



NBIA Disorders Association (NBIADA) and Hoffnungsbaum e.V. (HoBa)

Research Grant Call Invitation Information *for*

Pantothenate *Kinase-associated Neurodegeneration (PKAN)*

Submission Deadline for Letter of Interest (LOI) February 28, 2026
Submission Deadline for Requested Applications is May 30, 2026

Research Objectives

NBIADA and HoBa, together “The Funders,” are currently accepting applications from invited participants for a one or two-year grant proposal not to exceed \$100,000 USD for research studies related to the treatment of individuals with PKAN.

Our research objectives for the PKAN 2026 Collaborative Grant Call are to support high-quality, translational research that advances meaningful therapeutic progress for individuals living with PKAN. The Funders seek to support new or ongoing meritorious projects that advance the development or evaluation of therapeutic approaches for PKAN, including small molecules, gene-based therapies, biologics, repurposed drugs, or combination approaches, with a clear path toward clinical relevance.

Proposed studies may address key barriers to translation, such as delivery, safety, dosing, manufacturing readiness, or the generation of proof-of-concept data, and should demonstrate a rationale for how the work may improve symptoms, slow disease progression, or alter the course of PKAN. Prospective applicants must first submit a brief Letter of Interest, which will be used to assess programmatic relevance, alignment with the objectives of the call, and appropriateness for full application. Selected applicants will then be invited to submit a full proposal.

Projects may be preclinical or early translational in nature and will be evaluated using NIH-style peer review criteria. Final funding decisions will be made by the Funders.

Letter of Interest Deadline February 28, 2026 by 7 pm CST (U.S.)

Letters of Interest should be 2-3 pages in length and may include one figure.

Letters of Interest must be submitted by the deadline above to Amber Denton at adenton@NBIAdisorders.org. All Letters of Interest will be reviewed, and applicants will be notified by March 15, 2026 whether their proposal aligns with the research objectives and if they are invited to submit a full application.

Requested Full Application Deadline May 30, 2026, by 7 pm CST (U.S.)

Application must be submitted with all of the following documents to be considered.

- Narrative of proposal suitable for peer review, and statement why the funds from “The Funders” would be essential to the project. (One page)
- Specific goals: State the specific aims of the proposed research. (One Page)
- Background and significance. (One page)
- Methods. (Five pages)
- Facilities available and Budget. All amounts must be in U.S. dollars. (One page)
- Provide statement that there is no funding overlap in monies requested from “The Funders,” or explain in detail if such overlap exists and why funding is still essential from “The Funders.”
- Provide explicit explanation of future plans to secure funding to take project forward.
- Please provide a paragraph describing a sharing plan. Research resources developed under this funding initiative must be shared per National Institutes of Health guidelines at [8.2.3 Sharing Research Resources](#) (nih.gov). Model organism sharing guidelines can be found at [Model Organism Sharing Policy | Data Sharing](#) A guide to help determine which sharing policies may apply to your research can be found at [Which Policies Apply to My Research? | Data Sharing](#). In addition, investigators are encouraged to share novel cell and animal models or technologies that are not yet defined in the NIH guidelines.
- Up-to-date Curriculum Vitae and Bibliography.
- If applicable, attach copy of *patients Informed Consent* approved by Institution. **(Required before payment)**
- If applicable, attach copy of *Institutional Review Board (Ethics Committee) approval*. **(Required before payment)**
- If a clinical study involves human gene therapy, please remit a copy of the NIH Recombinant DNA Advisory Committee (RAC) review, or waiver of review. **(Required before payment)**
- If this is a multi-site study, Informed consent document and IRB approval is required from each.
- Submit application with the filename “2026 PKAN Grant Application-your last name” and convert word document with all required information to a pdf file before sending. Submission of all pertinent documents must be a **single pdf document** attached to an email addressed to adenton@nbiadisorders.org.

RFA Deadlines

- Letter of Interest due by February 28, 2026, by 7 PM CST (U.S.)
- Applications due by May 30, 2026, by 7 PM CST (U.S.)
- Award announcement by June 15, 2026 (if not sooner)
- Grant funding will begin in July 2026 or once all required paperwork is received, and no later than October 1, 2026. Delays beyond this date may result in loss of funding.

Further Information

- All requested full applications will be reviewed for scientific merit.
- Indirect costs are allowed up to a maximum of 15% of the grant request.
- PI salary of up to \$10,000 per year will be allowed in addition to other lab personnel salaries.
- All awardees may be asked to present at family conferences or scientific meetings organized by any of the funding organizations during or shortly after the award time frame to present their work and meet NBIA families. Travel costs may be reimbursed.
- If study involves humans, copies of the Informed Consent and the Institutional Review Board (Ethics Committee) approvals will be required from each site involved in the study before payment.
- Clinical drug trials must meet the requirements established by the Food and Drug Administration (FDA).
- All publications resulting from research funded by our organizations must acknowledge each of "The Funders" and should be provided to us when published.
- Grant recipients will receive 1 year funding in three stages: 1/3 at start of project; 1/3 at six months after an interim scientific and financial report is submitted and approved; final payment at the conclusion of the grant after final scientific and financial reports are submitted and approved. 2 year funding in three stages: 1/3 at start of project; 1/3 at one year after interim scientific and financial report is submitted and approved; final payment at the conclusion of the grant after final scientific and financial reports are submitted and approved. The PI must submit a final scientific & financial report within three months of the end of the Grant Period including any extension granted. No more than one NCE will be allowed. Those not in compliance with this requirement may forfeit their final payment.
- Any Budget expenses that include travel to present work at meetings and/or publication fees must be expensed within the grant timeline. A no cost extension (NCE) will not be granted for the purpose of completing these budget items.
- Grant period starts with signed grant award and any required paperwork submitted no later than a specified time decided by "The Funders."
- The designated grant manager must be informed immediately of any change to the status of the PI or other important contributors to the project which might affect their ability to comply with grant conditions.
- If the interim or final reports reflect serious deviations from the grant objectives and cannot be explained adequately, forfeiture of funds due or stoppage of the grant may be warranted.
- All research papers that have been accepted for publication in a peer-reviewed journal, and are supported in whole or in part by the Grant, must be made available at NIH PubMed Central as soon as possible, and in any event within six months of publication, in line with an Open Access policy.