FSHD SOCIETY

FSHD CANADA FOUNDATION
Curing the #1 Form of Muscular Dystrophy

FSHD 360 Conference

The Latest in Health & Research

Ontario, Canada

May 3, 2025

Our Organizational Mission, and Vision for the FSHD 360 Program

The mission of the **FSHD Society** is to accelerate the development of treatments and a cure for facioscapulohumeral muscular dystrophy (FSHD), while empowering individuals affected by FSHD to live their best lives.

The singular goal of the **FSHD Canada Foundation** is to help find a cure – as soon as possible – for Canadians who suffer with FSHD.

The vision of **FSHD 360 Program** is to create a future where every individual affected by FSHD is informed, empowered, and supported—living fully and confidently through access to knowledge, compassionate care, and a strong, united community. FSHD 360 envisions a world where patients, families, and healthcare professionals come together in partnership to transform the journey with FSHD.

Thank You to our SPONSORS & PARTNERS

AVIDITY
BIOSCIENCES

FSHD | CANADA FOUNDATION
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AGENDA

Thank you to our speakers:

Neil Camarta, FSHD Canada Foundation

Beth Johnston, FSHD Society

Hanns Lochmuller, MD PhD, University of Ottawa

Charles Kassardjian, MD, University of Toronto

Hernan Gonorazky, MD, Hospital for Sick Children

Marija Radenovic, PT

Victoria Larocca, PhD, MD Canada

Jennifer Wells, Lori Brand, Danika Painter

Lawrence Korngut, MD, University of Calgary

Amanda Hill, FSHD Society

Ryan Mitchell, PhD, Satellos

Henry Nchienzia, PhD, Avidity Biosciences

Carrie Wilkinson, Ontario Chapter Director

Samantha Johnston, Ontario Walk & Roll Leader

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10:00 am – 12:25 pm:

- Welcome
- FSHD 101 and research overview
- The neuromuscular care landscape in the Toronto region
- Care for pediatric patients with neuromuscular disease
- Exercise and physical therapy
- Services and resources provided by MD Canada
- Panel: Tips & tricks for navigating life with FSHD

12:25 pm – 1:25 pm: Lunch Break

1:25pm – 3:35 pm:

- Canadian Neuromuscular Disease Registry (CNDR)
- BetterLife FSHD
- Muscle regeneration research
- Clinical Trial Overview, drug development and readiness
- Project Mercury in Canada
- Activating the Local Community
- Closing remarks

Stay Connected, Get Resources

WALK & ROLL
TO CURE FSHD

FSHD Straight Talk
with Tim Hollenback

FSHD 360 Conference
The Latest in Health & Research

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Ontario Chapter

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FSHD University
Your questions. Expert answers.

The Gathering Place
Find Your Circle

FSHD Navigator

2026
FSHD
CONNECT

Building a Treatment-Ready Ecosystem

- ✓ **1. Participate in Research**
  Surveys, focus groups, CNDR, Natural History (MOVE) and other Studies
- ✓ **2. Get Genetic Testing**
  A genetic confirmation is required to patriciate in clinical trials and must be in your medical record to be prescribed future therapies, and for insurance to cover them.
- ✓ **3. Join CNDR.org, then BetterLife FSHD** (when it is available)
- ✓ **4. Update your medical records**
  The ICD-10 code for FSHD is **G71.02** – ensure your provider has this in your record!
- ✓ **5. (RE)Establish Care**
  To be ready for an approved treatment, you have to be an established patient with a doctor who is willing to prescribe it to you (GP/PCP, Neurologist, Neuromuscular Specialist)
- ✓ **6. Keep Well!**
  Until there is a treatment available, the best thing you can do is take care of yourself. Join one or more of the Gathering Places to do this!

Upcoming Virtual Events: Anyone can join from anywhere!

- May 7 | Women On Wellness | 5:00 - 6:00 PM ET
- May 8 | Feeling Fit with FSHD | 12:00 - 1:00 PM ET
- May 12 | Wellness Hour – 'Getting to know you' | 5:00 - 6:00 PM ET
- May 12 | Everything Early Onset – 'Netflix night' | 7:00 PM ET
- May 13 | FSHD Straight Talk podcast – new episode
- May 15 | FSHD University Webinar – 'The Pediatric MOVE Study' | 1:00 PM ET (registration required)
- May 19 | Young Adults | 8:00 – 9:00 PM ET
- May 20 | Parents' Roundtable | 8:00 – 9:00 PM ET
- May 22 | Feeling Fit with FSHD | 12:00 – 1:00 PM ET
- May 27 | FSHD Straight Talk podcast – new episode
- May 27 | CarePartner Hour | 8:00 – 9:00 PM ET
- May 28 | FSHD University Webinar *Special Edition* - 'Fulcrum's Phase 3 Clinical Trial' | 1:00 PM ET

Visit our Event Calendar for ALL events!
https://www.fshdsociety.org/fshd-events-calendar/

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Upcoming Events:

LET's LIGHT CANADA ORANGE!

JUNE 20
World FSHD Day!

(Toolkit > https://www.fshdsociety.org/world-fshd-day/)

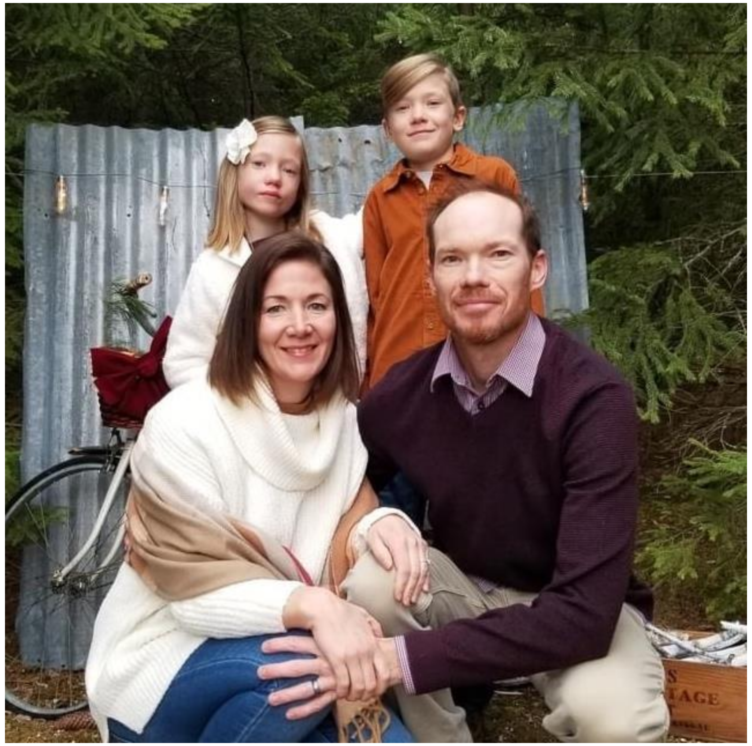
WORLD FSHD DAY

Unite to find a cure

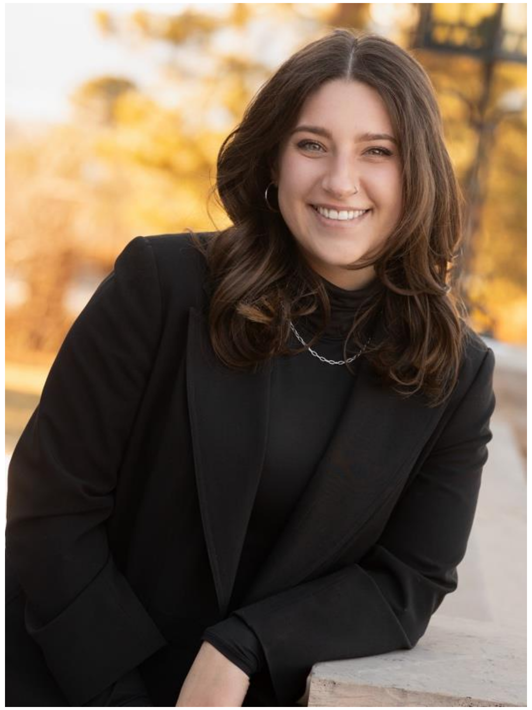
WALK & ROLL TO CURE FSHD

SEPTEMBER 13
Ontario Walk & Roll to Cure FSHD!

Meet your Volunteer Leaders



Carrie Wilkinson
Ontario Chapter Director



Samantha Johnston
Ontario Walk & Roll Leader

Community • Education • Advocacy

FSHD SOCIETY

WALK & ROLL TO CURE FSHD

Building and fostering community

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FSHD CANADA FOUNDATION

The FSHD Canada Foundation has joined forces with the FSHD Society to provide help and hope to those living with FSH Muscular Dystrophy. Generous donations make this possible, and advance research that gets us closer to treatments and a cure!

Over 2,000 participants across the U.S. and Canada

The Ontario Walk alone has raised over $200,000

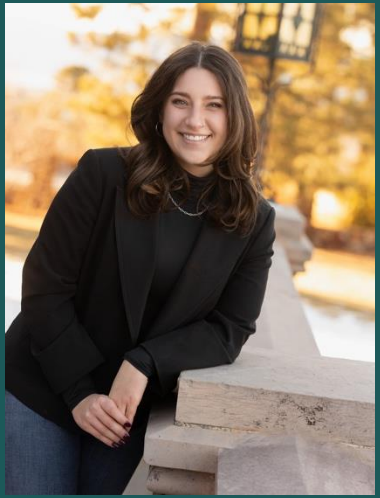
All Walks have raised over $4 million

Samantha Johnston

Ontario Walk and Roll leader

Contact

OntarioWnR@fshdsociety.org



Contact Us

Ensure you don't miss out on important information and events!

Join the Community Form:

SCAN ME

Ontario Chapter Director:

Carrie Wilkinson: OntarioChapter@FSHDSociety.org

Ontario Walk & Roll to Cure FSHD

Samantha Johnston: OntarioWnR@FSHDSociety.org

FSHD Patient Navigator

Navigator@FSHDsociety.org
781-301-6060 x4000

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