



Annual SMA Research and Clinical Care Meeting

Clinical Care Session Agenda

June 5th, 2024

	Abstract Number	Presentation Title
8:30 am to 9:00 am		Welcome and Cure SMA Update Mary Schroth, MD, Chief Medical Officer, Cure SMA Lisa Belter, MPH, VP, Research Data Analytics, Cure SMA
9:00 am - 9:15 am	1	Quantitative Evaluation of Upper Extremity Strength and Joint Contractures in Spinal Muscular Atrophy Type II: Implications for Motor Function Timothy Estilow, MS, OTR/L, Children’s Hospital of Philadelphia
9:15 am - 9:35 am	2 & 3	Impact of Comorbidities on Mortality in Spinal Muscular Atrophy Patients with Early Onset Scoliosis AND Risk Model for Proximal Junctional Kyphosis Following Spine Deformity Surgery in Spinal Muscular Atrophy Hiroko Matsumoto, PhD, Boston Children’s Hospital Brian Snyder, MD, Boston Children’s Hospital
9:35 am – 10:20 am	4, 5, 6	Panel Discussion: SMA Phenotypes Case series: Incidence of Torticollis and Early Scoliosis in SMA Patients Identified by Newborn Screening Carolyn Kelley, DPT, PCS, Children’s Hospital Colorado Emerging Upper Extremity Phenotype in Children with Spinal Muscular Atrophy AND Anatomic and functional oral deficits: a Feature of the New Natural History of Early Treated 2-copy SMN2 Infants Julie Patterson, MS, OTR/L, Johns Hopkins Hospital
10:20am- 10:35am	7	Adverse Immune Responses to AAV-based in vivo Gene Therapy Sofia Celli, BA, University of Colorado, Anschutz Medical Campus
10:35 am -10:55 am		Break
10:55 am -12:00 pm		Reproductive Health in Individuals with SMA: A Panel Discussion Natan Bar-Chama, MD, RMA of New York



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		Loralei Thornburg, MD, University of Rochester Medical Center
12:00 pm - 1:00 pm		Lunch
1:00 pm - 1:15 pm	8	Wearable-derived Patterns of Performance Fatigability During Gait in Spinal Muscular Atrophy Jacqueline Montes, PT, EdD, Columbia University Irving Medical Center
1:15 pm - 1:30 pm	9	Longitudinal Evaluation of Fatigue in Adult Patients with Spinal Muscular Atrophy and the Impact of Treatment with Disease-Modifying Drugs Felipe Franco da Graca, MD, University of Campinas, Brazil
1:30 pm – 1:45 pm	10	Case Series: Profound Improvements in Mouth Opening among patients with SMA following Orastretch Therapy Katlyn McGrattan, PhD, University of Minnesota
1:45 pm - 2:30 pm	11 & 12	Panel Discussion: Anesthesia Anesthesia and Procedure Concerns in the Administration of Nusinersen: Experience of a Large, Single-Institution Cohort Joanne Shay, MD, MBA, Johns Hopkins University Pitfalls in SMA Anesthesia. Nearing 10 years in the Nusinersen era Alan Bielsky, MD, University of Colorado School of Medicine, Children’s Hospital of Colorado
2:30 pm - 2:50 pm		Break
2:50 pm – 3:55 pm		Advocacy in Air Travel for Individuals with SMA: A Panel Discussion Maynard Friesz, VP, Policy & Advocacy, Cure SMA Sarah Bellish, BA, Manager, Policy & Advocacy, Cure SMA Courtney Gushue, DO, Nationwide Children’s Hospital
3:55pm- 4:00pm		Closing Remarks