

Annual Report 2013

Breaking Down the Mystery



Cover Illustration: “**Breaking Down the Mystery**” A graphic representation of the folding cristae in the

Historically, the editors of the annual report have chosen a theme for the cover. This year we are highlighting the horizon for breaking down the uncharted mystery of the Mitochondria present in every cell of our bodies. For diseases there has been new progress in diagnosis and deciphering more about the complexity of the mitochondrial **Fibers** which appear in a number of Mitochondrial Diseases.

Board of Directors



Blaine Penny, President and CEO



Ruth McLelland, Treasurer



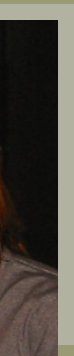
Joelle Pokrajac, Assistant Treasurer

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Assistant Treasurer



Duncan Marsden, Legal Advisor



Kitty Pryde, Secretary

Our Mission



MitoCanada provides support and Awareness to Canadians affected by Mitochondrial Disease while supporting advances in the field of research of Mitochondrial Disease.



MitoCanada exists to connect Canadians who are directly and indirectly affected by Mitochondrial Disease. Our goal is to reach all patients, 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 all patients and their families.



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



MitoCanada is an officially registered Canadian charitable organization; the registration number is 81258 6667 RR0001

From the CEO



This has been an immense year for MitoCanada and thank you to our staff, Board, committees, volunteers, and most importantly, the mito community for your support and involvement in the many events that help raise the profile and awareness of mitochondrial disease.

MitoCanada managed to receive several pieces of national awareness over the year including Stephanie Rount being one of the eight finalists in Wal-Mart's "Mom of the Year" contest and a Guinness World Record for the "Fastest Marathon by a Linked Team". Additionally, one of the largest head wear suppliers in the world, CTR/CAOS, has tagged thousands of clothing articles available in sporting goods stores across the country **with our mission statement.**

Our fundraising efforts were impressive and we saw a 53% increase in funds raised (380K). More and more third party events are selecting MitoCanada as their partner charity, which helps us raise awareness and funds. The participation in the Ottawa, Mississauga and Calgary Marathon charity challenge marathon programs has really bolstered our fundraising and is a great way to expand our reach to new people.

Our support program continues to grow and now has a training manual for our Peer Support Volunteers with the information needed to help them in their role of support vs. counseling, communicating, establishing boundaries and self care for volunteers.

2013 has been our biggest year for funding research with two new projects. MitoCanada is providing research funding for the extension of the Calgary NextGen sequencing project and funding for our second PhD student for three years. Combined, we allocated \$125,000 to new research in 2013.

Looking ahead to 2014, MitoCanada will be focusing on increasing its staffing plan to support other geographic regions and adding some new events to the calendar.

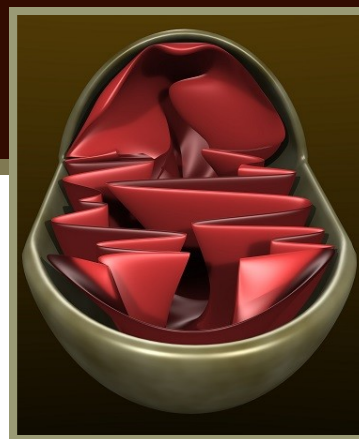
Thank you for all the hard work in moving us one step closer to achieving our mission as MitoCanada.

Blaine Penny,
President & CEO,
MitoCanada

A stylized, handwritten signature in blue ink, consisting of several loops and a long horizontal stroke.

Research

Dr. Aneal Khan, MSC,MO,FAAP,FRCPC,FCCMG,
Assistant Professor of Medical Genetics and Pediatrics, Alberta Children's Hospital,
University of Calgary **outlines progress being done at the Alberta**
Children's Hospital.



"Mitochondrial Disease is caused by mutations in both nuclear DNA (80% of cases) and mitochondrial DNA (20% of cases); however, only about 20-25% of cases are diagnosed using traditional methods of tissue biopsy, biochemical analysis and candidate gene sequencing. Since more than 1,500 genes are known to affect mitochondrial function, we propose an approach that initially involves non-invasive sequencing of nuclear and mitochondrial DNA to reduce the number of invasive procedures and their associated risks. Here we describe the methodology that will be used to analyze the exomes of approximately 30 Albertan patients with unsolved cases of mitochondrial disease.

Our project, entitled **A Novel Platform for Diagnosing Mitochondrial Disease**, has received approval from the Calgary Conjoint Ethics Board. We present data on 12 pilot cases, and outline the protocol we will use for an additional 30 undiagnosed cases.

Application of NGS to the Clinic

- Whole exome sequencing (WES) is particularly attractive for clinical diagnosis:
- Standard clinical testing is invasive and can cost approximately \$20,000 to \$25,000 per case with possible complications from the procedures.
- Mitochondrial diseases are phenotypically heterogeneous; presentations can mimic other neurological, neuromuscular and cardiac conditions
- Mitochondrial diseases are genetically heterogeneous; over 200 nuclear genes have been associated with mitochondrial disease and over 1500 genes have a mitochondrial function
- Current molecular gene testing (single genes or small gene panels) is costly with a low yield; out-of-province testing for rare genes or comprehensive gene panels is too costly
- With growing databases of validated disease variants, WES may be (and has been) a tool for diagnosing genetically heterogeneous disorders

Patients will be selected from the 292 cases for whom complete mitochondrial evaluation is available but there is no diagnosis established. The results of this study will provide preliminary data on the adaptation of an exome sequencing platform as the initial non-invasive test to investigate for mitochondrial disorders, eliminating a large number of invasive tissue procedures and avoiding complications from these procedures.

- We project a diagnostic yield of 50% to 60% using a protocol of exome sequencing of DNA extracted from lymphocytes, tissue DNA sequencing of mtDNA, and biochemical testing.

- With 50 cases investigated per year using tissue biopsy on average, the savings compared to health care resource usage for invasive procedures is projected to be \$900,000 per annum.

We would like to acknowledge all the incredible families and community partners that will make this work possible: MitoCanada, the Drew and Piper Clark Golf Tournament, the CIBC Children's Fund, Mr. Sean Messing (CIBC Wood Gundy) and the Pitchfords. We would also like to acknowledge the Alberta Children's Hospital Research Institute (ACHRI), the Alberta Children's Hospital Research Foundation, the Metabolic Clinic in Calgary, Dr. Rebecca Sparkes, Suhaib Aman, Maida Khan, Laurel Ryan, Shelly Jelinski and our research coordinator Connie Mohan."

From Dr. Josh Slatkoff, Ph.D., R.Psych, Chair, Research Committee, MitoCanada

In 2013, we continued to benefit from our 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 funding requests (RFP) based on alignment with MitoCanada's research priorities. These include: scientific merit, originality, feasibility, track record of the applicants and potential benefits to the Canadian Mitochondrial Disease community.

MitoCanada continues to focus on projects that have the potential to improve diagnosis and treatment rather than on those with a basic research orientation as relatively fewer funding opportunities currently exist for clinical research.

We are pleased to have been able to expand our research funding capacity in 2013. With an increased budget, we are funding two projects by seasoned investigative teams:

1. "An integrated mitochondrial diagnostics platform combining next generation sequencing with respiratory studies in patient cells" by Dr. Lines and colleagues at CHEO.

Award: \$31,813 for one year. This amount is being matched by the Children's Hospital of Eastern Ontario for a total award of \$ 63, 626

2. "Frozen versus fresh: What type of muscle sample works best for the diagnosis of mitochondrial disease in a clinical laboratory?" by Dr. Potter and colleagues at Mc Master University.

Award: \$32,500 for one year

Details about each of these projects as well as updates from previous MitoCanada funded projects can be found at <http://www.mitocanada.org/mitocanda-research/>.

Awareness

Through the generosity of our donors and the work of volunteer, Bernadette Lalonde (communications student) MitoCanada has produced and distributed professional physician packages to specialists in over 24 children's treatment hospitals across the country.

MitoCanada will continue to distribute these packages and use them at education symposiums. We have started to receive additional requests from health care providers from the initial mailing and are very excited for what this has and is accomplishing towards MitoCanada's national awareness campaign.

If you would like a package sent to a physician or health care provider, please e-mail info@mitocanada.org



MITO Quilts of Hope Project



The purpose of the "Quilts of Hope" Project is to raise public awareness about Mitochondrial disease by educating talented quilters about this disease and having them make and donate quilts to patients. We will also raise awareness with anyone who sees the quilts.

The project was conceived by Christine Knox who has Mito herself and wanted to do something to help raise awareness of the disease. She began the project in August of 2013 and hopes that it will make a difference in the lives of other Mito patients.

Every stitch will give hope for finding a treatment and eventually a cure for this disease while bringing warmth to someone who is very ill.

For more information, please visit
www.quiltsofhope.org

Support

The Peer Support Volunteer role is an important one. Being a contact for families and individuals who are looking for others who understand what they are going through so that they no longer feel alone. For some, we may be the first call they make after just receiving a diagnosis, while others may have had the diagnosis for a long time and are just starting to reach out for support. Some of our families / individuals who contact MitoCanada simply want information and others require ongoing support. Whatever the situation, we appreciate all of the time that our Peer Support Volunteers provide for Mito families and individuals. We are in this together and it is our hope that we can be of some help to others.

Accomplishments this past year include:

Setting up a Mito Mail Pal Program to connect children affected by Mito either personally or with siblings who somehow get forgotten. They can share stories, letters, cards or drawings; parents can assist when a child prefers a computer for the tool of communication.



Creation of a Medical Emergency Card that has important information right at your fingertips if you are admitted to Emergency. These cards that can be created online and printed contain name, address, phone, allergies and medical conditions.

Attended a **Taylor the Turtle** training workshop. The Taylor the Turtle program focuses on the human right to safety and well-being of all kinds. Rather than providing frightening scenarios like good touch/bad touch and stranger danger, it is meant to teach the children how to articulate their health and safety needs in a clear, assertive, non-aggressive way.

Taylor wants children to know they have the right to a safe body, a healthy body, a safe school, and a safe community – and the right to talk to someone when they do not feel safe. Taylor the Turtle teaches children emotional literacy and helps them connect their bodies, their feelings, and their expression.

Mito Loves On is a platform for dialogue that was created for families and individuals who have lost a loved one to this disease. Participants can dial in on specific evenings to communicate with others in grief.



TeamMito

In 2013/2014 TeamMito had everything from Guinness World Records to Olympians joining the Team.

The year started off with President Blaine Penny and a group of Calgary runners, including 6 more TeamMito members heading down to the Boston Marathon to run one of the top marathons in the world wearing the green and black Mito vests. While the day was marred by the tragedy that followed we were thankful to hear that everyone from TeamMito was safe and with their families after the race.

After Boston TeamMito continued with "marathon fever" and was involved at the Mississauga, Ottawa and Calgary Marathon race weekends. In Ottawa, Team Mito had almost 50 runners in the various events and raised over \$10,000.

On May 4-5, 2013, TeamMito made its first official appearance in the Greater Toronto Area. A group of 20 runners participated in the Mississauga Marathon Charity Challenge. Our participation was a great success and we raised almost \$2,200 for MitoCanada.

Running past the "MitoCanada" banner at the end of the race was a highlight for most! Thank you for all those who participated.



Out west in Calgary, MitoCanada was named a feature charity for the Calgary Marathon and with the support of the CIBC Wood Gundy group. Included in this group was the "Linking Strides towards a Mito Cure."

This team consisted of many of the Team Mito members who were down in Boston, plus a few more to create a 10-man team tied together at the hip for the entire marathon. Not only were they planning to run the marathon "linked" but they were attempting to do it in Guinness World Record time – under 2:57.

We are happy to report the "10 fast guys" broke the record and put Team Mito in the Guinness World Record book!



Even more overwhelming was the publicity and awareness created for MitoCanada from local TV and newspaper up to Runner's World magazine blogs. TeamMito had over 200 runners entered in the various events from 5K, 10K, half-marathon and the marathon and raised over \$109,000.



Through the rest of the summer Team Mito continued to not only participate at various events but also included volunteers and gave back to the various communities where the members train and race.

This was evident at Ironman 70.3 Calgary, 24 hours adrenaline in Canmore, the Tri Diva Tri in Olds and the 5 Peaks Trail Series in the Rocky Mountains.



Above: Brittany Webster

At the end of the summer, TeamMito had racers on the West Coast in both Ironman Whistler and Challenge Penticton– this showed great spirit and made MitoCanada proud.

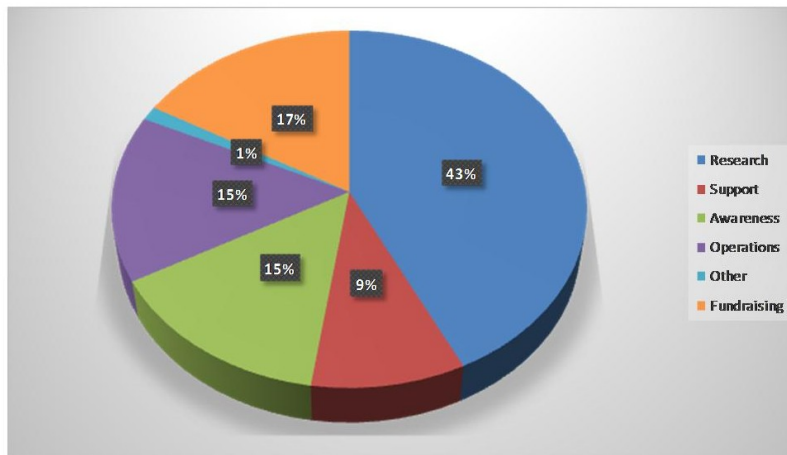
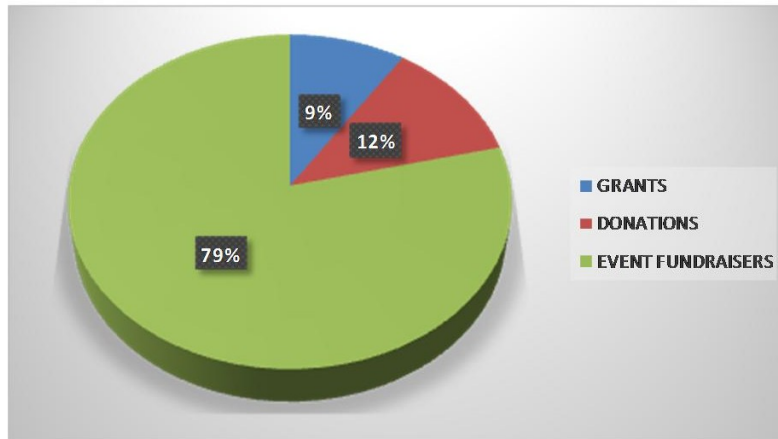
Finally, to top what was already an incredibly successful year, in the fall MitoCanada was approached by Canadian Cross-Country skier Brittany Webster about joining TeamMito. Brittany wanted to race her World Cup season in Team Mito colours as she attempted to qualify for the Sochi Winter Olympics. In February TeamMito was officially able to say an Olympic athlete was on its roster as Brittany competed in 4 events.

Looking forward to 2014/2015 TeamMito is excited to continue it's efforts to create awareness and raise funds for MitoCanada and Mitochondrial disease. This year we will again be at the Mississauga, Ottawa and Calgary race weekends as well as our own Running on Empty and Endurance Challenge.

Thank you everyone for your support and continued involvement with TeamMito.

Fundraising

Where our Revenue comes from



Where our Donor Dollars Go

We wanted to take this opportunity and thank you for your financial commitment and provide you with a glimpse into what we have been able to accomplish. The graphic above illustrates areas where your 2013 donations have been distributed.

Events Overview



Running on Empty Hamilton was held on Saturday, September 14th, 2013 at Confederation Park on the picturesque shores of Lake Ontario. It was our 4th annual event that attracts people from all over Ontario.

Over 500 people participated in the 2.5km or 5km walk which continues to grow in numbers every year. Many of the attendees have a connection with someone who suffers from Mitochondrial Disease. The sponsor for the day was Popeye's and this beautiful day was topped off with a BBQ from The Works Burger, Pony Rides, Bouncy Castles and many prize draws.

A tradition of the MitoCanada Running on Empty event is the balloon release at the start of the walk honouring those fighting the disease and those that have lost their lives.

An amazing \$42,295.46 was raised by dedicated individuals donating dollars to help find a cure for Mitochondrial Disease. We hope to see you all next September again at Running on Empty 2014 Thank you for your continued support of this great event.

Finance

MitoCanada Foundation Statement of Operations and Changes in Net Assets

	2014	2013
For the year ended March 31		
Revenues		
Donations	\$ 41,349	\$ 253,459
Grants	35,339	
Fundraising	302,541	
	379,229	253,459
Expenses		
Awareness		
Consulting	2,395	14,710
Advertising, Supplies, Conference	44,786	39,308
Fundraising		
Consulting	19,009	
Events	37,278	3,618
Administration		
Consulting	22,549	14,710
Professional Fees	9,360	4,000
Office	19,316	26,553
Research		
Consulting	7,627	4,903
Grants	137,563	45,000
Support		
Consulting	27,990	14,710
Office and Programs	3,429	
Non- recoverable HST	4,253	
eTapestry	4,142	
	339,697	167,512
Excess of revenues over expenses before other items	39,532	85,947
Other Items		
Interest Income	776	
Gains on disposal of Investment		65
	776	65
Excess of revenues over expenses for the year	40,308	86,012
Net assets, beginning of year	252,699	166,687
Net assets, end of year	\$ 293,007	\$ 252,699

Finance

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. In the 2013/2014 fiscal period we transitioned 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. Filings with Revenue Canada and presentation of financial statements in our annual report will use accrual accounting going forward.

Some items to highlight from April 1, 2013 to March 31, 2014 include:

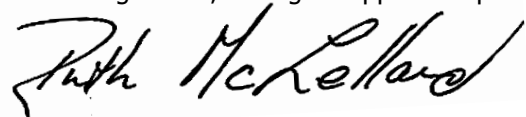
- Managing costs effectively to achieve a low operating cost ratio (less than 21% overall), allowing a greater percentage of funds received to be directed towards programs
- The continued growth of Team MitoCanada, which promotes awareness of mitochondrial disease through sport.
- The organic growth of support groups and outreach programs across Canada.
- Significantly increasing the research program and continuing our partnership with CIHR who matched the funds we committed for a PH.D. Scholarship, effectively doubling the impact of our research commitment.
- Investing in additional contract resources to work on program development and delivery.

MitoCanada Foundation received a 50% year over year increase in revenue, most of which is from the direct public. We are so very grateful to our donors for their on-going support. Their generous assistance has already made and will continue to make a difference in the lives of those impacted by mitochondrial disease. Through the commitment and dedication from our amazing volunteers, donors, sponsors and partners, we were able to raise an astounding \$379,229 in 2013/2014. We are pleased to announce that we were able to secure a significant CIBC grant to support research in Calgary on the NextGen research project. We also saw an increase in donations from memorials, tributes and our signature Running on Empty events in Hamilton and Calgary, as well as the solid contribution of TeamMito in raising funds and awareness.

In 2013, we partnered with the Canadian Institute of Health Research (CIHR) and have committed \$17,000 per year to fund 1 doctoral student for 3 years. Our funds are matched dollar-for dollar by CIHR, which doubles the impact of this commitment. Our call for proposals is receiving more high-quality proposals for research each year and the Research Committee has done an outstanding job of attracting and vetting these proposals.

Increasing the awareness of mitochondrial disease in Canada is a central program area for MitoCanada. Through TeamMito, the level of awareness and media coverage has increased substantially 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 have invested in the development of a training manual for support volunteers, and have broadened the support program across several provinces. With the establishment of the office in Brantford, we were able to provide more than an email and web-based contact and received many calls from families and patients across the country.

We continue to liaise with international organizations to push for more awareness, support and research into Mitochondrial disease, and are very excited to be contributing to better diagnostics, stronger support for patients and caregivers, and broader awareness of this disease.



MITOCHONDRIAL DISEASE

