

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 \$50,000 US for

Pseudomyxoma Peritonei (PMP)

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

NORD, with donations from the Pseudomyxoma Peritonei (PMP) community is accepting applications for one grant, up to \$50,000 US, for scientific and/or clinical research studies related to Pseudomyxoma Peritonei (PMP).

Pseudomyxoma peritonei is a rare malignant growth characterized by the progressive accumulation of mucus-secreting (mucinous) tumor cells within the abdomen and pelvis. The disorder develops after a small growth (polyp) located within the appendix bursts through the wall of the appendix, and spreads mucus-producing tumor cells throughout the surrounding surfaces (e.g., the membrane that lines the abdominal cavity [peritoneum]). As mucinous tumor cells accumulate, the abdominal area swells and digestive function becomes impaired.

Pseudomyxoma peritonei is a very rare disorder with approximately 2 cases per million individuals. Males and females are affected in equal numbers. The average onset of pseudomyxoma peritonei is 48 years. There are no genetic, familial, or environmental factors known to cause this disease. Symptoms of pseudomyxoma peritonei occur due to progressively increasing mucinous tumor within the abdomen and pelvis. The most common symptom is increasing belly size ("jelly belly") and abdominal discomfort from pressure. In males, the second most common finding is protrusion of parts of the intestines, in affected females, the second most common finding is usually an abnormally enlarged ovary.

Other names for pseudomyxoma peritonei include: low grade appendiceal mucinous neoplasm (LAMN); colloid carcinoma; disseminated peritoneal adenomucinosis (DPAM); malignant appendiceal tumor; malignant large bowel cystadenocarcinoma; malignant large bowel peritoneal carcinomatosis; malignant large bowel tumor; mucinous cyst adenocarcinoma; mucinous cystadenoma; peritoneal carcinomatosis; PMP pseudomyxoma ovarii

Reference

Sugarbaker, P. (2019, November 25). NORD Rare Disease Report: Pseudomyxoma Peritonei. https://rarediseases.org/rare-diseases/pseudomyxoma-peritonei/.

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 Pseudomyxoma Peritonei (PMP) 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)		
Biographical sketch	6	
List of co-investigators, if applicable		
Budget outline	7	
OPTIONAL ELEMENTS	PAGE	✓
Reviewer information	8	
Letter of support	8	

Email: research-programs@rarediseases.org

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) not to exceed \$50,000 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 □ Rare Disease Organizatio □ Professional Organizatio	_
Please be as specific as possible:		
Did you hear about this RFP via:	 □ NORD Website □ Google □ Social Media (Facebook, Twitter, Linked □ Other (please specify) 	□ Email□ Medical/Research Publication□ Rare Action NetworkIn, Instagram)
Please be as specific as possible:		

Email: research-programs@rarediseases.org

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 <u>principal investigator</u>. 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	Institution and Location	Degree	Year(s)	Field of Study
Begin with baccalaureate or other initial professional education and include postdoctoral training.				
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 <u>not</u> 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)
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Please list up to five areas of scientific/medical expertise needed to review this application (optional).	Do <u>not</u> 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/