



# MITOCHONDRIAL MEDICINE 2021



# JOIN US! EVENING OF



Thursday, June 24 - 6:00pm EDT

[www.umdf.org/eveningofenergy](http://www.umdf.org/eveningofenergy)

## energy for life walkathon

#WALKYOURWAY



## LIMITED TIME ONLY!

25th Anniversary Merchandise



Create a team, join a team or register as an individual:  
[energyforlifewalk.org](http://energyforlifewalk.org)

[www.umdf.org/25thstore](http://www.umdf.org/25thstore)

# Helpful Links



**June 24 -26, 2021**

## Watch Mitochondrial Medicine 2021

Register NOW to watch Mitochondrial Medicine 2021 LIVE! **Patient and Family sessions begin Friday, June 25, 2021 at 12:00pm Eastern / 11:00am Central / 9:00am Pacific.** Registrants will receive e-communications with instructions on how to watch online. If you do not receive something before Friday morning, please check your spam prior to contacting us at [helpdesk@umdf.org](mailto:helpdesk@umdf.org).

[www.umdf.org/mitomed2021](http://www.umdf.org/mitomed2021)

## Evening of Energy - Thursday, June 24 – 6:00pm EDT

Join us as we celebrate our 25th Anniversary. The evening will be highlighted by a conversation with past recipients of the UMDF Vanguard Award as they share their perspectives on 25 years of progress and what the future holds for the mitochondrial disease community. Join us as we reminisce with friends, recognize our volunteer leaders and honor all that we have accomplished together over the past 25 years.

[www.umdf.org/eveningofenergy](http://www.umdf.org/eveningofenergy)

## The Big Pitch - Friday, June 25 – 12:40pm EDT

Read the *accelerators* finalists' presentations prior to the Big Pitch on Friday, June 25 at 12:40pm Eastern / 11:40am Central / 9:40am Pacific. Become an *accelerator* now to participate in the Big Pitch voting!

[www.umdf.org/BigPitch2021](http://www.umdf.org/BigPitch2021)

## Speakers

View the full list of Mitochondrial Medicine 2021 moderators, speakers and panelists.

Patient/Families Program: [www.umdf.org/mitomedfamily](http://www.umdf.org/mitomedfamily)

Scientific/Clinical Program: [www.umdf.org/mitomedscientific](http://www.umdf.org/mitomedscientific)

## Sponsor Goody Bag

Download a virtual goody bag of information from the sponsors and partners of Mitochondrial Medicine 2021!

[www.umdf.org/symposium/goodybag](http://www.umdf.org/symposium/goodybag)

# TK2d

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A rare  
mitochondrial  
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**TK2d is a debilitating and life-threatening genetic disorder that causes progressive and severe muscle weakness. Many patients lose the ability to walk, eat, and breathe independently.**

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At Zogenix, we are committed to developing therapies that transform the lives of rare disease patients and their families and are proud to partner with physicians and patient communities in our work. **Together we can bring hope and support to patients and families impacted by rare diseases.** [www.zogenix.com](http://www.zogenix.com)

**Zogenix congratulates the United Mitochondrial Disease Foundation for 25 years of promoting research and education for the diagnosis, treatment, and cure of mitochondrial disorders and providing support to affected individuals and families.**





# Mitochondrial Medicine 2021

## VIRTUAL

### \*Clinical CME Session Agenda

#### ▪ Thursday, June 24 – 1:00pm-4:00pm EDT

##### Mitochondrial Medicine Society Platform - Updates in Mitochondrial Disease

Session Chair: *Amel Karaa, MD, Massachusetts General Hospital, Boston, MA*

- 1:00 **MMS Intro and Updates**  
*Amel Karaa, MD*
- 1:15 **Transitioning From Pediatric to Adult Oriented Health Care for Patients with Chronic Complex Medical Needs**  
*Reed Van Deusen, MD, MS, University of Pittsburgh School of Medicine, Pittsburgh, PA*
- 1:45 **The POLG Paradigm: From Patient to Petri Dish**  
*Laurence Bindoff MD, PhD Professor, University of Bergen & Neuro-SysMed, Haukeland University Hospital, Bergen, Norway*
- 2:15 **Break**
- 2:30 **Management of the Stroke-like Episodes in MELAS, Acute and Interictal Phase**  
*Yasutoshi Koga, MD, PhD, Kurume University Graduate School of Medicine, Kurume, Japan*
- 3:00 **Chronic Pain in Mitochondrial Diseases**  
*Susanne Becker, PhD, Balgrist University Hospital, University of Zurich, Switzerland and Institute of Mental Health, Heidelberg University, Germany*
- 3:30 **Live Q&A Panel Discussion**
- 4:00 **Closing and Adjourn**

### 25th Anniversary – An Evening of Energy

#### ▪ Thursday, June 24 – 6:00pm-

*Hosted by Brian Harman, UMDF President & CEO, and Philip Yeske, PhD, UMDF Science & Alliance Officer*

UMDF invites you to a special virtual event as we honor our mitochondrial medicine heroes and celebrate our 25th Anniversary. The evening will be highlighted by a conversation with past recipients of the **UMDF Vanguard Award** as they share their perspectives on 25 years of progress and what the future holds for the mitochondrial disease community.

Join us as we reminisce with friends, recognize our volunteer leaders and honor all that we have accomplished together over the past 25 years.

#### **Special Guests – UMDF Vanguard Award Recipients**

2013 – Salvatore “Billi” DiMauro, MD - Columbia University (*special video message*)

2014 – Chuck Hoppel, MD - Case Western Reserve University

2015 – Douglas Wallace, PhD - Children’s Hospital of Philadelphia

2016 – Richard Haas, MD - Rady Children’s Hospital/UC San Diego School of Medicine

2018 – Larry Grossman, PhD - Wayne State University

There are thousands of children with mitochondrial diseases and zero cures. We're working to change that.



At Akron Children's Mitochondrial Center, our world-renowned pediatric neurologists are helping lead the industry in mitochondrial research, treatment and the search for a cure. Using an integrative approach, we tailor our care to specifically meet the needs of each child and are dedicated to helping them thrive.

Visit us at: [akronchildrens.org/MitochondrialCenter](https://akronchildrens.org/MitochondrialCenter)

Mitochondrial Center



Akron  
Children's  
Hospital

## Clinician/Patient Session Agendas

### ○ Friday, June 25 – 12:00pm-5:00pm EDT

*\*Times are subject to change*

- 12:00p – **UMDF: Celebrating 25 Years** – Brian Harman, UMDf President & CEO
- 12:20p – **UMDF Impact** - Philip Yeske, PhD, UMDf Science & Alliance Officer
- 12:40p – **Big Pitch Accelerator Grant Program**
- 1:15p – **Clinical Trials Panel #1 Discussion** – Magali Taiel, MD, Gensight Biologics; Natalie Yivgi Ohana, PhD, Minovia Therapeutics; Matthew Klein, MD, MS, FACS, PTC Therapeutics; and Peter Stacpoole, PhD, MD, University of Florida
- 1:50p – **Clinical Trials Panel #2 Discussion** – Magnus Hansson, MD, PhD, Abliva; Fernando Scaglia, MD, Baylor College of Medicine; Chris Winrow, PhD, Cycleron Therapeutics; and Jan Smeitink, MD, PhD, Khondrion
- 2:25p – **Clinical Trials Panel #3 Discussion** – Gerard Marek, MD, PhD, Astellas Pharma; Alex Dorenbaum, MD, Reneo Pharmaceuticals; Jim Carr, PharmD, Stealth BioTherapeutics; and Joanne Quan, MD, Zogenix; Richard Haas, MD, University of San Diego, CA
- 3:00p – **Genetic Testing Panel Discussion** – Arnold Gammaitoni, PharmD, Zogenix; Sean Hofherr, PhD, FACMG, GeneDX; Lukas Lange, PhD, Probably Genetic; Elizabeth McCormick, MS, CGC, Children's Hospital of Philadelphia, Philadelphia, PA; and Doreen Casali, Adult Mito Patient/UMDF Ambassador
- 3:30p – **UMDF Supported Infrastructure Panel Discussion** – Michio Hirano, MD, North American Mitochondrial Disease Consortium (NAMDC); Amel Karaa, MD, Treat Mito; Sumit Parikh, MD, Mitochondrial Care Network (MCN); and Marni Falk, MD, Mitochondrial Disease Sequence Data Resource (MSeqDR)
- 4:00p – **Happy Hour/Special Patient Voice Networking Breakouts**

### ○ Saturday, June 26 at 10am-3pm EDT

- 10:00a-10:05a – **UMDF Welcome** - Brian Harman, President & CEO
- 10:05a-10:30a – **What is Mitochondrial Disease?** Bruce H. Cohen, MD, UMDf Chair, Scientific and Medical Advisory Board, Akron Children's Hospital, Akron, OH
- **Break**
- 10:40a-12p – **Ask the Mito Doc Panel for the Adult Patient Community**  
*Panelists: Amel Karaa, MD; Marni Falk, MD; Zarazuela Zolkipli Cunningham, MD; Mary Kay Koenig, MD; Michio Hirano, MD; and Mark Tarnopolsky, MD*
- 10:40-12p – **Coffee and Conversation - Breakout Networking Sessions for Parent/Caregivers** – (moderated virtual round table discussions – attendees are welcome to move from room to room)  
**Topics Include:**
  - Newly Diagnosed and General Networking
  - Cannabis
  - IEPs and School
- 10:40-12p -- **LHON Science/Research Panel** - Isabel Lopez Sanchez, BSc, PhD, Centre for Eye Research Australia, VIC, Australia; Giulia Amore, PhD, University of Bologna, Italy; Anne Chiaramello, PhD, George Washington University School of Medicine and Health Sciences, Washington, DC; Alfredo Sadun, MD, PhD, University of California Los Angeles, Los Angeles, CA  
*Moderators: Rustum Karanjia, MD, PhD, University of Ottawa Eye Institute, Ottawa, ON, Canada and Lissa Poincenot, LHON Program Chair/UMDF Ambassador*
- **Break - 25th Anniversary Moments with UMDf Staff**
- 12:30p-1:50p – **Ask the Mito Doc Panel for the Parent/Caregiver Community**  
*Panelists: Richard Boles, MD; Annette Feigenbaum, MD; Richard Kelley, MD, PhD; Russell Saneto, DO, PhD; Fernando Scaalia, MD; and Irina Anselm, MD*



## Moving Medicines to *Move People*

Reneo is a clinical stage company focused on improving the lives of people with rare genetic mitochondrial diseases. Our priority is finding a treatment for mitochondrial myopathy to improve daily function and quality of life.

Reneo is a proud sponsor of  
UMDF Mitochondrial Medicine 2021

To learn more about us, please visit [reneopharma.com](https://www.reneopharma.com)



- 12:30p-1:50p – **Coffee and Conversation - Breakout Networking Sessions for Adult Patient Community** – (*moderated virtual round table discussions – attendees are welcome to move from room to room*)
  - Topics Include:**
    - Adult – Managing Care or General Networking
    - Coping Strategies
    - Managing Fatigue
- 12:30p-1:50p – **Living with LHON Panel**
- **Break**
- 2:00p-3:00p – Breakout Sessions Running Concurrently
  - **Mitochondrial Patient Care for the Newly Diagnosed Panel**  
*Speakers: Sumit Parikh, MD; Austin Larson, MD; Colleen Clark Muraresku, MS, LCGC; and Lynne Wolfe, MS, CRNP*
  - **Management of Acute Emergencies (ICU) in Primary Mitochondrial Disease – for Traveling and at Home**  
*Speakers: Rebecca Ganetzky, MD; Divakar Mithal, MD; and Amy Goldstein, MD*
  - **LHON Community Update**
- **3:00p – Closing with Final Comments**

## Teen/Young Adult Program

### Monday, June 28 at 8:00pm EDT

8:00p-9:00p – **Virtual Art Class** led by young adult, Monica Chulewicz. Join us to create a "Work of Art" in your very own home with items you already have on hand.

### Tuesday, June 29 at 8:00pm EDT

8:00p-9:00p – **Dating and Relationships in Teens and Young Adults living with a Chronic Illness** – Teen/Young Adult Panel Discussion.

### Wednesday, June 30 at 7:00pm EDT

7:00p-8:00p – **Mito Doc Round Table Discussion** with Amy Goldstein, MD, Children's Hospital of Philadelphia. Join us for this special Teen and Young Adult Only (no Parents allowed) Q&A session. This is your opportunity to ask the questions that you need to know as you approach and enter adulthood.

### Thursday, July 1 at 8:00pm EDT

8:00p-9:00p – **Transitioning in a COVID World for the Mitochondrial Teen/Young Adult** with Beth Heuer, DNP, CPNP-PC, PMHS Pediatric Nurse Practitioner.

### Friday, July 2 at 8:00pm EDT

8:00p-10:00p – **Teen Prom** featuring D.J. Jake Maxwell

# Turning Innovative Science into Value for Patients

Through our 'Focus Area' approach, we examine combinations of biology, modalities, and technologies which we apply to a broad range of diseases with high unmet needs. This allows us to explore innovation from multiple angles and accelerate the pace of discovery and development. Our primary focuses include regenerative medicine and blindness, genetic regulation, immuno-oncology and mitochondrial biology.

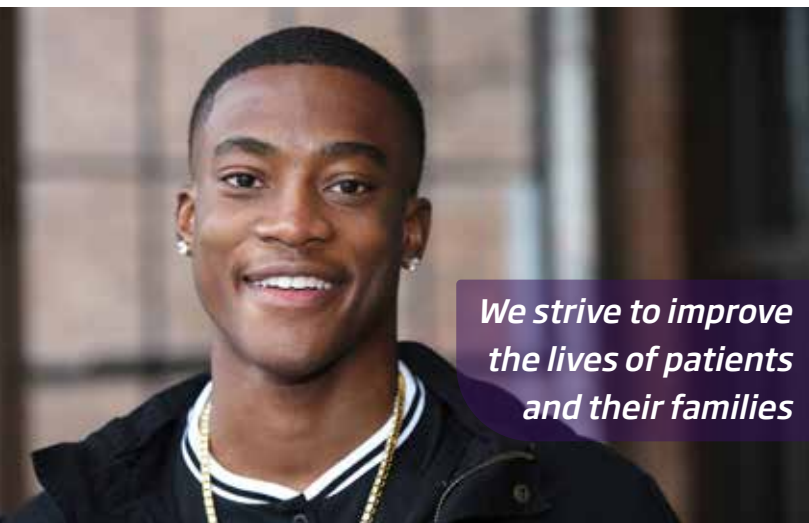
At Astellas, we are on the forefront of healthcare change.



[astellas.com/us](http://astellas.com/us)



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*We strive to improve the lives of patients and their families*



Aim to improve energy levels in mitochondrial disease

Research company with two medicines in development

Global, Phase 2/3 study start this year with most advanced drug candidate



Stealth BioTherapeutics is committed to the development of therapies for mitochondrial disease and is a proud supporter of UMDF's Mitochondrial Medicine Symposium.

To learn more about our work, please visit [StealthBT.com](http://StealthBT.com)

[www.abliva.com](http://www.abliva.com)

[info@abliva.com](mailto:info@abliva.com)

LinkedIn

YouTube



## **accelerators 2021 Finalists**

### **Lia Mayorga, MD, PhD**

Instituto de Histología y Embriología de Mendoza - Mendoza, Argentina

**Project:**

*Modulation of the epigenome as a new strategy for mtDNA heteroplasmy shift*



### **Michela Di Nottia, PhD**

Bambino Gesù Children's Hospital - Rome, Italy

**Project:**

*The role of inflammation in diseases related to mitochondrial DNA maintenance: new potential biomarkers to be used as therapeutic targets*

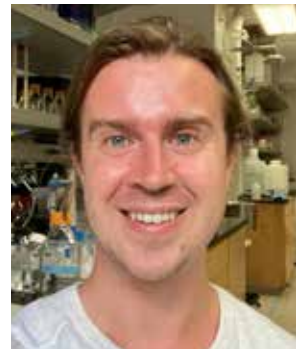


### **John Smolka, PhD**

University of California, Berkeley - California, USA

**Project:**

*Establishing roles for the mitochondrial tRNA biosynthetic machinery in mitochondrial genome maintenance*



#### **READ**

Read breakdowns of the finalist projects

[umdf.org/accelerators](https://umdf.org/accelerators)

#### **WATCH**

Tune in to the Big Pitch on  
Friday, June 25, 2021 at 12:40pm EDT

[umdf.org/BigPitch2021](https://umdf.org/BigPitch2021)



# The MIT-E Study

A clinical research study for children and teenagers who have mitochondrial disease with associated epilepsy.



Find out more at  
[www.themit-estudy.com](http://www.themit-estudy.com)



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**IW-6463  
for MELAS**



Cyclerion Therapeutics is investigating the use of study drug IW-6463\* in participants with MELAS as part of an ongoing Phase 2a clinical trial. If you or someone you know may be interested in discussing possible participation further, contact information can be found at [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

(Study Identifier: **NCT04475549**)

**4-5pm EST  
Friday 6/25**

For more information please visit us at the networking session and at our virtual booth.

Visit us at: [www.cyclerion.com](http://www.cyclerion.com)  
Connect with us on Twitter: [@cyclerion](https://twitter.com/cyclerion)

\*IW-6463 is an investigational therapy and is not approved for the treatment of people with MELAS.

# Speakers

## May 7 & 21, June 4 & 18, 2021

- **Heather Christofk, PhD**  
University of California Los Angeles, CA
- **Mickael Decressac**  
Grenoble Institute of Neuroscience, France
- **Steven Gray, PhD**  
University of Texas Southwestern Medical Center, Dallas, TX
- **Carlos Moraes, PhD**  
University of Miami, Miami, FL
- **Vamsi Mootha, MD**  
Harvard Medical School, Boston, MA
- **Jodi Nunnari, PhD**  
University of California Davis, Davis, CA
- **Dave Pagliarini, PhD**  
Washington University School of Medicine, St. Louis, MO
- **Josh Rabinowitz, MD, PhD**  
Princeton University, Princeton, NJ
- **Jared Rutter, PhD**  
University of Utah, Salt Lake City, UT
- **Anu Suomalainen-Wartiovaara, MD, PhD**  
University of Helsinki, Finland
- **Eric Schon, PhD**  
Columbia University, New York, NY
- **Phillip West, PhD**  
Texas A&M University College of Medicine, Bryan, TX

## June 24, 2021

- **Susanne Becker, PhD**  
Balgrist University Hospital, University of Zurich, Switzerland and Institute of Mental Health, Heidelberg University, Germany
- **Laurence Bindoff, MD, PhD**  
University of Bergen & Neuro-SysMed, Haukeland University Hospital, Bergen, Norway

- **Amel Karaa, MD**  
Massachusetts General Hospital, Boston, MA
- **Yasutoshi Koga, MD, PhD**  
Kurume University Graduate School of Medicine, Kurume, Japan
- **Reed Van Deusen, MD, MS**  
University of Pittsburgh School of Medicine, Pittsburgh, PA

## June 25, 2021

- **Jim Carr, PharmD**  
Stealth BioTherapeutics
- **Alex Dorenbaum, MD**  
Reneo Pharmaceuticals
- **Marni Falk, MD**  
Children's Hospital of Philadelphia, PA
- **Magnus Hansson, MD, PhD**  
Abliva
- **Michio Hirano, MD**  
Columbia University, New York, NY
- **Brian Harman, President & CEO**  
UMDF
- **Richard Haas, MB, BChir**  
University of California San Diego, CA
- **Matthew Klein, MD, MS, FACS**  
PTC Therapeutics
- **Amel Karaa, MD**  
Massachusetts General Hospital, Boston, MA
- **Gerard Marek, MD**  
PhD, Astellas Pharma
- **Natalie Yivgi Ohana, PhD**  
Minovia Therapeutics
- **Sumit Parikh, MD**  
The Cleveland Clinic, Cleveland, OH
- **Joanne Quan, MD**  
Zogenix

- **Peter Stacpoole, PhD, MD**  
University of Florida, Gainesville, FL
- **Jan Smeitink, MD, PhD**  
Khondrion
- **Fernando Scaglia, MD**  
Baylor College of Medicine, Houston, TX
- **Magali Taiel, MD**  
Gensight Biologics
- **Chris Winrow, PhD**  
Cyclerion Therapeutics
- **Philip E. Yeske, PhD**  
Science & Alliance Officer, UMDf

## June 26, 2021

- **Giulia Amore, PhD**  
University of Bologna, Italy
- **Irina A. Anselm, MD**  
Boston Children's Hospital, Boston, MA
- **Richard Boles, MD**  
NeurAbilities Healthcare, Pasadena, CA
- **Bruce H. Cohen, MD**  
Akron Children's Hospital, Akron, OH
- **Zarazuela Zolkipli Cunningham, MD**  
Children's Hospital of Philadelphia, PA
- **Anne Chiaramello, PhD**  
George Washington University School of Medicine and Health Sciences, Washington, DC
- **Marni Falk, MD**  
Children's Hospital of Philadelphia, PA
- **Annette Feigenbaum, MD**  
Rady Children's Hospital, San Diego, CA
- **Rebecca Ganetzky, MD**  
Children's Hospital of Philadelphia, PA
- **Amy Goldstein, MD**  
Children's Hospital of Philadelphia, PA
- **Michio Hirano, MD**  
Columbia University, New York, NY

# TARGETING SAFE VISION RESTORATION

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ANNIVERSARY!**

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NOW RECRUITING  
**Clinical Trial:**  
DCA in PDC Deficiency



**WHO?**

Patients with genetically confirmed pyruvate dehydrogenase complex (PDC) deficiency ages 6 months through 17 years.

**WHERE?**

9 academic health centers throughout the US. Visit <http://tinyurl.com/DCA-trial> to find a study site near you. Travel assistance is provided if needed.

**WHY?**

This is a study of an investigational drug called sodium dichloroacetate (DCA). Investigational means that the study drug has not been approved by the US Food and Drug Administration (FDA) and that its use in this study is experimental. The purpose of this research study is to see if DCA improves health and function for patients with PDCD.

**HOW?**

For more information contact Peter W. Stacpoole, PhD, MD, [pws@ufl.edu](mailto:pws@ufl.edu)



## Variantyx offers comprehensive testing for Mitochondrial disorders

Variantyx utilizes the Genomic Unity® single platform method allowing for full analysis of both the nuclear and mitochondrial genes. This provides two options for full phenotypic analysis of clinical symptoms consistent with mitochondrial disorders.

### Genomic Unity® Mitochondrial Genome Analysis

- ✓ Complete Mitochondrial genome analysis

### Genomic Unity® Mitochondrial Disorders Analysis

- ✓ Complete Mitochondrial genome analysis plus sequencing and duplications/deletions analysis of nuclear mitochondrial genes

Proprietary algorithms optimized for each variant type are used to perform discrete *in-silico* analyses of the data. These are brought together for collective interpretation, providing a complete genetic picture.

For more information, visit us on line <https://www.variantyx.com>.



# Speakers

- **Amel Karaa, MD**  
Massachusetts General Hospital, Boston, MA
- **Rustum Karanjia, MD**  
PhD, University of Ottawa Eye Institute, Ottawa, ON, Canada
- **Richard Kelley, MD**  
PhD, Johns Hopkins/Kennedy Krieger
- **Mary Kay Koenig, MD**  
UTHealth/McGovern Medical School, Houston, TX
- **Austin Larson, MD**  
Children's Hospital Colorado, Aurora, CO
- **Divakar Mithal, MD**  
Lurie Children's Hospital of Chicago, Chicago, IL
- **Colleen Clarke Muraresku, MS, LCGC**  
Children's Hospital of Philadelphia, PA
- **Sumit Parikh, MD**  
The Cleveland Clinic, Cleveland, OH
- **Lissa Poincenot**  
LHON Program Chair/UMDF Ambassador
- **Alfredo Sadun, MD, PhD**  
University of California Los Angeles, CA
- **Isabel Lopez Sanchez, PhD**  
Centre for Eye Research Australia, VIC, Australia
- **Russell Saneto, DO, PhD**  
Seattle Children's Hospital, Seattle, WA
- **Fernando Scaglia, MD**  
Texas Children's Hospital, Houston, TX
- **Mark Tarnopolsky, MD, PhD**  
McMaster University, Health Sciences Centre, Ontario, CA
- **Lynne Wolfe, MS, CRNP**  
NIH Undiagnosed Center, Bethesda, MD

## UMDF Ambassador – Coffee and Conversation Moderators

<b>Patti Ashmore</b>	<b>Jenny Hobbs</b>	<b>Tricia Melland</b>
<b>Bettemarie Bond</b>	<b>Alexis Keefer</b>	<b>Wendy Melland</b>
<b>Sydney Breslow</b>	<b>Joy Krumdiack</b>	<b>Liz Morris</b>
<b>Ashley Burrow</b>	<b>Hayley Leib</b>	<b>Laurel Smith</b>
<b>Sebastien Cotte</b>	<b>Jaci Leit</b>	<b>Gail Wehling</b>
<b>Anisa Derr</b>	<b>Aneesa Licorish</b>	
<b>Norma Gibson</b>	<b>Karen Loftus</b>	


# Planning Committee

- **Bruce Cohen, MD** - Course Chair  
Akron Children's Hospital, Akron, OH
- **Bill Copeland, PhD** - Course Chair  
National Institute of Environmental Health Sciences, Durham, NC
- **Brett Kaufman, PhD** - Bench-to-Bedside Chair  
University of Pittsburgh, PA
- **Amy Goldstein, MD**  
Children's Hospital of Philadelphia, PA
- **Larry Grossman, PhD**  
Wayne State University School of Medicine, Detroit, MI
- **Richard H. Haas, MB, BChir, MRCP**  
University of California San Diego, CA
- **Adam Hartman, MD**  
NINDS/NIH, Rockville, MD
- **Amel Karaa, MD**  
Massachusetts General Hospital, Boston, MA
- **Carla Koehler, PhD**  
University of California Los Angeles, CA
- **Giovanni Manfredi, MD, PhD**  
Weill Cornell Medicine, New York, NY
- **Robert K. Naviaux, MD, PhD**  
University of California San Diego, CA
- **Sumit Parikh, MD**  
The Cleveland Clinic, Cleveland, OH
- **Russell Saneto, DO, PhD** - Course Chair  
Seattle Children's Research Institute, Seattle, WA
- **Keshav Singh, PhD**  
University of Alabama at Birmingham, AL
- **Peter Stacpoole, PhD, MD**  
University of Florida, Gainesville, FL
- **Kara Strittmatter, CMM, MA**  
UMDF Meeting Event Director, Columbus, OH
- **Philip E. Yeske, PhD**  
UMDF Science & Alliance Officer, Pittsburgh, PA


Our mission is to deliver life-changing therapies by treating the root cause of mitochondrial diseases. Working hand in hand with patient's advocacy groups, from our beginning, was much more than an aspiration. This is the place where our science transforms into meaningful therapies.



Visit our site for more info:

 [www.minoviatx.com](http://www.minoviatx.com)

Contact us with any question:

 [info@minoviatx.com](mailto:info@minoviatx.com)

\*MAT is an investigational drug, currently undergoing a clinical trial for Pearson Syndrome.

About Mitochondrial Augmentation Therapy (MAT):



**Delta Gamma**

1873

**The Delta Gamma Foundation is proud to support the United Mitochondrial Disease Foundation.**

Learn about the Delta Gamma Foundation at [www.deltagamma.org/foundation](http://www.deltagamma.org/foundation)



# solace

## NUTRITION

**Nutritional Management for Mitochondrial Disease**

**PROUD TO SUPPORT UMDF**

# KHONDRION

bringing energy to life

Khondrion is a clinical-stage biopharmaceutical company discovering and developing therapies targeting primary mitochondrial disease

The Company is advancing a pipeline with the potential to deliver transformative medicines and treatments to patients

Khondrion congratulates UMDF on **25 years** of dedicated work bringing together all those fighting mitochondrial disease





# Energy

The **Energy Award** is designed to recognize an individual who embodies the spirit of the UMDF and its Mission: promoting research and education for the diagnosis, treatment and cure of mitochondrial disorders and providing support to those affected.

We are proud to recognize **Sebastian Cotte** of Stone Mountain, GA, as the 2021 Energy Award recipient. Sebastian is the energy behind patient families. As a UMDF Ambassador, Sebastian helps patient families on their own journey with mitochondrial disease. In addition, he has volunteered his time to presents numerous informational sessions during patient family meetings, has been on the Atlanta Energy for Life Walkathon Committee for many years and has been a tireless advocate for legislation impacting patient families. Sebastian also promotes UMDF activities and events through social media.



# Heartstrings

The **Heartstrings Award** recognizes a child or teen that has donated or raised funds for the UMDF, enabling the UMDF to continue its mission. The winner is chosen based on related criteria of age, time invested, talents demonstrated, effectiveness, generosity and how the individual has “tugged at the heartstrings.”

We are proud to recognize **Jackson Adams** of Woodhaven, WI, as the 2021 Heartstrings Award recipient. Jackson wrote an essay for his local Kiwanis Club Writing Contest. The topic was *“If I had \$100, I would give it to...”* and Jackson chose the UMDF. In the essay, Jackson talked about his cousin, Russell, who lost his battle with mitochondrial disease at 2 years old. Jackson was the winner of the contest and a donation was made in honor of his cousin. His touching essay is the reason why Jackson is our 2021 Heartstrings Award Winner.





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**Mitochondrial Disease.**



Visit [www.epic4health.com](http://www.epic4health.com) for all your CoQ10 needs

# LEAP

**L**EAP stands for Living, Encouraging, Achieving and Persisting. The award is presented to an individual who is age 14 or older living positively with mitochondrial disease. The awardee overcomes daily challenges to achieve goals in career, family, and volunteer service. The individual demonstrates a positive attitude, hope for a brighter future, and an enthusiasm that inspires others.

We are proud to recognize **Lily Finnigan** of Salt Lake City, UT, as the 2021 LEAP Award recipient. Lily has battled Mito Complex-1 for nearly 18 years. During that time, she has been to the ER more than 15 times due to varying issues related to the disease. Despite these challenges, Lily maintains a great outlook on life and is a positive force in the lives of the people she touches; she never loses that smile.

Her favorite thing to do these days is to ride in her Extreme Motus, which is an off-road “stroller on steroids” that allows her to discover bumpy new trails and awesome vistas that would be no place for a regular wheelchair. Lily’s goal this summer is to summit nearby Mount Timpanogas (elevation 11,700+) and visit the Delicate Arch in Southeastern Utah near Moab. Lily has weathered many storms and stayed strong through the illnesses and strokes that have been part of her young life in dealing with mito.

An inspiration to so many, Lily lives each day like a gift. A budding young artist, Lily’s plans after high school is to open an online art gallery with her aunt, Joan Matteucci (aka “Aunt Noni”). Many of Lily’s good friends compete for a local swim team; their swim caps say “Beat Mito” to raise awareness of the disease.



# Leadership

The **Stanley A. Davis Leadership Award** is presented annually to a UMDF leader who exemplifies dedication to the UMDF. The award was created to honor the work and dedication to the organization shown by the late UMDF Board Chairman, Stanley A. Davis.

We are proud to recognize **Howard and Ann Korsen** of Mount Laurel, NJ as the 2021 Stanley A. Davis Leadership Award recipients. Howard and Anne have been active volunteers with the UMDF since participating in the first Mitochondrial Medicine Symposium. The couple are the parents of Dana and Mara; Mara battles mitochondrial disease.

Howard has been incredibly helpful to the UMDF by advocating for issues impacting patient families on Capitol Hill. Ann has been instrumental in organizing and forming a team for the Del Val Energy for Life Walk. Ann also provides a lot of 'behind the scenes' support for the UMDF's annual symposium and the 'Evening of Energy'.



# SAVE THE DATE

## MITOCHONDRIAL MEDICINE 2022

**Phoenix, AZ**

**June 8-12, 2022**

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The United Mitochondrial Disease Foundation gratefully acknowledges the following organizations for their support of Mitochondrial Medicine 2021:

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