



European
Reference
Network

for rare or low prevalence
complex diseases

 Network
Neuromuscular
Diseases (ERN EURO-NMD)

Workshop for the multidisciplinary management and care specialty group

4th and 5th of May 2023

Program

Day 1, 4th of May

08.45 – 09.00 Digital connection too Zoom

09.00 – 09.15 **Welcome and presentation**

09.15 – 09.30 **European Reference Network from a Norwegian perspective**
By Stein Are Aksnes

09.30 – 09.45 **Multidisciplinary management and care form a patient perspective**
By Patricia Melsom

09.45 – 10.00 **Models for multidisciplinary management and care in neuromuscular disorders**
By Dr. Kristin Ørstavik

10.15 – 10.45 **The multidisciplinary approach status in European Countries**
By Eva Vrščaj

10.45 – 12.00 **Discussion on definition, needs and priorities of multidisciplinary management and care for persons with neuromuscular disorders**

12.00 – 13.00 Lunch

13.00 – 13.45 **Palliative care in adults with neuromuscular disorders**
By Prof. Marianne de Visser

14.00 – 14.30 **Pediatric palliative care and neuromuscular disorders**
By Dr. Ellen Annexstad

14.30 - 14.45 **The carer support needs assessment intervention paediatric – a tool for care planning**
By Marianne Nordstrøm

15.00 - 16.00 **Discussion on needs in palliative care for neuromuscular disorders**

19.30 Dinner



FRAMBU
KOMPETANSESENTER FOR SJELDNE DIAGNOSER



Enhet for medfødte og arvelige
nevromuskulære tilstander

Day 2, 5th of May

08.45 – 09.00 Digital connection too Zoom

09.00 – 09.05 **Welcome**

09.05 – 09.50 **Rehabilitation interventions for neuromuscular disorders**
By Dr. Nicole B.M. Voet

10.00 – 10.45 **The use of different biomarkers as clinical and research outcome measures (MRI, US, gait mats and other technological measures)**
By Gro Solbakken, Cecilie Hæstad, Hanne Ludt Fossmo, and Andreas Rosenberger

11.00 – 11.45 **Discussion on how to gather insight and harmonize the use of standardized measures within ERN Euro-NMD**

11.45 – 12.30 Lunch

12.30 – 13.15 **Pain and fatigue in neuromuscular disorders**
By Dr. Nicole B.M Voet

13.15 – 13.45 **Discussion on experiences with the use of measures on pain and fatigue**

13.45 – 14.00 **Where do we go from here? Action plan!**