



Berga Backe 2, Box 712, 182 17 Danderyd, Sweden

## **Patient Organisation Agreement**

This Patient Organisation Agreement has been drawn up and entered into as of 22 March 2024 by and between

**CSL Behring AB**, Box 712, 182 17 Danderyd, SWEDEN, Reg. no. 556530-1974

and **Sjaeldne Diagnoser Blekinge Boulevard 2, 2630 Taastrup, Denmark**

CVR-nr.: DK20514892, [lj@sjaeldnediagnoser.dk](mailto:lj@sjaeldnediagnoser.dk)

### **1. Background**

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.

### **2. Collaboration project**

#### **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 + VAT for this membership per year. Rare Diseases Denmark provides secretarial assistance, initiates and hosts the meetings.

#### 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 center 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 [etiske-regler-for-samarbejde-med-patientforeninger-version-30-juni-2022.pdf \(enli.dk\)](#)

### **3. Finances**

3.1 CSL Behring AB has undertaken to finance Rare Diseases Denmark's Round Table Forum with 12.500 DKK for raising awareness of rare diseases and strengthen the voice of patients and relatives afflicted by rare diseases. This is done through cooperation on problem areas of common interest. Payment shall be made against separate invoice. The invoice shall be sent to [DanderydPayables@cslbehring.com](mailto:DanderydPayables@cslbehring.com)



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State Marie Platon as reference on the invoice.

#### **4. Transparency**

4.1 Both Parties consent to the contents of this Agreement being shared with a third party.

4.2 Both parties consent to this agreement or a summary thereof being published on the company website and reported to ENLI in accordance with § 3 of the Patient Organizations Code regulated by the Ethical Committee for the Pharmaceutical Industry, ENLI.

#### **5. Consultation, evaluation**

5.1 Sjaeldne Diagnostiser has appointed Director Lene Jensen as their contact person in matters concerning this Agreement.

5.2 CSL Behring AB has appointed General Manager Lise Grove as their contact person in matters concerning this Agreement.

5.3 After completion of the project, the Parties shall jointly evaluate "Round Table Forum" and their collaboration in relation to this project.

#### **6. Agreement period and early termination**

6.1 This Agreement is valid from 01/01/2024 until 01/01/2025.

6.2 If either party fails to fulfil their obligations pursuant to this Agreement and adjustments have not been made within thirty (30) days of the party being requested in writing to do so, the other party will be entitled to terminate the Agreement immediately.

#### **7. Ethical rules and law**

7.1 Ethical rules and national law apply to this agreement. Sjaeldne Diagnostiser warrants that it will only use the funds received in accordance with national law and the Pharmaceutical Industry's Code of Ethics.

7.2 Sjaeldne Diagnostiser may not refer to or make any representation relating to CSL Behring or its products or the co-operation under this agreement without CSL Behring's prior written approval. Sjaeldne Diagnostiser shall submit all proposed materials mentioning CSL Behring, or referring to CSL Behring's products, or the co-operation under this agreement, to CSL Behring for written approval prior to publication or use.

#### **8. Disputes**

If a dispute should arise in conjunction with this Agreement, the Parties shall primarily attempt to resolve it through negotiation. In the event that the Parties are unable to reach an accord within thirty



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(30) days of the initial request for negotiation, the dispute shall be resolved in a Swedish Court.

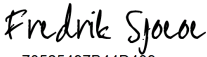
**9. E-signature**

The Agreement may be executed by means of wet ink signatures or by using electronic signatures. If the Agreement is signed using electronic signatures, in making proof of this Agreement, an electronic copy of the Agreement will suffice. The Parties undertake not to dispute the validity of the Agreement based on the signatures being electronic.


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This Agreement has been drawn up and signed in two (2) identical originals, of which each party has received an original.

Kgs. Lyngby on March 22-2024:  
**CSL Behring AB:**

DocuSigned by:  
  
3D5F992D0231447.....  
Lise Grove, General Manager Denmark:

DocuSigned by:  
  
70525497B44D409.....  
Fredrik Sjöo/Head of Medical Affairs

Taastrup on March 22-  
2024:  
**Sjaeldne Diagnostiser:**

DocuSigned by:  
  
4AF0FE0921A54C4:..  
Lene Jensen, Director