



Copenhagen, 12 June 2019
Lene Jensen, Director
Sjældne Diagnoser
Blekinge Boulevard 2
2630 Taastrup
Denmark

Dear Lene Jensen,

Following a review of your proposal for sponsorship of the Cooperation Committee (Samarbejdsudvalget) for 2019, I am pleased to inform you that Shire – now part of Takeda, located at Dybendal Allé 10, 2730 Taastrup, Denmark ("Takeda" or "Sponsor") will be able to offer Sjældne Diagnoser ("Rare Diseases Denmark") financial support of DKK 12,500 (the "Membership fee").

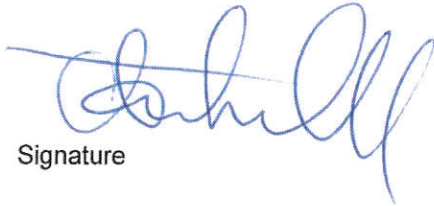
The purpose of our membership of the Rare Diseases Denmark's Cooperation Committee is to increase awareness of rare diseases and strengthen the voice of the rare patients. This is done through cooperation in issues of common interest. Furthermore, the Cooperation Committee will serve as a forum for exchanging experiences and information between Rare Diseases Denmark and involved companies.

The Membership will be subject to the following terms:

- I. The Membership is made in accordance with all relevant regulatory guidelines including, but not limited to the EFPIA (European Federation of Pharmaceutical Industries and Associations) Code, the Danish Ethical Rules for Promotion of Medical Products towards Health Care Professionals issued by The Ethical Committee for the Pharmaceuticals Industry in Denmark (ENLI), and all applicable legislation (including but not limited to anti-bribery/anti-corruption laws, the data protection laws and patient confidentiality laws). You agree to comply at all times with such guidelines and legislation. In accordance with such rules, Rare Diseases Denmark agrees that:
 - a. It is clearly declared that other pharmaceutical companies are supporting Rare Diseases Denmark as members.

Yours sincerely,

SHIRE DENMARK A/S – now part of Takeda



Signature

Name: Anna Lena Engwall


Title: Director of the Board Shire Denmark A/S

Date: June 12th 2019

AGREED TO AND ACCEPTED BY:

Lene Jensen, Director

Signature



Name:

LENE JENSEN

Title:

CEO

Date:

19/6-19

PromoMats Reference: C-ANPROM/DK/0240



Round Table Forum

For pharmaceutical companies with a focus on rare diseases

Since 2009, Rare Diseases Denmark (Sjældne Diagnoser) has had a Round Table Forum for pharmaceutical companies with a focus on rare diseases. The purpose of the Round Table Forum is to raise awareness of rare diseases and to strengthen the voice of patients and relatives afflicted by rare diseases. This is done through cooperation on problem areas of common interest.

Additionally, the Round Table Forum serves as a forum for exchange of experience and information between Rare Diseases Denmark and the companies.

Framework and membership benefits

The Round Table Forum meets as needed, typically 2-3 times a year. Companies that are a part of the Round Table Forum pay 12,500 DKK for this membership per year. Rare Diseases Denmark provides secretarial assistance, initiates and hosts the meetings.

- Members of the Round Table Forum will be called with the name and logo on Rare Diseases Denmark's website and in the Annual Report of Rare Diseases Denmark.

Guidelines

The Round Table Forum (2016) formulated the following core principles for the collaboration.

- The Round Table Forum is a joint forum for companies and Rare Diseases Denmark.
- The work is based on openness, transparency and mutual respect.
- The centre focus is on common agendas, not company-specific agendas.

Members of the Round Table Forum further undertake to accept and abide by Rare Diseases Denmark's Ethical Guidelines for the collaboration with pharmaceutical companies (see attached). The collaboration is also in accordance with the Patient Association Code formulated by the Ethics Board for the Pharmaceutical Industry, ENLI, see <http://www.enli.dk/media/49513/etiske-regler-for-samarbejde-patientforeninger-januar-2017.pdf>

Members of the Round Table Forum as per June 2019

- AKCEA Therapeutics
- Alexion
- Amicus Therapeutics
- Bayer
- BioMarin
- Celgene
- Chiesi
- CSL Behring
- Genzyme – a Sanofi Company
- Kyowan Kirin
- Recordati Rare Diseases / Orphan Europe
- Roche
- Santhera
- sobi
- Takeda



Ethical Guidelines

For Rare Diseases Denmark's collaboration with pharmaceutical companies

The following guidelines apply to the collaboration between Rare Diseases Denmark and pharmaceutical companies. By *Rare Diseases Denmark* it is understood here to mean the Executive Committee and the Secretariat, which is also called the *organisation*. By *pharmaceutical companies* it is understood here to mean the companies that have operations/activities pertaining to medicinal products for rare diseases.

Core Principles

- Each collaboration shall be subject to openness and Rare Diseases Denmark shall maintain complete independence in the case of the cooperation.
- Each collaboration shall be based on written agreements that are made available on Rare Diseases Denmark's website.

Financial Support

- Support is exclusively received for Rare Diseases Denmark's work, as well as participation in conferences that are relevant for its elected representatives and employees. Support can be direct financial support in the form of cash payments and/or support in the form of airline tickets, hotel accommodation or others.
- All agreements on financial support for Rare Diseases Denmark is handled by the President and the CEO.
- Rare Diseases Denmark shall not be or appear to be associated with any individual company.
- The overall financial support from the pharmaceutical industry must not have a scope or electrical nature that, in any way, casts doubt on Rare Diseases Denmark's independence.
- Funding and financial support should not be linked to specific conditions, apart from the funds' use for specific purposes.
- Member's of Rare Diseases Denmark's executive committee, employees and the secretarial service organisation shall not, in the capacity of their association with Rare Diseases Denmark, accept gifts of a value over 500 kr.

Mention of the cooperation

- The pharmaceutical company shall not have control of Rare Diseases Denmark's mention of cooperation.
- Any mention of a cooperation/collaboration with Rare Diseases Denmark, as well as the use of the organisation's name and logo must only take place after specific agreement with the President and the CEO of Rare Diseases Denmark.
- Rare Diseases Denmark does not recommend specific medicinal products or treatment methods.
- Rare Diseases Denmark mentions the cooperation on the organisation's website, such as financial grants from companies, apparent by the organisation's financial statement with the mentioned name of the grant-giving companies.

Appendix 1

Banking Details

Sjældne Diagnoser

Arbejdernes Landsbank

DK7853330000244622

Appendix 2

Membership Benefits

The Collaboration Committee meet 2 -4 times during 2019 discussing relevant topics for all members of the committee.

Sjældne Diagnoser acts as secretary to the Committee.