



Cure SMA Research and Clinical Care Meeting

Clinical Care Session Agenda

June 15, 2022

	<i>Abstract Number</i>	
8:30 am to 8:45 am		<b>Welcome and CMO update</b> Mary Schroth, MD, Chief Medical Officer, Cure SMA
8:45 am to 9:00 am		<b>Update on Cure SMA Real World Evidence Data Collection</b> Lisa Belter, MPH, Director of Research Data Analytics, Cure SMA
9:00 am to 9:20 am	1	<b>Proposal to Implement Cognitive and Language Screening Evaluations into Routine Clinic Visits and Care Guidelines in Children with Treated SMA Type 1</b> Natalie Katz, MD, PhD
9:20 am to 9:40 am	2	<b>Use of the Alberta Infant Motor Scale to Assess Motor Development in Infants Diagnosed by Newborn Screening and Treated with a Disease Modifying Drug</b> Lindsay Baker, PT
9:40 am to 10:00 am		<b>Break</b>
10:00 am to 10:20 am		<b>Hip Instability Effects Motor Function (HFMSE total score) Across SMA Phenotypes</b> Amy Pasternak, PT, DPT, PCS
10:20 am to 10:40 am	3	<b>Evaluating Responses to Treatment in Adults with Spinal Muscular Atrophy: 2 and 3 year Projections</b> Tina Duong, PT, PHD
10:40 am to 11:40 am	4	<b>Special Session: Ethics</b> Moderator: Julie Parsons, MD Panelists: Tom Crawford, MD., Bakri Elsheikh, MD., John Brandsema, MD. Ethicist: Brian Jackson, MD, MA
11:40 am to 1:00pm		<b>Lunch Break</b>
1:00 pm to 2:00 pm	5	<b>Newborn Screening Panel</b> <b>Newborn screening as an intervention for spinal muscular atrophy: the long-term outcomes of the Australian pilot program-</b> Didu Kariyawasama BA, MA, MBBS, MRCPCH, FRACP
	6	<b>Newborn screening for SMA in Italy: from the bi-regional pilot experience to the nationwide extension -</b> Francesco Danilo Tiziano, MD
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		<b>Newborn screening for Spinal Muscular Atrophy in New York State: Findings from the First Three Years - Bo Hoon Lee, MD</b>
2:00 pm to 2:20 pm		<b>Break</b>
2:20 pm to 3:20 pm	8	<b>Special Session: Nutrition</b> Rebecca Hurst-Davis, MS, RD, CSP, CD, CNSC Stacey Tarrant, BS, RD, LDN Laura Watne, MS, RD, CSP
3:20pm to 3:40 pm	9	<b>Unrestricted Oral Feedings Reported by Caregivers and Affected Persons Across Severity of SMA</b> Maureen A Lefton-Greif, PhD,CCC-SLP, BCS-S
3:40pm to 4:00 pm		<b><i>Weight for Age in a Long-term Natural History of Spinal Muscular Atrophy Types 2 and 3</i></b> Thomas Crawford, MD