

## A Proposal Summary

The Symposium is planned to be an intensive one-day conference on pulmonary hypertension (PH). It is intended for the research, medical, and public health communities, and aims to inform these communities regarding the difficulty of the diagnosis and treatment of PH, and the hardness of living with it. . PH is a rare disease with no cure as of now and also PHA Nordaica's desire that the symposium will help raise awareness of the disease, which is under-diagnosed, and motivate researchers and companies in Nordaica to look for cures.

We are reaching out to the primary care clinicians in order to extend the number of health professionals who will be able to diagnose patients at risk of developing PH. Moreover, we aim that different organizations specialize in different aspects of PH professional treating, will set different goals for different professional treating of PH.

The Symposium will hopefully begin an ongoing series of educational and other activities for creating a lively PH community comprising patients and caretakers on one hand, and clinicians, researchers, and industry groups, on the other hand.

We believe that a successful symposium will serve as a model for similar professional study days or conference. (197 words)

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1.

Primary Practitioners Symposium on Pulmonary Hypertension, Prospects for Progress.

#### 2. Applicant's Past PH-Oriented Activity Frederick Jameson, JD)

I helped found Pulmonary Hypertension Association of Nordica (PHA Nordica) because I understood that the disease was little known and many people who had it were being misdiagnosed. Also, there was little medical expertise, few specialists familiar with diagnosis and treatment options and no social support or advocacy for patients and their caregivers.

I have served as a board member of PHA Nordica for the last seven years and as president for the last two years. I manage the organizations' financial, and the main liaison with Nordica's medical specialists and medical centers.

I am one of two PHA Nordica's representatives to the Global Pulmonary Hypertension Association and attend the conferences and meetings as a chairman of the Global PHAs' Legal Committee. Additionally, I serve as a patient-teacher at the Community Medicine Course of the Faculty of Medicine, Nordica University. (139 words).

#### 4. Project Description and Anticipated Benefits

It is crucial that PA symposium will be held: PA symposium is essential for fostering cooperation among PH professionals and deepening theoretical and practical knowledge for finding cures and ways to alleviate the suffering PH causes. These anticipated benefits are especially needed facing the following situation:

Primary care practitioners are unfamiliar with PA, its devastating effects, the difficulty in diagnosing it, the limitations it imposes on patients' function, the complexity of treatment, the requirements of caring for its patients, and the stress involved in coping with the disease and treating its patients. Indeed, the aim of the Symposium to address these issues. Moreover, note that insurers, private services (such as airlines), and government agencies are poorly knowledgeable about PH. This further aggravates PH patients and their family's suffering, .

In its ten years history, PHA Nordica has **been recognizing** that increasing awareness of the disease is vital to the **well - being of** the people who suffer from it. . We believe that it is important that the primary care community ( family physicians, pediatricians, mental health specialists, among others) will be exposed to what is already known about the disease. Target groups include clinic and specialized nurses, pulmonary, physical and occupational therapists, medical psychologists and apothecaries. (206 words).

#### 5. Project *Goals*:

1. Increasing clinicians' awareness about the needs of peoples who have PH, their families and caregivers.
2. We invite schools of public health to take role in the symposium and Nordica PHA's activities; like creating patient's registry; investigating the epidemiology of the disease; identifying populations at risk, guiding healthcare policy and improving patient's advocacy.
- 3.
4. Urging Nordica's highly respected research and development community to search for ways for diagnosing PA and solutions for treating it. Delete: and solutions for PA diagnosis regarding disease diagnosis and treatment.
5. Educating future clinicians: Students in the relevant fields: medicine, nursing, physical and occupational therapy and pharmacy will also be invited to attend. Moreover, urging PH researchers, as well as biotech enterprises and pharmaceutical companies to stimulate research of new medications and treatments, including cell therapies and "off-label" applications..These will enable to harness these related expertise in the service of improving knowledge and treatment of patients with PH.
6. Establishing an inter-specialist medical board (including pulmonologists, cardiologists and rheumatologists) for gathering patient data, formulating policy recommendations to help authorities and **health** - care providers, and formatting standards of care.
7. Providing health journalists and other media professionals with information about the disease. This information will enable them to enhance awareness and understanding of PH and avoid thereby ignorance and superstitions. Moreover, PHA Nordica designs the symposium in such a way that it will lead to the establishment of the Council of PH specialists, **informing and updating thereby** the existing policy, articulate treatment standards, and guide research relating to the disease everywhere (258 words).

#### 6. **Project Plan and Implementation:** The way of making it start to happen and be used

##### a) *Preparatory Activities Already Completed*

- &&Creation of a working team for planning and implementation.
- Receiving the approval of PHA Nordica Board for holding the conference,
- Consulting with leading Nordica PH specialists and receiving their support for the symposium.
- Approaching specialists and assuring their consent to serve as presenters at the Symposium.

- Creating a first conference program draft and receiving feedback from clinicians and members of the Association's Board.

***November-Dec. 2019:***

Discussion regarding the relevance and feasibility of the conference among PHA Nordica board members.

- Consultation with PH specialists regarding the conference; receiving specialists' support and assurance they will attend.
- Redacting a proposed conference program; soliciting and receiving feedback from the specialists and revising the conference program accordingly.
- Conference date determined: *October 15, 2020* (due to coronavirus delay).
- Allocating responsibilities for PHA Nordica Symposium committee members for implementation (136 words)..

b) Preparatory Activities to be Completed Prior to Event

March 20

- 1) Formal invitations will be sent a few weeks later I
- Invitations to co-sponsor the symposium by mid-February will be sent to:
  - 2) Schools of medicine, nursing, public health, pharmacy, physical therapy, and occupational therapy.
  - 3) Professional studies departments of healthcare networks, medical centers, medical specialties societies.
  - 4) Schools of public health.
  - 5) Pharmaceutic, biotechnology and related companies.
  - 6) Research organizations.
  - 7) A suitable venue for the conference will be found.
  - 8) Search for materials support (like money, publication, etc.) from co-sponsoring institutions and firms.
  - 9) An information packet introducing participants to the disease will be prepared for the conference participants. • Guests from abroad including leaders of other PH nation l groups will be invited.
  - 10) Prominent among the guests will be senior PH specialist, Prof. Lindsburg of Liden University Medical Center. whose participation is aimed at assisting in the formation of the proposed PHA Nordica Experts Council.
  - 11) Assignment of event responsibilities among PHA Nordica Board Members.

12) Preparation of the R. Foundation's Final Version and approval by Nordaica's board (by *June 30, 2020*).

***January-March 2020:***

- 13) Sending the symposium's announcement to patients, family members, professionals, and organizations dealing with PH in Nordaica and abroad.
- 14) Solicitation of sponsorship and support from healthcare providers, professional schools, specialists' groups, associations of relevant industry representatives, research institutions
- ***April-June 2020:***
- 15) Sending out announcement regarding the new date
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- ***July 7, 2020***
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***July-2020:***

- 16) Planning of logistics
- 17) Liaison with all the relevant parties,
- 18) Preparation of participants' information packets and publishing it.
- 19) Submission to the Ricardian Foundation
- ***October 15, 2020***
- 20) Symposium Event
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21) Save-the-date announcement will be sent to the target groups by (260 words).

**7. Explain the **Project's adaptability** to other PH societies**

Nordaica scheduled PH conference aims at enhancing knowledge and understanding PH and improving treatment of this hard disease that affects people all over the world that does not distinguish between gender, age, class, and views. Moreover, it is a symposium which encompasses professionals from all over the world whose aim is to enrich knowledge and improving understanding and treatment all PH patients face. The symposium is inherently built to encompass overall PA issues in societies across the world. More specifically, due to the fact that Nordica is a multi-ethnic country consists of population from various parts of the world, it is plausible that disease patterns detected by epidemiology experts in Nordaica, are applicable

elsewhere too. As such, the organizers of the symposium invite professionals from all over the world to take part in the symposium (141 words).

## 8. Collaborative Activities

International PH **health caring** network embracing recognized centers of excellence, centers of competence, research programs and industry groups internationally and in Nordica in particular. . is extremely important as it enables sharing of information regarding cutting edge treatments, and creation of collaboration essential for alleviating PH patients' and their families' suffering. PHA Nordica hopes to create such a network in our country.

The establishment of a patient registry is a key to this purpose. . It would provide data for epidemiological studies, needs and standards of care and could serve as a communications facility for contacting patients regarding developments, when they are due for checkups and changes in protocols. We want to create a network and patient registry as part of an international commitment to sharing of PH resources and knowledge.

PHA Nordica would be very happy to share its knowledge and experience with PH patient's associations elsewhere. More specifically, we **intend to share the document** and the ensuing activities deriving from it with the conference and make them available to PH communities wherever they are found (179 words).

**Appendix I. Project Timetable** [assuming that the grant is received with a year lead time, describe activities by quarter in a table with three columns:

| Start                | End               | Description of activity   |
|----------------------|-------------------|---|
| <u>January, 2020</u> | <u>March 2020</u> | <p>Sending the conference announcement to professionals.</p> <p>Asking for sponsorship from healthcare providers, professionals' schools, associations of relevant industry representatives, research institutes</p> <p>Selection of the conference place</p> |
| <u>April, 2020</u>   | <u>June 2020</u>  | <p>Sending a message about the new date of the symposium.</p> <p>Assignment of event responsibilities to PH Nordica Board Members.</p> <p>Editing and approval of the Ricardian Foundation Proposal Final Version (by June 30, 2020)</p>                      |
| <u>?</u>             | July, 2020        | <p>planning of logistics,</p> <p>Liaison with all relevant parties,</p> <p>preparation of participants' information packets and press kit</p>   |

|                           |                           |                        |
|---------------------------|---------------------------|------------------------|
|                           |                           |                        |
| <u>October,15 th 2020</u> | <u>October,15 th 2020</u> | <u>Symposium event</u> |
|                           |                           |                        |





**Appendix II. Line Budget** [Provide a budget in tabular form. Consolidate line items to no more than five categories with one column listing the Category.

|  |          |
|--|----------|
| Item 1 Auditorium  | 3000     |
| Item 2 cateringServices: 6 Dinner and Expenses, Experts Council<br>Evening meeting | 15000    |
| Item 3 Video recording   | 2500     |
| Item 4 unknown Expenses Yet  | 1000     |
| Item5Telephone and Office services,  | 3700     |
|  |          |
| <b>TOTAL (New Nordica Shekels)</b>   | 25200NNS |

Gadi, shalom,

You have made progress in this draft.

Organizational consolidation and structural issues remain and you need to attend to these as indicated. Remember that this is a competitive grant competition and the proposal has to be correct in its structure and it must respond concisely and fully to the information requested.

There are a great many places where language improvements are necessary; many (but not all) of these are indicated in yellow. Start correcting these in your second draft (while attending to the structural issues already mentioned). Make sure that the text reads clearly and smoothly.

When I respond in a comment with "VA" as a prefix, it means I am responding as the author with the information you requested. Otherwise, my comments are instructional.

I am glad to see improvement here. Keep it up.

YG

Gadi,

You've improved regarding the placement order, although there are corrections to be made in the chronology. There remain a great many issues to resolve related to language (including those that I indicated in yellow highlighter in your earlier draft). As a proposal, this document has to read clearly, concisely and appealingly and the kinds of mistakes that remain would exclude it from consideration.

Work on these issues as well as formatting to produce a compelling proposal for the final draft. Adhere to the template guidelines. They guide the text's structure and your formatting of headings and bullet points should reflect the organization required.

Read my comments and those of the Virtual author (VA) throughout. Note the word count in parentheses at the end of each section.

There remains much work to be done here. Good luck in preparing the final draft.

YG

11 June 2020