

DANE, Living with hATTR Amyloidosis



CECE, Living with hATTR Amyloidosis



MARY, Living with an Acute Hepatic Porphyria



Advocacy for Impact Grants

APPLICATION GUIDE

Advocacy for Impact Grants is a global competitive grants program that aims to inspire patient advocacy groups to develop solutions to address critical unmet needs in the rare disease community they serve. At Alnylam’s core, we value and understand how exploring and developing new ideas has the potential to create high-impact initiatives that are a catalyst for change. Therefore, we want to give patient advocacy groups the resources and space to bring new projects and ideas to fruition.

Advocacy for Impact Grants is a global program, and Alnylam recognizes that unmet needs will differ across diverse communities and geographies. We encourage patient advocacy groups from around the world to apply with projects targeted to specifically meet the unique or special needs of their own communities.

To assist patient advocacy groups in the application process, we have put together this Application Guide, providing additional information on:

- [Eligibility](#)
- [The Application Process](#)
- [Review Criteria](#)
- [The Online Application](#)
- [Frequently Asked Questions](#)
- [How to Contact Us](#)

Please read the entire Application Guide before starting your online application.

ELIGIBILITY

Advocacy for Impact Grants will consider applications from advocacy groups around the world with a **charitable** status. Projects described in the application must be new projects that impact the ATTR amyloidosis, acute hepatic porphyrias or primary hyperoxaluria type 1 patient communities in at least one of the following ways:

- Increase disease awareness and access to diagnosis
- Offer education to patients, families, caregivers, healthcare providers and/or public
- Improve patient care

Projects described in the application can be a collaboration between two patient advocacy groups, but it is not a requirement.

ELIGIBLE PATIENT ADVOCACY GROUPS:

- Must have a nonprofit/charitable status in their country
- May also provide services to other patient communities, but their application must be focused on the ATTR amyloidosis, acute hepatic porphyrias and/or primary hyperoxaluria type 1 communities
- May submit their applications in any language and an independent translation company will translate all applications into English for a review committee that is comprised of external and internal experts
- May only submit one application each year, regardless of whether you are submitting as part of a collaboration or independently

Grant recipients will be eligible to apply again; however, they must wait one application cycle (one year) before applying to this program again.

All applications must be submitted through the online application process and all applications must be fully completed and include all required materials. Alnylam reserves the right to provide no funding if no applications are received that fully meet the eligibility and review criteria.

Grant recipients will be announced in early 2019. Projects outlined in the approved applications must be completed within a year and a half after the grant is awarded.

APPLICATION PROCESS

1

STEP 1: PREPARATION (OCT 24 - OCT 28)

Review the entire Application Guide which details eligibility, information and materials needed for the application, frequently asked questions, the review process and review criteria.

2

STEP 2: SUBMISSION (OCT 29 - DEC 10)

Applications will only be accepted [online](#). Groups will be asked to:

- Create an account
- Answer a short series of questions about the group's background and project
- Upload supporting documents, including a detailed description of the project, the metrics that will be used to measure the project's impact, and a detailed budget

See the "Online Application" section [below](#) for the list of the questions groups will be asked and the required supporting documents needed to complete the online application.

3

STEP 3: REVIEW (DEC 2018 – JAN 29)

After the application submission period has ended, all applications will be reviewed by a committee of external and internal experts. For more information on the review process and criteria, please refer to the [“Review Criteria”](#) section below.

4

STEP 4: NOTIFICATION (EARLY 2019)

All applicants will be informed of the results of the review process in early 2019. A public announcement listing the recipients and the selected projects will be distributed after all groups have been notified.

5

STEP 5: EVALUATION (MID 2020)

A year and a half after receiving funding, groups will be required to submit an evaluation form demonstrating the impact of the project.

REVIEW CRITERIA

A review committee comprised of a mix of external and internal experts will review applications and award grants based on the clear identification of an unmet need and how the project will meet that need, a detailed plan of execution, the estimated impact within the target community, and method for measuring the project’s success. Specifically, the review committee will evaluate each application based on the following categories:

UNMET NEED

- Clearly identifies an unmet need in the ATTR amyloidosis, acute hepatic porphyrias and/or primary hyperoxaluria type 1 communities
- Designed to 1) Increase disease awareness and access to diagnosis, 2) Offer education to patients, families, caregivers, healthcare providers and/or public or 3) Improve patient care.
- Advocacy for Impact Grants is a global program, and Alnylam recognizes that unmet needs will differ across diverse communities and geographies. We encourage patient advocacy groups from around the world to apply with projects targeted to specifically meet the unique or special needs of their own communities.

EXECUTION

- Outlines an effective, time appropriate and feasible strategy that is appropriately aligned with the size of the group and project staffing projections, allowing the patient advocacy group to realistically execute the project described in the application
- Can realistically be completed within the proposed timeline and budget

IMPACT

- Provides a unique solution to the needs of the ATTR amyloidosis, acute hepatic porphyrias and/or primary hyperoxaluria type 1 communities
- Clearly demonstrates how the project will be meaningful, relevant and make a difference to its community
- Offers potential for project learnings to be utilized to impact communities beyond initial program execution
- This category will have double the weight of the other categories in review

EVALUATION

- Describes clear success metrics and the methods that will be used to measure them

ONLINE APPLICATION

Applications will be accepted [online](#) in any language from Oct 29 to Dec 10, 2018. An independent translation company will translate all applications into English for the review committee.

The application requires contact and background information for the patient advocacy group applying for the grant, as well as details of the proposed project. Groups will have to answer a series of questions and submit:

- List of board of directors
- Group's annual operating budget
- Detailed and itemized budget of the project
- Project timeline
- Proof of Charitable Status [W-9, W-8 or other financial/tax form]
- If chosen as a recipient, a statement of commitment/letter of intent that provides written intent to execute the proposed project if funding is received.

Please find a preview and explanation of the questions that will be asked in the online application below.

GROUP INFORMATION

In this series of questions, you'll be asked to provide general background information about your group.

General Information

- 1) Group Name
- This must match the name that is registered with your government
- 2) Address
- 3) Country
- 4) Main Phone Number

- 5) Email Address
- 6) Fax (optional)
- 7) Website Address (optional)

Background Information

- 8) Year founded
- 9) What patient population do you serve?
 - You will be able to choose from a drop down that includes:
 - Amyloidosis/ATTR Amyloidosis
 - Porphyrias/Acute Hepatic Porphyrias
 - Hyperoxaluria /Primary Hyperoxaluria Type 1
 - Multiple Rare Diseases
 - Other
- 10) Additional patient population information
 - Please include geographic location and any other important information about the individuals you serve.
- 11) Mission Statement
- 12) Brief description of your group.
 - Provide an overview of your group's focus and primary program(s) in 300 words or less.
- 13) Number of employed employees
 - This should be the total number of full time and part time employees.
- 14) Number of volunteer employees/volunteers
- 15) Board of Directors
 - Please list out all current Board Members, first and last names, as well as their position OR attach a separate document with the information. If you attach a document below, please write "not applicable" in the text box below.
- 16) Do any public officials, government officials, or government employees currently serve on the group's Board of Directors?
- 17) If you answered "Yes" above, please identify a) the member, b) their position on the board, and c) what their public or government role is. If you answered "No" above, please write "not applicable" in the text box below.
 - Ex: John Smith – Secretary - Mayor of Chicago, IL
- 18) Please describe or upload your group's Annual Operating Budget by filling in the text box below OR clicking the "Upload" button below. If you attach a document below, please write "not applicable" in the text box below.
 - An operating budget is a detailed projection of all estimated **income** and **expenses** during a given period (usually one year). Income is the money a group brings into the organization through fundraising, grants etc. Expenses includes all money spent through operations of the organization, including overhead costs, program costs, etc.
- 19) Local Currency Code

- *A currency code is a code that indicates the currency used in your country. The code you enter determines the currency in which the funds will be paid. Payments will be made in U.S. dollars unless another currency is specified.*
- 20) Have you received support from Alnylam within this calendar year?
 - *You will be asked to answer Yes or No. Please note, if you have previously received funds, this does not disqualify your group from being awarded a grant. Please note that Alnylam is required to track and report all payments made to patient advocacy groups.*
- 21) If you answered “Yes” to the question above, how much support was received and for what?
 - *Please write the amount and a description of the purpose for which the funds were provided.*

CONTACT INFORMATION

In this series of questions, you will be asked to provide general contact information for the main point of contact for this application.

Main Contact Information

- 22) Prefix (optional)
- 23) First Name
- 24) Last Name
- 25) Title in the Group (ex: Executive Director, Development Officer, Secretary, etc.)
- 26) Phone Number
- 27) Email Address
- 28) Fax (optional)

Payee information

You will be asked to fill out this section only if the group receiving funds is different than the group previously identified in the "Group Information" section. Please note, if the group is different, all fields will be required.

- 29) Payee Group Name
- 30) Payee Full Address
- 31) Payee Country
- 32) Payee Tax ID
 - *This is only required for U.S. groups*
- 33) Local Currency Code
 - *A currency code is a code that indicates the currency used in your country. The code you enter determines the currency in which the funds will be paid. Payments will be made in U.S. dollars unless another currency is specified.*
- 34) Additional Payee Information/Notes
 - *If the payee is different than the requesting group, please explain the relationship between the two parties.*

PROJECT INFORMATION

In this series of questions, you will be asked questions related to the project you are proposing.

Project Information

- 35) Project Title
- 36) What is the amount of funding you are requesting (maximum of \$50,000 USD)?
- 37) What is the overall budget of this project?
- 38) Please outline or upload a detailed itemized budget of the project by filling in the text box below OR clicking the "Upload" button below. If you attach a document below, please write "not applicable" in the text box below.
- 39) If the project will not be fully funded by Alnylam, please describe how you will fund the remaining amount. If it will only be funded by Alnylam, please write "not applicable."
 - *If the project exceeds the maximum of \$50,000 USD, define how you will fund the remaining amount (additional funding sources, etc.).*
- 40) Please indicate which of the disease area(s) on which your application is focused.
 - *You'll be able to choose one or more of the diseases below that are most relevant to your proposed project*
 - *ATTR amyloidosis*
 - *The acute hepatic porphyrias*
 - *Primary hyperoxaluria type 1*
- 41) Please indicate which funding category your project seeks to impact (must be one or more of the below):
 - *Increase disease awareness and access to diagnosis*
 - *Offer education to patients, families, caregivers, healthcare providers and/or public*
 - *Improve patient care*
- 42) What geographic region or community will this project impact?
 - *Define where (which countries, regions or cities) the project will be executed, as well as which geographic areas will be impacted through the project (in 100 words or less).*
- 43) What is the landscape of the disease in the geographic area you are working in?
 - *For example, the level of awareness, government support, number of people affected, accessibility to medical care, challenges or barriers to diagnosis or care, etc.*
- 44) Please provide a summary of the proposed project, including what makes it new and/or a unique solution (1,000 words or less).
- 45) What is the unmet need within the ATTR amyloidosis, acute hepatic porphyrias or primary hyperoxaluria type 1 communities the project is designed to impact?
 - *Provide a summary of the specific unmet need(s) this project will address.*
- 46) What are the goals of the project?
 - *Summarize the measurable goal(s) of the proposed project in 500 words or less.*
- 47) What is the strategy to complete this project?
 - *Provide a detailed written summary of the strategy or approach you will take to complete this project including how you will staff it, resources/tools used, etc.*

- 48) Please describe or upload a detailed project timeline by filling in the text box below OR clicking the “Upload” button below. If you attach a document below, please write “not applicable” in the text box below.
- 49) How will the impact of the project be measured? What are the measures of success of this project and what methods will be used to measure them?
- *Outline the proposed measurement methods and tools used to measure.*

ATTACHMENTS

Each group will also need to attach the following:

- Payee Proof of Charitable Status
 - *The payee is the group that would receive the funding for the application if it is chosen as a recipient*
 - *U.S. Payee – please upload a copy of your U.S. IRS tax exemption letter showing the Tax ID and tax status or your w-9. Here is a link to a w-9: <https://www.irs.gov/pub/irs-pdf/fw9.pdf>*
 - *Outside of the U.S. Payee – please upload an official government document demonstrating the charitable status of the group in your country.*
- Additional Attachment – For any additional supporting documentation.
- Additional Attachment – For any additional supporting documentation.

FREQUENTLY ASKED QUESTIONS

1. What is Advocacy for Impact Grants?

Advocacy for Impact Grants program is a global competitive grants program that aims to inspire solutions for critical unmet needs in the rare disease community.

2. Why is Alnylam supporting such a program?

At our core, Alnylam values and understands how exploring and developing new ideas has the potential to create high-impact initiatives that are a catalyst for change. We are launching this competitive grants program to give patient advocacy groups the resources and space to bring new projects and ideas to fruition. This program encourages groups to be creative in designing and implementing new ideas that will continue to move their communities forward.

Advocacy for Impact Grants is a global program, and Alnylam recognizes that unmet needs will differ across diverse communities and geographies. We encourage patient advocacy groups from around the world to apply with projects targeted to specifically meet the unique or special needs of their own communities.

3. Who is eligible to submit a proposal?

Advocacy for Impact Grants is open to patient advocacy groups around the world. Eligible patient advocacy groups must have a nonprofit/charitable status in their country and may only submit one application per year. Projects may be a collaboration between two patient advocacy groups, but it is not a requirement. Patient advocacy groups may also provide services to other patient communities, but their proposed project must be focused on the ATTR amyloidosis, acute hepatic porphyrias and/or primary hyperoxaluria type 1 communities.

4. Are there any restrictions on the use of funds?

The funding provided through Advocacy for Impact Grants may not be used to support the below items, should they be a part of your overall project:

- Funds may not be used to treat patients
- Funds may not be used to enable patient access to a specific therapy or for branded treatment-specific education.

5. How does a patient advocacy group know if it has a charitable status in its country?

Different countries have their own way of recognizing groups' charitable status. To be eligible, a group must provide official documentation that demonstrates its charitable status within its country. Examples of charitable status documents are:

- 501 (c)(3) IRS Determination Letter
- A government letter officially recognizing a group as charitable

6. Can a patient advocacy group apply to Advocacy for Impact Grants if they have received funding from Alnylam previously?

Yes. There is a section of the online application that asks applicants to indicate if they have received funding from Alnylam previously. If groups answer "Yes," they should indicate the amount of funding they received. However, groups will not be excluded from the Grants Program if they have previously received funding.

Patient advocacy groups that receive a grant through this program will be eligible to apply again; however, they must wait one application cycle (one year) before doing so.

7. How do patient advocacy groups submit an application? When are applications accepted?

Applications will be accepted [online](#) between Oct 29 and Dec 10, 2018 in any language.

8. What is required as part of the application process?

The application requires contact and background information on the patient advocacy group applying for the grant, as well as the required details of the proposed project. All groups must also submit a project timeline, detailed budget, staffing plan, evaluation plan, proof of charitable status, [W-9 or other financial/tax form], as

well as an organizational (and partner) statement of commitment/letter of intent, which provides written intent that the group will implement the proposed project if funding is received.

9. Can patient advocacy groups submit multiple applications?

Eligible patient advocacy groups may only submit one application per year.

10. Can patient advocacy groups submit an application to expand or improve an existing program?

No. Advocacy for Impact Grants is only intended to fund new projects that impact the ATTR amyloidosis, acute hepatic porphyrias and/or primary hyperoxaluria type 1 communities.

11. What if an application is not in one of the three disease areas or does not fit into one of the specific categories?

In its first year, Advocacy for Impact Grants will focus on the ATTR amyloidosis, acute hepatic porphyrias and primary hyperoxaluria type 1 communities, and is looking specifically to fund projects that impact these communities through increased disease awareness and access to diagnosis, education, improved patient care.

Check back in mid-2019 for information about Year 2 of the program and eligibility requirements at that time.

12. How much support will be awarded?

Advocacy for Impact Grants will recognize and fund applications of up to \$50,000 USD from patient advocacy groups that aim to 1) increase disease awareness and access to diagnosis, 2) offer education to patients, families, caregivers, healthcare providers and/or public or 3) improve patient care.

13. When will the funds be provided?

Grant recipients will be announced in early 2019. Projects must be completed within a year and a half after the grant is given.

14. Does the project need to be exactly one and a half years? Can it be shorter or longer?

The project outlined in the application does not need to be exactly one and a half years, but projects must be completed one and a half years after the grant is given. A detailed timeline, including planning and execution, is required as part of the online application.

15. How will the funding decision(s) be made?

A review committee comprised of a mix of external and internal experts will review applications and determine grant recipient(s) based on the clear identification of an unmet need, plan of execution, level of impact within the target community and evaluation strategy.

16. Who is on the review committee?

The review committee includes internal (Alnylam) and external experts.

17. Will groups hear back if their applications do not receive funding? When will groups be notified?

All groups will be informed of the results of the review process. A public announcement listing the grant recipients and the selected projects will be distributed after all groups have been notified.

18. Can groups apply next year?

Patient advocacy groups that receive one of the Advocacy for Impact Grants will be eligible to apply again; however, they must wait one application cycle (one year) before applying again.

You can check back in mid-2019 for information about Year 2 of the program and eligibility requirements at that time.

19. Who should be contacted for additional questions?

You can learn more on our [website](#) or reach out directly to us at PatientAdvocacy@alnylam.com.

CONTACT US

You can learn more on our [website](#) or reach out directly to us at PatientAdvocacy@alnylam.com.

Anylam's Commitment to Rare Disease Patients

Patients living with rare diseases often endure a long diagnosis odyssey, suffer from suboptimal care, and do not have access to adequate disease information. This competitive grants program is designed to provide the flexibility for patient advocacy groups to create and implement high-impact initiatives that will truly serve their unique communities.

To learn more about Anylam's work within the rare disease community, click here to learn about our [science](#), [products](#) and [pipeline](#).