

SAVE THE DATE

12th April 2021: 13:00 – 17:00

13th April 2021: 13:00 – 16:00

Virtual Conference



NORDIC RARE DISEASE SUMMIT 2021

Join us in setting out a common aspiration to elevate rare diseases as a national health priority in the Nordic countries.

The Rare Disease Summit will evolve around three themes: Diagnostic Delay, Patient Empowerment and Patients Access to Innovative Treatment.

Opening Address (video) by HRH Crown Princess Mary, Patron of Rare Diseases Denmark

Key note speakers and panelists invited to the Summit includes representatives from across the Nordic region, Brussels, Belgium and the U.S.:¹

- Magnus Heunicke, Minister for Health, Denmark (tbc)
- Terkel Andersen, President of EURORDIS – Rare Diseases Europe, Brussels, Belgium
- Yann Le Cam, Chief Executive Officer, EURORDIS - Rare Diseases Europe; Brussels, Belgium
- Gregory Moore, Co-Chair Global Commission, Corporate Vice President, Microsoft Health, USA (tbc)
- Bertel Haarder, MP, President of Nordic Council 2021 and former Minister for Health, Denmark

The summit is organized by Takeda and hosted in collaboration with Rare Diseases Denmark (Sjældne Diagnoser). We will gather a broad range of participants including ministers for health from the Nordics, national and regional institutions, international organizations, patient associations, health care professionals, academics to foundations, NGOs, pharmaceutical companies and media.

The hosts and partners of the Summit aim to ensure a lasting legacy of the event by sharing a [“Nordic Roadmap for Rare Diseases”](#) setting out a common aspiration to elevate rare diseases as a national health priority in the Nordic countries.

The Nordic Rare Disease Summit will take place as a virtual event (free of charge).

INVITATION WILL FOLLOW

¹ A final programme with confirmed speakers and panelist will be made available closer to the event.

For more information contact:

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PARTNERS

Prominent organizations from across the Nordic countries and the wider Europe have joined as partners: EURORDIS, a non-governmental patient-driven alliance of patient organizations representing 932 rare disease patient organizations in 73 countries, SBONN, a network of six umbrella patient organizations for rare diseases in five Nordic countries and The Danish Association of the Pharmaceutical Industry (Lif).



SBONN



The following organizations have endorsed the Nordic Rare Disease Summit:



Code of Conduct Both Takeda (funder and organizer) and Rare Diseases Denmark (co-host) stress that it is a precondition for the collaboration that all activities comply with The Danish Association of the Pharmaceutical Industry (Lif) and EFPIA's Code of Practice on Relationships between The Pharmaceutical Industry and Patient Organizations, national and EU regulations governing interactions between the pharmaceutical industry and patient organizations and Rare Disease Denmark's ethical guidelines. The programme will ahead of the event be submitted for pre-approval by The Danish Ethical Committee for the Pharmaceutical Industry (ENLI).

About Takeda Takeda is a patient-focused, values-based, R&D-driven global biopharmaceutical company committed to Better Health for People, Brighter Future for the World. Our passion and pursuit of potentially life-changing treatments for patients are deeply rooted in over 230 years of distinguished history in Japan. We have presence in approximately 80 countries, with leading positions in Japan and the U.S., respectively the third and first largest pharmaceutical markets in the world. We will deliver highly innovative medicines and transformative care for more people globally. www.takeda.com

About Rare Diseases Denmark (Sjældne Diagnoser) Rare Diseases Denmark is a national alliance of 56 rare disease societies. Rare Diseases Denmark's work is based on volunteers and a minor professional secretariat, www.sjaeldnediagnoser.dk.