

Day 1

Conference language: English

9.30 – 9.50	Arrival, registration, and light breakfast
9.50 – 10.00	Welcome and introduction to the meeting Ulla Werlauff, head of research department, RCFM
Theme of day 1: Palliative care Moderator John Vissing, Professor, Rigshospitalet	
10.00 – 11.00	Palliative care in neuromuscular diseases Marianne de Visser, Professor, UMC Amsterdam
11.00 – 11.15	Coffee break
11.15 – 12.00	Leve NÅ and DMD UNG (live now and DMD young) Ellen J. Annexstad, Pediatric neurologist, PhD, Frambu Foundation, Leve NÅ - Paediatric Palliative Care Unit
12.00 – 12.30	Rehabilitation and collaboration in palliative care Anette Torvin Møller, neurologist, PhD, Aarhus University Hospital Sidsel Madsen, MD, consultant, RCFM
12.30 – 12.35	Short break
12.35 – 13.00	Group talk about palliative care in practice and preparation of questions for the afternoon panel discussion
13.00 – 14.00	Lunch
14.00 -15.00	Living with a potential life-threatening disease Patient and parent perspectives Johan Lauritsen, lecturer and founder of PROBE, has spinal muscular atrophy Vibeke and Niels Staghøj, parents of an adult with Duchenne muscular dystrophy Patient perspective from diagnosis to parenting and living with, to advance care planning Janet Hoskin, Associate Professor of Education, University of East London, and mother of a son with Duchenne
15.00 – 15.30	Photo Session
15.30 – 16.55	Changes in management of children with SMA who receive medical treatment Thomas Sejersen, Professor, Senior Physician, Karolinska Institutet, Stockholm

15.55 – 16.15	Burden of Disease of Duchenne Muscular Dystrophy in Denmark Peter Born, Pediatric neurologist, PhD
16.15 – 16.45	Panel discussion Moderator: John Vissing
18.00 – 19.00	Entertainment
19.00	Dinner

Day 2

Conference language: English or Scandinavian

7.30 – 8.30	Breakfast
8.30 – 10.00	Project and poster presentations In this session, we would like to hear about your own recent projects, studies, or posters. You will have 10 minutes for project and study presentations, and there will be a poster session in the middle of the session. Please sign up on the registration form.
10.00 – 10.15	Refreshments
10.15 – 11.45	Puberty and sexuality “It doesn’t get more normal than that!” – challenges and the need for knowledge and guidance about sexuality for people with NMD Charlotte Handberg, senior researcher, PhD, RCFM Patient perspective Antonielt Vebel Pharao, board member, RCFM and SUMH (The Danish association of Youth With Disabilities) Guidance and counselling in practice Sofie Krog, sexological coach and project manager at SUMH Medical management of issues related to puberty and sexuality Niels Illum, specialist consultant, clinical associate professor, Odense University Hospital, SDU
11.45 – 12.00	Closing and announcements – Ulla Werlauff, Charlotte Handberg, RCFM
12.00	Goodbye and Lunch to go