



Alone we are rare. Together we are strong.®

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 \$40,000 US for*

Peutz-Jeghers Syndrome (PJS)

DEADLINE FOR INITIAL APPLICATIONS: October 12, 2025 (11:59 pm PT)

NORD, with donations from the Peutz-Jeghers syndrome community is accepting applications for one grant, up to \$40,000 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

NORD REQUEST FOR PROPOSALS: Peutz-Jeghers Syndrome

Email: research-programs@rarediseases.org

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

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 small 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) is the leading independent advocacy organization representing all patients and families affected by rare diseases. NORD is committed to the identification, treatment and cure of the more than 7,000 rare diseases, of which approximately 90 percent are still without an FDA-approved treatment or therapy. Rare diseases affect 25-30 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. 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 300 disease-specific member organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease patient community.

APPLICATION PROCESS OVERVIEW

INITIAL APPLICATIONS

- Requests for proposals will be released by NORD.
- Letters of intent will be due **October 12, 2025**.
- Letters of intent will be reviewed by NORD reviewers.
- Requests for full proposals will be issued via email in late December 2025.

FULL PROPOSALS

- Full proposal invitations will be issued via email.
- Application requirements for full proposals will accompany these invitations.

AWARDING OF GRANT

- Award announcements will be made via email and posted on NORD's website in May 2026.
- Funding will begin after all necessary documents (e.g., IRB forms, patient consent forms, signed grant agreements) have been received by NORD.

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.

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 applications must be received by **October 12, 2025 (11:59 pm PT)**.

REQUIRED ELEMENTS CHECKLIST	PAGE	✓
Application summary	4	
Letter of Intent (Maximum Length 2 Pages)	5	
Biographical sketch	6	
List of co-investigators, if applicable	7	
Budget outline	7	
OPTIONAL ELEMENTS	PAGE	✓

NORD REQUEST FOR PROPOSALS: Peutz-Jeghers Syndrome

Email: research-programs@rarediseases.org

Reviewer information	8	
Letter of support	8	

APPLICATION SUMMARY

Deadline for Initial Applications: October 12, 2025 (11:59 pm PT)

PRINCIPAL INVESTIGATOR INFORMATION	
Name	
Position/Title	
Email	
Mailing Address	
Telephone	
PROPOSAL INFORMATION	
Project Title	
Project Term	2 YEARS
Funding Amount Requested (\$ US) <i>not to exceed \$40,000 US</i>	
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)

NORD REQUEST FOR PROPOSALS: Peutz-Jeghers Syndrome

Email: research-programs@rarediseases.org

	☐ 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. Applicant 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 not 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/>