Mayor Bob Bratina
Hamilton City Hall
2nd Floor – 71 Main Street West
Hamilton, Ontario
L8P 4Y5

Dear Mr. Bratina:

I am writing to request your support and assistance in declaring a Mitochondrial Disease Awareness Week in Hamilton, for the third week of September every year.

This year Mitochondrial Disease Awareness Week is from September 18, 2011 to September 24, 2011. I am asking you to sponsor the pronouncement of a "Mitochondrial Disease Awareness Week" in the city of Hamilton for the third week in September every year, from 2011 and onwards. I do realize this is very short notice but it has really been on my heart to get this done. If you are unable to get this done for this year then I would ask that it be done for third week in September every year, from 2012 and onwards. I am part of the Support Committee for MitoCanada. We are a newly founded not-for-profit organization primarily constructed of family and friends with Mitochondrial Disease. MitoCanada provides support and awareness to Canadians affected by Mitochondrial Disease, while also supporting the advance of research in this field. MitoCanada is connecting Canadians who are directly and indirectly affected by Mitochondrial Disease. Our goal is to reach all patients, parents, caregivers, and the medical community by providing support and practical information that will help to improve the quality of life and offer a sense of community for patients and their families. It is our goal to have the development of a "National Mitochondrial Disease Awareness Week" in Canada.

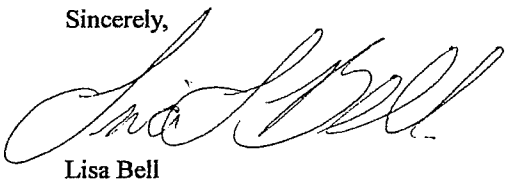
In Canada there are approximately 9000 people with definite Mitochondrial Disease, about 1 in 40000. However, even the largest Mito Clinic in Canada by far, at Hamilton Health Sciences McMaster Children's Hospital, sees only about 300 cases, which means that many people are going unrecognized. The bigger issue is also that the symptoms can be so diverse, that many folks are being labeled as having other diseases. Also, many people need to be screened and that takes more resources to fund the few specialty clinics that have expertise to screen them. (Dr. Tarnopolsky, 2008)

While every child and person affected by this disease is important with their own story, like our family's story attached, they are only examples of what is present in our society. Early research shows that far more people in our society are affected by Mitochondrial Disease in its many variations than most people realize, and connections to diseases like diabetes, autism and Parkinson's, just to name a few, are only starting to be understood. It is for this reason that I am appealing to you to support our efforts to raise awareness of this disease. Awareness and research will go a long way towards improving the difficult process of diagnosis and the treatment of this chronic illness.

I appreciate you taking the time to read Andrew's story and the additional information about Mito that I have included, and hope that you will assist me in this quest.

Thank you in advance for your assistance.

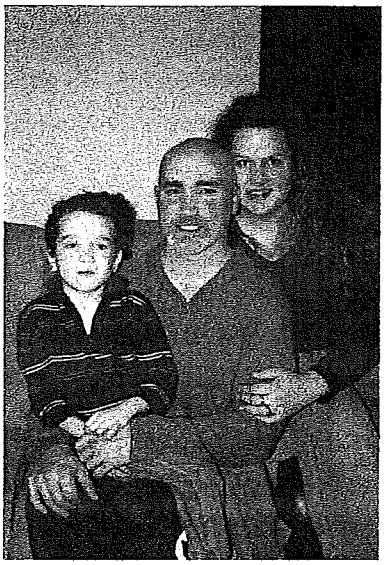
Sincerely,



Lisa Bell

email: lisa.bell@mitocanada.org

Our family's story...



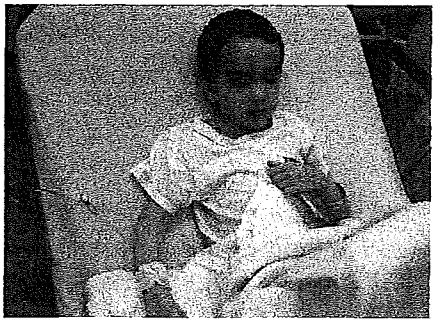
Let me take a moment to explain where the very personal motivation for this request comes from. My husband and I have been married for almost 10 years and we have a son Andrew 6.

Andrew was born at McMaster Hospital on September 25, 2004 two weeks early. Everything seemed fine except that they were unable to stabilize his sugar levels which is normal for babies that are born early. He stayed in the NICU at McMaster Hospital for 5 days but then was discharged. He was a blessing to our lives. He met all his milestones (crawling, walking, etc.) except his speech was delayed. They had said it was from all the ear infections he had as a baby. When he was two they put the tubes in his ears and things were getting much better. No more ear infections! He began speech therapy at St Josephs Ambulatory in Stoney Creek and was making great progress. On August 11, 2008 everything changed for our family. Andrew had woken up and was perfectly fine, we headed out to his speech therapy class and all of a sudden he went awfully greyish in colour and began vomiting. We thought it was just a bad flu bug but by the time evening came he just wasn't looking very good. I called telehealth Ontario and they gave me a few suggestions of things to try and if they didn't work we had to take him to emergency. We tried everything they told us to but he wasn't even able to keep a teaspoon of liquid in. My husband and I took him to the Hamilton General because it was the closest. While sitting in the waiting room he began vomiting blood. They took him in right away and did some blood work. His blood sugar had dropped to 1.5 and they hooked him up to IV right away and had him transferred to McMaster.

We stayed at McMaster for 4 days to only leave there not knowing what happened and what was wrong with our son. They had said it was a viral infection. Two weeks later the same thing happened and again his sugars dropped, got dehydrated, and stayed in hospital for 4 days and then released. A month later we were back again but this time they had other medical teams involved. He has had numerous hospital stays, blood tests, ct scans, x-rays, ultra sounds, ECG and an MRI.

We were finally put in touch with Dr. Tarnopolsky at McMaster Hospital and he did a muscle and skin biopsy on Andrew. He was testing for Mitochondrial Disease for which there is no cure as of yet. On December 11,2009 our son was diagnosed with Definite Mitochondrial Disease. They had found 10 different mutations in his Mitochondria. Two of the mutations are unknown and haven't been reported anywhere in the world so Dr. Tarnopolsky had done a muscle and skin biopsy on my brother, sister and myself to see what information he could gather from that.

My brother was diagnosed with White Wolf Parkinson's Syndrome, which is under the Mitochondrial Diseases. My sister was fine. I was also found to have some of the same mutations in my mitochondria that my son has. Dr. Tarnopolsky has resent our muscle and skin biopsies to get further testing done. In the meantime, Andrew and I are taking the Mito Cocktail which consists of vitamins and supplements. Andrew is followed by Dr. Tarnopolsky and Dr. Isserman at McMaster Hospital and they have been great to deal with.

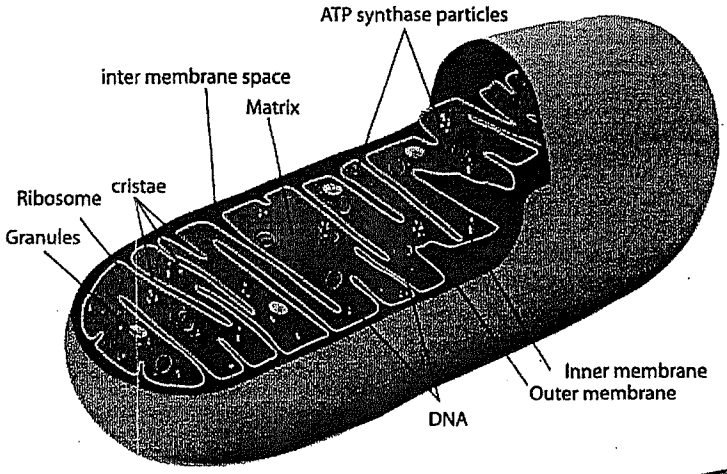


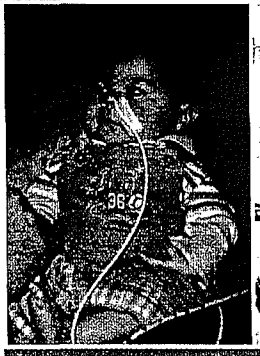
Due to his numerous hospital stays they are working on having him flagged at the hospital to cut down the waiting time for IVs to get started. He still continues to have these episodes, isn't gaining weight, has good and bad days, not much of an appetite cause he always feels sick and he lacks energy at times. His immune system is also so low that when he gets a cold it's not just a cold, it turns into one of these episodes. To many people he looks normal but unless you live with him day to day you really don't see the full story. His last hospital stay was middle of August 2011. Despite everything he has been through he is such a trooper and is a very happy, compassionate little boy.

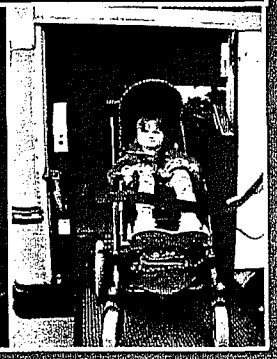
Since being connected with MitoCanada I have seen many families say goodbye to their loved ones due to this disease. This brings me back to the reason for my letter. I am hoping that you will help me in my quest to honour Andrew and all the others who struggle with this disease every day, and those who have lost their battles with Mito. The only way that we will find a cure for the disease is through raising awareness and funds for research. I am enclosing some additional information about Mitochondrial Disease but you may also choose to check out MitoCanada's website at www.mitocanada.org

What is Mitochondrial Disease?

Mitochondria are considered the "powerhouse" of cells and are responsible for creating more than 90% of energy required to sustain life and support growth. Mitochondrial Diseases result from failures of the mitochondria and appear to cause the most damage to cells of the brain, heart, liver, skeletal muscles, kidney and the endocrine and respiratory systems. Mitochondrial Diseases are the result of either inherited or spontaneous mutations in mtDNA or nDNA. There is no cure for Mitochondrial Disease.







MitoCanada is a registered charity that provides awareness and support, while also promoting the advancement of Mitochondrial Disease research.

Awareness

Educating the public and medical community about Mitochondrial Disease.

Establishing the 3rd week of September as Mitochondrial Disease Awareness week.

Hosting an annual National Conference.

Support

Our website provides links to resources for families across Canada.

We hope to connect families living with Mitochondrial Disease, and establish local community support groups.

Research

Raising funds to support research for Mitochondrial Disease in Canada.

New research will provide new information and a better understanding. MitoCanada will have up to date content on the latest research.

Mito facts:

Approximately 1 in 4,000 people have a Mitochondrial Disease.

Mitochondrial Disease affects both children and adults.

Symptoms can appear anytime in life.

The severity of symptoms varies significantly and affects everyone differently.

There is no cure; treatment consists of a vitamin cocktail and various therapies.

Mitochondrial Diseases are inherited or caused by a point mutation before birth.

Mitochondria contain 2 types of genetic material:

1. Mitochondria mtDNA (which can only be passed on from the mother).
2. Nuclear nDNA (which is passed on from both parents).

What you can do:

- Educate yourself about Mitochondrial Disease.
- Be an advocate for your health and the health of your family.
- Use the many resources available to children and adults.
- Life balance is important - don't forget to look after yourself.

mitocanada

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awareness · support · research

Information about Mitochondrial Disease and MitoCanada