

Nordic Rare Disease Summit 2023

On 17 April 2023, during the Swedish Presidency of the European Union, a wide range of delegates – policy makers, healthcare professionals and representatives from patient associations, health authorities, media, academia, life science, and the tech industry - will gather in Stockholm for the Nordic Rare Disease Summit 2023.



The summit will serve as a platform for policy discussions within rare diseases, as well as facilitate the exchange of best practices, aiming to elevate rare diseases as a national health priority in the Nordic countries. It will be organized and financed by **Takeda Pharma**, with contribution from **Alexion AstraZeneca Rare Disease**, **Novo Nordisk** and **Sobi** as a hybrid meeting to enable virtual participation. Partners include **Rare Diseases Sweden** (national association representing approximately 70 rare diseases patient organizations and 16 000 individual members) and **Lif Sweden** (the trade association for the research-based pharmaceutical industry) as well as prominent organizations from across the Nordics and Europe, including:

- ♦ **EURORDIS** – Rare Diseases Europe, a unique, non-profit alliance of over 1000 rare disease patient organizations from 74 countries
- ♦ **SBONN** - a network of six umbrella patient organizations for rare diseases in five Nordic countries
- ♦ **EUCOPE** - The European Confederation of Pharmaceutical Entrepreneurs
- ♦ **EFPIA** - The European Federation of Pharmaceutical Industries and Associations.

Background

The impact of rare diseases on both patients and their families can be profound. Rare diseases often lead to negative impacts on patients' quality of life, including high levels of disability, stigmatization, and social isolation. As patients living with rare diseases in the Nordic countries are facing similar challenges, as well as opportunities, related to diagnosis, social wellbeing, and quality of care, the rare disease area requires stronger Nordic collaboration and greater sharing of experiences. This could ultimately result in improving the quality of care and long-term benefits for both patients and the healthcare systems in the Nordics. The summit will build on both the strong engagement and legacy of the first Nordic Rare Disease Summit in 2021 as well as the focus given on rare diseases during the French and Czech Presidencies of the EU during 2022. That is why it is being investigated to host Nordic Rare Disease Summit 2023 under the auspice of the Swedish Presidency of the EU.

The first summit

On 12th and 13th April 2021, the first Nordic Rare Disease Summit brought together 486 participants from 17 countries to share experiences and launch a new Nordic Roadmap for Rare Diseases. Her Royal Highness Crown Princess Mary of Denmark, Patron of Rare Disease Denmark, inaugurated the summit, which included keynote speeches, panel discussions, and active engagement by the audience.

Following the summit, The Nordic Roadmap for Rare Diseases - which outlines the status and recommendations for how to reduce the diagnostic delay for people with rare diseases, empower patients and their relatives, and secure access to care – has been shared with over 500 organizations and individuals active in the rare disease field. At a meeting in November 2021, the roadmap was used as a reference point in the planning of future activities by the Nordic Network for Rare Diseases under the Nordic Council of Ministers. In addition, over 20 follow up activities have taken place across the Nordic region based on the first summit.

Building on the momentum

The Nordic Rare Disease Summit 2023 aims to further elevate the efficacy and relevance of rare disease policy across the Nordic countries by driving tangible progress in the areas of early diagnosis, patient empowerment and access to innovation.

The idea is to move the discussion forward from *what* needs to be done to *how* we can work together to implement improvements across the Nordic region. Prominent guests including the Swedish Minister for Health, Care Ankarberg Johansson, has accepted the invitation to speak. The opportunity to have Her Royal Highness Crown Princess Victoria of Sweden, Patron of Rare Diseases Sweden, inaugurate the summit is being explored.

Leading up to the summit, Nordic working groups will be established to obtain input into the summit's planning and explore policy solutions for early diagnosis, patient empowerment, and access to innovation. At the summit, the overall focus will be to discuss and reflect upon the following questions:

- What measurable changes do we want to see regarding Early Diagnosis, Patient Empowerment and Access to Innovation?
- What concrete actions do we need to take to ensure measurable improvements?
- *Who* assumes ownership of *what* to drive the desired change?

Examples of Recommendations from the Nordic Roadmap for Rare Diseases

Early Diagnosis

To shorten the journey towards accurate and timely diagnosis, it is necessary to invest in pioneering diagnostic platforms and exploit digital innovation to find novel solutions. Timely diagnosis requires timely action, including up-to-date neonatal screening programs in all Nordic countries and establishment of registers on both national and international levels. This requires an updated legislation and procedures for handling health data.

Patient Empowerment

Patients' knowledge and expertise should be recognized and promoted as a resource on all levels within healthcare and policy systems. Patients and their relatives need to gain greater control over decisions and actions concerning their health and wellbeing. Also, patients can contribute to the development of sustainable healthcare systems.

Access to Innovation

As part of addressing the unmet medical needs of people living with rare diseases, we need to break the deadlock in access to specialist care by recognizing the value of treatment in a holistic way and investing in innovation that adds true value to patients, while securing financially sustainable healthcare systems.

In co-operation with our partners, we are looking forward to offering a forum that enables active engagement and a constructive dialogue about how the quality of life and standard of care for people living with rare diseases can be improved.

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NORDIC RARE DISEASE SUMMIT 2023 PARTNERS

