

MSMDS Conference Agenda



Friday, May 24th, 2019

- 8:00AM: **Breakfast**
- 8:30AM: **Conference Welcome**
 - Family Introductions
 - Goals of the Conference
- 9:00AM: **Keynote Speaker – Overview of MSMDS – What Do We Know About the Disease?**
 - Introduction to ACTA2/MSMDS Clinical & Research Current Knowledge [Dr. Dianna Milewicz (UTHealth)]
- 10:00AM: **Rare Disease Research Roadmap**
 - Working towards improving outcomes and development of treatment options
 - [Dr. Eichler (MGH), Rebecca Oberman]
- 11:00AM: **MSMDS Fundamentals and Q&A: Heart/Aorta and Pulmonary**
 - Heart/Aorta [Dr. Mark Lindsay (MGH), Dr. Dianna Milewicz (UTHealth)]
 - Pulmonary [Dr. Bernard Kinane (MGH)]
- 12:00PM: **Lunch**
- 1:00PM: **MSMDS Fundamentals and Q&A: Brain, Eye, Rehabilitation and Dysautonomia**
 - Brain & Development [Dr. Patricia Musolino (MGH)]
 - Neurosurgery [Dr. Edward Smith (BCH)]
 - Ophthalmology [Dr. Brian Gise (MEEI), Dr. Joseph Rizzo (MEEI)]
 - Rehabilitation [Dr. Elizabeth Shainker (Franciscans), Dr. Brian Wishart (Spaulding)]
- 2:45PM: **MSMDS Fundamentals and Q&A: Critical Care, Anesthesia**
 - Critical Care Kids/Adults [Dr. Patty Musolino (MGH), Dr. Phoebe Yager (MGH)]
- 3:30PM: **MSMDS Fundamentals and Q&A: Gastroenterology, Bladder, Airway/Swallowing**
 - Gastroenterology [Dr. Leonel Rodriguez (BCH)]
 - Bladder [Dr. Jack Elder (MGH)]
 - Airway & Swallowing [Dr. Christopher Hartnik (MEEI)]
- 4:30PM: **Summary of Monitoring and Management Recommendations**
[Dr. Dianna Milewicz (UTHealth), Dr. Patricia Musolino (MGH)]
- 5:00PM: **Closing Remarks with Cocktail Hour**
- 6:00PM: **Conference Dinner/Social for Families and Participants**

Saturday, May 25th, 2019

- 8:00AM: **Breakfast**
- 8:30AM: **Roadmap Specific to ACTA2** [Dr. Dianna Milewicz (UTHealth), Dr. Patricia Musolino (MGH)]
 - What Do We Need To Find Out?
 - What Do We Need To Move Forward?
 - How Do We Get There?
- 9:30AM: **ACTA2 Alliance Introduction- Who We Are & How We Can Help Each Other?**
 - Overview of the Foundation
 - Specific Goals
 - Resources Available
 - Fundraising in Local Communities
 - Research Participation
- 12:00PM: **Lunch**
- 1:00PM: **Patient & Parent Personal Stories**
 - Road to Diagnosis: Struggles Faced Along the Journey
 - Youth Speakers/Patient Videos
- 3:00PM: **Patient Learning Academy**
 - Coping Skills
 - Nutrition
 - Exercise
- 5:00PM: **Closing Remarks**