



Theme: Multi-professionalism in rehabilitation of NMD

Day 1

Conference language: English

9.30 – 9.50	Arrival and registration
9.50 – 10.00	Welcome and introduction to the main theme Ulla Werlauff, Head of Research, RCFM
10.00 – 13.00	Multi-professionalism from different perspectives Moderator: Ulla Werlauff, PT, PhD
	10.00 – 11.30 Multi-professionalism in rehabilitation – collaboration in the clinic and across sectors and 'ownership' of the patient' Professor Derick Wade, Oxford University
11.30 – 12.05	Coffee break
	12.05 – 12.25 Multi-professionalism from a patient perspective Ditte Guldbrand Christensen 12.25 – 13.00 Cross-sectorial collaboration in multi-professional teams Charlotte Handberg, PhD, Senior Researcher, RCFM
13.00 – 14.00	Lunch
14.00 – 16.00	Multi-professionalism in oral motor function Moderator: Stefan Axelsson, PhD, specialist in orthodontics, TAKO-senteret, Oslo, Norway Contributors: Anna Ödman Roussakis, PhD, specialist in orthodontics Lisa Bengtsson, speech and language therapist <i>All from Mun-H-Center, Göteborg, Sverige</i> 14.00 – 14.20 Introduction 14.20 – 14.40 Experiences from a patient 14.40 - 15.00 Challenges to oral health 15.00 – 15.20 Oral function 15.20 – 15.40 Exercises to increase function 15.40 – 16.00 Questions and discussion



16.00 – 16.30	Coffee break
16.30 – 18.00	<p>Bowel and bladder function in NMD</p> <p>Moderator: Peter Born, Senior Hospital Physician, Department of Pediatrics and Adolescent Medicine, Rigshospitalet</p> <p>16.30 – 17.10 Bowel function in neuromuscular diseases – what do we know and what can be done? How can problems be solved through a multi-professional approach?</p> <p>Peter Christensen, professor, MD, Aarhus University Hospital</p> <p>17.10 – 17.40 Hap-pee - Going to the toilet when away from home:</p> <p><i>Presentation of the project</i></p> <p>Ulla Werlauff, RCFM</p> <p><i>Experiences from a patient</i></p> <p>Sarah Glerup</p> <p>17.40 – 18.00 Plenary discussion: How do we, by taking a multi-professional approach, address bowel and bladder problems in persons with NMD. Exchange of local experience.</p>
18.00 – 19.00	Break
19.00	Dinner



Day 2

Conference language: English or Scandinavian

7.30 – 8.30	Breakfast
8.30 – 10.15	New pharmaceutical treatments – coping with hope, uncertainty and frustration Moderator: Charlotte Handberg, PhD, Senior Researcher, RCFM 8.30 – 9.00 How do we cope with uncertainties Lone Knudsen, psychologist, PhD, RCFM 9.00 – 9.30 Patient presentations Simon Philbert, patient with NMD Anne Gautier Hansen og Jens Christian Hansen, parents 9.30 – 10.15 Group reflection and summing up
10.15 – 10.40	Coffee break
10.40 – 11.45	Project presentations Presentation of the participants' own finished or ongoing projects. Andreas Dybesland Rosenberger, Helge Hæstad: Sneak peak – Redskaper for analyse og håndtering av personer med arvelige, nevromuskulære tilstander. Et nettkurs for fysioterapeuter Hanne Ludt Fossmo: Symptoms, Outcome measures and treatment of arm and hand function in myotonic dystrophy type 1 Kristin Allergodt: Identificering og udvikling af en rehabiliteringsintervention for at sikre adherence til livslange hospitalskontroller af patienter med dystrofia myotonica type 1 (DM1) Ann-Lisbeth Højberg: TRANSIT - Uddannelse og beskæftigelse hos unge med muskelsvind efter afsluttet grundskole Sofie Skoubo: My avatar - Equal mobility in education for children and adolescents with neuromuscular diseases in Scandinavia through the use of telepresence robots
11.45 – 12.00	Future Brickless meetings Ulla Werlauff, RCFM <i>Suggestions for a new organization structure</i>
12.00	Goodbye and Lunch to go