

Expert Masterclass on Spinal Muscular Atrophy – Programme

Monday 19 - Tuesday 20 November 2018

Sheraton Roma Hotel & Conference Centre, Rome, Italy.

Meeting Objectives

- Provide high quality educational and interactive meeting for neurologists and other related specialities who may be diagnosing and/or managing the care of patients with spinal muscular atrophy (SMA)
- Present the natural history of SMA
- Provide a comprehensive overview of the updated standard of care guidelines for SMA in the era of new treatment opportunities.
- Consider the importance of physiotherapy in the management of SMA
- Provide an overview of therapies that are currently in late stage of clinical development and discuss the challenges in gaining access to new therapies – what are the lessons learned from Nusinersen (Spinraza).
- Understand the importance of nutrition in the management of SMA

Meeting Format

- The masterclass will include lectures with a significant amount of time allocated to discussion
- Every delegate will be asked to download the Meetoo polling app onto their phone or tablet. This is to encourage participation and interactivity.

Co-chairs

- **Professor Nathalie Goemans**, University Hospitals Leuven, Belgium
- **Professor Eugenio Mercuri**, Universita Cattolica del Sacro Cuore, Rome, Italy.





Please note this programme is subject to change

Day 1 Monday 19 th November		
11:30 – 12:00	Registration	
12:00 – 13:00	Lunch	
13:00 – 13:20	Welcome, programme overview and introduction to TREAT-NMD	Professor Nathalie Goemans , Paediatric Neurologist, University Hospitals Leuven, Belgium Professor Eugenio Mercuri , Paediatric Neurologist, Universita Cattolica del Sacro Cuore, Rome
13:20 – 13:50	Impact of SMA: Adult perspective	Laëtitia Ouillade , SMA Europe
13:50 – 14:50	Genetics and diagnosis of SMA	Professor Annemieke Aartsma-Rus , Geneticist, Leiden University Medical Centre and Newcastle University Professor Nathalie Goemans , Paediatric neurologist, University Hospitals Leuven, Belgium
14:50 – 15:20	Break	
15:20 – 15:50	Newborn screening - Pilot study	Dr Emanuela Abiusi , Clinical geneticist, Universita Cattolica del Sacro Cuore, Rome
15:50 – 16:50	Updated 2017 standard of care guidelines	Professor Eugenio Mercuri , Paediatric neurologist, Universita Cattolica del Sacro Cuore, Rome
16:50 – 17:20	Plenary discussion – Standards of care	All faculty
17:20 – 17:30	Summary	Professor Nathalie Goemans , Paediatric neurologist, University Hospitals Leuven, Belgium Professor Eugenio Mercuri , Paediatric Neurologist, Universita Cattolica del Sacro Cuore, Rome
19:00	Meeting dinner (at venue)	
Day 2 Tuesday 20 th November		
08:30 – 08:35	Welcome back	Professor Nathalie Goemans , Paediatric Neurologist, University Hospitals Leuven, Belgium Professor Eugenio Mercuri , Paediatric Neurologist, Universita Cattolica del Sacro Cuore, Rome
08:35 – 09:35	Overview of functional outcome measures	Robert Muni Lofra , Neuromuscular research physiotherapist, JWMDRC, Newcastle University, UK
09:35 - 10:35	Nutritional management in patients with SMA	Rebecca Hurst Davis , Clinical Nutrition Manager, Intermountain Healthcare, USA
10:35 – 11:00	Break	
11:00 – 12:00	Overview of therapeutics in development and approved	Professor Laurent Servais , Neurologist, Institut de Myologie, Paris, France
12:00 – 13:00	Lunch	
13:00 – 14:00	Anticipatory care	Professor Anita Simonds , Consultant in respiratory and sleep management, Royal Brompton Hospital NHS, UK
14:00 – 15:00	Patient involvement in therapy development from start to finish	Dr Alex Murphy , Neurologist, JWMDRC, Newcastle University, UK
15:00 – 15:30	Break	
15:30 – 16:30	Access to treatments for patients with SMA in Europe	Mencia de Iemus , President of SMA Europe
16:30 – 17:20	Access to treatments in Europe 20 minute breakout session 30 minute group feedback	Facilitated by faculty
17:20 – 17:30	Summary and meeting close	Professor Nathalie Goemans , Paediatric Neurologist, University Hospitals Leuven, Belgium Professor Eugenio Mercuri , Paediatric Neurologist, Universita Cattolica del Sacro Cuore, Rome

Transparency

Declaration of funding

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	Educational grant
	Educational grant
	Sponsorship
	Sponsorship

Acknowledgements

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