

**Attending** **Cancelled** **Available via Skype**

## **Friday 6 March 2020**

- 12.30-14.00 Lunch
- 14:00-14:15 Welcome speech Introduction into ENMC, **Dr Alexandra Breukel**, ENMC Managing Director
- 14:15-14:30 Introduction by **Michel Toussaint** and **Michelle Chatwin**
- Meeting Objectives
  - Terminology-protocols-decisional trees with regards to MPV
  - Preparation for the guideline
  - What is lacking?
- 14.30-14.45 Survey: Overview of MPV practices in NMD across countries, discussion session, **Miguel Gonçalves** **Michelle Chatwin**,
- Is there a standard approach to management?
  - What is recommended?
  - Feedback from survey on MPV to help reach consensus
- 14:45-15:15 Physiology and indications for when to start more than night time ventilation, **Jesus Gonzales**
- 15:15-15.45 The difference between night time vs daytime NIV (or the specificity of daytime ventilation-MPV), **Laura Verweij-van den Oudenrijn**, **Michel Toussaint** **Peter Wijkstra**,
- 15.45-16.30 Discussion: NIV versus tracheostomy ventilation in the management of daytime ventilatory support. Moderators: **Michel Toussaint and Miguel Gonçalves**, **Jes Rahbek**
- 16:30-16:45 Break
- Technicalities of MPV**
- 16:45-17:30 MPV modes and setting; (debate and discussion with video examples) **Michel Toussaint and Miguel Gonçalves**
- 17:30-18.00 The ventilators, The tubing support and mouthpiece commercial/custom made: Vote and consensus for custom made or commercially made, **Doug McKim**, **Michel Toussaint**, **Annalisa Carlucci**
- 18:00-19:00 Break – informal personal meetings
- 19.00 Dinner

## **Saturday 7 March 2020**

- 09.00-09.05 Welcome back and introduction to the days program, **Michel Toussaint** and **Michelle Chatwin**
- 09.05-09.15 MPV what patients and families what healthcare professionals to know! (timing, ventilators, and accessories), **Johan Chaulet**, **Wendy Hughes**
- 09.15-09.45 Ventilators, modes and dedicated modes of MPV. Evidence from bench studies, **Hélène Prigent** **Adam Ognà**,
- 09.45-10.15 Discussion: Decisional tree on the techniques available to extend ventilatory support: start algorithm (1)  
Moderators: **Michel Toussaint, Miguel Gonçalves**

	<b>Conditions for success of MPV</b> Mod: Michel Toussaint, Michelle Chatwin, Valeria Sansone
10.15-10.30	Managing alarms, Annalisa Carlucci Michel Toussaint
10.30-10.45	Timing of implementation of MPV, Josh Benditt
10.45-11.05	Monitoring for initiation/long-term (download data from device), Miguel Gonçalves and Jesus Gonzales
11.05-11.25	Break
11.25-12.00	Discussion: Decisional tree on the practice guidelines for MPV: algorithm (2) Moderators: Michel Toussaint, Christian Devaux
12.00-12.15	Alternate MPV with Nasal mask (stable/unstable conditions), Peter Wijkstra, Jesus Sancho
12.15-12.30	Safety-risk management (Ambu-bag, tape, electric connector, external batteries, procedures), Jesus Gonzales, Wendy Hughes
12.30-12.45	Education, training, families, Johan Chaulet, Laura Verweij-van den Oudenrijn
12.45-13.00	<b>TALK CANCELLED: Airway clearance techniques</b> , Barbara Garabelli
13.00-13.15	Wheelchair and Ventilator external batteries, Tiago Pinto, Nicolas Audag
13.15-14.15	Lunch
14.15-14.45	Discussion continued: Decisional tree on the practice guidelines for MPV: algorithm (3) Moderators: Michel Toussaint, H�el�ene Prigent
	<b>The experience (and effects) of MPV NMD's, acute care and exercise</b> Moderators: Michel Toussaint, Kathi Kinnett
14.45-15.00	The effects of MPV on swallowing, speech and other factors, Josh Benditt, Johan Chaulet
15.00-15.15	MPV in Duchenne Muscular Dystrophy, H�el�ene Prigent, Johan Chaulet
15.15-15.45	MPV in ALS PRO/CON, Doug McKim, Jesus Sancho
15.45-16.15	Break
16.15-16.30	MPV in SMA (open discussion), Brit Hov
16.30-16.45	MPV in other NMD's , Michelle Chatwin, Wendy Hughes
16.45-17.00	MPV in Acute Care, Annalisa Carlucci, Miguel Gonc�alves
17.00-17.15	MPV supporting exercise (walking) in NMD, Miguel Gonc�alves
17.15-17.30	MPV and patient reported experience measurements, Joan Escarrabill
17.30-18.00	Discussion continued: Decisional tree on the practice guidelines for MPV: Patient Groups (4), Michel Toussaint and Josh Benditt Consensus
18.00-19.00	Break – informal personal meeting
19.00	Dinner

## Sunday 8 March 2020

09:00-10:00	Review of current documents: defined objectives. Consensus opinion vs. survey results, Michel Toussaint ; Jesus Gonzalez, Miguel Goncalves, Michelle Chatwin
10:00-11:30	Edition of a protocol, Cost of MPV vs. benefits (survey results),+ What studies do we need in the future, which outcome measures? Moderators: Michel Toussaint and Jesus Gonzales
11:30-12:00	Summary and Post-workshop follow-up, Michelle Chatwin and Michel Toussaint
12.00 – 13.00	Lunch and departure