

Alone we are rare. Together we are strong.®

REQUEST FOR PROPOSALS

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

The Appendix Cancer/PMP Research Foundation

Announces a research grant opportunity for two grants
In the amount of \$50,000 US each for

Appendix Cancer and Pseudomyxoma Peritonei (ACPMP)

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

NORD, with funding from the patient member organization Appendix Cancer/Pseudomyxoma Peritonei Research Foundation ("ACPMP"), is accepting applications for two grants in the amount of \$50,000 US each, for scientific and/or clinical research studies related to appendiceal cancer, including pseudomyxoma peritonei (PMP).

Cancers and tumors (neoplasms) of the appendix are extremely rare with an estimated incidence of 0.15-0.9 per 100,000 people. The average age of onset is between 50 and 55 years, and they affect men and women equally. They most typically present either as appendicitis, a hernia filled with mucin, increasing abdominal girth, abdominal discomfort, an abdominal/pelvic mass, as an incidental finding on some form of imaging or at the time of surgery for a different indication. In women, they often spread to the ovaries and can be easily confused with ovarian cancer. Making the diagnosis of appendiceal cancer requires examination of a tumor specimen. After starting in the appendix, appendiceal tumors and cancers frequently spread inside the abdominal cavity. Depending on the type of tumor or cancer, this can lead to either the build-up of mucinous fluid in the abdomen known as pseudomyxoma peritonei or a condition referred to as peritoneal carcinomatosis (a growth of cancer cells in the abdominal cavity). Treatment for appendiceal tumors and cancers varies depending on the stage (extent) of disease and the subtype.

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.

The ACPMP Research Foundation Catalyst Research Grants Program is intended to support basic scientific, clinical, or translational research that is focused on appendix cancer and/or appendiceal pseudomyxoma peritonei (PMP). This grant program focuses on expanding fundamental knowledge about appendix cancer by promoting studies of the biology,

epidemiology, genetics, pharmacology, immunobiology, or biochemistry of malignant epithelial neoplasms of the appendix that have the potential to yield diagnostic, therapeutic, or population-based advances for these rare cancers. These studies may focus on appendiceal mucinous neoplasms, appendiceal adenocarcinomas (including signet ring cell adenocarcinoma and goblet cell adenocarcinoma), and/or pseudomyxoma peritonei of appendiceal origin.

Applications will be considered based upon the potential to translate research to extramural funding applications (e.g. NIH, DoD, FDA, corporate sponsors), additional pre-clinical studies and clinical trials and the innovation of the proposal aligned with the goals of the grant program.

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.

About the Appendix Cancer PMP Research Foundation

Founded in 2008, the ACPMP Research Foundation was created by a community of individuals affected by appendix cancer, pseudomyxoma peritonei (PMP), and related peritoneal surface malignancies. The ACPMP Research Foundation is dedicated to supporting and funding promising research and education that moves us toward a cure for appendix cancer and PMP. The Foundation also endeavors to support the appendix cancer community of patients and their caregivers by providing the latest and most accurate information.

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 <u>research-programs@rarediseases.org</u> 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)**.

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Letter of Intent (Maximum Length 2 Pages)	5	
Biographical sketch	6	
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Budget outline	7	
OPTIONAL ELEMENTS	PAGE	1
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Email: research-programs@rarediseases.org

Letter of support	8	
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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		
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 Network dlin, Instagram)

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	
 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 	
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	Dograd	Voar(s)	Field of Study
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				

Email: research-programs@rarediseases.org

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	

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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/