

# Easing the pain when a sibling has cancer

Non-profit group helps 'well ones'

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Spencer Yon's older brother was found to have cancer six years ago, when Spencer was 4 years old. While his family concentrated on helping his brother fight the disease, Spencer became an afterthought.

It's a common ordeal for siblings of children with cancer. Their lives are uprooted. They are barked at for unknowingly violating rigid care guidelines. They endure lengthy car rides and anxious stays in hospitals and doctors' offices. They even lose their names, routinely referred to as "the well one."

Spencer's mother, Melanie Goldish, noticed the inequity after a family friend who wanted to give Spencer a boost sent him a trophy engraved with his name. That simple gesture made the boy beam and had such a powerful effect on Goldish that she quit her marketing executive job to pursue a solution to the tumultuous experience endured by siblings of children with cancer.

The result is SuperSibs!, a non-profit organization run from Goldish's Hoffman Estates home and supported by some prominent sports and corporate entities.

"These kids are collateral damage in the war against pediatric cancer," Goldish said. "They're really in the shadows. They are truly suffering from emotional cancer."

Research suggests that more than 12,000 children are stricken with cancer every year. They have about 18,000 brothers and sisters.

"If a family is having any sort of relational problems, this kind of stress just blows it out of the water," said Sheila Vetter, social worker in Loyola University Medical Center's pediatric oncology department. Apart from the emotional upheaval, the stress brought by a child with cancer can dismantle a marriage and devastate a family's finances, she said. It can be particularly agonizing for younger children, Vetter said.

"I've heard young kids say that they wish they had cancer, because they would get more attention from their parents," she said. "These kids feel very left out and unwanted."

SuperSibs! pursues a relatively simple mission: "to honor, support and recognize" those siblings. The organization attempts that through measures that include sending personalized "smile cards," producing newsletters and booklets for the siblings and parents, offering journals, providing college scholarships, hosting parties, sending CD cases--and mailing trophies.

"I think it's really helped," said Judi Kramer of Naperville, "just knowing that there are other kids out there, that there are other families out there going through this and much worse."

Kramer's son, Ryan, was found to have a benign brain tumor in July 2002, when he was 12. His younger sister, Erin, was 10, and very soon after the diagnosis, she began feeling pushed aside, particularly when a card, letter or gifts would arrive for Ryan and she would receive nothing.

"I was kind of sad at some points and angry at other points," Erin Kramer said, "because I felt I was the only person in the room who wasn't paid attention to."

Ryan has been treatment-free for nine months, and the cards and letters have slowed. Erin, however, continues to receive a little something once a month from SuperSibs!

"I'm really happy," she said. "It makes you feel special that you weren't left out."

Added Judi Kramer: "I know she loves it. When she receives mail with her name on it, you can just tell. Her face lights up, and she saves the envelope. She saves everything in her room. Ryan will stand there with his hands on his hips and say, 'What about me?'"

Gilda Thomas of Chicago could have used SuperSibs! eight years ago, when her 1-year-old daughter, Uhura, was diagnosed with clear cell sarcoma. She said the program would have helped the girl's brother, Malik, 3 at the time, but particularly her older sister, Octavia, who was then 8.

"At school, she kind of felt like she wasn't liked, as if the kids there were picking on her," Gilda Thomas recalled. At the same time, Octavia kept volunteering to give blood or to donate a kidney for her little sister, neither of which was possible. It was a frustrating, heart-wrenching time, Gilda Thomas recalled.

But at a hospital picnic in July for cancer survivors, Gilda Thomas found a SuperSibs! booklet. She signed up for the program and, a few weeks later, Octavia received a trophy engraved with her name. She also received tickets to the U.S. Women's Soccer Open at Soldier Field, where she and her mother saw Mia Hamm, a financial supporter of SuperSibs! whose brother died in 1997 from the bone marrow disorder aplastic anemia. Cycling legend Lance Armstrong is another backer, as is Kraft Foods Inc.

"It's unbelievable what these people did for us," Gilda Thomas said. "I thought people just don't do things like this, and then I thought, you know, maybe I've been running in the wrong crowd."

Goldish quit her marketing job with the Carlson Marketing Group in 2002 and launched the program in Illinois and Wisconsin the next year. The organization served 483 siblings in 2003.

SuperSibs!, which Goldish runs full-time with a part-time staff member and more than 100 volunteers, expanded in January 2004 to include the entire U.S. and Canada. Now the organization is serving 1,600 kids in 45 states and Canada.

"As wonderful as that is--it means we've reached out to a lot of people--but quite frankly, we have not even scratched the surface of the need," Goldish said.

Her immediate plans call for moving the headquarters from her home office, her sons' playroom and the garage to larger accommodations. She also has received a contract from the U.S. Department of Health and Human Services to organize a conference in February in Chicago. The first "sibling-resource collaboration conference" will bring together leaders of about 20 pediatric cancer organizations to minimize overlapping services, and to find gaps in services.

"What we feel is so important is that SuperSibs! doesn't have to solve the problems," Goldish said. "We just want the problems to be solved."

"The long-term goal really is that I hope we fold up shop because there's a cure for pediatric cancer."