



3rd NORDIC CONFERENCE ON RARE DISEASES

September 4 - 5, 2014 HELSINKI, FINLAND

Thursday, September 4

8.30 - 9.00 **Registration**

9.00 - 9.10 **Welcome and opening words**

Ministry of Social Affairs and Health, Finland

Plenary Session

NORDIC COOPERATION WITHIN RARE DISEASES

9.10 - 9.25 **Sustainable Nordic welfare - rare diseases**

Speaker from the Welfare Committee of the Nordic Council

9.25 - 9.40 ***Rare Diseases Nordic Network of Patient Organizations***

Hedevig Castberg, FFO, Norway

Birthe Byskov-Holm, Sjældene Diagnoser, Denmark

9.40 - 10.20 ***Coffee and poster presentations***

10.20 - 10.40 **National plan for rare diseases in Finland**

Jaakko Yrjö-Koskinen, Ministerial Counsellor, Health/Medical Affairs, Dpt for Social and Health Services, the Ministry of Social Affairs and Health

10.40 - 11.00 **National plan/strategy for rare diseases in Sweden**

Veronica Wingstedt de Flon, General Manager, National Funktion for Rare Diseases (NFSD)

11.00 - 11.20 **National plan/strategy for rare diseases in Norway**

Stein Are Aksnes, General Manager, Norwegian Resource Services for Rare Disorders (NKSD)

11.20 - 11.40 **National plan/strategy for rare diseases in Iceland**

Solveig Sigurðardóttir, the State Diagnostic and Counselling Centre

11.40 - 12.00 **National plan/strategy for rare diseases in Denmark**

Marianne Jespersen, Senior Medical Officer, Danish Health and Medicine Authority

12.00 - 13.00 ***Lunch***

Parallel Sessions

RESEARCH AND EXPERTISE IN RARE DISEASES

13.00 - 16.00 **Session 1 A**

Centers of Expertise

Session 1 B

Research with and for Patients

19.00 - 21.00 ***Welcome reception at the House of Estates (Säätytalo) in Helsinki***

organised by the Ministry of Social Affairs and Health





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Friday, September 5

Plenary Session

RARE DISEASES HAVE NO BORDERS

9.00 - 12.00 **European reference networks**

Jaakko Yrjö-Koskinen, Ministerial Counsellor, Health/Medical Affairs, Dpt for Social and Health Services, the Ministry of Social Affairs and Health

Patient-centered care and patient involvement

Anders Olauson, President of the European Patients' Forum

Eurordis

Terkel Andersen, President of EURORDIS

Coffee and networking

Cross-border genetic testing

Helena Kääriäinen, Research Professor, the Finnish National Institute for Health and Welfare

Other themes and speakers in this session will be confirmed later

Announcing the next NCRD 2016

"Passing on the baton" to the representative of Denmark

12.00 - 13.00 **Lunch**

Parallel Sessions

EMPOWERMENT AND EXPERIENCE BASED PRACTICES

13.00 - 15.30 Session 2 A

Lifelong Empowerment

Session 2 B

Experience Based Practices

15.30 We thank you all for participating and wish everyone a safe journey home

Please note that this is a preliminary program and the content may be subject to have minor changes and adjustments. The conference schedule, however, will remain unchanged.

