Biographies

NINA BENAN, nurse and Head of The National Centre for Rare Epilepsy – related Disorders. She has extensive clinical experience with epilepsy, disability and rare disorders.

JOHANNES LEMKE, MD, PhD. and professor at Institute of Genetics, University of Leipzig, Germany. He is a geneticist and scientist with focus on genetic causes of epilepsy. His contributions in the discovery of many novel genes in epileptic encephalopathy's has been instrumental. Most recently he published a paper on the gene KCNA2 in Nature Genetics. He is currently the head of Institute of Genetics, University of Leipzig.

RIKKE S. MØLLER, assistant professor and molecular geneticist at the national centre for epilepsy in Denmark, Filadelfia. She has a PhD in epilepsy and genetics and has the past decade contributed with numerous papers on the genetic etiology of epilepsy, including Dravet syndrome.

SAMEER M. ZUBERI, MB, ChB, MD, FRCP, FRCPCH. Sameer is Consultant Paediatric Neurologist at the Royal Hospital for Sick Children and Honorary Professor at the University of Glasgow. He graduated in Medicine from Edinburgh University and trained in paediatrics and neurology in Edinburgh, Sydney and Glasgow. His clinical & research interests include epilepsy, neurogenetics and the neurological sleep disorders. He leads the Paediatric Neurosciences Research Group and is clinical head of the Glasgow Epilepsy Genetics Service. His other roles include Editor in Chief of the European Journal of Paediatric Neurology, Board Member of the European Paediatric Neurology Society and Chair of the International League Against Epilepsy Commission on Classification & Terminology. He is a Professional Advisor to Dravet Syndrome UK.

TOVE HALLBÖÖK, MD, PhD, Senior Consultant Paediatric Neurology, Head of Epilepsy at Queen Silvia Children's Hospital, Sahlgrenska University, Gothenburg, Sweden. She has a particular interest in, and has worked with and performed studies on Dravet syndrome for many years.

HELLE HJALGRIM, MD and Medical Director at The Danish Epilepsy Center, Filadelfia, Dianalund. She has been working with and studied epilepsy for many years, and has published numerous papers contributing to an improved understanding of epilepsy and its underlying molecular pathomechanisms.

TRUDE RATH OLSEN, MD, paediatrician, counsellor, the medical head of The National Center for Rare Epilepsy - related disorders, and has worked as a senior MD for several years. She has been a board member in the community of neuro-paediatricianers and the head of the Norwegian disabled children's board working group. She has also been the head of a working group for the Norwegian Directorate for health and social affairs, emphasising on health priorities for disabled children. At present she is the Norwegian delegate in the Nordic Neuro Paediatric Society (NNPS). She is skilled in child neurology, -rehabilitation and -epilepsy, and has a special interest in SUDEP research.

KAJA SELMER, MD, PhD. Scientist at Department of Medical Genetics, Oslo University Hospital and medical advisor at The National Center for Rare Epilepsy - related Disorders. The main focus of her research is to unravel the underlying genetic and epigenetic factors of neurogenetic disorders, and epilepsy in particular.

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DESITIN

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PROGRAM

2nd Nordic meeting
on
Dravet syndrome

Oslo, September 25th 2015

Oslo universitetssykehus

Dear Colleagues

The National centre for Rare Epilepsy – related Disorders, Oslo University Hospital, and The Steering Group for Nordic Dravet Syndrome Collaboration is glad to host the 2nd Nordic meeting on Dravet Syndrome.

The aim of this year's meeting is to:

1. Update and inform about recent news and research on Dravet Syndrome
2. Discuss the draft of a common Nordic treatment and follow-up protocol of Dravet Syndrome, and agree on which features that should be included in Dravet databases across the countries

Nina Benan Tove Hallböök Helle Hjalgrim Rikke S. Møller Kaja Selmer

SJELDEN & SYNLIG

- et åpent, lærende og helhetstenkende kompetansesenter

Program September 25th 2015

09.00 - 09.30	Registration, coffee
09.30 – 09.45	Welcome *Nina Benan*
09.45 – 10.30	**Dravet Syndrome – clinical picture form child to adult life** *Johannes Lemke*
10.30 - 11.00	Coffee break
11.00 – 11.45	**Dravet Syndrome and genetics** *Rikke S. Møller*
11.45 – 12.30	**Early predictors of outcome in Dravet Syndrome** *Sameer Zuberi*
12.30 – 13.30	Lunch
13.30 - 15.00	Nordic collaboration session: **Nordic cooperation plans: Dravet syndrome registry – common protocol** *Tove Hallböök* **Tentative collaboration studies -** discussion *Helle Hjalgrim*
15.15 – 15.30	Coffee break
15.30 – 16.15	**Dravet Syndrome and SUDEP** *Trude Rath Olsen*
16.15 - 17.00	Panel discussion: **What do we know about prognostic factors? Do we have data to support that early initiation of DS-specific treatment improve the prognosis?** *The speakers/all*
17.00	Closing remarks *Kaja Selmer*