MitoCanada Annual Report

2011

…Baby Steps…

mitocanada


2011

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Our Mission

MitoCanada provides support and awareness to Canadians affected by Mitochondrial Disease while also supporting the advance of research in the field of Mitochondrial Disease.

MitoCanada exists to connect Canadians who are directly and indirectly affected by mitochondrial disease. Our hope 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 sense of community for patients and their families.

MitoCanada was formed by a group of mitochondrial disease patients, families, caregivers, and friends, with support from dedicated medical professionals, to provide support and practical information that will help to improve the quality of life and sense of community for patients of all ages, and their families.

MitoCanada Foundation is an officially registered Canadian charitable organization.

Charitable registration number: 81258 6667 RR0001

MitoCanada was started and is currently operated entirely by volunteers who graciously give their time to our worthy cause. We have organized ourselves in a simple structure that allows effective operation in the early start-up phase and is easily expandable to accommodate our future growth initiatives, programs, and volunteer/staffing needs.

Baby Steps is the theme throughout this Annual Report.

An organization such as MitoCanada needs to start somewhere and "baby steps" lead to bigger steps and even larger steps over time.

mitocanada

awareness • support • research

teammito

awareness • support • research

From the CEO

President & CEO
Blaine Penny

It was evident early on in the development of MitoCanada that there was great potential to grow quickly as a new (and the only charity) for mitochondrial disease in Canada. We recognized the need for support is immense as more and more people are diagnosed, awareness is paramount and the need to raise funds for research has become more apparent.

In 2011 we saw our revenues almost double and MitoCanada truly began to take off. The majority of our revenue still came from grass roots fundraising (mostly event based) and we were the recipients of a $20,000 grant from the CIBC Children's Foundation – this was our first grant!

I am constantly moved by the number of individuals, groups and organizations that have come forward to do 3rd party fundraising or volunteer for MitoCanada. It has ranged from kids donating their birthday money and lemonade stands, to gold plate dinners and galas, to numerous sporting events. Team MitoCanada – our latest initiative using sport as a platform to raise awareness and funds – has proved to be a huge success and has the potential to be the next Livestrong.

We have made significant steps on the research front and funded a study at McMaster University led by Dr. Mark Tarnopolsky and new diagnostics at the Alberta Children's Hospital led by Dr. Aneal Khan using the state-of-the-art Next Gen sequencer.

International collaboration is key to moving awareness and research forward. We have developed strong relationships with both the United Mitochondrial Disease Foundation (UMDF) and the Australian Mitochondrial Disease Foundation (AMDF). Together we launched the Global Mitochondrial Disease Awareness website for Mitochondrial Disease Awareness Week. We see more and more interest from other like organizations signing up and this is a really positive step in joining the global mito community.

Our next big step is to move from a strictly volunteer based organization and transition to paid professional staff who can help us make that next leap.

Fundraising

The past year, MitoCanada had an increase in the number of 3rd party events held.

In May of 2011, The Wagler Family held “Jump and Jive for Mito” in Kitchener, Ontario. The event was a black and white gala dinner and auction and featured Walter Gretzky as guest speaker. The event raised $15,000 for MitoCanada. MitoCanada appreciates the hard work the Wagler Family put in to running this amazing event!

In July of 2011, Chantel Sharp held her 2nd “Mito Day at the Beach” at Gulliver’s Lake in Freelton, Ontario. Part of the proceeds raised from this years event went to MitoCanada. It was a beautiful sunny day and many families came out to enjoy this event. Thanks again to Chantel Sharp for organizing such a great family event!

MitoCanada’s major fundraiser, “Running on Empty” was held in September 2011 in both Hamilton, Ontario and Calgary, Alberta. The Hamilton event consisted of a 2.5km or 5km walk or roll. Over 300 people attended the event at Confederation Park. There was a BBQ, children’s activity area, and many amazing prizes! Participants gathered pledges to attend and $36,000 was raised. It was a fun day for the families. It was also a great way for families affected by Mitochondrial Disease to meet other families who are also affected by this devastating disease.

The "Running on Empty" Alberta event had over 30 participants (in the 100, 50, 25 and 15 km events) and introduced a 100 km mountain bike ride to the roster of events. There was great coverage of the event in on-line articles and blogs and a couple TV interviews raising awareness. The event raised $40,000.

Awareness & Support

Over the past year there was a shift in roles of the Awareness Committee. The former chair Christine Gowland stepped down and Julie Drury was elected for the role, with Christine Gowland and Sarah Antonakis as acting Co-chairs. Individual members of MitoCanada who remain on the committee with an interest in awareness are as follows;

- Kyle McLaughlin
- Michelle Firlit
- Carolyn Scholey

Updates

- Development of rough draft of The Canadian Mitochondrial Disease Awareness Action Plan which is An action plan for a national Mitochondrial Disease awareness campaign for patients, families, caregivers, physicians, and general public.
- Brainstorming the contents and intent of the Mito Awareness Tool Kit for physicians
- Mitochondrial Disease Awareness Week Proclamation was attained from the City of Burlington for the fiscal year 2012.
- Planning for upcoming MitoCanada events for the 2012 fiscal year- Running on Empty-Calgary Ultra Marathon, Running on Empty Hamilton Walk & Roll, Stay in Bed Day, etc.
- Global Mitochondrial Disease Awareness Website was active again this year and MitoCanada remains a key partner
- MitoCanada attended the UMDF Conference for the first time as a vendor.
- Secured a vendor booth at McMaster Children's Hospital to sell merchandise and spread awareness
- Articles written and published in various newspapers in Hamilton/Burlington Ontario and Calgary Harold for Mitochondrial Awareness week
- Ironman Double Double Online Blog continues to reach readers–written and posted by Kyle McLaughlin
- Television Interview on CHCH News-Ontario for the second year in a row, along with radio advertisements and promos

Team Mito

Dr. Kyle McLaughlin attended the Canmore MitoCanada Fun Run in May and would have no idea how this run would impact him. Through meeting the Penny family and learning a bit more about mitochondrial disease and MitoCanada that day, he was inspired to do something big. Kyle had some big triathlon goals and decided to take on 2 Ironman Triathlons in what he dubbed the MitoCanada Ironman Double-Double over 2 months and raise funds and awareness for MitoCanada along the way. Over the course of these few months, Kyle raised more than $17,000 and inspired many people to run and ride further for MitoCanada.

After completing the Ironman Double-Double, Kyle felt a need to do more. He was amazing how many people commented on his flashy MitoCanada triathlon racing kit and had many people asking how they could get one. Kyle stepped forward saying he wanted to do more for MitoCanada and this is when he came up with the idea of 'Team Mito'.

Team Mito essentially uses sport as a platform for raising awareness and funds through "competing for those who can't". In Kyle's spare time (outside being a parent of 2 boys and a full-time Emergency Physician) he got right to work in designing the kit, finding sponsors, recruiting teams and signing up for more races. Shortly thereafter a website was up with stories being shared and race reports coming every weekend. The momentum was incredible and sparked the interest of many people as something very unique in the sporting community.

Research

This year has heralded significant growth in our capacity to fund research. Our expanding research committee, in consultation with leading Canadian Mitochondrial Disease researchers, has set our focus on supporting research that aims to improve the identification and treatment of Mitochondrial Diseases. We have established two streams of funding. First, in partnership with the Canadian Institutes of Health Research, we will co-fund two doctoral awards with a total value of $210,000 between 2013 and 2016. These awards will not only support worthy research, but will also serve as an incentive to attract highly qualified scientists to the field of Mitochondrial Diseases. More information on these awards can be found at this link.

Our second stream of funding will be awarded directly by MitoCanada. Up to $50,000 per year will be awarded to new and seasoned investigators whose projects fall within our priority areas. Please visit our website soon for more information about these awards. We have established a formal process for soliciting and adjudicating project proposals. Our Scientific Advisory Board will review requests for funding based on alignment with MitoCanada's research priorities, scientific merit, originality, feasibility, track record of the applicants, and potential benefit to the Canadian Mitochondrial Disease community.

In addition to planning future funding, MitoCanada has also actively supported current research efforts in 2011/12. First, we awarded $41,000 to Dr. Mark Tarnopolsky and his colleagues at McMaster University for their project entitled: “Identification of Serum Factors Responsible for Systemic Mitochondrial Biogenesis.” Details of the study are on our website http://www.mitocanada.org/2012/03/04/mitocanada-supports-mito-research/

and early results are promising. Second, we have committed $1000 to Dr. Jane Shearer and colleagues at the University of Calgary to study: “Strategies to enhance stem cell mediated mitochondrial transfer: potential for the treatment of mitochondrial disease.” Dr. Shearer’s study is very innovative and has the potential to significantly advance the treatment of Mitochondrial Diseases using stem cells. Third, in matching funds with the Alberta Children’s Hospital, CIBC and a private donor (Sean Messing), MitoCanada was able to contribute $50,000 to support University of Calgary Dr. Aneal Khan’s project: “Calgary Mitochondrial Disease Next Gen Sequencing Diagnostics Project.”

In the coming year, we hope to expand our Scientific Advisory Board. We also plan to develop a research portal on our website where we can update our community about our current and future research funding activities as well serve as a venue for Mito researchers to network.

Communication (IT and Social Networking)

The MitoCanada website is set up to provide information about Mitochondrial Disease to those who are looking for information online, in particular the “Mito What?” section. The website includes information about MitoCanada’s mission, board members, advisors and committees, a list of resources that affected individuals might need to access in their journey with Mitochondrial Disease, as well as upcoming and past events, and information about how to become involved either for support, or to promote awareness and support research.

MitoCanada continues to build a social media presence on Facebook, Twitter, and other social media sites.

A “Team Mito” web site was launched. The Team MitoCanada Project was created to provide a means to raise awareness for MitoCanada and Mitochondrial Disease through the participation of team members in sport of all types. Our goal is to have Team Members wearing the MitoCanada Green and Black in all forms of sport – from walking in a local charity 5km event to running in a 100km Ultramarathon, from cycling and triathlon to swimming and skiing – it will all help to raise awareness.

The Team MitoCanada website will serve as a hub for interaction with the public and participants. It will provide a specific forum for organizing and showcasing Team MitoCanada Events and Particpants.

MitoCanada currently uses a web-based database solution called eTapestry to track our donors, set up our Fundraising events, build an online cart, and generally support our web presence where possible.

We are continuing to enhance our database so we can better use it to build our support network, communicate via emails, and ensure improved communications with the people it is our mission to support.

Finance

These financial statements are the responsibility of the MitoCanada Board of Directors and executive team. The auditors have been appointed and these statements will be updated with the reviewed statements when that activity is complete.

Some items to highlight from April 1, 2011 to March 31, 2012 include:

- Managing costs effectively to achieve a low operating cost ratio (less than 21% overall), allowing a greater percentage of funds received in 2011/2012 to be directed towards programs in the next fiscal period,
- The establishment of Team MitoCanada, which promotes awareness of mitochondrial disease through sport.
- The organic growth of support groups and outreach programs across Canada.
- Receiving research proposals and green-lighting two important initiatives which were funded in May 2012
- Committing to grants for doctoral candidates specializing in fields of study related to mitochondrial disease for 2013, 2014, and 2015. Those grant funds are matched, effectively doubling the impact of our research commitment.

With $227,701.47 dollars in capital available for programs in 2012-2013 we will be increasing spending in our key program areas - awareness, support and research.

Despite the economy, MitoCanada was overwhelmed with a 62% year over

year increase in financial support and donations. We are so very grateful to our donors for their on-going support. Your most generous support has already made and will continue to make a difference in the life of those impacted by mitochondrial disease. Through the commitment and dedication of our amazing volunteers, donors, sponsors and partners, this national charity was able to raise an astounding $177,852 in the last fiscal year 2012. We are pleased to announce that we were able to secure a significant CIBC grant to support research in Calgary on the NexGen research project. We have committed $25,000 to this research commencing May 2012. We also saw an increase in donations from memorials, tributes and our signature Running on Empty events in both Hamilton and Calgary, as well as the initiation of Team MitoCanada.

With the increase in revenue capital we have begun to commit funding for various research projects which will extend beyond the next few years. In mid 2012 we committed $41,000 in funding for research at the clinic at McMaster Hospital. In 2013, we will be collaborating with CIHR and have set aside an additional $37,000 per year to fund 2 doctoral students for the following 3 years. Our funds are matched dollar-for dollar by CIHR, which doubles the impact of this commitment.

Increasing the awareness of mitochondrial disease in Canada is a central program area for MitoCanada. Through Team MitoCanada the level of awareness and media coverage has substantially increased through participation in competitive athletic events such as running, cycling, and triathlons. Our goal is to continue to grow awareness of MitoCanada and mitochondrial disease within Canada through liaisons with metabolic clinics across Canada, targeted awareness campaigns, and social media. From a support perspective, we look forward to continuing to develop our support function and will be providing various grants to families within the mitochondrial community.

Charity Name: MitoCanada Foundation
Financial Statement prepared on a cash basis. Fiscal Period Ending March 31, 2012

Financial Statements Information
Statement of Assets and Liabilities

Assets	
Current Assets	
Bank Balance	$227,701.47
Inventory	**$2,000**
	Total $229,701.47
Liabilities	
Current Liabilities	$0
	Total $0

Statement of Revenue and Expenditures

Revenue	
Corporate Grants	$20,000.00
Individual Donations	$129,705.80
Third-party events	$21,565.18
United Way – designated donations	$746.00
Special Event Sales	$5,835.15
Revenue Total:	**$177,852.13**
Expenditures	
Business Registration Fees	$53.00
Fundraising Fees (Canada Helps, IATS)	$2,905.08
Systems configuration	$2,100.06
Facilities and Equipment	915.00
Software Licensing	$4,732.44
Postage and Mailing	$549.20
Brochures and printing (awareness)	$2,818.82
Supplies (awareness and support)	$2,423.63
Merchandise and event expense (awareness)	$14,327.65
Telephone	$797.92
Vehicle Expenses	$303.05
Support	$400.33
Advertising	297.00
Insurance	3,866.40
Interest and Bank Fees	74.42
Memberships and Dues	$525.00
Expenditures Total:	**$37,089.00**

Treasurer Signature:

Expenditure Allocation

Expense	Awareness	Fundraising	Support	Management & Admin	Total
Business Registration Fees	0.00	0.00	0.00	53.00	$53.00
Fundraising Fees (Canada Helps, IATS)	0.00	2905.08	0.00	0.00	$2,905.08
Systems configuration	0.00	721.38	0.00	1378.68	$2,100.06
Facilities and Equipment	915.00	0.00	0.00	0.00	915.00
Software Licensing	0.00	2071.17	0.00	2661.27	$4,732.44
Postage and Mailing	52.77	41.52	0.00	454.81	$549.20
Brochures and printing	1225.14	944.87	648.81	0.00	$2,818.82
Supplies	0.00	2423.63	0.00	0.00	$2,423.63
Merchandise and event expense	858.83	5560.25	208.57	0.00	$14,327.65
Telephone	0.00	200.00	0.00	597.92	$797.92
Vehicle Expenses	0.00	303.05	0.00	0.00	$303.05
Support	0.00	400.33	0.00	0.00	$400.33
Advertising	0.00	297.00	0.00	0.00	297.00
Insurance	0.00	1904.04	0.00	2772.36	3,866.40
Interest and Bank Fees	0.00	0.00	0.00	74.42	74.42
Memberships and Dues	0.00	500.00	0.00	25.00	$525.00
Expenditures Total:	**10,751.74**	**17,062.09**	**1257.71**	**2871.78**	**$37,089.00**
Percentage of revenue	**6%**	**9.6%**	**.7%**	**1.6%**	**21%**

End of 2011 Financial Report

“Baby Steps” are taken one step at a time, side by side steps.

Step by Step as a team we will improve treatments and find a cure to Mitochondrial Disease.

It takes baby steps to grow.

Remember to dream big, think
long-term and take baby steps.

That is the key to long-term success.

Take baby steps and don't give up! Keep moving in the right direction.
Trust yourself and your abilities.

OUR THANKS TO THESE SPONSORS

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