



Nordic Rare Disease Summit 2023 Draft Agenda

17th April 2023, 7A Posthuset, Stockholm

09.00 - 10.00	Registration and light breakfast
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10.00 – 11.00	OPENING SESSION
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10.00 - 10.20	Welcome Video followed by opening remarks led by Ricardo Marek, President Europe & Canada, Takeda Caroline Åkerhielm, Chair, Rare Diseases Sweden On stage: All partners to the Nordic Rare Disease Summit
10.20 – 10.25	Introduction to program Line Friis Frederiksen, moderator, biologist, science journalist
10.25 – 10.40	Improving conditions for people with rare diseases in the Nordics and in Europe. A political perspective. Acko Ankarberg Johansson, Minister for Health Care, Sweden
10.40 – 10.55	Innovating for people living with rare disease – Why partnerships and incentives matter in the context of EU Orphan Medicinal Products regulation Alexander Natz, Secretary General EUCOPE Pernille Weiss, Member of European Parliament, Denmark
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10.55 – 12.00	RARE DISEASES – SETTING THE SCENE FOR CHANGE
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10.55 – 11.05	From roadmap to reality: Outcomes and actions since the first Summit Video followed by interview with Birthe Byskov Holm, Chair, Rare Diseases Denmark and Yann Le Cam, CEO EURORDIS – Rare Diseases EUROPE
11.05 – 11.45	Equal opportunities for people with rare diseases: How do we go from “what” to “how”? Panel discussion involving: Avril Daly, President of EURORDIS – Rare Diseases EUROPE

Professor Anna Wedell, MD, Director of Precision Medicine Center, Karolinska
Satu Wedenoja, Chief Physician, THL – The Finnish Institute for Health Welfare
x, Member of the Health Care Committee of the Parliament, Denmark (TBC)
Bård Hoksrud, Member of Parliament, Spokesperson for Health, Former
Minister for Agriculture, Norway

11.45 – 12.30

LUNCH

12.30 – 13.30

**EARLY DIAGNOSIS, PATIENT EMPOWERMENT, ACCESS TO INNOVATION –
DRIVING CHANGE THROUGH BEST PRACTICES**

12.30 – 12.45

**Early Diagnosis (Partnership Screen4care – An innovative research approach
to accelerate rare disease diagnosis, based on genetic newborn screening
and digital technologies) Speaker TBD**

12.45 – 13.00

**Patient Empowerment – The value of bringing in the patient perspective
when forming a national strategy for rare disease**

Speaker from Danish Health Authority - TBC

13.00 – 13.30

**Clearing the path for innovation/Leading the way for patients' access to
innovation**

Key note speech by Adam Hutchings, CEO DOLON

followed by panel debate

Yann Le Cam, CEO EURORDIS – Rare Diseases EUROPE

Ludovic Helfgott, Executive Vice President, Rare Diseases, Novo Nordisk

Jørn Schultz-Boysen, Vice President, HAE Scandinavia ,

Niklas Hedberg, Chief Pharmacist TLV, Sweden, Chair EUnetHTA Executive
Board

Lars Ehlers, CEO, Nordic Institute for Health Economics

13.40 – 16.00

BREAKOUT SESSIONS

**Breakout sessions will constitute of three parallel streaks – Early diagnosis, Patient Empowerment and
Access to innovation.**

Each break out session will be opened with a brief keynote speech, followed by a discussion between three
panelists. Delegates will be invited to pose questions.

The delegates will reflect on these questions:

- What measurable changes do we want to see in this area?
- What concrete actions do we need to take?
- Who assumes ownership of what in the desired change?

To maximize the outcome for all delegates, it will be possible to attend each of the breakout sessions either physically at the venue or virtually

16.00 – 16.45

CLOSING SESSION

16.00 – 16.15

Key take aways from Breakout sessions

Short interview of break out session moderators:

Anna Nehrgård, Rud Pedersen

Hans Winberg, Secretary General Leading Healthcare (TBC)

Adam Hutchings, CEO DOLON

16.15 – 16.45

Next steps & ownership for change

Dialogue with the Nordic Network for Rare Diseases under the Nordic Council of Ministers

Anders Olauson, Founder of Ågrenska, Nordic Network for Rare Diseases

Karen Ellemann, Secretary General of the Nordic Council of Ministers - TBC

Tone Wilhelmsen Trøen, Chair of the Norwegian health and welfare committee, Deputy chairman of Nordic council of ministers' health and welfare committee

16.45

END OF PROGRAM

NORDIC RARE DISEASE SUMMIT 2023 PARTNERS



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