**ENLI-tilsluttede virksomheders samarbejde med patientforeninger mv. 2025**

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| **Navnet på den virksomhed, der indberetter** | **Samarbejds-projektets navn** | **Navnet på de parter, der har indgået aftalen**  **(Lægemiddel-virksomheder, organisationer og evt. tredje part)** | **Type af projekt**  **(Dvs. oplysninger om der er tale om generelle driftstilskud, konkrete møder, sponsorater, pjecer, informations-kampagner, uddannelses-programmer, rejser**  **m.v.)** | **Formål**  **(Hvilket formål tjener samarbejdet)** | **Parternes rolle i projektet** | **Tidsramme** | **Den økonomiske støttes størrelse**  **(Samt hvad pengene skal bruges til – hvis dette ikke i forvejen fremgår under ”Formål” eller ”Type af projekt”)** | **Omfang og indhold af ikke-finansiel støtte**  **(Ikke-finansiel støtte af betydeligt omfang, som ikke kan opgøres med en meningsfuld finansiel værdi, skal indeholde en beskrivelse, som klart redegør for den ikke-monetære fordel, som organisationen modtager.)** |
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| **CSL Behring AB** | Collaboration Project | CSL Behring AB  Alpha 1 Norden | 1. Nordic membership weekend, 2-4 May 2025 in Denmark  2. A physical board meeting  3. New educational content and language adaptations to existing material  4. Language adaptations and updates to our website  5. Advertorial addressing knowledge void in Sweden  6. Awareness podcast addressing unmet medical need | 1. Provide members with educational content on Alpha-1 antitrypsin disease management.  2. Plan strategies for the board advocacy efforts in securing access to augmentation therapy, access to health care and increased Alpha-1 awareness among primary care physicians and pulmonologists, in all the Scandinavian countries.  3. Have the material accessible to our Swedish and Norwegian member  4. Updates and language adjustments to reflect that we are now a multilingual Nordic patient organization  5. This advertorial will inform on the nature of Alpha-1 deficiency, risk populations, who and how to test, family screening, lifestyle interventions, referral centers, available treatment options, and the benefits of augmentation therapy  6. Production of a podcast that highlights the dilemmas of being diagnosed with progressive emphysema without access to treatment. Used for general disease awareness | CSL Behring AB will support the activities financially, whereas planning and execution will be done by the Alfa-1 Norden | 01/04/2025 until 30/09/2025 | 100.411 DKK +  10000 EUR (punkt 5) + 8070 EUR (punkt 6) = 134790 DKK  Totalt  100.411+134790 = 235201 DKK |  |
| **CSL Behring AB** | Collaboration Project | CSL Behring AB  Danmarks Bløderforening | Patient material gene therapy  Annual membership meeting April 26-27th 2025 | Contribute to the development of the association and to mutual exchange of experience with the Danish Society for Bleeding in Denmark, as well as to support the association's activities in Denmark. | CSL Behring AB will support the activities financially, whereas planning and execution will be done by Danmarks Bløderforening | 26/04/2025 until 30/06/2025 | 45.000 DKK |  |
| **CSL Behring AB** | Collaboration Project | CSL Behring  AB  Sjældne Diagnoser | Round Table Forum | 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. | 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. | 03/04/2025 until 31/12/2025 | 12.500 DKK |  |
| **CSL Behring AB** | Collaboration Project | CSL Behring AB  HAE Scandinavia | Translation of “Understanding HAE” folder and  “Women and HAE” folder,  Company Membership in HAE Scandinavia for 2025 | Disease awareness | CSL Behring AB will support the activities financially, whereas planning and execution will be done by the HAE Scandinavia | 05/05/2025 until 31/12/2025 | 60.000 DKK |  |
| **CSL Behring AB** | Collaboration Project | CSL Behring AB  HAE Scandinavia | F2F lecture about HAE disease awareness. | Disease awareness | A representative from the HAE Scandinavia, PAG group to share his personal experiences from coping with HAE. Audience is CSL Behring Nordic Team. | 19/08/2025 | 3750 DKK |  |
| **CSL Behring AB** | Awareness project | CSL Behring AB  HAE Scandinavia | Survey study - 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. | Improving HAE treatment and care and to drive advocacy for improved patient access to treatment and care. | 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 | 13/6/2024 until 30/04/2025 | 61 500 DKK  CSLB is the study sponsor. CSLB has reimbursed HAE Scandinavia with total  123 000 DKK. 50% has been invoiced at start of recruitment, 50% now after recruitment completion. |  |