

# Nordic conference for rare diseases in Stockholm 2nd – 3rd October 2023

## Rare diseases are the engine of the healthcare of the future

On behalf of the Nordic Network for Rare Diseases, the Swedish National Board of Health and Welfare would like to invite you to the Nordic Conference for Rare Diseases.

Rare diseases are the engine of the healthcare of the future and with this conference we aim to bring politicians, officials, profession and patient representatives together for discussions regarding high impact issues.

### *Agenda, 2nd October*

- National strategies
- Digitalisation, data sharing and registries

### *Agenda, 3rd October*

- Collaborations cross border
- Precision medicine

We will meet at Clarion Hotel Sign in Stockholm for a lunch to lunch meeting on the **2nd – 3rd October in 2023**. The conference is organised as a hybrid event, which will allow for both physical and online participation of the attendees.

The conference is for free but you will have to pay for travel and accommodation yourself.

Registration for physical participation is now closed, but you can still register for digital participation.

If you have any questions e-mail us at [NNRD@socialstyrelsen.se](mailto:NNRD@socialstyrelsen.se)

[Link to registration](#)



## AGENDA DAY 1

11.00 – 12.00 Registration

12.00 – 13.00 Lunch

**Welcome and introduction to the meeting.** Anders Olauson, chairman of Ågrenska foundation and NGO Committee for Rare Diseases and Lena Löfvqvist, the National Board of Health and Welfare

13.10 – 13.20 Tem Folmand, Danmarks Bløderforening and SBONN – The life journey of person living with rare disease in a Nordic perspective

13.20 – 13.30 Acko Ankarberg Johansson, Swedish minister for healthcare – Opening speech

13.30 – 13.40 Hans Kluge head of WHO Europe. Insights from the European perspective – Where are we today and where are we going in Rare Disease?

### **National strategies – how do we plan for the future in a resilient way?**

13.45 – 14.00 Ane Just Ohrt, Senior Medical Officer at the Department of hospital planning at the Danish Health Authority

14.00 – 14.15 Satu Wedenoja, Senior medical officer, Finnish Institute for Health and Welfare – National strategies in Finland – from comprehensive plans towards a policy brief

14.15 – 14.30 Toril Orrestad, Chief Adviser, Medical and Health Services, South-Eastern Norway Regional Health Authority

14.30 – 14.40 Stephanie Juran, Riksförbundet Sällsynta Diagnoser /Rare Diseases Sweden and Guðrún Helga Harðardóttir, Einstök börn / Unique Children in Iceland – Why is it so important to have a national strategy? How can a Nordic collaboration help?

14.40 – 14.55 Coffee break

### **Digitalisation, data sharing and registries**

14.55 – 15.05 Katri Asikainen, chair, Harso ry Finland – The needs and hopes of people living with rare diseases

15.05 – 15.15 Ulf Sigurdson, Manager of e-health, Department of technology and e-health, South-Eastern Norway Regional Health Authority

15.15 – 15.25 Ulf Petrusson, professor of jurisprudence, Director, Institute for Innovation and Societal Change, School of Economics at the University of Gothenburg, Sweden

15.30 – 16.00 Panel discussion, moderated by Anders Olauson

Anna Ödman Roussakis, Övertandläkare, Odontologie doktor,  
Mun-H-Center

Ane Just Ohrt

Stephanie Juran

Toril Orrestad

Ulf Petrusson

19.00 Dinner

## AGENDA DAY 2

08.30 – 09.00 Registration

### **Collaborations cross border, not just health care (European reference networks [ERN] and other collaborations)**

- 09.05 – 09.20 Hans Tómas Björnsson. MD PhD, Chief of department, Department of Genetics and Molecular Medicine, Landspítali. Professor of Translational Medicine and Pediatrics, University of Iceland. Associate Professor of Genetics and Pediatrics, Johns Hopkins University (part time) – Three ongoing revolutions in genetics: are the Nordics ready?
- 09.20 – 09.35 Mikko Seppänen, Head Physician of Pediatric Research, Pediatric Research Center, Children and Adolescents, Chief Physician, HUS Rare Disease Center, Specialist in Internal Medicine and Infectious Diseases, Adjunct Professor, FCIS (USA), HUS Helsinki University Hospital – Collaboration in research, success and obstacles
- 09.35 – 09.50 Stein Are Aksnes, Head of Department, Norwegian National Advisory Unit on Rare Disorders
- 09.50 – 10.05 Rula Zain-Luqman, Associate Professor, Karolinska Institutet, Centre for Rare Diseases, Karolinska University Hospital. Swedish ERN coordinator & Nordic Orphanet coordinator
- 10.05 – 10.20 Monica Benson, e-PAG ERN-RND – The patient perspective in ERN-RND
- 10.30 – 10.45 Coffee break

### **Precision medicine – Diagnostics and treatments of today and for tomorrow**

- 10.45 – 11.00 Malene Bøgehus Rasmussen, Specialized Medical Officer Danish National Genome Center
- 11.00 – 11.15 Olve Moldestad, PhD, Avdelingsleder, Avdeling for nyfødtscreening. Senter for presisjonsmedisin innen sjeldne sykdommer, Oslo universitetssykehus
- 11.15 – 11.30 Anna Wedell, Professor/senior consultant at the Centre for Inherited Metabolic Diseases, Karolinska University Hospital
- 11.30 – 11.45 Douglas Lundin, chief economist, The Dental and Pharmaceutical Benefits Agency, TLV – Government assignment on medicines for rare conditions
- 11.45 – 12.00 Karolina Antonov, The trade association for the research-based pharmaceutical industry in Sweden (Lif)
- 12.00 – 12.30 Panel discussion, moderated by Anders Olauson  
Anna Wedell  
Hans Tómas Björnsson  
Karolina Antonov  
Satu Wedenoja  
Oskar Ahlberg, Riksförbundet Sällsynta Diagnoser
- 12.30 – 12.45 Summary of meeting – Anders Olauson and Lena Löqvist
- 12.45 – 13.45 Lunch

## **Travel information**

Traveling from Stockholm Arlanda Airport: Taking the Arlanda Express is the quickest way to travel from Arlanda Airport to Stockholm Central Station with a journey time of just 20 minutes. You can purchase your ticket at [arlandsexpress.com](http://arlandsexpress.com) and it is valid for 90 days in either direction.

Traveling from Bromma Stockholm Airport: The journey time is approximately 20 minutes and you can purchase your ticket at [flygbussarna.se](http://flygbussarna.se). The ticket is valid for 3 months in either direction.

- Upon arrival at Stockholm City Terminal the NNRD-conference venue at Östra Järnvägsgatan 35 is a few minutes' walk.
- Please note, the entrance to the NNRD-conference is also the main entrance to the hotel at the address Östra Järnvägsgatan 35.

## **Special needs accessibility**

- Please notify us when you arrive if you have the need for hearing aid in the conference rooms.
- Toilets are accessible for wheelchair users.

## **Contacts**

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