

Dad runs to help his 3 sons

More than a marathon challenge, man and family raise funds for a cure

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Francis "Bob" Evanosky is limbering up to run four marathons today.

Every step the Aurora man takes on his 26.2-mile mission in Chicago will resonate with three little pitter-patters in his heart: One for each of his boys, who are wracked by a debilitating genetic illness that has no documented cure and where death is all but certain.

Still, Evanosky has hope. He has seen evidence that new treatments and even cures are on the verge of being realized.

Just meet his youngest son, Jack. The 2½-year-old is making great strides thanks to a life-saving transplant. Without the procedure, his condition, metachromatic leukodystrophy - or MLD - is terminal.

So when 38-year-old Evanosky's hips ache and lungs burn today during the LaSalle Bank Chicago Marathon, he said he will turn his thoughts to Jack and his twin 4-year-olds, John and Christopher.

His fatigue won't matter, he said. He will be reminded that six hours of grueling running might well be something to appreciate. And he will look to Jack for a boost of energy.

It is risky for someone like Jack, who had been on the cusp of serious advancement of the disease, to receive a transplant, experts say. A number of children don't survive the procedure.

"That kid is stronger than all of us," his dad said. "That kid's a fighter."

It's a strength that Evanosky said he hopes to channel when trudging through mile after marathon mile.

"I'm honoring my boys," he said. "I'm doing all I can for them."

Evanosky, a stay-at-home dad and former airline pilot, is running to raise money and awareness to combat MLD. He is running for the families he befriended while frequenting hospitals for the past two years. And he is running for the children of strangers.

It's a long journey, but Evanosky said he believes the finish line is within reach.



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Aurora resident Bob Evanosky gets a laugh out of his 4-year-old twins John, left, and Christopher. Son Jack, 2½, is on his dad's lap. All three boys have metachromatic leukodystrophy, or MLD, which is a terminal genetic disease. Evanosky has established The Evanosky Foundation to raise money for research toward a cure.

Roughly one in 40,000 people has MLD. Those affected are missing the enzyme in the blood needed to break down sulfatides, according to The MLD Foundation. Instead, the sulfatides build up on the white matter of the brain and on the central nervous system, destroying the protective myelin coating on nerves.

"It's like battery acid," Evanosky said.

The result is a breakdown in communication between nerve and brain, which leads to loss of physical abilities, paralysis, blindness, seizures and eventual death.

"They are cognitively active in a broken body" is how the Aurora father describes the boys' conditions.

The Evanosky Foundation and other groups seek to learn more about the disease so they can not only slow it, but stop it in its tracks.

Evanosky will run with 15 family members and friends today in hopes of collecting more money for the cause.

Charity's role in the marathon is significant, and growing, event spokesman Shawn Platt said.

Today, more than 5,000 participants from 60 nonprofit organizations will take to the streets. The roughly \$7.5 million that has been pledged is the highest amount in the run's 29-year history.

Kim Vice, Evanosky's sister, made the trip from California to run. It's a sign of solidarity and support, she said.

"This isn't supposed to happen to kids," she said. "This has made me more aware of what families go through. I just want to help raise money."

Vice and her brother plan to run the distance together.

"He's younger than me. If he can do it, I can do it," she said.

Evanosky and his wife, Sonya, first suspected something might be wrong with the twins, who were born prematurely, when they turned 15 months old and still struggled to walk.

A battery of tests led to an initial misdiagnosis of cerebral palsy. So the Evanoskys took the prognosis and enrolled the boys in therapy for cerebral palsy.

The couple decided to expand their family and in January of 2004 Jack was born. That fall, the twins took a turn for the worse. Physically, they were not improving and they had problems eating.

That's when a different doctor discovered the pair had MLD.

"It's a sneaky little disease," Evanosky said. "It masks itself."

As soon as they realized the disease was genetic, Bob and Sonya had Jack tested for it. And he tested positive.

There is no documented cure for MLD, which is considered a terminal illness. The only treatments are bone marrow transplants or stem cell transplants that can delay the progression of the disease in candidates who do not show significant symptoms.

For Jack's brothers, their cases were too advanced. But Jack was on the cusp and, therefore, qualified for a stem cell transplant from a donated umbilical cord of a healthy baby girl.

"Basically, we had to replace his blood factory," Evanosky said. "So now he has two DNAs. He bleeds girl (but DNA in his hair and skin is what he was born with)."

Today, Jack is making major progress. And physically, he is doing things he would not be able to do at this age if the disease still was advancing. He is now expected to live a full life.

"In a sense, his older brothers saved him," Evanosky said. "He's going to make it. He's going to beat it. We're lucky we didn't lose Jack."

A bulk of the money being raised through The Evanosky Foundation is going toward medical experiments and, the family hopes, human trials soon to come if the FDA consents.

"This is pioneering research," Evanosky said. "The children who are going to be involved in this don't have any other options. This is it for them."

His sons, John and Christopher, now look to be solid candidates for a second phase of human trials. The hope then would be to stabilize the disease and reverse at least some of the effects.

"We are the kind of people who take adversity and make opportunity," Evanosky said. "We're going to do the best we can with this opportunity because we're obligated to. It's that simple."

But mostly, the Evanoskys and their supporters are working toward an effective solution. A cure.

"It's just looking out for future children," Evanosky said. "It has to be done. This disease is going to be around as long as mankind is around."

"There is a great unknown out there in a good way. There is much more potential for the upside than the downside. We have only one way to go and that's in a positive direction."

Marathon spokesman Platt attributes the record-high number of charity runners this year to the rise in popularity of distance running as well as people's inherent goodness.

"There's a goodwill effort," he said. "People feel compelled to rise to a call, a purpose."

After all, if someone's going to spend months training to run 26 miles, chances are there's a driving force behind it.

"We say that there are 40,000 runners and 40,000 stories," he said.

And some runners, like Bob Evanosky, have four.

How to help

To donate to The Evanosky Foundation, visit www.evanoskyfoundation.org or send a check to The Evanosky Foundation, P.O. Box 9234, Naperville, IL 60567.