Application Guide

Overview

Sanofi Genzyme’s Global Patient Advocacy Team launched the PAL Awards program in 2011 to encourage bold new ideas and programs to support the lysosomal storage disorder (LSD) community worldwide. The PAL Awards program funds collaborations that support innovative projects in disease awareness and education, community mobilization, non-profit development and good governance activities, patient care and support programs. Overwhelmingly successful in its first five years, we are delighted to launch PAL Awards 2016.

The PAL Awards program is open to non-profit patient organizations, professional associations, and academic institutions. Only proposals involving collaboration between two or more organizations will be considered. For example, an LSD patient organization in one region of the world may choose to partner with an allied organization in another country to support learning exchanges between patient groups. Or, a patient group may partner with a university or hospital to further medical education.

A total of $50,000 (USD) may be awarded through competitive grants funding new initiatives that support the LSD community. All eligible applicants may apply for a maximum grant of $25,000 (USD).

Application Process & Timelines

The submission period opens on April 28, 2016 and closes June 20, 2016. In order to be considered eligible, all applications must include: a project proposal, a completed Application Form, and acceptance of the PAL Awards Program Terms & Conditions. The application process includes the following steps:

- **STEP 1**: Develop a three-page proposal and budget outlining your proposed project. The roles and responsibilities of each partnering organization involved in the collaboration must be clearly defined. Remember, a PAL Award for projects that have already occurred or been completed will not be considered.
- **STEP 2**: Complete the online Application Form, agree to the program Terms & Conditions, and attach your three-page proposal and budget.
- **STEP 3**: All applicants will be notified of the results at the end of the judging period.
- **STEP 4**: Recipients will be publicly announced before the end of 2016.

We strongly encourage all applicants to apply online, through the PAL Awards website. If you are unable to apply online, please download the Project Proposal Form and submit it by email to PALAwards@genzyme.com, or fax to +1 617-768-6421.

Grant Guidelines

The full application package consists of:

- A three-page (3-page) project proposal
- Completed Online Application Form
- Acceptance of the program’s Terms & Conditions

All of these items must be received in order for a proposal to be considered eligible. Proposals must include a budget and adhere to the program guidelines and criteria. **Proposals may be submitted in the applicant’s native language. All proposals will be translated into English for review and judging purposes.**
The three-page proposal must be comprised of: a brief description/background of the partnering organizations, a project description, a project budget, and project evaluation. The roles and responsibilities of each collaborating organization must be clearly defined. Proposals cannot exceed three (3) pages in length.

- **ORGANIZATION DESCRIPTIONS/BACKGROUNDS:** For each organization involved in the collaboration, include a brief summary of the organization’s history and mission, as well as any short or long-term goals you have identified.

- **PROJECT DESCRIPTION:** Describe the overall objectives of the project and specific project activities. This includes describing the need or problem that this project seeks to address. Describe the roles and responsibilities of each partnering organization.

- **PROJECT BUDGET:** Please provide itemized costs of the project. This helps grant reviewers/judges to understand how PAL Awards funds will be spent if you are chosen to receive a PAL Awards grant.

- **PROJECT EVALUATION:** Please describe how you will evaluate the success of your project. How will you know it was successful? What could be the barriers to success? If you anticipate any barriers, explain how you will try to work around them?

**PROJECT PROPOSAL FORM**

You may use the Project Proposal Form, however you are welcome to use your own format. The form is meant to help guide you in your thinking and can be used as a helpful tool, if you wish. The Project Proposal Form is meant to help you organize your proposal and is based on standard fundraising practice in many countries.

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**Program Criteria and Important Information**

Applicants are encouraged to review the Grant Guidelines and FAQ carefully before applying. Below are the eligibility requirements to this year’s program:

- The PAL Awards program requires that all proposed projects involve collaboration between two or more organizations serving the lysosomal storage disorder community.

- The program is open to all eligible patient organizations. Applicants may partner with one or more of the following: another non-profit patient group, a professional association, an academic institution and/or medical institution.

- Organizations do not have to reside in the same country; collaboration may be from the same or across different disease states, provided that the project is focused on the LSD community.

- Within the framework of the PAL Awards program, proposals focusing on the following **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
  - third party submissions will not be accepted

- If a previous PAL Awards grant recipient wishes to apply for a new or future award, the required Final Report (or Progress Report) must have been submitted prior to the submission of a new proposal.

- Organizations that participated in the Proposal Writing Workshop offered by Sanofi Genzyme are prohibited from submitting a proposal for the same project reviewed in the workshop.

**Review Process**

Each proposal will be judged on six criteria: **COLLABORATION, BUDGET, CREATIVITY, FEASIBILITY, IMPACT, and SUSTAINABILITY.**

Proposals are reviewed by an External Review Committee and selected through a blinded selection process. PAL Awards grants will be awarded to the most creative, feasible, and sustainable proposals submitted. The Review Committee is comprised of up to four committee members with expertise in such areas as philanthropy, rare disease advocacy, rare disease research and treatment, communications, and non-profit management.
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.

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.

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.

- Guidestar – Fundraising and Sustainability Articles
- Lone Eagle Consulting – Grantwriting Tips
- Third Sector New England – fund development tips

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

Why does the PAL Awards program require collaboration between two or more groups?
The ability to collaborate with other organizations in a meaningful way is essential to long term progress towards achieving shared goals. Collaboration – whether across borders, disease states, or areas of expertise – has been proven to be key to advancing a social movement on a global scale.

Can I submit a proposal in a language other than English?
Yes. 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.
Are there any types of project topics that will not be considered?

Yes. Within the framework of the PAL Awards program, proposals focusing on the following will not be considered:

- newborn screening programs
- projects seeking to generate income for affected individuals
- any project or initiative related to promoting 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
- third party submissions will not be accepted

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

To ensure that all funding complies with both Sanofi Genzyme and local government regulations, each recipient is required to complete online administrative forms and to co-sign an agreement documenting Sanofi Genzyme’s support and your agreement documenting Sanofi Genzyme’s support and your agreement to the terms and conditions of the program. As part of this, you will be required to provide a brief Final Report (including an expense report) upon completion of the project or within one year of receipt of PAL Awards funds. Submission of this report is a requirement of receiving a PAL Awards grant.

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

Absolutely. Please check out the “Project Ideas” section of this guide (above) for summaries of past PAL projects that have been collaborative in nature.

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 Project 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.

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 be a collaboration between two or more non-profit organizations and support the lysosomal storage disorder community in some way that seeks to address an unmet need. Remember that the primary goal of the PAL Awards program is to inspire new ideas, so we encourage you to be creative with your project. Activities such as innovative disease awareness campaigns, novel patient care and support programs or new outreach/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 non-profit patient organization serving the LSD community that is registered or has some kind official recognition from the government. To collaborate on a proposal, your group may form a partnership with one or more of the following: another non-profit patient group, a provider or professional organization, and/or an academic institution that is registered or has some kind official recognition from the government. Third party submissions will not be accepted.

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) that serve a need in the community. 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 organization is a recognized charitable organization. To be eligible for the PAL Awards program, organizations need to be able to provide appropriate documentation that they are a recognized organization within their country.

Can we apply for a PAL Awards grant even if my project is already completed?

No. PAL Awards funds cannot be applied retroactively. All PAL projects must be conducted during the one-year grant period. 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.
Our organization received a PAL Awards grant in the last program cycle. Can we apply again this year?
Yes. However, you must have submitted a Final Report or interim report on your previous award if you wish to apply again.

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 may submit an application for a project to develop educational materials specifically for families of Fabry patients in order to help them manage the effects of the disease.

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. 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. 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. Our potential partner organization may also be receiving funds from Sanofi Genzyme. Can we also apply for a PAL Awards grant?
Yes. The difference with the PAL Awards is that it is a competitive program – we are looking for new and innovative ideas from patient organizations, and it is the most compelling and promising applications that will win an award.

Can we apply more than once, if the collaboration is with a different partner?
No. Organizations can only apply for one grant, so we encourage organizations to consider their projects carefully.

How do we apply?
First, review the PAL Awards program information in the Grant Guidelines section of this guide. Then, write your proposal (maximum of 3 pages). You will need to answer some basic questions and submit a project idea – along with the expected costs – in your proposal. You may use the provided Project Proposal Form. Go to the PAL Awards website to complete the application and submit your proposal online, or submit by email by sending to PALAwards@genzyme.com or fax at +1 617-768-6421. The application and proposal must be submitted by June 20, 2016.

How competitive is the PAL Awards Program?
This depends on how many organizations submit proposals. The PAL Awards program is somewhat similar to the way in which many private foundations handle their grant giving, whereby non-profit organizations are required to compete for limited funds based on certain criteria. We encourage unsuccessful PAL Awards applicants to consider using their proposal to approach other possible funders, such as a private foundation or corporate sponsor.

How are the recipients determined?
An external review committee reviews the applications in a blinded process. That means that they will not know who 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. The committee reviews each submitted proposal on a “blind” basis, and collectively decides on the recipients.
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, 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 20, 2016 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.