

CONFERENCE ON RARE DISEASES

May 31 and June 1, 2012

REYKJAVIK
ICELAND



Ministry of Welfare



The State Diagnostic
and Counseling Centre



norden

Preliminary program

Wednesday, May 30

18.00 "Get-together" in the Blue Lagoon
Bathing and Dinner

Thursday, May 31

09.00 Welcome and opening, **Guðbjartur Hannesson**, Minister of Welfare, Iceland
Rare Diseases Europe (EURORDIS), **Terkel Andersen**, President of EURORDIS
RARELINK – An example of a Nordic cooperation within rare diseases
10.10 Poster walking and coffee
10.40 Useful websites – Perspective on rare diseases
Benefits of Nordic cooperation
Holistic perspective on rare diseases
12.00 Lunch
13.00 Parallel sessions
A) RAREDIS – The Nordic database for Rare Diseases
B) Education – Curriculum and e-learning on rare diseases
15.00 Poster walking and coffee
15.30 The Nordic perspective on rare diseases
Parent stories
16.20 Summary
19.00 Conference Dinner

Friday, June 1

09.00 The Nordic perspective on rare diseases within the European Union
Research programmes on rare diseases;

- Latest areas in rare diseases
- Social and educational perspectives
- Nordic perspective
- New areas of importance

10.40 Coffee and networking
11.00 Presentation of abstracts and poster walking
12.15 Lunch
13.15 Parallel sessions
A) Empowerment of patient organisations within the Nordic countries
B) Educational implications of rare diseases – Educational challenges
14.15 Last minute networking
14.30 Summary of the parallel sessions
Messages from the **Five Nordic Governments**
16.15 Recommendations from the conference and the way forward!

Registration fee before March 1, EUR 250 / DKK 1750

Registration fee after March 1, EUR 285 / DKK 2000

Conference-web: www.greining.is



facebook.com/rarenordic

