

ENLI-tilsluttede virksomheders samarbejde med patientforeninger mv. 2024

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.)
CSL Behring AB	Collaboration Project	CSL Behring AB Alfa-1 foreningen, Denmark	Nordic meeting in Malmö, March 8-10, 2024. Annual member weekend meeting, June 14-16, 2024 Company membership in Alfa-1 Danmark during calendar year 2024.	Support awareness about lung disease and rare liver disease caused by Alpha-1-antitrypsin deficiency and support the work to optimize living conditions for	CSL Behring AB will support the activities financially, whereas planning and execution will be done by the Alfa-1 foreningen in Denmark.	29/1/2024 until 31/12/2024	94.602 DKK	

				people with these diseases.				
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.	01/01/2024 until 01/01/2025	12.500 DKK	
CSL Behring AB	Collaboration Project	CSL Behring AB Danmarks Bløderforening	Sponsorship of the organisations participation in the WFH congress in Madrid, April 21-24th 2024. Sponsorship of the organisations Blødt igennem campaign 2024 (awareness of women with	Contribute to the development of the association and to mutual exchange of experience.	CSL Behring AB will provide financial support, and Danmarks Bløderforening will be responsible for planning and execution of the activities.	04/01/2024 until 09/01/2024	53.445 DKK	

			bleeding disorders) including participation with booth and materials (postcards and congressnbags) at Sundhedsplejerskernes landskonference (Nurses national congress), 23-24 Sep 2024. Sponsorship of Danmarks Bløderforenings årsmøde April 2024.					
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.	<u>CSLB is responsible for</u> • 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	13/6/2024 until 31/12/2024	61 500 DKK CSLB is the study sponsor. CSLB will reimburse HAE Scandinavia with total 123 000 DKK. 50% has been invoiced at start of recruitment and the rest after recruitment completion	

					• Data collection and analysis <u>HAE</u> <u>Scandinavia is responsible for</u> • 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			
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