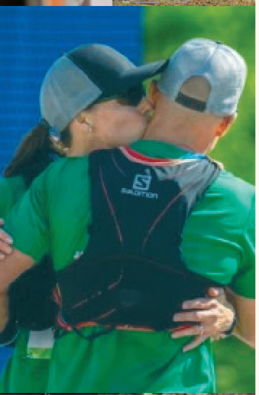
mito canada

Annual Report
2022/2023



Chair and CEO

Message from the Chair and CEO

As we reflect on the past year, we are filled with gratitude for your unwavering support and dedication to MitoCanada's mission. Together, we have made significant strides in advancing research, education, advocacy, and support for those affected by mitochondrial disease in Canada. At MitoCanada, our vision is clear: to create a world where all lives are powered by healthy mitochondria. To achieve this vision, we are deeply committed to fostering growth across four crucial areas: *education*, *support*, *awareness and research*.

We dedicate ourselves to improving the lives of those impacted by mitochondrial disease and propelling MitoCanada's vision forward. With guidance from our board, committees, dedicated staff, and partnerships with international mito-patient associations, we celebrate the strides made thus far and remain resolute in our commitment to driving growth, delivering value, and offering solutions to Canadians battling this challenging disease.

Feedback from the mito community has led to a greater emphasis on building support and education programs and resources. By working closely with the mito community, we have expanded our support services to meet their most pressing needs and now provide more services and resources than ever before.

We recognize and appreciate the contributions of our devoted donors, volunteers, board members, and committee members. They are the backbone of our organization, and their dedication has paved the way for MitoCanada's achievements.

In closing, we extend our sincerest thanks to all who have played a role in improving the lives of Canadians impacted by mitochondrial disease.

Your support is invaluable, and together, we will continue to make a difference.

Sean Messing

Kate Murray

K. Murray

Sean Messing
Board Chair/Director

Kate Murray
CEO & President

Board of Directors

Claudia Aguirre
Director

Steen Hendry
Treasurer, Director

David Mosher
Director

Zach Seymour
Secretary, Director

Dilek Dag
Director

Sean Messing
Board Chair, Director

Blaine Penny
Director, Co-founder

Dr.Neal Sondheimer
Director, Medical Advisor

Who We Are

MitoCanada is Canada's *only registered* health foundation dedicated to transforming the lives of individuals, families and caregivers with mitochondrial disease.

Every day, we support those living with mitochondrial disease with information, initiatives and opportunities to inspire, empower and connect while enhancing quality of life. We develop education, support and awareness programs for those living with or at risk of developing mitochondrial disease. We also fund research that is patient-focused and transformational.

Empowering Through Education

Education stands as a cornerstone of MitoCanada's commitment to community investment. It serves as an empowering force, fostering informed decision-making and enhancing overall quality of life. MitoCanada is steadfast in its dedication to creating and delivering diverse education programs and resources tailored to the unique needs of the MitoCommunity.

We offer a range of resources, from webinars featuring medical professionals and mitochondrial experts to educational guides, infographics, and animations. Our resources aim to educate Canadians about the diagnosis and everyday management of mitochondrial disorders. Rooted in research, our education resources are presented in an accessible, reader-friendly format.

Our education guides, animations and infographics are valuable in building disease understanding, symptom management and coping strategies, and enhancing communications with healthcare providers.

In 2022/23, we created *three* on-line seminars*, two* education guides and *one* animation.
(see next page)

Education Seminars

Our webinar series helps **connect** doctors practicing in the field of mitochondrial health and patients who are affected by mito from across Canada. Through our comprehensive webinars, MitoCanada provides valuable information to individuals living with mitochondrial disorders.

Dr. Mark Tarnapolsky
"Exercise as Medicine for Mitochondrial Health"

Dr. Shailly Jain
"Exploring and living with LC-FAOD"

Dr. Aneal Khan
"Understanding Clinical Trials from a Patient Perspective"

Education Seminars

“Exercise as Medicine for Mitochondrial Health”

With Dr. Mark Tarnapolsky

Exercise is good for almost everyone, especially mito patients. It can improve strength, endurance and quality of life. Exercise as Medicine for Mitochondrial Health was created specifically for people living with mitochondrial disease. Dr. Mark Tarnopolsky explains how different exercises benefit those with mito, how to manage exercise after setbacks and illness, and important exercise do’s and don’ts our community should

“Exploring and living with LC-FAOD”

With Dr. Shailly Jain

Dr. Shailly Jain explores living with LC-FOAD which occurs when enzymes that help make energy from fatty acids are missing or defective. LC-FOAD is a rare inherited disease that can affect multiple organs.

“Understanding Clinical Trials from a Patient Perspective”

With Dr. Aneal Khan

Our muscles need energy from our mitochondria to function. People who do not have enough healthy mitochondria often face unique physical challenges that can be debilitating and even life-threatening. Dr. Aneal Khan explains the current gaps in care and explores potential future therapies for those living with mitochondrial disorders.

Education Guides

MitoCanada Education Guides are valuable to mito patients and their caregivers in building disease understanding, symptom management and coping strategies, and enhancing communications with healthcare providers.

They are relied upon by **healthcare professionals** to maximize knowledge translation and increase efficiencies in patient care. These attractive and comprehensive resources feature custom illustrations, condition overviews, symptoms, suggested tests, possible therapies and tips for better living, as well as additional information specific to the topic.

Education Guides

Exercise as Medicine Guide

Safe **and** ***mindful*** **exercises can be highly beneficial for those with mito.** Exercise can improve mitochondrial quantity and function, improve muscle strength, and help reduce fatigue. The benefits of exercise extend to every part of the body and improve mitochondrial health.

Our **Exercise as Medicine Guide** highlights the importance of exercise for mito patients.

Understanding Clinical Trials Guide

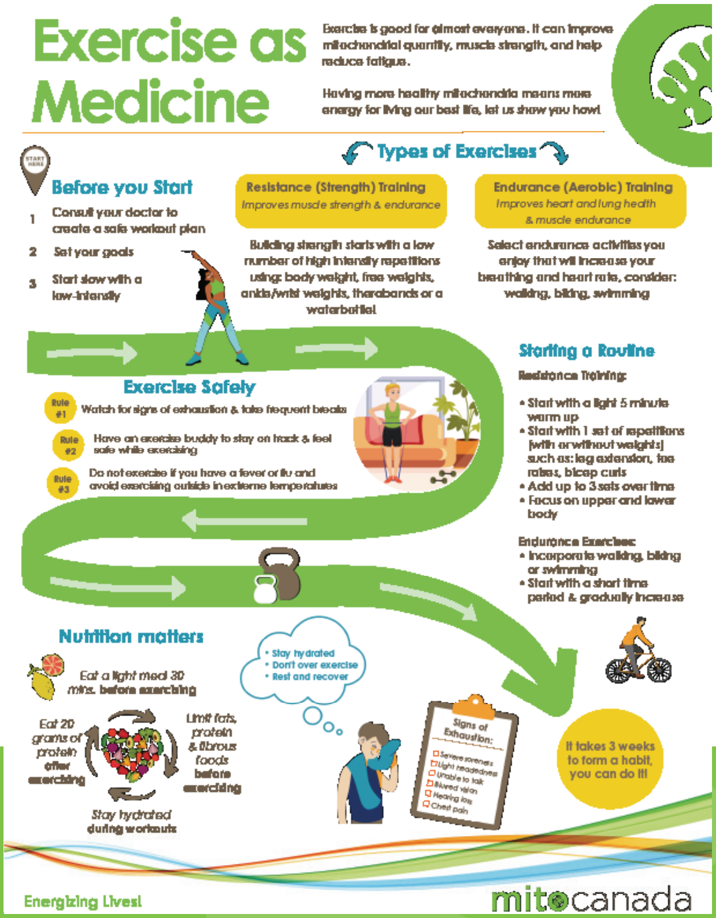
MitoCanada believes in the power of research. Clinical trials are studies conducted to acquire important data. They are essential to the discovery and advancement of medicine and medical knowledge.

Our **Understanding Clinical Trials Guide** discusses the importance of clinical trials, what participation may look like, and the benefits for patients.

Animations

Studies say that audiences retain up to 40% when they both see and listen to educational materials. With this in mind, MitoCanada produces 3–5 minute animations on various topics related to mitochondrial disease. Each animation is unique and combines voice, illustrations, animations, and/or live commentary.

Our 2022 animation, **Exercise as Medicine**, with Dr. Tarnopolsky features fun and informative



Exercise as Medicine

Exercise is good for almost everyone. It can improve mitochondrial quantity, muscle strength, and help reduce fatigue.

Having more healthy mitochondria means more energy for living our best life, let us show you how!

Types of Exercises

Before you Start

1 Consult your doctor to create a safe workout plan
2 Set your goals
3 Start slow with a low-intensity

Resistance (Strength) Training
Improves muscle strength & endurance

Building strength starts with a low number of high intensity repetitions using: body weight, free weights, ankle/wrist weights, therabands or a waterbottle!

Endurance (Aerobic) Training
Improves heart and lung health & muscle endurance

Select endurance activities you enjoy that will increase your breathing and heart rate, consider: walking, biking, swimming

Exercise Safely

Rule #1 Watch for signs of exhaustion & take frequent breaks
Rule #2 Have an exercise buddy to stay on track & feel safe while exercising
Rule #3 Do not exercise if you have a fever or flu and avoid exercising outside in extreme temperatures

Starting a Routine

Resistance Training:

- Start with a light 5 minute warm up
- Start with 1 set of repetitions (with or without weights) such as: leg extension, toe raises, bicep curls
- Add up to 3 sets over time
- Focus on upper and lower body

Endurance Exercises:
- Incorporate walking, biking or swimming
- Start with a short time period & gradually increase

Nutrition matters

Eat a light meal 30 mins. **before exercising**

Eat 20 grams of protein **after exercising**

Limit fats, protein & fibrous foods **before exercising**

Stay hydrated **during workouts**

- Stay hydrated
- Don't over exercise
- Rest and recover

Signs of Exhaustion:
☐ Severe soreness
☐ Light headedness
☐ Unable to talk
☐ Blurred vision
☐ Hearing loss
☐ Chest pain

It takes 3 weeks to form a habit, you can do it!

Energizing Lives!

mitocanada

Infographic

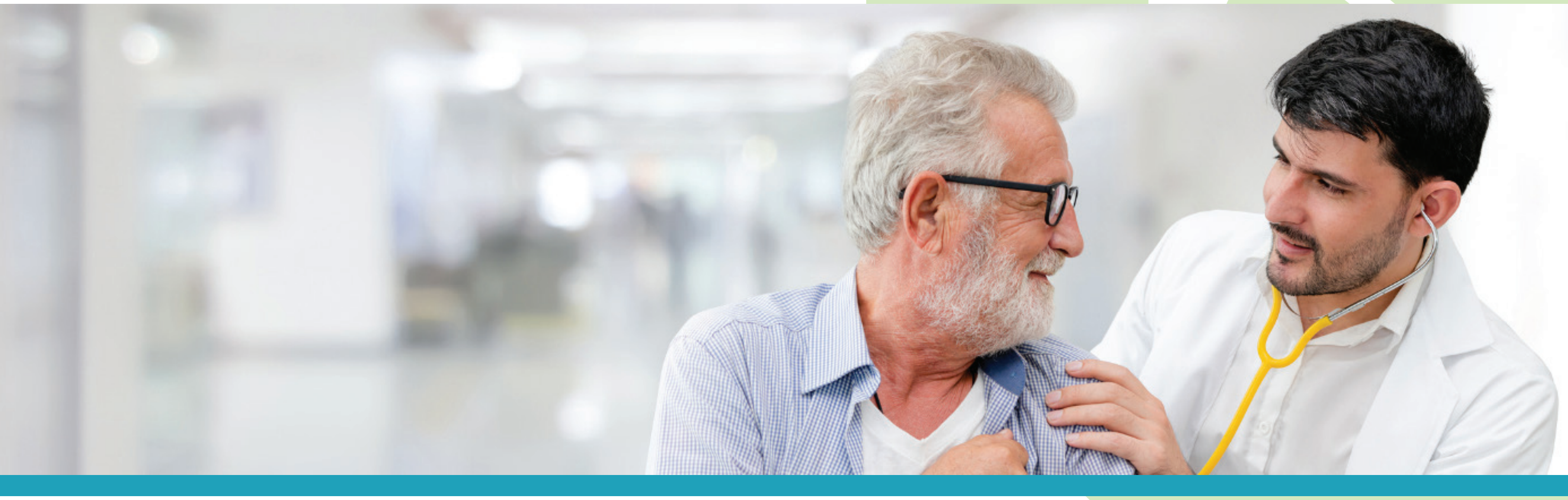
Infographics are precise, well-organized and present complex information in a way that is visually stimulating and easily understandable.

Exercise as Medicine Infographic presents information about the importance of exercise for mito patients in a creative and concise manner.

Awareness

MitoCanada is dedicated to increasing awareness and fostering connections among various stakeholders, including the public, healthcare providers, government, corporations, and employers. We achieve this through a range of activities, such as organizing fundraising and educational events, participating in professional conferences, and disseminating information about mitochondrial disease through social media, eNewsletters, and digital/print media campaigns.

Our goal is to improve the lives of those affected by mitochondrial disease by promoting knowledge, providing education and support, and advancing research towards finding a cure.



We envision a future in which Canadians impacted by this challenging disease feel inspired, empowered, and well-supported to live fulfilling lives. Our focus includes access to timely and accurate diagnostic tests and introducing effective therapies that bring hope and protect quality of life. Every day, we offer resources, programs, and opportunities to inspire, empower, and connect individuals living with mitochondrial disease.

Faces of Mito

Sharing the lived experiences of individuals within the MitoCommunity is a powerful, uplifting, and impactful way of educating the public. Our Faces of Mito stories showcase the personal journeys of MitoCommunity members who willingly share their experiences with mitochondrial disease.

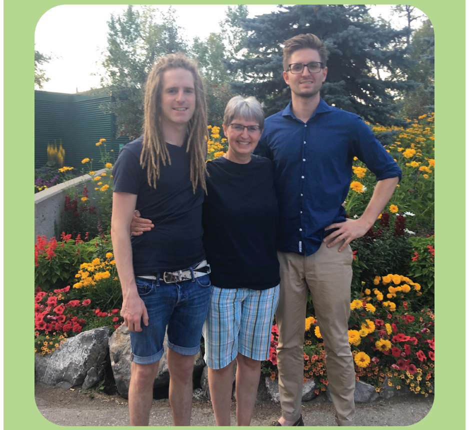
These stories can be found on our website and are regularly featured on our social media platforms, during events, and in our newsletters.

In 2022/23, we heard from three people in our MitoCommunity:

Zack Seymour

"My experience has motivated us all to find solutions. My commitment to MitoCanada will help us uncover those

Read Zack's story **here**



Aiden Procyshyn

"Preferring people to toys, Aiden loves to connect and interact with others."

"Aiden's cells can't generate enough energy for him to function the way he'd like to."

Read Aiden's story **here**

Alyson Maxwell

"I have hope that there will someday be a proper treatment for mito and possibly a cure, but I can't just sit around being complacent waiting for it."

Read Alyson's story **here**

Support

MitoScholars/+

Whether supporting people who are newly diagnosed with mito, those who have had it for a long time, caregivers, or community members looking to make a difference, MitoCanada welcomes all Canadians affected by mito.

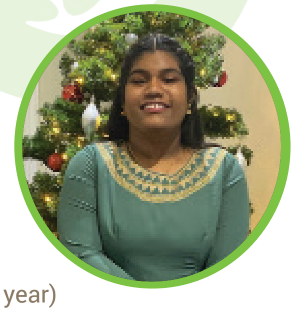
Scholarships help these students realize the careers they dream of.

MitoCanada is very proud to support its MitoScholars (young adults living with mito) and MitoScholars+ (young adults who have siblings or parents living with mito).

Our 2022/23 MitoScholars/+ shared:

“Recognition of our rare conditions means so much to us who have overcome so much to pursue a post secondary education but have so many other expenses due to our dietary needs and other accommodations.”

“Education is something I’m so passionate about and because of you, I can finish my master’s degree without any extra financial burden. I would just like to thank each and every one of you for what you do. You are truly making a difference in people’s lives.”



Mathusa Inthirarasa

Social Work (first year)
Toronto Metropolitan University
(formerly Ryerson University)

Jodi Young

Masters Boreal Ecosystem & Agricultural Sciences (second year) Memorial University

Andrew Ouellette

Sports Psychology (fourth year)
Laurentian University

Nelson Currie

Biology-Psychology (first year)
University of Victoria

Research

MitoCanada is dedicated to collaborating with the medical community to support clinical trial recruitment and bring effective mito treatments to Canadians. We also play a role in bringing together the brightest minds to develop better solutions for supporting the MitoCommunity, and we do so by supporting patient-focused research that brings the community closer to finding a cure.

Medical Research

In 2022/23, MitoCanada provided research grants to scientists and physicians conducting research in various areas associated with mitochondrial disease.

MitoCanada granted a $75,000 award to Dr. Mark Tarnapolsky to support his research exploring the sedentary lifestyles of older people. Dr. Tarnapolsky's study, *Acute, Exercise-Induced Alterations in Cytokines and Chemokines in the Blood Distinguish Physically Active and Sedentary Aging,* was supported by MitoCanada.

MitoCanada and other international patient associations collaborated with Mito2i to invest research dollars that would support mitochondrial research studies that would generate **new knowledge and ideas** in a broad range of research areas to **expand the field of mitochondrial medicine and research.**

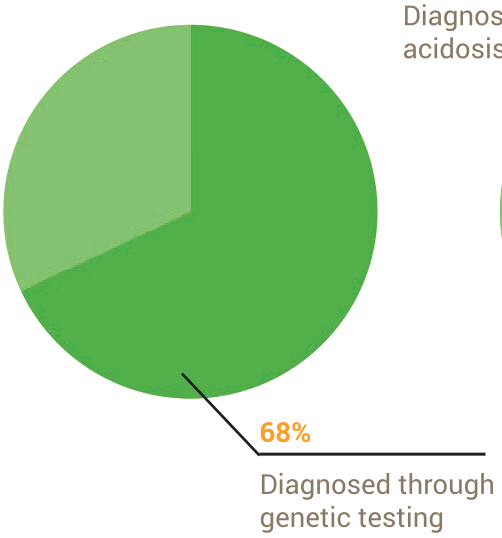
Patient Contact Registry

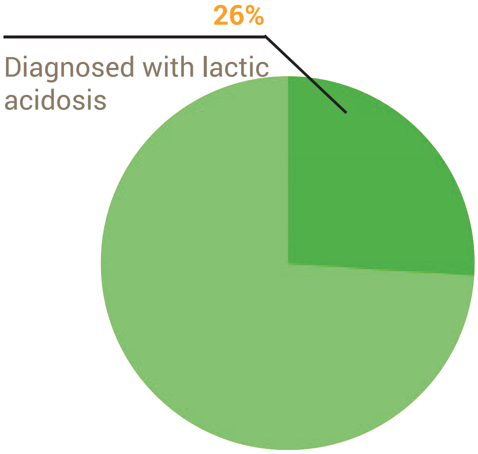
Knowledge is power

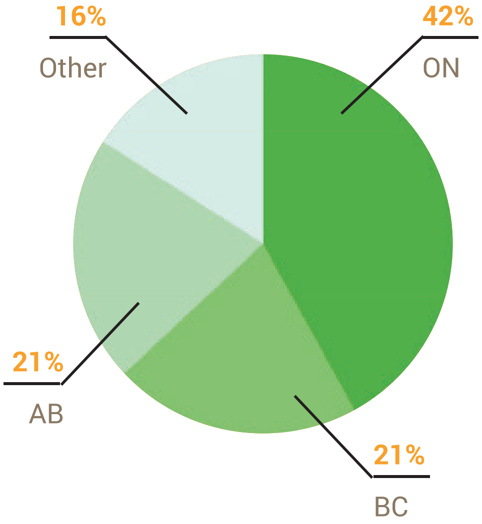
MitoCanada launched the first Canadian patient-populated contact registry in 2022. The database invites Canadian patients and caregivers aged 18 and older with a formal mito diagnosis to participate.

Our registry collects data on diagnosis history, disease-specific symptoms, symptom and treatment management to help doctors, researchers, and MitoCanada deepen our understanding of mitochondrial disease, develop research studies and clinical trials, and build programs and resources to improve the health and quality of life of Canadians affected by mito.

Mito patients and caregivers have joined the Patient Contact Registry from **across Canada.** Here are the Patient Contact Registry Fast Facts:







Eligible patients and caregivers, please sign up at: ***mitocanada.org/patient-contact-registry****.*

Community Insights Report

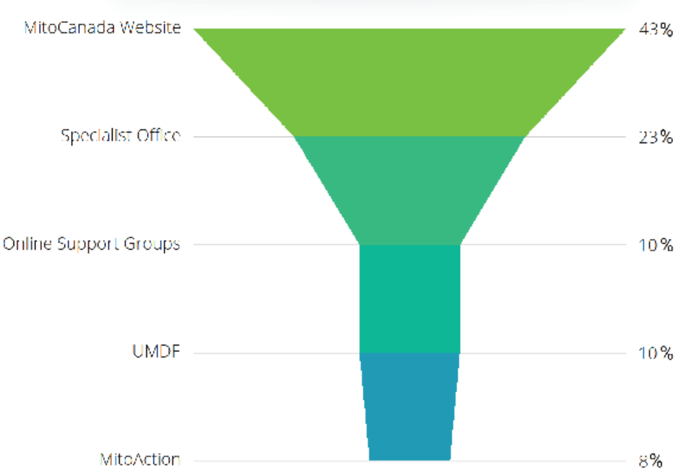
Our 2022 **Community Insights Report** has served as a valuable tool in deepening our understanding of the needs and experiences of the MitoCommunity.

The data were collected using a mixed-methods approach, distributing a comprehensive survey and conducting semi-structured interviews. Participants included adults diagnosed with a mitochondrial disease and parents/caregivers caring for an individual diagnosed with mito.

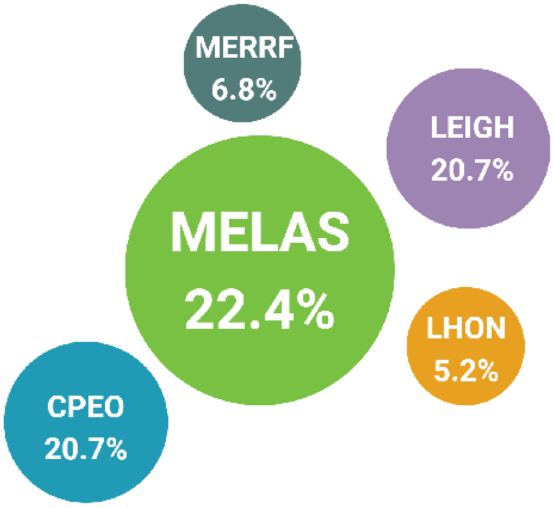
The insights uncovered from this community report have aided our efforts in planning *effective events, supporting relevant research, guiding our advocacy efforts and providing educational resources* that speak to the community's priorities and deliver meaningful and valuable support.

The report can be found at:
mitocanada.org/insights-report.

Reported Information Sources



Top 5 mitochondrial disease diagnosis



Our Reach

21,482,900
Media Impressions

17,000
Page views of mitocanada.ca

12
Partner organizations

Social Media

900,500
Total

833,500
Facebook

67,000
Instagram

Total number of followers on social media

As of March 31st

3,608
Facebook

1,432
Instagram

1,647
Twitter

825
LinkedIn

MitoCanada Signature Events

Our signature events, **MitoSpin** and **Walk N Roll 4 Mito** serve to raise awareness and funds for our ***education, awareness, support,*** and ***research*** initiatives. These events happen annually and help to bring our MitoCommunity together to ensure all lives are powered by healthy mitochondria.

Walk N' Roll 4 Mito 2022

Walk N Roll 4 Mito **raised a total of $32,000** in 2022.

In 2022, the 7th annual Mississauga event was held virtually and in person at beautiful Aquitaine Park in Mississauga, ON, where passionate participants from the community came out to support MitoCanada and Louise in raising awareness and funds to fuel MitoCanada's initiatives.

Thank you to all the participants and dedicated fundraisers who helped raise $22,660.

Bonnie Procyshyn, mother of Aiden Procyshyn who has Leigh's Syndrome, also organized a Walk N Roll 4 Mito event in Winnipeg, MB. **This event, held on Sunday, September 24 brought passionate MitoCanada supporters together to raise $9,340.**

We would like to extend our thanks to the event sponsor: ultragenyx

MitoSpin 2023

MitoSpin is our annual winter fundraising event to raise funds and awareness to help provide support and services to Canadians impacted by mito.

On February 26, 2023, MitoSpin was held virtually and in person in Calgary and Winnipeg.

Participants across Canada cranked up their gears and shared their energy to raise awareness and funds for mito. These passionate and dedicated spinners and our long-standing, committed sponsors **raised over $86,000**.

We would like to extend our thanks to the event sponsors and partners:

CIBC
CIBC PRIVATE WEALTH
MESSING ROSS ADVISORY GROUP
MNP COMMUNITY & SPORT CENTRE
ultragenyx
LIVE The DREAM TRI-IT EST. 2006

mitospin 2023
Energizing Lives!

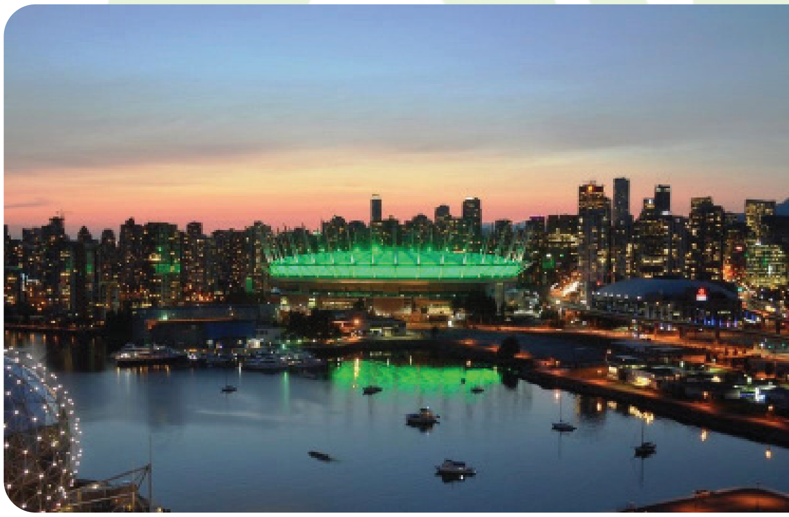
Find more details about MitoSpin 2023 at ***mitocanada.org/2023mitospin/***

2022 World Mitochondrial Disease Week

World Mitochondrial Disease Week is an initiative started by the International Mito Patients (IMP) organization that encourages people worldwide to raise awareness for mitochondrial disease and disorders.

To celebrate World Mitochondrial Disease Awareness Week 2022:

- Hosted events in Mississauga and Winnipeg
- 56 landmarks across the country were lit up in green
- Oshawa provided a proclamation for awareness week
- Hosted a Twitter Takeover
- Had a contest on Instagram, giving away 5 Prize Packs



CITY OF OSHAWA PROCLAMATION

Third Party Events

Third-party fundraising events are independently organized by an individual or group to help raise funds and awareness to benefit MitoCanada.

We appreciate our third-party event organizers' hard work to support our mission and priority areas. In the 2022/23 year, a variety of third-party events were organized by community partners who rallied their local communities to raise awareness and funds in support of MitoCanada!

5 PEAKS

5 Peaks delivers some of the best trail races Canada has to offer. This cross-Canada series runs from May to September.

In 2022/23, 12,000 people participated in the series and **raised over $4,200** for MitoCanada!

BE THERE RACES

Proudly offering six distinctly different running events, Be There Races aims to provide a relaxed and fun atmosphere where athletes can connect with their community. Their signature events include Spring Trio 5/10/15 km, Tri for Evan (sprint and kids triathlon), Kananaskis 100-mile relay race, and more!

In 2022, Be There Races **raised $6,500** to support MitoCanada and Canadians impacted by mito.

Thank you to all who participated and donated!

CBTU
CANADA'S BUILDING
TRADES UNIONS
Value on Display. Every Day.

Annually, the Hamilton Brantford Building Trades Association organizes the Swing for a Cure charity golf tournament to benefit MitoCanada. This event gathers 120 golfers from the Ontario building and construction trades community, uniting them in a common cause to raise funds and awareness for mitochondrial disease research, aiming to find a cure.
This collective effort showcases the community's commitment to being a beacon of hope in the fight against mitochondrial disease.

$10,174.09 was raised in 2022!

"My family and I began hosting our third-party fundraiser, called Frankie G Pub Night, in January 2014. My son, Frankie, passed away on May 14, 2013. Our family and friends (including Frankie's dad and I) had never heard of mitochondrial disease so ***we thought hosting an event would be a great way to get everyone together in Fankie's memory and raise awareness for mitochondrial disease****."* - Celia McGrath

mito Power 8

Power of 8 MTB is an endurance mountain biking event at Buffalo Pound Provincial Park visitor centre. This 8 km solo and relay event **raised $6,800** in 2022/23 for MitoCanada!

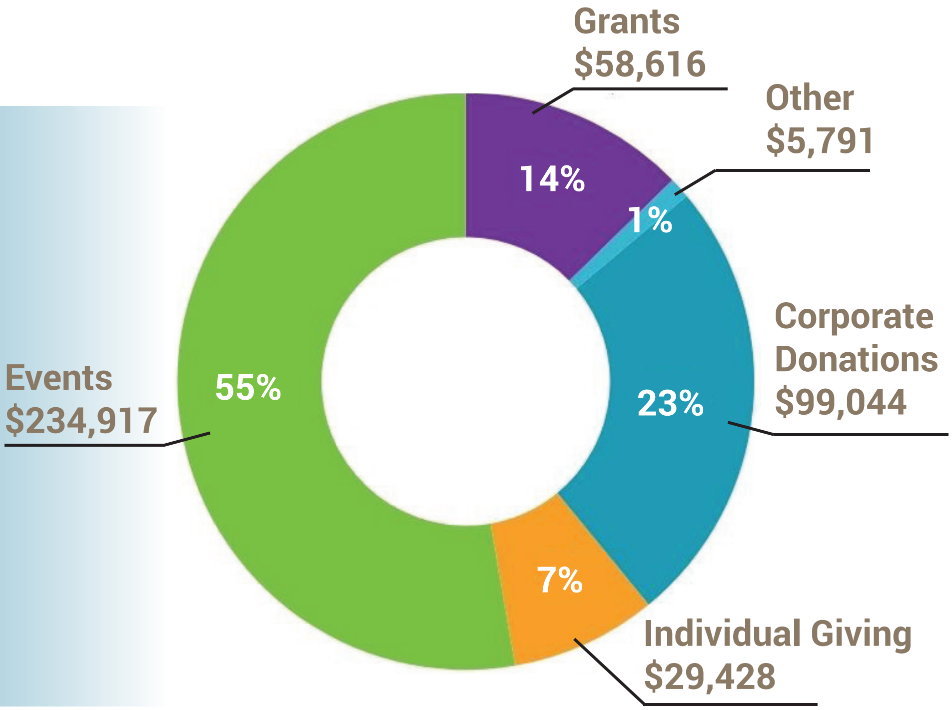
TRANSROCKIES™
RACE SERIES

TransRockies Race Series organizes the very best mountain biking, trail running, gravel biking, endurance and stage races in Alberta & British Columbia, Canada, and Colorado & Utah, USA. Fully supported, fun and challenging races in spectacular destinations are the hallmark of TransRockies events. TransRockies hosts 10 events – race or run or ride for fun, there is an adventure for everyone!

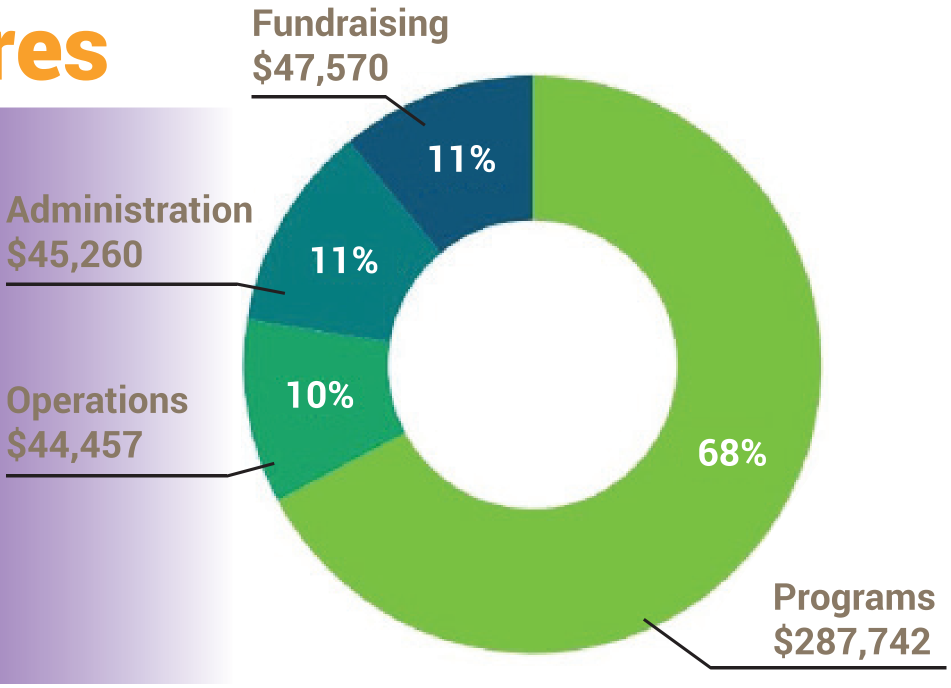
In 2022, MitoCanada was the National Charity Partner for the Transrockies Series race. Their events **raised $2,500** for MitoCanada.

Financials

Revenue



Expenditures



Partners

MitoCanada partners with a variety of mitochondrial-focused organizations both in Canada and globally. Collectively, these relationships support the advancement of knowledge, research, and care for the MitoCommunity and MitoCanada's vision of creating a world where all lives are powered by healthy mitochondria.

2022/23 partnerships included:

CORD

imp
international mito patients

MITO2i MITOCHONDRIAL iNNOVATION iNITIATIVE

mito FOUNDATION
Hope for mitochondrial disease

lumiio™

Our Supporters

From the entire team at MitoCanada, we would like to acknowledge and express our sincere appreciation to all our 2022/23 supporters. Your commitment to our cause is deeply valued and essential. Because of your support, we can continue providing impactful assistance to many Canadians with mito who depend on our programs and services. We couldn't fulfill our mission without the generous support of supporters like you; thank you!

Corporate and Foundation Supporters ($1,000+):

CIBC Foundation

CIBC PRIVATE WEALTH MANAGEMENT

ATCO Gas

Shaw) Birdies for Kids
Presented by: ALTALINK
A BERKSHIRE HATHAWAY ENERGY COMPANY

RBC Foundation

PTC THERAPEUTICS

QV INVESTORS

ultragenyx

Government Supporters ($1,000+):

Canada
Government of Canada

Signature Event Fundraisers

Raised $1,000+

WALK N' ROLL4mito

ENERGIZING LIVES

2022

Individuals

Louise Gibson, Mississauga, ON
Gisele Hansen, Winnipeg, MB
David Mosher, Oakville, ON
Bonnie Procyshyn, Winnipeg, MB

Teams

MitoPower, Mississauga, ON
Energizing Lives, Oakville, ON

mitospin 2023

Energizing Lives!

Individuals

Ironmike Bock (Calgary, AB)
Sean Messing (Calgary, AB)
Victoria Mosher (Oakville, ON)
Kate Murray (Oakville, ON)
Bonnie Procyshyn (Winnipeg, MB)
John Savoie (Calgary, AB)

Teams

BowTies for Mito (Toronto, ON)
Calgary Flames Alumni (Calgary, AB)
Ironman Financial Inc. (Calgary, AB)
Mighty MNGIE Spinners (Victoria, BC)
Shari Mager (for Aiden) (Palo Alto, CA)
Ultragenyx (California, USA)
We ride for Aiden! (Winnipeg, MB)

Our Team

Kate Murray
CEO and President

Nella Perri
Finance Manager

Tania Amardeil
Social Media Coordinator

Catherine Mulvale
Chief Development Officer

Emily Ing
Events and Community Awareness Coordinator