



## 2025 CMTA PATIENT & RESEARCH

# SUMMIT

# Agenda

## SUMMIT | SATURDAY, SEPTEMBER 6, 2025

### 8:00 AM – 9:00 AM REGISTRATION CHECK-IN AND BREAKFAST

We welcome attendees to check in at the registration table during this time, then join us in the ballroom for a full plated breakfast, coffee, and refreshments.

### 9:00 AM – 9:20 AM WELCOME ADDRESS

**Speaker: Sue Bruhn, PhD**

Chief Executive Officer, Sue Bruhn, PhD, will give the opening address which will include CMTA highlights, the Summit flow of the day, and much more.

### 9:25 AM – 10:10 AM IU HEALTH CMT CLINIC TEAM

**Speakers: Laurie Gutmann, MD and her CMT clinic team**

During this session, you will have the opportunity to meet the CMTA Center of Excellence team from IU Health. This panel discussion will be led by CMT Clinic Director, Dr. Laurie Gutmann. This will be an interactive, open Q&A panel discussion.

### 10:15 AM – 10:50 AM CMT & Exercise

This session focuses on the most important exercises people with CMT can do daily to help manage CMT. Mary Schmidt, DO, a physiatrist at the CMTA Center of Excellence at the University of Michigan, shares best practices for physical activity in people with CMT. Published studies provide evidence that exercise significantly benefits how people with CMT feel and function, and this session will help you to get started or build on your current practice.

### 10:50 AM – 11:20 AM BREAK

Take a moment to enjoy the exhibit hall, have a snack, join a mini workout session led by Julie Stone, and mingle with other attendees.

### 11:20 AM – 12:00 PM HELP FOR TODAY: GADGETS AND ASSISTIVE TECHNOLOGY

**Speaker: Ashley McLeroy, MSME**

This session focuses on the best gadgets, adaptive tools, and assistive technology devices that can make activities of daily living easier for people with CMT.



### 12:05 PM – 12:45 PM CMT SURGERY PANEL

**Speakers:**

▣ **Session Chair: Glenn Pfeffer, MD**  
**Cedars-Sinai Medical Center**

▣ **Paul Talusan, MD**  
**University of Michigan**

▣ **Tyler Gonzalez, MD, MBA**  
**Prisma Health**

This session is a panel discussion led by renowned foot and ankle orthopedic surgeon Dr. Glenn Pfeffer. The discussion will focus on the best surgical options, practices, and outcomes for CMT foot reconstruction.

### 12:45 PM – 1:45 PM LUNCH

Take time to enjoy lunch, the exhibit hall, join a mini workout with Julie Stone, and mingle with other attendees.

### 1:45 PM – 2:30 PM BRACING SESSION

**Speakers: David Meisner, BSc (HK), CPO, MBA and local orthotist TBD**

This panel discussion on bracing and AFOs for CMT patients will be led by orthotist David Misener. The panel will share information on cutting-edge bracing options for drop-foot and balance issues.

### 2:35 PM – 3:00 PM YOUR STORY, YOUR MOJO, YOUR MOVE

**Speaker: Jeana Sweeney**

**CMTA Chief Engagement & Gift Officer**  
In this session, you will hear from Jeana Sweeney, a CMT community member, parent of a CMT patient, and a passionate and dedicated CMTA staff member. Hear her story and find yours while learning how we can all make a difference.

### 3:15 PM – 4:30 PM SMALL GROUP TABLE TALKS

You are invited to join one of three small groups to discuss some of the challenges of living with CMT, such as 1) being newly diagnosed and wanting to learn what's next in your CMT journey, 2) parents wanting to chat with other parents to learn tips on how best to support your child with CMT, and 3) the mental health side of living with CMT.

#### 1. Newly Diagnosed

*Facilitated By: TBD*

#### 2. Parents to Parents

*Facilitated By: TBD*

#### 3. Mental Health Wellness

*Facilitated by: Elizabeth Misener, PhD, LMSW*

## ALSO ON SATURDAY

### 9:15 AM – 3:15 PM DRALLA DAY YOUTH OUTING

**Led by Jonah Berger**

**(Registration is required to attend)**

Jonah Berger and chaperones will take CMT youth ages 8-18 out for a day full of fun and connection.

### 5:00 PM – 6:30 PM COMPASS YOUNG ADULTS HAPPY HOUR (ages 19-31)

**(Registration is required to attend)**

### 6:30 PM – 8:30 PM SUMMIT DINNER RECEPTION

**(Registration is required to attend)**

Join us for dinner to unwind, connect, and celebrate community with CMTA Summit attendees, researchers, doctors, and CMTA staff.





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## SUMMIT CMTA-STAR | SUNDAY, SEPTEMBER 7, 2025



**8:30 AM – 9:00 AM**

### BREAKFAST AND KEYNOTE ADDRESS

**Keynote Speaker: Dustin Turner**

Please join us for a full plated breakfast, coffee, and refreshments. The keynote address will be given during this time.

**9:05 AM – 9:25 AM**

### RESEARCH ROUNDUP:

#### CMTA-STAR IN SUMMARY

**Speaker: Katherine Forsey, PhD**  
*CMTA Chief Research Officer*

There is so much going on in CMT research and treatment development right now that we need a roundup to share it all with you. This session will be a comprehensive summary across the projects CMTA is funding, thanks entirely to the support of the CMT community.

**9:30 AM – 10:00 AM**

### TREATMENT APPROACHES FOR CMT

**Speakers:**

- ▣ **Session Chair: John Svaren, PhD**  
*University of Wisconsin*
- ▣ **Jordan Verplank, PhD**  
*Uniformed Services University*

There are several different types of treatments in development for CMT at the moment. This session will explain the different treatment approaches and deep dive into a couple of examples in development in Biotech and Academic Labs.

**10:05 AM – 10:30 AM**

### STAGES OF DRUG DEVELOPMENT

**Speaker:**

▣ **Sue Bruhn, PhD**

*CMTA Chief Executive Officer*

This session focuses on the different phases of drug development from conception to bringing a drug to market, and how CMTA works with patients to accelerate progress toward treatments.

**10:30 AM – 11:00 AM**

### BREAK

Take a moment to enjoy the exhibit hall, have a snack, join a mini workout with Julie Stone, and mingle with other attendees.

**11:00 AM – 11:20 AM**

### CLINICAL TRIAL DEVELOPMENT IN CMT

**Speaker:**

▣ **Josh Burns, PhD**

*St. Jude's Children's Research Hospital*

Dr. Burns summarizes the most up-to-date research perspective on how we can measure change over time in patients with CMT, and the importance of studying different outcome measures, biomarkers, and Natural History to accelerate the development of new treatments.

**11:25 AM – 12:10 PM**

### EXCITING PROGRESS IN CLINICAL TRIALS FOR CMT

**Speakers:**

▣ **Session Chair / Panel Moderator:**

**Joshua Burns, PhD, St. Jude's Children's Research Hospital**

▣ **Daniel Brennan, NMD Pharma**

▣ **Evan Bailey, MD, Applied Therapeutics**

▣ **Michael Imperiale, Actio Biosciences**

2025 is a pivotal year for clinical trials in CMT, with five active trials in the US as we go to press and more on the horizon. You will hear a discussion of clinical development for CMT with CMTA-STAR Alliance Partners NMD Pharma, Applied Therapeutics, and Actio Biosciences.

**12:15 PM – 12:25 PM**

### PATIENTS AS PARTNERS IN RESEARCH

**Speaker: Katherine Forsey, PhD**

*CMTA Chief Research Officer*

CMT research and clinical trials cannot happen without you. In this session, learn how you can become a Patient as Partner in Research and participate in the critical work of furthering the development of treatments for CMT. Your voice shapes the future of CMT research, and we cannot wait to hear from you.

**12:25 PM – 12:30 PM**

### SUMMIT CLOSING REMARKS

**Speaker: Gilles Bouchard**

*CMTA Board Chair*

