



RESEARCH GRANT DONATION POLICY

Effective: 10/6/26

1. BACKGROUND

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD is committed to the diagnosis and treatment of rare disorders through programs of education, advocacy, research, and patient services. NORD represents the estimated 25-30 million Americans with over 10,000 rare “orphan” diseases. Under the federal Orphan Drug Act of 1983, a rare disease is defined as a health condition that affects fewer than 200,000 people in the United States. Because each disease affects a small number of people, there is generally limited commercial interest in conducting research or developing new products to diagnose or treat these conditions. Moreover, with few funding sources available to support rare disease research, academic scientists may not have access to resources to support the conduct of novel rare disease research studies.

2. PURPOSE

NORD's Rare Disease Research Grant Program, which is focused on disease-specific funding, provides small seed grants to researchers and clinicians performing basic or translational science, clinical research, studying new treatments, or developing diagnostic tests for rare diseases. The goal of the small studies supported by NORD's research grants is to provide preliminary data or expand on existing data that may one day lead to improved diagnosis and/or a treatment (drug, device, or medical food) for patients with rare disorders. Researchers can use the preliminary data funded by NORD's Rare Disease Research Grant Program to apply for larger multi-year grants, or to attract commercial sponsors. NORD's grant review process is adapted from the peer review standards utilized by the National Institutes of Health.

3. DONATING TO RARE DISEASE RESEARCH

NORD will accept gifts restricted to research grant funds in support of a specific rare disease (or group of related rare diseases) or to NORD's general research grant fund. Because medical research is costly, a minimum amount of \$62,500 U.S. is required to fund one grant in support of a specific rare disease (or group of related rare diseases). Donors interested in establishing a research grant fund with a donation below the threshold of \$62,500 will be required to sign a pledge agreement. If gifts less than \$62,500 are received but no pledge agreement is signed, donated funds will be applied to related rare disease research priorities funds. If no related rare disease research funds are identified, donated funds will be allocated to NORD's general research grant fund. Interested donors must contact donate@rarediseases.org to discuss restricted donations prior to providing funding.

It is not possible for donors to signify how they want their donations spent (e.g. on a genetic test rather than development of a treatment), or which researcher should be funded. If the RFP for a specific disease state is issued and a qualified applicant is not identified, the RFP will be re-issued a maximum of two times, for a total



of three application cycles. If a qualified applicant is not identified after the third application cycle, funds for the project will be redistributed to NORD's general research fund.

4. FEES

NORD will apply an administrative fee each research grant award of up to 25% of the amount of the award . These fees support NORD's operational infrastructure, grant management and administration (including, peer-review coordination and reporting, targeted outreach to qualified scientists and clinicians, marketing of available grant opportunities, content development for the request for proposal, management of applications, consultation with NORD's legal team for contract negotiations, and oversight of the fund).

5. GRANT CYCLES

NORD issues Requests For Proposals (RFPs) on a cyclical basis. Adequate funds must be in place before preparations to initiate an RFP begin. Therefore, to maximize the full benefits of international advertisements and wide circulation of the funding opportunity, donors should understand that it takes several months after an RFP is issued until the grant is awarded and actual research can begin. The following table depicts a representative cycle; funding cycles are based on the availability of funds. For deadline information about open funding opportunities, please visit [Current Requests for Proposals](#).

May-June	NORD prepares to issue RFPs.
August-November	NORD issues RFPs and accepts preliminary applications.
December-January	Peer review of preliminary applications. Finalists are invited to submit full proposals.
February-March	NORD accepts submissions of full proposals.
April-June	Peer review of full proposals. Awardees are notified and announced.

6. ADDITIONAL POLICIES

The grant selection process is unbiased and independent; awards are based solely on scientific merit and grant reviewers must declare any potential conflicts of interest. Only the highest-quality, highest- impact research projects will be funded. Research grant awards are subject to compliance, operational feasibility, and risk assessment. NORD reserves the right to approve, condition, or decline any application based on funding source restrictions, regulatory considerations, audit risk, or other factors deemed relevant to the organization's fiduciary responsibilities.

Please refer to the Research Grant Administration Policy for additional details on how research grants are reviewed, awarded, and administered. NORD is grateful for the continued support and generous gifts that have enabled us to continue to promote critical foundational research for rare diseases, accelerating scientific discovery related to the identification, treatment, and cure of rare disorders. Please contact NORD's development team with any questions about this policy: donate@rarediseases.org



RESEARCH GRANT ADMINISTRATION POLICY

Effective: 10/6/26

1. BACKGROUND

The National Organization for Rare Disorders (NORD), a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD is committed to the diagnosis and treatment of rare disorders through programs of education, advocacy, research, and patient services. NORD represents the estimated 25-30 million Americans with over 10,000 rare “orphan” diseases. Under the federal Orphan Drug Act of 1983, a rare disease is defined as a health condition that affects fewer than 200,000 people in the United States. Because each disease affects a small number of people, there is generally limited commercial interest in conducting research or developing new products to diagnose or treat these conditions. Moreover, with few funding sources available to support rare disease research, academic scientists may not have access to resources to support the conduct of novel rare disease research studies.

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3. SELECTION OF GRANTEES

Each initial request for proposals asks applicants to submit a brief description (abstract) of their proposed research project along with their professional qualifications and a budget. Unless indicated in the RFP, funding cannot be used to cover PI salary, overhead or indirect costs, but may be used to cover expenses such as staff salary, technical assistance, supplies and small equipment. For each proposal, the principal investigator must have sufficient education and experience to demonstrate subject matter expertise. Unless indicated in the RFP, strong preference is given to researchers holding a faculty-level appointment or senior scientific position at an academic or non-profit institution or foundation. Grants are available to researchers both within the United States and internationally. International applicants are responsible for all document translations.

Applications must reflect the original intellectual contributions of the applicant; proposals substantially generated by artificial intelligence tools will not be considered. Limited use of AI to assist in preparation is permissible, provided applicants ensure accuracy, proper attribution, and compliance with standards for scientific rigor, reproducibility, and research integrity.



NORD will consider no more than two applications per Principal Investigator per calendar year.

Once all application materials have been submitted, applications are reviewed (peer review) and finalists are invited to submit a full grant application describing their proposed project in detail. Selected grant reviewers then review the full grant applications and adjudicates the proposals based on scientific merit. NORD's grant review process is adapted from the peer review standards utilized by the National Institutes of Health. The grant selection process is unbiased and independent; awards are based solely on scientific merit and grant reviewers must declare any potential conflicts of interest. Only the highest-quality, highest- impact research projects will be funded. Research grant awards are subject to compliance, operational feasibility, and risk assessment. NORD reserves the right to approve, condition, or decline any application based on funding source restrictions, regulatory considerations, audit risk, or other factors deemed relevant to the organization's fiduciary responsibilities.

After a grant is awarded, NORD monitors the progress of the research. Every six months awarded investigators must submit financial and scientific progress reports. At the conclusion of a grant, any unused funds are returned to the NORD general research fund.

Please contact NORD's research team with any questions about this policy: research-programs@rarediseases.org