

2012 Annual Report

A TransCanada Journey

2012



Pictured Above: this photo represents the diverse third party activities that encourage mitochondria to be used to the max!

Pictured on Front Cover: The theme for this year's annual report is to depict "mito miles" and to highlight our "milestones" as a charity, the miles that team mito conquers and the miles that pull MitoCanada together as a national charity.

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Board of Directors:

President and CEO	Blaine Penny, Alberta
Vice President	Stephanie Rount, Ontario
Executive Director	Vicky Spadoni, Ontario
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Treasurer	Joelle Pokrajac, Ontario
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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.

This disease causes abnormal function of the heart, brain, liver and muscles leading to poor development, strokes, multiple body dysfunctions and a shortened lifespan; Mitochondrial Disease affects 1 in 5000– children and adults.



MitoCanada exists to connect Canadians who are directly and indirectly affected by mitochondrial disease.

MitoCanada was formed by a group of mitochondrial disease patients, families, caregivers, and friends, with support from dedicated medical professionals.

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 Foundation is an officially registered Canadian charitable organization.



Charitable registration number: 81258 6667 RR0001

From the CEO

Looking back on 2012, it has been another very successful year for MitoCanada with several things standing out – our first paid hire (Executive Director – half time), healthy increase in revenue, significant progress with research grant(s) and establishing a Canada wide survey providing a baseline for awareness.

Pictured at Right: Blaine and Evan Penny



We made the successful transition to the day-to-day operations of the charity being led by our Executive Director (Vicky Spadoni). Vicky has done a great job moving many things forward and keeping the momentum. We even now have office space in Ontario and a place to call home.

We have seen a very healthy increase in revenue and received our first official grant of \$25,000 from the CIBC Children's Foundation. We were an officially registered charity in the Calgary and Ottawa Marathons and raised more than \$45,000 in a new stream of revenue. We were also selected as 1 of 2 feature charities at the 2013 Calgary Marathon (amongst 76 charities), which will provide significant awareness and fundraising opportunities. I feel the Marathons will prove to be very successful in future fundraising.

I am very impressed with the work Dr. Josh Slatkoff (Research Committee Chair) has done. Josh has assembled an effective and competent team that has established a process for RFPs for research grants. We saw the \$41,000 research grant get awarded to Dr. Mark Tarnopolsky, \$25,000 to Dr. Aneal Khan and the signed agreement with the CIHR SHOPP for 1 doctoral student (contributing \$16,500 per year for 3 years).

A handwritten signature in blue ink, appearing to read 'Blaine Penny'.

President & CEO
Blaine Penny

Awareness

MitoCanada has witnessed an increase in public awareness which was benefited by the fact that Carleton University completed a baseline Awareness Survey which was pro bono as it was part of a Communications course. This provided the measuring stick for future comparisons. Through this awareness, we see MitoCanada being invited to be a partner charity for many more events. This translates into increased awareness and dollars donated.

To enhance our visual awareness we networked with graphic designer John Kormos at Korporal Images and upgraded the brochures. Two concepts that Vicky generated were a tear-off donation section and a QR barcode suitable for cell phone scanning which would enable donors to make online donations easily.

E- blasts from our etapestry system have been sent to our constituents on a regular basis keeping them up to date as well as Vicky Spadoni's well received communications piece, "From the Executive Directors Desk".



Christine Gowland, Joelle Pokrajac and Stephanie Rount pictured here at the 2012 UMDF Symposium held in Bethesda, Maryland. MitoCanada was able to provide financial grants to three more individuals to attend.

Bernadette Lalonde, a graduate from Royal Roads University, living in Calgary, has approached MitoCanada with her interest in completing her practicum hours with the organization and a possible task will be to develop a physician/healthcare provider package of information. We are very grateful for student support of our cause. We have also presented to Laurier University, Mohawk College, Conestoga College, Humber College and Nipissing University for student placement opportunities.

*A unique awareness opportunity called, "**Turn Your Porch Light Green**" was spearheaded by volunteer Sarah Antanakis from the Ottawa area. MitoCanada encouraged Canadians from across the country to turn your porch light green in recognition of **Mitochondrial Awareness Week in September.***



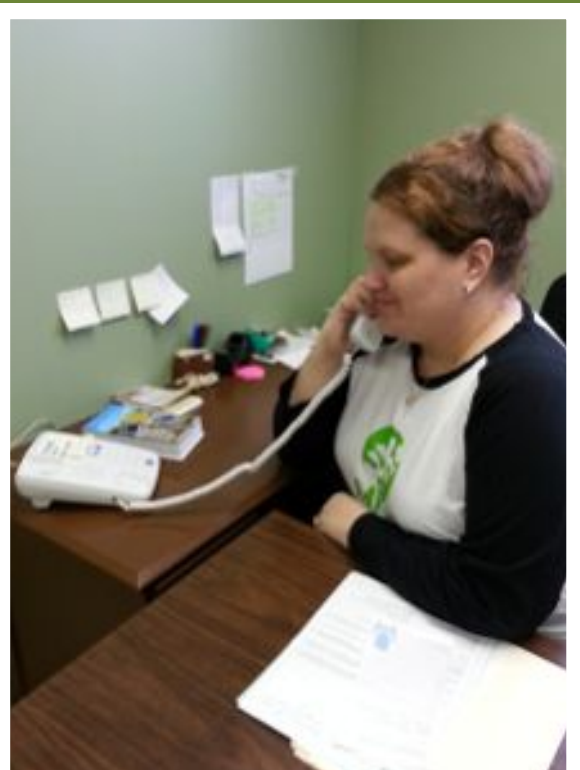
Fundraising



Third party events were held throughout the past year. Scott's Ride, a Spinathon, our annual Stay in Bed Day, Running on Empty walk in Hamilton and Alberta , a lemonade sale, are only a few charity events that compliment the funds raised by our signature sports events.

Support

Since April of 2012, MitoCanada made great strides in solidifying our support team and their initiatives. The most outstanding accomplishment was the creation and adoption of our Peer Support Manual – a professional document that confirms MitoCanada as trailblazers in forward thinking and strategic planning. This did not happen without the appreciated assistance of Kara from the United Mitochondrial Disease Foundation. Additional research was completed utilizing the resources of Canadian Cancer Society, Cystic Fibrosis, Kidney Foundation, Leukemia and Lymphoma Society of Canada and HEP CBC.



In observing an increase in external support calls, the Support Team developed a system to process these inquiries. The initial call or e-mail goes to Vicky; it is sourced through her and then forwarded to Lisa who makes the initial contact with the family within 24 hours.



Peer Support Volunteer Manual



“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”

Leo Buscaglia

The Daval Hospice in Niagara Falls held an event called HOPP for organizations that offer care giver support. Our table was hosted by our Support Team Leader, Lisa Bell and provided give-aways and an abundance of information.



Looking forward, we are planning to create an intake/follow up form with a confidentiality agreement to facilitate a seamless flow of communication. Additionally, we have finely tuned our internal client database which encompasses all our donors, supporters and vendors.

Research

“All the effort you are putting in is working. The powers that be are seeing the combined internal and community efforts and it is making things move forward.”

*Pictured Right: Dr. Aneal Khan, MSC,MO,FAAP,FRCPC,FCCMG
Assistant Professor of Medical Genetics and Pediatrics,
Alberta Children’s Hospital, University of Calgary*



In the 2012 Research Report from our Research Committee Chair,
Dr. Josh Slatkoff, he states:

“This year we have continued to expand research funding efforts. We have now established a formal process for soliciting and adjudicating project proposals. After MitoCanada conducts a nation-wide call for proposals to Universities, teaching hospitals and research centres, our Scientific Advisory Board reviews requests for funding (RFP) based on alignment with MitoCanada’s research priorities, scientific merit, originality, feasibility, track record of the applicants, and potential benefits to the Canadian Mitochondrial Disease community. The 2012 \$50,000 RFP had 11 applications. In the process, the Research Committee was able to develop a database of suitable proponents and now many more academic institutions know about MitoCanada and that we have funds available.

Our committee is particularly focused on projects that have the potential to improve diagnosis and treatment rather than on those with a basic research orientation. This process has resulted in the funding of **two projects** this year focusing on treatment of Mitochondrial Disease.

In partnership with the Canadian Institutes of Health Research, we are co-funding one doctoral award with a total value of \$105,000 between 2013 and 2016. This award will not only support worthy research, but will also serve as an incentive to attract highly qualified scientists to the field of Mitochondrial Diseases. This award has been presented to Alex Green studying at McMaster University. The project title is “**AMP – Activated Protein Kinase (AMPK) Activation for the Treatment of Mitochondrial Disease.**”

MitoCanada awarded \$45,000 to Dr. Jane Shearer and colleagues at the University of Calgary for the study of **“Strategies to Enhance Stem Cell Mediated Mitochondrial Transfer: Potential for the Treatment of Mitochondrial Disease.”**



In March 2012, the CIBC provided a \$20,000 grant to MitoCanada which was complimented with an additional \$5,000 donation from Sean Messing of CIBC. This was awarded to Dr. Aneal Khan to develop a platform to diagnose Mitochondrial Disease using the Next Generation Sequencing Method (NGS). The Alberta Children’s Hospital Research Institute (ACHRI) provided matching funds.

In Calgary, 12 patients have been sequenced through this NGS pilot. Previous methods of diagnosis involved invasive tissue biopsy, could only test a handful of genes, put patients at risk for procedural complications and could only make a diagnosis in a small number of cases. Doctors can now make more precise decisions about treatment. The funds from this CIBC grant will expand the significant impact to patients suffering from complex metabolic issues and mitochondrial disease.

Details about each of these projects as well as other MitoCanada-funded research projects can be found at <http://www.mitocanada.org/mitocanada-research/>. In the coming year, we hope to establish our own stream of doctoral-level funding as the CIHR program has ended. We also anticipate funding 1-2 projects led by seasoned Mitochondrial Disease researchers.

Finance

MitoCanada Foundation Balance Sheet

As at	March 30, 2013	March 30, 2012 (Unaudited)	April 1, 2011 (Unaudited)
Assets			
Current			
Cash (Note 3)	\$ 190,066	\$ 161,701	\$ 89,609
Short term investment (Note 4)	50,000	-	-
HST recoverable	5,700	2,471	-
Prepaid expenses	4,368	5,014	2,349
	<u>250,134</u>	<u>169,186</u>	<u>91,958</u>
Long term investment (Note 4)	50,000	-	-
	<u>\$ 300,134</u>	<u>\$ 169,186</u>	<u>\$ 91,958</u>
Liabilities and Net Assets			
Current liabilities			
Accounts payable and accrued liabilities	\$ 52,300	\$ 2,499	\$ -
Net Assets			
Unrestricted	<u>247,834</u>	<u>166,687</u>	<u>91,958</u>
	<u>\$ 300,134</u>	<u>\$ 169,186</u>	<u>\$ 91,958</u>

By the Board of Directors

—  —  —, Director
 _____, Director

These financial statements are the responsibility of the MitoCanada Board of Directors and executive team. The Auditors have conducted a review and audit of these statements and have found no material issues. A copy of the audited statements is available on request (these use accrual accounting). In the 2013/2014 fiscal period we will transition from cash basis accounting to accrual basis accounting. Our statements are reviewed and audited using accrual accounting, so this move brings us into line with the method used by our auditors. These financial statements presented in this annual report use cash basis accounting which matches what was reported to Revenue Canada on our T3010. Future filings with Revenue Canada and presentation of financial statements in our annual report will use accrual accounting.

Some items to highlight from April 1, 2012 to March 31, 2013 include:

- Managing costs effectively to achieve a low operating cost ratio (less than 15% overall), allowing a greater percentage of funds received in 2012/2013 to be directed towards programs

- The growth of Team MitoCanada, which promotes awareness of mitochondrial disease through sport.

- The organic growth of support groups and outreach programs across Canada.

- Strengthening the research committee and approving several initiatives, including a doctoral scholarship through a partnership with CIHR who matched the funds we committed, effectively doubling the impact of our research commitment.

- Hiring an Executive Director (contract basis, half-time) to drive program development forward.

MitoCanada Foundation
Statement of Operations and Changes in Net Assets

For the year ended March 31

	2013	2012
	(cash basis)	(reviewed - cash basis)
Revenues		
Grants	25,000	20,000
Fundraising		45,000
ROE Calgary	58,739	
ROE Hamilton	53,635	42,000
Team MitoCanada	75,136	
Third Party Events	23,000	21,565
Other Donations	13,149	49,287
	248,659	177,852
Expenses		
Office, administration, insurance	13,128	5,267
Association Fees	90	525
Awareness expenses	3,497	5,539
Bank Charges	12	74
Contract staff for program development	49,988	
Merchandise and Event expenses	37,781	14,328
Facilities	1,989	915
Fundraising expenses (IATS fees)	3,629	2,905
Training and travel	75	303
Research Grants	66,000	
Software	5,344	6,833
Support	1,521	400
	183,054	37,089
Excess of revenues over expenses	65,605	140,763
Net assets, beginning of the year	229,701	91,958
Net assets, end of the year	295,306	229,701

Expenditure Allocation

Item	Charitable	Administration	Fundraising
Administration		19,203	
Fundraising costs			7,629
Program Spending	156,222		
Total	156,222	19,203	7,629
Percentage	85.34%	10.49%	4.17%

NOTES

Administration costs include office and administration expenses, bank fees, shipping, facilities, training and 4k of contract staff spending

Fundraising costs include IATS fees and 2k from software and 2k from events

Program spending includes association fees, awareness spending, and the remainder of contract staff, software, and event spending

Team MitoCanada

After only one year, Team Mito has over 250 members across 8 provinces. We have ordered over \$20,000 worth of Team Mito gear/clothing thanks to the amazing ongoing efforts from our registrar Marla Moncrieff and one of the foundation visionaries of Team Mito, Kyle McLaughlin.



We started a Cycling Team with club status in the Alberta Bicycling Assoc lead by David Lendrum (Road) and Brendan MacCracken (Mountain). We had many podium finishes including the Banff Bikefest, 24 Hours of Adrenaline, Furious 3 and Salty Dog Enduro race with many more Personal Bests. We had tremendous turnouts for many Gran Fondos including Highwood, Banff and San Diego.

The MitoCanada Road Cycling Team is an exciting team of cyclists participating in all levels of racing (Cat 2-5) and group large event riding in Alberta, across Canada and even around the world. With well over 50 team members sporting the MitoCanada Road Cycling kit, this team has become a well-recognized group of riders known for their friendly inclusive attitude, pursuing individual and team goals and raising awareness for Mitochondrial diseases.



The MitoCanada Triathlon Team is a new sport added for 2013. Our emphasis is to encourage involvement of all abilities in all distances of triathlon in order to raise awareness. We will have an elite team that will compete at 3 or higher profile events along with our sport team members. In addition to competing at marquis events together, our team will have group training workouts and camps. We look forward to increasing the number of Team Mito Triathletes this year and share in the goal of “swimming, riding and running for those who can’t”.

Our Nordic Ski team was created this year with Tony Smith as the lead. We had a huge performance in the Lake Louise to Banff Loppett and 24 Hour Canmore Skifest. The 2nd annual 100km ski of Peter Lougheed Provincial Park was a tremendous success and continues to grow. The MitoCanada Nordic Ski Team consists of athletes from across Western Canada and Ontario, all with a variety of backgrounds and reasons for joining our team.

The MitoCanada Mountain Bike Team

is a growing group of riders. Team Mito Mountain Bikers competed in several events last year including Transrockies Bike Race, BC Bike Race, 24 Hours of Adrenalin, and the Bow 80. Twelve riders also completed 100km of single track in the Canadian Rockies as part of the 2012 MitoCanada Running on Empty event. While a number of the team members perform at a very high level, the team has a broad appeal, which has created an enjoyable team environment. This is reflected in the growing reputation that Team MitoCanada athletes are earning for sportsmanship and camaraderie with our fellow competitors. We’re excited for 2013 and to once again “ride for those who can’t”.



TeamMito skiers made their mark last season by placing many athletes on the podium of several major events. We intend to build on this success for the 2012 – 13 season. The Nordic Team will be competing in numerous race formats including a stage race, individual time trials, long distance marathons/loppet and the Canadian 24 hour National Ski Championships. Our team consists of past national champions, Canadian Masters podium winners, loppet and marathon winners.

Our Trail Running team dominated. We had 6 people in the top 20 overall at Calgary Marathon, took top 2 overall in Calgary Half marathon, 8 of top 9 at the Powderface Trail Marathon, Overall champ at the Ironlegs 50 miler, 2 in the top 3 at the Xterra Enduro trail half marathon, 3rd overall at the Stinson Beach Trail Marathon in California.



MitoCanada was an official charity for over 10 events this past year. Of note, as an official charity for the Ottawa and Calgary Marathon we had over 100 runners at each event with many more supporters and volunteers cheering them on. Team Mito was well represented at our premier event, Running on Empty. With many runners, riders and volunteers sharing the energy.





As well, we unveiled our new Team Mito Promo Tent and Flags to a multitude of positive comments.

Our website continues to grow with close to 50 event reports, 20 athlete profiles and informative articles like Coach tips from Cal Zaryski. Our Facebook page has 275 followers and we have added a trail running and cycling subgroup to coordinate training and races. This upcoming year we will continue the momentum from Running on Empty with more race reports and athlete profiles. In addition, we would like to increase sport, medicine, science and nutrition knowledge transfer amongst our members with more contributions to the website from experts in the field.

We will continue with online membership registration but are looking at ways we can streamline the clothing purchase process (i.e. online shopping, increased inventory, etc).

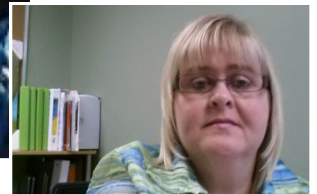
With an ever increasing membership we may need to look at creating Team Mito Sections to allow for greater involvement and notification of local events. These topics will be discussed at the second Annual General Meeting in early October in Calgary.

Our next goal is to obtain sponsorship to cover the costs of promotion, marketing, team fees and of course to give back into MitoCanada. With this goal in mind, we have welcomed the help of Tara Kabatoff as Team Mito's marketing and sponsorship coordinator.

Our Team continues to increase awareness and inspire and we are routinely blown away by the stories of our members. We are excited to see what the next year brings for Team Mito.



Looking Ahead—2013 Goals



The coming year is very exciting and we have set some challenging goals.

- We would like to see a 50% increase in revenue, with diversification including approximately \$100,000 in grants.
- Increased awareness: 1) in the general public with more national media coverage, and 2) within all major Children's Hospitals across Canada.
- Extend support reach to more provinces and assess needs for additional support funding services (e.g. medical equipment, etc.)
- Develop and implement volunteer coordination program.
- Develop long-term Team Mito strategy.
- Increase funding of research.
- Attain a grant to hire a PR/Communication Specialist to develop national awareness campaign.

