

AGREEMENT WITH PATIENT ASSOCIATION Project support

This agreement is linked to the contract 2031058.
This Agreement is made by and between

JANSSEN-CILAG A/S, a Johnson & Johnson company with its registered address at Bregnerødvej 133 2, DK-3460 Birkerød , Denmark, VAT no.: DK19248615

hereinafter “**Company**”;

and

LYLE LYMFEBKRÆFT OG LEUKÆMI, Banetoften 26, 4700 Næstved, Denmark, Org. ID no: 31 30 68 33,

hereafter referred to as “**Organization**”

Company and Organization are individually referred to as a “**Party**”, collectively referred to as the “**Parties**”.

WHEREAS:

- Company is a research-oriented pharmaceutical company active in the development and marketing of medicinal products;
- Organization is a patient organization that serve 2.600 people living with blood cancers such as lymphoma, leukemia or MDS.
- Organization has asked Company to support one of its projects and Company has agreed to provide support under the terms of this agreement.

THE PARTIES TO THIS AGREEMENT AGREE AS FOLLOWS:

Article 1: Scope

1. Organization will carry out the Project for which Company will provide support and Organization shall ensure that the contribution is used in a professional and ethical manner consistent with this Agreement and applicable rules, legislation and code of practice. More details on the Project (including the objective, roles and

responsibilities of both parties, contact persons, outputs, reporting and timelines) are included in **Annex 1**,

2. Organization will use the support provided by Company exclusively for the purpose of the Project.

Article 2: Support

1. The total amount of support that Company will provide for the Project amounts to 8,500.00 DKK.
2. Further details on the level and type of support, including payment method and timelines, are included in **Annex 1**.
3. Organization and Company acknowledge and agree that the support shall not obligate Organization to purchase, use, recommend, or arrange for the use of any products of Company.
4. EU and National legislation and codes of practice prohibiting the advertising of prescription-only medicines to the general public, apply. Organization and Company acknowledge and agree that Company shall not request, nor shall Organization undertake, the promotion of a particular prescription-only medicine.
5. Organization represents and warrants that it is a tax-exempt entity under the applicable laws and that it is authorized to accept support in the form of financial contribution or other support from private companies such as Company, and that, to the extent applicable, it has performed the necessary notifications or received the necessary approvals. Organization will also keep Company regularly informed of its direct or indirect relationships with government officials and/or government authorities.
6. If any funds provided by Company to Organization under this Agreement remain upon completion of the Project, such surplus shall be refunded by Organization to Company within forty-five (45) days of completion of the project.

Article 3: Use of name and logo or other proprietary materials

1. Organization will publicly recognize that Company provides support for the Project in the following manner: by ensuring reporting to the ENLI codex.

Article 4: Transparency

1. In order to create appropriate transparency on the support to patient organizations by Company, and in line with the applicable code(s) of practice, Company will make the existence of this agreement and details relating thereto publicly available at Janssen Denmark Website www.janssen.com/denmark and Organization explicitly agrees with such disclosure. More precisely, Company will make the following details publicly available:
 - a) Date that the contract was executed;
 - b) Name of the patient organization;
 - c) Country of the patient organization;
 - d) Web address of the patient organization, if available;
 - e) Description of the nature and the purpose of the contribution;
 - f) Amount as contracted, if financial.

In addition, Company will also make copies of this contract available to interested parties upon their request.

2. Company is entitled to increase the level of details made publicly available to patient organizations either as required by applicable rules and legislation, or upon notice to Organization.
3. This article shall survive any termination of the Agreement.

Article 5: Term and termination

1. This Agreement will take effect on the date when the last of the parties has signed, hereafter the Effective Date, and will remain in effect up until the completion of the Project [as described in **Annex 1.**]
2. Both parties have the right to terminate this Agreement upon 2 months written notice notified by registered mail. The respective rights and obligations of both parties in case of early termination of the Project or this Agreement are included in **Annex 1.**

Article 6: Right of Use

1. Organization hereby grants Company a non-exclusive worldwide and in time unlimited right to use in all possible forms and media all copyrightable documents

or products which are created by Organization in the course of performance of this Agreement (hereinafter the “**Work**”), including, without limitation the right to use, adapt, edit, chose a title for the Work, translate, input and/or combine into (conventional, electronic, digital) database, reproduce (regardless of media of reproduction and of number of reproduced copies), publish, make available online (including in intranets and in the internet), sell, lease, give away for free, exhibit, record, film, and broadcast the Work, in its entirety or in part, in all forms of media, whether in printed or recorded form (analogous or digital), and regardless of whether in writing, as sound and/or as image, and regardless of whether for commercial or charitable purpose (“**Right of Use**”). The remuneration of Organization pursuant to this Agreement shall serve as sufficient consideration for granting of the Right of Use.

2. The Right of Use shall survive the termination of this Agreement. Company shall be entitled to assign or to sublicense in part or in full said Right of Use.
3. Organization warrants that in granting the Right of Use, no rights of third parties, including data privacy rights have been infringed and that where necessary, Organization has obtained approval by third parties in order to grant said Right of Use to Company. Organization shall hold Company harmless against third party claims for infringement of copyrights related to the Right of Use granted to Company and shall assist Company in defending against such third party claims.

Article 7: General Provisions

1. General Anti-Corruption Compliance Provision

Neither party shall perform any actions that are prohibited by local and other anti-corruption laws (collectively “**Anti-Corruption Laws**”) that may be applicable to one or both parties to the Agreement. Without limiting the foregoing, neither party shall make any payments, or offer or transfer anything of value, to any government official or government employee, to any political party official or candidate for political office or to any other third party related to the transaction in a manner that would violate Anti-Corruption Laws.

2. Personal Data

Company needs to collect personal information from the Organization, and Company and its affiliates will use such information, in order to manage Company's relationship with the Organization pursuant to this letter agreement. A list of affiliates is at <http://www.investor.jnj.com/sec.cfm> (click on the link to Form 10K, Exhibit 21, under "SEC Filings"). Company may also disclose the Organization's personal information to third-parties service providers, such as technology and marketing service providers, and parties engaged in the organization of events, including hotels and airlines. If the Organization does not provide the personal information requested, Company will not be able to fulfill its obligations to the Organization pursuant to this letter agreement. Based on the Company's legitimate interests, Company may use the Organization's personal information to compile statistical data based on the information in our databases, as well as on surveys, customer feedback questionnaires, and similar communications.

The Organization may contact Company with questions or request to review the personal information Company has collected and/or to request its correction, deletion, blocking, data portability or restriction at: jacdk@its.jnj.com. The Organization may also lodge a complaint with a data protection authority for the Organization's country or region.

The use and disclosure of personal information may involve a transfer to other jurisdictions, including the U.S., which may provide for different data protection rules than in the Organization's country. Appropriate contractual and other measures are in place to protect personal information when it is transferred. The Organization may obtain a copy of these measures by contacting the Company's data protection officer responsible for the Organization's country or region, if applicable, at emeaprivacy@its.jnj.com.

Company will retain the Organization's personal information for as long as needed or permitted in the light of the purpose(s) for which it was obtained, based on: (i) the length of time Company has an ongoing relationship with the Organization; (ii) whether there is a legal obligation to which Company is subject; and (iii) whether retention is advisable in light of the Company's legal position.

3. Governing Law

This Agreement shall be governed by and construed under the laws of Denmark, without reference to the conflict of law rules.

4. Dispute Resolution

In case of any dispute arising out of or in connection with this Agreement, the Parties shall first attempt (in good faith) to reach an amicable settlement. Should

such amicable settlement fail, the courts of Denmark shall have exclusive jurisdiction.

5. Electronic Signatures

The Parties explicitly agree to execute this Agreement by way of an electronic signature, and agree this shall constitute a valid and enforceable agreement between the Parties. The present Agreement is made in an electronic pdf-version (using Adobe Sign) which shall be electronically signed by each Party. Each Party hereby acknowledges receipt of the e-signed agreement, electronically signed for approval by both Parties.

For Company:

Mikkel Johansen

Electronically signed by: Mikkel Johansen
Reason: I acknowledge that my electronic
signature is the legally binding equivalent
for my handwritten signature
Date: Mar 17, 2025 15:02 GMT+1

Market Access & Public Affairs Director

For ORGANIZATION:

Rita Christensen

Electronically signed by: Rita Christensen
Reason: I acknowledge that my
electronic signature is the legally binding
equivalent for my handwritten signature
Date: Mar 17, 2025 15:40 GMT+1


Rita Christensen

Annex 1: Project details

Janssen will in addition to the amount from contract 2031058, give the additional amount of 8.500 DKK for the creation of "hvidbog". We will receive an invoice from LYLE and we will post information regarding the cooperation on our web page.

We will receive information regarding the paper when finished. On the paper it will be written that it has been made with our financial support.

[EXTERNAL] Yderligere støtte til PA-indsats ang LYLE's hvidbog

 Rita Christensen <rita@lyle.dk>
To: Børstinggaard, Dorthe [JACDK]
Cc: Tscherning Jacobsen, Johannes [JACDK NON-JBU]

[Reply](#) [Reply All](#) [Forward](#) [...](#)
Thu 06/03/2025 15:13

Kære Dorthe,

Jeg håber du har det godt og alt vel!

Vi har tidligere sendt en ansøgning om støtte til yderligere PA-indsats med promoveringen af Hvidbogen LYLE har skrevet vedr. Kræftplan 5. Vi er ikke helt nået i mål med det politiske arbejde, og vi derfor gerne føre vores ambitioner til dørs. Det drejer sig kun om **8500 kr.** fra hvert firma der allerede har støttet os. Så vi vil gerne høre om i vil støtte sidste del, så vi når i mål?

Ansøgning handler om tilskud til opfølgende PA-indsats i forbindelse med hvidbogen.

LYLe har et ønske om at styrke sin Public Affairs-indsats i forbindelse med foreningens hvidbog om behandlingen af blodkræft i Danmark.

I forbindelse med lanceringen af hvidbogen i efteråret 2024 var der planlagt en PA-indsats, som vi nu ønsker at give yderligere styrke. Den tidlige periode på året, som vi befinder os i nu, er et godt tidspunkt at få regeringsbærende medlemmer af sundhedsudvalget i Folketinget i tale.

Til det arbejde, hvor vi samarbejder med PA-rådgiveren Morten Reimar (reimarsbureau.dk), har vi brug for økonomisk bistand til at sætte (flere) møder op med relevante regeringsbærende politikere. Dvs. S, M og V. Indsatsen er pt. allerede igangsat, og vi har på nuværende tidspunkt flere politiker-møder i kalenderen i januar - april.

Hensigten med møderne er, med afsæt i hvidbogen, at få mulighed for direkte at præsentere patientforeningen LYLE og navnlig de særlige omstændigheder omkring behandlingen af blodkræft i Danmark. Der til knytter sig også de særlige udfordringer, man står overfor som patient med en forholdsvis sjælden og ofte alvorlig blodkræftsygdom. Indsatsen skal ses i lyset af, at Folketinget i dette forår skal vedtage Kræftplan 5.

Vi har kort sagt brug for at styrke vores formidlingsindsats i de kommende måneder overfor relevante regeringsbærende folketingspolitikere, og det tænkes gjort i et forsat samarbejde med Morten Reimar og Lyles faste journalist Finn Stahschmidt.

Samlert budget for denne indsats forventer vi at skulle bruge 75.000 DKK, og vi ansøger hermed jer om et beløb på kr. 8.500, for en del af udgifterne, da vi også søger støtte hos andre firmaer.

Hvis spørgsmålet, så er du meget velkommen til at kontakte mig igen 🍌

Mange hilsener

Rita O. Christensen

Bonnetofte 26
4700 Næstved

Tlf. 31 68 26 00 - mail: formand@lyle.dk
Patientforeningen for Lymfekræft, Leukæmi og MDS





Patientforeningen for
Lymfekræft, Leukæmi og MDS



Ansøgning om støtte til produktion af en hvidbog om de hæmatologiske sygdomme i forbindelse med Kræftplan V

Behandlingen af blodkræftsygdomme taber terræn i Danmark

I Lyle har vi noteret os regeringens initiativer til at skabe forbedringer på kræftområdet, og vi har et stærkt ønske om – gennem udarbejdelsen af en hvidbog for hæmatologien – at bidrage til og sætte vores specifikke aftryk i Kræftplan V, der forventes lanceret i efteråret 2024. Kræftplan V har som sit hovedfokus at genskabe tilliden til kræftbehandlingen og sikre en fortsat videreudvikling og fremtidssikring af kræftområdet. Kernetemaer er her forebyggelsen af kræft, at sikre at flere overlever kræft gennem anvendelse af nye, effektive og målrettede lægemidler, og at flest muligt får et godt liv som raske eller kroniske kræftpatienter.

Vi anbefaler derfor, at Kræftplan V har fokus på hele patientens forløb og ønsker at sætter fokus på tre kerneområder for hæmatologien, som ikke er tilstrækkeligt implementeret efter Kræftplan IV :

Det er:

1. Tidlig diagnose
2. Opdateret behandling
3. Mere fokus på senfølger

1. Diagnose: Tidlig diagnose er et vigtigt tema for hæmatologiske patienter. Ligesom med andre kræftsygdomme er tidlig diagnose vigtig for patientens sygdoms- og behandlingsforløb og for muligheden for at overleve sygdommen med en god livskvalitet. I processen frem mod en præcis diagnose er blodkræftpatienter ofte udfordret af, at symptomerne på fx akut leukæmi eller lymfekræft er diffuse og kan forveksles med symptomer på mere almindelige infektionssygdomme.

Imidlertid dækker blodkræft over en lang række relativt sjældne sygdomme, som en praktiserende læge vil møde meget sjældent. Derfor kan vejen fra tidlige symptomer til en præcis diagnose og adækvat behandling være meget lang med risiko for sygdomsforværring, livstruende komplikationer og unødvendig, tidlig død. Af den grund er der behov for at udvikle værktøjer til et generelt vidensløft i behandlingssystemet og blandt en række særlige målgrupper.

2. Behandling: Behandlingen af de hæmatologiske sygdomme har oplevet betydelige fremskridt de senere årtier. Sandsynligheden for at overleve blodkræft er blevet mærkbart forbedret, ikke mindst fordi behandlingen er blevet mere målrettet og personligt tilpasset. I en række af de mest almindelige sygdomme er kemoterapi på tilbagetog. Med avancerede, nye lægemidler er det blevet muligt ikke kun at forbedre overlevelsen, men også at begrænse skaderne af ofte meget bivirkningstunge ældre behandlinger. Desværre oplever vi i Danmark, at det etablerede

Lyle – Patientforeningen for Lymfekræft, Leukæmi og MDS
Banetoften 26 · 4700 Næstved · tlf. 31 68 26 00 · CVR 31 30 68 33 · lyle@lyle.dk · www.lyle.dk



Patientforeningen for
Lymfekræft, Leukæmi og MDS



godkendelses- og ibrugtagningssystem for nye lægemidler er trægt, og det ses stadig hyppigere, at behandlinger, der er etableret i landene omkring os, ikke er tilgængelige her i landet. I Lyle har vi eksempler på patienter, der har opsøgt fx CAR-T-cellebehandling i Tyskland for egen regning, fordi det ikke er muligt at få denne behandling herhjemme.

Danmark taber med andre ord terræn, når det gælder kræftoverlevelse, men også som kvalificerede partnere i forsøgs- og forskningssammenhæng. Dertil kommer at uligheden i behandlingen er et tiltagende problem. Ressourcestærke og indsigtfulde patienter har generelt langt bedre forudsætninger for at få den optimale behandling og dermed komme bedre gennem deres behandlings- og sygdomsforløb.

3. Senfølger: I Danmark er der knapt 400.000, der har eller har haft kræft, og af dem oplever mere end halvdelen at være ramt af senfølger. Der er en direkte sammenhæng mellem omfanget og alvoren af senfølger af kræftbehandling og adgangen til nye og mere effektive lægemidler. Samfundsøkonomisk taler meget for, at det, der kan spares på ikke at tage nye, dyre lægemidler i brug, går tabt, når regningen for behandling af senfølger skal betales.

Når det gælder de hæmatologiske sygdomme, skyldes senfølgerne i meget høj grad højdosis kemoterapier, og den helt store udfordring for patienterne er, at de ikke ved, hvad de selv kan gøre for at lindre de ofte meget ubehagelige gener, eller hvor de kan få hjælp.

Senfølger betragtes af det danske sundhedssystem som selvstændige sygdomme og bliver ikke set i den sammenhæng, de er opstået i. Derfor er behandlingen af senfølger spredt fægtning. I hæmatologien har vi dygtige læger, men de ved ikke nok om, hvad de skal stille op med senfølger. Hvis vi for alvor skal gøre noget ved det, skal der tænkes mere holistisk, og det kan vores sundhedssystem ikke håndtere på nuværende tidspunkt. Derfor er det nødvendigt, at Kræftplan V får et specifikt fokus på senfølger.

Budgetoverslag:

Indledende arbejde og research	30.000,- DKK
Tekstproduktion	75.000,- DKK
Grafisk tilrettelægning	40.000,- DKK
Produktionsstyring og tryk (2-300 stk)	30.000,- DKK
Formidlingsindsats og medierettet kommunikationsindsats	35.000,- DKK
PA Indsats*: (anslået)	50.000,- DKK

I alt: 260.000,- DKK eks. moms

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***PA indsatsen omfatter i korthed:**

Research på sagen og kortlægning af relevante 'targets'
Opsætning af personlige møder mellem relevante politikere og Lyle.
Opfølgning
Løbende møder mellem Lyle, Eyelevel og Reimars Bureau
Oversigt over resultater, modtagelse og erfaringer til det videre forløb.

Fakta:

2.600 danskere får hvert år enten lymfekræft, leukæmi eller MDS, og tallet er stigende. I dag lever godt 20.000 danskere med hæmatologisk kræft, også kaldet blodkræft. Mange dør med livsdelæggende senfølger af behandlinger, der hører fortiden til.

Lyle er en selvstændig, patientnær patientforening for mennesker med lymfekræft, leukæmi og myelodysplastisk syndrom (MDS). Foreningen blev stiftet i 2007 og er landsdækkende med en aktiv rådgivningsvirksomhed, en lang række lokale netværksgrupper og en vidtfavnende kommunikations-virksomhed på både digitale og fysiske platforme. Foreningen har ca. 1.100 medlemmer, men et betydelig større antal søger viden på LyLes indholdsrige og frit tilgængelige hjemmeside og læser foreningens nyhedsbreve og bladudgivelser. Lyle arbejder målrettet på at være opdateret på de hæmatologiske sygdomme og deres behandling ligesom vi gennem vores internationale patient-samarbejde nøje følger udviklingen i vores nabolande og hele Europa.

Mange hilsner fra

Rita O. Christensen

Lyle – Patientforeningen for Lymfekræft, Leukæmi og MDS
Banetoften 26 · 4700 Næstved · tlf. 31 68 26 00 · CVR 31 30 68 33 · lyle@lyle.dk · www.lyle.dk

Payment method:

Company shall pay the Support within 45 days of being issued an invoice. Payments shall be made by bank transfer and only to a bank account held in the name of the Party on Invoice. Invoices should, as a minimum requirement, contain the following items: (a) full name and address of Party issuing the invoice; (b) where applicable tax number of Party issuing the invoice; (c) full name and address of the Company or its appointed agent; (d) place and date of invoice; (e) brief description of services invoiced with date of service rendered; and (f) where value added tax (VAT) is applicable, invoicing Party's VAT number, statement of net amounts invoiced, VAT rate, amount and gross amounts. Company will inform the Organization in case the invoice needs to be addressed to its appointed agent instead of to Company.

Reporting:

Within 1 month from the activity, the organization will write a small report as proof of event. The report should consist of:

- A letter on the organization's own letterhead-paper, signed by them, where they explain how the grant/support was used and confirm that the grant/support (amount) has been used as agreed upon.

And at least one of following:

- Final agenda/Advertisement/ Receipts of costs/ detailed financial accounting for use of the support

Those parts can be combined in the same document, but the content must align with the requirements.


[2193829] Sponsorship - Other

Final Audit Report

2025-03-17

Created:	2025-03-17
By:	J&J ICD system (icdsup@its.jnj.com)
Status:	Signed
Transaction ID:	CBJCHBCAABAAbnhzHHP4q4xCHQD9ngmBUHLTIgcYa0Rt


"[2193829] Sponsorship - Other" History

 Document created by J&J ICD system (icdsup@its.jnj.com)

2025-03-17 - 1:56:18 PM GMT- IP address: 199.65.128.88

 Document emailed to Mikkel Johansen (mjohan12@its.jnj.com) for signature


2025-03-17 - 1:57:22 PM GMT

 Document emailed to rita@lyle.dk for signature

2025-03-17 - 1:57:22 PM GMT

 Email viewed by Mikkel Johansen (mjohan12@its.jnj.com)

2025-03-17 - 2:02:14 PM GMT- IP address: 165.225.194.159

 Mikkel Johansen (mjohan12@its.jnj.com) has agreed to the terms of use and to do business electronically with JOHNSON AND JOHNSON SERVICES, INC.

2025-03-17 - 2:02:59 PM GMT- IP address: 165.225.194.159

 Document e-signed by Mikkel Johansen (mjohan12@its.jnj.com)

Signing reason: I acknowledge that my electronic signature is the legally binding equivalent for my handwritten signature


Signature Date: 2025-03-17 - 2:02:59 PM GMT - Time Source: server- IP address: 165.225.194.159

 Email viewed by rita@lyle.dk

2025-03-17 - 2:38:13 PM GMT- IP address: 104.47.22.190

 Signer rita@lyle.dk entered name at signing as Rita Christensen

2025-03-17 - 2:40:42 PM GMT- IP address: 80.208.65.219

 Rita Christensen (rita@lyle.dk) has agreed to the terms of use and to do business electronically with JOHNSON AND JOHNSON SERVICES, INC.

2025-03-17 - 2:40:44 PM GMT- IP address: 80.208.65.219

 Document e-signed by Rita Christensen (rita@lyle.dk)

Signing reason: I acknowledge that my electronic signature is the legally binding equivalent for my handwritten signature

Signature Date: 2025-03-17 - 2:40:44 PM GMT - Time Source: server- IP address: 80.208.65.219

✔ Agreement completed.

2025-03-17 - 2:40:44 PM GMT