



mitocanada

awareness • support • research

2010 Annual Report



Contents

Our Mission	1
A Word From the CEO	1
Who We Are	3
Board of Directors	3
Advisors	4
Committees	4
Fundraising & Events	5
Awareness & Support	6
Awareness Outreach in the General Community	6
Awareness in the Medical Community	6
Support	7
Research	8
International Collaboration	8
IT Working Committee	9
Finance	10
Financial Statements Information	11

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.



A Word From the CEO

“Creating Positive Energy to Help People Affected by Mitochondrial Disease”

After becoming officially incorporated and receiving charitable status on April 12, 2010, MitoCanada has been very busy moving its mission forward over the last year. We have spent the last year focusing on raising awareness, developing our support framework and completing a strategic plan. For a group of volunteers with very busy lives (and many caring for sick children or family members), it's absolutely incredible what we have achieved in this short period of time. It's another reminder that great things happen when you put a team of passionate people together to reach a common goal.

The ideas created in this group continue to amaze me each time we get together and we have had many late Sunday night meetings to keep things moving forward. There is definitely some irony in the energy theme – those affected have so little energy, while so much energy is required to achieve our mission. The concept of “Running on Empty” as our major fundraising theme is a great parallel for understanding this disease and how it impacts the energy system.

As with any exciting new initiative / organization, many great ideas are generated and there is a lot of enthusiasm to make a difference and conquer the world. MitoCanada has an exceptional group of people who are very passionate to advance our mission. We quickly found that our ability to prioritize and turn all the great ideas into initiatives and actions was a challenge. We are very fortunate to have the mentorship and guidance from Stephen Legault (who has come on as an advisor) to help guide us along this journey and to focus our objectives and goals through developing a five-year strategic plan. This has been an immense help in keeping us focused in the short term, while developing the long-term vision for MitoCanada.

I look back over the last year, and I am proud to say we have connected with hundreds of people affected by this disease, and helped them find a community of people who face similar challenges. Our awareness efforts have reached literally hundreds of thousands of people across Canada. We continuously get feedback about how great it is to have MitoCanada and the difference it is making.

Ahead of us we have another exciting year focusing on improving public communications, fundraising programs, support and awareness reach, and our operational effectiveness to ensure we can continue to engage new volunteers to take MitoCanada to the next level.



President & CEO
Blaine Penny

Who We Are

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.

We have 3 facets to how we have organized MitoCanada. The following outlines their structure as of September, 2011.

Board of Directors

Oversee day-to-day operations, provide governance, and strategic direction.

President	Blaine Penny, Calgary, AB
Vice President	Stephanie Rount, St. George, ON
Secretary	Kitty Pryde, Calgary, AB
Treasurer	Ruth McLelland, Milton, ON
Vice-Treasurer	Joelle Pokrajac, Mississauga, ON
Legal Advisor	Duncan Marsden, Calgary, AB



It's a rare thing to see an organization combine the passion and dedication of a start up with the unmitigated qualifications and maturity of an established organization. MitoCanada manages this with a professional integrity that take many NGO's a decade to achieve.



– Stephan Legault

Advisors

Provide operational and strategic guidance as well as alignment with medical community

Dr. Aneal Khan SC, MD, FAAP FRCPC, FCCMG	Assistant Professor of Medical Genetics and Pediatrics, Alberta Children's Hospital, University of Calgary
Dr. Mark Tarnopolsky M.D., PhD., FRCPC	Professor, Department Pediatrics and Medicine, Division of Neuromuscular and Neurometabolic Disorders, McMaster Children's Hospital, McMaster University, Hamilton, Ontario
Stephen Legault	Principal, Highwater Mark, Strategic Consulting
Vicky Spadoni	Operational Advisor

Committees

Execute strategic plan and mission. Each headed by a Chairperson.

Awareness	Christine Gowland, Burlington, ON
Support	Rebecca Daum, Dundas, ON
Fundraising	Chantel Sharp, Dundas, ON
Public Relations & Communications	Blaine Penny, Calgary, AB (interim)
Research	Dr. Josh Slatkoff, Victoria, BC
Executive	Blaine Penny, Calgary, AB
Finance Working	Ruth McLelland, Milton, ON
IT Working	Suzanne Gowland, Burlington, ON



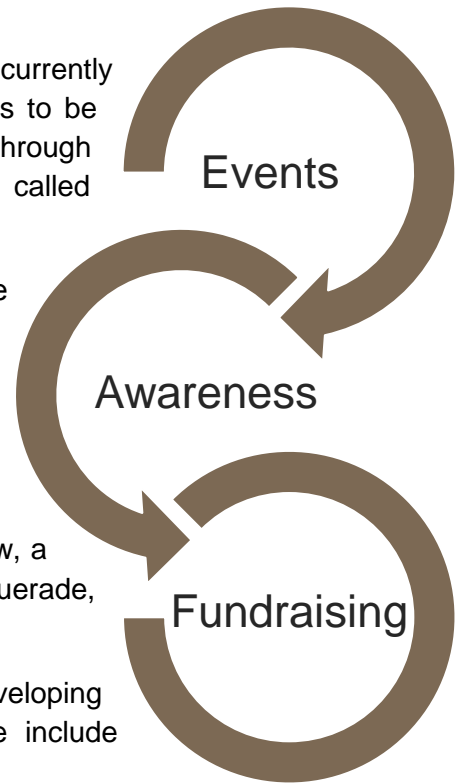
Fundraising & Events

The Fundraising & Events committee consists of 9 people and is currently organizing committee members into roles and delegating responsibilities to be more effective for future event planning. The majority of fundraising was through event pledges and donations which included our major fundraiser called “Running on Empty” as well as several third party events.

“Running on Empty” was hosted in Hamilton, ON and Calgary, AB. The Hamilton event attracted over 300 people in the inaugural walk/run/roll event and was a huge success. The Calgary event was a 100 km Ultra Marathon that had a select 20 runners channel their efforts for the cause. The events combined raised over \$70,000 - an incredible achievement for our first year.

Third party events across Canada included garage sales, a fashion show, a scrap-a-thon, Mito Day at the Beach, benefit dinners, Halloween Masquerade, bottle drives and several other smaller events.

The Fundraising & Events Committee have been very creative in developing MitoCanada branded products to raise awareness and funds. These include t-shirts, water bottles, bracelets, key chains, soaps, stickers, etc.



“ I am delighted to see how far MitoCanada has come in such a short period of time and look forward to its further development. Venues such as “Running on Empty” have raised awareness and money for this important cause. Organizations such as MitoCanada are essential to raise the awareness of this important disease, support patients and their families and to support important grassroots research aimed at finding effective therapies. I am pleased and delighted to be part of this organization and thank the volunteers for their many hundreds of hours of effort. ”

– Dr. Mark Tarnopolsky



Awareness & Support

Over the past year the Awareness Committee was created and includes 5 members. Our main awareness initiatives were through general community outreach (events, website, brochures, newsletters, and media), participation in medical community events, and using sport as an awareness platform. Awareness through sport has been an opportunistic way to reach people and is seen as an emerging way to engage a greater network of supporters.

Awareness Outreach in the General Community

- **Mitochondrial Disease Awareness Week** (September 17 to 23, 2010)
- **“Running on Empty”** Documentary submitted to several film festivals: Toronto International Film Festival, Calgary International Film Festival, and the Banff Mountain Film Festival
- Articles written and published in **various regional and local newspapers** and on-line: Brabant Papers, Hamilton Spectator, Evening Telegram, CBC, Calgary Herald, Canmore Leader, Banff Cragg and Canyon and Rocky Mountain Outlook
- **Website:** general information, resources, and events
- **Social media:** regular updates on Facebook and Twitter
- **Television:** CHCH News-Ontario, CTV, Global TV
- **Radio:** CBC, Fan960, Mountain FM, Astral Radio
- MitoCanada booth at **Michael Bernard Fitzgerald Rock Concert** (Calgary)
- Many **3rd Party events** – see events summary
- **Sport:** Many people are now aware of MitoCanada and the disease through various cross-country ski, running and triathlon events.



Awareness in the Medical Community

- **Metabolic Family Day**, London, Ontario (May, 2010)
- Mito Talks – **McMaster Children’s Hospital**, Hamilton, ON (April, 2010)
- Mito Talks - **Alberta Children’s Hospital**, Calgary, AB (September, 2010)

Medically, the term Mitochondrial disease includes a large number of heterogenous disorders characterized by a genetic change to the normal DNA coding for the mitochondria. As this DNA codes for mitochondria in all organs, the symptoms and severity can be quite variable. Unfortunately, this often leads to a long, confusing journey towards an accurate diagnosis. Even when a diagnosis is reached, treatment consists of vitamins and supplements to try to maintain the function of the mitochondrial systems, as there is currently no cure.

Historically, due to the poorly understood etiology, diverse number of symptoms and lack of sophistication in diagnostic testing many physicians have only received brief training regarding Mitochondrial disease. With ongoing improvements in the understanding of metabolic and genetic disorders like Mitochondrial disease and the influence of organizations like MitoCanada on increasing the awareness in the medical community, the diagnosis and treatment of mitochondrial disease will continue to improve. It is through these goals of increasing awareness, promoting research for a cure and providing support for families affected by Mitochondrial disease that MitoCanada will help the lives of all Mito patients.

Support

The Support Committee has 12 committee members and meets monthly. MitoCanada has connected with approximately 50 families to provide direct support relating to challenges faced with mitochondrial disease. Most support requests come through our info@mitocanada.org email address and are then re-directed to the committee chair. A welcome email is then sent to the family to invite them to set up a telephone appointment to share their story and to introduce them to MitoCanada. The Support Committee makes hospital support visits, telephone support calls and home support visits.

The Support Committee had a presence for all four days at the 2011 UMDF Symposium in Chicago that provided a great opportunity to understand how other organizations reach out to support people. The Support Committee Chair (Rebecca) is continuing into 2011.

A general survey was sent out asking questions of what our families would like to see in terms of support, and the most conclusive result was face-to-face contact or a support group allowing them to connect with other families. This has its challenges of freeing up parents or caregivers' time to meet and also requires child care and costs to get support. The Committee is still working out the best way to offer some form of a face-to-face support group.

We have just recently established *Condolence Guidelines* for the unfortunate situations where MitoWarriors have passed after succumbing to the disease.



Research

Dr. Josh Slatkoff joined MitoCanada as its first Research Committee Chair in April 2011. The first task has been to focus on establishing an agenda for funding research. Considerations have included identifying topics in need of research, deciding on the types of researchers whom we would like to support (e.g., doctoral, post-doctoral, young scientist, established principal investigator), enticing researchers to the field of mitochondrial diseases early in their career, maximizing our ability to fund high quality research with our available financial resources, and using our research funding strategy to support further fundraising. Consultation with current mitochondrial disease researchers and research directors at other non-profits has informed this process. At this time, we are considering partnering with the Canadian Institutes of Health Research as well as seeking out and funding an existing well established project investigating assessment and/or treatment of mitochondrial diseases.



International Collaboration

MitoCanada is very keen to openly work with other like organizations and feel that collaboration will help advance our mission and goals. Over the last year, we have been collaborating with our Australian and US counterparts – **Australian Mitochondrial Disease Foundation (AMDF)** and **United Mitochondrial Disease Foundation (UMDF)**.

The focus of the collaboration to date has been around the topics of awareness. The 3rd week of September has been considered Mitochondrial Disease Awareness Week for several years by most Mito organizations and we have agreed to maintain and adopt this going forward.

One of the great outcomes from this was the joint effort to launch the Global Mitochondrial Disease Awareness Week website: <http://www.gmdaw.org>. This has become a global platform for raising awareness and has since attracted several other Mito organizations from around the world to participate as well.



IT Working Committee

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 presence on Facebook and Twitter, and the two are linked together.

MitoCanada initially started out using Excel spreadsheets to manage donor information. However, to accurately keep track of our generous donors, our events and ensure that we could accurately report and audit our information, it quickly became clear that we needed a more robust database solution. With our volunteer base spread out across the country, we chose and implemented a web-based 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 enhancing 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

MitoCanada exists because donors like you continue to support our mission of providing hope to those affected by mitochondrial disease through awareness, support and research. We are grateful for your support and dedication to our cause – your gifts are very important.

MitoCanada does not hire fundraising staff or fundraising consultants on a commission basis, or on a percentage of revenues-raised compensation basis: all fundraising efforts are provided by volunteers.

We believe that by providing information, donors can make responsible and educated choices about their donations. By making information on MitoCanada's finances and activities available to our donors, the organization fulfils its commitment of accountability to its stakeholders. Donors have many ways of receiving information about MitoCanada: our Annual Report is produced once per year, our newsletter is published twice a year, and complete audited financial statements are also available upon request.

These are the unaudited financial statements for the first fiscal year. The auditors have been appointed and these statements will be updated with the audited statements when that activity is complete.

Some items to highlight from our first year include:

- Managing costs effectively to achieve a low operating cost ratio (less than 19% overall), allowing a greater percentage of funds received in year one to be directed towards programs in year two,
- First year focus on getting the website up and running, which has provided both a vehicle for fundraising and awareness as well as a list of resources for those affected by mitochondrial disease.
- The organic growth of support groups and outreach programs across Canada.

With \$89,000 dollars in capital available for programs in year two we will be allocating funds toward awareness, support and research activities. Our commitment to you – our donors, volunteers, and supporters – is to allocate those funds wisely and with maximum impact.

The following outlines the MitoCanada balance sheet for the 2010 financial year.



Financial Statements Information

Charity Name: MitoCanada Foundation

Fiscal Period Ending: March 31, 2011 (for 2010 Fiscal Year)

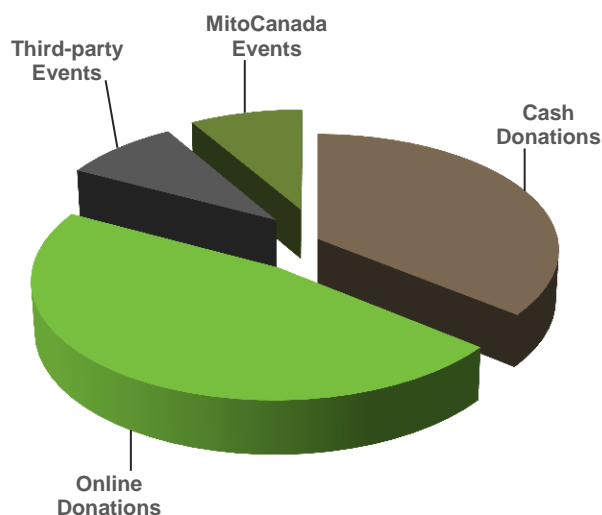
Statement of Assets and Liabilities

Assets	
Current Assets	
Bank Balance	\$89,609
Total	\$89,609
Liabilities	
Current Liabilities	
	\$0
Total	\$0

Statement of Revenue

Revenue	
Cash and Cheque Donations	\$39,134.18
Online Donations	\$51,493.98
Third-party Events	\$9,669.96
MitoCanada Events – Non-Pledge Revenue	\$9,272.09
Total	\$109,570.21

Revenue by Source



MitoCanada Treasurer
Ruth McLelland

“Mitochondrial diseases are chronic diseases that require the awareness of primary care physicians, medical subspecialists including acute care physicians and allied health staff. A better understanding of the challenges patients and their families face can help prepare them for future care needs and help care providers provide the supportive care that improves their quality of life.”

– Dr. Aneal Khan

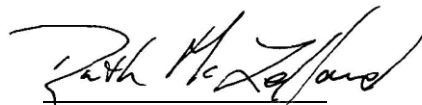


Statement of Expenditure Allocation

Item	Charitable	Administration	Total
Bank Charges		\$56.32	\$56.32
Canada Helps fees		\$2,016.61	\$2,016.61
Legal Fees		\$490.38	\$490.38
Travel expenses		\$1,235.48	\$1,235.48
Training		\$1,625.00	\$1,625.00
Office Expenses and Supplies		\$1,376.33	\$1,376.33
Insurance		\$2,574.72	\$2,574.72
Event expenses	\$1,346.49		\$1,346.49
Merchandise expense (awareness)	\$7,789.74		\$7,789.74
Brochures and printing (awareness)	\$760.14		\$760.14
Website Hosting (support and awareness)	\$540.00		\$540.00
Support	\$100.00		\$100.00
CORD affiliation membership		\$50.00	\$50.00
Total	\$10,536.37	\$9,424.84	\$19,961.21

Notes: Financial Statement prepared on a cash basis.

This is the first fiscal year of the organization. The accumulated funds on hand at the end of the fiscal period will be allocated towards programs in year two (Fiscal 2011 – 2012) and reported on in the next annual report.



MitoCanada Treasurer
Ruth McLelland



Looking Ahead

Moving forward, MitoCanada will continue to expand on its three goals of **Awareness**, **Support** and **Research**.

While MitoCanada is currently **run solely by volunteers**, recruiting more volunteers in the near future will be crucial for MitoCanada's continued growth and success. MitoCanada hopes to soon hire an executive director (on a part-time basis) that brings significant not-for-profit leadership experience. This will enhance the day-to-day operational effectiveness, increase fundraising efforts, improve communications, and enable volunteers to be more effectively utilized through committees and special events.

Future goals from an IT perspective include making the website available in both French and English (at the moment it is mainly English, with only a couple of key pages in French), developing eCommerce, improving social media links on the site, as well as having a dedicated resource who can keep the information as current as possible.

The next steps for Support will involve reaching out to the community to expand our support committee members through bringing on more specialized support expertise (e.g. Social Worker, a Mental Health Professional, Counsellors, and Support Workers).

We would like every Canadian to one day know what Mitochondrial Disease is and to provide support for those affected by the disease. This will require MitoCanada to increase its geographic reach across Canada. 'Team MitoCanada' is being developed to use sport as a platform for awareness and will be launched in 2011.

MitoCanada will be further developing the granting process for Research. This is a very important step in finding new treatments, and ultimately, a cure for Mitochondrial Disease.

MitoCanada will also continue its collaboration with several global charitable organizations in the fight against Mitochondrial Disease.

*Together we
can find a cure*



MitoCanada thanks these
corporate supporters



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