### June 29-July 1, 2023 – Patient/Family/*LHON Sessions

Sheraton/Le Meridien Hotel, Charlotte, NC

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>12:00pm-7:00pm</td>
<td>Registration Opens <em>(Patients/Families/LHON/Teens)</em> – Carolina/Meckensburg Foyer</td>
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<td>3:00pm-4:30pm</td>
<td>UMDF Kick-off to Patient Family/LHON Attendees – Symphony 4&lt;br&gt;  ● What to Expect this Weekend&lt;br&gt;  ● Getting to Know You&lt;br&gt;  ● Navigating Friday/Saturday Sessions and Meals&lt;br&gt;  ● Programming to Checkout – mitoSHARE, Clinical Trial Finder, No-Cost Genetic Testing, etc.</td>
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<td>4:30pm-6:00pm</td>
<td>Mobile App Workshops – Learn How to Navigate the Mobile App <em>(Symphony 4)</em>&lt;br&gt;  LHON Attendees - Mobile App Workshop <em>(Symphony 3)</em></td>
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<td>4:00pm-6:00pm</td>
<td>Doc is In Registration Opens</td>
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<td>6:00pm-8:00pm</td>
<td>Symposium Mitochondrial Family &quot;Mixer&quot; <em>(All Patients/Families, Teens, and LHON attendees will come together to enjoy an evening to network with each other prior to Friday’s opening – Symphony 4 and LHON Attendees to stay in Symphony 3)</em></td>
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### Combined Sessions - Researchers, Scientists, Clinicians, Patients, LHON Community, Families, Industry are included in Combined Sessions in the Symphony Ballroom 1-4

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<tr>
<td>7:00am</td>
<td>Registration and Continental Breakfast – Symphony Ballroom/Foyer and Carolina Foyer</td>
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<td>8:00am-10:00am</td>
<td>Combined Session - Welcome: UMDF and the State of the Mitochondrial Medicine Community and IMPACT– Symphony Ballroom 1-4&lt;br&gt;  Brian Harman, UMDF President &amp; CEO, Philip Yeske, PhD, UMDF Science &amp; Alliance Officer, and Special Guests from the Community</td>
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<tr>
<td>9:15am-9:45am</td>
<td>TEEN/Young Adult – Staying Safe at Mito Med 2023 - Governor 1</td>
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<td>10:00am-10:30am</td>
<td>Break</td>
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<tr>
<td>9:45am-10:45am</td>
<td>TEEN/Young Adult - Chat with Dr. Amy Goldstein – Governor 1</td>
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<tr>
<td>10:30am-12:30pm</td>
<td>Combined Session - Clinical Trial Updates – Carolinas DE and AC&lt;br&gt;  Session kick-off with Mitochondrial Myopathy Symptoms Over Time – Sharing New Natural History Data, Zuela Zolkipli-Cunningham, MD, Children’s Hospital of Philadelphia, PA&lt;br&gt;  Session will include:&lt;br&gt;  Clinical Research Pavilion Outcomes - Dr. Zolkipli-Cunningham, Casimir, and Dr. Peter McGuire&lt;br&gt;  Clinical Trial Updates - presenters and industry noted in Mobile App&lt;br&gt;  Clinical Trial Readiness Project - Dr. Amel Karaa and Dr. Austin Larson</td>
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| 10:30am-11:00am | LHON Welcome: LHON Families - **Mecklenburg 2-3**  
*Maria Johnson, Program Chair and Jessica Loomer, Program Co-Chair* | **Mecklenburg 2-3** |
| 11:00am-12:00pm | TEEN/Young Adult – Dance with Wendy – **Governor 1**                                        | **Governor 1**    |
| 11:00am-12:30pm | Living with LHON Panel #1 - **Mecklenburg 2-3**                                           | **Mecklenburg 2-3** |
| 12:30pm-2:00pm | Lunch - Networking by Geographic Region – Symphony Ballroom                                      | **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**                                                | **Mecklenburg 2-3** |
| 1:00pm-2:00pm | TEEN/Young Adult – STEM Activity with Discovery Place – **Governor 1** | **Governor 1**    |
| 2:30pm-3:30pm | TEEN/Young Adult – Music Therapy with Miriam Tart, MMT, MT-BC – **Governor 1**       | **Governor 1**    |
| 2:00pm-3:30pm | Mitochondrial Disease and Therapy Track – **Carolinias D-E**                          | **Carolinias 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**                                        | **Mecklenburg 1** |
|              | **Elizabeth McCormick, MS, CGC**                                                                |                   |
| 2:30pm-3:30pm | Disease Specific Breakouts – **Mecklenburg 1, Governor 2, 3 and 5**               | **Mecklenburg 1, Governor 2, 3 and 5** |
|              | **Special Disease Specific Breakout Sessions. NOTE: Room locations may change.**            |                   |
|              | **Leigh Syndrome** - Mary Kay Koenig, MD; Amy Goldstein, MD - **Mecklenburg 1**        | **Mecklenburg 1** |
|              | **Pyruvate Dehydrogenase Complex Deficiency (PDCD)** - Jirair K. Bedoyan, MD, PhD, FACMG; Peter Stacpoole, PhD, MD; James Peterson, MS, LCGC - **Mecklenburg 1** | **Mecklenburg 1** |
|              | **POLG/CPEO/KSS** - Zuela Zolkipli Cunningham, MD; Bruce Cohen, MD - **Governor 2**     | **Governor 2**    |
|              | **MELAS/Primary Mito Myopathy** - Fernando Scaglia, MD and Andrea Gropman, MD - **Governor 5** | **Governor 5**    |
|              | **TK2D** - Michio Hirano, MD - **Governor 3**                                               | **Governor 3**    |

*Leber’s Hereditary Optic Neuropathy (LHON)*
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
    Ludivine Tandazo

10:30am-12:45pm  Family Planning Track Symphony 1-2
    Moderator: Beth Whitehouse
    ● Reproductive Planning - Marni Falk, MD, Children’s Hospital of Philadelphia
    ● Financial Planning - Hampton Hodge, Planning Associate
    ● Housing Transitioning - Margaret Gaffney, Transition & Government Benefit Specialist
    ● Grief - Loss of a Loved One - Brooke Yates, Kindermourn

10:30am-11:45am  Ask the Mito Doc Panel – Carolina D-E
    Moderator: Margaret Moore
    ● Clinician Panelists - 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

10:30am-11:45am  Living with LHON Panel #2 – Mecklenburg 2-3
    Moderator: Jessica Knight
    Panelists: John Coughlin, Kevin Wright, Rashell Lewis, and Jon Lacis

11:30am-12:30pm  TEEN/Young Adult - Yoga with Cristy - Governor 1

12:00pm-12:45pm  Positive Mindset for Life – Mecklenburg 2-3
    Ludivine Tandazo

12:45pm  LHON Group Photo – Mecklenburg 2-3

12:45pm-2:00pm  Lunch (LHON attendees will have a designated area within meal space)
    Breakouts from Planning Track in Symphony Rooms TBD

1:30pm-2:30pm  Are you Out of Breath – Carolina D-E
    Zarazuela Zolkipli Cunningham, MD, Children’s Hospital of Philadelphia

2:00pm-3:15pm  Family Planning Track Continues – Symphony 1-2
    ● Govt Programs (Medicaid waivers) - Jenny Hobbs and Stacy Taylor
    ● Loss of Mobility - Lauren Falduti and Brooke Yates, Kindermourn
    ● Positive Mindset for Parent/Caregivers - Ludivine Tandazo

2:00pm-3:30pm  Navigating Employment with LHON – Mecklenburg 2-3
    Moderator: Jessica Loomer
    Panelists: Rich Archuleta, Julie Poincenot, and John Walters

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

*Leber’s Hereditary Optic Neuropathy (LHON)
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