

**Oslo 6th - 7th February 2020**

# 7th Nordic Narcolepsy Symposium



**Wifi at Ingeniørenes hus**

The wifi: Eurest

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## Thursday 6<sup>th</sup> of February 2020

9.30-10.00 Registration and coffee

10.00-10.05 Welcome, introductory remarks by Stine Knudsen Heier and Martin Aker (NevSom)

### Part 1

#### **10.05-11.00 Clinical Keynote: Narcolepsy after H1N1: 10 years in review**

Markku Partinen. Introducer of keynote: Poul Jennum.

11:00-11:15 Coffee

### **Part 2 11:15-13:00 Narcolepsy in the Nordic countries – patients' needs and the way forward**

11.15-12.15 Patients view on 10 year in review: improvements, problems, needed focus areas.

Chair: Ragnhild Berling Grande

Narcolepsy patient organizations from the Nordic countries and UK

12.15-12.30 Norwegian health authority representative

12.30-13.00 Panel discussion: future focus areas for narcolepsy in the Nordic countries.

Chair: Berit Hjelde Hansen

The patient organisation's representatives are asked to discuss what areas clinicians and researchers should focus on in the future to meet the patient's needs.

### **13.00-14.00 Mingling lunch**

### Part 3

#### **14.00-15.40 Narcolepsy in the future - Young Scientists**

Joint chairs: Hilde T. Juvodden and Tomi Sarkanen

14.00-14.12 ADHD, sleep and sleep disorders – especially the occurrence of symptoms related to narcolepsy, Lukas Wilenius

14.12-14.24 Can Pandemrix cause hypersomnia? Anna Kristoffersson

14.24-14.36 Expression levels of P2RY11 in CD4+ and CD8+ T-cells in post- H1N1 NT1 patients and firstdegree relatives, Rannveig Viste

14.36-14.48 Impact of treatment on weight-regulation of patients with narcolepsy,  
Paul Christian Baier

14.48-15.00 Chronic treatment with sodium oxybate high-affinity target ligand improves daytime symptoms in narcolepsy type I mice, Louise Piilgard Petersen

15.00-15.12 Effect of pitolisant, clinical observations in Uppsala, Helga Gretarsdottir

15.12-15.24 Narcolepsy in women, Hannes Hällgren

15.24-15.36 Structural anomaly in brainstem of pediatric patients with narcolepsy type 1,  
Natasha Morales Drissi

**15.40-16.00 Coffee**

**Part 4**

**16.00-17.00 Narcolepsy in the Nordic countries - Status in Norway. Chair: Kornelia Beiske**

- 16.00-16.12 Demography of narcolepsy in Norway, Stine Knudsen Heier  
16.12-16.24 Role of NevSom - Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias, Berit Hjelde Hansen  
16.24-16.36 Clinical organization/follow-up of narcolepsy in Norway, Ragnhild Berling Grande  
16.36-16.48 Scientific focus 1: Neuroimaging and HLA, Hilde T. Juvodden  
16.48-17.00 Scientific focus 2: Somatic and psychiatric comorbidity and QoL, Sebjørg Hesla Nordstrand

**Part 5**

**17.00-18.00 Narcolepsy in the Nordic Countries - Status in Finland. Chair: Anne Hutoniemi**

- 17.00-17.15 Demography of narcolepsy in Finland, Tomi Sarkanen  
17.15-17.30 Clinical follow-up/organization/medication of narcolepsy in Finland, Markku Partinen  
17.30-17.45 Scientific focus 1:  
Epidemiological and clinical studies on H1N1- vaccination-associated narcolepsy in Finland, Tomi Sarkanen  
17.45-18.00 Scientific focus 2: Finnish autoimmunity findings in narcolepsy since H1N1, Ilkka Julkunen

**19:00 Symposium Dinner at Pascal Restaurant**

Henrik Ibsens gate 36. (See map last page.)

# Friday 7<sup>th</sup> of February 2020

**8:30 Coffee**

## **Part 6**

**9.00-10.00 Basic Science Keynote: Narcolepsy after H1N1: 10 years in review**

Birgitte R. Kornum. Introducer of keynote: Stine Knudsen Heier

**10.00-10.15 Coffee**

## **Part 7**

**10.15-11.15 Narcolepsy in the Nordic countries - Status in Denmark. Chair: Poul Jennum**

10.15-10.27 Demography of narcolepsy in Denmark, Poul Jennum

10.27-10.39 Organisation and follow-up of narcolepsy in Denmark, Cresta Asah

10.39-10.51 Role of the national Danish Centre for Sleep Medicine (DCSM-model),  
Poul Jennum

10.51-11.03 Scientific focus 1: Narcolepsy in children with brain tumors, Line Pickering

11.03-11.15 Scientific focus 2: Diagnostics in narcolepsy/hypersomnias – test-retest of  
biomarkers, Eva W. Torstensen

## **Part 8**

**11.15-12.15 Narcolepsy in the Nordic countries - Status in Sweden. Chair: Lena Leissner**

11.15-11.27 Demography of narcolepsy in Sweden, Anne-Marie Landtblom, Katarina Fink

11.27-11.39 Organisation and follow-up of narcolepsy in Sweden, Lena Leissner

11.39-11.51 Scientific focus 1: Neuroimaging, Maria Engström

11.51-12.03 Scientific focus 2: HLA and autoantibodies, Alexander Lind

12.03-12.15 Scientific focus 3: Psychiatry and QoL in narcolepsy, Attila Szakasc

**12.15-13.00 Mingling lunch**

## **Part 9**

**13.00-14.00 Clinical challenges – diagnostic/treatment pitfalls. Chair: Anne-Marie Landtblom**

13.00-13.12 Diagnostic borderland of narcolepsy: role of actigraphy, Kornelia Beiske

13.12-13.24 Narcolepsy/hypersomnia after stroke, Poul Jennum

13.24-13.36 Role of neurophysiological digital markers in narcolepsy, Poul Jennum

13.36-13.48 Focus on the right parameters?

- Experiences from the Finnish translation of Narcolepsy Severity Scale, Tomi Sarkanen

13.48-14.00 Health economic perspectives in treatment of narcolepsy, Thomas Fast

## **Part 10**

**14.00 -15.15 Translational/basic science challenges. Chair: Birgitte R. Kornum**

14.00-14.20 Population cohorts and biobank discover novel associations in NT1 and related  
sleep disorders, Hanna Ollila

14.20-14.35 Sensitivity/specificity of hypocretin-1 radioimmunoassay, Helene Ægidius

14.35-14.50 CSF hypocretin-1 measurements by mass spectrometry, Kjetil Bårdsen

14.50-15.10 Influenza (H1N1) T cell epitopes in Pandemrix-associated narcolepsy, Tobias Freitag

**15.15 Coffee break, next meeting and final farewells**

PARTNERS



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## NEVSOM'S NEWSMAIL

Please sign up for NevSom's newsmail on [www.nevsom.no](http://www.nevsom.no).

## PRESENTATIONS

Some of the presentations will be available on the conference website until May 22nd: [www.oslouniversitetssykehus.no/nns](http://www.oslouniversitetssykehus.no/nns)

## SHARING IS CARING! PLEASE LET US SHARE YOUR KNOWLEDGE ONLINE!

We would very much appreciate if you could share the slides/abstracts from your talk.

If you would like to do so, please send your file (power-point, pdf or word) to [marit.skram@ous-hf.no](mailto:marit.skram@ous-hf.no). She can convert power-points to pdf if you don't do it yourself. In that way the content cannot be changed.

The presentations will be available on [www.oslouniversitetssykehus.no/nns](http://www.oslouniversitetssykehus.no/nns) until May 22nd.

Thank you for your cooperation!





## **Organizers:**

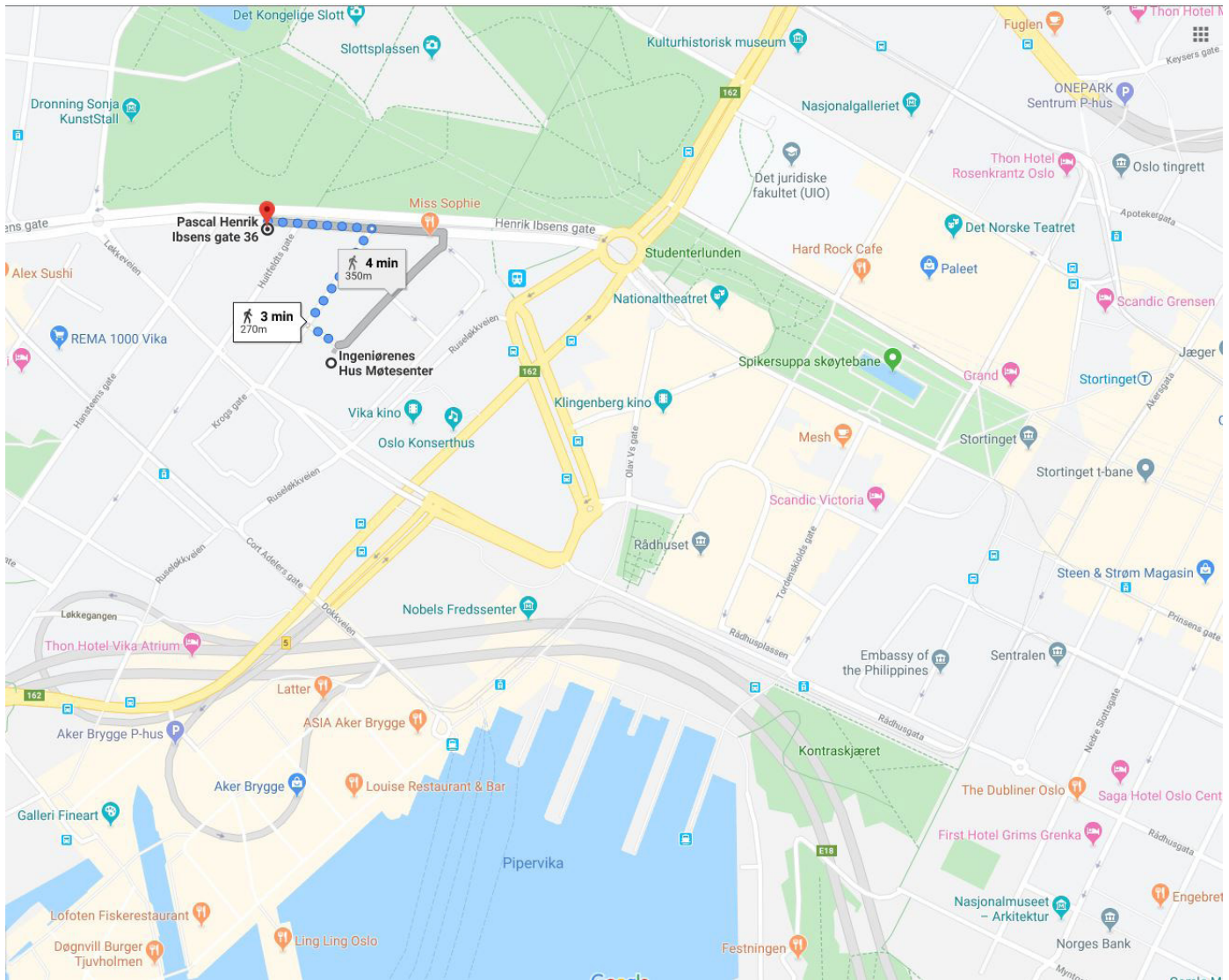
### **Local Organizing Committee:**

NevSom - Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias,  
Oslo University Hospital

Berit Hjelde Hansen, Martin Aker, Ragnhild Berling Grande, Stine Knudsen Heier, Hilde T. Juvodden,  
Janita Vevelstad, Marit Skram, Hege Skoghus.

### **Scientific Committee:**

Markku Partinen (FI), Anne Huutoniemi (FI), Poul Jennum (DK), Birgitte R. Kornum (DK),  
Stine Knudsen Heier (NO), Kornelia Beiske (NO), Anne-Marie Landt blom (S), Lena Leissner (S).



The conference venue is at Ingeniørenes Hus(Kronprinsens gate 17) and the dinner venue, Pascal Restaurant, (Henrik Ibsens gate 31) have a three minutes walk between them. The Royal Castle is right above Pascal Restaurant on the map. The National Theatre Station is the closest train and metro station.