

Poster number	Title	Submitting author	Organisation
1	Neck strength in SMA:  A reliable outcome and a	Channa Hewamadduma	University of Sheffield
	predictor of functional status,		
	health-related quality of life and		
	respiratory dysfunction.		
2	PROMIS nuero-quality of life	Channa Hewamadduma	University of Sheffield
	fatigue Scale: For assessing		,
	fatigue in adults with SMA.		
3	Bone health in adults with SMA:	Jing Ming Yeo	Sheffield Teaching Hospitals
	A UK multi-centre study		
4	Lumbar port system for	Jing Ming Yeo	Sheffield Teaching Hospitals
	nusinersen injection: Experience		
	from 2 UK centres		
5	Investigating	Chiara Brusa	Great Ormand Street Institute of
	neurodevelopmental trajectories		Child Health
	in children with SMA type 1:		
	Current knowledge and future		
	directions		
6	Improving SMA Treatment Access		Roche
	for Individuals with SMA Who are		
	on Permanent Ventilation	Panel	
7	Heart involvement in SMA type 1:	Nikki Cornell	Great Ormand Street Institute of
	Should heart monitoring be		Child Health
	implemented in the standards of		
	care?		
8	SMA REACH UK: The delivery of a	Emer O'Reilly	Great Ormand Street Institute of
	physiotherapy network		Child Health
9	Adult SMA REACH: A real-world	Aleks Carver	Newcastle University
	data collection study and		
	infrastructure to support research		
	improvement initiatives in SMA.		
10	The UK SMA Patient Registry:		
	Integrating PROMs and real-world		

			Spinal
			Spinal Muscular Atrophysic
	data to characterise disease impact in spinal muscular atrophy		SUPPORTING • INFORMING • ADVOCAT
11	UK Real World longitudinal data collection and analysis in adult SMA: The adult SMA REACH data collection study	Elena Karkkainen	John Walton Muscular Dystrophy Research Centre.
12	A service review of the information gathered on SMA 1 patients' communication skills.	Katie Cassidy	Great Ormand Street Institute of Child Health
13	A hydrotherapy service in a tertiary centre and its benefits for SMA patients	Nikki Foster	Alder-Hey Childrens hospital
14	How does loss of muscle on SMA affect whole body metabolism?	Melissa Bowerman	Keel University
15	Describing the characteristics of gait in adults with type 3 SMA.	Sherryl Chatfield	St Georges University Hospital
16	Consensus statement on the orthopaedic management of hip displacement in SMA in the UK.	Maria Vanegas	Evelina London Childrens Hospital
17	A nationwide study on parents' perspective on their child's treatment for SMA.	Ulrika Kreicbergs	Great Ormand Street Institute of Child Health
18	multidisciplinary therapy led	Natasha Taylor Lucy Lidgett	Bristol Royal Hospital for Children
19	SMA CARE UK: A national initiative to ensure that those living with SMA receive the best possible care.	Vanessa Christie-Brown	John Walton Muscular Dystrophy Research Centre, Newcastle University
20	SMA CARE UK: Ensuring the best respiratory care for individuals with SMA across the UK.		SMA UK
21	SMA CARE UK: Spinal management guidelines for people living with SMA in the UK.		

			Spinal Muscular Atrophysik
22	Essential Information for Emergency Services when assessing and caring for a child with SMA.	Portia Thorman	SMA UK SUPPORTING • INFORMING • ADVOCAT
23	Exploring the support sought by individuals online with SMA: A qualitative internet-mediated study.	Sian Moorcroft	Bournemouth University
24	An introduction to STABLE  SMA: A study to investigate spinal bracing use in SMA across the UK.	Min Ong	Sheffield Childrens Hospital
25	PRISM-SMA: Priorities in information sharing and management in SMA, a mixed methods study.	Will Quench	Sheffield Childrens Hospital
26	Exploring the impact of disease modifying therapies on quality of life and participation in adults with SMA.	Pamela Appleton	St Georges University Hospital
27	Description of SMA cohorts in the UK since the introduction of disease modifying therapies.	Robert-Muni Lofra	John Walton Muscular Dystrophy Research Centre, Newcastle University
28	Addressing procedural anxiety in patients with SMA who are receiving intrathecal nusinersen.	Natalie Smith	Great Ormand Street Institute of Child Health
29	SMA REACH UK: Collecting real- world data in SMA across the UK	Claire Fitzpatrick	Great Ormand Street Institute of Child Health