mito ACTION

MITO MATTERS

STAY UPDATED ON NEWS
AND MITO MATTERS

May 2023

This Month's Highlights

Annual Sandra K. Russell Derby Day Benefit for Mito Has a Successful Debut at an All-New Venue

The May 6th **Derby Day** event in Boston was a huge success. This year's event debuted an all-new venue, Mémoire at Encore Boston Harbor Resort & Casino.

Guests enjoyed signature cocktails, watched the live race, listened to music from Boston Celtic's DJ BREK, and had the opportunity to bid on auction items like court-side Celtics tickets (courtesy of BREK's generosity), weekend getaways, golf packages, and more. The highlight of the evening was perhaps the chance to hear more about Sandra, Dalia, and Matthew, who's legacies live on through the programs directly supported by the event. Our programs wouldn't be possible without your support.

Another major event highlight was the chance to honor mito warrior, Adam Johnson, host of the Parents as Rare podcast and an incredible advocate for the mito community, with this year's Making a Difference Award. MitoAction is deeply grateful for Adam's dedication to providing support for others.

Adam and Victoria Johnson

Special thanks to the SKR Derby Day Committee, sponsors, donors, volunteers, guests, and all who made this event possible!

If you attended the event and haven't had a chance to fill out our event feedback survey, please click below. All surveys completed in-full will be entered into a raffle for a chance to win complimentary Jockey Club tickets to the 2024 SKR Derby Day event!

Guest Feedback Survey

Save the date for next year's event!
Saturday, May 4, 2023

Programs & Special Events

Dalia's Wish Sends the Taylor Family to Give Kids the World Village

We are thrilled to report we sent our most recent Dalia's Wish recipients, the Taylor family, on the trip of a lifetime to Give Kids the World Village. The Taylors had a blast, but their most favorite part was just getting to enjoy being together as a family.

"We had great adventures at the parks we visited - but my favorite evening was when we came home from Hollywood Studios and all watched Star Wars together at our villa. It's been awhile since all six of us have been in the same room just hanging out and it was magical.Thank you to MitoAction for giving us all the opportunity to do that."

Learn More About or Donate to Dalia's Wish Today!

Applications to nominate a family or receive a Wish Trip are now open!
Click **here** to nominate or apply today!

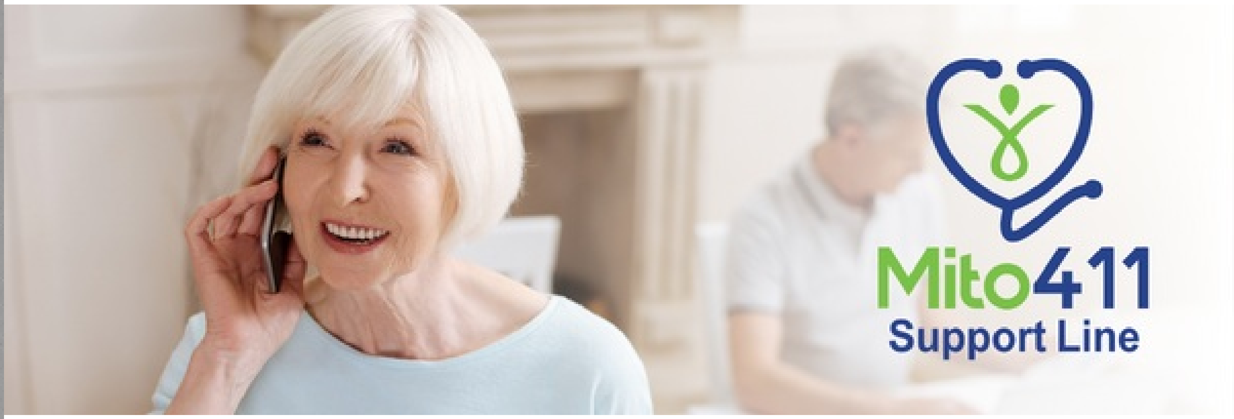
SAVE THE DATE!

Mark your calendars for this year's Energy Walks - Boston, Syracuse and Rochester! More details and registration information coming soon!

For more information, please visit: https://www.mitoaction.org/events/energywalk/

If you are interested in hosting an Energy Walk in your local community,
please contact Hilary Romkey

Patient Support



Mito411 offers live, one-on-one support, education, advocacy, and a direct connection with someone who understands. The mitochondrial disease journey is long and often difficult, but we want you to know that you are never alone on this road - so please don't hesitate to reach out!

Reach us by phone at **(888) MITO-411**, by email at **mito411@mitoaction.org** or via the **LIVE CHAT** feature in the lower right corner of our website!

Whether you need help managing your mitochondrial disease symptoms or if you care for someone with mitochondrial disease, **MyMito** *(formerly MitoAction Mobile)* is here for you. MyMito is the only HIPPA compliant digital platform specifically created to manage the mitochondrial disease lifestyle, while also providing critical data to clinicians and researchers in their quest to develop therapies.

MyMito will help you manage mitochondrial disease each step of the way by allowing you to:

- **Track** current mitochondrial disease systems to uncover correlations and causes of symptoms and medical events
- **Access** and view past health history on demand
- **Manage** future appointments and tasks, to avoid obstacles and triggers
- **Research** opt-in to share your de-identified data with clinicians and

researchers working tirelessly to develop treatments and a cure for mitochondrial disease

Join Now **Schedule Training**

Consider Joining one of our new Monthly Support Groups!

"Our Space" Is a space for young adults with mito and FAODs to connect and network! These meetings will occur every second Wednesday of the month. Please join our host, FAOD extraordinaire, Alex Salser June 13th at 8:30pm EST.

Register for Our Space

Join us for **"CPEO and Me"** every 1st Thursday of the month at 6:00pm EST! This is a special place carved out for individuals impacted by CPEO to share about their experiences. Join MitoChampion, Jeremy Silverthorn, as we learn more about CPEO by sharing our stories.

Register for CPEO and Me

Our **"Men's Support Group"** is a safe place for men to gather and share about their experiences with mitochondrial disease. Please consider joining rare disease dad and podcast host, Adam Johnson (@RareDiseaseDad), June 11th at 1:00pm EST.

Register for Men's Support Group

Upcoming Weekly Support Calls

No matter where you are on your journey with mito, whether you are a patient, *caregiver, or loved one, everyone is welcome to join our weekly support calls!*

- June 2nd - 12:00pm EST
- June 9th - 12:00pm EST
- June 16th - 12:00pm EST
- June 23rd - 12:00pm EST

Register

Education & Awareness

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Monthly MitoExpert Series

Traveling with an FAOD

Sunday, June 4, 2023 7:00 pm EST / 4:00 pm PST

Join MitoAction as Tasia Rechisky and Stephanie Harry lead us in a presentation and conversation surrounding traveling with an FAOD. They both offer unique perspectives, the adult patient perspective and parent perspective! They will seek to offer practical tips, while joining your conversation about how to navigate your own traveling adventure!

Stephanie Harry

Tasia Rechisky

www.mitoaction.org

Register for June 4

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Monthly MitoExpert Series

Aging with Mito

Friday, June 16, 2023 12:00 pm EST / 9:00 am PST

Dr. Tarnopolsky is a neuromuscular and neurometabolic clinician-scientist who received an MD and PhD. His research focuses on pharmacological, nutraceutical, and exercise therapies for neuromuscular and neurometabolic disorders, aging, obesity, and other disorders that affect the mitochondria and muscle function.

Mark Tarnopolsky, MD, PhD, FRCP(C),

Professor of Pediatrics and Medicine, CEO and CSO, Exerkine Corporation

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Our educational webinars feature guest speakers addressing topics important to the mito community, giving patients and families unprecedented access to leading clinical experts. Past presentations can be listened to in our Spotify, Google Podcasts, Amazon Music, iHeartRadioand iTunes podcast libraries as well as on our website.

Is there a topic you'd like to hear more about? Please email us at info@mitoaction.org

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MitoAction's podcast series, **Energy in Action**, consists of conversations with patients, families, researchers and thought leaders in the mitochondrial disease communities. These podcasts give you a glimpse into the lives of families affected by mitochondrial disease and the latest in clinical trials, diagnosis, research and the advancement of therapies.

On the 3rd Wednesday of the month, listen in for **Parents as Rare** episodes, hosted by the 'Dadvocate,' Adam Johnson.

New episodes will be released in our Spotify, Google Podcasts, Amazon Music, **iHeartRadio** and iTunes podcast libraries as well as on our website.

If you would like to be a guest or suggest a topic, please email us at info@mitoaction.org.

FAOD Support

mito ACTION INFORM

INTERNATIONAL METABOLIC CONFERENCE

FOR FAMILIES AND INDIVIDUALS IMPACTED BY FATTY ACID OXIDATION DISORDERS

Friday, July 21 - 23, 2023

Get ready to connect, engage and learn with other FAOD families and clinicians!

REGISTER NOW!

mitoaction.org/internationalmetabolicconference

Upcoming Fatty Acid Oxidation Disorder (FAOD) Support Call Dates

These support calls create a safe and confidential place to connect with others with FAOD. Parents, spouses, caregivers, and adults on the FAOD journey are welcome to join in to share their experiences, ask a question, and offer and receive individualized support.

- June 8th - 8:15pm EST
- June 22nd - 1:00pm EST

RSVP

Research & Clinical Trials

For the latest updates, and to search current clinical trials, visit ourwebsite.

Please click **here** to read a special announcement from Ultragenyx regarding the closing of their LC-FAOD Odyssey Study to allow their team to focus on the LC-FAOD Disease Monitoring Program (DMP), a long-term prospective, observational outcomes study aiming to collect information for up to 10 years from adult and pediatric patients with LC-FAOD, regardless of treatment.

Positive Peach Packages

Through Positive Peach Packages, recipients are reminded that there is a positive person that cares about how they are feeling, both physically and mentally. Let someone in the mito community know they are not alone.

Nominate someone

today!

TK2D SELFIE VIDEOS

TK2d Community - can you help?
We need volunteers (patients, parents, partners, family members) to talk about life with TK2d for a #TK2dTuesday awareness project.

Please email Cristy to get more details
cristy.balcells@ucb.com

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About Mito

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