

Agenda

2019 MTM-CNM FAMILY CONFERENCE "Through the Gateway: Expanding Possibilities" Hilton St. Louis Airport, St. Louis MO

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

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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**

Part 1: Panel Presentations & Discussion: Respiratory, Neurology, Spinal Fusion for Neuro-muscular Scoliosis: Shared Decision-Making
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

(continued next page)

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

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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)



Stay Connected!

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



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