

Application Guide

Overview

Sanofi Genzyme's Global Patient Advocacy team launched the Patient Advocacy Leadership (PAL) Awards grants program in 2011 to encourage bold new ideas and programs to support the Lysosomal Storage Disorder (LSD) community worldwide. In the 6 years since the program was started, Sanofi Genzyme has awarded over \$545,000 to support 43 unique projects.

The PAL Awards program funds innovative projects focused on disease awareness and education, community mobilization, non-profit development, and patient care and support programs to allow organizations to begin new efforts to address unmet needs in their local LSD patient community. We are delighted to launch the 2017 PAL Awards and encourage you to read this guide to consider whether your organization should apply.

The PAL Awards program is open to charitable, not for profit organizations from around the world. There is no requirement for organization size or history in order to apply. Applicants may apply for up to \$25,000 (USD) to support new projects. Organizations may apply each year, but may not apply for a program for which they've previously requested funding.

Detailed information about eligibility requirements and the application process can be found below. For more information, or with any questions, please contact PALAwards@sanofi.com.

Application Process & Timeline

The submission period opens on May 15, 2017 and closes June 30, 2017. In order to be considered eligible, all applications must follow these steps:

STEP 1: Fully complete the [Project Proposal Form](#) or by going to the "[Application Process](#)" page on www.palawards.com.

You will need to provide:

1. A description of your organization
2. An outline of your proposed project including how it will address unmet needs and what actions will be taken to ensure the project is successful
3. A thorough, detailed project budget showing estimated expenses to execute the program and amount of funding needed
4. A plan to evaluate the success of your project

Remember, projects that have been completed will not be considered. Once you complete the project proposal form, save the document as it will be required as an attachment when you submit your application online.

STEP 2: Complete the formal application via [GiftsOnline through this link](#). You will be required to create an account to access the system, which will only take a few minutes. You will then be asked to attach your Proposal Form at the end of the application in the "Attachments" section.

If you have any trouble submitting your application online, require a print copy, or need a translated document, please reach out to us at PALAwards@sanofi.com or through the "[Contact Us](#)" page on www.palawards.com.

STEP 3: Once submitted, all applying organizations are run through a local pre-screen to identify any compliance or ethics issues. Approved applications are submitted to an independent panel of judges for review. These judges make recommendations for PAL Awards. All applicants will be notified of the results at the end of the judging period.

STEP 4: Recipients will be publicly announced by Sanofi Genzyme before the end of 2017 and payments will be processed once recipients are announced.

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Grant Guidelines

The Proposal Form is designed to help you organize your proposal and is based on standard fundraising practices in many countries. It consists of the following four sections:

ORGANIZATION DESCRIPTION:

- This is where you should tell us about your organization. Provide a brief summary of your history and mission, how you interact with patients in your country, and what services you provide. How many staff members do you have? Do you have specialized skills or abilities to meet needs in the community?
- Help us understand what the environment is like for patient organizations in your country for this particular LSD. Are there many projects to support patients or are you beginning to build patient programming? What role do you play in the LSD community in your country? Is there a strong patient network or are you still trying to build the patient community?

PROJECT DESCRIPTION:

- Tell us about how this project addresses unmet needs or solves a problem in the community. Help the judges understand what the unmet needs are, or challenges currently are, and why it's important to address them.
- Describe why it is necessary that this project take place. Why is this project important? How is this project unique or innovative? Why is it important that this project take place in your country?
- You should also use this section to describe the project for the judges, including its main objectives, and also provide specific project activities and steps you'll take to make sure the project is a success. Help us understand what it will take to execute the project and how you will do it.

PROJECT BUDGET:

- The reviewers and judges need to understand how you will use PAL Awards funds, and any other funds you have to support the project. This helps them evaluate if you are really able to execute the project with the amount of funding requested and also shows that you understand the anticipated costs of the project.
- Use this section to provide an itemized budget. It's okay to estimate costs. For example, you may estimate \$500 for mailing of 100 education packets at \$5 each. Help the judges understand how you calculated the costs. You can also provide this budget in your local currency.
- Remember, the maximum PAL Award is \$25,000, one time. So, you can also include other funds here that might support the project if it receives a PAL Award but needs more funds than you're asking for.

PROJECT EVALUATION:

- It's important that there are measures of success for the project. Share with the judges how your organization will evaluate the success of your project. How will you know the project addressed the unmet need or problem? If you anticipate any barriers, explain how you will try to work around them.

Each section of the Project Proposal Form must be completed for a proposal to be considered eligible. Applications must be submitted within the stated application period in order to be considered. Projects submitted without a budget will not be considered. Proposals must adhere to the program guidelines and criteria outline in the section below.

Please Note, proposals may be submitted in the applicant's native language. All proposals will be translated by a validated 3rd party into English for review and judging purposes.

Program Criteria and Important Information

Applicants are encouraged to review the information contained in this document carefully before applying. Below are the eligibility requirements for this year's program:

All proposed projects must directly serve the lysosomal storage disorder (LSD) community. Your organization may provide services to other patient communities, but the project must directly address unmet need for the LSD community.

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- You may choose to collaborate with another organization to execute a project, but it's not a requirement for consideration in 2017. You may only submit a request on behalf of your own organization; you may not submit a request for another organization.
- Certain projects are not eligible for funding through PAL. Projects including the following activities will not be considered:
 - Newborn screening programs
 - Projects seeking to generate income for affected individuals
 - Any project or initiative related to products or treatments, e.g. home infusion, access to treatment
 - Political lobbying activities
 - Supplemental support provided by other funding sources
 - Ongoing or completed projects where expenditure has already been incurred (PAL can only support new, proposed projects)

Organizations that have previously received a PAL Award may apply again, for a new project. They must have completed the required Final Report, or Progress Report, for the prior PAL Award. They also must have waited one awards cycle (one year) between applications.

Organizations may not submit an application for the same project more than once. If you've previously applied for a PAL Award for a project, and were unsuccessful, your PAL Award submission for the new cycle must be for a different project.

Review Process

Each proposal will be pre-reviewed at the time of submission for completeness and also sent for a local review to identify any known compliance or ethics issues. Once cleared, the application will be sent to an independent panel of judges for review.

The review committee is comprised of judges with expertise in such areas as philanthropy, rare disease advocacy, research, communications, non-profit management, and patient organization capacity building. They are not employed by Sanofi Genzyme, but Sanofi Genzyme may provide information to the judges about the LSD community in your country. Since this is a global program, the committee may consider the need for geographic distribution in granting PAL Awards when making funding recommendations.

Judges evaluate complete project proposal forms and applications based on 5 criteria: impact, innovation, feasibility, sustainability, and need. Please keep these criteria in mind when you're writing your project proposal form. The intent of the PAL Awards is to provide funding for new, unique projects that address an unmet need or problem in the LSD community in your country. Please provide as much information as you can for the judges about how your project fits into the intent of the PAL Awards.

Proposal Help

Knowing how to write and present a good proposal is necessary to ensure the long-term sustainability of any organization, given the important role it plays in enabling groups to raise funds from many sources. Proposal development can be challenging, particularly for smaller groups with limited time and resources.

PROPOSAL WRITING RESOURCES

Here are some online tips for grant writing that are straightforward, insightful and universal. Most are compilations from experts in the field. Though not specifically geared towards the rare disease space, the basic elements of all proposals are largely the same.

- <http://www.fundraiserhelp.com/grant-writing-funding/>
- <https://www.thebalance.com/how-to-write-a-grant-proposal-2501980>
- <http://www.lone-eagles.com/granthelp.htm>

Sanofi Genzyme offers translations to all non-English speaking patient organizations. You can submit your proposal in your native language. Your proposal will be translated into English for judging purposes by an agency appointed by Sanofi Genzyme.

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PROJECT IDEAS

Need some ideas for your proposal? To support you in writing proposals you may want to consider the examples below for your next proposal submission. Remember that these examples are provided only to encourage creative thinking and do not necessarily guarantee a future PAL Awards grant.

In 2014, **The Croatian Alliance for Rare Diseases** received an award to support a travelling photo exhibition of people living with LSDs in cooperation with rare disease organizations from Croatia, Serbia, Macedonia, and Bosnia and Herzegovina. This project was the first regional cooperation on a specific group of diagnoses. The hope is to build awareness of LSDs throughout the region through photos of patients in their everyday lives, and to address the disparities that exist in terms of access to care. The opening of the exhibition took place in Zagreb, Croatia on September 26, 2015 at the Public Open University Zagreb (the largest educational and cultural institution in Croatia) and it attracted much interest. The exhibition has already visited Macedonia, Serbia and Bosnia and Herzegovina and continues to travel within the region.

The International Pompe Association (IPA) was selected as a PAL Award recipient in 2014 to support the Pilot Phase of a **Pompe (Em)Power Program**. The goal of which is to encourage, train, and mentor future international Pompe patient advocates that are interested in becoming involved with international patient advocacy for Pompe disease. The program involves face-to-face meetings, the creation of training materials, and tool kits for future use.

A joint initiative of the **U.S. and Canadian National Niemann-Pick Disease Foundations** was submitted in 2014. The project, "Bridging the GAP to the Future," was a two-day training session for board members that included topics such as best practices in governance, roles and responsibilities of effective boards, the board/staff partnership, and other critical areas. The ultimate goal of the training is to allow the board to be more effective at meeting the needs of family members and constituents as they move through clinical trials working towards appropriate treatments and therapies.

Frequently Asked Questions

Can I submit a proposal in a language other than English?

Yes. You can submit your proposal in your native language and your proposal will be translated into English for judging purposes by an agency appointed by Sanofi Genzyme at no cost to your organization.

How do I know if my project is appropriate for a PAL Award?

First, your project must be new, and address an unmet need within the LSD community.

You cannot have submitted a request for funding for this project before and, if you've previously received a PAL Award, even if for a different project, you must have waited a year between cycles to apply. For example, if you received a PAL Award in 2015, you can apply in 2017. If you received a PAL Award in 2016, you are not eligible to apply in 2017, but would be eligible to apply in 2018.

You must be submitting a request on behalf of your charitable, not-for-profit organization. You may not apply for funds for another organization or on behalf of any profitable organization.

Your project must not include the following types of programs:

- Newborn screening programs
- Any efforts seeking to generate income for affected individuals
- Projects or initiatives related to promoting products or treatments, e.g. home infusion, access to treatment, etc.
- Political lobbying activities
- Supplemental support provided by other funding sources
- Ongoing or completed projects where expenditure has already been incurred

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If my organization receives an Award, what will be required of us?

If you receive a PAL Award, you'll be required to comply with Sanofi Genzyme and local government regulations about charitable donations and transparency. This includes completing online administrative forms and co-signing an agreement documenting Sanofi Genzyme's support of the program and your agreement to execute the project as you've described it in your application. You may need to complete additional forms based on local compliance regulations.

To document that funds were used as requested, you'll also need to provide Sanofi Genzyme with a brief final report, including an expense report, for the funded project. This is required at the completion of the project, or within one year of receiving the PAL Award, whichever comes first.

Do you have examples of previous projects the PAL Awards program has supported?

Absolutely. Please check out the "Project Ideas" section of this guide (above) for summaries of past PAL projects. All previous recipients of PAL awards are listed on www.palawards.com, with brief descriptions of the projects funded.

We would like to submit an idea for funding but we don't have much experience writing proposals. Where can we get help?

We understand that some organizations may not have as much experience writing grant proposals as others. We encourage you to look through the "Proposal Help" section of this guide, and use the on-line [Proposal Form](#). The form is meant to help guide you in your thinking and your writing. This form may help you organize your proposal and is based on standard fundraising practice in many countries. It is important that you submit an application that is your own work.

We would like to apply but we're not sure what kind of project to propose. Can you give us some ideas?

First and foremost, your project must support the lysosomal storage disorder patient community in an innovative, unique way that addresses a problem or an unmet need. One of the goals of the PAL Awards Program is to inspire new ideas and support new programs, so we encourage you to be creative with your project proposal. Knowing what you know about the LSD community in your country, what are the needs that need to be addressed, and what are unique ways that your organization can help achieve success in that area? Activities such as innovative disease awareness campaigns, novel patient and family support programs, or new outreach and education initiatives are among the many possibilities that will be considered for funding.

Who is eligible for a PAL Awards grant?

The applicant must be a charitable (not for profit) organization serving the LSD community that is registered or has official recognition from the government. You must not have received a PAL Award during the previous cycle and your organization must not be under any ethics or local compliance review.

What does it mean for an organization to be "registered" or "officially recognized?"

Every country has different ways of recognizing the legal status of charitable, non-governmental organizations (NGOs). For example, in the United States the government grants tax-exempt status to certain non-profit organizations (often called 501(c)(3) organizations), which indicates the group meets the requirements to be recognized as a charitable organization. Some other countries provide official letters from the government, or an official form that acknowledges that the organization is an official group, and a not-for-profit charity. To be eligible for the PAL Awards program, organizations need to be able to provide documentation that they are a recognized organization within their country and that they are a charitable organization.

Can we apply for a PAL Awards grant even if our project has already been started, or completed?

No. PAL Awards funds cannot be applied retroactively to expenses that have already been incurred. All PAL projects must be conducted during the one-year grant period for which the PAL Award is made. The one-year grant period typically begins from the day you receive your PAL Awards grant funds. Slight modifications to the start/end dates of the grant period may be considered on a case-by-case basis. You may elect to continue the project in coming years but funds from PAL can only be applied in the particular year of the grant cycle.

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Our organization focuses on many rare diseases, but we have an idea for a project that is specifically targeted to the LSD community. Can we apply for funds?

Yes. Rare disease organizations are eligible to apply if the project idea they are submitting for funding focuses on the LSD community. For example, a rare disease organization covering many types of muscle disease including Pompe (a recognized LSD), may submit an application for a project specifically for the Pompe community to address an unmet need.

Our organization sponsors an annual family conference and conducts on-going programs such as patient education. We would like to apply for a PAL Awards grant to help cover recurring and general operating costs. Would this be considered a compelling PAL Awards proposal?

The PAL Awards program is designed specifically to support new and innovative ideas and projects. General operating costs or overhead for your organization would be more appropriately considered by a Sanofi Genzyme local grant or other program. Though conferences and on-going activities are important, the judges will probably not view this as “new” or “innovative.” As such, your proposal may receive a lower creativity score. Could you instead come up with a new program to address an unmet patient education need? Or, is there a need for a special patient conference to focus on something the family conference doesn’t address? We encourage you to review the Past Awards section of the [PAL website](#), and the Proposal Help and Grant Guidelines sections of this guide to prompt your thinking about new and effective ways of reaching the LSD community.

Our organization already receives funding from Sanofi Genzyme. Are we still eligible to apply for PAL?

Yes. Receiving funds from Sanofi Genzyme for ongoing programs, conferences, or through other grants does not disqualify your organization from receiving a PAL Award. You are required to disclose those donations, though, as part of your project proposal. PAL Awards is a competitive grant program to make a one-time gift of seed funding for a particular project, so it is designed to identify compelling, promising applications to address unmet need on a one-time basis.

How do we apply?

First, review the PAL Awards program information in the Grant Guidelines section of this guide. Make sure that you’re project proposal form is complete and includes an itemized project budget. Save the completed form. Then, submit your online project application via the PAL Awards website. You’ll be required to attach your completed project proposal form, your project budget, a list of your Board of Directors, and you’ll have the option to provide other attachments that may help the judges when considering your application.

If you are unable to apply online, or require additional translations, please contact us at PALAwards@sanofi.com or through the “[Contact Us](#)” page on www.palawards.com, and we will provide alternate means of submitting an application.

How competitive is the PAL Awards Program?

This depends on how many organizations submit proposals, and for how much money. Sanofi Genzyme is interested in awarding grants to the most innovative projects that address unmet need, and will consider the landscape in different geographic regions when considering how competitive a particular program is. The PAL Awards program is somewhat similar to the way in which many private foundations handle their grant giving, whereby not for profit organizations are required to compete for limited funds based on certain criteria. If you’re not successful in receiving a PAL Award, it doesn’t mean your project idea isn’t a good one. Sanofi Genzyme enlists a third-party organization to provide feedback on your application, and offers a one-hour coaching session, to address how to strengthen the proposal and how to approach other possible funders, such as a private foundation or corporate sponsor.

How are the recipients determined?

An external review committee of judges reviews the applications in a blinded process. That means that they will not know what organization submitted the application. The review committee is comprised of professionals in a variety of areas, such as the life sciences, non-profit, medical or philanthropic fields. Each judge on the committee reviews each submitted proposal individually and selects their top choices. The committee of judges then meets as a group collectively decides on the recipients.

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PAL Awards Program Terms & Conditions

Last updated March 2016.

SANOFI GENZYME PATIENT ADVOCACY LEADERSHIP (“PAL”) AWARDS PROGRAM TERMS & CONDITIONS

By submitting an application and proposal (together, the “Proposal”) to the Sanofi Genzyme Patient Advocacy Leadership Awards Program (the “Program”) for consideration, I (“Applicant”) agree, on behalf of myself and my Organization (as defined below), regardless of whether my Proposal is selected to receive a Sanofi Genzyme PAL Awards grant (a “Grant”), to the following Terms and Conditions:

Eligibility

Applicant’s organization is a non-profit, charitable organization that is properly and officially recognized by the applicable laws and regulations governing non-profit, charitable organizations of each country in which the organization is located (the “Organization”). If awarded a Grant, Applicant shall, upon request by Sanofi Genzyme, provide documentation confirming the charitable or not-for-profit status of the Organization as recognized by the governing laws and regulations in the country in which the Organization is registered.

Organizations that have received a Grant are not eligible to participate in the Program for one year following the receipt of such Grant. Applicants receiving a Grant are required to submit a final narrative and financial report, not to exceed three (3) pages, no later than twelve (12) months following the date of receipt of the Grant, or in approved cases, the initiation of the project. Organizations that have received a Grant(s) in the past, but have not submitted a final report for each such Grant received are not eligible to participate in the Program.

Selection Process

An independent review committee (the “Committee”) will review, evaluate, and score all Proposals based on established criteria. The Committee will include one representative from Sanofi Genzyme who will facilitate the Proposal review process and ensure that Proposals selected to receive a Grant meet the intended purpose of the Program. The Committee will have sole discretion in the selection of Proposals based on the established criteria and the amount awarded for each Proposal, which may include partial funding for some or all of the Proposals.

Rights of Use

Sanofi Genzyme shall have a nonexclusive, perpetual right and license to use all Proposals and any other related materials submitted to Sanofi Genzyme in connection with the application process for purposes of and in connection with the Program, to make public and promote the activities conducted with Grants awarded through the Program, and to otherwise promote the Program and Sanofi Genzyme. Neither Sanofi Genzyme nor its affiliates shall have any liability to Applicant or the Organization in the event Applicant’s Proposal is similar to an existing or future Sanofi Genzyme program.

Personal Data

Proposals submitted to Sanofi Genzyme may include Applicant’s personal data. In processing such personal data in connection with the Program, Sanofi Genzyme shall abide by the relevant laws and regulations on the processing of personal data. All personal data provided by Applicant may be retained and used by Sanofi Genzyme as provided in these Terms and Conditions, and may be distributed by Sanofi Genzyme to its affiliated companies, including Sanofi Genzyme and Sanofi in the United States, for internal purposes, including but not limited to global and local transparency reporting and other administrative purposes. Jurisdictions outside the European Economic Area may not provide the same level of protection for such personal data. Applicant, at any time, has the right to access and, where appropriate, rectify and/or delete any personal data retained by Sanofi Genzyme and its affiliated companies.

Transparency

If Applicant’s Proposal is selected to receive a Grant, Sanofi Genzyme may be required to make public or otherwise disclose the details of the support provided to the Organization in one or more countries, including without limitation the amount of funding provided, a short description of the nature of the support provided,

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together with any further information that may be required to be disclosed by Sanofi Genzyme under applicable laws, regulations and/or industry standards (e.g., British Pharmaceutical Industry Code of Practice for the Pharmaceutical Industry 2016).

Applicant Warranties

If Applicant's Proposal is selected to receive a Grant, Applicant and the Organization shall use the granted funds solely for the purposes stated in the selected Proposal and not for salaries, direct patient care, direct payment for medications, travel expenses, or other individual benefit. The Organization shall at all times have sole and exclusive control over the use and disbursement of the granted funds. Granted funds may not be applied to past activities or expenses, or applied to activities or expenses retroactively. No obligation to any third party will prevent Applicant or the Organization from carrying out the activities as described in the selected Proposal. Applicant and the Organization shall use best efforts to complete the activities as described in the selected Proposal and shall be fully responsible for the direction, control and performance of such activities. Any substantial change to the activities agreed to in the selected Proposal shall require prior written approval by Sanofi Genzyme.

Applicant and the Organization own all of the rights to the Proposal and any related materials, and nothing shall prevent or restrict in any manner Applicant and the Organization from further granting the rights, title and other interests granted hereunder. Applicant and the Organization will be fully responsible for any claims to the contrary made by third parties.

General Conditions

Applicant agrees to be bound by these official Terms and Conditions and to conform to all federal, state, and local laws and regulations.

To the extent permitted by law, Applicant and the Organization assume all liability for any damages that may arise from a Proposal and the performance thereof, and will indemnify, defend and hold harmless Sanofi Genzyme, its affiliates, including Sanofi, and their directors, officers, representatives, employees and agents against all related losses, expenses (including legal expenses), liabilities and claims.

Sanofi Genzyme's provision of a Grant does not impose any obligation to solicit, refer, or solicit referrals of any patients for any Sanofi Genzyme business on Applicant or the Organization. Neither Applicant nor the Organization will receive any benefit of any kind for making any referrals nor suffer any detriment for not making such referrals.

Proposals received after June 30, 2017 will not be considered. Responsibility for lost, late, or misdirected Proposals remains solely with the Applicant.

This offer is void where prohibited. Sanofi Genzyme reserves the right to cancel the Program at any time and for any reason.