

#### ANAKHA'S STORY

Should you meet Anakha, you will instantly agree she is a beautiful bright-eyed child with an impish sense of humour and a smile that will instantly steal your heart. There isn't anyone around Anakha that would take her smile for granted; but behind that smile is a strong, brave four year old.

Anakha fell ill when she was just 9 months old. Over the course of four weeks, she abruptly lost her ability to move, see, and speak. A few short days into her hospitalization, Anakha's parents were told she had leukodystrophy – abnormal development or destruction of white matter in the brain. The next step was to determine the disease causing the condition. Transferred to the Hospital for Sick Children, specialists immediately began administering tests and genetic sequencing.

It was the genetic sequencing that reveal Anakha had Multiple Mitochondrial Dysfunction Syndrome, Type 3 (MMDS-3).

At the time of her diagnosis, only three other children were known to have this condition, and sadly all had passed away before 18 months of age. No one expected Anakha to survive, no less get better. Despite the grim prognosis, Anakha's parents refused to give up. They began searching for anything and anyone that could help their family through these dark times. One of those supports was MitoCanada.

"Through the support of groups like MitoCanada, we were able to educate ourselves very early on in our journey on what makes mitochondrial diseases unique, and advocate for key interventions.

Today, at four years old, Anakha is thriving. She expertly handles her wheelchair, uses a walker, reads books, attends school, and won't stop talking – her current favourite expression is

"Try Again! Never Give Up!"

# WE CANNOT THANK YOU ENOUGH

Through the passion and commitment of our donors, our 2017/2018 fiscal year was the most successful in MitoCanada's history. The generosity from our donor community totalled just over \$340,000.

There were a number of factors which helped drive this growth: an increase in awareness through high profile fundraising events, our first patient researcher conference, and securing matching and new foundation grants.

These factors have both helped further our mission and raised our media profile, helping us drive broader awareness.

We are tremendously proud of the achievements made in 2017/2018, our results are a testament to our donors generosity and support.

There is much ahead of us to accomplish, but your dedication to MitoCanada will continue to build a brighter future for Canadians living with mitochondrial disease. Working with our community champions inspires us to build onto the momentum created every year.

With gratitude,

**David Mosher**Board Chair

Blaine Penny

Chief Executive Officer

# **OUR FINANCES**

MitoCanada strongly believes accountability, transparency and efficiency are core guiding principals in stewarding all donated dollars. In carefully managing costs, we reduced expenses and closed the 2017/2018 fiscal year with a \$13,000 surplus.

# 2017-2018 AUDITED FINANCIAL STATEMENTS

#### Revenue

Individual Giving	\$14,790
Events	\$256,920
Grants	\$31,624
Corporate Donations	\$36,350
Other	\$599
Government	\$0
Total Revenue	\$340,283

#### Expenses

Research, Awareness,	
Support & Education	\$235,956
Fundraising	\$18,868
Operating	\$60,254
Administration	\$12,193
Total Expenses	\$327,271

# 2017 -2018 OBJECTIVES

### MITO2017

2017 marked a milestone achievement for MitoCanada hosting the first ever Canadian mitochondrial disease conference. The two day event was a gathering of 120+patients, families, scientists, clinicians and other stakeholders to start a dialogue about a national strategy for mitochondrial disease.

To enable patients' and families' attendance, MitoCanada offered ten patient advocate scholarships to partially offset the cost of the participation. This was made possible, in part, because of our loyal donors who have supported the MitoCanada Foundation over the years.

#### mitoNET

MitoCanada's conference spawned a game-changing partnership that launched mitoNET.ca. mitoNET.ca is a new Canadian research network comprised of 120 researchers and clinicians, patients and advocates, over 140 trainees and 25 partners.

Together with mitoNET, MitoCanada seeks to transform our understanding of the role of mitochondria in human health to develop preventative, diagnostic and therapeutic interventions as part of our precision health arsenal for rare and chronic diseases.

For patients, this means improved diagnostic tools and new medicines offering optimized treatment of symptoms, fewer hospitalizations, improved quality of life, increased productivity, and importantly, extended lives.

#### **Public Education**

Beyond MitoCanada's research related priorities, we remain committed to becoming a trusted source of information for patients, the public and healthcare providers. To that end, MitoCanada partnered with *The Rare Disease Review* to produce a specially curated edition devoted to raising awareness about mitochondrial disease and the work of our organization.

Featured in the magazine is an interview with a mother whose young daughter fought a valiant battle with an ultra rare form of mitochondrial disease called SIFD.

Sharing stories is a powerful way for others to gain an understanding of what young patients and their families face and the complexity in living with and managing the disease.

#### OUR LEADERSHIP

The following leaders comprise MitoCanada's volunteer advisory board of directors:

David Mosher, Board Chair Matt Kielbasinski, Treasurer Julie Drury, Director

Freddy Arcos, Director

Shannon James, Secretary Benedict Albensi, Director Ron Dunn, Director

Blaine Penny, Chief Executive Officer

### 2017 MITOCANADA BEACON AWARDS

Every year, MitoCanada likes to recognize and honour the exceptional individuals and organizations making a difference in the mitochondrial community.

#### 2017 MITOCANADA BEACON AWARDS

Community Service Celia McGrath Public Partner
Beth Potter

Corporate Partner
Jeremy Deere, Strides

**Health Champion**Dr. Aneal Khan

**Media** Annie Boucher, Fuse **Volunteer**Gibson Family

Community Spirit
Hamilton/Brantford
Building Trades (HBBT)

**NEW Trailblazer**Marilyn Macaulay

# 2017 TEAMMITO BEACON AWARDS

**Athlete of the Year** TEAMmito Kids

**MVP of the Year**Julie Drury

**Volunteer of the Year** Keith Bradford

