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Ensuring Money You've Raised Goes to Help Your Sick Child

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A little more than a year after their daughter was diagnosed with a brain tumor, Andrew and Cindy Janower organized Team Samantha, a group of friends and family who rode bicycles in the Brain Tumor Society's annual Ride For Research.

Of the more than \$1.1 million in funds raised from the 2005 ride, over \$494,000 was generated by Team Samantha. The Newton, Mass., family had hoped the money could fund research into the kind of tumor that Samantha has, a juvenile pilocytic astrocytoma, or JPA. In the end, the society funded projects focusing on other areas of brain-tumor research. The thinking was that the projects eventually would help all brain-tumor patients, including those with JPA.

Disappointed, the Janowers worried that it wouldn't be in time to make a difference for their daughter, whose tumor cannot be completely removed surgically. Now age 6, she is undergoing more chemotherapy because it is growing again in her brain stem.



The Janowers at last year's Ride For Research, with Samantha in her dad's arms.

This is the dilemma that families often face when raising money for rare, under-researched diseases: Many organizations aim to support the best research out there, but that research might not apply to a loved one's form of a disease.

In the Janowers' case, they took steps to ensure that their efforts benefited their child. The family worked with the Brain Tumor Society to create a special fund where all the money would go toward research on JPA and similar types of

pediatric brain tumors. "We wanted to find a way to set it up so we could raise money to go not to the best brain-tumor proposals they get, but to the best JPA proposals they get," Mr. Janower says.

"We don't encourage this normally," says Neal Levitan, executive director of the Brain Tumor Society, in Watertown, Mass. "We fund the most promising research that we find out of all the applications that we receive." Mr. Levitan says he recognized the family was raising sizable funds for an area that needed more attention.

Although JPAs are the most common pediatric brain tumor, they have been understudied because they tend to be slower-growing and have a better five-year survival rate than other tumors. Still, the tumors can be life-threatening if they grow in sensitive areas of

the brain and they cannot always be fully removed. The chemotherapy and radiation treatments carry their own risks, including serious cognitive damage.

At the May 2006 Ride For Research, the Janowers teamed up with John and Liz Ragnoni, whose 4-year-old son, T.J., has JPA, and the two families raised \$620,000 -- this time, for research into JPA and other similar brain tumors. Research proposals are due Feb. 15. In the hopes of creating a scientific road map, the day after the ride, they flew to Bethesda, Md., where they helped initiate the first scientific workshop dedicated to JPA research, with 25 experts from around the world.

"I understood the challenges of trying to provide dedicated funding when an organization is trying to serve many interests," Mr. Ragnoni says. "But unless the funding is specific, no progress will ever be made in this disease."

Linda Janower, Samantha's grandmother, set up FightJPA.org and convinced the Children's Brain Tumor Foundation in Maryland to create a JPA-designated fund, which has raised \$120,000 to date. A former public-relations professional, Mrs. Janower offered to work with any group willing to raise JPA-specific research funds. Last October, the first "5K for JPA" organized by the Boston University chapter of FightJPA raised more than \$26,000; Mrs. Janower hopes to roll out similar fund-raisers at campuses across the country this year. She says people like knowing the money is going for something specific. "I am driven by the question, 'How will this help my granddaughter?' " she says.

At the Childhood Brain Tumor Foundation, President Jeanne Young says the success of the JPA initiative has led other families to inquire about setting up more-targeted funds.

The Janowers, Ragnonis and others who have joined them say they now are raising funds and negotiating the next step: getting a major cancer institution to set up a program dedicated to the disease. "The field is going to start to notice there is money going into this," says Mr. Janower.

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