

Patient Organisation Agreement

This Patient Organisation Agreement has been drawn up and entered into as of 04 March 2024 by and between

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

and

Alfa 1 Danmark, Sangfuglestien 5, st. 2400 København NV, formanden@alfa-1.dk

1. Background

Alpha-1-antitrypsin deficiency (ZZ) can cause lung disease, rare liver disease in adults and in some children also liver disease from birth.

The purpose of the Alfa-1 Danmark is to optimize life conditions for people with Alpha-1 antitrypsin deficiency and create a forum for Alfa-1 patients and their relatives for mutual support, exchange of experience and knowledge acquisition. The aim is also to gain public understanding, acceptance and support to meet the needs of Alpha-1 patients and promote international collaboration on Alpha-1 antitrypsin deficiency. CSL Behring operate in this field by improving treatment for patients living with alpha-1-antitrypsin deficiency (ZZ) and supports education and events in this therapeutic area.

2. Collaboration projects

Nordic meeting in Malmö, March 8-10, 2024

Alfa-1 DK will organise a Nordic meeting in Malmö for 10 participants with the aim to discuss and develop a Nordic Alfa-1 patient organisation to create better opportunities to raise awareness and influence on the quality of life for Alfa-1 patients and access to replacement therapy in the Nordic countries. Today, Norway is lacking a patient organization, Alfa-1 Sweden will discontinue during 2024 and Alfa-1 Danmark is foreseeing a lack of board members in the near future. A joint organisation between Sweden, Denmark and Norway, and in the longer term also Finland, Iceland and the Faroic islands, will ensure a strong organisation working for the rights of Alfa-1 patients. See budget specification below.

CSL Behring will support this meeting with 44 262 DKK. and will be mentioned in the program as sponsor. Alfa-1 DK will provide CSL Behring with a specification of the meeting costs after the meeting.

Annual member weekendmeeting, June 14-16, 2024

Alfa-1 DK will organise a memberweekend for Danish patients where patient-oriented lectures about Alfa-1 will be held, preliminary agenda in appendix 1.

CSL Behring will support the meeting with 42.880 DKK, 25 % of the total costs of 171 522 DKR. The organisation has applied for sponsorship for the same amount from Grifols. CSL Behring will be mentioned in the program as sponsor and be able to attend the meeting with 1-2 participants and an exhibition. Alfa-1 DK will provide CSL Behring with a specification of the meeting costs after the meeting.

Budget specification for above 2 meetings:

	Costs
2 flight tickets, see appendix 2	3 762,00 DKK

Transport costs 3 cars	5 000,00 DKK
Konference incl. Overnight stay for 10 persons, see appendix 3	35 500,00 DKK
Memberweekend meeting total cost 171.522 DKR, see appendix 4. 25% applied for.	42 880,00 DKK
Total costs:	87 142,00 DKK

Company membership in Alfa-1 Danmark during calender year 2024

Alfa-1 offers company memberships in Alfa-1 Danmark, the yearly cost is 1 000 EUR (7460 DKK). CSL Behring will become a member in Alfa-1 DK for the calender year 2024. CSL Behrings logo will be published on the website of Alfa-1 <https://alfa-1.dk/> during 2024 and CSL Behring will also receive invites to participate to the organisations information meetings that are being held once or twice yearly with up to 2 participants. Once yearly, the support from CSL Behring will be made visible on the facebook page of Alfa-1 DK.

3. Finances

- 3.1 CSL Behring AB has undertaken to finance the three projects in p2 with a total sum of 94 602 DKK . Payment shall be made against separate invoice. The invoice shall be sent to DanderydPayables@cslbehring.com

State Pia Naested 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 Alfa-1 Danmark has appointed Claus Astradsson as their contact person in matters concerning this Agreement.
- 5.2 CSL Behring AB has appointed Tove Andersson as their contact person in matters concerning this Agreement.
- 5.3 After completion of the project, the Parties shall jointly evaluate the projects in p.2 and their collaboration in relation to these.

6. Agreement period and early termination

- 6.1 This Agreement is valid from 29/1/2024 until 31/12/2024.
- 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. Alfa-1 Danmark warrants that it will only use the funds received in accordance with national law and the Pharmaceutical Industry's Code of Ethics, as defined in the current "Ethiske regler for lægemiddelbranchens samarbejde med patientforeninger mv. (Patientforeningskodekset)", appendix 1. In particular, the financial support must not be used for any kind of entertainment or social activities.
- 7.2 Alfa-1 Danmark 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. Alfa-1 Danmark 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 (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.



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

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 240306

CSL Behring AB:

DocuSigned by:

.....70525497E44D409.....
Fredrik Sjöö
Head of Medical Affairs, Nordic Region

Place and Date:
07-03-2024

Alfa-1 Danmark:

DocuSigned by:

.....48E142EE6E1F4E9.....
Claus Astradsson
Formand/Chairman

Place and Date:
Danderyd 07/03/2024

CSL Behring AB:

DocuSigned by:

.....39ACB73D6009466.....
Aymeric Angé
General Manager

Attachments:
Agenda



Program for medlemsweekend den 14. – 16. juni 2024

Fjelsted Skov Kro

FREDAG 14. juni 2024

Kl. 14.00 – 18.00 Ankomst

Kl. 18.00 – 20.00 Middag

Kl. 20.00 – 21.00 Evt. foredrag med tidl. direktør fra Mosgaard Museum Jan Skamby Madsen.

Åbentstående (Jan Skamby holder ikke foredrag længere pga demens)

LØRDAG 15. juni 2024

Kl. 7.00 – 9.00 Morgenmad

Kl. 9.00 – 9.15 Fælles morgensang

Kl. 9.15 – 11.00 **Ib Søndergaard, cand.scient i biokemi. Undervist i immunologi**

Immunsystemet indgår i en række processer, der er afgørende for organismens beskyttelse mod infektioner, f.eks. med visum, bakterier og svampe samt nogle kræftformer

Kl. 11.00 – 12.15 **Jens-Ulrik Jensen, professor Gentofte Hospital**

”20 spørgsmål til professoren” – evt. i tråd med ”gå-hjem-mødet” på Gentofte Hospital.

Kl. 12.15 – 13.30 Frokost og pause

Kl. 13.30 – 15.00 **Claus Astradsson, formand for Alfa1-Danmark**

Præsentation og information om nordisk samarbejde om stiftelsen af Alfa-1 Norden

Kl. 15.00 – 15.30 Kagebuffet og kaffe/te

Kl. 15.30 – 16.30 **Carsten Simonsen, psykolog**

Carsten Simonsen blev omtalt meget positivt under mødet i SD.
Indlæg om den psykologiske påvirkning af pårørende/hele familien/den syge med en diagnose på en sjælden sygdom

Kl. 16.30 – 18.00 Efterfølgende tid til samtalegrupper/pårørende og syge – evt. i separate grupper

Kl. 18.30 Middag

Kl. 20.00 - ? Musik: Peter Søvad – Underholdning af The Sands

SØNDAG 16. juni 2024