

Invitation to the Nordic Rare Disease Summit 2023

There is momentum for change. Join us to discuss how to make that change happen!

The challenges we are facing today within rare diseases are complex and extensive. To understand and overcome these, we need to work together and share knowledge across countries, between expert groups and involve people who are living with rare diseases.

On April 17, 2023, the Nordic Rare Disease Summit will bring together experts and decision makers, building on the success of the first Nordic Rare Disease Summit in 2021. The Summit will be organised during the Swedish Presidency of the Council of the European Union.

A key to improving overall strategies for rare diseases in the Nordic countries is to ensure they are aligned with the European healthcare development. The European Commission's current work within rare diseases plays an important role for the Nordic countries when developing policies and solutions to shorten time to diagnosis, strengthen the empowerment of patients and ensure access to innovative treatments.

Key Speakers



**Acko Ankarberg
Johansson**
Minister for Health
Care, Sweden



Yann Le Cam
Chief Executive Officer
of EURORDIS - Rare
Diseases Europe



Anna Wedell
Prof. Medical Genetics,
Director of Precision
Medicine Center Karolinska
University Hospital

[See the full list of speakers →](#)

Date: April 17, 09.00-17.00 CEST
Place: Posthuset 7A, Stockholm
Mäster Samuelsgatan 70
Virtual attendance possible

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The Nordic Rare Disease Summit 2023 is an arena for knowledge sharing and dialogue between decision makers and representatives from healthcare, patient organizations, authorities, academia, media and life science companies. At the Summit, leading experts within rare diseases from all Nordic countries and beyond will share best practice, present new findings, and discuss how to elevate the area of rare diseases in order to make a difference for the 1 million* people in the Nordics who live with a rare disease.

The Summit will result in a 'Nordic Roadmap for Rare Diseases 2.0'. The Summit is a unique opportunity to take a major leap forward – to move from what needs to be achieved to how it will be done.

The working language for the Summit is English. Digital attendance is possible. Read more and register to participate at www.nrds2023.org.

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Agenda

Registration is open from 09.00 and includes a light breakfast. The Summit commences at 10.00 with an introductory welcome followed by presentations by keynote speakers.

The focus of these sessions will be on *Improving conditions for people with rare diseases in the Nordics and in Europe: A political perspective* and *Innovating for people living with rare disease – Why partnerships and incentives matter in the context of EU Orphan Medicinal Products regulation*. The morning session will conclude with a panel discussion on equal opportunities for people with rare diseases: How do we transition from “what” to “how”?

After lunch, the Summit will continue with presentations in plenary focusing on three key policy themes – early diagnosis, patient empowerment, and access to innovation. These themes will then flow into the breakout sessions. Each breakout session will commence with a brief presentation by a moderator, followed by a discussion between the three panelists. Delegates will be invited to pose questions.

The Summit will conclude with panel discussions focusing on the key take aways from the day and the next steps. The program ends at 17.00.

[See the full agenda →](#)

Accommodation

Hotel rooms have been pre-reserved for guests attending the Nordic Rare Disease Summit 2023. Accommodation is available at Radisson Blu Royal Viking Hotel and Scandic Continental from April 16 to April 18, 2023. Both hotels are located within walking distance to Posthuset. More information will be provided upon registration. The hotel rooms are available for reservation until March 16 and March 11, respectively.

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NORDIC RARE DISEASE SUMMIT 2023 PARTNERS



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Nordic Rare Disease Summit 2023 is organized and financed by Takeda Pharma with contribution from Alexion AstraZeneca Rare Disease, Novo Nordisk and Sobi.

The Nordic Rare Disease Summit 2023 is organized in Stockholm on 17 April 2023 by the pharmaceutical company Takeda Pharma with contributions from Alexion AstraZeneca Rare Disease, Novo Nordisk, and Sobi. Additional partners are Rare Diseases Sweden, Lif - the research-based pharmaceutical industry in Sweden, EURORDIS - Rare Diseases Europe, SBONN - a network of six umbrella patient organizations for rare diseases in five Nordic countries, EUCOPE - The European Confederation of Pharmaceutical Entrepreneurs, and EFPIA - The European Federation of Pharmaceutical Industries and Associations.

Participation in the meeting is free of charge. Lunch and coffee will be served. **Note for attending healthcare professionals:** Please note that you comply with your internal regulations in attending external events. Travel or accommodation costs cannot, unfortunately, be reimbursed by the organizers.

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