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From tragedy, help for caregivers

Ashley Fraiman died of an incurable disease. Her parents were inspired by the care she received.

By Bonnie L. Cook
Inquirer Staff Writer

Until 1995, Kara Fraiman and her husband, Howard, of Bala Cynwyd longed for a child.

As if on cue, Ashley Faye Fraiman arrived July 20, but from the moment the dark-haired infant was born, everything changed.

"It was immediately apparent that she was very ill," said Kara Fraiman, now 39.

At Children's Hospital of Philadelphia, doctors diagnosed a rare brain disorder in which cells fail to migrate into proper position in the nervous system during gestation.

"Day after day, watching your child in pain, it's beyond words," Ashley's mother said.

But then the Fraimans, both practicing dentists, were referred to the hospital's Pediatric Advanced Care Team - a network of specialists entrusted with helping dying children and their families - then in its infancy.

The aid the Fraimans received inspired them to start a foundation, Ashley's Angels. The foundation will hold its fourth fund-raiser Saturday in Philadelphia.

Composed of a doctor, social worker, chaplain, nurse coordinator and child-life specialist, the care group had the sad job of telling the couple what they least wanted to hear: "Your child is not going to survive."

The group's candor came six months before Ashley's death.

"We unfortunately did not know till very, very late, close to when she was dying, that she would not live to a ripe old age," Kara Fraiman said.

"So we went full force hoping for a cure, so that she could get well. As we kept fighting upward, she kept going downward."

Once the Fraimans knew the truth, they began, with the help of the team, to manage Ashley's pain and do everything possible to make her last days pleasant.

"She was not suffering," Kara Fraiman said. "That was a gift that they gave me - it took that parental burden off, the feeling that you can fix it, when you can't."

When Ashley died without ever being able to speak, at 10:50 p.m. on Thanksgiving Day 2000, she was in the hospital, where her parents felt she'd be most comfortable.

"I thought when she stopped breathing, I'd stop breathing," Kara Fraiman said, "but it was the most peaceful she was in her life."

Since Ashley's passing, the Fraimans have grown to appreciate how the palliative-care team improved their daughter's quality of life and supported the whole family through the ordeal, including sons Lucas and Cory, now 10 and 9.

"People have a hard time with this topic because it's hard to think of a child dying," Kara Fraiman said. "The reality is, medicine isn't there yet; somebody's child won't be cured and is going to die."

With that in mind, the Fraimans created the nonprofit foundation in 2001. Its logo is bright pink, Ashley's favorite color.

Its aims: to help other very sick children and their families, to give "a public face" to end-of-life care for youngsters, and to bolster the fortunes of the palliative care group at CHOP with an infusion of cash.

Help came from an unexpected source in 2004. Jamie Robinson and his wife, Nicole de Botton Robinson, won a free dental procedure from Howard Fraiman, 40, at a raffle. The Robinsons, of Penn Valley, befriended the Fraimans and heard their story.

"How can we help?" the Robinsons wanted to know.

"Let's put a party together," suggested Nicole Robinson, 40.

Jamie Robinson, 43, a marketing specialist, favored something different and lively; thus was born the "Monster Mash," an annual Halloween costume party and fund-raiser.



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In its first outing, the 2004 Monster Mash netted \$25,000 for the medical team, in 2005, the total was \$40,000, and in 2006, \$75,000.

So successful were the two couples in raising the public profile of Children's Hospital that in May, the hospital made Ashley's Angels the honorary focus of its 51st annual Daisy Day luncheon.

The luncheon raised \$1.3 million for palliative care.

"Helping all these families has been incredible," Nicole Robinson said.

Tammy Inyoung Kang, the palliative-care team's medical director, said Ashley's Angels had helped put the palliative-care team on the medical map.

"They have not only given us financial support, but have helped us raise community awareness about pediatric palliative care through their fund-raising events and willingness to share their story," Kang said.

More than 320 children and their families have benefited from palliative care in the last three years, according to a hospital fact sheet. The team's future seems bright.

An endowed fellowship in palliative care will start next July. The Fraimans would like to see the palliative-care program at Children's Hospital become a model for the nation.

Since 2000, several things have happened. Kara Fraiman has found a true calling in developing Ashley's Angels. And there has been another addition, Alexa, 31/2, to the Fraiman household.

Alexa, with pale skin and dark hair, looks just like Ashley.

"Alexa talks about her sister," Kara Fraiman said. "We're a happy, healthy family."

If You Go

Monster Mash, the fourth annual Halloween costume party and fund-raiser for Ashley's Angels, will be at 7 p.m. Saturday at Sherman Mills, 3502 Scotts Lane, in Philadelphia's East Falls section. Tickets are \$150 per person. To order, call 610-639-6362 or visit www.monstermashphilly.com.

com.

Contact staff writer Bonnie L. Cook at 610-313-8232 or bcook@phillynews.com.

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