

The Colonial

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They're making the best of it

By: M. English , Correspondent

Eleven years ago, Joan Kerpan was as clueless as most of us about pediatric brain tumors. These days - eight years since son Kyle, 11, was diagnosed with the condition - the Lafayette Hill woman is convinced that "public awareness is one of the most important tools we have ... for encouraging research and offering hope to all the other children and families that are dealing with this."

To that end, Kerpan has organized "Pediatric Brain Tumor Awareness Day" - scheduled to take place at Conshohocken's Fellowship House Oct. 22 from 3 to 6 p.m. The free event will feature a silent auction, free massages, snacks, a balloon release and a DJ. Special "awareness" T-shirts and bracelets will be available for sale, with a portion of the proceeds earmarked for pediatric brain tumor research.

"I did something similar last year, and, for me, the important thing is the awareness it creates," she says. "That's really what drives me ... trying to make people realize how many kids out there have brain tumors and the effect that has on the families. Hopefully, as awareness increases, more money for research will become available.

"Kyle's been sick for eight years now, and his treatment options are pretty much the same as they were in the beginning. And there's no cure."

Kerpan - in conjunction with "a few other moms I've mostly connected with through the Internet" - has already raised awareness on more than one front. Just last month, their efforts prompted members of the Pennsylvania Legislature "with the help of [Rep.] Mike Gerber" to declare October "Pediatric Brain Tumor Awareness Month."

Unfortunately, such achievements don't begin to define the daily realities of life in the Kerpan household.

Dealing with chronic illness is messy, complicated and exhausting to a degree most of us can only imagine. Kerpan's husband, Allen, works for the State Department in Washington, D.C., Monday through Friday, so her sister has moved in with the family to help them cope. Kerpan calls her assistance "invaluable." Still, she worries "constantly" - about Kyle ... and Tessa.

"I think concentrating on raising people's awareness is what keeps me going," she says. "I feel that I have to get the word out because most people have no idea how many children are affected by this."

Oct. 10 was the Kerpan twins' 11th birthday. Kyle had spent the preceding week in Children's Hospital, recuperating from the latest round of physical complications triggered by his tumor. That placed him - and his mother - at the center of the recent shooting tragedy that hit Amish families in Nickel Mines, Pa.

Notes Kerpan in the online journal she maintains to keep friends and family posted on Kyle's condition:

"I read these words yesterday about our dear Amish friends, and it could not be said better: 'And in the end, it's not the years in your life that count. It is the life in your years.' With this, I move forward to a special tomorrow for my twins." She explains her own family's ordeal began when doctors diagnosed Kyle - two-and-a-half at the time - with a "low-grade tumor ... in his brain and spine."

"He was waking up in the middle of the night, thrashing around in his crib, crying, vomiting, and we thought, maybe he had a stomach flu," Kerpan recalls. "We were living in Albuquerque back then - my husband was in the Air Force, and we lived there for 14 years - but it just persisted.

"They did a CT scan as a last resort, and that's when we knew there was a problem. We were from Philadelphia originally, and we moved back here in 2000 because of the great medical care. We've been at CHOP (Children's Hospital of Philadelphia) ever since."

According to Kerpan, the "disseminated" nature of Kyle's tumor is rare.

"Over the years, he's had several surgeries and been on numerous, numerous chemotherapies, which would keep him stable for a while," she says. "Because his tumor is low-grade, it's grown at a slow pace. But it's been growing in bits and pieces all these years. Kyle's tumor is unusual because he's had it for so long, and it's complicated because it's not localized."

Illness ended the local boy's first semester at Colonial Elementary School prior to last Thanksgiving. He returned to CES for fifth grade this fall but was able to attend only one day.

"I knew he was 'off,'" Kerpan says. "He was hospitalized two days later.

"Kyle's quality of life was really pretty good until last year. In January 2005, he had full brain and spine radiation, because they were concerned that the [tumor] in the spine was growing and might cause paralysis. That was a six-week event. We had to be at Children's Hospital every morning at 6:30 for the radiation. Kyle got through that, but he began having pain in

his hip area. Then, nearly a year later - last December - he became paralyzed from the waist down.

"Since then, he can move his upper body, but he can't walk. He's also on steroids, which have made him puffy, and he has two shunts because he has hydrocephalus ... another complication. With everything, he complains ... not at all. He's a very up kid ... a real trooper."

If Kyle's health permits, he'll be at the Fellowship House on Oct. 22 and, his mother says, "would love to see his classmates and friends from Colonial Elementary School."

SIDEBAR:

On the eve of their 11th birthday, the Kerpan twins took a few minutes to offer these words of advice to other kids who are dealing with serious illnesses:

"I would just say try to ignore the pain," says Kyle, who enjoys reading cookbooks, watching Food Network chefs on TV - particularly Rachael Ray, whom he met at Williams-Sonoma in King of Prussia - and playing video games.

"Try to think of something else. That's what I do when everything's hurting. Think of things you love ... like, with me, I like cookbooks or fishing books ... or music. My favorite is Phil Collins."

This is Tessa's recommendation to other sisters and brothers who are helping siblings - or friends - get through the kind of troubles Kyle's been dealing with:

"I think if they just try to find something to do that doesn't involve anyone else ... trying to find something to do that they like when they have to amuse themselves ... like video games," says Tessa, a video game whiz who attends Mount Airy's Waldorf School and particularly enjoys gym and handcrafts.

"I like knitting a lot, too. Or movies ... my favorite is 'Monty Python and the Quest for the Holy Grail.'"

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