

The high cost of loving

Fundraising concert set for February 19, 2005

By DONNA DANIELLI

In the New Year, like countless parents before them, Peter and Melissa Papaioannou will take part in a time-honoured ritual as they formally baptize their eleven-month-old son, Michael. The joyous occasion will be bittersweet for the young couple, as Michael has recently been diagnosed with Lesch-Nyhan Disease (LND).

LND is caused by a genetic mutation of the X chromosome and its symptoms are varied, but may include the compulsion to self injure. The symptoms and severity can vary from patient to patient. Michael is only the third diagnosed case in Canada, and he is also the youngest patient to ever be diagnosed with LND. The disease is often first suspected because of an orange crystal substance found in the diaper, as well as poor motor control and difficulties sitting, standing and walking. The life expectancy of a LND patient can be shortened and the high uric acid they produce can cause kidney failure if left untreated.

"It's a devastating diagnosis," says Peter, owner and operator of the popular Trail Eatery in Campbellville. "It's a hard thing to swallow when your child is diagnosed with a disease that is incurable, especially a disease like this." Peter and Melissa are determined not to let the diagnosis of LND define their child though. "Michael is a very happy, very bright child, who also happens to have an incurable disease," explains Peter. "He smiles every morning as he wakes up. He gives us hope as parents, that we're going to get through this."

Growing increasingly concerned with Michael's difficulty in sitting up and that mysterious orange crystal substance in Michael's diaper, and facing a long wait before they could be seen by a doctor at the Hospital for Sick Children, Peter, Melissa and Michael headed to Boston. "My cousin is a neurosurgeon there, and arranged for us to be seen at one of the best children's hospitals in the world," explains Peter. A week's worth of extensive testing brought a diagnosis that staggered the young parents. Michael had LND.

"My odds of winning a lottery are higher than the odds of my child having

this disease," says an emotional Peter. "I may never see my son run and play with other children. I would give anything if it could be me that was sick instead of him."

Heartbroken, the Papaioannous returned to Canada, knowing there was little to be done for Michael in terms of treatment. So much is still unknown about this extremely rare disease, with only three cases in Canada and twenty in the U.S., and there is no way yet to tell how severe or mild Michael's symptoms may be. Dr. Nyhan,

who originally identified the disease in the 1964, still runs a research facility in San Diego and has communicated an interest to see and work with Michael. However, the payments for the bills incurred in Boston still hang over Peter and Melissa's head along with concerns about setting aside money for future medical needs and covering travel expenses as they take Michael as often as necessary to see Dr. Nyhan in San Diego

The Halton Compass is proud to announce its support of a fundraising event for the Papaioannou family, a benefit concert to be held on Saturday February 19. Many thanks go to Country Heritage Park for their generous donation of the Gambrel Barn for the event, Allison's of Milton for their help coordinating the event and local musicians Kelly Macintyre and friends, the Caroline Wiles Band, country singer Alysha, rock band LTD and sound manager Greg Parsons for volunteering their services for the night. Tickets for the event are \$40 per person and will include live entertainment, a cold buffet, silent auctions, cash bar and more. Tickets are available at the Trail Eatery in Campbellville and the Vacuum Store in Milton. Any person or business wishing to volunteer, donate a silent auction item, purchase a ticket or help out in any way, are encouraged to contact Donna Danielli at 905-854-2469. Cash donations can be made at any Scotiabank to Account # 10652 0036188, the Michael Carl Papaioannou Fund. For more information on Lesch-Nyhan Disease, see the website at www.Indinfo.org.



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