

Nordic conference on 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.

Sign up before May 31st to reserve your seat at the conference. You will receive confirmation after May 31st due to limited number of seats.

If you have any questions e-mail us at NNRD@socialstyrelsen.se

[Link to registration](#)

Any questions? E-mail us at NNRD@socialstyrelsen.se

AGENDA DAY 1

12.00 – 13.00	Lunch
13.00 – 13.10	Welcome and introduction to the meeting, Anders Olauson/Lena Löqvist/Stephanie Juran
13.10 – 13.20	The life journey of person living with rare disease in a Nordic perspective – TBC
13.20 – 13.30	Welcome from Acko Johansson Ankarberg, Swedish minister for healthcare
13.30 – 13.40	European perspective - Where are we today and where are we going in RD? Insights from Hans Kluge head of WHO Europe
13.50 – 14.30	National strategies - how do we plan for the future in a resilient way? Denmark: TBC Finland: Satu Wedenoja, Chief Physician, The Finnish Institute for Health Welfare Norway: TBC Sweden: TBC
14.30 – 15.00	Digitalisation, data sharing and registries Norway: Stein Are Aksnes, Leader of the National Competence Service for Rare Diagnoses Finland: TBC Sweden: Ulf Petrusson, professor of jurisprudence, Director, Institute for Innovation and Societal Change, School of Economics at the University of Gothenburg

15.00 – 15.15	Coffee break
15.15 – 16.00	Panel discussion, moderated by Anders Olauson
17.30	Dinner

AGENDA DAY 2

09.00 – 10.30	<p>Collaborations cross border, not just health care (European reference networks and other collaborations)</p> <p>Finland: TBC</p> <p>Norway: TBC</p> <p>Sweden: Rula Zain-Luqman, Associate Professor, Karolinska Institutet, Centre for Rare Diseases, Karolinska University Hospital. Swedish ERN coordinator & Nordic Orphanet coordinator</p>
10.30 – 10.45	Coffee break
10.45 – 12.00	<p>Precision medicine – Diagnostics and treatments today and treatments for tomorrow</p> <p>Denmark: TBC</p> <p>Norway: TBC</p> <p>Sweden: Anna Wedell, Professor/senior consultant at the Centre for Inherited Metabolic Diseases, Karolinska University Hospital</p>
12.00 – 12.45	Panel discussion, moderated by Anders Olauson
12.45-13.00	Summary of meeting – Anders Olauson