

## SPONSORSHIP AGREEMENT

This sponsorship agreement (the “**Agreement**”) is made effective as of 3. June 2026 (the “**Effective Date**”), between Swedish Orphan Biovitrum A/S, Sorgenfrivej 17, 2800 Lyngby (“**Sobi**”) and Sjældne Diagnoser, Blekinge Boulevard 2, 2630 Taastrup (“**Recipient**”). The above Parties may also be referred to jointly as the “**Parties**” and individually as “**Party**”.

WHEREAS, Sobi A/S is an affiliate of an international biopharmaceutical company dedicated to rare diseases;

WHEREAS, Recipient is Patient Organisation and

WHEREAS, Sobi has agreed to sponsor the flight of 360 Euro for one participant from Sjældne Diagnoser in attending in European Conference on Rare Diseases & Orphan Products (ECRD) (the “**Event**”) on the terms and conditions set out below.

NOW, THEREFORE, the parties agree as follows:

### 1. TERMS AND CONDITIONS OF SPONSORSHIP

- 1.1 Sponsorship: Sobi hereby agrees to sponsor the Event by paying the total amount of 360 Euro for the purpose as specified in Schedule 1. (the “Sponsorship”).
- 1.2 Scope: The Sponsorship shall only cover actual, documented, reasonable and direct costs that are necessary in order to carry out the Meeting, as further specified in Schedule 1. Recipient warrants that Sobi’s support under this Agreement shall be used solely for the Sponsorship in compliance with this Agreement, that the Sponsorship and Event will be carried out in accordance with all applicable laws, regulations and in-dustry code requirements, including without limitation, any transparency regula-tions and disclosures (“Applicable Law”) and that any activities performed and ma-terials generated in connection with the Event shall comply with Applicable Law.
- 1.3 Follow-up and Repayment: Within thirty (30) days of the Event, Recipient shall provide Sobi with a signed declaration that the Event has taken place and the funds provided under the Sponsorship used in full in accordance with the terms of this Agreement or inform Sobi if any funds provided remain. Recipient undertakes to repay refundable parts of the Sponsorship if the Event is cancelled, if this Agreement is terminated pursuant to Section 3.5 or if there are any remaining funds after the Event. Such payment shall be made within thirty (30) days of the cancellation, termination or Event.

- 1.4 Benefits of Sponsorship: In return for Sobi sponsoring the Meeting Recipient shall provide Sobi with the benefits specified in Schedule 2.
- 1.5 Payment:
- 1.6 The Sponsorship will be paid as specified in Schedule 1.
- 1.7 Payment Terms: All payments hereunder shall be made within thirty (30) days via bank transfer or from receipt of invoice provided that the following conditions shall have been met: invoices shall be specified as to Sobi contact person Mia Enochsén. Sobi's invoice address is: Sobi, Sorgenfrivej 17, 2800 Lyngby.
- 1.8 Use of Sobi name: Recipient shall only use the name and logotypes of Sobi, in publications, presentations, programmes, other printed or orally presented materials or otherwise, after prior review and approval of Sobi.
- 1.9 Publication of Sponsorship: Recipient undertakes to declare that the Event has been sponsored by Sobi whenever any written or oral information is shared in public about the Event. If Recipient has a website, then this shall include publishing information of the Sponsorship on its website. Sobi may use the name or logo of Recipient to publish the Sponsorship on its website, as well as reporting it to all local governing bodies, as appropriate, in accordance with transparency requirements. No inducement: Recipient acknowledges that provision of the Sponsorship is in no way an inducement to recommend, prescribe, purchase, supply, sell or administer a particular medicinal product.
- 1.10 Hospitality, programme and venue of the Meeting: The Recipient represents and warrants to Sobi that
- (a) Hospitality made directly or indirectly available during the Meeting shall be kept at a reasonable level and remain secondary to the principal scientific purpose of the Meeting, be limited to the organisation and/or defrayment of the costs of travel, meals, accommodation and registration, shall not extend beyond the official duration of the Meeting and shall not include payment for or the organization of sports or leisure activities or any other form of entertainment;
- (b) The value of meals provided, drinks included, shall not exceed the limits laid down by Applicable Law, including applicable local industry guidelines;
- (c) The Meeting shall be predominantly scientific in nature and activities with a scientific purpose shall, in terms of time, take up the greater part of each

day of the Meeting; and

(d) The Meeting shall take place at a suitable venue that aids the scientific purpose of the event and the place, date and duration of the Meeting and travel shall not in any case be of a nature to create any uncertainty as to its scientific nature.

(e) Where applicable, a positive e4ethics assessment has been obtained for the Event, as required under the EFPIA Code, a copy of which shall upon request be provided to Sobi.

## **2. DATA PRIVACY AND TRANSPARENCY**

2.1 EU privacy law requires that Sobi provide Recipient and/or its representative(s) notice that Sobi and its group companies may collect, use and retain such representatives' personal data (e.g. name and contact details) provided in this contract Agreement for administration, reimbursement, and internal evaluation purposes. Sobi will process the personal data to the extent necessary to fulfil Sobi's duties under this contract Agreement and for the purpose of Sobi's legitimate interest as contractor. Sobi may share the representatives' personal data within the Sobi group and with Sobi service providers and agents for the purposes stated in this Section 3.1. Such sharing may include transfer to third countries, i.e. countries outside the EU/EESA area. When transferring the representatives' personal data to third countries, Sobi will ensure that the transfer is subject to appropriate safeguards and that the representatives' rights are protected. Typically, Sobi will enter into standard contractual clauses adopted by the eu commission with companies in third countries receiving personal data from Sobi. Sobi applies different retention periods for different categories of personal data. When processing of the repre-sentatives' personal data is no longer necessary in relation to the purpose for which it was collected Sobi will erase the personal data. The representatives have the right to access the personal data that Sobi processes concerning the repre-sentatives and to request that Sobi rectifies any inaccurate personal data and un-der certain circumstances request erasure and/or restriction of processing of the personal data. The representatives have the right to object to processing and to receive the processed personal data in a structured, commonly used and machine-readable format and has the right to transmit those data to another controller. The representatives also have the right to lodge a complaint to the local supervisory authority ("Datatilsynet") regarding how Sobi processes such representatives' personal data. Recipient undertakes to share the information pro-vided in this Section 2.1 with all representatives

engaged by Recipient or on its behalf in connection with this Agreement and whose personal data will be shared with Sobi..

2.2 “Parties”/”Party” further acknowledges and agrees that Sobi has an annual reporting obligation to ENLI (Ethical Committee for the Pharmaceutical Industry) about the HCO/PO they have had a relationship with during the year.

2.3 In addition, “Parties”/”Party” acknowledges and agrees that Sobi documents all relationships required to be disclosed with ENLI and maintains the relevant records of the disclosures for a minimum of 5 years after the end of the relevant reporting period (unless a shorter period is required under applicable national data privacy or other laws or regulations). Thereafter the data will be deleted by Sobi.

### 3. MISCELLANEOUS

3.1 **Entire Agreement:** This Agreement, including its Schedules, constitutes the entire understanding between the parties with respect to the subject matter hereof and supersedes all prior oral or written agreements of the parties with respect to such subject matter

3.2 **Amendments:** No provision of this Agreement may be amended, modified or otherwise changed, other than by an instrument in writing duly executed on behalf of the parties to this Agreement.

3.3 **Assignments:** This Agreement is personal to the parties who shall not have any right to assign it without the prior written consent of the other party, except that Sobi shall have the right to assign the Agreement to its affiliates.

3.4 **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 Sobi and Recipient. 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.

3.5 **Termination:** Without limiting any rights or remedies under the governing law pursuant to Section 2.7, Sobi is entitled to terminate this Agreement at any time with immediate effect if in Sobi’s reasonable opinion the PCO and/or the HCO commits a material breach of any of its undertakings pursuant to this Agreement,

in which case the PCO promptly shall see to it that all references to Sobi are removed from any Meeting announcements and materials.

- 3.6 Survival: Sections 1.3, 1.9, 2.6, 2.7, 2.8, 3.2 shall survive the termination or expiration of this Agreement.
- 3.7 Governing Law: This Agreement shall be governed and construed by the substantive laws of Denmark. Any dispute, controversy or claim arising out of or in connection with this Agreement, or the breach, termination or invalidity thereof, shall be finally settled by the courts of the above said country..

**Signatures to follow on the next page.**

This Agreement has been signed by each Party's duly authorized signatory(ies). This Agreement may be executed in one or more counterparts, each of which shall be deemed to be an original and all of which shall constitute together one and the same document. The Parties agree that the execution of this Agreement by electronic means using standard industry signature software and/or by exchanging PDF signatures shall have the same legal force and effect as the exchange of original signatures, and in any proceeding arising under or relating to this Agreement, each Party hereby waives any right to raise any defense or waiver based upon execution of this Agreement by means of such electronic signatures or maintenance of the executed Agreement electronically.

**Swedish Orphan Biovitrum A/S**

**Sjældne Diagnoser**

DocuSigned by:  
*Mia Enochsén*  
D16E8BF483E3474...

Signed by:  
*Dorit Wahl-Brink*  
5D73146B537F444...

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Name: Mia Enochsén  
Title: Country Manager Denmark/Iceland  
Date: 09-Feb-26

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Name: Dorit Wahl-Brink  
Title: CEO Sjældne Diagnoser  
Date: 16-Feb-26

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## SCHEDULE 1

### SPONSORSHIP AND COSTS

Sobi has agreed to sponsor the flight (economy class) of 360 Euro for one participant from Sjældne Diagnoser in attending in European Conference on Rare Diseases & Orphan Products (ECRD) 2026 in Prag.

#### Budget for Participation

The costs of participating in the ECRD are substantial for an organisation like Rare Diseases Denmark, which operates with very limited funds. The estimated budget for one patient representative participating in the conference is approximately €1,160:

- Registration fee: €130
- Transport: o Domestic transport: €50
- Flight (economy class): €360
- Transport to and from the venue: €50
- Accommodation: Three nights in a 3–4 star, handicap-friendly hotel: 3 × €190 = €570

## **SCHEDULE 2**

### **BENEFITS OF THE SPONSORSHIP**

ERCD is the largest patient-led, policy-shaping event on rare diseases in Europe. In 2026 the conference theme is Rare Diseases in a Changing & Competitive Europe. Shaping policies to address the unmet needs of people living with rare diseases. The conference brings together people living the rare diseases and patient advocates alongside policymakers, healthcare industry representatives, clinicians, regulators, and member State officials.

As a partner at the The Nordic Rare Disease Summit 2025 Sobi wants to point out the importance of a larger (European) collaboration and network. Especially within the Rare Disease area.

**SCHEDULE 4****PRIVACY CONSENT FORM**

Apart from personal data listed and addressed in Article 3.1 of the Agreement, Sobi will, based on your explicit consent freely chosen to be given by you in this Privacy Consent Form, process also your personal information on medical condition, any Recording (audio/video) of yourself, and your affiliation with organizations (“**Personal Data**”).

Sobi is the data controller for the processing of the Personal Data which means we decide how to use it and are responsible for looking after it in accordance with the relevant legislation, including the General Data Protection Regulation (GDPR).

**How we use the Personal Data**

We will use the Personal Data for the purposes as set out in the Agreement, including Schedule 1 of the Agreement, specifically for the purpose of performing the Assignment and related activities described in this Agreement.

We are processing Personal Data for these purposes only because you have given us your consent to do so, by signing this Privacy Consent Form.

You can withdraw your consent at any time by contacting us at the address set out below. In this event, we will stop the processing as soon as we can. However, this will not affect the lawfulness of any processing carried out before your withdrawal of consent. Furthermore, Sobi will not be able to remove Personal Data appearing in publications already in circulation.

We will only use the Personal Data for the purposes for which we collected it, unless we reasonably consider that we need to use it for another related reason and that reason is compatible with the original purpose. If we need to use the Personal Data for an unrelated purpose, we will seek your consent to use it for that new purpose.

**Who has access to your Personal Data?**

Access to Personal Data within Sobi, and Sobi group companies, will be provided to those who need to view it as part of their work in carrying out the purposes described above.

We may share the Personal Data with companies who provide services to us, such as e.g. printing, web hosting, consulting services. These companies are required to take appropriate security measures to protect the Personal Data in line with our policies. We do not allow them to use the Personal Data for their own purposes. We permit them to process the Personal Data only for specified purposes and in accordance with our instructions.

We may also share the Personal Data with other recipients if legally required or if required by the relevant pharmaceutical trade associations.

**Retaining the Personal Data**

We will only retain the Personal Data for as long as we need it to meet our purposes, including any relating to legal, accounting, or reporting requirements.

**Transfer of Personal Data outside the European Economic Area (“EEA”)**

The Personal Data may be transferred outside the EEA when Personal Data is published, e.g.,

on the internet, social media etc. Furthermore, Sobi may transfer the Personal Data to its group companies and service providers outside EEA, when doing so we will enter into a personal data sharing agreement to protect the Personal Data.

**By signing this Privacy Consent Form, you confirm that you understand that the Personal Data shared outside the EEA may not be subject to the same level of protection as in the EEA and you approve of such sharing outside EEA.**

### **Your rights**

If you want us to stop using the Personal Data, we ask you to contact Sobi's data protection officer using the contact details below. We will then no longer use the Personal Data in new material, but Personal Data may continue to appear in publications already in circulation.

You have the right at any time to request from Sobi access to and rectification, or erasure of the Personal Data, or restriction of processing, or to object to processing as well as the right to data portability by contacting Sobi at [privacy.dk@sobi.com](mailto:privacy.dk@sobi.com). If you have any comments or complaints regarding the way Personal Data is being handled, you also have the right to contact the supervisory authority in Denmark (Datatilsynet) in the country where you live, to lodge a complaint.

Depending on the circumstances and the nature of your request, it may not be possible for us to do what you have asked, for example, where there is a statutory or contractual requirement for us to process your Personal Data and it would not be possible to fulfil our legal obligations if we were to stop.

### **Contact**


If you wish to raise any queries or concerns about our use of your Personal Data, please contact us at [privacy@sobi.com](mailto:privacy@sobi.com)

**Please tick one of the boxes below indicating your position on Sobi's processing of your Personal Data as described in this Privacy Consent Form and date and sign this Form.**

- x  **I consent** to Sobi's processing of my Personal Data as explained in this Schedule 4.
- I do not consent** to Sobi's processing of my Personal Data as explained in this Schedule 4.

I have the right to be informed if the processing of my Personal Data is affected in a way that may have a negative impact on me. For this purpose, I provide my email address or phone number to enable Sobi to contact me.

**Signed by Speaker:**

Signed by:  
  
5D73146B537F444...

Name: Dorit Wahl-Brink

Date: 16-Feb-26

Email address: [dwb@sjaldnediagnoser](mailto:dwb@sjaldnediagnoser)