

# Living with myasthenia gravis

Updates on psychosocial issues and training

Friday, 30 September – Saturday, 1 October 2022  
Musholm, Denmark



MUSKELSVINDFONDEN



The National Rehabilitation  
Center for Neuromuscular Diseases

## Day 1, Friday, 30 September

11.30-12.30	<b>REGISTRATION AND LUNCH</b>	
12.45-13.00	<b>Opening</b> Ulla Werlauff, Head of Research, PhD, PT, the National Rehabilitation Centre for NMD	
13.00-13.45	<b>Update on MG</b> Jan J.G.M. Verschuuren, Professor of Neurology, Head of Department of Neurology, Leiden University Medical Centre	
13.45-14.45	<b>Training and exercise</b>	<b>Myasthenia Gravis and physical exercise</b> Anna R. Punga, Professor of Clinical Neurophysiology, Upsala University
		<b>Physical activity in patients with MG – results from a Danish cohort</b> Linda K. Andersen, PT and PhD, Rigshospitalet
	<b>Questions</b>	
14.45-15.15	<b>BREAK</b>	
15.15-15.35	<b>Pregnancy and birth</b> Nils Erik Gilhus, Professor of Neurology, University of Bergen	
15.35-15.55	<b>Juvenile Myasthenia Gravis - prevalence and management</b> Trine Haug Popperud, MD, PhD, Oslo University Hospital	
15.55-16.05	<b>Questions</b>	
16.05-16.25	<b>Fatigue in myasthenia gravis</b> Anna R. Punga, Professor of Clinical Neurophysiology, Upsala University	
16.25-16.45	<b>Health-related quality of life in patients with MG</b> Marion Boldingh, MD, PhD, Oslo University Hospital	
16.45-16.55	<b>Questions</b>	

16.55-17.15	<b>BREAK</b>	
17.15-18.10	<b>Comorbidities</b>	<b>Outcome measures and gender differences in patients with MG</b> Jan Lykke Scheel Thomsen, MD, PhD <b>Psychological effects and risk of comorbidity</b> Henning Andersen, Professor of Neurology, Aarhus University
	<b>Questions</b>	
18.10-18.20	<b>Recapping</b>	
18.20-19.00	<b>BREAK</b>	
19.00	<b>DINNER</b>	

## Day 2, Saturday, 1 October

7.00-8.15	<b>BREAKFAST</b>	
8.30-9.45	<b>Involvement of patient in research</b> <b>Interaction between patients and professionals in clinical activities and research</b> Henning Andersen, Professor of Neurology, Aarhus University	
	Charlotte Handberg, Senior Researcher, PhD, RCFM, Associated Professor, Aarhus University	
	Liselotte Schirakow, MG patient	
	Thomas Holm Pedersen, NMD Pharma, Associated Professor, Aarhus University	
9.45-10.00	<b>BREAK</b>	
10.00-11.00	<b>Young Scientists</b> Podium presentations	
	<b><i>Effect of gender on symptoms at onset, diagnostic delay and response to thymectomy in patients with myasthenia gravis</i></b> Chris Myllynen, PhD student, medical student University of Helsinki	
10.00-11.00	<b><i>Societal costs of Myasthenia Gravis in Norway</i></b> Ingrid Engebretsen, Analyst OSLO ECONOMICS	
	<b><i>Ectopic germinal centres in the thymus accurately predict prognosis of myasthenia gravis after thymectomy</i></b> Sini Laakso, MD, PhD Helsinki University Hospital and University of Helsinki	

11.00-11.20	<b>Activities of daily living as indicator for disease progression and treatment effect</b> John Vissing, Professor of Neurology, Rigshospitalet, Copenhagen University
11.20-11.55	<b>MG and covid-19. Factors influencing the Covid-19 vaccine immune response</b> Marion Boldingh, MD, Oslo University
11.55-12.10	<b>The need for International MG-guidelines in diagnostic and care</b> Nils Erik Gilhus, Professor of Neurology, University of Bergen
12.10-12.40	<b>Panel debate</b> Participants from the previous sessions
12.40-12.50	<b>Closing and bridging to patients' seminar</b> Simon Toftegaard, Chairman of Muskelsvindfonden Ulla Werlauff, Head of Research, PhD, PT, the National Rehabilitation Centre for NMD
12.50-13.45	<b>LUNCH</b>

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