

## Sons' disease leads parents on quest for cure

Being a good parent is a challenge for everyone, but Oakhurst subdivision residents Sonya and Bob Evanosky are incredible. Bob shared his family's story with me in hopes of enlisting some help from the community.



The story began in 2001 when Bob and Sonya had identical twins, John and Christopher. The babies were premature so when they were not reaching various developmental milestones at 15 months, the couple had the boys evaluated. They were told that the children had cerebral palsy but were high functioning. The couple accepted the diagnosis and gave birth to Jack a short time later. But in the fall of 2004, they noticed that the twins' development began to slow down. They knew that cerebral palsy doesn't degrade, so they took the twins back for further tests.

Early in 2005, they learned that their twins had a rare genetic disorder called metachromatic leukodystrophy or MLD. They are missing an enzyme which breaks down sulfatides in the body. The accumulation of sulfatides destroys the protective covering on nerve fibers, which allows communication between the nerves and the brain. They were also told that the twins would most likely not live past the age of six.

They immediately had the baby tested and weeks later learned that little Jack also had MLD although he was showing no symptoms. I can't imagine how devastating it was for them to learn that all their children had an incurable disease. But Bob and Sonya didn't give up. "We starting researching the Internet frantically," recalled Bob. "There was no treatment in Chicago but we found a Web site that linked us to research at Duke University." Bob's hopes were raised when he learned that Dr. Joanne Kurtzberg, an expert in stem cell transplants, had a way to treat MLD. She told them that children needed to be treated before they became symptomatic, so the twins didn't qualify. However, Jack could have a stem cell transplant.

### Lengthy procedure

Bob was a stay-at-home dad caring for the children, so he became the parent to take Jack to Durham, N.C., for the procedure. He was told the treatment would take six months to one year.

So in February 2005 as Bob prepared to leave his wife and the twins to go to North Carolina, there was a knock at his door. He answered and found his friend Barb Hoskins standing there. She had organized 50 neighbors to cook dinners for the family during his absence and collected donations to buy a freezer to put in the Evanoskys' garage to store the meals. The neighbors also voiced a willingness to raise money to cover the costs of the stem cell transplant. Bob told them that insurance would cover his costs but that there was a more important role they could play. He challenged them to help fund Dr. Kurtzberg's research which could, if funded quickly, be a way to save the twins' lives. The neighbors accepted the challenge and the Evanosky Foundation was founded in the family's garage.

Bob took Jack, who was only 13 months old, to Duke University. Father and son moved into the transplant unit. "Our goal for the first six months was to keep my son alive," said Bob. For eight days, Jack underwent chemotherapy to kill all his bone marrow. Next, Jack was given stem cells from a donated frozen umbilical cord. "There was a tube right into Jack's heart and those stem cells found their way into the bones and began to make new bone marrow. There were 5.7 million stem cells in that little packet." Jack's body began to produce new blood that had the missing enzyme. Bob described the process as "getting a new blood factory."

"Jack now has two DNAs — one for his blood and one for his hair and skin," said Bob. Jack continued to degrade for about nine months after the transplant while his body changed. But now the progression of the disease has stopped.

Jack and Bob spent 45 days in the hospital and then another 4½ months in an apartment in North Carolina.

"I was Jack's care provider. They trained me to do everything," Bob said. A former airline pilot, Bob learned how to deal with Jack's IVs and other medical needs. He also became acquainted with other families at Duke University who were there to get treatment for their children. "About half the kids had cancer and the other half were children with diseases that could only be fixed with stem cell transplants," said Bob. "My experience at Duke changed my character. I now know more children who have died than adults. It really weighed heavily on me. All the people there were just trying to keep their kids alive."

Bob's experiences fueled his desire to establish the foundation. He has two goals. The first is to fund Dr. Kurtzberg's research into developing a substance that can stabilize the symptoms of MLD so that more children can undergo the transplant. About \$105,000 is needed to finish the current phase.

"It is a race against time," said Bob. Every day that research is delayed, the disease progresses in his twins and others. "The unique thing about research is that doctors can't get money until they have proven themselves. Once they have some success, then the big organizations step in with large funding. We are hoping to get that first step done quickly," said Bob.

The second goal of the foundation is to establish programs to screen newborns. Currently New York is the only state that tests for these types of genetic diseases known as leukodystrophies. When identified early, more help can be given. "New York was number one and I want Illinois to be number two," said Bob.

Aug. 4 fundraiser

The Evanosky Foundation will hold its first annual fundraiser on Friday, Aug. 4 at the White Eagle Owner's Club. Tickets are \$50 and include food, beverages, a raffle and a silent auction. Tickets can be purchased online at <http://www.evanoskyfoundation.org/> or by calling Bob at (630) 236-8039.

Although this is the first fundraiser, the foundation has already made great progress. Bob, who is an Eagle Scout, hired Kevin Dubbins, a scout from Troop 81 to make 50 rocker boards for use by special need kids. These boards are very costly from commercial vendors but can be made at about one-tenth the cost. The boards will be given to area families who need them.

Scouts from Troop 81 are also volunteering at the August fundraiser. Waubonsie Valley High School senior Ernesto Flores and his friends in the band Whiplash are providing music for the event.

Edward Hospital in Naperville recently gave the foundation about \$35,800 in equipment that was no longer needed at the hospital. Bob quickly found homes for the power lift tables and other handicap aids. Someone recently came forward willing to donate a minivan with a wheelchair lift to the foundation.

"Our foundation has no overhead," noted Bob. Sonya and Bob are covering all operating expenses from postage to printing so "100 percent of the funds raised goes to where it is meant to go," he said.

There are other ways to donate to the organization listed on the foundation's Web site. If funds are raised, there is a chance that human trials can take place at the end of 2006. The Evanosky twins could be a part of those trials or benefit from the research.

Each day, John and Christopher slip away a little more. Dealing daily with their children's needs while holding onto hope and working to save others qualifies Sonya and Bob as amazing parents worthy of our support.

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