

This year's target for Mito March is \$50,000

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Staff Writer

Since Mito March: Kure for Kirkland was launched in 2005 it has raised more than \$68,000 for mitochondrial disease research, and organizers want to keep the momentum going with this year's event.

Event organizer, and Kirkland Kilbride's mom, Kelly said they are hoping to raise \$50,000 at the 2007 Mito March set for Sunday, May 27 from 9 a.m. to noon at the Gellert Community Park in Georgetown. For links to on-line registration and pledging for the event visit www.mito-march.ca

The event was conceived by family and friends of Kirkland, a six-year-old Georgetown boy who suffers from a rare and fatal mitochondrial disease-complex one deficiency.

Participants collect pledges for the 5 km family walk/run that's designed to promote awareness and raise funds in support of mitochondrial disease research at The Hospital for Sick Children.

At this year's Mito March, along with the walk/run, there will also be many draw prizes including foursomes of golf at Glen Abbey and Eagle Ridge Golf Clubs and an appearance by Maple Leaf Kris Newbury.

Kirkland's family recently learned the disease is actually secondary to another fatal genetic disorder—Niemann-Pick Type C (NPC).

The disorder results in an inability to properly metabolize cholesterol and fats.

Kelly Kilbride is hopeful her son will be well enough to attend the Mito March, but she said it has been a rough few months for Kirkland.

"He's been struggling after having pneumonia prior to Christmas," said Kilbride.

She said Kirkland was not expected to live much beyond then, but he has "plateaued again."

"His current health status is quite fragile. He's fairly critical, but he's stabilized at this point. You can tell by his symptoms where he's headed," she said.

Kilbride said she is prepared for the inevitable.

"You watch this kid suffer like this as long as you can, basically you want him to be at peace," she said.

She said her son is experiencing pain and is now on 24-hour morphine.

"We're trying to keep him comfortable. Our main goal is to keep him at home and be part of the family."

They have eight nurses who come in throughout the day to care for Kirkland.

For Kilbride it's important that Kirkland's life have meaning.

"Every parent with a child like this wants there to be some purpose to his life," she said.



Toronto Maple Leaf forward Matt Stajan joined Kelly Kilbride and son Kirkland for the annual Mito March: Kure for Kirkland last year at the Gellert Community Centre. Kris Newbury of the Leafs is expected to attend the March 27 event.

File photo

And the money raised through the Mito March— all of which goes towards research at The Hospital for Sick Children— has been making a difference.

Kilbride said money raised last year went specifically to funding a study currently being conducted in the hospital's Metabolics Lab. Scientists are analyzing the DNA of sibling pairs from different families with complex one deficiency.

By using methods very similar to those used by the Hospital for Sick Children researchers who found the gene responsible for cystic fibrosis, metabolic scientists are mapping out and identifying mitochondrial genes that are common to both siblings. These common genes are in

turn, linked to the genes shared by siblings from other families with the intention of narrowing down the location of defect and eventually pinpointing the specific gene responsible for complex one deficiency.

"It's hopeful. They are making some discoveries that are giving them some clues," said Kilbride.

Money raised this year will fund the second part of that study.

Funding from the Mito March has also resulted in the purchase of a Real Time PCR Machine that has allowed researchers to examine cultured cells from patients to determine where there is a gene defect.

The slogan for this year's Mito March is "Generating Energy Link by Link" because an energy deficiency of the cells is the common thread of mitochondrial diseases.

In Kirkland's case, the respiratory chain is the specific energy process that is affected.

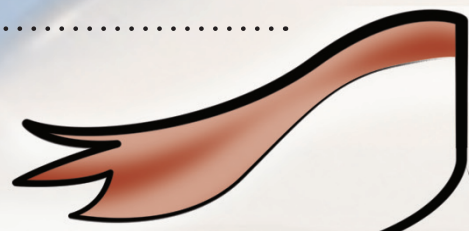
Mito March organizers invite everyone to take part in building an energy chain, which they hope will be a year-round fundraiser for mitochondrial research. To build a chain, people make a dollar donation for a link. Organizations, groups and businesses are urged to build their own chains.

Chains like the one recently built at Georgetown's Wal-Mart are currently under construction throughout the community and GTA. They will be collected prior to the Mito March and displayed that day along the walk/run route at the park. The names of the businesses, schools or organizations will be recognized beside their chain along the route.

Registration for the Mito March will begin at 8 a.m. with the official start time at 9 a.m.

Organizers are still accepting donations of prizes for the draw table at the event.

To donate a prize, or for more information on the energy chains and the Mito March contact organizers at info@mito-march.ca or call Kilbride at 905-873-4737.



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