



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 18 June 2024 by and between

CSL Behring AB, Box 712, 182 17 Danderyd, SWEDEN, Reg. no. 556530-1974 (thereafter CSLB)

and

HAE Scandinavia Vejlevej 16, 1., 8700 Horsens, Denmark, 31981670, hbb@haescan.org

1. Background

HAE Scandinavia focuses to improve quality of life and to support patients and their caregivers in Denmark, Sweden and Norway. The organization is working to establish a stronger collaboration between different stakeholders within the HAE field to enable optimal treatment and management of HAE patients and to raise awareness of the disease. CSLB operates in the HAE field by improving treatment for patients. There is a common interest in improving HAE treatment and care and to drive advocacy for improved patient access to treatment and care.

2. Collaboration project

The objective of this survey study is to capture the patients' and caregivers' satisfaction and perception on current HAE treatment options available in the Nordics and to assess potential unmet needs regarding treatment and beyond.

CSLB is responsible for

- Survey development in local language (SE, NO, DK), programming and generation of generic survey links and QR-codes
- Provide HAE Scandinavia with a survey invite text (inclusive texts for reminders) in local language (SE/DK/NO) and country-specific generic survey links as well as country-specific QR-codes
- Data collection and analysis

HAE Scandinavia is responsible for

- Sending the survey invitation (incl. generic links) through e-mail to their registry of members in SE/DK/NO (patients and caregivers)
- Sending the survey invitation (incl. QR-codes/generic links) via additional member channels upon consultation with CSLB
- Sending 2 reminders with revised text provided by CSLB, via the same channels used for sending the survey invitations in SE/DK/NO, respectively

General terms and conditions

- The recruitment cost is fixed and independent on the amount of individuals who answer. HAE Scandinavia is not involved in the development of survey questions, but will perform courtesy review of the questions to ensure GDPR regulations are met (although the survey is anonymous and should not trigger any GDPR issues). Review will be done by: Henrik Boysen and timeline for review after questionnaire receipt is 10 days.
- Timelines: Invitations will be sent out during August 2024. Data collection occurs normally during a 2-3 week period but may be prolonged by mutual consultation.



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- Timeline of sending email reminders: in consultation with CSLB.
- CSLB is not given access to the registry of members.
- CSLB are not storing any personal data and answers are completely anonymous.
- The results of this survey study may be published at scientific congresses and be used in communication with Health Care Providers, Patient Organizations and Authorities.
- Data Ownership: All data, information and results generated through the provision of the services outlined in this agreement shall be the sole and exclusive property of CSLB.

3. Confidentiality Clause

HAE Scandinavia shall comply full confidentiality to not disclose and/or use any information they receive in connection with this contract. HAE Scandinavia shall also undertake not to record, forward or use this information, unless in accordance with the provisions of this contract. The obligation according to this section shall continue for ten (10) years after the term of this contract.

Requirements to fulfill applicable laws and regulations for transparency reporting in accordance with § 3 of the Patient Organizations Code regulated by the Ethical Committee for the Pharmaceutical Industry are not to be infringed by the confidentiality clause.

4. Finances

- 4.1 CSLB is the study sponsor. CSLB will reimburse HAE Scandinavia with 123 000 DKK for their work tasks as outlined in the table below.

"CSL Behring Patient Survey HAE"		Unit price DKK	Total DKK
Country coordination fee (DK, NO, SE)	3	4.500,00	13.500,00
Project Management	3	7.000,00	21.000,00
Maintenance confidentiality & GDPR	3	2.500,00	7.500,00
Online survey recruitment			
Denmark			27.000,00
Norway			27.000,00
Sweden			27.000,00
		TOTAL DKK	123.000,00

Payment shall be made against separate invoice. 50% will be invoiced at start of recruitment and the rest after recruitment completion. The invoice shall be sent to DanderydPayables@cslbehring.com

State Marie Platon as reference on the invoice.



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5. Transparency

- 5.1 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.

6. Consultation, evaluation

- 6.1 HAE Scandinavia has appointed Henrik Balle Boysen as their contact person in matters concerning this Agreement.
- 6.2 CSLB has appointed Tove Andersson as their contact person in matters concerning this Agreement.
- 6.3 After completion of the project, the Parties shall jointly evaluate the projects listed in p2 and their collaboration in relation to these projects.

7. Agreement period and early termination

- 7.1 This Agreement is valid from 13/6/2024 until 31/12/2024.
- 7.2 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.

8. Ethical rules and law

- 8.1 Ethical rules and national law apply to this agreement. HAE Scandinavia warrants that it will only use the funds received in accordance with national law and the Pharmaceutical Industry's Code of Ethics.
- 8.2 HAE Scandinavia may not refer to or make any representation relating to CSLB or its products or the co-operation under this agreement without CSLB's prior written approval. HAE Scandinavia shall submit all proposed materials mentioning CSLB, or referring to CSLB's products, or the co-operation under this agreement, to CSLB for written approval prior to publication or use.

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

10. 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.

Place and Date: Stockholm
CSL Behring AB: 18 June 2024 | 13:37:19 CEST

Place and Date: Horsens
HAE Scandinavia: 18 June 2024 | 14:57:58 CEST

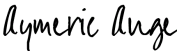
DocuSigned by:

.....7D525497E44D409.....
Name and title:
Fredrik Sjöö
Head of Medical Affairs

DocuSigned by:

.....8238B2D4A9F84C0.....
Name and title:
Henrik Balle Boysen
President HAE Scandinavia

Place and Date: Orta 18/6/24
CSL Behring AB: 18 June 2024 | 13:11:46 BST

DocuSigned by:

.....39ACB73D6009466.....
Name and title:
Aymeric Angé
General Manager