



SPONSORSHIP AGREEMENT

("Agreement")

between

Kyowa Kirin AB

Organisation No.: 556662-3038

Torshamnsgatan

39 164 40 Kista

Sweden

("Kyowa Kirin")

And

Sjældne Diagnoser/Rare Diseases Denmark

Blekngø Boulevard 2

DK-2630 Taastrup

("Organiser")

Organiser and Kyowa Kirin may be referred to individually as "Party" or collectively as "Parties".

1. OBJECTIVE

1.1 Organiser has asked Kyowa Kirin to sponsor the Rare Disease Day ("Event"). The Event will be held on 29th February 2024.

Further description on the Event, including a budget for the event, is inserted in Appendix 1.
In connection with such sponsorship, Kyowa Kirin will receive the following benefits in return:

1.2 Kyowa Kirin shall be designated as sponsor to the Event. This among other things means that Organiser will state that: *"This event has been sponsored by Kyowa Kirin AB"* or other statement agreed between the Parties in invitations, programs, and other relevant documents, related to the Event, including the Organiser's website or a designated website for Third Party Event. The declaration of sponsorship must be sufficiently prominent to ensure that participants, other sponsors, beneficiaries and others in the sponsored activity in an appropriate time before the activity are aware of the sponsorship from the outset. Acknowledgement of the sponsorship shall be made, using Kyowa Kirin's name and/or logo in accordance with Appendix 2.
The Parties agree to adhere to Swedish law and regulations, including *Läkemedelsbranschens etiska regelverk* ("LER").



2. FINANCIAL FUNDING

- 2.1 Kyowa Kirin shall provide financial support to Organiser in the amount of **20,000 Danish Kroner** (“Sponsorship”). The aforementioned amount is exclusive of VAT which the Organiser shall charge in accordance with applicable laws. Sponsorship shall be invoiced detailing which elements of the Event that the funding is covering. Subject to the provisions set forth in Article 3 Organiser agrees to use the financial funding primarily for professional content.
- 2.2 The Sponsorship shall be used solely for the Event and for actual, documented, reasonable and direct costs, e.g. venue hire, speaker fees, educational materials, reasonable meals and similar. Travel and accommodation for individual participants may not be funded as part of the Sponsorship. Organiser cannot use the Sponsorship to cover other types of costs associated with the Event or for other purposes, e.g. to finance regular day-to-day activities of the Organisation. Any unused funds shall be returned. If the Event should be terminated for whatever reason, Organiser is obligated to return to Kyowa Kirin any unused funds within three (3) months of such termination. Kyowa Kirin may after the conclusion of the Event also ask Organiser for subsequent evidence in the form of accounts in which the Event's income and expenditure is accounted for.
- 2.3 The amount specified in Article 2.1 is exclusive of direct or indirect taxes and the total remuneration to be paid by Kyowa Kirin under this Agreement cannot be increased by direct or indirect taxes or fees of any kind levied by governmental authorities or other local authorities. Such taxes include but are not limited to excise duties, sales tax, stamp duty and customs duty levied on imports. Responsibility of payment of any taxes, if applicable, will be the responsibility of the organisation. In the event the Consultant is a VAT registered organisation, an invoice is to be issued to Kyowa Kirin shall as a minimum state (i) Kyowa Kirin’s company name, address, contact information, VAT/Org no., (ii) the date of invoice, invoice number, (iii) a reference to the Sponsorship and (iv) bank details.
- 2.4 Kyowa Kirin shall pay the sponsorship funds in accordance with this Agreement by no later than sixty (60) days following receipt of the Organiser’s invoice. The invoice from the Organiser shall state (i) Organiser’s name, address and VAT number (ii) invoice number and the amount payable, (iii) name and date of the activity, (iv) Organiser’s bank details (Giro, IBAN and SWIFT Code mandatory) and (v) Kyowa Kirin’s contact person Victoria Hayes and VAT/organisation number.

The invoice can be sent electronically to the following inbox: kki-nordics-finance@kyowakirin.com.

3. OBLIGATIONS

- 3.1 Organiser undertakes to comply with all applicable laws, regulatory requirements, and guidelines in force from time to time. Such compliance shall be the sole responsibility of Organiser requiring no supervision, direction, responsibility, or liability on behalf of Kyowa Kirin. As a part of the obligations under this Article 3.1 the Organiser will among other things ensure that the venue for the Event is appropriate.
- 3.2 Organiser is solely responsible for the execution of the Event and/or the activities to be performed as part hereof. Organiser has the full proprietary rights of the outcome of the Event.



Kyowa Kirin shall not influence any material which Organiser produces as part of the Event in a manner favourable to Kyowa Kirin's commercial interests.

4. TRANSPARENCY

4.1 Kyowa Kirin is, according to an increasing number of national laws or pharmaceutical industry standards, required to ensure pre-approval, tracking, reporting and/or public disclosure of all direct and indirect transfers of value, whether in cash, in kind or otherwise, ("Transfer of Value") made to or for the benefit of, inter alia, a Patient Organization. Accordingly, when such national laws or pharmaceutical industry standards apply, Kyowa Kirin is obligated to disclose information regarding the Transfer of Value, for example on Kyowa Kirin's website and/or to relevant industry bodies or authorities (who may publish the information on their websites).

Kyowa Kirin is obligated to publish a summary of the Sponsorship in LIF's database in accordance with Chapter 3, 1 in LER. The information is published for a duration of 3 years from the date of publication.

4.2 The content of the Agreement may be published on Kyowa Kirin's corporate website and/or on that of Kyowa Kirin's affiliate in the country where the Organisation has its address. If the Agreement on information herein is published, the information will be available at all times during the period when the Agreement is in force and as long as required by applicable laws and regulation.

4.3 Organiser hereby acknowledges and accepts that Kyowa Kirin will publicly disclose the information provided by the Receiver as set out in this Article 4.

4.4 Organiser may be required to publish the content of this Agreement on their website. Organiser must declare receipt of funding from Kyowa Kirin if required to do so by applicable laws or codes.

5. PUBLIC USE OF NAME AND LOGO

5.1 Organiser accepts that Kyowa Kirin may use Organiser's name on Kyowa Kirin's website in order to fulfil the requirements in applicable regulations as stated in Article 4.4 and in accordance with Article 5. Except as permitted under Article 1, Organiser may only use Kyowa Kirin's name and/or logo if specifically accepted by Kyowa Kirin in a separate agreement.

6. INDEPENDENCE

6.1 Organiser will act independently of Kyowa Kirin and shall always perform in its own name and for its own account for all purposes. This Agreement is not intended as, nor shall it be construed to create a partnership or joint venture between the Parties. Neither Organiser nor any of its representatives shall be employees or agents of Kyowa Kirin.

6.2 Both Parties agree that this Agreement shall in no way prevent Organiser from collaboration with other companies or Kyowa Kirin from cooperating with other organisations.

6.3 Kyowa Kirin will not impose any conditions upon Organiser with regard to Organiser's academic or political views and Kyowa Kirin holds no chair or position in Organiser, which will affect the collaboration under this Agreement. Further the Sponsorship from Kyowa Kirin do not constitute an inducement to recommend, prescribe, purchase, supply, sell or administer specific medicinal products.



7. BREACH

7.1 Failure or breach by either Party to comply with any of the obligations and conditions hereof, shall entitle the other Party to terminate the Agreement by giving notice to take effect immediately and/or to invoke any applicable remedy for breach under Swedish law, including the right to claim compensation for damages.

8. TERM

8.1 This Agreement shall become effective on the date of the last signature of a Party and shall continue until event has been completed.

9. GOVERNING LAW AND VENUE

9.1 Any dispute arising from or relating to this Agreement shall be governed by, construed and settled in accordance with Swedish law, without regard to its conflict of laws rules. In the event of any controversy or claim arising out of or relating to any provision of this Agreement or the breach, termination or invalidity thereof, the Parties shall try to settle the problem amicably. Should they fail to agree, the matter in dispute shall be settled by arbitration.

10. MISCELLANEOUS

10.1 Any change of or amendment to this Agreement shall be agreed upon in writing by both Parties.

11. SIGNATURES

This Agreement has been made in duplicate and signed by the Parties hereto.

Kyowa Kirin AB
Place: 01 August 2023 | 01:52:04 PDT
Date: _____

x
Place: 01 august 2023 | 10:30:02 BST
Date: _____

Kyowa Kirin AB

Organiser

vicky Hayes

Lene Jensen

DocuSigned by:
Vicky Hayes
D3D16DE08D864C7...

DocuSigned by:
lene Jensen
4AE0EE0921A54C4...

APPENDIX 1

Support rare visibility and community Have you ever heard of Bardet-Biedl syndrome, Osteogenesis Imperfecta or Gaucher disease? These are three of the approx. 1,500 different rare diagnoses present in Denmark. In general, they are congenital, have a genetic origin and they are severe. None of them can be cured and treatment is only available for a few. Many of the patients are children. But there is hope. New and better tools for diagnostics and treatment are emerging. At the same time, there is also an increased interest in the rare life - e.g. "The rare Danes" on national TV2 gives all "Family Denmark" the opportunity to have a look into everyday life with a rare disease. Nevertheless, it is still the case that attention and resources are concentrated on the large patient groups. It is important to create visibility about the common issues experienced by rare patients and their families. It is also important to create a community for people living with a rare disease. An obvious platform for both visibility and community is Rare Disease Day/Sjældne-dagen. The next Rare Disease Day will take place in 2024 on the rarest date of all: February 29. Rare Disease Day is celebrated in more than 100 countries around the world. For Rare Disease Day 2024, Rare Diseases Denmark focus on the importance of the small voluntary rare associations for community. It is in the associations and in the Network for Ultra Rare Diseases and other networks people with rare diseases find each other. Together they find their way to knowledge and information about living down their rare diagnosis. The experiencebased knowledge is essential to be able to handle the rare everyday life. We are planning several activities and efforts in connection with Rare Disease Day - you can read more about them in the attached project description. We need your help. The implementation and impact of Rare Disease Day depends on donations from foundations, endowments, companies, and others who can and will contribute.

Budget for Rare Disease Day 2024 Budget totaling: 550.000 DKK

1. Exhibition in The House of Disability Organizations in February, budget: DKK 85.000
 - a. Selfie booth rental (also used for joint event)
 - b. Association portraits (also used at Christiansborg and for joint event) – 1 roll up for each member association + the "Sjældne-netværket", a total of 56 roll ups
2. Marking on social media, budget: DKK 5.000
 - a. Visibility campaign and announcement for mail event
3. Rare Disease Day on 29 February 2024, mail event, budget: DKK 250.000
 - a. Rare Disease Day at Christiansborg
 - i. Room rental and other meeting costs
 - ii. Light catering
 - iii. Possibly fees for professionals
 - iv. Transport costs
 - b. Rare Disease Day march in public
 - i. Many colored Gloves
 - ii. Tote bags
 - iii. Glow sticks
 - iv. Signs with association names
 - v. Alternative transport
 - vi. Light catering
 - vii. Information materials for distribution
 - c. Joint event in central Copenhagen
 - i. Rent of premises
 - ii. Possibly fees
 - iii. Various materials for activities
 - iv. Catering
 - d. Regional/local activities
 - i. Basic budget for own activities
 - ii. Package with information materials and other visuals
 - e. Documentation of Rare disease day 2024
 - i. Photojournalist/photographer
4. The Rare Prize", budget: DKK 20.000
 - a. Materials for making the Rare Prize brooch /sculpture
5. Project management, auditing and expenses derived from volunteers, budget: DKK 195.000.
 - a. Salary, project manager DKK 130.000
 - b. Other working hours in the Rare Diagnoses secretariat DKK 30.000
 - c. Expenses derived from voluntary labor DKK 15.000
 - d. Audit project accounts and other administration DKK 15.000



APPENDIX 2

Kyowa Kirin's corporate logo:

