

Rare Epilepsy Partnership Award

**Our mission is to cure epilepsy,
by promoting and funding patient-focused research.**

Funding Opportunity

CURE Epilepsy recognizes the urgent need to understand and treat rare epilepsies. We seek to partner with rare epilepsy advocacy groups to co-fund the development of necessary research tools, model systems, techniques, data collection platforms, and studies that will help accelerate discoveries in the rare epilepsies represented by each partner organization. Further details are available in the 'Research Priority Areas' section below.

CURE Epilepsy is the leading non-profit funder of epilepsy research. We have funded over 285 grants in 18 countries and driven research in several key areas such as infantile spasms, Sudden Unexpected Death in Epilepsy (SUDEP), and post-traumatic epilepsy.

Partnering with CURE Epilepsy to advance research specific to your rare epilepsy has many benefits including:

- Access to a robust grant funding and management process (see 'Grant Process' section below)
- PhD level staff to manage the funding process and provide oversight for funded awards
- Reports on your grant's progress and key findings in a lay-friendly format at 6-month intervals
- Interactions with funded researchers via virtual and/or in-person meetings
- Attracting talented scientists to study your rare epilepsy
- Ability to bring your voice to the grant review process
- Joint branding on award-related material and announcements
- Acknowledgement of the joint funding by grantees in publications and presentations
- Requiring that grantees make any research models/tools/assays resulting from the grant freely available to the research community

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CURE Epilepsy will partner with up to 5 rare epilepsy groups with the goal of co-funding three independent research projects.

Each grant will be funded for a maximum of \$100,000 for 1 year. We will require grant applicants to submit projects that are milestone-based. Grant payments will be contingent upon the achievement of agreed-upon scientific deliverables and milestones.

By partnering with CURE Epilepsy, organizations will commit to contributing \$50,000 towards funding a research project specific to their rare epilepsy, plus \$5,000 towards administrative expenses in funding and managing the grant. CURE Epilepsy will commit to contributing \$50,000 towards the research project, in addition to providing staff time and grant management resources as outlined above.

The anticipated start date for awards is March 2025.

Funded awards must address our mission to cure epilepsy, affirming our core belief that the only acceptable final goal is “no seizures, no side effects.”

This award is not intended to fund research focusing solely on a comorbid condition associated with a rare epilepsy without also seeking to understand or develop tools to understand the causes and treatments of the accompanying seizures.

How to Partner

To participate, potential partners must:

- Commit to a contribution of \$50,000 towards a research project and \$5,000 towards administrative costs. No payment is required to participate in the initial stages of development of the request for proposals or review of the grant opportunity. If, after the review of the grant applications, CURE Epilepsy and the partner agree to fund a grant, the partner will sign a gift agreement committing to give **CURE Epilepsy** a gift in the amount of **\$55,000** to be paid in cash or readily marketable securities. A general breakdown of the payments is below. The initial payment

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of \$5,000 is required in December 2024. The timing and frequency of the additional payments can be customized per the partner's needs and capabilities, but an example includes the following payment schedule:

<u>Payment Due Date</u>	<u>Payment Amount</u>
December 31, 2024	\$5,000
December 31, 2025	\$25,000
December 31, 2026	\$25,000

CURE Epilepsy will send reminders for payments, which will be detailed in the agreement.

- If you are interested in partnering with us, please provide the following information by **February 15th, 2024** via the survey here: <https://www.surveymonkey.com/r/G96KWWH>
 - Three critical research needs or priorities that can meaningfully impact understanding of your rare epilepsy. These could be as simple as developing an assay to study the function of your genetic mutation or developing an animal model specific to your rare epilepsy to a more complex project using one or more models to study a specific therapeutic target. Priorities will be reviewed by CURE Epilepsy to ensure alignment with the intent of the funding opportunity.
 - Name of at least one scientific advisor who has worked with your organization to develop the research priorities outlined above. Note that the advisor(s) named here, and their laboratory team members, are not allowed to submit applications in this grant cycle. All other advisors not named here, and/or their team members, are eligible to apply.
 - The name of at least one person from your organization who will be a contact person for the development of the Request for Proposals and participate in the lived-experience grant review process. See more information about the review process in the sections below.
 - Details on any existing grant funding and management programs in your organization.
 - Information on fundraising capabilities.

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CURE Epilepsy will prioritize potential partners that a) do not already have grant funding and management capabilities, b) have a scientific advisor(s) to consult on research priorities, c) can provide three specific research priorities, d) can nominate at least one person to participate in the grant development and review process and e) have available or demonstrate the potential to raise \$55,000. CURE Epilepsy encourages all interested partners to apply but will prioritize those that we did not partner with in previous years.

Research Priority Areas

This funding mechanism is intended to support the development of research tools, models, assays, etc., to enhance the understanding of and help identify new therapeutic targets in one or more of the rare epilepsies represented by partner organizations. Research must align with CURE Epilepsy's mission to find a cure for epilepsy. The following areas of research are offered as examples of research that may be considered to address the specific needs of partner organizations.

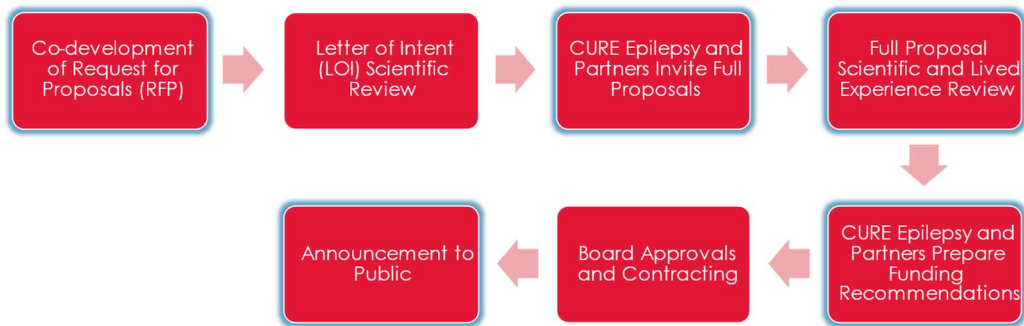
- Development of rare epilepsy-specific cellular models including but not limited to patient-derived stem cells, iPSC lines, 3D organoid models, or fused organoid models.
- Development of appropriate genetic animal models.
- Development of novel in-vitro or in-vivo assays/techniques that can enhance research in a specific rare epilepsy.
- Building data repositories or registries to better understand the natural history of one or more rare epilepsies, or to help identify common therapeutic targets/pathways. Projects utilizing existing registries or databases are allowed and must clearly articulate the specific rare epilepsy that will be studied.
- Transformative research to enhance understanding of the cellular, molecular, genetic, and systems-level biology of rare epilepsies, facilitating the continued investigation of disease-modifying or preventative strategies.
- Use of Electronic Health Record data to better understand disease burden in a specific rare epilepsy and develop therapeutic strategies.
- Technology that can lead to improved and faster diagnoses.

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Grant Process

CURE Epilepsy’s stringent grant review process ensures that we only fund high-quality research. The Rare Epilepsy Partnership Award will progress through the steps outlined in the figure below. Boxes with a blue outline represent steps requiring partner involvement.

Rare Epilepsy Partnership Grant Process



Below is a timeline and brief details for the grant review and management process for this program.

Activity	Date
Registration Opens for Partner Organizations	Tue, 01/16/24
Registration Deadline for Partner Organizations	Thu, 2/15/24
Selected Partner Organizations Informed	Fri, 03/01/24
Request for Proposals	Tue, 5/14/24
Letter of Intent Deadline	Tue, 06/11/24
Full Application Invitations	Friday, 07/26/24
Full Application Deadline	Wed, 08/28/24
Anticipated Award Announcement	December 2024-January 2025
Earliest Award Start Date	Spring 2025

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1. Request for Proposals (RFP)

Partners will provide a list of three research priorities to be included in the guidelines for researchers. A request for proposals with guidelines for applicants will be released to the research community in the second week of May 2024 through various channels including the Rare Epilepsy Network, emails to CURE Epilepsy's researcher database, social media, etc. Partners will also be expected to disseminate the RFP to their community of researchers.

2. Letter of Intent Phase

Grant applicants will submit a 2-page letter of intent (LOI) describing the main goals of their proposed project. LOIs will be reviewed by scientific reviewers who are experts in rare epilepsy research. LOIs will be evaluated for alignment with the mission of this program, feasibility, and significance of the proposed project. Scientific reviewers will be carefully selected by CURE Epilepsy and Partners based on expertise in rare epilepsy research. CURE Epilepsy and partners will review scores and comments and invite full applications.

3. Full Proposal Phase

Each full proposal will be reviewed by three scientific reviewers and one lived experience reviewer. Scientific reviewers will be carefully selected by CURE Epilepsy based on the specific expertise needed to accurately evaluate applications. Each partner will nominate one lived experience reviewer who will review applications pertaining to their rare epilepsy. A lived experience reviewer can be anyone who is touched by the specific rare epilepsy as a patient, family member, or caregiver. Lived experience reviewers are only responsible for reading ½ page lay summaries but are welcome to read the entire application. CURE Epilepsy will organize a review teleconference with scientific and lived experience reviewers to discuss scores and comments for each grant.

4. Internal Review to Assemble Funding Recommendations

Following the review panel teleconference, CURE Epilepsy and partners will assemble funding

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recommendations for Board approval.

5. Board Approval and Contracting

Once approved by CURE Epilepsy's Board and by partners, grantees will be informed, and CURE Epilepsy will prepare contracts with institutions. Awardees will be required to agree to share with the research community any research tools, animal models, assays, etc., that are developed as a result of this funding. Grants will remain confidential until contracting is complete which can take several months.

6. Announcement to the Public

Once grants are contracted, a lay summary for each funded grant will be prepared by CURE Epilepsy's research staff and made available to partners for sharing with the community via their website, social media, emails, etc. CURE Epilepsy will also share this information via our website, emails, and social media. CURE Epilepsy will organize introductory virtual or in-person meetings for awardees and partners.

7. Grant management

All awards will be managed by CURE Epilepsy's research staff. Grantees will submit a report of expenditures and a scientific report at the end of every six-month performance period. CURE Epilepsy will make grant payments in installments, and payments will be contingent upon receipt, review, and approval of scientific and financial reports. Grantee progress will be monitored against agreed-upon milestones in their application. A final payment of \$5,000 will be withheld until final reports are submitted and approved by CURE Epilepsy. CURE Epilepsy will prepare two reports in lay language to describe progress made in the project, one at 7 months after commencement of the project, and one upon completion of the project. CURE Epilepsy will prepare a lay-friendly report for each partner within one month of deliverable submission by the grantee. CURE Epilepsy will facilitate an initial virtual meeting between each partner and the grantee. Grantees will be expected to present their research to a larger audience for example at the American Epilepsy Society conference, a patient-focused family conference, or a CURE

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Epilepsy-facilitated webinar. Grantees will acknowledge both CURE Epilepsy and the partner organization in any publications resulting from the award.