

1<sup>ST</sup> INTERNATIONAL CLINICAL CARE SYMPOSIUM ON SMA | MILAN, ITALY  
Medical Emergencies in SMA: pathophysiology, prevention, and response

## Programme

**Friday 29<sup>th</sup> August 2025** (main sessions also streamed live)

13.15 - 14.00 Opening remarks

Dr. Nicole Gusset, SMA Europe CEO and Dr. Yasemin Erbas, SMA Europe President

“Patient advocates: Testimony about acute events”

*Speakers:* Mr. Stefan Bos, SMA Europe; Ms. Laëtitia Ouillade, AFM Téléthon

Opening remarks by the Chairs of the Medical Panel:

Prof. Stefania Corti, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Italy; Prof. Valeria Sansone, Centro Clinico NeMO, Italy

14.00 - 15.30 “Respiratory insufficiency in SMA: physiology, prevention and management”

*Keynote speaker:* Dr. Esther Veldhoen, University Medical Center Utrecht, Netherlands

Prof. Claudio Bruno, Istituto Giannina Gaslini, Italy;

Ms. Lisa Edel, Great Ormond Street Hospital for Children, UK;

Ms. Femke Vercoelen, University Medical Center Utrecht, Netherlands.

15.30-16.00 *Coffee Break*

16.00 - 17.30 “Metabolic disturbances in SMA: physiology, prevention and management”

*Keynote speaker:* Prof. Stefania Corti, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Italy

Ms. Fay-Lynn Asselman, University Medical Center Utrecht, Netherlands

Prof. Simona Bertoli, DeFENS, University of Milan - IRCCS Istituto Auxologico Italiano, Italy

Dr. Lydia Forestier-Zhang, The University of Sheffield, UK

17.30 - 18:30 Poster session

18.30 - 20.00 Networking dinner

**Saturday 30<sup>th</sup> August 2025** (main sessions also streamed live)

08.30 - 09.00 “Bulbar system in SMA: physiology, prevention and management”

*Keynote speaker:* Ms. Emily Johnson, Great Ormond Street Hospital for Children, UK

09.00 - 11.00 “Country experiences: best practices and existing gaps in managing critical events”

*Speakers:*

Prof. Francesco Muntoni, Dubowitz Neuromuscular Centre (UK)

Dr. Mirella Gaboli, Hospital Universitario Virgen del Rocío (Spain)

Prof. Thomas Sejersen, Karolinska Institutet (Sweden)

Prof. Susana Quijano-Roy, Hôpital Raymond Poincaré (France)

Prof. Anna Kostera-Pruszczyk, Medical University of Warsaw (Poland)

Prof. Claudio Bruno, Istituto Giannina Gaslini (Italy)

11.00 - 11.15 Closing Remarks

11.15 - 11.45 *Coffee Break*

11.45 - 13.15 Practical Workshops (*in-person only*)

“Emergencies encountered in Physiotherapy”

*Speakers:* Dr. Charlotte Lilien, University of Oxford, UK; Ms. Lisa Edel, Great Ormond Street Hospital for Children, UK

“Home-Based Emergency Scenarios in Children with SMA Type 1 Before and After Pharmacologic Treatment: The Role of Early Parental Empowerment”

*Speaker:* Ms. Chiara Mastella, SAPRE- UONPIA Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico Milano, Italy

*In parallel:*

11.45- 16.00 Final Workshop (*by invitation only*)

“Open discussion to draw conclusions on the addressed topics”