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Hope fuels local walk: Families come together to fight brain disorder

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By Keighla Schmidt, Staff Writer

Hope.

Hope for a cause. Hope for a cure. Hope for a future.

That's what Race Against the Odds, a 5K walk in Lakefront Park in Prior Lake, is all about on Sunday, Sept. 19.

But there's another kind of hope at the heart of the event -- Ella Hope Hauschildt.

Ella was diagnosed with Diffuse Intrinsic Pontine Glioma (DIPG) on Dec. 7, 2007. After fighting the rare brain tumor for almost a year, Ella died on Nov. 21, 2008.

"Now that she's gone I can't do anything for her. As a mother you're supposed to take care of your child," said Ella's mom, Erika. "This isn't going to replace her or be her substitution, but I have to do something. I don't want to see other families go through this and this is how I'm going to take care of things for her."

The Hauschildt family lives in Lakeville and has dedicated some of their energy to organizing the Race Against the Odds. They also started a Minnesota chapter of The Cure Starts Now, a national nonprofit group raising



awareness and funds for research on pediatric brain cancer.

Against the Odds: The Hauschildt family, John, Caden and Erika (from left) organized Race Against the Odds, a walk in memory of their daughter and sister Ella Hope. Ella died nearly two years ago from Diffuse Intrinsic Pon-tine Glioma (DIPG).

Race

Lakefront Park, 5000 Kop Parkway, S.E., Prior Lake will be filled with events on Sunday. In addition to the 5K, which starts at 9 a.m., the day will include "Ella's favorite things" like carnival games, crazy hair, bounce houses, airbrush tattoos, archery, skateboard demonstrations and food. The entertainment and fun will start around 10 a.m.

“It’s a big family event,” Ella’s dad John said. “That’s what Ella was all about. She loved parties and she loved people. Plus it’s for kids and the kind of cancer she had affects kids.”

Other local families know the pain of having a child suffer with DIPG.

Gregg and Mary Magnuson’s son Tyler died on Oct. 10, 2009, less than a year after Ella from the same tumor.

“Everyday is a battle. It’s real and he’s not here. It’s a void in our hearts. His brother and sister lost their brother; my wife and I lost our son,” Gregg said. “It’s difficult to see the kids walking to the bus for school and not see Tyler with them. Everyday is difficult but it becomes only more tolerable.”

According to another nonprofit organization for DIPG, Just One More Day, “The prognosis for diffuse pontine gliomas remains poor. Median survival is less than one year and the two-year survival rate is less than 20 percent.”

The tumor is located on the pons of the brain stem and as it spreads through the sensitive areas of the brain, many "normal" functions people take for granted are very difficult, if not impossible, to perform.

John said many researchers are saying if a cure or effective treatment plan can be found for DIPG it will help cure many cancers because of DIPG’s powerful nature. It’s resilient to many treatments and has a little bit of all types of cancer in it.

“If something can be done about this kind, a lot of doors to other cancer’s treatment options will be opened,” John said.

All the money raised will at Race Against the Odds will be donated to the Minnesota chapter of The Cure Starts Now Foundation. This is the second walk held in Ella’s name. The first one was in May 2009 in Lakefront Park.

Tyler

The Magnuson family is from Savage and Gregg, Mary, Marissa and Tanner all volunteered to help at Sunday’s event. Gregg said being involved is therapeutic for them.

“It makes us feel better, like we’re doing something to try and help other children to find a cure and find a cause,” he said. “We have to do something. We can’t sit around and mope all the time – we have to let people know the effects this has on kids and how it destroys families.”

Tyler was diagnosed with the rare brain tumor on May 8, 2008. He was a student at Hidden Oaks Middle School at the time.

His treatment plan included radiation and he was participating in clinical trials.

When the family first found out about the diagnosis, Gregg started feverishly researching. He found an Internet group with resources, trial information and contacts for other families – which Erika had started.

He went to Lakeville to visit the Hauschildt family and bring Ella some gifts.

“At the time Tyler was doing so well,” Gregg said. “But I had to see them and meet them. I had no idea where they lived when I found the group. Then when I found out they were so close and just over in Lakeville I had to



go.” **Tyler Magnuson**

It was then that Gregg’s mission took off. DIPG, he said, it is considered rare with fewer than 200 cases across the nation each year, yet there is a high-incident rate in this area.





“I think they’re somehow linked and we have got to find out the cause of the tumor and what’s going on so we can prevent it,” he said.

From 2008-09 there were 11 cases in Scott, Dakota, Carver and Hennepin counties, and all of those children have died, Gregg said.

He is seeking help for legislators to pass the National Childhood Brain Cancer Prevention Act. With little avail he’s contacted state departments and politicians trying to help fund research to find the cause of the disease.

Participating in Race Against the Odds helps accomplish the goal of raising awareness, he said.

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“Hopefully we can get the message about this tumor out to more people and we can find a cure and a cause,” Gregg said. “You don’t want to be a member of our group. You don’t want to be a member of the DIPG group. We’re all thrown into it and want to do something in memory of our child.”

Ella

Ella Hope earned her middle name just by being born to Erika and John, whose first-born daughter was stillborn.

“She gave us the hope that we could have a family; she was our daughter,” Erika said. “Never in a million years did we see ourselves here.”

John said while Race Against the Odds is a good outlet for Erika, he struggles with the very idea that he and his



family have succumbed to organ **Ella Hauschildt**izing an event in memory of Ella.

“It’s not that I don’t like the idea of the walk, I don’t like that we have to do a walk, and not have Ella,” he said.

Approaching the second anniversary of her death and remembering where they were two years ago at this time gets to be a large load emotionally for him, he said. But it’s the good memories that keep them going.

Ella was diagnosed with the cancerous brain tumor after she complained of having double vision. Right away they were told her prognosis wasn’t good.

“Hearing doctors tell you there is nothing they can do to keep your child alive is the worst thing a parent could hear,” Erika said.

She tried some radiation therapy and had success with alternative medicine when she and John spent over a month in Arizona filling her body with vitamins and minerals.

“We were told there was no mass observed, we were all doing cartwheels,” Erika recalled.

“We were all excited except for Ella. She had this look on her face and said ‘You don’t know it’s not still there hiding,’” John recalled.

For a few months Ella was in the honeymoon phase. The family took a trip to Disneyworld. She spent the summer running around her neighborhood, riding her bike and being a kid. In July her scans still showed she was in the clear.

Ella and her younger brother Caden along with John and Erika would have dances in their living room and life was happy.

The honeymoon was officially over when the doctor’s confirmed John’s suspicions in September.

“Her balance was off,” John said.

Erika said she didn’t want to acknowledge the balance issue or the fact that Ella’s eye started to turn inward – a symptom of the tumor nesting on the brain stem.

“In September the tumor was back and it was bigger than ever,” John said. “From that day on things went down hill every day.”

The tumor stripped Ella of her ability to walk, talk, eat, swallow and be a child.

On Halloween, 21 days before she died, Ella insisted she go trick-or-treating. John pushed her around the neighborhood in a large stroller. The night got long as the pair went door-to-door for nearly two hours before they came home.

“I asked her many times if she was done and if she wanted to go home. She told me ‘I am not a quitter,’” John recalled.

That message, Erika said, has rung in her ears constantly since Ella died.

“If 21 days before she passes a 7-year-old girl who has a brain tumor that’s taking her life from her says ‘I am not a quitter’ who am I, a healthy woman, to quit? How can I quit?” Erika said. “We plan to keep doing this until people stop coming.”

“She taught me to never give up,” Caden said of his big sister. “She taught me by never giving up.”

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