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Parents of Tecumseh girl with rare disease continue fight

BY SONJA PUZIC, THE WINDSOR STAR FEBRUARY 2, 2010 COMMENTS (1)

STORY

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Michaela Kameka was born with a rare disease called MPS III. Her parents are looking for a cure.

Photograph by: Tyler Brownbridge, The Windsor Star

TECUMSEH More than a year after she was diagnosed with a rare degenerative disorder, little Michaela Kameka hasn't changed much.

And that's a good thing.

By now, she could have started losing her vision or the ability to eat on her own, become aggressive and hyperactive. But although her verbal skills are very limited and she's not developing like other five-year-olds, Michaela still goes to school and plays with her siblings, Faith and Aidan.

That could all change this year, or next. Such is the unpredictability of Sanfilippo syndrome, or MPS III (Type B), a genetic condition caused by a missing enzyme responsible for breaking down a type of complex sugar molecule that leads to a buildup of cellular waste in the body. The

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result is progressive neurological and physical damage, which can include blindness, loss of speech and dependence on a feeding tube and a wheelchair. As the body slowly shuts down, life expectancy is drastically reduced.

As soon as they got the devastating diagnosis, Michaela's parents Glenn and Ann Kameka began searching for a cure. They learned about stem cell transplants being done in children with MPS III with promising results in North Carolina and launched a fundraising campaign to cover the estimated \$500,000 cost of the procedure.

Despite an outpouring of support from the community — everyone from school kids who handed over their lunch money to businesses and organizations that pitched in — the Kamekas were not able to raise enough money in time. At five, Michaela is too old for the stem cell transplant and her disease has progressed too far to risk doing the procedure.

Undeterred, the Kamekas continued doing their own research and have come up with a regimen they believe is helping slow the progression of Michaela's disease.

"She is on a very stringent array of supplements, some of which we actually get shipped in from Texas," Glenn Kameka said. "We give her an injection every day ... the bulk of which is B vitamins. There is also a soy isoflavin which reduces the amount of stuff that builds up in her system. Her diet is very limited. She is almost on a full protein diet and these supplements.

"We're just buying our time, honestly, until we find a therapy that works. Michaela is very strong."

The Kamekas have to pay for all the supplements out of pocket and have been relying on the generosity of others for help. Kameka stays home full-time and his wife works as a school teacher.

The couple has also found other rays of hope. One of them is Dr. Haiyan Fu at the Nationwide Children's Hospital in Columbus, Ohio, whose team has been developing gene therapies to treat MPS III, but needs approval from the U.S. Food and Drug Administration to take the research to the next level. Then there's Team Sanfilippo, an American group of families affected by the disease whose goal is to raise enough funds to develop a treatment for MPS III that can be clinically tested within three years.

All those efforts require financial support and the Kamekas are eager to help.

"We want to get the money into the hands of Team Sanfilippo," Kameka said. "We're not fundraising just for Michaela anymore, we are fundraising for the cure of MPS."

The family's next fundraiser will be an indoor rummage sale and barbecue March 6 at the Knights of Columbus hall on 152 Lesperance Rd. in Tecumseh. Volunteers, contributors and donations are welcomed.

For more information and other ways to donate, visit www.hopeformichaela.com.

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Stink Eye...

February 02, 2010 - 9:22 PM

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With the amount of money that our province wastes everyday, \$500,000.00 is a drop in the bucket for them . OHIP should cover this for you as the treatment is not available here and if it has even helped one person then the treatment shouldl be worth pursuing! Good Luck with you chld. My prayers are with you!



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