

## Program 7th END Helsinki March 19-20, 2016



### Saturday, March 19<sup>th</sup> at Porthania, University of Helsinki, Yliopistokatu 3

8:30-9:00	Registration	
9:00	Welcome	Local Organisation Committee European Narcolepsy Network University of Helsinki, Helsinki, Finland
	Opening:	Ministry of Social Affairs and Health, Finland

#### **Scientific Open Symposia (Clinicians, researchers, patients)**

#### **Research topics 1. Clinics and epidemiology**

*Chairpersons: Hanna Nohynek (Finland) and Claudio Bassetti (Switzerland)*

- 9:10 Predicting features of narcolepsy from the EU-NN database. Ramin Khatami (Switzerland)
- 9:30 Follow-up of patients with Pandemrix-related narcolepsy. Tomi Sarkanen (Finland)
- 9:50 Acute neuropsychiatric diseases, PANS and PANDAS. Susanne Bejerot (Sweden)

#### **Research topics 2. Methodological issues**

*Chairpersons: Gert-Jan Lammers (The Netherlands) and Joan Santamaria (Spain)*

- 10:10 Metabolomics, obesity, diabetes, and sleep. Modern omical studies. Mika Ala-Korpela (Finland)
- 10:35 Histamine in relation to hypocretin. Pertti Panula (Finland)
- 11:00 Discussion

#### **11:05 Coffee break**

#### **Research topics 3. Infections, inflammations and autoimmune diseases of the CNS**

*Chairpersons: Ilkka Julkunen (Finland) and Janet Cunniffham (Sweden)*

- 11:25 The nasal cavity as railway of pathogens to the brain – relevance to narcolepsy: Krister Kristensson (Sweden)
- 11:55 Microbiota and CNS disease. A railway between gut and brain. Petri Auvinen (Finland)
- 12:15 Infections, inflammation, and other autoimmune CNS disorders – relevance to narcolepsy. Angela Vincent (The UK)

#### **12:45 Lunch**

#### **13:45 Business Meeting of the EU-NN for members of the EU-NN / Free time for others**

#### **Laudationes and Practical Working Session for all participants**

#### **15:15 Laudationes**

*Chairpersons: Gert Mayer (Germany) and Rosa Peraita-Adrados (Spain)*

- 15:15 Honours to the First Honorary Member of the EU Narcolepsy Network,
- 15:20 Announcing the Young Investigator Award Winner
- 15:25 Presentation of the Award Winner

#### **15:40 Patient Related Outcome Measures (PROMs).**

*Chairpersons of the working groups: Markku Partinen (Finland) and John Chaplin (Sweden)*

- 15:40 Introduction to ICF classification and development of PROMS . Markku Partinen (Finland)
- 16:00 Working session – selection of the most important items from the comprehensive Sleep Core Set to the future Narcolepsy Core Set; Multivoting / Web-based voting
- 17:30 Presentation of results and general discussion. How to go on ?

#### **18:00 End of day 1**

**19:15 Dinner; Restaurant Pompier, Albertinkatu 29, Helsinki**

## Sunday, March 20<sup>th</sup>, at Hotel GLO ART, Lönnrotinkatu 29, Helsinki

### **Current status of narcolepsy in Europe,**

*Chairpersons: Markku Partinen (Finland) and Poul Jennum (Denmark)*

- 8:30 Narcolepsy and driving license. Results of the EU-NN survey. Renata Riha (The UK)  
8:50 Discussion on driving issues  
9:00 Risk window between Pandemrix and onset of narcolepsy? Hanna Nohynek (THL, Finland)  
9:15 Reimbursement issues in narcolepsy. Rules and current situation. Helena Gylling (Finland), The Finnish Pharmaceutical Insurance Pool  
9:30 Reports from different countries: Patient Societies (6' per country)

- Krister Olsen (Norway)
- Matthew O'Neill (The UK)
- Marie Olsson (Sweden)
- Tom Matthews/ Mary Fitzpatrick (Ireland)
- France
- Germany
- Denmark
- The Netherlands
- Spain
- Italy

**10:40 Coffee Break**

### **Current treatment and clinical issues,**

*Chairpersons: Geert-Jan Lammers TBC (The Netherlands) and Stine Knudsen (Norway)*

- 11:00 Current treatment of adult narcolepsy: Geert Mayer (Germany)  
11:20 Current treatment of childhood narcolepsy: Giuseppe Plazzi (Italy)  
11:40 ADHD in relation to narcolepsy: Michel Lecendreux (France)  
12:00 Narcolepsy in relation with other autoimmune disorders: Rosa Peraita-Adrados (Spain)  
12:20 Pregnancy and narcolepsy: Karel Sonka (The Czech Rep)

### **Current research issues, methods, diagnostic markers and late breaking news**

*Chairpersons: Karel Sonka (The Czech Rep) and Ulf Kallweit (Switzerland)*

- 12:40 PSG micro- and macrosleep in narcolepsy: Poul Jennum (Denmark)  
12:55 CSF-hypocretin levels changes by time of year and length of daylight. Birgitte Kornum (Denmark)  
13:10 The Swedish clinical narcolepsy database: Ann-Marie Landtblom (Sweden)  
13:25 Conclusions

**13:30 Buffet and farewell**

### **NOTES:**

- 1. Booths for patients groups – contact local organisers**
- 2. Exhibition booths – contact local organisers**
- 3. Posters in GLO ART – contact local organisers**

4. Dinner on Saturday in Restaurant Pompier, Albertinkatu 29, Helsinki. Seats are limited to 100 persons. About 200 metres from GLO Art, about 1 km from Seurahuone and 1.2 km from Porthania.

**Own cost for dinner 30 €.**

5. The Saturday meeting occurs in Porthania (Yliopistonkatu 3) and the Sunday meeting occurs in Hotel GLO ART. Other suggested hotels include e.g. Hotel Seurahuone (Most Finnish Narcolepsy Patients are staying there) or Hotel GLO KLUUVI (very close from Porthania, about 1 km to GLO ART).

## **QUERIES**

**European Narcolepsy Day 2016 in Helsinki**

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Welcome