

THANKS TO YOU, WE'RE MAKING PROGRESS

2016/17 ANNUAL REPORT

mitoCanada

*"I truly believe in my lifetime
we will unlock the secret to
preventing and reversing
mitochondrial disease"*

-Blaine Penny



THE PENNY'S STORY

Blaine, Sarah, Evan and Julia were like any typical Canadian family living at the foothills of the majestic Canadian Rockies. As a family they enjoyed an active outdoor life with Blaine pursuing his passion for running ultramarathons. Then in 2008 his son Evan, aged 3 years at the time, woke up with intense stomach pain. His complaints were so severe that Blaine and Sarah took him to the Alberta Children's Hospital (ACH). After an ultrasound, the doctors were 80% certain Evan was suffering from appendicitis, so they scheduled emergency surgery.

But Evan seemed to sense that something bigger, something life altering, was about to happen. Just as Evan was being wheeled into the operation, Blaine recalls his son looking him in the eye and asking: "Daddy, can we play together again sometime?" Those are the last words Evan has spoken since 2008. When Evan didn't wake up from the surgery, it became clear that was something very wrong. They soon realized he'd suffered severe brain damage.

Evan spent several months in the hospital "clinging to life," says Blaine. "We didn't know what the next hour would bring for Evan. At one point, he suffered hundreds of seizures a day." Eventually, Evan was diagnosed with a probable mitochondrial disease. Today, Evan is a spastic quadriplegic who can't talk or eat. He's fed by a tube, has trouble lifting his head, suffers chronic bouts of pain, and has no reliable way to communicate with the outside world. From what the Penny's and their doctors can tell based on how Evan reacts to those around him, he seems to have cognitive function. It's just that he's effectively trapped inside his body.

"I think that, because of Evan's situation, my family and I actually enjoy a greater quality of life, if you can believe that, in the sense that we really make the most of everything. We're reminded daily that we've got to keep doing what's important in life, and that's looking after our family and looking after our health. When we go to work, we give it our all. And we keep working to grow MitoCanada, because it provides that hope for a future, for a better life for Evan." - [Blaine Penny](#)

WE'D LIKE TO SAY THANK YOU

We are honoured to share how your commitment and generosity have fortified our work to ensure Canadians living with mitochondrial disease have a voice.

As a year of continued growth, 2016/17 saw the realization of several key initiatives including the first-ever study of health care for mitochondrial disorders in Canada: A survey of physicians. This landmark research project was made possible by our partnership with the Canadian Inherited Metabolic Research Network (CIMDRN.)

Also, in June 2016, we embarked upon a path that has led to the beginnings of a national network of researchers and clinicians united by a common interest in unveiling the role of mitochondrial function and genetics in human diseases. To be known as mitoNET, the network will be disease agnostic and will focus on understanding how mitochondria acts as the common denominator among diseases. Ultimately, mitoNET will pursue innovative and ground-breaking research leading to effective treatments for different forms of mitochondrial dysfunction and disease and to provide opportunities for training and education of the next generation of leaders. In the immediate term, we aim to build and strengthen the mitochondrial research community in Canada, to encourage collaborative research and develop public awareness.

We still have much to do, but your dedication to MitoCanada is building a better future for Canadians living with mitochondrial disease. Working hand-in-hand with our community advocates inspires and motivates us and the tremendous generosity you've shown pushes us forward every day.

With gratitude,

David Mosher
Board Chair

Maureen Latocki
Executive Director

COLLABORATION AND ENGAGEMENT

No single individual or organization can do this work alone. Foundation leaders, researchers, clinicians, patients, families, fundraisers and donors bring unparalleled energy, passion and creativity to our mission. This year, hundreds of you joined with us making our success your success. In 2016/17, MitoCanada made extraordinary strides in developing meaningful partnerships and alliances.

A SENSE OF URGENCY

"While it may be too late for me, finding better and faster ways to diagnose and treat mitochondrial disease is important because it will help future generations – maybe even my family members." A donor

MitoCanada continues to make progress as evidenced by the momentum that we have with mitoNET. But in many ways we're just now getting to the hardest part – bringing a sense of urgency and keeping our foot on the gas. We're working diligently to bring together all the key players to ensure that promising ideas draw attention for greater funding.

POWERED BY TEAM MITO

In 2016/17, TeamMito members, from near and far, again brought their A game to raising awareness and funds in support of MitoCanada. Highlights were the 7 Guinness World Records set at the Calgary Marathon. MitoCanada would not exist if it were not for the passion and commitment from TeamMito to our cause.

2016 BEACON AWARDS

The Board of Directors of the MitoCanada Foundation established The Beacon Awards in 2015. The annual awards recognize and honour those individuals and organizations making an exceptional contribution in service to the MitoCanada Foundation.

We congratulate our 2016 award winners:

Community Service Person of the Year – Jean Shepherd
Corporate Partner of the Year – Tony Smith, Grizzly Events
Healthcare Champion of the Year – Dr. Mark Tarnopolsky
Media Person of the Year – Joanna Frketch
Volunteer(s) of the Year – The Penny Family

A LOOK AHEAD

Moving forward, the Foundation will pursue a strategic deployment of our limited resources to attract greater interest and investment in our work. An example is our plan to host the first-ever national mitochondrial disease conference in 2017. Already we are witnessing a keen interest from stakeholders in a pivotal role for MitoCanada in nurturing a vibrant and patient-informed agenda to advance national mitochondrial disease strategy.

OUR LEADERSHIP

MitoCanada Foundation is governed by a volunteer skill-based board of directors.

David Mosher
Chair

Chuck Gibson
Vice Chair

Matthew Kielbasinski
Treasurer

Benedict Albensi
Director

Jeff Mamer
Director

Julie Drury
Director

Ron Dunn
Director

Freddy Arcos
Director

Shannon James
Director

Maureen Latocki
Executive Director

OUR FINANCES

Accountability, transparency and efficiency are core values that will continue to guide our progress. Notwithstanding a very challenging fundraising environment, careful management of costs has helped us end the year with a small operating deficit of \$7,380.

It is worth noting that since year end we are experiencing an uptick in our fundraising success, putting us on track for a record year in 2017/18.

Matthew Kielbasinski
Treasurer

2016/17 AUDITED FINANCIAL SUMMARY

Revenue	
Individual Giving	\$15,735 (5%)
Events	\$234,702 (76%)
Grants	\$14,150 (5%)
Corporate Donations	\$42,888 (14%)
Other	\$1,488 (0%)
Government	\$0 (0%)
Total Revenue	\$308,963
Expenses	
Research, awareness, support, education	\$215,693 (68%)
Fundraising	\$36,029 (11%)
Operating	\$58,184 (18%)
Administration	\$6,437 (2%)
Total Expenses	\$316,343