

2024 LGMD GRANT AWARD PROGRAM FAQ

1. Who is Sarepta?

Sarepta Therapeutics is a global biotechnology company on an urgent mission: to engineer precision genetic medicine for rare diseases that devastate lives and cut futures short. We have more than 40 programs across our portfolio and currently have clinical programs in development for patients with Limb-girdle muscular dystrophies, Duchenne muscular dystrophy, and other neuromuscular and CNS-related conditions. We are headquartered in Cambridge, Massachusetts with offices around the globe.

2. What is the LGMD Grant Award Program's goal?

This grant program is seeking applications that support earlier LGMD diagnosis and/or increased participation in established genetic testing programs. Proposals must be original, meaningful, and should include ways to address one or more of the following areas:

1. Promoting recognition of early signs and symptoms of LGMD.
2. Enhancing participation in genetic testing and genetic counseling programs.
3. Empowering families to take an active role in pursuing a confirmed diagnosis to learn their subtype.

3. What is the goal of Sarepta's efforts?

The goal of our efforts is to ultimately offer long-term impact for families, such as earlier access to specialized care, increased clinical trial participation, and improving access to potential future treatments for the LGMD community.

4. What is the application deadline?

The grant award program invites Patient Advocacy Organizations and non-governmental organizations to submit an original project proposal between March 19th, 2024 – July 19th, 2024. Late applications will not be accepted.

5. May individuals who are not employed by a Patient Advocacy Organization or non-governmental organization apply?

Individuals who are inspired by this effort must align with a non-profit organization that elects to support your idea for submission. The aligned organization will oversee the completion of the application and your proposed work. If you would like help identifying a potential collaborating Patient Advocacy Organization, you may email advocacy@Sarepta.com.

6. Please describe important elements of the grant program.

- a. Applications are accepted from March 19th, 2024, through July 19th, 2024.
- b. Qualifying applications will be evaluated as described in this document.
- c. Applicants will be notified of the results of the application review by September 30th, 2024.
- d. A brief contracting period will occur if your application is awarded a grant. The recipient(s) of the grant funding will be announced publicly.
- e. Funds will be distributed to your organization upon completion of the contract.
- f. Following distribution of funds, your organization will have up to one year to complete the activities described in your proposal.
- g. At the end of the year, recipients of a grant award will provide a summary of efforts and describe key outcomes.
- h. Sarepta maintains the right to audit use of funds for the intended purpose described in the proposal.

- i. Sarepta may choose to highlight your organization’s work through our communications. This may include internal and external communications, Sarepta’s websites, and social media.

7. Who will review applications and select recipients?

The Sarepta Grant Committee will review applications and select recipients.

8. What if I have already applied for the LGMD Grant Award Program in the past (in 2022). May I re-apply?

Yes, you are welcome to apply for funding again even if you previously applied. Regardless of whether you received funding or not, you may re-apply.

9. Where is the website to apply?

You may submit your request on the following page: <https://Sarepta.com/LGMDGrantAwardProgram>

10. Awards:

Sarepta will grant monetary awards so that Patient Advocacy Organizations or non-governmental organizations may implement their projects. Up to \$100,000 United States Dollars (USD) will be awarded, and the number of awardees will be determined by the selection committee to optimize the available funds. Please specify in your application the funding amount you wish to receive up to \$100,000 (USD) and please provide a supporting budget. All applicants will receive a response noting the result of the review of their application.

11. After awards are granted:

Sarepta may wish to share information about selected proposals in order to highlight the valuable work that has been undertaken in different regions of the world. In doing so, Sarepta may choose to share the name of your organization and information about your described efforts on our social media channels, and U.S. websites (Sarepta.com and Limbgirdle.com). As is standard grant procedure, Sarepta maintains the right to audit use of funds designated for this purpose.

12. How does an application qualify?

- Application must be submitted between March 19th, 2024 and July 19th, 2024.
- Applications must be submitted with appropriate documentation of non-profit or non-governmental organization status.
- Applications must describe activities that aim to shorten the LGMD diagnostic journey and/or enhance participation in existing genetic testing programs.
- The activities described in the proposal should be completed within one year.
- An organization’s proposed work should not be specific to a certain subtype.
- The Sarepta Grants Committee will further evaluate the qualifying applications using an evaluation guide shown below.

13. Once qualified, how is an application evaluated by the Sarepta Grants Committee?

The grants committee will evaluate applications for specific, measurable impact that may form from the effort. Additionally, Sarepta will be interested in understanding some of the less tangible values. Below, please find the rubric that will be used by the grants committee to aid in the decision-making process.

Program Rationale	
	How is this project proposal a meaningful and effective way to support earlier LGMD diagnosis and/or enhance participation in genetic testing?
Assessment of Success Factors	
	Is there a tangible, measurable way to evaluate the success of the program? Which region(s) could be impacted by the efforts described?
Creativity of Proposal	
	How unique is this program proposal?
	What new mechanisms are built, what new parts of the health community will be engaged, or what new community connection is formed through this effort?
Inspirational Nature of Proposal	
	Does the proposal spark interesting and new ways to engage the LGMD community? Which region(s) might be impacted by the work?
	Does the proposal have potential to inspire other advocacy organizations or empower the LGMD community to act?
	How does the proposal encourage participation in genetic testing and counseling programs?
	Does the program have an enduring impact at an individual or community level?
Inclusivity of the Entire LGMD Community	
	Does the project proposal address the needs of the entire LGMD community and not single out specific genetic subtypes?
	How will the project address issues of global diversity and equity within the LGMD community and foster a global, unified LGMD community?

14. When will applicants be notified of the decisions?

Applicants will be notified of grant committee decisions by September 30th, 2024.

15. How and when will the grant program funds be awarded?

If your organization is chosen as an award recipient, you will receive a contract from Sarepta. Upon completion of the contract, the Patient Advocacy Organization or non-governmental organization will receive a check in the mail (inside the US) or wired funds (outside the US). Funds provided under the Grant are non-transferable and that no substitutions will be made except at the sole discretion of the Sponsor as described in this FAQ document. The Patient Organization or non-governmental organization will be responsible for all federal/national, state and local taxes.

16. What are my responsibilities if my organization is chosen as an award recipient?

After the program has been implemented (within 12 months of receiving funds), your organization will be responsible for sharing a summary of the program which outlines the outcome of your efforts. The summary may include information such as:

- Patient/caregiver testimonials
- Photographs (must receive appropriate permissions to share)
- Statistics on the number of individuals reached (please omit any individual patient health information)
- Statistics on the subtype specific increases there were (for instance, how many new individuals living with LGMD2E were identified).
- Organizational leaders should be prepared to give a verbal/written deliverable on their program for internal Sarepta colleagues in the form of a presentation (~20 minutes). And, be prepared to potentially share their deliverable externally (for instance, as an abstract/posterboard at a conference or a scientific journal article). Any project work that is shared will go through Sarepta's internal legal and compliance review process.
- Other measurable ways to illustrate the success of the program.

17. What if I have additional questions?

Please reach out to: advocacy@Sarepta.com directly with your questions.

18. How do I apply?

1. Please complete the online submission form found here: <https://Sarepta.com/LGMDGrantAwardProgram>
The form asks for standard contact information as well as:
 - a. Documentation of your non-profit or non-governmental organization status.
 - b. Identifier Number (your unique identifier code for your organization, typically a tax number or other registrant number provided by the government. Examples include TIN, VAT, BRN, etc.)
 - c. Budget information
2. Please attach the program details including a letter of request, program overview information, and a budget for the project

19. What should be included in the program details that I upload?

Please provide a Word document or PDF that includes a signed letter of request, a program overview, and a project budget.

Letter of request:

- Please provide a signed Letter of Request on your organization's letterhead.
- Please share your organization's mission, a title for the proposed effort, and a short description of the effort you are proposing. A letter of request is often 1-2 pages.

Program overview:

- Name/title of the proposal.
- Specific goals of the program, reference the geographic region of impact.
- Description of how you will achieve the program goals and how you plan to identify subtype specific genetic diagnosis received as part of your program.
- Approximate timing for project execution, illustrating use of budget within one year.
- If content has been developed (slide presentation, manuals, educational promotional materials, social media, planned content), please provide.
- All proposals submitted MUST be original content. If you reference material that is already public (such as articles or medical standards, please reference the source but do not include re-prints).
- Please share how you will measure the success of the effort described in your proposal.

Budget: Please share total budget amount requested (in USD) and how these funds will be allocated.