

Chan Zuckerberg Initiative

FREQUENTLY ASKED QUESTIONS (FAQ)

Science in Society Rare As One (Cycle 3)

This FAQ aims to answer questions about the recently announced Rare As One Network Cycle 3 Request For Applications (RFA). Many items are addressed in the [RFA packet](#) and we encourage you to read those materials carefully. Please contact sciencegrants@chanzuckerberg.com with additional questions.

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Eligibility

How do I confirm if my disease is classified as one of the three areas of scientific focus (channelopathies; ciliopathies; or inborn errors of metabolism)?

To confirm if your disease area is one of the three classes of disease, we encourage you to engage in discussion with your key research partners. In doing so, please refer to the RFA instructions as follows:

For the purposes of this RFA:

- (i) Channelopathies are defined as a heterogeneous group of disorders resulting from the dysfunction of ion channels located in the membranes of all cells and many cellular organelles;
- (ii) Ciliopathies, a group of genetic disorders caused by structural or functional disruption of cilia, or by abnormal cilia biogenesis, including both motile and immotile/primary ciliary disorders;

and/or (iii) Inborn Errors of Metabolism (IEMs), a group of diseases that result primarily from defects in specific enzymes that lead to the failure of the metabolic pathways involved in the breakdown or storage of various substances, such as carbohydrates, fatty acids, and amino acids.

If, after review of the definitions given above and discussion with your research community, you feel that your disease area falls within one of the categories above, we encourage you to apply and provide a published reference (link to a peer-reviewed paper or website). This reference should associate your organization's disease area with one or more of the areas of scientific focus for this RFA (channelopathies, ciliopathies, inborn errors of metabolism), or otherwise clearly demonstrate that the disease falls within one of these areas of scientific focus.

Application reviewers will have access to the full text of paywalled articles.

Is my disease a rare disease?

For the purposes of this RFA, we are defining a rare disease, disorder, or syndrome, or group of closely related rare diseases, disorders, or syndromes as either, in the U.S., as a condition that affects fewer than 200,000 people, or based on the relevant definition in the country or region where your organization is based.

We collaborate with multiple organizations operating within our disease area. Can we apply together as one?

We recognize there may be multiple organizations operating within a single disease area, including across multiple countries, and we encourage collaboration. For this RFA, we will be assessing whether to accept multi-organization applications on a case-by-case basis. To help us understand whether your specific collaboration would be a good fit for this opportunity, please contact us directly at rareasone@chanzuckerberg.com, with a brief description of the organizations who would be involved in the collaboration, the history of collaboration between your organizations, and how you would propose at a high level sub-allocating grant funds between your organizations. Please also share which organization leader would serve as the grant lead and whether the organization leaders of each organization involved would be able to participate in regular calls and activities. Any relevant organization leaders should be included in your email.

Can international patient organizations apply?

Yes, patient organizations based outside of the United States are eligible to apply for this round of funding.

Patient organizations must be organizations that are tax-exempt under section 501(c)(3) of the United States Internal Revenue Code, or have a valid fiscal sponsor that is tax-exempt under section 501(c)(3) of the Internal Revenue Code, or a 501(c)(3) charity/non-profit organization equivalent for non-US based organizations. Non-US based organizations will be subject to Equivalency Determination.

Can you define a patient-led organization?

We are defining “patient” for purposes of this CZI initiative as: patients who are affected by the rare disease, their family members, and caregivers. Patient-led organizations are advocacy groups/disease foundations or other organizations that represent patients, employ patients in key leadership roles (e.g., Founder, Executive Director, Board of Directors), are patient-centered in their programming, and representative and inclusive of the community they serve.

My organization applied and wasn’t selected for previous cycles of the Rare As One Network RFA. Are we allowed to apply again?

Thank you for your continued interest. Unsuccessful applicants to the Rare As One Cycle 1 and 2 Request for Applications are welcome and encouraged to apply for the Cycle 3 RFA. Please note that prioritization criteria in the selection process for the Cycle 3 RFA are different from the Cycle 1 & 2 RFA (these criteria are available within the application).

Organizations that have been previously funded through any of the following multi-year CZI Science grant programs are not eligible to apply:

- Rare As One Network Cycle 1
- Rare As One Network Cycle 2 (note: Cycle 2 applicants who received [one-time awards of \\$50,000](#) are eligible to apply)
- Patient-Partnered Collaborations for Single-Cell Analysis of Rare Inflammatory Pediatric Disease
- Patient-Partnered Collaborations for Rare Neurodegenerative Disease

Can an application be submitted to the Rare As One Network while 501(c)(3) status is in process?

Your organization may apply if you have identified a fiscal sponsor or have obtained 501(c)(3) status by the time the grant would be awarded. Organizations with pending IRS approval should enter Pending123 in the tax ID field in the application. In the event IRS approval is not received by the time the grant would be awarded, it is recommended — though not required — that the organization secure a fiscal sponsor as a back-up. Additional information about fiscal sponsorship is available [here](#).

Application Process and Evaluation Criteria

Can we schedule a call to discuss the application?

To ensure fairness in our process, we are handling all inquiries by email so that they are recorded and we can assure that all potential applicants receive the same information. We are happy to reply to general questions regarding the grant program submitted via email to sciencegrants@chanzuckerberg.com. To be fair to all applicants, CZI does not offer feedback on proposals in advance of submission or advise about application strategy.

Can you share an application from a successful applicant to a previous Rare As One cohort as an example so we know what a successful application looks like?

We are not authorized to share past applicants' materials. Additionally, we want to emphasize that there is no "one-size-fits-all" approach to a successful application and the application criteria for the different RAO funding opportunities have differed. We encourage you to view the [grant writing training](#) and grantee vignettes embedded in the application instructions for further guidance.

Can you share additional details about budget requirements?

Per the application instructions, grant funds should be used to further the four grant objectives, specifically to:

1. strengthen the organizational and scientific capacities of the applicant organization
2. assemble or strengthen a collaborative research network in the disease area
3. convene the disease community
4. develop a patient-prioritized research agenda within the disease area

We recognize priorities and projects will evolve within the grant period. At this application stage, we ask for a window into how your organization would anticipate allocating the grant award.

In furtherance of the grant objectives, past grantees have utilized funding to support the grant objectives in a variety of ways, including, but not limited to:

- Hiring key staff to support work towards grant objectives: i.e. Executive Director, Project Coordinator, Research Coordinator, Chief Scientific Officer, and similar roles.
- Contracting with specialists to support work towards the grant objectives: i.e. financial consultants, fundraising experts, board development coaches, science consultants, etc.
- Acquiring, developing and implementing website improvements, research network hub platforms, organizational tools such as CRMs, financial software, language translation, project management, and digital communication tools
- Providing funding for research enabling tools that are openly available to researchers within the research network and support the development and engagement of the research network as a whole: i.e. registries, cell lines, animal models, etc. *(Please note that although the development of such research-enabling tools may be in scope, funds may not be utilized to directly support other scientific research that does not directly support network engagement.)*
- Conference planning and support, venue, travel stipends, etc.

If your application is selected for funding, we will work with you to review your budget to ensure that all budget line items are in scope and support the achievement of all grant objectives.

Other Questions

If my disease does not qualify, are there any other opportunities for CZI support? Do you anticipate there will be other opportunities for other organizations in the future?

The Rare As One Program does not currently have other opportunities available. We update our website regularly as new opportunities become available and would encourage you to sign up there for funding and programming updates. We encourage you to sign up for our [CZ Science funding newsletter](#) to get notifications on future opportunities.

Can you share more about the terms in the grant guidelines on code & data sharing?

At CZI, we believe that the velocity of science and pace of discovery increase as scientists build on each others' discoveries. We support a culture of open science that shares results, experimental methods, open source software and biological resources as early as possible to accelerate scientific progress. CZI is committed to developing and using platforms that disseminate data openly and freely. In support of these goals, the language in question pertains to software and datasets developed with CZI funds.