

# Brickless 2026

## Program

### Day 1 – Tuesday, September 8

Conference language: English

<b>9.30 – 9.50</b>	<b>Arrival and light breakfast</b>
<b>9.50 – 10.00</b>	<b>Welcome and introduction to the meeting</b> Charlotte Handberg, Professor, Head of Research, RCFM, Denmark
<b>Moderator for day 1: John Vissing, Professor, MD, Rigshospitalet</b>	
<b>10.00 – 11.00</b>	<b>Respiratory insufficiency in SMA</b> Esther Veldhoen, Pediatric intensivist, Ph.D., MD, University Medical Center Utrecht, the Netherlands.
<b>11.00 – 11.15</b>	<b>Break</b>
<b>11.15 – 12.00</b>	<b>Psychological care in NMD</b> Sabrina Sayah, Clinical Psychologist, Pitié-Salpêtrière Hospital, Paris, France
<b>12.00 – 13.00</b>	<b>Exercise in NMD</b> John Vissing, Professor, MD, Rigshospitalet, Copenhagen, Denmark <b>Exercise from a patient perspective</b> Kasper Stokholm Leerskov, Ph.D. student, Aalborg, Denmark Tina Struck, Denmark (video)
<b>13.00 – 14.00</b>	<b>Lunch</b>
<b>14.00 – 15.00</b>	<b>Health literacy and equity in health – optimizing communication and interaction within the healthcare system</b> Anna Aaby, Ph.D., MD, Department of Public Health, Aarhus University, Denmark
<b>15.00 – 15.30</b>	<b>Introduction to workshops including photo session, break, and refreshments</b>
<b>15.30 – 17.00</b>	<b>Workshops 1: Weight loss medication and NMD</b> Marianne Nordstrøm, Clinical Nutritionist, Ph.D., National Center for Rare Diagnosis, Frambu, Norway <b>Workshop 2: Multidisciplinary rehabilitation and follow-up in a life-course perspective</b> Andreas Dybesland Rosenberger, PT, Head of the National Neuromuscular Centre, University Hospital of North-Norway, Tromsø
<b>17.00 – 17.30</b>	<b>RCFM 50 Years - anniversary lecture</b> Ulla Werlauff and Birgit Steffensen, both Ph.D., PT, Researcher Emerita, RCFM, Denmark
<b>18.15</b>	<b>Entertainment and drinks (Hall B)</b>
<b>19.15</b>	<b>Dinner at Restaurant Evald Krog</b>

## Day 2 – Wednesday, September 9

Conference language: English

**7.30 – 8.30**

**Breakfast**

**Moderator for day 2: Lone Knudsen, Researcher, Ph.D., RCFM, Denmark**

**8.30 – 9.30**

**Project presentations**

**Denmark:**

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

Kristin Allergodt, postdoc, RCFM

**Identifying needs and preferences for treatment and rehabilitation interventions in the end-of-life phase among adults with DMD**

Sanne Okkels Birk Lorenzen, Ph.d. 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, Ph.D., Social Worker, Oslo University Hospital

**9.30-9.40**

**Break**

**9.40-10.40**

**Project presentations continued**

**Norway:**

**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 Stenseth, PT, Head IT Architect, Odfjell Technology

**Sweden:**

**Children with congenital myopathy who received treatment with salbutamol**

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

**Iceland:**

**Myasthenia Gravis in Iceland: A National Perspective**

Ólöf Jóna Elíasdóttir, 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**

## Day 2 - continued

Conference language: English

<b>11.00-12.15</b>	<b>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</b>  Signe Versterre, Ph.d. student, PT, RCFM, Denmark  <b>Patient perspectives on living with a personal assistant</b>  Isak Kornerup Houe, Patient and Documentation and analysis manager, The Danish Muscular Dystrophy Foundation  <b>Children living with a personal assistant - findings from a master thesis</b>  Anne Heindorff, MSc education  <b>Panel discussion</b>
<b>12.15 – 12.20</b>	<b>Closing and announcements</b>
<b>12.20</b>	<b>Goodbye and Lunch to go</b>