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Livonia family channels grief of child's death

BY TOM LANG • FREE PRESS SPECIAL WRITER • MAY 18, 2008

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Leah James frequently spoke of being happy by telling her mom and dad, Phil and Karen James of Livonia, that "my heart is happy."



Phil and Karen James and their daughter Kylie, 11, sit in front of a tree planted in the backyard of their Livonia home in memory of their daughter Leah, who died of cancer three years ago at the age of 5. Phil James holds a heart-shaped plaque made in memory of Leah.

(BRIAN KAUFMAN/Detroit Free Press)



Leah James

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Thus the foundation in her memory -- Leah's Happy Hearts -- after her death from an inoperable brain tumor in August of 2005. She was 5 years old and ready to begin kindergarten.

Karen James is very open about using the foundation's mission as her main coping mechanism for grief.

"I needed a way to channel my grief into something positive," she said. "You either sink or swim, and I chose to swim.

"After the diagnosis for the tumor, Leah started saying to me and Phil that 'my heart's happy.' Sometimes it would happen playing board games or shopping at the mall -- just out of the blue, she'd say, 'My heart's happy' and I was so touched by how special that is for a child to express her joy by saying her heart is happy -- and I wanted everyone to know just how special she was."

Leah endured 26 radiation treatments in the one year from diagnosis until she passed away from diffuse pontine brain stem glioma. The cancer cells grow in between and around healthy cells in the brain stem.

The foundation has two main goals: to fund research for pediatric brain tumors and to host fun events for children battling life-threatening illnesses. A fund-raising event is coming up May 31 -- a 5K family fun walk at Maybury State Park in Northville.

"It makes me feel good that I can talk about Leah, to keep her spirit and memory alive," James said. "Not that it would ever leave my heart, but it feels good to talk about her. ...

"A lot of people are afraid to ask me about it and I'm kind of the opposite of what people would expect. I like to talk about her. I like to share my experience through this, how awful it was, but how wonderful my memories are of her."

Foundation's friends help

The eighth-grade honor society at Northville Christian School is helping provide many of the volunteers needed to operate the Happy Feet for Happy Hearts walk.

WALK TO HELP

The Happy Feet for Happy Hearts 5K Walk is May 31 at Maybury State Park. The fee is \$20 for adults and \$10 for children. Participants will receive T-shirts on a first-come-first-served basis. Bringing in donations of \$100 or more will enter participants into a drawing for a Nintendo Wii or Detroit Tigers tickets and other prizes. For more information and to sign up, go to www.leahshappyhearts.org.

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Karen and Phil's daughter Kylie, 11, attends the school, and her gymnastics school, Miss Peggy's Kids Fitness Center in Livonia, also will bring a large contingent of walkers.

The walk will raise money for research and for what the foundation hopes will become an annual Christmastime visit to C.S. Mott Children's Hospital in Ann Arbor, where Leah received radiation treatment.

On Dec. 23, members and friends of the foundation went to Mott to give gifts to about 60 children, and brought items for the children to pick and have wrapped as presents for their parents and siblings. Infants received blankets, and their parents were given gas cards to help offset travel costs.

"The Mott event was really fun and I believe worthwhile for the kids and the families," said Phil James. "You could tell they really appreciated it, especially because it was Christmastime."

The foundation also donated \$10,000 to the hospital from the previous spring's fund-raising event.

"Our goal is to lift the spirits of children and families that are in the hospital" at Christmas, "not enjoying all the other festivities with their families," said Anne Doulette, a neighbor of the James family in Livonia and vice president of the board of Leah's Happy Hearts. "So we hope this gives them some joy during that time when other kids are out enjoying themselves. For us as outsiders looking in, it made the holidays that much more special to be able to participate."

Faith, comfort, spiritual growth

Karen James said the hospital trip was comforting for her and her husband.

"I didn't feel like we were still alone," she said. "When you are the parent of a child that passed away you feel like you're isolated, but in the hospital environment you see that other people are going through the same thing you went through. And all the planning for the event was definitely a distraction, in a very positive way."

The distraction was welcome as the family deals with having a hole in their own celebrations for holidays and birthdays. Those days, along with the date of Leah's prognosis and the date of her death, are still the toughest to get over.

"Being ready to help others has been a step," Karen James said. "I've also become more spiritual. I figured I could run away from God, or turn toward him, and I chose to turn toward him."

"I was angry at God and I'm still mad, but because of my spiritual growth, I have more hope. My faith is giving me hope that I'll be with her again someday, and that's stronger now."

"It's still really hard to accept, but I'm trying to climb that spiritual ladder because I don't know any other way to see her again."

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