

**DANE**, Living with hATTR Amyloidosis



**CECE**, Living with hATTR Amyloidosis



**MARY**, Living with an Acute Hepatic Porphyrria



# 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 that address critical unmet needs in the rare disease communities 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 Application](#)
- [Frequently Asked Questions](#)
- [How to Contact Us](#)

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

## ELIGIBILITY

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Advocacy for Impact Grants will consider applications from patient advocacy groups around the world with a **charitable** status. Projects described in the application must be new projects that have not been previously implemented by the group, that impact the ATTR amyloidosis, acute hepatic porphyria and/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

## ELIGIBLE PATIENT ADVOCACY GROUPS:

- Must have a legal charitable status in their country
- May provide services to other patient communities, but their application must be focused on the ATTR amyloidosis, acute hepatic porphyria 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 comprises external and internal experts
- May submit applications for projects that are a collaboration between two patient advocacy groups, but it is not a requirement
- May **not** submit applications solely focused on research or for registries; these applications will not be considered as part of this program
- May only submit one application each year, regardless of whether they are submitting as part of a collaboration or independently

Recipients of the 2018 Advocacy for Impact Grants must wait one application cycle before applying again, and therefore are not eligible to apply for this year's cycle.

## APPLICATION PROCESS

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### STEP 1: PREPARATION AND SUBMISSION (NOVEMBER 19, 2019 - JANUARY 3, 2020)

- Review this entire Application Guide which details eligibility, information and materials needed for the application, frequently asked questions, the review process and review criteria
- Download the Application Form [here](#)
- Fill out the Application Form in its entirety and compile the required supporting documents
- Email the completed application and requested attachments to [AdvocacyForImpact@alnylam.com](mailto:AdvocacyForImpact@alnylam.com) by 11:59pm U.S. Eastern Time on January 3, 2020
- Please note that late or incomplete applications will not be accepted

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

2

### STEP 2: REVIEW (MARCH - APRIL 2020)

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.

3

### STEP 3: NOTIFICATION (MAY - JUNE 2020)

All applicants will be informed of the results of the review process in mid-2020. A public announcement listing the recipients and the selected projects will be distributed after all groups have been notified.

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### STEP 4: EVALUATION (LATE 2021)

Projects outlined in approved applications must be completed within a year and a half after funds are provided. A year and a half after receiving funding, groups will be required to submit an evaluation form describing the impact of their project.

## REVIEW CRITERIA

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A review committee comprising both external and internal experts will review applications and select 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. Applications are reviewed based on their own merit and are reviewed independently from one another.

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 porphyria 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
  - 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 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
- Does not solely focus on research or registries

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## IMPACT

- Provides a unique solution to the needs of the ATTR amyloidosis, acute hepatic porphyria 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

Alnylam reserves the right to provide no funding if no applications are received that fully meet the eligibility and review criteria.

# THE APPLICATION

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Applications will be accepted from Nov 19, 2019 to Jan 3, 2020. Applications may be submitted in any language and an independent translation company will translate all applications into English for the review committee.

Applications will only be accepted via email to [AdvocacyForImpact@alnylam.com](mailto:AdvocacyForImpact@alnylam.com). Please email your completed application and requested attachments by 11:59pm U.S. Eastern Time on January 3, 2020. Please note that late or incomplete applications will not be accepted.

- All submissions should include the following subject line:  
**AFI Application [Name of Organization], [Country].**
- All attachments must be clearly labeled and provided in a PDF format. [Click here](#) for more information on saving files as a PDF.

The application requires contact and background information for the patient advocacy group applying for the grant, as well as details of the proposed project. Applicants will be required to answer a series of questions and will need to provide:

- Proof of charitable status
- Itemized project budget
- Annual operating budget
- Detailed project timeline

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

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## 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) Website Address (optional)

### Main Contact Information

*In this series of questions, you will be asked to provide contact information for the main point of contact for this application — this should be the individual who will be able to respond to questions about the application.*

- 5) Prefix (optional)
- 6) First Name
- 7) Last Name
- 8) Title in the Group
- 9) Phone Number
- 10) Email Address
- 11) Fax

### Group Information

- 12) Year founded
- 13) What patient population does your group serve?  
*You will be able to choose from the following options. If you choose "other" you may elaborate.*
  - ATTR Amyloidosis
  - Porphyria
  - Primary Hyperoxaluria
  - Multiple Rare Diseases
  - Other
- 14) What geographic location(s) does your group serve?
- 15) Mission Statement  
*Please keep your response to under 300 words.*

## Background Information

16) 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 funding from Alnylam, this does not disqualify your group from being awarded a grant. However, recipients of the 2018 Advocacy for Impact Grants must wait one application cycle before applying again and therefore are not eligible to apply for this year's cycle. Alnylam is required to track and report all payments made to patient advocacy groups.*

16a) If you answered "Yes" to the question above, how much support was received and for what? If you answered "No" above, please write "not applicable."

*Please write the amount and a description of the purpose for which the funds were provided. If no funds were provided, please write "not applicable."*

17) Do any public officials, government officials, or government employees currently serve on the group's Board of Directors? If yes, please identify a) the member, b) their position on the board and c) what their public or government role is. (Ex: John Smith, Secretary – Mayor of Chicago, IL; John Smith, Chairman – Member of Parliament, Leeds East) If the answer is no, please write "not applicable" in the text box below.

*You will be given space within a text box to include this information. Please note we only require the names and information for board members if they are also a current public official, government official or government employee.*

18) Local Currency Code

*Please include the local currency code for the group applying for the grant. 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. Ex: USD, EUR, JPY.*

## ATTACHMENTS

*Please include the following attachments when you submit your application. Attachments should be submitted as a PDF and should be clearly labeled with the title outlined below.*

*Sample: **Annual Operating Budget\_ [Name of Organization]***

- Annual Operating Budget

*Please submit your organization's detailed annual operating budget.*

- Payee Proof of Charitable Status

*The payee is the group that would receive the money for this 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. — Please upload an official government-issued document demonstrating the charitable status of the organization in your country.

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## PROJECT INFORMATION

- 19) Project Title
- 20) Please indicate which of the following disease area(s) your application is focused.  
*You will be asked to choose one or more of the diseases listed below that are most relevant to your proposed project.*
- ATTR amyloidosis
  - Acute hepatic porphyria
  - Primary hyperoxaluria type 1
- 21) 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
- 22) What is the amount of funding you are requesting?  
*You may request a maximum of \$50,000 USD or the equivalent in your local currency. Please provide the amount in your local currency and specify your currency type. Selected recipients will receive funding amounts based on conversion rates at the time of the payment disbursement.*
- 23) What is the overall budget of this project? Please only provide the total amount and include the currency. You will be asked to provide a detailed budget as an attachment.
- 24) If the project will not be fully funded by Alylam, please describe how you will fund the remaining amount. If it will only be funded by Alylam, please write "not applicable."  
*If the project exceeds the maximum of \$50,000 USD, describe how you intend to fund the remaining amount (additional funding sources, etc.)*
- 25) 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 (100 words or less).*
- 26) What is the landscape of the disease in the geographic area in which you are working?  
*For example, the level of awareness, government support, number of people affected, accessibility to medical care, challenges or barriers to diagnosis or care, etc. (500 words or less).*
- 27) Please provide a summary of the proposed project, including what makes it new and/or unique (1000 words or less).
- 28) **Unmet Need:** What is the unmet need within the ATTR amyloidosis, acute hepatic porphyria or primary hyperoxaluria type 1 community the project is designed to impact?  
*Provide a summary of the specific unmet need(s) this project will address in 500 words or less.*
- 29) **Goals:** What are the goals of the project?  
*Summarize the measurable goal(s) of the proposed project in 500 words or less.*

30) **Execution:** What is the strategy to complete this project?

*Please outline the following in 1000 words or less.*

- A detailed written summary of the strategy or approach you will take to complete this project
- Outline your number of employees and volunteer employees/volunteers
- Include a staffing plan for your proposed project
- Outline resources/tools you will use, etc.

31) **Evaluation:** 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 in 1000 words or less.*

## ATTACHMENTS

*Please include the following attachments when you submit your application. Attachments should be submitted as a PDF and should be clearly labeled with the title outlined below.*

*Sample: **Itemized Project Budget\_ [Name of Organization]***

- Itemized Project Budget
- Detailed Project Timeline

*Please outline timing for all project activities from planning to execution and evaluation.*

## FREQUENTLY ASKED QUESTIONS

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### 1. What is Advocacy for Impact Grants?

Advocacy for Impact Grants is a global competitive grants program that aims to inspire patient advocacy groups to develop solutions to address the critical and unique unmet needs of the rare disease communities they serve. In its second year, the program will continue to focus on the ATTR amyloidosis, acute hepatic porphyria and primary hyperoxaluria type 1 communities around the world.

### 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 developed Advocacy for Impact to give patient advocacy groups the resources and space to bring these types of creative ideas to fruition. By supporting groups from all over the world, we're able to help them implement programs that best address the unique unmet needs of their diverse geographies, thus making the biggest impact possible on the rare disease community.

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 apply?

Advocacy for Impact Grants is open to patient advocacy groups around the world. Eligible patient advocacy groups must have a charitable status in their country and may only submit one application per year. Recipients of the 2018 Advocacy for Impact Grants must wait one application cycle before applying again, and therefore are not eligible to apply for this year's cycle.

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 porphyria 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 company's drug (product, therapy, etc.) or for branded treatment-specific education

Please note that applications solely focused on research or for registries are not eligible for support through the Advocacy for Impact program.

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

Each country has its 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 or other documentation officially recognizing a group as charitable

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

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

However, recipients of the 2018 Advocacy for Impact Grants must wait one application cycle before applying again for this program, and therefore are not eligible to apply for this year's cycle.

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

Applications are available to download [online](#) and submissions will be accepted only via email to [AdvocacyForImpact@alnylam.com](mailto:AdvocacyForImpact@alnylam.com) between Nov 19, 2019 and Jan 3, 2020 in any language. Please email your completed application and requested attachments by 11:59pm U.S. Eastern Time on January 3, 2020. Please note that late or incomplete applications will not be accepted.

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

The applicant must submit a completed application form via email, which requires contact and background information for the patient advocacy group applying for the grant, as well as details of the proposed project. All groups must also submit a proof of charitable status (W-9 or other financial/tax form), an itemized project budget, annual operating budget and a detailed project timeline. Incomplete submissions will not be accepted.

**9. Can patient advocacy groups submit multiple applications?**

Eligible patient advocacy groups can 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 porphyria 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 second year, Advocacy for Impact Grants will continue to focus on the ATTR amyloidosis, acute hepatic porphyria and primary hyperoxaluria type 1 communities. Alnylam is looking specifically to fund projects that impact these communities through increased disease awareness and access to diagnosis, education and improved patient care.

**12. How much support will be awarded?**

Advocacy for Impact Grants will recognize and fund projects, each in an amount 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 3) Improve patient care.

**13. When will the funds be provided?**

Immediately following the public announcement of grant recipients, Alnylam will reach out to each recipient organization to collect any required information and to begin the contracting process. We are committed to the goal of making payments within 90 days of receiving fully executed contracts.

**14. If chosen as a recipient, what information will groups need to provide in order to receive funding?**

Recipients will be required to share the following information in order to receive funding:

- Payee details, including group name, address, country, currency code and tax ID
- Banking information, including institution name, branch address, transit number, account number and SWIFT

More information and directions will be provided to recipients at the time they are notified of their selection.

**15. 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 funding is received. A detailed timeline, including planning and execution, is required as part of the online application.

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

A review committee comprised of both external and internal experts will review applications and select 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. Applications will be reviewed based on their own merit and are reviewed independently from one another. Please note that applications solely focused on research or for registries will not be considered as part of this program.

**17. Who is on the review committee?**

The review committee includes both internal experts from Alnylam and external experts with experience in nonprofits and rare disease.

**18. 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.

**19. 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.

All projects outlined in applications must be new projects that have not previously been implemented by the group.

**20. Who may be contacted for additional questions?**

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

## CONTACT US

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

### **Alnylam's Commitment to Rare Disease Patients**

Patients living with rare diseases often endure a long diagnosis journey, suffer from suboptimal care and do not have access to adequate disease information. Advocacy for Impact Grants 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 Alnylam's work within the rare disease community, click here to learn about our [science](#), [products](#) and [pipeline](#).