February 2021

Nordic Rare Disease Summit 2021

Introduction

The impact on those who suffer from rare disease and their families can be profound. Rare Diseses can often lead to low levels of quality of life and high levels of disability, stigmatization and social isolation. Patients with rare diseases living in the Nordic countries face many similar challenges and opportunities related to diagnosis, social wellbeing, treatment and care quality of care. Challenges that may even have been reinforced by the Covid-19 situation.

We therefore wish to exchange experiences and best practices across the Nordic countries. To facilitate this – and with the aim of elevating rare diseases as a health priority – Takeda will organize and fund a high-level virtual Nordic Rare Disease Summit on **12-13 April 2021**. The summit is hosted in collaboration with Rare Diseases Denmark (Sjældne Diagnoser) under the patronage of HRH Crown Princess Mary.

Teaming Up

Prominent organisations from across the Nordic countries and the wider Europe have joined as partners:

- EURORDIS – Rare Diseases Europe, a non-governmental patient-driven alliance of patient organisations representing 932 rare disease patient organisations in 73 countries
- SBONN, a network of six umbrella patient organisations for rare diseases in five Nordic countries, and
- The Danish Association of the Pharmaceutical Industry (Lif).

The Rare Disease Summit is a Nordic event gathering a broad range of participants including government representatives from the Nordic countries, national and regional institutions, international organisations, patient associations, health care professionals, academics to foundations, NGOs, representatives from pharmaceutical companies and media.

Summit Themes

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

The Summit will include an opening address by HRH Crown Princess Mary in her capacity of patron to Rare Diseases Denmark. Following the opening of the summit and as part of the first theme **'Diagnostic Delay'** Dr. Gregory Moore, Co-Chair Global Commission, Corporate Vice President, Microsoft Health, USA, will share the work and aspiration of "The Global Commission" – a strategic alliance of EURORDIS, Microsoft and Takeda created to establish a roadmap for improved diagnostics. The alliance focuses on solutions to core barriers preventing timely diagnosis for all rare diseases – with an emphasis on those affecting children.

By dedicating the second part of the agenda to **'Patient Empowerment'** we seek to facilitate the learning process across borders and across professions. Terkel Andersen, President of EURORDIS – Rare Diseases Europe, will introduce the concept of empowerment for People Living With Rare Disease (PLWRD), discuss how empowerment may have an impact on policy level and present EURORDIS' recommendations for patient empowerment initiatives. There is a need to learn from each other across the region and share best practice examples in the field of support to self-care and health literacy as well as education and capacity-building targeted professionals. To improve the understanding of the true potential of increased patient empowerment among health care professionals, patients, their relatives and policy makers, we will investigate how empowerment works on both micro (patient) level; at macro (community) level and at policy level.

To introduce the third theme **'Patient's Access to Innovation'** Yann Le Cam, CEO EURORDIS, Member of ORPH-VAL Working Group, will present the recommendations from the European Working Group for Value Assessment and Funding Processes in Rare Diseases (ORPH-VAL). Further, Lieven Annemans, Professor of health economics, Ghent University, Member of ORPH-VAL Working Group, will share the findings of a new study on how the Nordic countries align with the nine European ORPH-VAL principles for assessment of medicines for rare diseases and a panel with representatives from the Nordic countries will discuss how patient's access to innovative medicines for rare diseases may be improved.

Elevating rare diseases as a health priority

The organizer and hosts of the Summit aim to ensure a lasting legacy of the event by inviting partners and endorsers to share a "Nordic Roadmap for Rare Diseases" setting out a common aspiration to elevate rare diseases as a national health priority in the Nordic countries. Further, Bertel Haarder, President of The Nordic Council, (MP) and former Minister of Health, Denmark, will reflect on the journey 'From the first National Strategy to a Common Nordic Roadmap for Rare Diseases'. Finally, key stakeholders from across the Nordic countries will comment on key take home messages from the summit and their priorities for the future. Confirmed are Pasi Nevalainen, Head of Rare Diseases Unit, Senior Consultant at Tampere University Hospital and Stinus Lindgreen, MP, (The Social-Liberal Party), Denmark.

For more information contact:

DENMARK & ICELAND	Hans Lynggaard Jørgensen, Senior Manager, Public Affairs & Communications, hans.lynggaard@takeda.com, mob: +4520805854
SWEDEN:	Carl-Johan Glans, Public Policy Lead, Carl-Johan.Glans@takeda.com, mob: +46703705010
NORWAY:	Eli Synnøve Gjerde, Patient Advocacy & Communication Lead, eli-synnove.gjerde@takeda.com, mob: +47 402 19 735
FINLAND:	Saku Torvinen, Head of Patient Value & Access and Public Policy, FI, Saku.Torvinen@takeda.com, mob: +358405511119

PARTNERS

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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).

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), The Norwegian Association of the Pharmaceutical Industry's rules (LMI rules) 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 program will ahead of the event be notified to 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.