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COMMUNITY

Family of ill-stricken boy fighting back

Research fund established in battle against rare disorder

By **Stephanie Thiessen**
 CANADIAN CHAMPION STAFF

Each day, Peter and Melissa Papaioannou grapple with their fear of the unknown, trying to remain hopeful despite odds that often seem to be working against them.

Is a cure anywhere in sight for their three-year-old son, Michael? It's a question that can alternately bring hope and discouragement.

Two-and-a-half years ago, Michael was diagnosed with Lesch-Nyhan Disease, a rare disorder caused by a genetic mutation of the X chromosome.

There are only three other people living with the disease in Canada, and Michael is the youngest worldwide.

A grueling therapy schedule and the affect the disease has on Michael's childhood can take its toll on his parents, who live in Kitchener and run the Trail Eatery in Campbellville.

But they can't give up.

Instead, the Papaioannous recently decided to start a research fund that would hopefully unlock some of the mystery that surrounds the disease and maybe even find a cure.

The Michael Carl Lesch-Nyhan Research Fund was started last summer at Toronto's Hospital for Sick Children.

"They're trying to fix the broken link," Peter explained.

But with the hope the research brings comes a hefty price tag — almost half a million dollars, of which the Papaioannous must fund \$100,000.

Fortunately, the Milton community has been generous. Last year, a fundraising dinner was held that raised \$43,000, allowing the research to start. The previous year, a similar event was held.

Now, once again, the couple is looking to members of the community to lend their assistance.

If we don't raise (the money), nobody will and it (the research) will just stop," Melissa said.

This year's fundraising event will be held Saturday, with proceeds going to the research fund.

The event will take place in the Gambrel Barn at Country Heritage Park from 5 to 11 p.m. and will include dinner at 6 p.m. provided by Allison's Gourmet Catering. There'll also be entertainment, a bar and both a silent and a live auction.

The concert portion of the evening will feature Canadian Idol season one finalist Billy Klippert, who recently released his second album, *Naked and The Simple Truth*.

Also providing entertainment will be local musician James Sawyer, who released his debut album last year — which includes a song written for Michael — as well as local crooner Kelly MacIntyre, who'll sing and emcee the night.

Tickets cost \$60 each and are tax deductible.

"If we don't raise (the money), nobody will and it (research) will just stop."
MELISSA PAPAIOANNOU



GRAHAM PAINE / CANADIAN CHAMPION

RARE SUFFERER: Melissa Papaioannou flashes a big smile while embracing son Michael, who's afflicted with an extremely rare disorder known as Lesch-Nyhan Disease.

The benefits of the research will extend beyond people with Lesch-Nyhan Disease, Peter said, explaining it could help any child with a neuro-muscular disease.

Melissa said she and Peter are well aware that the research holds no guarantees.

"The way I look at it, it's worth a shot," Melissa said, adding, "We always knew it was a gamble, but it's a gamble worth taking."

Peter agreed.

"Even if it doesn't work, at least we tried," he said.

Cognitively, Michael is a normal little boy. He'll be starting pre-school in September.

But he can't sit up, walk on his own or talk — he communicates using a board with picture symbols.

He also experiences one of the most heart-breaking symptoms, a compulsion to self injure — in his case, by biting his fingers.

"You think he has a disability and you're dealing with it, and then he starts the self injuring and it blows you out of

the water," Peter said.

With all that's going on, Michael's an incredibly happy little guy, Melissa said.

"I describe him as my angel. He's the biggest inspiration in my life," she said.

Simple activities — like eating popcorn together, Michael snuggled in her lap — have become treasured moments, she said.

Michael has a life span of 20 to 25 years, Peter said, and he and Melissa have no intention of doing anything less than everything they can for him.

"If we have to fight for 20 years to save his life, we will," Peter said.

Tickets to the concert are available at the Trail Eatery in Campbellville and The Vacuum Store in town, or by calling Peter or Melissa at (519) 896-9784 or (905) 854-2505.

For more information, visit www.themichaelfund.com.

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Cogeco Cable Channel 14 Programming Schedule — Tuesday, February 20 - Monday, February 26, 2007

Tuesday, February 20	Wednesday, February 21	Thursday, February 22	Friday, February 23	Saturday, February 24	Sunday, February 25	Monday, February 26
8:00am - 1:00pm Plugged In! EXTRA	8:00am - 1:00pm Plugged In! EXTRA	8:00am - 12:00pm Plugged In! EXTRA	8:00am - 1:00pm Plugged In! EXTRA	8:00am - 4:00pm Plugged In! EXTRA	8:00am - 10:00am Plugged In! EXTRA	8:00am - 1:00pm Plugged In! EXTRA
1:00pm SportsZONE Live	1:00pm Halton Hills Council (cc)	12:00pm Swap Talk	1:00pm Halton Region Council Feb 14, 2007	4:00pm TVCogeco Sports: JrA Hockey - Playoffs	10:00am TVCogeco Sports: Halton HS Sr. Boys Basketball Finals	1:00pm Halton Hills Council (cc)
2:00pm - 6:30pm Plugged In! EXTRA	3:00pm - 7:00pm Plugged In! EXTRA	1:00pm - 8:00pm Plugged In! EXTRA	3:00pm - 5:00pm Plugged In! EXTRA	6:00pm TVCogeco Sports: Halton HS Sr. Boys Basketball Finals	2:00pm - 6:00pm Plugged In! EXTRA	3:00pm - 8:00pm Plugged In! EXTRA
6:30pm Optimist TV Bingo (Live)	7:00pm Simply Halton	8:00pm Living Healthy	5:00pm - 7:30pm Plugged In! EXTRA	6:00pm TVCogeco Sports: AHL Hockey - Syracuse vs Hamilton (Live)	6:00pm Halton Hills Council (cc)	8:00pm SportsZONE Live
7:30pm Plugged In!	7:30pm Plugged In! EXTRA	9:00pm Halton Region Council Feb 14, 2007	7:30pm TVCogeco Sports: AHL Hockey - Syracuse vs Hamilton (Live)	10:00pm - Midnight Plugged In! EXTRA	9:00pm - Midnight Plugged In! EXTRA	9:00pm - Midnight Plugged In! EXTRA
8:00pm Auto Experts (Live)	8:00pm Swap Talk (Live)	11:00pm - Midnight Plugged In! EXTRA	11:00pm - Midnight Plugged In! EXTRA			
9:00pm Halton Hills Council (cc), Feb 19, 2007	9:00pm - Midnight Plugged In! EXTRA					
11:00pm - Midnight Plugged In! EXTRA						