Sponsorship Agreement
Between
Chiesi and Patient Advocacy Group

This Sponsorship agreement ("Agreement") is made and entered into by and between Chiesi Pharma AB, registration no. 556827-5746, a company duly organized and existing under the laws of Sweden, with its principal place of business at Klara Norra Kyrkogata 34, 5th Floor, 111 22 Stockholm ("CHIESI")

and

Sjældne Diagnoser, registration no. 20514892, an organization duly organized and existing under the laws of Denmark, with its principal place of business at Blekinge Boulevard 2 DK - 2630 Taastrup ("PAG").

1. Background

Chiesi is active in the field of Rare Diseases and will sponsor a survey amongst people with rare diseases.

2. Sponsorship Project

Sjældnediagnoser (Rare Diseases Denmark) (PAG) seeks financial support for the following activities to take place in 2024. The sponsorship will be given in conjunction with the rare disease day.

Financial support to the able to conduct the premium customer survey (see attached description)

More companies in the field of rare diseases will be asked to support but Chiesi will be the first. ("Sponsorship Project").

3. The commitments of the parties

3.1 CHIESI shall be responsible to sponsor the Sponsorship Project with 6000 EUR

3.2 PAG shall be responsible for:
- i) Financial support to be able to conduct the survey
- ii) Post on the 29th that that Chiesi has give the amount to support the project)

3.3 The parties shall evaluate the activity within 30 days after the Sponsorship Project has been completed.

3.4 The contractual relationship with CHIESI shall be declared when a representative of PAG is writing or speaking in public about a matter that is related to this agreement or CHIESI.

4. Economy

4.1 CHIESI has agreed to finance the Sponsorship Project with 6000 EUR in regard to costs relating to the event, lecturers, moderators and project managers. The target group is patients. The parties shall bear their own administrative costs.

4.2 The financing provided by CHIESI shall only cover actual, documented, reasonable and direct costs that are necessary in order to carry out the Sponsorship Project, and PAG shall use the funding provided by CHIESI solely and exclusively for legitimate and fair market value expenses and activities of the Sponsorship Project, as specified in clause 2 above or the project plan as attached to this Agreement. The PAG shall invoice CHIESI upon completion of the Sponsorship Project. Payment shall be made by CHIESI no later than thirty (30) working days following receipt of invoice.

The invoice shall be addressed to:

Chiesi Pharma AB
Klara Norra kyrkogata 34, 5th floor
111 22 Stockholm, Sweden

Please send the invoice (pdf) by email to: invoice-se@chiesi.com

4.3 Unused budget resources shall be repaid to CHIESI without delay after the completion of the Sponsorship Project or immediately if the Sponsorship Project is cancelled or terminated.

4.4 PAG acknowledges that CHIESI's financial support of the Sponsorship Project is in no way an inducement to recommend, prescribe, purchase, supply, sell or administer a particular medicinal product, product or pharmaceutical company and does not support PAG's ordinary activities.

5. Transparency

5.1 The Parties agree that the content of this Agreement may be disclosed to third parties who shall also have the right to consult the Agreement. Informational material and invitations, if any, shall clearly state that it is a Sponsorship Project.

5.2 The Parties agree that information about the Sponsorship Project will be published in accordance with applicable (local) Pharma Industry Code of Ethics. The PAG is aware that CHIESI, in order to comply with applicable Pharma Industry Code of Ethics will publish information on the transfer of value made to the PAG.

6. Data protection

CHIESI and PAG act as data controllers and, thus, independently undertake at all times to comply with all applicable data protection laws and regulations applicable to the processing of personal data, hereunder - but not limited to - ensure legal basis for the processing of personal data (e.g. performance of contract, legitimate interest, consent etc.), provide the data subjects with information on the performed processing of personal data, ensure implementation of technical and organizational security measures, etc.

7. Contact and evaluation

7.1 PAG
Lene Jensen

7.2 CHIESI
Alice Wolf

7.3 After completed activity, the Parties should jointly evaluate the cooperation.

8. Contract time and early termination

8.1 This Agreement is valid from 2024-02-29 to 2024-12-31 or until the parties have fulfilled all obligations.

8.2 If any of the parties substantially breaches their obligations under this Agreement and does not take correction within thirty (30) days from the written request of the breaching party, the other party has the right to terminate this Agreement with immediate effect.

9. Independent Contractors

In making and performing this Agreement, the parties are acting and shall act at all times as independent contractors, and nothing contained in this Agreement shall be construed or implied to create any agency, partnership or employer and employee relationship between CHIESI and PAG. At no time shall any party make commitments or incur any charges or expenses for or in the name of any other party, other than as expressly set forth herein.

10. Dispute

This Agreement shall be governed by and construed in accordance with the laws of Sweden. If a dispute arises as a result of this Agreement, the parties shall first and foremost try to resolve the dispute through negotiations. In the event that the parties cannot agree within thirty (30) days after negotiations have been called for by one party, the dispute shall be resolved by the Swedish court, with the Stockholm District Court as first instance.

CHIESI Pharma AB

Patrick Svarvar, Head of Rare Diseases

[Place & Date]:
Stockholm 19.2.2024

Sjældne Diagnoser

Lene Jensen

Lene Jensen, CEO

[Place & Date]:
Høje Taastrup 21/2-2024

Attachment 1

Sjældne Diagnoser

Chiesi Pharma AB
Att.: Alice Wolf, Rare Diseases Manager Nordics
a.wolf@chiesi.com

Blekinge Boulevard 2
DK - 2630 Taastrup

Telefon: +45 33 14 00 10
mail@sjaeldnediagnoser.dk
www.sjaeldnediagnoser.dk

Under protektion af
H.K.H. Kronprinsesse Mary

06.02.2024/LeJ

Application "Premium costumer survey"

Who are we?
Rare Diseases Denmark is the Danish National Alliance for 55 small, voluntary based associations with app. 12,500 members with rare diseases and disabilities. Rare Diseases Denmark also hosts the Network for Ultra Rare Diseases, which has more than 1,000 members with ultra-rare diseases. All in all, Rare Diseases Denmark in our community has contact with people with a total of more than 500 different rare diagnoses.

What is the "Premium Customer Surveys"?
When the disease is rare, there is little knowledge about living with it. One of the tasks of Rare Diseases Denmark is to create and disseminate new knowledge about living with rare diseases and disabilities. In 2004, for the first time, we carried out a major questionnaire survey on the rare everyday life at the crossroads between the health system and the social system. We repeated the survey in 2014 and the results speak for themselves:

- More than half of PLWRD experience, that being rare is a "problem enforcer" when navigating the health care sector and the social system
- More than 1 out of 5 with severe loss of functional ability meet negative reactions from their healthcare professionals
- More than 3 out of 4 points out the need to contact other PLWRDs as the most important thing, when diagnosed.

The results of the surveys have been widely used as a source in various works on the living conditionsand challenges of rare citizens. We call the surveys the "Premium Customer Surveys"/"Guldkundeundersøgelserne", because rare citizens - patients and relatives - are frequent users in both the hospital system and the social system.

Attached is a poster about the studies to date, presented at the European Conference of Rare Diseases and Orphan Drugs 2016. For further details about the studies and their results, see https://sjaeldnediagnoser.dk/guldkundeundersoegelse/

It is our clear ambition to conduct the Premium Customer Survey again in 2024. By doing so, we can create a time series of unique data over a period of 20 years. Data that can contribute with important knowledge about the living conditions of rare citizens anno 2024. And which can also form a basis for analyzing the development of these living conditions over the past 20 years. Such data will help us in both our knowledge-creating and advocacy work for the benefit of all rare citizens across diagnosis.

In need of assistance

In both 2004 and 2014, we did the surveys in collaboration with excellent expertise in the field of disability policy research in Denmark. Thus, senior researcher, now emeritus Steen Bengtsson from the Social Research Institute (SFI2004)/The National Research and Analysis Center for Welfare (VIVE/2014) has assisted with the design of the questionnaire and the analyze of data. Steen Bengtsson has agreed to also participate in a third edition of the survey.

However, Rare Diseases Denmark does not have the financial means to carry out such a study, which has a total budget of €70,000:

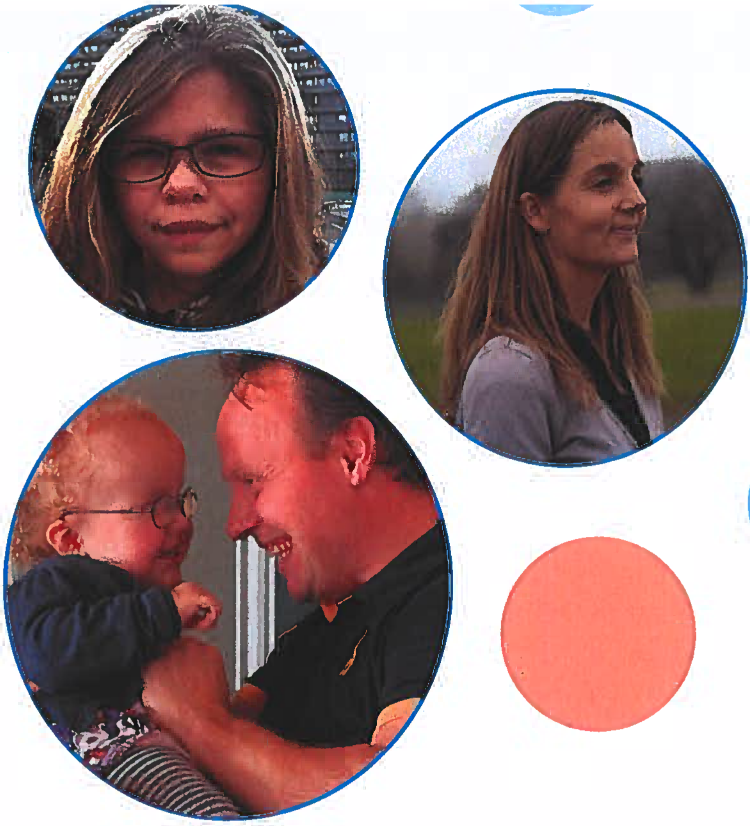
- Professional assistance from estimated, senior scientist(s): €20,000
  - Update of the questionnaire
  - Analysis of the data collected
- Working hours in the Rare Diagnoses secretariat: €40,000.
  - Preparation of the survey
  - Collection of data
  - Preparation of data for analysis
  - Reporting of data
    - Full report
    - Summary
- Publications and dissemination activities as well as administration and accounting: €10,000
  - Hybrid dissemination seminar in the The House of Disabled People
  - Print and distribution of reports
  - Full, audited accounts to be made public

Starting from the Rare Disease Day 2024, we are initiating a project to raise sufficient funds from foundations, pharmaceutical companies and others who will contribute to a stronger knowledge base about life with rare diseases and disabilities.

We would be very pleased if Chiesi would contribute to this work. We would be happy to announce on Rare Disease Day 2024 if Chiesi has made the first donation to the project. The contribution will also be mentioned at our website and in the reports published with the result. Also, all contributors will be invited to the Hybrid dissemination seminar.

With best regards

Lene Jensen, CEO



Rare Diseases Denmark

- Rare Diseases Denmark is a national alliance of 52 small rare disease societies. The societies are mainly run through voluntary work by patients and their relatives. Rare Diseases Denmark also hosts NURD – Network for patients and relatives affected by Ultra Rare Diseases.

- The work of Rare Diseases Denmark is based on volunteers and a minor professional secretariat.

- Rare Diseases Denmark has an ambition to work for all rare citizens, also those without a patient network or society.

- For more information: Contact
  - mail@sjaeldnediagnoser.dk
  - phone +45 3314 0010

- More than 3 out of 4 points out the need c table 2.

Table 2. What was needed the most, when the ra

Needed psychological help or crises counselling the most
Needed social counselling the most
Needed contact to other PLWRDs the most

Information and counseling

PLWRD experience, that their needs for inform organisations play an important role:

- More than 1 out of 3 is strongly unsatisfiec

- 9 out of 10 suffering severe loss of functior information is massive for all groups

- The most used counselling is the services c More than 60 pct. of the sum of counsellin

Social support from the public secto

8 out of 10 families with rare children and 2 ou system is intense. The 10 pct. of PLWRD who h 2014 and dealt with up to 30 different professi

- more than half of PLWRD suffering from a

- 3 out of 4 grown PLWRD with severe loss o public sector.

Being Ultra Rare

Rare Diseases Denmark hosts a Network for pa The survey shows, that members of the NURD

- The members of the NURD need even mor

- They need more help from psychologists a

- They are even more unsatisfied than other

Concluding remark

The title "Premium Customer survey" refers to t VIP treatment. The survey shows that this is ce survey conducted in 2005, there have only bee