

## Day 1

Conference language: English

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

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

## Day 2

Conference language: English or Scandinavian

7.30 – 8.30	<b>Breakfast</b>
8.30 – 10.00	<b>Project and poster presentations</b> 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	<b>Refreshments</b>
10.15 – 11.45	<b>Puberty and sexuality</b> <b>“It doesn’t get more normal than that!” – challenges and the need for knowledge and guidance about sexuality for people with NMD</b> Charlotte Handberg, senior researcher, PhD, RCFM <b>Patient perspective</b> Antonielt Veibel Pharao, board member, RCFM and SUMH (The Danish association of Youth With Disabilities) <b>Guidance and counselling in practice</b> Sofie Krog, sexological coach and project manager at SUMH <b>Medical management of issues related to puberty and sexuality</b> 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	<b>Goodbye and Lunch to go</b>