

Program

Day 1 – Tuesday, September 8

Conference language: English

9.30 – 9.50 **Arrival and light breakfast**

9.50 – 10.00 **Welcome and introduction to the meeting**

Charlotte Handberg, Professor, Head of Research, RCFM, Denmark

Moderator for day 1: John Vissing, Professor, MD, Rigshospitalet

10.00 – 11.00 **Physiology and management of respiratory failure in spinal muscular atrophy**

Esther Veldhoen, Pediatric intensivist, PhD, MD, University Medical Center Utrecht, the Netherlands.

11.00 – 11.15 **Break**

11.15 – 12.00 **Psychological care in NMD**

Sabrina Sayah, Clinical Psychologist, Pitié-Salpêtrière Hospital, Paris, France

12.00 – 13.00 **Exercise in NMD**

John Vissing, Professor, MD, Rigshospitalet, Copenhagen, Denmark

Exercise from a patient perspective

Kasper Stokholm Leerskov, Post Doc, Aalborg University, Denmark

Sofie Skoubo, PhD candidate, RCFM, Denmark

13.00 – 14.00 **Lunch**

14.00 – 15.00 **Health Literacy: Enabling Equity-Driven Communication and Interaction in Healthcare**

Anna Aaby, PhD, MD, Ass. Professor, REACH, Department of Public Health, Aarhus University, Denmark

15.00 – 15.30 **Introduction to workshops including photo session, break, and refreshments**

15.30 – 17.00 **PARALLEL SESSIONS:**

15.30– 16.10 **Workshop 1: Weight loss in NMD, including the use of pharmacological treatments (15 minutes presentation and 25 minutes discussion)**

Marianne Nordstrøm, Clinical Nutritionist, PhD, Norwegian Centre for Rare Diseases, Unit Frambu

Workshop 2: Multidisciplinary rehabilitation and follow-up in a life-course perspective (15 minutes presentation and 25 minutes discussion)

16.10 – 16.20 Andreas Dybesland Rosenberger, PT, Head of Norwegian Centre for Rare Diseases-unit for neuromuscular disorders, University Hospital of North-Norway, Tromsø

16.20 – 17.00 **Break and change of workshop**

Parallel workshops 1 and 2 are repeated

17.00 – 17.30 **RCFM 50 Years - anniversary lecture**

Ulla Werlauff and Birgit Steffensen, both PhD, PT, Researcher Emerita, RCFM, Denmark

18.30 – 19.15 **Entertainment and drinks (Hall B)**

19.15 **Dinner at Restaurant Evald Krog**

Day 2 – Wednesday, September 9

Conference language: English

7.30 – 8.30 **Breakfast**

Moderator for day 2: Lone Knudsen, Researcher, PhD, RCFM, Denmark

8.30 – 9.30 **Project presentations**

Denmark:

FORMY: Preventive home visits – a rehabilitation intervention for adults with DM1

Kristin Allergodt, postdoc, RCFM

Investigating needs and challenges for palliative rehabilitation interventions of adults with Duchenne muscular dystrophy in the last years of life

Sanne Okkels Birk Lorenzen, MD, PhD student, RCFM

Norway:

Implementing muscle ultrasound in clinical practice: Challenges and opportunities

Cecilie Aronsen Hæstad, PT, University Hospital of North Norway, National Neuromuscular Center, Tromsø

Mapping and understanding health literacy in adults with rare diagnoses

Una Stenberg, PhD, Social Worker, Norwegian centre for rare disorders, unit Frambu, Oslo University Hospital

9.30-9.40 **Break**

9.40-10.40 *Project presentations continued*

FKRP natural history in Norway - physical tests over a 2-year span

Tine Stokmo, Assistant Professor, Department of Clinical Medicine, University of Tromsø

CMT- postural steadiness through a light finger touch

Fredrik Hellem Stenseth, PT, MSc in neurological conditions, Oslo University Hospital,

Sweden:

COMPIS - COngenital Myopathy Intervention Study

Eva Michael, MD, Child neurologist, Queen Silvia Children's Hospital

Iceland:

Myasthenia Gravis in Iceland: A National Perspective

Ólöf Jóna Elíasdóttir, Assistant Professor of Neurology, Landspítali - University Hospital, and Marianne Elisabeth Klinke, Professor, School of Health Sciences / Faculty of Nursing and Midwifery

10.40 – 11.00 **Refreshments**

11.00-12.15 **Impact of living with personal care on biopsychosocial health and quality of life when having a neuromuscular disease or a spinal cord injury - Patient reported outcomes from a national survey**

Signe Versterre, PhD student, PT, RCFM, Denmark

Patient perspectives on living with a personal assistant

Isak Kornerup Houe, Patient and Documentation and analysis manager, The Danish Muscular Dystrophy Foundation

Children living with a personal assistant - findings from a master thesis

Anne Heindorff, MSc education

Panel discussion

12.15 – 12.20 **Closing and announcements**

12.20 **Goodbye and Lunch to go**