

Norwegian Conference for Hereditary Neuromuscular Disorders

Fagkonferansen for arvelige nevromuskulære tilstander
Tromsø 3rd-5th of September 2025



PROGRAM

Scandic Ishavshotel Tromsø

THE NORWEGIAN NMD - COLLABORATION



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From the 2023- conference

Day 1

Program Wednesday September 3rd

Lunch at the Hotel restaurant 12:45-13:45



Location: Ishavet (Main conference hall)

13:45
-
14:00

Welcome!
Introduction

National neuromuscular centre Norway

14:00
-
14:30

Diagnosis as an adult
-A patient story

Tor Egil Roheim, FFM

14:30
-
15:30

Gene therapy in neuromuscular disorders:
What are we learning?

Laurent Servais, University of Oxford and University of Liège

Break with refreshments
(15:30 - 16.00)



Day 1 continues



Day 1

Program Wednesday September 3rd

Location: Ishavet (Main conference hall)

16:00
-
17:00

«A birds eye view at the neuromuscular patient»

Nicol Voermans, Radboud UMC

17:00
-
17:45

The model of care pathway from trial readiness to standards of care updates.
Insights from Newcastle

Meredith James, John Walton MDRC

Short break (17:45-18:00)

18:00
-
19:00

Conversation:
Exceeding all expectations: Life as one of the most profiled neuromuscular Norwegians

Torstein Lerhol, User rep. and media profile

19.30
...

«Get-together»



Location: SKIRRI

Day 1 finished



Day 2

Program before lunch Thursday September 4th

Alternative 1 →

LMS-kurs:

«Nye muligheter gir nye behov»

Location: Ishavet 2

09:15
-
09:45

LMS-kurs:

Oppstart og bli kjent

Nevromuskulært
kompetansesenter

09:45
-
10:15

LMS-kurs (foredrag):

Nye muligheter, nye
behov

Tollef Ladehaug og Charlotte Mørch
Foreningen for muskelsyke

Pause (10:15-10:45)

10:45
-
11:45

LMS-kurs (foredrag):

«Nå får det fanmeg
være nok!»

Einar Angelsen

Pause (11:45-12:00)

12:00
-
12:35

**LMS-kurs gruppe-
samtale**

Alternative 2 →

Parallels for health care professionals/researchers/others

Location: Ishavet 1

08:30
-
09:15

Lecture

*The role of the muscle
biopsy in diagnostics of
NMDs in 2025 and
forward (digital)*

Teresinha Evangelista, AP-HP – Pitié-
Salpêtrière Hospital and ERN Euro-NMD

09:15
-
10:00

Lecture

*Anesthesia and neuro-
muscular disorders:
what a neurologist
needs to know.*

Nicol Voermans, Radboud UMC

Alternative 3 →

Location: Radisson Blu, Tromsøsal 3

08:15
-
09:45

Workshop

*North Star Assessment
for Limb Girdle Type
Muscular Dystrophies
(NSAD)*

Meredith James, John Walton MDRC

09:45
-
10:10

Lecture

*A motor control and
movement quality
approach to neuro-
muscular physiotherapy:
Does numerical test data
fully capture changes in
function?
A clinical perspective*

Helge Haestad
National neuromuscular centre Norway

Break with refreshments
(10:00 - 10:30)



Location: Ishavet (Main conference hall)

10:30
11:15

Accelerating clinical development in rare disease.
How can we be more efficient?

Laurent Servais, University of Oxford and University of Liège

11:15
12:00

Clinical trials— experiences from Denmark

Nicolai Preisler, Rigshospitalet Copenhagen

12:00
12:45

Pathophysiology and management of
respiratory failure in NMD

Tiina Andersen, Western Norway University of Applied Sciences and
Haukeland UH

Lunch break 12:45—13:45



Day 2 continues



Day 2

Program after lunch Thursday September 4th

Location: Ishavet (Main conference hall)

13:45
-
15:15

Panel discussion: «Start and stop criteria in advanced therapies»

Chair: Kjell Arne Arntzen

Panel:

Torstein Lerhol
Morten Horn

Sean Wallace
Robert Muni Lofra

15:15
-
15:45

Nutrition and neuromuscular disorders (in the age of Wegovy)

Marianne Nordstrøm, Frambu and Oslo University Hospital

Break with refreshments ☕
(15:45 - 16:00)

16.00: Academic program finished



Approximately from
16:15 to
18:15

Social activities (separate registration)

RIB-tour

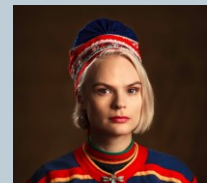
City Walk

Mack brewery tasting

Afternoon tea

19.15
-
...

Conference dinner



Scandic Ishavshotell

Day 2 finished



Location: Ishavet (Main conference hall)

09:00
-
10:00

Duchenne muscular dystrophy and other
NMDs- associated neurobehavioral
difficulties

Sam Geuens, University Hospital Leuven

Break with refreshments
(10:00 - 10.15)



10:15
-
11:30

Projects in the Nordic countries

Denmark, Sofie Skoubo: «*An investigation of the interaction between students with neuromuscular diseases and teachers when using telepresence robots in the Scandinavian educational setting*»

Norway, Kristin Ørstavik: «*Personalised training for people with rare neuromuscular disorders (PETRA-NMD)*»

Sweden: Jonas Gillenstrand: «*Developmental Trajectories in relation to Behavioural problems during Childhood and Adolescence for boys with DMD*»

Finland, Johanna Ranta-Aho: «*Molecular disease mechanisms of ACTN2-related myopathies*»

Iceland, Kristjan Dereksson: «*Stabilize or strengthen? Results from a 4-year follow-up study of respiratory function during sleep and from a 6 month respiratory training program in children with SMA type 2 and 3 on disease modifying treatment*»

Lunch break 11:30—12:30



12:30
-
13:15

ERN Euro-NMD: what is it, and why do we
need it? (*digital*)

Teresinha Evangelista, ERN-Euro NMD

13:15
-
13:45

National reference network (NRN) in
Norway. Answering the needs of tomorrow.

The national consortium on rare neuromuscular disorders in Norway

13:45
-
14:00

Goodbye and welcome back

National neuromuscular centre Norway



Speakers

Tor Egil Roheim

**-Neuromuscular Disorders
Association of Norway (NMD
Norway)**



Wednesday September 3rd: «Diagnosis as an adult- a patient story»

Tor Egil Roheim has been the leader of the Neuromuscular Disorders Association of Norway (NMD Norway) since June 2024. He has also been the leader of the local chapter of NMD Norway in Oslo and Akershus from 2015 to 2025. Tor Egil graduated as a civil engineer in structural and construction engineering from the Norwegian Institute of Technology at the University of Trondheim in 1995. He currently works as a consulting engineer.

Tor Egil has a special interest in universal design and accessibility for people with disabilities so that they can participate in society on an equal footing with everyone else.

He was diagnosed with FSHD at the age of 42 in 2010 after a period of frequent stumbling and difficulty walking up stairs. Initially he was determined never to end up in a wheelchair, but changed his mind in 2015 (mostly out of need). He was active in various sports during his childhood and youth, but naturally, this has decreased. The diagnosis made him realize that he wasn't lazy, but that there was actually a reason why he couldn't run long distances.

Laurent Servais

**-University of Oxford, UK, and
University of Liège, Belgium**



Wednesday September 3rd: «Gene therapy in neuromuscular disorders: what are we learning?»

Thursday September 4th: «Accelerating clinical development in rare disease. How can we be more efficient?»

Laurent Servais is Professor of Paediatric Neuromuscular Diseases at the University of Oxford in the UK, and invited Professor at the University of Liège in Belgium. He graduated in medicine and pediatrics from the University of Louvain (in Louvain-la-Neuve and Brussels in Belgium) then trained as a child neurologist in the Robert Debré Hospital in Paris, France, and as a myologist at the Institute of Myology, Pitié-Salpêtrière University Hospital, Paris.

Professor Servais' main research interests cover innovative outcome measures and clinical trials design and newborn screening (NBS). He has been involved as Principal Investigator in several clinical trials in spinal muscular atrophy (SMA), Angelman Syndrome X-linked myotubular myopathy, and Duchenne muscular dystrophy (DMD), and in leading the NBS program for SMA NBS in Belgium and in the UK.

He is the coordinating investigator of two large natural history studies in Angelman in the UK and in Belgium that aims to identify and validates innovative outcome measures and biomarkers.

Speakers

Nicol Voermans

-Radboud University Medical Center, Netherlands



Wednesday September 3rd: «A birds eye view on the neuromuscular patient»

Thursday September 4th: «Anesthesia and neuromuscular disorders: what a neurologist needs to know»

Nicol C. Voermans is a distinguished neurologist specializing in neuromuscular disorders at Radboud University Medical Center (Radboudumc) in Nijmegen, Netherlands. She completed her studies in Medicine and Philosophy at Radboud University, earning her PhD in 2011 with a thesis on the neuromuscular aspects of Ehlers-Danlos and Marfan syndromes.

Since joining Radboudumc as a medical specialist in 2008, she has focused on congenital myopathies and facioscapulohumeral muscular dystrophy (FSHD). Her research emphasizes genotype-phenotype correlations, trial readiness, and the development of optimal symptomatic treatments. She has collaborated with esteemed researchers, including Prof. Jungbluth in London and Prof. Treves in Basel.

In 2021, she launched the FSHD European Trial Network, uniting researchers and clinicians across Europe to advance FSHD research and clinical trials. Her contributions to the field are reflected in her extensive publication record, with over 11,000 citations, underscoring her impact on neuromuscular research. In recognition of her significant contributions, she was appointed Professor of Muscular Diseases at Radboudumc, effective October 1, 2023.

Prof. Voermans's dedication to bridging the gap between neuromuscular research and clinical practice continues to enhance the understanding and treatment of rare genetic muscle disorders

Meredith James

-John Walton Centre for Muscular Dystrophy Research, Newcastle UK



Wednesday September 3rd: “Model of care in Newcastle– from trial readiness to standards of care updates”

Thursday September 4th: «Workshop North Star Assessment for Limb Girdle Type Muscular Dystrophies (NSAD)»

Dr Meredith James PT PhD is a Clinical Specialist Neuromuscular Physiotherapist and Principal Investigator at the John Walton Centre for Muscular Dystrophy Research at Newcastle, where she is involved in clinical and research activity for children and adults with Neuromuscular disorders.

Clinically, Meredith is responsible for the physiotherapy management of both children and adults with neuromuscular diseases.

In her clinical research capacity, Meredith is responsible for the clinical evaluation of children and adults involved in natural history and clinical trials, as well as the development of clinically meaningful, reliable and sensitive outcome measures for Neuromuscular disorders.

Meredith has been involved in the development of the North Star Ambulatory assessment (NSAA), the Performance of upper limb (PUL) and led the development of the North Star Assessment for Limb Girdle Type Muscular Dystrophies (NSAD) now utilised in clinics and clinical trials in Limb Girdle Muscular Dystrophy, Becker Muscular dystrophy and Late Onset Pompe Disease

Speakers

Torstein Lerhol

-Regional manager, historian, politician, media profile and speaker, Norway



Wednesday September 3rd: “Exceeding all expectations: *Life as one of the most profiled neuromuscular Norwegians*”

Born with SMA in 1986, Torstein Lerhol has far exceeded all expectations. Holding a master’s degree in history, he now works as Regional Manager at Medvind Assistanse, a company providing user-controlled personal assistance (BPA). He is also a politician for the Sentrum party, a sought-after public speaker, and a well-known media profile, having appeared on several of Norway’s most popular TV shows. In addition, Torstein is part of the comedy collective *handicrapcrew*, reaching millions of viewers and followers on platforms such as Instagram and TikTok.

Teresinha Evangelista

**-AP-HP – Pitié-Salpêtrière
Hospital and ERN Euro-NMD,
Paris, France
(digital)**



Thursday September 4th: «*The role of the muscle biopsy in diagnostics of NMDs in 2025 and forward*»

Friday September 5h: «*ERN Euro-NMD: What is it, and why is it important?*»

Dr Teresinha Evangelista has over 20 years’ experience working as a Neurologist and later as a Consultant at the Neurosciences Department of the Hospital de Santa Maria in Lisbon. These roles have been completed in conjunction with research work as a member of the Neuromuscular Research Unit at the Institute of Molecular Medicine as well as has an Invited Lecturer at the Faculty of Medicine at Lisbon University in addition to a range of other teaching and advisory posts. She is now the ERN Euro-NMD coordinator, based at AP-HP – Pitié-Salpêtrière Hospital in Paris

After working in Paris, at the Unit 153 of INSERM and having finish a post-graduation in Neuropathology, she set up a fully equipped Neuromuscular Laboratory at the Hospital de Santa Maria in Lisbon. The establishment of this laboratory stimulated the activity within the field of Clinical Neuromuscular research at other facilities in Portugal. The laboratory became a Reference Laboratory for the South of Portugal. Dr Teresinha Evangelista played an important role in the development of a diagnostic network for Neuromuscular Diseases during the years working in Portugal and was appointed as President of the Portuguese Society for The Study of Neuromuscular Diseases in 2009 in recognition of status as a leading reference for Neuromuscular Diseases in Portugal.

Her work currently focuses on clinical and research work on hereditary muscle diseases, FSHD and Congenital Myasthenic Syndromes. Simultaneously as a member of the Joint Actions for rare diseases (EUCERD Joint Action and RD-Action), developed a particular interest on Rare Diseases policies. As a result of the policy work she became responsible for the concept and setting up of the neuromuscular ERN (EURO-NMD) that integrates 61 healthcare providers from across Europe.

Thus far, she has published over 70 peer-reviewed papers and 5 book chapters. She has given many invited lectures at meetings, symposiums and workshops as well as patient/parent organizations meetings.

Speakers

Helge Hæstad

**-National neuromuscular
centre, UNN, Norway**



Thursday September 4th: «A motor control and movement quality approach to neuromuscular physiotherapy: Does numerical test data fully capture changes in function? A clinical perspective»

Helge Aronsen Hæstad is a clinical specialist in neurological physiotherapy at The national neuromuscular Centre of Norway, He has more than 30 years of clinical experience in hands-on work with a mixture of neuromuscular and central nervous system conditions and postgraduate teaching.

He has been involved in several research projects related to physiotherapy interventions at NMK, as well as innovation projects on e-learning courses to physiotherapists and the use of state of the art outcome measures such as gait mats.

A major field of interest is the interaction between the peripheral neuromuscular system and the systems within the brain to activate and sustain functional movements.

Nicolai Preisler

**-Copenhagen Neuromuscular
Center, Rigshospitalet,
Denmark**



Thursday September 4th: «Clinical trials– experiences from Denmark»

Nicolai Preisler is a Consultant Neurologist and the Head of the Clinical Trial Section at the Copenhagen Neuromuscular Center, Rigshospitalet. He holds an MD and a PhD from the University of Copenhagen and has dedicated his career to advancing clinical research in neuromuscular disorders.

With extensive experience in conducting and overseeing clinical trials, Dr. Preisler has served as Principal Investigator in more than 10 sponsor-driven studies and as a Sub-Investigator in over 25 trials, covering phases I, II, and III. He has significant expertise in gene therapy trials and is ICH-GCP certified, ensuring the highest standards in clinical research.

His work with clinical trials spans various neuromuscular conditions, including mitochondrial disorders, myasthenia gravis, limb-girdle muscular dystrophy, and fatty acid oxidation defects. He has also been involved in studies focusing on Charcot-Marie-Tooth disease, Pompe disease, centronuclear myopathies, dysferlinopathy, facioscapulohumeral muscular dystrophy, spinal muscular atrophy, and dystrophinopathy.

Dr. Preisler has a strong publication record in international peer-reviewed journals. His primary research interests focus on neuromuscular diseases, particularly metabolic myopathies and the role of exercise as a treatment for neuromuscular disorders.

In addition to his clinical and research roles, Dr. Preisler contributes to national healthcare policy as a committee member of the Danish Medicines Council, serving in the specialist group for congenital metabolic disorders, where he has been Deputy Director since 2023.

At the conference, Dr. Preisler will present insights into the ongoing and upcoming clinical trials at the Copenhagen Neuromuscular Center, highlighting their impact on advancing therapies for neuromuscular disorders.

Speakers

Marianne Nordstrøm

**-Frambu Resource Centre for
Rare Disorders and Oslo
University Hospital, Norway**



Thursday September 4th «Nutrition and NMDs (in the age of Wegovy)»

Marianne Nordstrøm is a clinical dietitian and researcher at the Frambu Resource Centre for Rare Disorders and at the Unit for Rare Neuromuscular Disorders, Oslo University Hospital. She also holds a part-time position in the Department of Neurohabilitation at Oslo University Hospital.

Her research focuses on nutrition in Spinal Muscular Atrophy and Primary Periodic Paralysis. She currently serves as Chair of the Multidisciplinary Management and Care Working Group and sits on the Executive Committee within the European Reference Network for Neuromuscular Diseases (ERN-NMD).

Tiina Andersen

**-Western Norway University of
Applied Sciences and
Haukeland University Hospital,
Norway**



Thursday September 4th: “Patophysiology and management of respiratory failure in NMD”

Tiina Andersen is a Physiotherapist and Specialist in Cardiopulmonary Physiotherapy with a PhD. She is currently serving as an Associate Professor at the Physiotherapy Education, Faculty of Health and Social Sciences, Western Norway University of Applied Sciences, and has a clinical position at the Advanced Home Hospital at the Thoracic Department of Haukeland University Hospital in Bergen, Norway.

She worked at the Norwegian Advisory Unit for Home Mechanical Ventilation (Bergen, Norway) from its establishment in 2002 until its closure in 2023. This unit played a pivotal role in developing and disseminating expertise on the assessment and treatment of patients requiring long-term mechanical ventilation across Norway.

Tiina was specifically responsible for advancing knowledge and practices related to airway clearance techniques for this patient group. Her research has particularly focused on the role of the upper airways during these techniques, with the goal of enhancing respiratory care for patients. In addition to her research, she has been deeply involved in education, teaching patients, caregivers, students, and healthcare professionals. Today, Tiina is recognized as one of the world’s leading physiotherapists in the field of chronic respiratory failure.

Sam Geuens

**-University Hospital Leuven,
Belgium**



**Friday September 5th: «Duchenne muscular dystrophy (and other NMDs)-
associated neurobehavioral difficulties»**

Sam Geuens, PhD, is a pediatric neuropsychologist specialized in the neurobehavioral and psychosocial development of children and young adults with neuromuscular or neurological disorders. He works at the University Hospitals in Leuven, Belgium, where he provides psychological counseling to children with neurological disorders and their family.

He combines his clinical work with research to gain a better understanding of neurobehavioral aspects of neuromuscular diseases and has published in international peer-reviewed journals about these topics.

Speakers

Sofie Skoubo

**-National Rehabilitation Center,
Denmark**



Friday September 5th: "An investigation of the interaction between students with neuromuscular diseases and teachers when using telepresence robots in the Scandinavian educational setting"

Sofie Skoubo is Ph.d student at the National Rehabilitation Center for Neuromuscular Diseases in Denmark. The PhD project, "My Avatar," explores using telepresence robots in the educational setting to reduce school absence for children and adolescents with neuromuscular diseases.

The project cooperates with the Norwegian company No Isolation, which has developed a telepresence robot. Since 2020, Sofie has worked with telepresence robots for children and adolescents with different illnesses in Denmark.

Sofie was diagnosed with neuromuscular disease when I was six years old and have experienced the tough years of being in compulsory education and accepting a physical diagnosis

Kristin Ørstavik

**-Section for rare neuromuscular
disorders, Oslo University
Hospital, Norway**



Friday September 5th: Personalised training for people with rare neuromuscular disorders (PETRA-NMD)»

Kristin Ørstavik is a MD and PhD, currently working as a Senior consultant in Neurology and Clinical Neurophysiology. She is the Head of Section for Rare Neuromuscular disorders and EMAN; Department of Neurology, Oslo University Hospital.

Her research interest covers multiple disorders and thematic fields, including Myotonic dystrophy type 1, pain, effect of exercise in Neuromuscular disorders and Cardiomyopathy in patients with neuromuscular disorders.

She took the initiative to an informal National Reference network for Rare Neuromuscular disorders in Norway over 10 years ago. This network is a model for future NRNs in Norway. From 2022 she has been the board representative from the Consortium for Rare neuromuscular disorders in Norway to ERN Euro-NMD.

Johanna Ranta-aho

**-Folkhälsan Research Center
and University of Helsinki,
Finland**



Friday September 5th: Molecular disease mechanisms of ACTN2-related myopathies»

Johanna Ranta-aho is a PhD student in the Myofin group lead by Dr. Marco Savarese. The group is part of Folkhälsan Research Center and the University of Helsinki, and is based in Helsinki, Finland.

The group's research is focused on hereditary neuromuscular disease, with an emphasis on titinopathies, other distal myopathies, and progressive muscular dystrophies.

As part of her PhD project, she aims at characterizing the genotype-phenotype correlations and molecular disease mechanisms of a specific gene known to cause myopathy, ACTN2.

Speakers

Kristjan Dereksson

**-Landspítali University Hospital,
Reykjavik, Iceland**



Friday September 5th: «Stabilize or strengthen? Results from a 4-year follow-up study of respiratory function during sleep and from a 6 month respiratory training program in children with SMA type 2 and 3 on disease modifying treatment»

Kristjan Dereksson is a pediatrician since 2014, specialized in pediatric lung medicine. He lives in Reykjavik Iceland with his wife and 3 children and works at Landspítali university hospital, in Reykjavik, with treatment related to sleep and breathing in both children and adults.

He also works at the pediatric unit of Skåne university hospital, in Lund, Sweden where he is responsible for pediatric sleep studies and works extensively with children with breathing difficulties related to neurologic- and neuromuscular-diseases.

His research into SMA is part of doctorate studies at Lunds University, Sweden.

Jonas Gillenstrand

**-University of Gothenburg,
Sweden**



Friday September 5th: «Developmental Trajectories in relation to Behavioural problems during Childhood and Adolescence for boys with DMD»

Jonas Gillenstrand is a Phd student and specialist neuropsychologist with expertise in neurodevelopmental disorders and executive functions.

His research is mainly about how DMD effects Intelligence, Executive functions and behaviours during childhood and adolescence. Jonas works in Habilitation and Health as Specialist Psychologist in Västragötalands regionen and are affiliated at the Psychological Institute in Gothenburg University.

He is planning to do his dissertation in late 2025

Ledere av LMS-kurs

Maria Lee Finsrud

-Studiesykepleier NMK

Ann Tove Buene

-Ergoterapeut, NMK



Maria Lee Finsrud



Ann Tove Buene

Tollef Ladehaug

-Foreningen for muskelsyke

**LMS-kurs torsdag 04.september: "Nye muligheter, nye behov"**

Tollef Ladehaug er statsviter og ansatt i foreningen for muskelsyke der han blant annet er ansvarlig for søknader om prosjektmidler og som prosjektleder for de mange av foreningens prosjekter.

Han har i den kapasitet ledet ey titalls prosjekter for FFM. 13 av dem har munnet ut i publikasjoner han har skrevet, inkludert "Du ser da frisk ut - Fatigue for muskelsyke og alle andre", "Selvforsvar uten muskelstyrke", "Fysiske funksjonshemninger og utmattelse – En kartlegging av elever med muskelsykdommer i grunnskolen" og "Min Kropp, mine grenser" om assistanse og grensesetting.

Charlotte Mørch

-Foreningen for muskelsyke



Er utdannet pedagog og arbeider som organisasjon- og prosjektkonsulent i Foreningen for muskelsyke. Har bidratt på flere sider i foreningens arbeid, blant annet gjennomføring av prosjekter og bearbeidelse av foreningens informasjon om diagnoser.

Einar Johan Angelsen



LMS-kurs torsdag 04.september: "Nå får det fanmeg være nok!"

Einar er mannen ingen synes synd på. Burde vi det? Eller bør vi spørre oss selv hva han kan lære oss? Han ble født uten fingre og høyre fot, noe han har brukt et halvt liv på å lære å mestre.

Det er likevel lite som stopper Einar. Men så - i sommer, hadde han max uflaks på terrengsykkel og pådro seg fem brudd i ryggen, en ryggmargsskade og fire ribbebeinsbrudd. Endelig var det noen som syntes synd på han, men hvor lenge kunne det vare?

Einars mindset, pågangsmot, vilje og humor vil inspirere og berøre oss.

Noen vil kjenne Einar igjen fra NRK-serien «Ingen grenser» med Lars Monsen på tur til Snøhetta i 2012. Mange har sett filmene hans på Youtube, ofte med humoristiske kommentarer, men alltid med fantastiske bilder og god formidling. Einar er høy og lavt – fra kaikanter og asfalt midt i Tromsø by til toppen av Stetind

Panel discussion: «Start and stop criteria in advanced therapies»

Chair of session



Kjell Arne Arntzen

Consultant neurologist

National Neuromuscular
Centre Norway, UNN

Speakers:



Sean Wallace

Consultant paediatric
neurologist

EMAN, Oslo University
Hospital



Torstein Lerhol

User representative



Morten Horn

Consultant neurologist

Oslo University Hospital



Robert Muni Lofra

Consultant physiotherapist

John Walton Muscular
Dystrophy

Program committee:

Head of committee: Andreas Rosenberger (NMK)

Cathrine Ramberg (NMK)

Maria Lee Finsrud (NMK)

Gry Hege Sjøhaug (NMK)

Geir H. Ringvold (NMK)

Cecilie Hæstad (NMK)

Ann Tove Buene (NMK)

Ane Fadnes (NMK)

Kjell Arne Arntzen (NMK)

Trine H. Popperud (EMAN)

Fredrik Stenseth (EMAN)

Solvor Sandvik Skaar (Frambu)

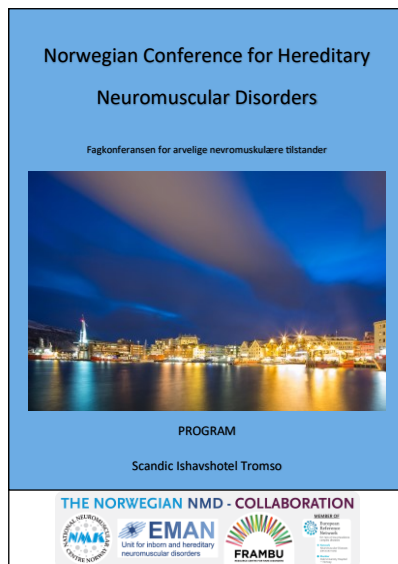
Susann Simensen (Frambu)

Tor Egil Roheim (FFM)

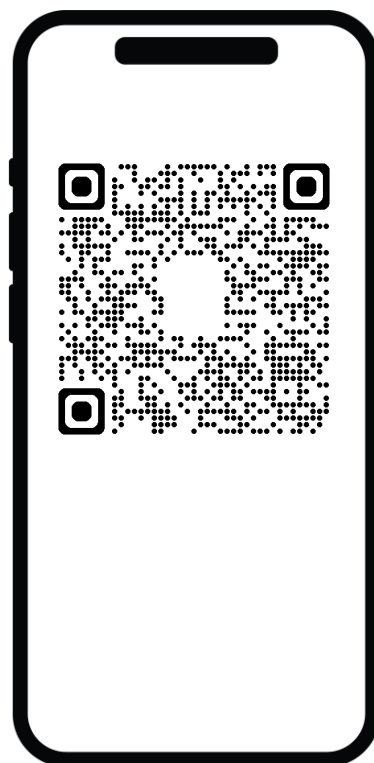
Charlotte Handberg (RCFM)

Inger Johanne Thuestad (Skåne Universitetssykehus)

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Notes:

FINNES DET EN FYSIOTERAPEUT FOR EN SOM MEG?

Klikk deg inn på denne siden:

www.fysioforsjeldne.no



I dette samarbeidsprosjektet samler og tilgjengeliggjør vi informasjon om fysioterapeuter med kompetanse/interesse for sjeldne nevromuskulære tilstander i en nasjonal oversikt.

Vi har utviklet et norgeskart med søkefunksjoner for hvor i landet man bor, og aktuelle fysioterapeuter i nærliggende område. Vi ønsker å legge til rette for bedre lokal oppfølging for pasienter i hele landet ved å gjøre kunnskapen om lokale ressurspersoner lettere tilgjengelig for hele målgruppen.

Slik ser oversikten ut



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