REQUEST FOR PROPOSALS

The National Organization for Rare Disorders (NORD)'s Rare Disease Research Grants Program

Announces a research grant opportunity for one grant
up to $152,000 US for

Peutz-Jeghers Syndrome (PJS)

DEADLINE FOR INITIAL APPLICATIONS: January 19, 2027 (11:59 pm PT)

NORD, with donations from the Peutz-Jeghers syndrome community is accepting applications for one grant, up to $152,000 US, for scientific and/or clinical research studies related to Peutz-Jeghers syndrome.

Peutz-Jeghers syndrome (PJS) is a very rare genetic condition characterized by the development of benign polyps in the stomach and intestines and by distinctive dark spots on the skin and mucous membranes. Symptoms usually appear during the first decade of life and begin with spots of dark skin freckling (melanocytic macules) around the mouth, eyes, nostrils, fingers as well as inside the mouth (oral mucosa) and around the anus (perianal). Non-cancerous polyps called hamartomas also begin to grow in the gastrointestinal (GI) tract of affected individuals around that age. Polyps are located throughout the GI tract and can cause nausea, vomiting, abdominal pain, intestinal obstruction and rectal bleeding.

Peutz-Jeghers syndrome is caused by changes (variants) in the *STK11/LKB1* gene. Around 94% of people diagnosed with PJS have an identified variant in the *STK11* gene. The penetrance of these variants is thought to be 100%, meaning that a person carrying the pathogenic variant in the *STK11* gene will always develop in features characteristic of PJS. Inheritance is autosomal dominant. PJS affects 1/25,000 to 300,000 individuals.

Symptoms of Peutz-Jeghers syndrome can occur throughout life, with onset and severity varying widely. Symptoms of PJS may include: abdominal pain, vomiting, diarrhea, blockage in the intestines, bleeding from the rectum which may lead to anemia, and intestinal folding. People with PJS may have poor mental health due to their syndrome. People with PJS have a higher risk of developing cancer, especially in the digestive systems and other organs.

Other names for Peutz-Jegher syndrome include: PJS; hamartomatous intestinal polyposis; polyps and spots syndrome; intestinal polyposis-cutaneous pigmentation syndrome; periorificial lentiginosis syndrome; Peutz-Jeghers polyposis; lentiginosis, perioral; polyposis, intestinal, II; Hutchinson Weber-Peutz syndrome

Reference

Hougo, C. et al. (2025, February 26). NORD Rare Disease Report: Peutz-Jeghers Syndrome. https://rarediseases.org/rare-diseases/peutz-jeghers-syndrome/.

Email: research-programs@rarediseases.org

Research Objectives

The NORD Rare Disease Research Grant Program was established in 1989 to encourage meritorious scientific and clinical studies designed to improve the diagnosis, understanding of underlying disease mechanisms, or therapy of specific rare diseases. Studies related to Peutz-Jeghers syndrome will be considered. Grants will be awarded to qualified researchers to initiate scientific research studies or clinical trials, the results of which could be used to obtain funding from the NIH, FDA, or other funding agencies, or to attract a corporate sponsor. Ideally, the proposed research should have the potential to lead to the ultimate development of a new or better therapy. Evaluation of proposals will include careful consideration of protocol design, objectiveness of parameters measured, and statistical evaluation proposed.

About NORD

The National Organization for Rare Disorders (NORD), a 501 (c)(3) organization, is a patient advocacy organization dedicated to representing all patients and families affected by rare diseases and the organizations that serve them. NORD is committed to the identification, diagnosis and treatment of the more than 10,000 known rare diseases, of which fewer than 5 percent have an approved treatment. Rare diseases affect more than 30 million Americans. More than half of those affected are children. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983 (ODA). For more than 35 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research and providing patient and family services for those who need them most. NORD is made strong together with over 340 Patient Advocacy Organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease patient community.

APPLICATION PROCESS

OVERVIEW

- Requests for proposals will be released by NORD in November 2026.
- Letters of intent/Initial Applications will be due January 19, 2027.
- Letters of intent/Initial Applications will be reviewed by NORD reviewers.
- Full proposal invitations will be issued to finalists via email in March 2027.
- Application requirements for full proposals will accompany these invitations.
- Full proposals are subject to a second round of review.
- Award announcements will be made via email and posted on NORD's website in June 2027.
- Funding will begin after all necessary documents (e.g., IRB forms, patient consent forms, signed grant agreements) have been received by NORD.

SELECTION OF GRANTEES

- Application is open to researchers both within the United Sates and internationally. International applicants are responsible for all document translation.
- 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.
- The principal investigator must have sufficient education and experience to demonstrate subject matter expertise.
- 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. 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. Only the highest-quality, highest-impact research projects will be funded.

USE OF ARTIFICIAL INTELLIGENCE (AI)

- Applications must reflect the original intellectual contributions of the applicant.
- Proposals substantially generated by AI 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.

FURTHER INFORMATION

- If the study involves human or animal subjects, copies of governance documents will be required from each site involved in the study before payment can be issued.
- Clinical drug trials must meet requirements established by the U.S. Food & Drug Administration (FDA).
- Duplicate/overlapping funds from any other private or public source are not to be used.
- All applications determined to have scientific merit will be considered, however before an award is issued compliance with international funding regulations must be confirmed when applicable.
- Funds cannot be used for indirect costs, overhead or PI salary, unless otherwise indicated in the RFP.
- Grant awards are expressly subject to compliance review, 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.

INITIAL APPLICATION

Interested applicants should submit a completed application and letter of intent electronically to research-programs@rarediseases.org with "NORD Letter of Intent" as the subject line. Applicants can complete the requested information directly in the document provided below and/or merge any additional required documents into a single PDF file. Incomplete applications may not be considered. All initial applications must be received by **January 19, 2027 (11:59 pm PT)**.

REQUIRED ELEMENTS CHECKLIST	**PAGE**	✓
Application summary	5	
Letter of Intent (Maximum Length 2 Pages)	6	
Biographical sketch	7	
List of co-investigators, if applicable	8	
Budget outline	8	
OPTIONAL ELEMENTS	**PAGE**	✓
Reviewer information	8-9	
Letter of support	9	

APPLICATION SUMMARY

Deadline for Initial Applications: January 19, 2027 (11:59 pm PT)

PRINCIPAL INVESTIGATOR INFORMATION	
Name	
Position/Title	
Email	
Mailing Address	
Telephone	
PROPOSAL INFORMATION	
Project Title	
Project Term	[ ] 1 YEAR [ ] 2 YEARS
Funding Amount Requested ($ US) *not to exceed $152,000 US*	
Institution(s) where research will be conducted	
City, State/Province, Country of Institution(s)	
Will research involve human subjects?	[ ] YES [ ] NO
Will research involve animals?	[ ] YES [ ] NO
How did you hear about this RFP?	☐ NORD ☐ Academic Organization ☐ Rare Disease Organization ☐ Referral from Colleague ☐ Professional Organization ☐ Other (please specify)
Please be as specific as possible:	
Did you hear about this RFP via:	☐ NORD Website ☐ Email ☐ Google ☐ Medical/Research Publication ☐ Social Media ☐ Rare Action Network

	(Facebook, Twitter, LinkedIn, Instagram) ☐ Other (please specify)
Please be as specific as possible:	

LETTER OF INTENT

Please provide a Letter of Intent addressing the following elements of your research. Applicants may use the form below or attach a separate document to address the following details.

Letter of Intent (Not to exceed 2 pages)	
Summary Statement	
Statement of Need • What issue will the research address • Significance of the work • Why you have chosen this issue • Who will benefit from this research • Why this funding is essential	
Project Activity • Overview of research activities • Why this approach is novel • How the research builds upon and differs from previous research (if applicable)	
Credentials • Why your institution/program is best equipped to do this research	
Closing	
Principal Investigator Signature **REQUIRED**	

BIOGRAPHICAL SKETCH

Please provide a biographical sketch and bibliography for the principal investigator. Applicants may use this form or the NIH Biosketch form. Please modify the form to include, when applicable, the following:

Name Position/Title				
Education/Training Begin with baccalaureate or other initial professional education and include postdoctoral training.	Institution and Location	Degree	Year(s)	Field of Study
Research and Professional Experience Concluding with present position, list in chronological order previous employment, experience, and honors. Include present membership on any advisory committee.				
Honors and Awards				

CO-INVESTIGATOR(S)

Name of Co-Investigator	
Position/Title	
Institution	
Email	

Name of Co-Investigator	
Position/Title	
Institution	
Email	

Name of Co-Investigator	
Position/Title	
Institution	
Email	

BUDGET

Please provide a brief budget outline describing how the funding will be used. **Do not include PI salary, overhead, or indirect costs.** Funding can be used to cover expenses such as staff salary, technical assistance, supplies, and small equipment.

REVIEWER INFORMATION (OPTIONAL)

Please list up to five areas of scientific/medical expertise needed to review this application (optional). Do not list names of individuals.

1.
2.
3.
4.
5.

Please list below any individuals who should <u>not</u> review this application (optional).

NAME	INSTITUTION	JUSTIFICATION

LETTER OF SUPPORT (OPTIONAL)

Please include a letter of support for your research from an individual advocate (e.g., patient, care partner) or patient advocacy group in this disease space (optional but encouraged).

To receive notification of future funding opportunities through NORD, sign up for NORD research news here: https://rarediseases.org/communications-sign-up/