

## **Educational Grant Agreement – event support**

Between

Incyte Biosciences Denmark ApS, Suomisvej 4 1927 Frederiksberg C, Denmark (“**Incyte**”)

and

Lyle Patientforeningen for lymfekraft, leukaemi og MDS, Banetoften 26, 4700 Naestved, Denmark (“**Recipient**”)

### **BACKGROUND INTRODUCTION**

Incyte is committed to positively impacting the lives of patients with cancer and other diseases. Recipient is a Patient Organisation with the aim to participate in the Annual Meeting of Nordic Patient Associations to be organized in August 2023. Recipient requested a financial support from Incyte (as per the Original Request for Support herein attached in Schedule 2) to fund the Event described above and in Schedule 1 (“**Event**”). Incyte as part of its commitment to support medical education and quality patient care is willing to provide such support, subject to the terms of this Agreement.

### **Article 1 - Support**

1.1 Incyte will provide Recipient with Fifty Thousand DKK (50,000 DKK) (“**Support**”) which shall be used by Recipient for the event described below (“**Event**”).

### **Article 2 - Payment of Support**

2.1 Payment of the Support shall be made by Incyte to the bank account of Recipient identified on the Original Request for Support received from Recipient.

2.2 The Parties expressly acknowledge, for the avoidance of doubt, that the execution of this Agreement and/or the payment of the Support is not intended to and will not in fact influence any prescribing, or procurement decisions favourable to Incyte’s commercial interests.

### **Article 3 - Transparency**

3.1 Recipient shall be responsible to disclose that Incyte has provided Support for the purposes of the Event only and no other purpose, including but not limited through displaying Incyte logo (in the color and shape as communicated by Incyte) in any relevant format. Except as provided herein, Recipient undertakes not to use Incyte name nor any trademark or other distinctive signs belonging to the Incyte group of companies (“**Incyte Group**”) in any statements or public announcements without Incyte's prior written consent. The Incyte Group shall have the right to use the name of Recipient for the sole purpose of complying with transparency reporting requirements to which it may be subject.

3.2 Incyte may publicly report or disclose the details of funding provided to Recipient under this Agreement. To enable Incyte to fulfil such reporting/disclosure activities, Recipient shall provide Incyte with information and data upon reasonable request of Incyte and Recipient consents to such public reporting/disclosure.

#### **Article 4 - Compliance**

4.1 Incyte shall have no control or influence over the Event.

4.2 No part of the Support may be paid to any third party, other than as reasonable fair market value compensation for items and services provided to Recipient in connection with the Event in accordance with applicable laws, regulations and applicable industry codes of practice (including those pertaining to spend transparency reporting).

4.3 No portion of the Support shall be used by the Recipient to provide unlawful benefits to a healthcare professional or to any government employee or official.

4.4 The Recipient is free to seek funding from other companies. If any additional funding reaches a level such that all or part of the Support is no longer required by the Recipient, the Recipient shall refund such amount of the Support that is no longer required.

4.5 Any discussion of medicinal therapies at the Event shall be non-promotional, balanced, accurate and complete and shall comply with applicable laws and regulations.

4.6 The following provisions shall apply to the extent necessary:

- a. The Event shall be held in a modest and appropriate location and shall not involve any entertainment, touristic or leisure activities. Attendees shall be healthcare professionals only and no portion of the Support shall be used to cover costs of accompanying persons, partners or spouses. Any hospitality will be modest and secondary to the educational purpose of the Event. Accommodation shall be restricted to maximum four (4) star hotel and all airfare shall be economy class only, except for intercontinental flights.
- b. Recipient confirms that the selection of the location of the Event is based on one of the following criteria: (i) the majority of the attendees are resident in the country where the Event will take place, or (ii) the attendees at the Event are coming from different countries and, therefore, the Event location was selected based on logistical convenience considering the country of residence of the attendees.
- c. If hotel accommodation will be provided to any attendees at the Event, including healthcare professionals, such hotel accommodation shall be restricted to the minimum number of nights necessary to facilitate attendance at the Event (considering available inbound and outbound flights or other reasonable travel options). In no event shall such accommodation be extended beyond the minimum necessary, unless any such extension is at the sole private cost of the participants. No extra costs for accompanying persons shall be covered using the Event Support.

4.7 Recipient shall keep and maintain until ten years after the Event have been completed full and accurate records relating to (i) the Event and the Support; (ii) all expenditure reimbursed by the Recipient; and (iii) all payments to any third party (HCPs included) made by the Recipient in connection with this Agreement.

4.8 To ensure compliance with any applicable law and regulation by Incyte, Recipient shall promptly on request afford Incyte or Incyte's representatives access to all records relating to (i), (ii) and (iii) above at Incyte's

expenses. Such records shall be made available to Incyte during normal business hours at the Recipient's office or place of business or, in the event that no such location is reasonably available, via email.

- 4.9 Recipient shall refund to Incyte any unused Support after the Event has been completed. Accordingly, within 30 working days of the completion of the Event, the Recipient shall complete and sign the Support Use Certification form, which is attached herein as Schedule 2, and shall send the completed form to Incyte, in order to provide information on the usage of the Support received from Incyte. Recipient shall also provide Incyte with any additional information reasonably requested regarding the completion of the Event and use of the Support, subject to confidentiality and privacy laws. Failure to provide the completed Support Use Certification form and/or to refund unused Support (if applicable) shall exclude Recipient as an eligible funding recipient in the future.

#### **Article 5 - Duration**

- 5.1 This Agreement shall continue in full force and effect from the date of signature until the earlier to occur of either (a) the date when both Parties completed their obligations from this Agreement, or (b) when either Party terminates this Agreement.

- 5.2 Party may terminate this Agreement if the Support is no longer required/needed by Recipient.

#### **Article 6 - Miscellaneous**

- 6.1 Both Parties shall comply with applicable laws, regulations and guidelines in the performance of the Agreement including but not limited to the LIF and ENLI codes, practices and guidelines, e.g., the Promotional Code, Donation Code, Patient Organisation Code, Transparency Affiliation and Anti-corruption/bribery Regulations. The Recipient agrees that Incyte shall publish payments made to Recipient under this Agreement, including the Recipient's name, trademark, logo and the amount of the Support and such other information as may be required by the aforementioned laws, regulations or industry codes or practice. This Agreement constitutes the entire Agreement between the Parties relating to the subject matter of this Agreement. Changes and amendments to this Agreement are valid only if they are made in writing and signed by a duly authorised representative on behalf of each Party. This Agreement may be executed in counterparts all of which taken together shall constitute one agreement and copies may be exchanged electronically, such as by e-mail (e.g. PDF) and such electronic copy of the signed document will be considered valid and binding on the signing Party.


### **Event Details**

**Title of Event:** Nordic Patient Associations Meeting

**Date of Event:** August 2023 (on a date to be confirmed)

**Location of Event:** Helsingborg, Sweden

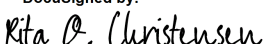
### **Incyte Biosciences Denmark ApS**

DocuSigned by:  
  
92852CD85D47446...

Name (CAPS): Erik Fromm

Date: 28-Mar-2023 | 09:40 EDT

### **Lyle Patientforeningen for lymfekraft, leukaemi og MDS**

DocuSigned by:  
  
F92DBD4EBA834E6...

Name (CAPS): Rita O. Christensen

Date: 29-mar-2023 | 09:49 EDT

## **Schedule 1 – Event details & Agenda**

## BUDGET OF TWO MEETINGS BETWEEN NORDIC BLOOD CANCER PATIENT ASSOCIATIONS, 2023:

THE MEETINGS WILL TAKE PLACE TWICE (IN AUGUST AND NOVEMBER OR JANUARY '24), AND BELOW BUDGET COUNTS THE COSTS OF THE TWO MEETINGS (INCLUDING PLANNING, EXTERNAL COSTS<sup>1</sup> ETC.). ALL COSTS ARE INCL. DANISH VAT.

### Meeting facilities & accommodation 88.000 DKK

- External costs for conference/meeting facilities at hotel  
(14 pax, moderator, and planner - incl. coffee and lunch for 16 pax)
- External costs for accommodation  
(14 pax, moderator, and planner - 1-2 nights stays incl. breakfast for 16 pax)

### Transportation (to and from meeting) 72.000 DKK

- External costs for transportation with flight/train<sup>2</sup> to Stockholm  
(14 pax, moderator, and planner - Lowest fare possible)
- External costs for other transportation to/from  
airport (e.g., Arlanda Express, 16 pax)

### Network Dinner

12.400 DKK

- External costs for dinner day 1  
(16 pax (12 participants, moderator, and planner))

### External costs for materials

5.000 DKK

- Handling and print of materials for the  
meeting (e.g., agenda, folder etc.)

### Production and graphics

22.500 DKK

- Development of program, invitation, and evaluation sheet
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**Organizing the meetings****105.000 DKK**

- Planning of the meeting (booking, practical arrangements etc.) and ongoing dialogue (estimated 35 hours pr. meeting)

**Participation and moderating 135.000 DKK**

- Participation of Partner at Kompas Kommunikation incl. moderating the meeting and preparation (estimated 2,5 days incl. travel time pr. meeting)

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<sup>1</sup> **ALL EXTERNAL COSTS, ACCOMMODATION, TRANSPORTATION ETC., WILL BE IN ACCORDANCE WITH THE ENLI-RULES**  
(E.G., 3-4 STAR HOTELS, LUNCH WILL NOT EXCEED 300 SEK INCL. VAT PR. PERSON, DINNER WILL NOT EXCEED 850 SEK PR. PERSON).

**2TRANSPORTATION WILL BE BOOKED TO ASSURE THE MOST EFFECTIVE AND CLIMATE FRIENDLY TRANSPORTATION POSSIBILITY**  
(E.G., IF THERE IS A TRAIN POSSIBILITY WHEREAT THE JOURNEY TAKES LESS THAN 5 HOURS AND HAS NO MORE THAN 3 CHANGES ALONG THE JOURNEY, TRAIN MUST BE CHOSEN OVER FLIGHT.

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- Participation of planner and note taker from Kompas Kommunikation. (estimated 15 hours incl. travel time pr. meeting)

**Follow up and project management 45.000 DKK**

- Evaluation of meeting (based on evaluation sheet) (5 hours pr. Meeting)
  - Follow up email with evaluation and key findings from the meeting (PPT) (2 hours)
  - Project management and ongoing dialogue with LyLe (5 hours pr. meeting)
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**TOTAL INCL. DANISH VAT**

**507.400,00 DKK**

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# INVITATION

## NORDIC PATIENT ASSOCIATIONS MEETING

19<sup>TH</sup> – 20<sup>TH</sup> OF JANUARY 2023 IN HELSINGBORG

How can we reduce the inequality in treatment? How can existing programs be implemented better, and how can patient/doctor dialogue be improved?

Join next years meeting and work together cross country to discuss main issues in haematological treatment and share insights and challenges with your Nordic colleagues.

19<sup>TH</sup> – 20<sup>TH</sup> OF JANUARY  
2023 IN HELSINGBORG

### THE MEETING TAKES PLACE AT COMFORT HOTEL

GASVERKSGATAN 11, 252 25 HELSINGBORG, SWEDEN

We will start with half a day about equality in treatments and discussion about mutational testing, followed by dinner for all the attendees. Next day we continue with clinical trials in the Nordics and involvement of patients in the treatment programs.

*We are looking forward to seeing you all again*

#### Registration and booking of hotel and transportation:

Anna Dalgaard  
Anna@kompas.dk

#### Further contact information:

LyLe, Rita O. Christensen  
rita@lyle.dk  
+45 31 68 26 00

When participating in this meeting LyLe and Kompas Kommunikation will gather and keep your contact information for administration of your participation in and transportation to the meeting. Your contact information will be kept confidential and will not be disclosed to others. Your contact information is not stored longer than allowed in accordance to applicable laws and regulations. You can get access to, edit or delete your contact information at any time by contacting LyLe or Kompas Kommunikation.

This meeting is sponsored by:  
BeiGene | Incyte Biosciences Nordic AB



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# Nordic Patient Associations Meeting in Hematology Helsingborg 2023



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## Introduction

- Welcome and a short status from each country; DK, SE & FI
- The associations did not officially meet since 2019 (before corona)
- **Status Denmark:**  
Problems with Covid19-vaccines not working on blood cancer patients. The doctors got angry, and the patients needed someone to take action. The patients got many different answers on, what to do when getting corona, when to have the vaccine etc. This will also be a problem in the future, as many patients are not immune. The CML-group in DK is also a little vaccine-sceptic as in Finland. Denmark is inspired by Sweden's blood cancer foundation: Though, would have to employ someone to do the administration; they also recommended and support certain research by writing a letter to Kræftens Bekæmpelse (the cancer association) and thereby supporting research without having to have a foundation). Lyle as an association can not be saving up money, they need to use all the money they get on activities (due to some tax/legislations rules).
- **Status Sweden:**  
Immunity for Covid has also been a problem there, but not as much as Denmark describe it. CML patients are more valuable. No discussions in Sweden about generics. Sweden has also been busy with patient trials, patient involvement, their own foundation offering financial support to researchers within hematology. The association has to parts: (1) The Blood Cancer Association and (2) The Blood Cancer Foundation.
- **Status Finland:**  
Finland have not experienced those Covid-problems. However, they have a vaccine sceptis in Finland: People do not think it works. And patients do not trust generics. The association in Finland is doing very well – a lot of online-support-programs activity, which works very well.

### Discussion about establishing a Nordic Board:

- All associations agree that the administration of a Nordic Board will be too much work and maybe not worth the effort.  
As long as the associations stand together, work together in some common-Nordic-projects and inspire each other they can be strong without having to administer a Nordic Board.
- Important:
  - To network, inspire each other and meet regularly and collaborate when relevant.
  - To respect that each country is in a unique position – and very different from each other.
  - If necessary, a position paper on the collaboration could be made.
- It is of great interest to have both Norway and Iceland in the networking group. Also, it would be great if both groups within myeloma and lymphoma would participate.
- The pharma industry will still be sponsor of meetings – but have no influence on the agenda – nor will they participate in the meetings.
- Nadia will not be having a formal role in the network since there will be established no board. If interested she is of cause welcome to attend meetings.



# Equality in treatment

- **Status Denmark:**  
Politicians/doctors talk about it, but nothing really happens. They were not very keen to collaborate with patient association before, but now they are more open: Lyle is part of a regional group, whereat they can discuss with doctors, clinical personnel etc. It is still going slow – but it is going. Camille mentions Amgros (the Danish regions buying company for medicines to be used at public hospitals). In Denmark, there is equal access to medicine (in theory), but in the regions the doctors can decide and do not always follow the guidelines, so equal treatment is not happening in reality. Patients do have the opportunity to travel for a specific treatment (so called ‘free choice of hospital’). They find out through network, social media and Lyle.
- **Status Sweden:**  
The regions pay for the treatments needed within the region. But not all regions can afford / will afford expensive treatments. The bureaucracy is one of the big issues in providing equal access to treatment. The association has pushed the politicians to take more responsibility for this. The association is also advocating more patient involvement: The patients must be asked about the value of a treatment. In a Myeloma survey from last year: 96% wants access to new treatments. 83% wants to participate in trials (only 21% have been in a clinical trial). Sweden would like to do a Nordic survey on this to get a comparative. In Sweden, a similar survey within CML is being made now with Pfizer as sponsor. Both general and diagnose-specific surveys are important. In Sweden the surveys are used to push for treatment approval.

- **Status Finland:**  
Finland read and comment on professional’s papers/surveys. In some cancer areas there is a close collaboration between patients and professionals/researchers. This is a positive feedback process. ). In Finland, patients must pay the difference – if they travel for a treatment that is more expensive than the one offered. Finnish patients (in Myeloma) think that they have the best treatment in the world. The association doesn’t believe the patients know about unequal treatment. The association needs knowledge about it – but do not want to ‘rock the boat’. Also, Finland is lacking hematologist and this amongst other things causes unequal access.

## Discussions:

- What is equal access? Within a country or across the Nordics? Might not be the same...
- In both Denmark and Sweden new treatments are not always used – even though they have recommendations in the National Guidelines. How can this be changed?
- Is Myeloma foundations making surveys on equal access? If yes, are they used?
- Everyone is eager to hear from the patients; do they know about equal access? Do they get access to new treatments? Combining medical data/company with patient data.
- Camille: Consider the companies (new) focus on sustainability; hence, equal access (use this as an argument, when asking for support). Should a common Nordic survey on equal access be made?



# Mutations & mutational testing

- **Status Denmark:**  
The patients do not know their subtypes; Lyle is pushing the patients to ask for it in magazines and through Facebook. They feel like it is becoming better, but slowly. I should be your right to know your subtype. The doctors usually did not tell the patients; but now they do (at least more often). Many patients do not know that their disease is mutated and how it can affect the treatment choice. The treatments are different; some subtypes have more direct treatment. The doctors do not always know the subtypes. Sometimes people get tested, but the information does not travel from the bioanalytic department to hematologist and further on to the patients.
- **Status Sweden:**  
It was part of the myeloma survey; the number was very low. It is defined in the guidelines how many patients should be tested. Patients are not aware whether they have been tested. The association published this on social media and in MyNewsDesk the week before Christmas, so they did not get enough attention. Maybe a new post could be needed?
- **Status Finland:**  
Some patients say that they don’t want to know it; they trust the doctors; put themselves in the doctor’s hands. This should be respected. It seems like it is not a big problem in Finland. Therefore, the association don’t think they have the same need.

## Discussions:

- Sequencing is in the guidelines but not always accepted and initiated by the HCPs. How can this be changed?
- The doctors are getting better. However, they lack information; they don’t follow-up on the many different types. It would be nice to get someone to explain the relevance of sequencing within each disease areas. And a summary on, how it affects the treatment. And also, visualizing the benefits for the hospital. Rita already have an article, which could be easily translated into e.g., Swedish and Finnish.
- The above could be done as a simple one pager with infographics:

### PAGE 1: For patients

What is a subtype and a gene mutation?

Why test for mutations? And why know your subtype?

How does subtype and mutations affect the treatment of your disease?

CML/ALL/CLL/AML/MM etc. >

What is being tested for in each disease? XX, XXX, XXXX

What should I ask my hematologist?

1) XXXX, 2) XXXX, 3) XXXX

### PAGE 2: For HCPs

What are the economic benefits of testing for mutations and subtype?

For the patient: XXXXX

For your as a hematologist: XXXXX

For the hospital: XXXXXXXX



# Clinical trials

- **Status Denmark:**  
Patients are not asked in the right way, so they do not desire to attend in trials. People think that there's always a placebo arm – but that is not the case in blood cancer. This information MUST be communicated. DK need a flyer or something else to explaining it. The patients don't know the possibilities and the possible benefits, and they don't get enough information, which makes the patients not wanting to participate. Often the doctors rush it, which makes the patients scared. The other countries finds this interesting as DK is in front in number of trials. A database exists – but only for HCPs.
- **Status Sweden:**  
Patients do want to participate in trials. However, the patients do not get informed either; if e.g., a relevant trials that fit them comes up. Often if a trial is not on the hospital whereat a patient get his/her treatment, the doctors do not have the time to refer the patients to the other hospital. And most trials are done by the pharma companies. A database for this exists. But recruitment is a problem.
- **Status Finland:**  
No problem with patients being scared: Almost everyone who is asked is participating. The association have had a discussion on how to make a database where patients themselves can sign-up to participate. But more information is needed: e.g., how do we get the patients on-board who are not so digital etc. Trials are often held in big cities and university hospitals; so how do we get patients from far away on-boarded in trials? The amount of money from the government to academic trials is decreasing. No one is working with getting an overview within clinical trials. The clinical trials available is public in the hospital's websites, and the patients can look there and talk with their doctor about it; in the end the doctors are the ones deciding whether you fit a certain trial. Also, the patients are compensated their expenses to travel to participate in trials. Good leaflets on clinical trials exist; but they are not on the association's website.

## Discussions:

- Could national or maybe a common Nordic databases be made with public overview of both company trials and other trials? Is this need already met in e.g. [clinicaltrials.org](http://clinicaltrials.org) / .com?
- Do patients know enough about the available trials – how to apply for them – and the benefits of attending a trial? Could be a mini-guide on how you as a patient could find out about trials (e.g., what does it mean to participate in a clinical trials, where to find clinical trials, what are the risks and benefits?) be developed – maybe as a common Nordic project?
- Finland and Sweden see recruitment for trials through social media. Could the associations also communicate more about clinical trials on their SoMe? To have a better dialogue with the patients about this.
- More information about the patient's knowledge and thoughts of clinical trials is needed. A Nordic survey (inspired from the Swedish one)?
- Could the associations make media (and through them the HCPs) pay more attention to trials? Could they push for more academia trials as well? There has to be a bridge between clinical trials, access and patient involvement.
- ALL to share what they have of material on clinical trials.



# Patient involvement

- **Status Denmark:**  
It is Medicinrådet's responsibility to get patients educated and involved – they are saying they are doing it, but it is going slowly. Lyle should be pushing this to happen faster: e.g. together with the lung cancer association and KIU. Also, CDDF have nice things on patient advocacy/involvement. DK has patient involvement on paper, but not in reality, and this is often because they don't know how to be involved.
- **Status Sweden:**  
The association has a patient panel, which works well. This is started in a research setting (the research that the association funded). It is a Patient Partner Program, where patients are being paid to be educated and each patient are then involved in a specific project – helping with different things related to the research. All countries agree that this model can possibly be used in the other countries as well. In Sweden, the cancer foundation also have a reviewing committee looking at applications. Sweden also shares their own files and surveys with the TLV even though they're not asked. Hoping it will be noted and taken into account some day.
- **Status Finland:**  
There is patient panels doing some kind of panel reviewing of research applications before they go to the ethical committee (only in Helsinki hospital now – but they work to spread this out). In Finland the pharma pays. And in all respect, it has been really good. It has been mixed patients – not only cancer and hematology patients.

## Discussions:

- A PRO-form is not relevant since the treatment is so different amongst hematologic patients.
- In UK, they do all research with a patient partner involved.
- Sweden to share the model on patient involvement
- Important to note, that patient involvement now is required and stated in the national goals.
- Making pharma pushing for more education of patients could also be argued as part of their sustainability goals.
- Associations need to work towards two goals educating patients:
  - 1) What is research and why should patients be involved?
  - 2) How can patients be involved the best?
- All associations agree on trying to do a joined patient-education-and-involvement-program. Potentially funded broadly across several pharma companies in the Nordics. Maybe an adjusted and translated version of the Swedish program? Though a model for the payment would be needed in both DK and FI.



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## Sum-up and further actions

### Action points for the four themes:

- **Equal access:** Sweden to share survey and report – could be of great inspiration for all
- **Mutational testing / subtypes:** A common Nordic project could be in the interest of all; e.g., a simple patient leaflet / one pager with page 1) why mutational testing is important for the patient –how it can determine what treatment to use – and what to ask the hematologist. Also, on the same page listing each disease type and what is tested for in each type. On page 2) the economic and resource benefits of testing the patients (arguments for the healthcare professionals).
- **Clinical trials:** Countries are very different BUT all should share what they each have, to inspire each other. Also, important to continue the conversation; do the patients have good enough access? Are there enough trials in each country? Do the patients know how to find relevant trials? Do the HCPs? Could the associations push for more trials via the companies? Etc.
- **Patient involvement:** Sweden will share experience with “Patient Partners Program” and report back on Swedish version of EUPATI. Maybe a common Nordic version of a patient partner program could be made? Or Finnish and Danish versions of the Swedish one?
- **Ad on:** DK was offered a good deal with Medicinske Tidsskrifter. Rita will forward dummy to Sweden.

### Conclusions on the form of the meeting & future meetings:

- General happiness about meeting again and having discussions facilitated
- Swedish activities are good inspiration
- Good not to have external speakers – leaving more time to talk and learn about each other (maybe one or two of the attendees could make a short speak at the next meeting – sharing a learning or project...)
- The four themes (equal access, mutational testing, clinical trials and patient involvement) should be kept for future meetings – making new follow up and action points at every meeting. Since these themes are the most important for the associations to work for, and they are closely interlinked
- Meetings should probably be held in Stockholm – to make it easier for all to attend, and one meeting every 6 months is preferred
- From now on these meetings will be called ‘Network Meetings’ – since a Nordic Board will not be established



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## Evaluations

### Overall:

Very positive feedback on all aspects of the meeting – thank you for that!

Though – something can always be improved. So, for next meeting we will:


- If possible, upgrade the hotel and meeting facilities a bit
- Upgrade lunch
- Make sure travel arrangements are done as easy as possible for you



Best regards

Emilie & Camille from Kompas Kommunikation, Denmark – on behalf of Lyle





# PROGRAM

**MODERATOR:** CAMILLE AULKÆR ANDERSEN, PARTNER, KOMPAS KOMMUNIKATION

**Thursday the 19<sup>th</sup> of January 2023**

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<b>14.00 - 14.15</b>	<b>Welcome, introduction &amp; coffee/refreshments</b> <i>By Camille Aulkaer Andersen</i> – presenting the agenda for the two days and the goals for the meeting
<b>14.15 - 15.30</b>	<b>The Board and goals for the NBCC*</b> <ul style="list-style-type: none"> <li>• The board is confirmed – Sweden, Finland, Denmark and Island</li> <li>• Definition of Nadias role</li> <li>• How can we get Norway into the Council? Anything new?</li> <li>• Status on financing future meeting in the NBCC and Nadias help</li> </ul>
<b>15.30 - 15.45</b>	<b>Short break</b>
<b>15.45 - 16.30</b>	<b>Equality in treatments*</b> How is e.g. Amgro and TLV working with new financial models to reduce the inequality in treatment?  <i>External presenter, name to be confirmed</i>
<b>16.30 - 17.00</b>	<b>Discussion:</b> Is a Nordic corporation needed? And should Patient Advocacy Groups be more involved?
<b>17.00 - 17.15</b>	<b>Coffee break</b>
<b>17.15 - 18.00</b>	<b>Mutations &amp; mutational testing</b> <b>Discussion:</b> How do we inform patients about the importance of knowing your subtype?
<b>18.00 - 18.15</b>	<b>Sum up from today</b>
<b>18.15 - 19.00</b>	<b>Break</b>
<b>19.00 - 22.00</b>	<b>Dinner</b>

*\*Minor changes to the program can occur*

**PROGRAM**

**MODERATOR:** CAMILLE AULKER ANDERSEN, PARTNER, KOMPAS KOMMUNIKATION

**Friday the 20<sup>th</sup> of January 2023**

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**09.00 - 09.15** Introduction of today's program & coffee

**09.15 - 10.00** **CAR-T treatment & Clinical Trials in the Nordics\***  
What is going on in the Nordics regarding lymphoma and myeloma and where are we going?  
*External presenter, name to be confirmed*

**10.00 - 10.30** **Discussion:** How can Patient Advocacy Groups help communicating the trials (application, participation and results)?

**10.30 - 10.45** Short break

**10.45 - 11.30** **Patient Programs & Patient Involvement**  
How can existing programs be implemented better? And how can patient/doctor dialogue be improved?  
*External presenter, name to be confirmed*

**11.30 - 12.15** **Patient Reported Outcome in hematology**  
**Discussion:** Should the Patient Advocacy Groups design a Nordic PRO Measurement tool as a Pilot Project and get it implemented?

**12.15 - 12.30** Sum up from today

**12.30 - 13.30** Lunch and goodbye

*\*Minor changes to the program can occur*

## Schedule 2 – Original Request for Support





Patientforeningen for  
Lymfekræft, Leukæmi og MDS



Til

Incyte Biosciences Denmark ApS Att.: Peter Frandsen  
Suomisvej 4,  
1927 Frederiksberg C

The Nordic countries, i.e. the Nordic countries, are not the only ones. Scandinavia and Iceland would like to continue our good cooperation and relations in order to do more about the differences in the Nordic region in the area of treatment.

We have talked about continuing to meet and we have a lot of topics to work on. We believe we have a bigger voice if we join forces than fighting for a cause individually.

We would like to request support for the project below, as we - patient associations for blood cancer in the Nordic region - would like to make a difference.

The intention is to hold a meeting in one of the Nordic countries together with the other blood cancer-related patient associations. It is popular among patient organisations and organisations to meet at European level, but we in the Nordic region are more directly comparable, which is why in our view it makes perfect sense to hold a joint Nordic meeting.

We would like to meet in August 2023 and believe there is to discuss what the future will be with the treatments for blood cancer patients. Our agenda will include the following themes:

***Finding common grounds for the Nordics on a HTA level:***

- ***Equity in treatment***
- ***Spotting mutations/subtypes from the beginning***
- ***Clinical trials***
- ***Targeted medicine in first line***
- ***Patient involvement***
- ***QoL issues like as PRO's***

The patient organisations from

Denmark, "LyLe - Patient Association for Lymphoma, Leukemia and MDS" <https://lyle.dk/> and "Danish Multiple Myeloma Association" <https://www.myelomatose.dk/>



Danish MPN Association: <https://www.danskmpnforening.dk/>

Sweden, Blood Cancer Association <https://www.blodcancerforbundet.se/>

Norway, the "Blood Cancer Society" <https://www.blodkreftforeningen.no/> and the "Lymphoma Society" <https://kreftforeningen.no/om-kreft/kreftformer/lymfekreft/>

Finland, The Finish Cancer Patient Association: <https://www.syopapotilaat.fi/>

og Island <http://www.ncu.nu/Default.aspx?ID=31>

will be invited – 2/3 people from each association – and discuss how we can influence decision-makers to create a united front for all Nordic blood cancer patients.

The patient organisations met in January 2023 and agreed that we should meet twice a year to continue strategies for how to move forward.

In the long term, our ambition is to establish a roundtable discussion with any Nordic politicians, doctors, etc. who can make decisions about the above topics. Due to the corona pandemic, it has not been possible to move forward in this case.

The meeting will take place in English, as Finland and Iceland have shown interest in taking part in the meetings and can better communicate in English.

At the already held meetings, we got help from the communication company Kompas, and would like to see if we could get the same assistance again with the practicalities of the event and subsequently get a report from the meeting.

We would of course like to send a budget and separate application on request.

I would like to hear your opinion and any comments, if it is something you would support!

Of course, I also answer questions on this email or the phone number below.

For the record, this application has been sent out to several pharmaceutical companies!

Many greetings from

Rita O. Christensen

Chairman

LyLe – Patientforeningen for Lymfekræft, Leukæmi og MDS  
Banetoften 26 · 4700 Næstved · tlf. 31 68 26 00 · CVR 31 30 68 33 · [lyle@lyle.dk](mailto:lyle@lyle.dk) · [www.lyle.dk](http://www.lyle.dk)

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### Schedule 3

#### EDUCATIONAL GRANT - EVENT SUPPORT USE CERTIFICATION

*(To be drafted on letterhead of Grant Recipient)*

Event description:	Annual Meeting of Nordic Patient Associations in August 2023
Grant Provider:	Incyte Biosciences Nordic AB
Grant Recipient:	Lyle Patientforeningen for lymfekraft, leukaemi og MDS
Total Grant Funding Amount:	Fifty Thousand DKK (50,000 DKK)

Addressee: Incyte Biosciences Nordic AB

By signing below, I confirm the following with regard to the above grant funding support received from Select Incyte Entity under the signed Educational Grant Event Support Agreement between Incyte Biosciences Nordic AB and the Grant Recipient Event identified above (the "Educational Event Support Agreement"):

1. The grant funded event has been fully completed in accordance with the Event description provided at the time of of grant funding request and signature of the Educational Grant Agreement.
2. Please tick the applicable option:

☐ All of the above educational grant financial support provided by Incyte has been fully utilized for the purpose of the grant funded event and there is no unused balance due to Incyte Biosciences Nordic AB as a refund per the terms of the Educational Grant Agreement; or

☐ Part of the educational grant financial support provided by Incyte has been utilized for the purpose of the grant funded event and there is an unused balance due to Incyte Biosciences Nordic AB as a refund per the terms of the Educational Grant Agreement in the amount of: \_\_\_\_\_ Euro/CHF/DKK/GBP.

I am authorized to sign on behalf of the Grant Recipient identified above.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name in CAPS

\_\_\_\_\_  
Title in CAPs

\_\_\_\_\_  
Date