

ENLI-tilsluttede virksomheders samarbejde med patientforeninger mv. 2025

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 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	1. Provide members with educational content on Alpha-1 antitrypsin disease management. 2. Plan strategies for the board advocacy efforts in securing access to	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	235.201 DKK	

			<p>4. Language adaptations and updates to our website</p> <p>5. Advertorial addressing knowledge void in Sweden</p> <p>6. Awareness podcast addressing unmet medical need</p>	<p>augmentation therapy, access to health care and increased Alpha-1 awareness among primary care physicians and pulmonologists, in all the Scandinavian countries.</p> <p>3. Have the material accessible to our Swedish and Norwegian member</p> <p>4. Updates and language adjustments to reflect that we are now a multilingual Nordic patient organization</p> <p>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</p>				
--	--	--	---	---	--	--	--	--

				<p>treatment options, and the benefits of augmentation therapy</p> <p>6. Production of a podcast that highlights the dilemmas of being diagnosed with progressive emphysema without access to treatment. Used for general disease awareness</p>				
CSL Behring AB	Collaboration Project	CSL Behring AB Danmarks Bløderforening	<p>Patient material gene therapy</p> <p>Annual membership meeting April 26-27th 2025</p>	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	The Round Table Forum meets as needed, typically 2-3 times a year. Companies that are a part of the Round	03/04/2025 until 31/12/2025	12.500 DKK	

				afflicted by rare diseases. This is done through cooperation on problem areas of common interest.	Table Forum pay 12,500 DKK + VAT for this membership per year. Rare Diseases Denmark provides secretarial assistance, initiates and hosts the meetings.			
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	