THURSDAY, JULY 18TH

3:00PM - 4:00PM .................. Orientation & Welcome Reception for 1st Time Families

5:30PM - 9:30PM .................. Pre-Conference Community Dinner
(If you did not sign up for this during registration, and would like to attend, please contact info@mtm-cnm.org as soon as possible)

FRIDAY, JULY 19TH

2:00PM - 5:00PM .................. Conference Sign-In and Community Connections Reception
Pickup welcome packets, enjoy light refreshments, and engage in some fun and informational activities

5:00PM - 9:00PM .................. Opening Dinner and Evening Program
Community Social (cash bar), Welcome Address
Understanding Treatment and Trials: Robert Graham, MD, Boston Children’s Hospital
Buffet Dinner, Professional and Family Introductions

9:00PM - Close .................. Connections After-Hours
Networking, sharing, socializing, and learning together for all in the Constellation Lounge
9:30 Men’s SALT group discussion with Levi Gershkowitz

SATURDAY, JULY 20TH

7:45AM - 8:15AM .................. Morning Yoga (optional)
Welcome the new day with gentle movement, breathing, and mindfulness: Kristen Roberts

8:00AM - 8:45AM .................. Breakfast

8:45AM - 9:00AM .................. Announcements and Welcome

9:00AM - 10:30AM ............... Scientific Session 1: Genetics and Basic Research
The View From Top of The Arch: Alan Beggs, PhD, Boston Children’s Hospital
Genetics of Centronuclear Myopathies: Johann Böhm, PhD, IGBMC
Understanding YOUR Genetics: Jill Madden, PhD, MSc, CGC, Boston Children’s Hospital
Centronuclear Myopathy Research at IGBMC: Johann Böhm, PhD, IGBMC

10:40AM - 12:00PM ............... Scientific Session 2: Pre-clinical Therapy Development
Tamoxifen as a Therapy for MTM: Jonathan Volpatti, MSc, The Hospital for Sick Children
ASO as a Therapy for CNM: Belinda Cowling, PhD, Dynacure
UNITE-CNM Clinical Trial Update: Chris Freitag, MD, Dynacure

12:00PM - 12:45PM ............... Lunch Break
SATURDAY, JULY 20TH (continued)
12:45PM - 2:00PM .................. Scientific Session 3: Gene Therapy
Late Rescue and Redosing in XLMTM Dogs: David Mack, PhD, University of Washington
Audentes Patient Advocacy: Kimberly Trant, Chelsea Karbocus, Audentes
Gene Therapy Clinical Trial Update: Sal Rico, MD, PhD, Audentes
Audentes Panel Discussion: Sal Rico, MD, PhD, Eric Mosbrooker, Kimberly Trant

2:00PM - 4:00PM.................. Caring For Individuals With MTM/CNM
   Barbara Smith, PT, PhD, University of Florida
   Robert Graham, MD, Boston Children’s Hospital
   Sarah Neuhaus, DO, National Institutes of Health
   Lucia Bastianelli, RN, MSN, CPNP, Boston Children’s Hospital

Part 2: Clinical Care Guidelines for Myotubular & Centronuclear Myopathy
Published Clinical Care Guidelines are important for promoting best practices amongst doctors and caregivers, especially for Rare Diseases. Families and medical professionals collaborate in a moderated open-forum to discuss further development of guidelines specific to MTM/CNM.

4:30PM.............................. Group Photo
Wear your conference t-shirt! Don’t miss this chance to be a part of MTM-CNM History!

5:00PM - 9:00PM............... Evening Program
Community Social (cash bar)
Legislative Advocacy Panel
   Marie Wood, MTM-CNM Family Connection
   Lindsay Lykens, Parent Advocate
   Max Bronstein, Audentes
Buffet Dinner, followed by the world-famous MTM-CNM Family Talent & Variety Show!

9:00PM - Close .................. Connections After-Hours
Networking, sharing, socializing, and learning together for all in the Constellation Lounge

KIDS ACTIVITIES
Kids of all ages are always welcome in the main conference sessions, but will also enjoy these fun activities in the "Kids Room" throughout the day on Saturday and Sunday morning:
Balloon Animals & Facepainting
Music Therapy Group Sessions and songwriting
Arts and Crafts
Video Games and Movies
Variety Show preparation and more!

Note: while activities will be provided, the Conference will not provide nursing, healthcare supervision, babysitting, or childcare.
**Agenda**

**SUNDAY, JULY 21ST**

8:30AM - 8:45AM .................. Nondenominational Inspiration & Reflection Service (optional)
Join us in the Reflection Room for uplifting verses, music, and fellowship

8:30AM - 9:15AM ................. Breakfast

8:45AM - 9:15PM ............... Women’s Coffee Chat

9:15AM - 12:15PM .............. Gateway Moments & Expanding Possibilities
   X-Linked Carriers Discussion Panel
      Jill Madden, PhD, MSc, CGC, Boston Children's Hospital
      Cristina Liberati, MD, University of Florida
      Emma Bliss, Remember The Girls

   Emergency Preparedness
      Robert Graham, MD, Boston Children's Hospital

   Therapeutic Strategies: PT/OT/Music/Tech
      Jenna Lammers, MSR, PT, University of Florida
      Jaime Wilhite, MMT, MT-BC, Music Therapy St. Louis
      Erin Ward, MTM-CNM Family Connection

   Family Voices Panel: Overcoming Obstacles

12:15PM - 1:00PM ............ Lunch Buffet

1:00PM - 2:00PM ............... Closing Program
   Final thoughts from the MTM-CNM Family Connection team, and an "Open Mic" forum
   for all to share reflections on the Conference and next steps ahead.

5:00PM - 9:00PM .......... Post-Conference Community Dinner
   (If you did not sign up for this during registration, and would like to attend, please contact
   info@mtm-cnm.org as soon as possible)
While nothing quite compares with gathering in one place together at the MTM-CNM Family Conference, we are grateful to have so many ways to connect virtually online! Reach out, give us a Like, a Tweet, a Post, or a Share! We’d love to hear what you are up to, and to keep you posted on our activities. Stay connected, and help spread the word!

mtm-cnm.org

facebook.com/mtmcnm (public page)
facebook.com/groups/mtmcnmcnfamlyconference (private group)

linkedin.com/company/mtm-cnm-family-connection-inc

youtube.com/user/mtmfamconf

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