



Annual SMA Research and Clinical Care Meeting

Clinical Care Session Agenda

June 28, 2023

Carol	<b>Abstract Number</b>	<b>Presentation Title</b>
8:30 am to 9:00 am		<b>Welcome and Cure SMA Update</b> Mary Schroth, MD, Chief Medical Officer, Cure SMA Lisa Belter, MPH, Director of Research Data Analytics, Cure SMA
9:00am to 9:15am	<b>1</b>	<b>The Spinal Muscular Atrophy-Health Index Short Form: Validation of a Novel Outcome Measure for Therapeutic Trials</b> Spencer Rosero, BS, University of Rochester
9:15 am to 9:30 am	<b>2</b>	<b>Manifestations of Bulbar Problems Reported by Affected Adults with SMA</b> Maureen Lefton-Greif, PHD, CCC-SLP, John Hopkins Medical Institutions
9:30 am to 9:45 am	<b>3</b>	<b>Development of a 12-tier Functional Scale for Spinal Muscular Atrophy</b> Meghan Moore Burk, PT, DPT, Children’s Hospital Colorado
9:45 am to 10:00 am	<b>4</b>	<b>Bracing Early Onset Scoliosis in SMA Patients Impacts Function but Not Progression</b> Brian Snyder, MD/PhD, Boston Children’s Hospital, Harvard Medical School
10:00 am to 10:15 am	<b>5</b>	<b>Hip Dysplasia and Dislocations in Children with Spinal Muscular Atrophy</b> Caroline Conlan, MS2, Medical Student, University of Pennsylvania Perelman School of Medicine
10:15 am to 10:30 am		<b>Break</b>
10:30 am to 12:00 pm		<b>Hip and Spine Management in the New Phenotypes of SMA: A Panel Discussion</b> Anne Stratton, MD, FAAP, FAAPMR, University of Colorado School of Medicine, Children’s Hospital Colorado Carolyn Kelley, DPT, PCS, Children’s Hospital Colorado Brian Snyder, MD/PhD, Boston Children’s Hospital, Harvard Medical School Terri Carry, PT, Children’s Hospital Colorado Patrick Curran, MD, MS, Pediatric Orthopaedic Surgery, University of California San Diego/Rady Children’s Hospital Sayan De, MD, Children’s Hospital Colorado Amy Pasternak, PT, DPT, PCS, Boston Children’s Hospital Sally Dunaway Young, PT, DPT, Stanford University



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		Brian Snyder, MD/PhD, Boston Children's Hospital, Harvard Medical School
12:00 pm to 1:00 pm		<b>Lunch</b>
1:00 pm to 2:15 pm		<b>Mapping the Trajectory of a Treated Patient: Case Studies</b> Jane Taylor, MD, MsCR, UPMC, Children's Hospital of Pittsburgh Julie Parsons, MD, Children's Hospital Colorado Stacey Tarrant, RD, LDN, Boston Children's Hospital Tina Lewis, SMA Parent Jason Edinger, DO, UPMC Children's Hospital of Pittsburgh Al Freedman, PhD, Freedman Counseling Associates Matt Halanski, MD, Phoenix Childrens Hospital/University of Arizona
2:15 pm to 2:30 pm		<b>Break</b>
2:30 pm to 2:45 pm	<b>6</b>	<b>Evolving Expectations and Unmet Needs in Acute Care for Spinal Muscular Atrophy Patients in the Therapeutic Era: Insights on Emergency Room Visits and Hospitalizations</b> Tai-Heng Chen, MD, PhD, Kaohsiung Medical University Hospital
2:45 pm to 4 pm		<b>What We Have Learned in the Past Year</b> John Brandsema, MD, Children's Hospital of Philadelphia Melissa Gibbons, MS, CGC, University of Colorado SOM/ Children's Hospital Colorado Bakri Elsheikh, MD, Ohio State University Aravindhan Veerapandiyan, MD, Arkansas Children's Hospital
4 pm		<b>Closing</b>