NORDIC
RARE DISEASE
SUMMIT 2025

# Memorandum of Understanding

## BETWEEN

**Alexion Pharma Nordics AB (AstraZeneca Rare Disease)**
Hagaplan 4, 113 68 Stockholm, Sweden

**Novo Nordisk Health Care AG**
The Circle 32/38, 8058 Zurich, Switzerland

**Swedish Orphan Biovitrum AB (publ)**
SE-112 76 Stockholm, Sweden

**Takeda Pharma A/S**
Delta Park 45, 2665 Vallensbæk Strand, Denmark

**&**

**Sjældne Diagnoser**
Blekinge Boulevard 2, 2630 Taastrup, Denmark

**SBONN**
Nordic network for people living with rare diseases.

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*This Memorandum of Understanding covers the*

**Nordic Rare Disease Summit**
**and the launch of the Nordic Rare Disease Roadmap**
**across the Nordics and the EU**

(2024/2025)

## 1. Industry Partners and Patient Partners

The below undersigned Industry Partners:

**Alexion Pharma Nordics AB (AstraZeneca Rare Disease)**
Hagaplan 4, 113 68 Stockholm, Sweden

**Novo Nordisk Health Care AG**
The Circle 32/38, 8058 Zurich, Switzerland

**Swedish Orphan Biovitrum AB (publ)**
SE-112 76 Stockholm, Sweden

**Takeda Pharma A/S**
Delta Park 45, 2665 Vallensbæk Strand Denmark

*(here after referred to as "Industry Partners")*

And Patient Partners:

**Sjældne Diagnoser**
Blekinge Boulevard 2, 2630 Taastrup, Denmark

**SBONN**
Nordic network for people living with rare diseases.

*(here after referred to as "Patient Partners")*

The Industry Partners and the Patient Partners have entered the following non-binding Memorandum of Understanding ("MoU"). For the avoidance of doubt, this MoU replaces the latest version of the Memorandum of Understanding entered into in November 2021 between Takeda and Sjældne Diagnoser.

This MoU sets out to reflect the collaboration between the Industry Partners and the Patient Partners and outline how these partners will work together in 2024 and 2025 to launch the Nordic rare Disease Roadmap across Denmark, Finland, Norway, Sweden and at EU-level, as well as outlining how the partners will work together to co-host the Nordic rare Disease Summit under the Danish EU Presidency in 2025 ("Nordic Rare Disease Summit 2025").

Note should be taken that formal contracts between the partners might be needed for specific tasks that goes beyond the content in this MoU. Such contracts will be subject to separate discussions.

## 2. Launch of the Nordic Rare Disease Roadmap and Nordic Rare Disease Summit 2025

To raise awareness of rare diseases throughout the Nordic countries, the Industry Partners and Patient Partners mentioned above are in partnership organising the launch of Nordic Rare Disease Roadmaps (in Sweden, Norway, Finland, Denmark, and Brussels) and co-hosting the Nordic Rare Disease Summit, to take place under the Danish EU Presidency in 2025. The organisation and planning of the Nordic Rare Disease Summit and Roadmap launch is handled by FTI Consulting. The Industry Partners are contributing economically to facilitate the launch of the Nordic Rare Disease Roadmap, as well as the organisation of the Nordic Rare Disease Summit. The launch of the Nordic Rare Disease Roadmap, as well as the Nordic Rare Disease Summit are organised as non-promotional meetings.

The aim of the Roadmap launch and the Summit is threefold:

1. To raise awareness about the challenges faced by rare disease patients in the Nordics and across the EU, and to support the development of better policies and guidelines, enhancing the quality of life for those living with rare diseases in the region.
2. To share existing best practice examples (diagnosis and quality of care/treatment/services) and to foster consensus around solutions and approaches that should be broadly implemented.
3. To investigate how empowerment can be used as a resource for patients and their relatives to secure better outcome of diagnostic and care.

These aims will be pursued through:

1. The launch of the Rare Disease Roadmap (In Sweden, Denmark, Finland, Norway, and EU-level/Brussels).
2. The Rare Disease Summit's execution (programme, themes, speakers).
3. The launch and presentation of relevant evidence at the Nordic Rare Disease Summit, including a new study on patient empowerment.
4. The strengthening of relations between key stakeholders and follow-up collaboration for improvement of national rare disease plans.
5. Securing a lasting legacy of the Rare Disease Summit through building stronger collaboration between industry, academia, policymakers, and patient associations in the Nordics.

For the planning of the Nordic Rare Disease Summit, the Parties have had multiple discussions and will continue to work together and provide input to the planning and execution of the roadmap launch and Summit, as per this MoU. As further outlined below, the Industry Partners and Patient Partners will act as co-hosts of the Rare Disease Summit.

## 3. National and International Codes, Laws and Regulations

All involved partners will by signing this MoU commit to ensuring that activities for the roadmap launch and the summit itself adhere to the following: LIF Denmark's, LIF Sweden's, ENLI's, PIF's, LMI's, and EFPIA's Code of Practice on Relationships between The Pharmaceutical Industry and relevant stakeholders (Patient Organisations, Health Care Professionals, and Governmental Officials) as well as national and

EU regulations governing interactions between the pharmaceutical industry and patient organisations. The relation between the partners should also be fully compliant with Sjældne Diagnoser´s ethical guidelines for the collaboration with the pharmaceutical industry.

## 4. Scope

The launch of the Nordic Rare Disease Roadmap (in Sweden, Norway, Finland, Denmark, and Brussels) and the Nordic Rare Disease Summit will gather participants representing governments, national and regional institutions, international organisations, patient associations, health care professionals, academia, foundations, NGOs, and media. The majority of participants should come from countries within the Nordic region, representatives from European and international organisations and institutions will also be invited.

## 5. Roles and Responsibilities

**Secretariat**

FTI Consulting is acting as the secretariat for the launch of the Nordic Rare Disease Roadmap and for the organisation of the Nordic Rare Disease Summit.

FTI Consulting is working with the Industry Partners and the Patient Partners to:

1. Invite a balanced group of speakers consisting of both industry, policymakers, academia, and patient representatives to the Rare Disease Summit.
2. Have Nordic delegates present at the Rare Disease Summit.
3. Help identify Nordic delegates and invite them to the Rare Disease Summit.
4. Be responsible for organising the Rare Disease Summit:
   a. Facilitate and manage contacts with relevant external stakeholders (Remuneration in accordance with fair market value).
   b. Facilitate communication between the partners.
   c. Support the Rare Disease Summit in external communications before, during and after the Rare Disease Summit.

**Industry Partners and Patient Partners**

The Industry Partners and Patient Partners will work together to launch the Nordic Rare Disease Roadmap and they will provide input to the set up and design of the Rare Disease Summit. As such, the partners will:

1. provide input on:
   - Objectives and themes of the Rare Disease Summit;
   - Program and keynote speakers;
   - List of invitees and format for distributing invitations;
   - List of endorsers;
   - Communication strategy.
2. Allow FTI Consulting to use their name and logo in all communication materials related to the Rare Disease Summit.
3. Contribute with at least one speaker/panelist from their organisation to the Rare Disease Summit, subject to specific contract(s).
4. Suggest delegates to be invited to the Rare Disease Summit.
5. Be part of the strategy making regarding communications before, under, and after the Rare Disease Summit.

**Sponsoring partners**

The Industry Partners and Patient Partners may invite other selected parties as either “supporters” or “sponsoring partners” of the Nordic Rare Disease Summit. These will not have a seat on the Board, however, can have seats in selected committees and task forces as defined in the governance model. They may contribute to the Summit in the following way:

1. Take part in selected committee's and task forces.
2. Allow the usage of their name and logo as "supporters” and "sponsoring partners” of the Nordic Rare Disease Summit on branded materials in relation to the Rare Disease Summit.
3. Provide funding into the organisation of the launch of the Nordic Roadmap and the Nordic Rare Disease Summit 2025.

**Supporters: Nordic and European associations**

The Industry Partners and Patient Partners may invite other selected parties as “supporters” of the Nordic Rare Disease Summit 2025, such as, EURORDIS, a non-governmental patient-driven alliance of patient organisations and EFPIA and EUCOPE (European industry trade associations).

Supporters of the Summit may contribute to the Summit in the following way:

1. Provide input to agenda of the summit.
2. Take part in selected committee's and task forces.
3. Allow the usage of their name and logo as "supporters" of the Nordic Rare Disease Summit on branded materials in relation to the Rare Disease Summit.

**Expert Advisors**

The expert advisors will typically have a specific type of expertise of importance for the planning of the Nordic Rare Disease Summit. They may join Board meetings as expert advisors when invited. Expert advisors of the Summit may contribute to the Summit in the following way:

1. Provide scientific/expert input to agenda of the summit.
2. Take part in selected Board meetings, committee's and task forces.
3. Opportunity to use their individual names as expert advisor on materials in relation to the Rare Disease Summit.

## 6. Partners

Sjældne Diagnoser

**Sjældne Diagnoser**

**Alexion Pharma Nordics AB (AstraZeneca Rare Disease)**

SBONN

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**Novo Nordisk Health Care AG**

**Swedish Orphan Biovitrum AB (publ)**

**Takeda Pharma A/S**

## 7. Supporters

**Eurordis**

**Takeda:** C-ANPROM/BE/NON/0005_01.2025
**Alexion:** NORD/UNB-U/0014