



June 29-July 1, 2023 – Patient/Family/*LHON Sessions
Sheraton/Le Meridien Hotel, Charlotte, NC

12:00pm-7:00pm	Registration Opens (<i>Patients/Families/LHON/Teens</i>) – Carolina/Meckenburg Foyer
3:00pm-4:30pm	UMDF Kick-off to Patient Family/LHON Attendees – Symphony 4 <ul style="list-style-type: none"> • What to Expect this Weekend • Getting to Know You • Navigating Friday/Saturday Sessions and Meals • Programming to Checkout – mitoSHARE, Clinical Trial Finder, No-Cost Genetic Testing, etc.
4:30pm-6:00pm	Mobile App Workshops – Learn How to Navigate the Mobile App (Symphony 4) LHON Attendees - Mobile App Workshop (Symphony 3)
4:00pm-6:00pm	<i>Doc is In</i> Registration Opens
6:00pm-8:00pm	Symposium Mitochondrial Family "Mixer" (<i>All Patients/Families, Teens, and LHON attendees will come together to enjoy an evening to network with each other prior to Friday's opening</i>) – Symphony 4 and LHON Attendees to stay in Symphony 3
7:00am	Registration and <i>Continental Breakfast</i> – Symphony Ballroom/Foyer and Carolina Foyer
<i>Combined Sessions - Researchers, Scientists, Clinicians, Patients, LHON Community, Families, Industry are included in Combined Sessions in the Symphony Ballroom 1-4</i>	
8:00am-10:00am	Combined Session - Welcome: UMDF and the State of the Mitochondrial Medicine Community and IMPACT– Symphony Ballroom 1-4 <i>Brian Harman, UMDF President & CEO, Philip Yeske, PhD, UMDF Science & Alliance Officer, and Special Guests from the Community</i>
9:15am-9:45am	TEEN/Young Adult – Staying Safe at Mito Med 2023 - Governor 1
10:00am-10:30am	Break
9:45am-10:45am	TEEN/Young Adult - Chat with Dr. Amy Goldstein – Governor 1
10:30am-12:30pm	Combined Session - Clinical Trial Updates – Carolinas DE and AC Session kick-off with Mitochondrial Myopathy Symptoms Over Time – Sharing New Natural History Data, <i>Zuela Zolkipli-Cunningham, MD, Children's Hospital of Philadelphia, PA</i> Session will include: Clinical Research Pavilion Outcomes - <i>Dr. Zolkipli-Cunningham, Casimir, and Dr. Peter McGuire</i> Clinical Trial Updates - <i>presenters and industry noted in Mobile App</i> Clinical Trial Readiness Project - <i>Dr. Amel Karaa and Dr. Austin Larson</i>

- 10:30am-11:00am** **LHON Welcome: LHON Families - Mecklenburg 2-3**
Maria Johnson, Program Chair and Jessica Loomer, Program Co-Chair
- 11:00am-12:00pm** **TEEN/Young Adult – Dance with Wendy – Governor 1**
- 11:00am-12:30pm** **Living with LHON Panel #1 - Mecklenburg 2-3**
Moderator: *Maria Johnson*
Panelists: *Jessica Knight, Rob Packard, Xavier Marsh, and Dani Ort*
- 12:30pm-2:00pm** **Lunch - Networking by Geographic Region – Symphony Ballroom**
Teen Lunch will begin at Noon
(LHON attendees will have a designated area within meal space)
- 2:00pm-3:30pm** **LHON Science Session - Mecklenburg 2-3**
Moderator: *Lissa Poincenot*
Speakers: *Mays Dairi, MD and Mark Tarnopolsky, MD, PhD, BPE*
- 1:00pm-2:00pm** **TEEN/Young Adult – STEM Activity with Discovery Place – Governor 1**
- 2:30pm-3:30pm** **TEEN/Young Adult – Music Therapy with Miriam Tart, MMT, MT-BC – Governor 1**
- 2:00pm-3:30pm** **Mitochondrial Disease and Therapy Track – Carolinas D-E**
Moderator/Speaker:
Jennifer Poirier, DPT
Speakers:
- *Jenna Lowrey, OT*
 - *Brenda Sorrells, Orthotist*
 - *Kelvin Jones, Orthotist*
 - *Scott Staley, ATP*
 - *Cassandra Stolting, SLP*
 - *Katie Parsons, Patient/OT Student*
- 2:00pm-2:30pm** **Genetic Testing Landscape – Mecklenburg 1**
Elizabeth McCormick, MS, CGC
- 2:30pm-3:30pm** **Disease Specific Breakouts – Mecklenburg 1, Governor 2, 3 and 5**
Special Disease Specific Breakout Sessions. NOTE: Room locations may change.
Disease Specific Breakout Sessions
- **Leigh Syndrome** - *Mary Kay Koenig, MD; Amy Goldstein, MD - Mecklenburg 1*
 - **Pyruvate Dehydrogenase Complex Deficiency (PDCD)** - *Jirair K. Bedoyan, MD, PhD, FACMG; Peter Stacpoole, PhD, MD; James Peterson, MS, LCGC - Mecklenburg 1*
 - **POLG/CPEO/KSS** - *Zuela Zolkipli Cunningham, MD; Bruce Cohen, MD - Governor 2*
 - **MELAS/Primary Mito Myopathy** - *Fernando Scaglia, MD and Andrea Gropman, MD - Governor 5*
 - **TK2D** - *Michio Hirano, MD - Governor 3*



- 3:30pm-4:00pm** **Break**
- 4:00pm-5:00pm** **Importance of Physical Therapy - Carolina D-E**
Jean Flickinger, PT, DPT, PCS
- 4:00pm-5:00pm** **LHON Community Update – Mecklenburg 2-3**
Moderator: *Lissa Poincenot*
Speakers: *Chris Marsh, Malinda Marsh, Maria Johnson, Jessica Loomer, and Jerrie Lore*

Join us for...

- 5:30pm** **Reception and Cash Bar Symphony Foyer then into Ballroom**
- 6:30pm** **An Evening of Energy Banquet Celebration and Big Pitch – Symphony Ballroom**
(LHON attendees will have a designated area within Banquet space)
- After programming is complete, please feel free to join the Teens for a Little Music and Dancing – Symphony Ballroom**

Saturday, July 1

- 7:30am** **Continental Breakfast**
- 8:00am-9:00am** **LHON Coffee and Conversation - Mecklenburg 2-3**
LHON Data Collection Program (DCP), LHON Collective, Metrolina Association for the Blind (MAB), National Center on Health, Physical Activity and Disability (NCHPAD), and North Carolina Assistive Technology Program (NCATP)
- 8:00am-10:00am** **Coffee and Conversation - Symphony Ballrooms**
The UMDf and our Ambassadors invite you to casual networking time. We will have table signs set-up in the Symphony 4 for family groupings.
Tentative Topics: IEPs, Adults with Mito, Parents/Caregivers, Grief, and Getting Involved
- NOTE:** TWO Special Coffee & Conversation Breakout Rooms will be designated for the following Topics:
- **Navigating a Dx - Moderator: Patricia Arnold, LCSW, UTHealth, Houston, TX**
Symphony 2
 - **Leigh Syndrome – Meet the Researchers – Moderator: UMDf Staff and Taylor Connor -**
Symphony 3
- 9:00am-10:00am** **TEEN/Young Adult – Healthy Mind and Body - Governor 1**
James Peterson, MS, LCGC
- 9:00am-10:00am** **LHON – The Top Five Questions I Get Asked About Assistive Technology – Mecklenburg 2-3**
Sara Nappi
- 10:00am-10:30am** **Break**



10:00am-11:00am	TEEN/Young Adult – Positive Mindset with Lu - Governor 1 <i>Ludivine Tandazo</i>
10:30am-12:45pm	Family Planning Track Symphony 1-2 Moderator: Beth Whitehouse <ul style="list-style-type: none"> ● Reproductive Planning - <i>Marni Falk, MD, Children’s Hospital of Philadelphia</i> ● Financial Planning - <i>Hamptom Hodge, Planning Associate</i> ● Housing Transitioning - <i>Margaret Gaffney, Transition & Government Benefit Specialist</i> ● Grief - Loss of a Loved One - <i>Brooke Yates, Kindermourn</i>
10:30am-11:45am	Ask the Mito Doc Panel – Carolina D-E Moderator: Margaret Moore <ul style="list-style-type: none"> ● Clinician Panelists - <i>Austin Larson, MD; Eva Morava-Kozicz, MD; Jaya Ganesh, MD; Abdulrazak (Abdu) Alali, MD; Mary Kay Koenig, MD; Muge Gucsavas Calikoglu, MD, MPH and Russell Saneto, DO, PhD</i>
10:30am-11:45am	Living with LHON Panel #2 – Mecklenburg 2-3 Moderator: <i>Jessica Knight</i> Panelists: <i>John Coughlin, Kevin Wright, Rashell Lewis, and Jon Lacin</i>
11:30am-12:30pm	TEEN/Young Adult - Yoga with Cristy - Governor 1
12:00pm-12:45pm	Positive Mindset for Life – Mecklenburg 2-3 <i>Ludivine Tandazo</i>
12:45pm	LHON Group Photo – Mecklenburg 2-3
12:45pm-2:00pm	Lunch (<i>LHON attendees will have a designated area within meal space</i>) <i>Breakouts from Planning Track in Symphony Rooms TBD</i>
1:30pm-2:30pm	Are you Out of Breath – Carolina D-E <i>Zarazuela Zolkipli Cunningham, MD, Children’s Hospital of Philadelphia</i>
2:00pm-3:15pm	Family Planning Track Continues – Symphony 1-2 <ul style="list-style-type: none"> ● Govt Programs (Medicaid waivers) - <i>Jenny Hobbs and Stacy Taylor</i> ● Loss of Mobility - <i>Lauren Falduti and Brooke Yates, Kindermourn</i> ● Positive Mindset for Parent/Caregivers - <i>Ludivine Tandazo</i>
2:00pm-3:30pm	Navigating Employment with LHON – Mecklenburg 2-3 Moderator: <i>Jessica Loomer</i> Panelists: <i>Rich Archuleta, Julie Poincenot, and John Walters</i>
2:15pm-3:00pm	TEEN/Young Adult - Art Project
3:15pm	Break
3:30pm-4:30pm	Closing Session – Looking to the Future for Mito Medicine – Carolina A-C



3:30pm-4:30pm

LHON Raffle and Closing Conversation – **Mecklenburg 2-3**

with Maria Johnson, Program Chair and Jessica Loomer, Program Co-Chair

4:30p

UMDF Mito Med 2022 Adjournment

