



Tentative Agenda

Sessions
Welcome and Introduction
GM1 Family Speaker Series
Keynote: How to Handle More Than You Can Handle A guide to navigating the emotional experience of caring for and raising disabled children with high-support needs
Cure Batten Story
Supporting Your Family with a Special Needs Master Plan
Azafaros Clinical Trial: NAVIGATE Study
The Theory of Applying Tanganil and Acetyl-L-Leucine to Neurological Diseases
Fetal Gene Therapy and ERT
GM1 Research Landscape
Foundation-Led ICV Enzyme Replacement Therapy

Sessions Continued
The Realities of ICV ERT in the Real-World and ICV 101
AllStripes and Picnic Health UCSF Data Presentation
Medical Symptoms and Well-being for People with Morquio B and Juvenile (Type II) and Late- Onset (Type III) GM1 gangliosidosis.
Care Tips from A to Z, Lessons Learned from a Lifetime of Care
What is Compassionate Use, Managed Access, or Expanded Access? Clinical Trial Pros and Cons
Surf and Turf Therapy: Surfing and Riding Therapy
The Benefits of VNS for Seizures
Swim Therapy and Your Loved One
Ultrarare Act
How to Read Your Genetics Report
Cure GM1 Overview, Initiatives, and Research
Fundraising for ICV ERT and for Cure GM1
Interactive In-Person Roundtables Caring for the Caregiver All Needs Planning Fundraising Care tips Reading Your Genetics Report