because of the awareness raised by the Leukemia and Lymphoma Society and because of the funds raised, now 90 percent of the kids live who have (leukemia)," Kristen says. "We need to get there with brain tumors."

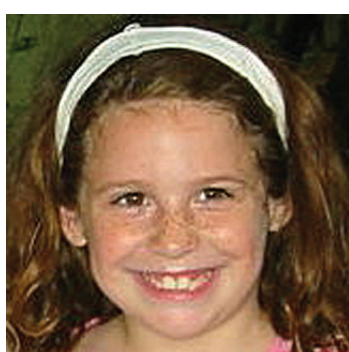
"People have to know that brain tumors are the number one cancer cause of death in children," she says. "If we can get that word out there, it (the money) will follow. It's been slow.

So in addition to raising money for brain cancer research and CHOP, Kristen has launched a campaign to raise awareness of the disease. She lobbied state legislators to designate May as Brain Tumor Awareness Month in New Jersey. With the help of Assemblyman Declan O'Scanlon, Assemblywoman Caroline Casagrande and state Senator Jennifer Beck the bill was passed in February 2009 and signed by Governor Jon Corzine that April.

Following Senator Edward M. Kennedy's death from brain cancer, a similar bill was passed on the national level the following year.

This past May, Kristen and other supporters of the Kortney Rose Foundation packed a van and headed to Manhattan to stand outside 30 Rockefeller Plaza for filming of the *Today Show*. They carried their message of brain tumor awareness and were successful in getting on air twice during the show, with show host Matt Lauer standing in front of them.

The Kortney's Rose Foundation has channeled the spirit and



KORTNEY ROSE GILLETTE

energy of young Kortney Rose Gillette and to raise hundreds of thousands of dollars to help advance research aimed at curing brain cancers.

With few connections or networks – Kristen works at Monmouth University and Rich is a postal worker – the Kortney Rose Foundation has raised and donated approximately \$378,000, all through many small fundraisers.

"I have a lot of stumbling blocks but I'm determined," she said.

The Oceanport schools and several other area schools raised the money through a "Kiss Childhood Brain Tumors Goodbye" fundraiser. Several area business – Distinctive Toys in Fair Haven, Simone's Jewelry in Monmouth Mall, Shaka Luau in Pier Village, Turning Point restaurants and Fa Nagle the Bagel in Long Branch – have chipped in with their own fundraisers. The foundation is also a beneficiary of the New Jersey Marathon.

Money raised by the foundation funds a brain tissue repository at CHOP.

"Working in conjunction with other hospitals, they're trying to collect enough brain tissue samples that they can share with other hospitals and spread the research.

"Recently, funding from our foundation was used in a study conducted by CHOP and Johns Hopkins University together," Kristen says.

That research yielded promising findings, she says.

They studied the medulloblastoma – a common childhood brain tumor. "They were able to totally sequence the DNA of that tumor using the tissue from the repository and made some significant clinical findings," she says. Those finding could lead to a breakthrough.

"Our money helped bank the tissue that they used in that study," Kristen says. "It's really exciting for us."

According to Dr. Peter C. Phillips, director of neuro-oncology programs at CHOP, funding from the Kortney Rose Foundation was instrumental in the study, in which they were able to "identify new mutations that represent a substantial sub-population of these tumors and have major clinical significance."

We are delighted that your support was able to bear fruit so quickly," he wrote.

These small successes are what keep Kristen motivated to push on with her work. "It's a hard thing to support research because you don't see immediate results," she said. "I was really feeling like, how are we making a difference? And then I got the letter from Dr. Phillips and it really reinvigorated me."

This year, CHOP will recognize the efforts of the Kortney Rose Foundation by naming Kristen the honorary chair of one of the hospital's major fundraisers, the All in For Kids Poker Tournament to be held October 20 in New York City. All of the funds raised this year – last year the event raised \$950,000 – will be earmarked for brain tumor research.

For the foundation, the next major fundraiser is Kortney's Challenge on August 28, a two-mile fun run/walk, day at the races and barbecue at Monmouth Park racetrack. The Oceanport PBA, longtime supporter of the foundation, will prepare the food.

Following Kortney's Challenge is the organization's major fundraiser when Team Kortney runs in the New York Marathon on November 6.

How You Can Help

Kortney's Challenge

August 28

A two-mile fun run/walk followed by a day at the races, barbecue and family fun at Monmouth Park racetrack.

Great Food For A Great Cause

October 28-29

Fundraiser at Turning Point restaurants.

Team Kortney at the ING New York City Marathon

November 6

Runners can join Team Kortney by raising money for the foundation.

www.thekortneyrosefoundation.org

"This will be our third year in it," Kristen said. She is actively recruiting runners to participate. "It can be their first marathon. They don't have to qualify – that's what's great." Runners who don't qualify to participate in the marathon can run by joining a team that raises money for a charity.

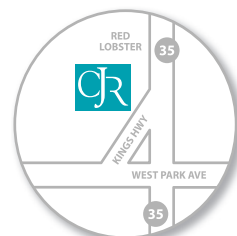
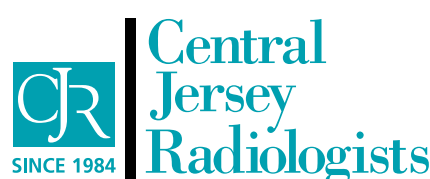
Kristen successfully applied to have the foundation designated as an approved charity for the marathon three years ago. Team size is limited to 20 runners, but she didn't fill the team the last two years. Runners must raise \$2,500 for the foundation – nearly \$20,000 was raised each of the first two years they participated.

"For a lot of people, if it's their first time, that's the route they take and it's a really rewarding experience for me and the people who run in it."

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DIABETES AND HEARING LOSS

By Jessica Miller, Doctor of Audiology, Coastal Ear, Nose and Throat

HEARING LOSS IS about twice as common in adults with diabetes compared to those who do not have the disease, according to a study funded by the National Institutes of Health (NIH) and published in the *Annals of Internal Medicine*. Yet hearing screenings typically are not part of the regular regimen of care that people with diabetes are routinely recommended to receive. Nor do the vast majority of doctors in today's health care system include hearing health as a routine part of annual exams.

"For years, physicians who treat people with diabetes have regularly ensured that their patients receive regular vision check-ups," said Sergei Kochkin, PhD, Better Hearing Institute's executive director. "But they also need to encourage each of their patients to get their hearing checked as well."

The NIH study suggests that diabetes may lead to hearing loss by damaging the nerves and blood vessels of the inner ear. People with diabetes should have their hearing screened once every 1-2 years as part of their preventative care protocol. It is important that the diabetic population seek care from a hearing healthcare professional who understands the complex issues involved in managing their overall hearing health care.

Coastal Ear, Nose, & Throat encourages all people with diabetes and/or a hearing loss to seek assistance from our hearing healthcare professionals and to explore the options for improving their hearing – and their lives. For information call (732) 280-7855 or visit www.coastalhearing.com

For more information about the relationship between diabetes and hearing loss visit www.betterhearing.org.

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