

# Chan Zuckerberg Initiative

## REQUEST FOR APPLICATIONS

### Rare As One Network (Cycle 2)

The Chan Zuckerberg Initiative invites applications for three-year collaborative projects from patient-led, U.S.-based nonprofit 501(c)(3), rare disease advocacy organizations to develop a patient-led collaborative research network, with a key focus on improving diagnosis and diversity, equity, and inclusion within the disease area.

## OPPORTUNITY

### Overview

At the Chan Zuckerberg Initiative (CZI), we believe in supporting and leveraging the power of patients to accelerate research and drive progress against rare diseases. That's why—with continued guidance from patient communities, rare disease experts, and advocacy organizations—we are continuing, through the [Rare As One Project](#), to lift up the work of patient communities and scale a model in which patients, researchers, clinicians, and others work together to advance progress against their diseases.

Through the Rare As One Network (Cycle 2) Request for Applications (RFA), CZI is inviting patient-led, U.S.-based nonprofit 501(c)(3), rare disease advocacy organizations to apply for a three-year grant opportunity to support the development (or meaningful expansion) of an international, patient-led collaborative research network in the disease area. CZI will provide support to 20 patient-led organizations to build a network of researchers, clinicians, and patients working together to align on the state of the science, identify the open research questions, and develop shared research priorities—putting emphasis on addressing diagnosis-related research challenges, and directing attention to the diversity of needs of the full patient community. Throughout the grant period, CZI will provide grantee organizations with capacity building support, including funding, training, community learning opportunities, and mentorship. In turn, we ask the organizations to share experiences and learnings with one another, and together work to identify how to best address the most pressing needs across a spectrum of rare diseases. Read our [Medium post](#) to learn more.

We recognize patient communities as the agents and architects of their own change. We are connecting and partnering with the rare disease community to provide resources and tools for patient communities to be more effective advocates for, and partners in, research. Please visit our [website](#) to learn more.

This grant program will accept applications starting at 9 a.m. Pacific Time Tuesday, March 23, 2021 until 5 p.m. Pacific Time on Tuesday, June 2, 2021. If awarded, each grant will be up to \$600,000 total costs over a period of three years.

## ELIGIBILITY

- Applicant organizations must be patient-led organizations that represent patients, engage patients in key leadership roles (e.g., as founder, executive director, board member, key staff, etc.), and are patient-centered in their programming.
- Applications must be submitted by organizations that are tax-exempt under section 501(c)(3) of the Internal Revenue Code OR have a valid fiscal sponsor that is tax-exempt under section 501(c)(3) of the Internal Revenue Code.
- Applicant organizations must be focused on a rare disease, disorder, or syndrome, or group of closely related rare diseases, disorders, or syndromes (defined in the U.S. as a condition that affects fewer than 200,000 people).
- Applicant organizations must have an annual budget of less than \$2 million averaged over a two-year period.
- Facebook employees, including employees of any subsidiary Facebook entities, as well as employees of Chan Zuckerberg Initiative, LLC, are not permitted to apply.

For questions about eligibility for this award or the application process, please contact us in advance of the proposal deadline at [sciencegrants@chanzuckerberg.com](mailto:sciencegrants@chanzuckerberg.com). Deadline extensions will not be granted.

**Diversity and Equity:** We believe the strongest teams — encompassing ourselves, our grantees, and our partners — incorporate a wide range of backgrounds, lived experiences, perspectives, and voices that guide them to the most important unsolved problems. To enable our work, we incorporate diverse perspectives into our strategy and processes, and we also seek to empower community partners to engage in science. We are committed to building a grant program that fosters diversity and addresses systemic inequities. We are working to build tools and infrastructure and disseminate methods and skills, aiming for conditions in which a diverse range of prospective patient advocates can thrive and grow. Women, those with disabilities, underrepresented racial and ethnic groups, and organizations representing disease areas that disproportionately impact underrepresented or underserved communities are strongly encouraged to apply.

## APPLICATION REQUIREMENTS

### Key Dates

March 23, 2021:	Application portal opens
June 2, 2021:	Applications due by 5 p.m. Pacific Time
July 21- August 4, 2021:	Video call interviews of finalists, as needed
September 2021:	Earliest notification of decisions (subject to change)
October 1, 2021:	Earliest start date of award period (subject to change)

**Award period and start date:** Awards will be three years in duration with a project start date of no earlier than October 1, 2021. Actual start date may vary.

**Budget:** \$600,000 total costs over three years (inclusive of up to 15% indirect/overhead costs). Indirect costs cannot exceed 15% of direct costs. A budget is not required at the time of application, but will be requested at a later time during the review process if selected as a finalist. The Chan Zuckerberg Initiative will work closely with finalists to arrive at a mutually acceptable budget after review.

All applications must be completed and submitted through CZI's online grants management portal at <https://apply.chanzuckerberg.com>. It is recommended that applicants familiarize themselves with this portal well in advance of the application deadline. Detailed application instructions are available on the [Chan Zuckerberg Initiative website](#), as well as in the [grants management portal](#). We also invite you to watch a short training video, [The Basics of Grant Writing](#).

## SELECTION PROCESS

The Chan Zuckerberg Initiative's [core values](#) center around people, technology, collaboration, and open science. We adhere to those values in both proposal selection and evaluation of progress. CZI will evaluate all applications and will seek independent expert review. As needed, finalists may be invited for a video interview with CZI staff and/or advisors between July 15-August 4, 2021. CZI reserves the sole right to decide if an applicant or applicant organization meets the eligibility requirements. CZI reserves the sole right to not recommend the funding of any applications. CZI does not provide feedback on decisions for unfunded proposals.

## PRIORITIZATION CRITERIA

While the application will be reviewed in full, and multiple factors will be evaluated, applications will be prioritized in the review process based on the following criteria:

- **The patient-centered nature of the organization**, as demonstrated by how it represents, engages, and reflects the patient voice, and is representative and inclusive of the diversity of the patient community in its approach.

- **The ability of the leadership team** to lead the development of a patient-led research network, as demonstrated by the motivation, commitment, and ability of the patient leader; current and/or planned engagement with the research community; the inclusion of individuals from underrepresented groups in the leadership team; and the combined strengths of the leadership team that will be involved in this work.
- **The need for a patient-led research network**, as demonstrated by insufficient activity dedicated to the formation of shared, patient-centered research priorities within the disease area and the potential of a research network to advance scientific understanding and progress in the disease area.
- **The potential to address challenges related to diagnosis** through the enhanced capacity and work of the patient organization and the development/expansion of a patient-led research network.
- **The commitment of the organization to centering diversity, equity, and inclusion** throughout all its work, including current or planned efforts to reach and serve patients, families, and communities of color affected by the disease, develop/expand the research network, identify shared priorities, and address scientific and systemic barriers to diagnosis.
- **The potential of the organization to benefit from this opportunity**, as demonstrated by the organization's strengths, needs, and collaborative orientation.

## POLICIES

- Funds from this award are intended to support rare disease organizations in the development of patient-led research networks. Grants are made to organizations and reasonable flexibility on how these funds are utilized is allowed, provided that the funds are used to support the development and maintenance of a research network for the organization's disease area of focus. The funds may not be used to directly fund research, although they may be used to develop research-enabling infrastructure (i.e. biobanks, data collection efforts, etc).
- For awarded projects, financial statements and progress reports will be due at the conclusion of each grant year. Specific deliverable requirements will be outlined in the award notification.
- Grantees of funded projects will be asked to participate in regular trainings and events (which may be in person or virtual). Travel support for any in-person meetings will be provided by CZI separately from the requested grant funds.
- Grantees may obtain funding from other funding sources, provided that there is no conflict with meeting the terms of the CZI award.
- **Ethical conduct:** CZI advocates the highest standards for the ethical conduct of research. In addition to requirements of their own countries, grantees must adopt procedures for the use of animals in research and for the ethical treatment of human subjects and tissue donors, including obtaining their or their appropriate proxy's written informed consent. CZI regards the policies of the National Institutes of Health as a strong model for such procedures.

- **Data, publication and dissemination:** Although it may not be the specific goal of this RFA or the project funding, CZI seeks to accelerate scientific discovery and collaboration. In many cases, this is accomplished by supporting a sharing and publication policy for open and rapid dissemination of results, including methods, data and reagents, and software that maximizes accessibility and reuse. Situations where this type of sharing is not possible (e.g. personally identifiable information) will be considered. If you have specific questions, please contact us at [sciencegrants@chanzuckerberg.com](mailto:sciencegrants@chanzuckerberg.com).
- Unused research funds may be carried over to the following year, and requests for no-cost extensions will be considered at the end of the overall project period and upon receipt of an annual report.
- Indirect costs cannot exceed 15% of direct costs. Indirect costs may not be assessed on capital equipment or subcontracts, but subcontractors may include up to 15% indirect costs of their direct costs.
- Applications selected through this process will either be funded by the Chan Zuckerberg Initiative Foundation (CZIF) or recommended for funding through the Chan Zuckerberg Initiative Donor-Advised Fund (CZI DAF) at the Silicon Valley Community Foundation (SVCF).

## **CONFIDENTIALITY**

All submitted applications will be kept confidential, except (1) as necessary for our evaluation or to comply with any applicable laws; and (2) to the extent that the application is made public or available to others without a duty of confidentiality through no fault of CZI. Notwithstanding, successfully funded proposals may be made publicly available and/or shared with other grantees or collaborators. Unfunded proposals will remain confidential as provided herein; however, information, including brief summaries of the proposed projects, project metrics, and the types of organizations that have applied for funding, may be made publicly available in aggregate form. Application materials will not be returned to applicants.

## **RFA CONTACT**

For administrative and programmatic inquiries, or other questions pertaining to this RFA, please contact [sciencegrants@chanzuckerberg.com](mailto:sciencegrants@chanzuckerberg.com).

## **IMPORTANT DOCUMENTS**

[Application Instructions](#)

# Chan Zuckerberg Initiative

## APPLICATION INSTRUCTIONS Rare As One Network (Cycle 2)

Some helpful information as you get started:

- This document contains:
  - [General guidance on using the portal](#)
  - [How to submit an application](#)
  - [Application details specific to the Rare As One Network \(Cycle 2\) RFA](#)
- Please review the [Request for Applications](#).
- The Chan Zuckerberg Initiative uses SurveyMonkey Apply (SMAppl) as its grants management portal. All applications must be submitted through this portal (<https://apply.chanzuckerberg.com>). SMAppl is configured to work best using the Google Chrome browser. It is recommended that you familiarize yourself with this portal well in advance of any deadlines. Deadline extensions will not be granted.
- **Key dates:**

March 23, 2021:	Application portal opens
June 2, 2021:	Applications due by 5 p.m. Pacific Time
July 21- August 4, 2021:	Video call interviews of finalists, as needed
September 2021:	Earliest notification of decisions (subject to change)
October 1, 2021:	Earliest start date of award period (subject to change)
- **Application specifics:**
  - **Eligibility:** Please refer to the [RFA announcement](#).
  - **Award Period:** Proposals should be three years in duration with a project start date of no earlier than October 1, 2021. Actual start date may vary.
  - **Budget:** \$600,000 total costs over three years (inclusive of up to 15% indirect/overhead costs). Indirect costs cannot exceed 15% of direct costs. **A budget is not required at the time of application**, but will be requested at a later time during the review process if selected as a finalist. The Chan Zuckerberg Initiative will work closely with finalists to arrive at a mutually acceptable budget after review.

# GETTING STARTED

**Account setup:** The applicant (i.e., the person completing the application on behalf of the applicant organization) must first set up an account in the CZI online grants portal at <https://apply.chanzuckerberg.com/>.

To set up an account:

1. Go to <https://apply.chanzuckerberg.com/>.
2. Click the green **Register** button in the upper right corner.
3. Complete the requested fields and then click the green **Create Account** button.
4. Click the green **Continue** button to proceed to the site.

Please note you will need to verify your account through the auto-email that you receive after registering. You will not be able to submit an application until your account is verified.

**Personal data:** Where we ask for personal data of individuals in grant applications, please only submit personal data that you have a right to provide. We will use and store any personal data collected through the application process for grant-related purposes (e.g., administering the grant, analyzing and improving our grant practices). The Chan Zuckerberg Initiative Foundation and Chan Zuckerberg, LLC (collectively "CZI") will be the "data controllers" for any such personal information, and the data may be stored on servers outside of your home country, including within the United States. If you have any questions or concerns regarding our privacy practices or collection or use of personal data, you can contact us at [privacy@chanzuckerberg.com](mailto:privacy@chanzuckerberg.com).

**Navigating the portal:** Once you have set up an account, you can log in to the grants portal at <https://apply.chanzuckerberg.com/>. Using the links in the upper right corner, you can access available programs (which includes RFAs for all CZI areas, not just Science) and any applications you have in preparation or previously submitted. Use the information ("i") link to get help with the portal. To access your account information, click on your name in the upper right. Your application will pre-populate with the name and email listed in your account information so if you need to edit it, click on your name in the upper right corner to make any necessary changes.

**Forgotten username or password:** If you have forgotten your username or password, please navigate to the grants portal at <https://apply.chanzuckerberg.com/> and click on the Log In link located in the upper right corner. Click the Forgot your password link and then enter the email address associated with your SMAApply account. You will then receive an email with information to reset your password. Please note that your username is your email address.

**Other questions:** If you have other questions about using the portal, please use the information ("i") link in the upper right corner of the window. Here you will find a link to FAQs about using the portal, as well as links to submit specific help requests. If you have specific questions about the RFA, please contact us at [sciencegrants@chanzuckerberg.com](mailto:sciencegrants@chanzuckerberg.com).

## SUBMITTING AN APPLICATION

### To submit an application:

1. Go to <https://apply.chanzuckerberg.com>.
2. Log in.
3. Click the green View Programs button that is displayed or click on the Programs link in the upper right corner. This will bring you to a listing of all programs/RFAs that CZI is hosting in SMAApply. To **find the program/RFA** you are looking for, you may need to scroll down.
4. Find the program/RFA you are interested in and click the green More button.
5. Click the green Apply button in the upper right and complete all sections (details below).
  - a. You will first be prompted to **enter the title** of your application (**which should be the name of your organization**), after which you will have access to the application tasks to complete. Project title is limited to 75 characters, including spaces.
  - b. The application is made up of several sections called **tasks** that are listed in a menu on the left side of the page. **For this RFA, the eligibility task must be completed before the other tasks will become available and visible.** It is strongly recommended that you complete the eligibility task/questionnaire well in advance of the submission deadline. Once the eligibility task has been completed, you can edit and complete tasks in any order. To **open a task**, click on the one you would like to work on in the table on the left hand side. You may need to scroll down to see the remaining tasks.
  - c. Once you **complete a task**, click the green Mark as Complete button within the task. To **navigate to the next task**, click on the one you would like to work on in the table on the left hand side. All required tasks must be marked as complete before submitting. To **edit a task** after marking it as complete, click the three dots in the upper right of the task and select edit, which will re-open the task.
  - d. Your application will autosave every few seconds, but you can also click the Save & Continue Editing on each task as you go along to **save your application**.
  - e. In the tasks that require a PDF upload: If you need to **delete and replace a PDF** after you have uploaded it, click on the three dots to the right of the file under the Attach File section within the task and select Remove from the dropdown menu.
  - f. To **download your application**, click on the three dots in the upper right corner of the application page and select download. If you are within a task, first click on the Back to application link in the upper left. Please **be aware of any pop-up blockers** in your browser that may prevent downloading your application.
  - g. To **access an application that you have previously saved**, click on the My Applications link in upper right and click the green Continue button on the application you wish to edit.
6. Once all tasks are completed, click the green Submit button **to submit your application**.
  - a. If the button is grayed out, it means your application is not yet complete; please be sure all required fields and uploads are complete within each task and that you have



- clicked the Mark as Complete button within each task.
- b. Review your application in the window (or in the PDF that you have downloaded- see 5f). If you want to make changes, navigate back to your application and reopen/edit any tasks that need editing. **It is strongly recommended that you download your application as a PDF (instructions above in 5f) to review your application before clicking submit.**
  - c. Once you are **ready to submit**, click the green Submit Your Application button on the left side of the window. You will need to confirm your submission by clicking the green Submit button in the pop up window. **Once your application has been submitted, it cannot be edited. Please be sure that your application is complete BEFORE submitting.** If you inadvertently submit your application and it is before the deadline, please contact [sciencegrants@chanzuckerberg.com](mailto:sciencegrants@chanzuckerberg.com).
7. Once your application is submitted, you will **receive an auto-email** confirming submission within a few minutes. If you do not receive a confirmation email within a few minutes, please check your spam folder. If you still did not receive your confirmation email, please email [sciencegrants@chanzuckerberg.com](mailto:sciencegrants@chanzuckerberg.com).
  8. If you would like to view your application after you have submitted it, it can be accessed through the My Applications link in the upper right corner.
  9. The grant writing process can feel overwhelming, especially for newer organizations. If you have not written a grant before, or would like to review tips from an experienced grant writer, we invite you to watch a short training video, [The Basics of Grant Writing](#).

**The application should be completed and submitted by the Patient Leader. The Applicant/Patient Leader must be affiliated with the organization listed, and grant funds will be awarded to this organization.**

**The application consists of the following sections (called tasks in the grants portal):** Eligibility, Applicant/Patient Leader, Equal Opportunity/Diversity (optional), Patient-Led Organization, Disease Area Details, Short Answer Questions

- **Eligibility:** In an effort to ensure your organization meets the eligibility requirements to apply, this eligibility questionnaire must be completed first. Once you have completed the questionnaire and confirmed your eligibility, the rest of the application will become available. It is strongly recommended that you complete the eligibility questionnaire well in advance of the submission deadline. No extensions will be granted.
  - Is your organization a patient-led organization (an advocacy group/disease foundation or organization that represents patients, employs patients in key leadership roles (e.g., Founder, Executive Director, Board of Directors) and is patient-centered in its programming)?
  - Is your organization focused on a rare disease, disorder, or syndrome, or group of closely related rare diseases, disorders, or syndromes (defined in the U.S. as a condition that affects fewer than 200,000 people)?

- Is your organization tax-exempt under section 501(c)(3) of the Internal Revenue Code? Or, does your organization have a valid fiscal sponsor that is tax-exempt under section 501(c)(3) of the Internal Revenue Code?
  - Does your organization have an annual budget of less than \$2 million averaged over a two-year period?
- **Applicant/Patient Leader:** The information entered should be for the Applicant/Patient Leader (i.e. Executive Director, CEO, or head of the organization) who will be taking responsibility for the grant and will be the administrative point of contact for CZI.
  - Name and email (auto-filled): To edit your name or email, please do so in your account information by clicking your name in the upper right corner and clicking My Account in the dropdown menu.
  - Organization.
  - Title/Position at organization.
  - Please upload a PDF of your resume.
- **Equal Opportunity & Diversity (optional):** CZI Science supports the science and technology that will make it possible to cure, prevent, or manage all diseases by the end of this century. Everyone is affected by disease, yet different communities are affected by or experience disease in different ways. Moreover, due to systemic barriers, the scientific enterprise itself is not a place where all voices and talents thrive. We believe the strongest scientific teams — encompassing ourselves, our grantees, and our partners — incorporate a wide range of backgrounds, lived experiences, and perspectives that guide them to the most important unsolved problems. To enable our work, we incorporate diverse perspectives into our strategy and processes, and we also seek to empower community partners to engage in science.

We track demographic information associated with applications submitted to CZI in response to our open calls. This information helps us learn from the RFA process, as well as improve our strategies to help ensure people who identify as members of underrepresented or marginalized groups in science are aware of and able to apply to CZI opportunities. **Please note that answering all questions below is voluntary, and demographic information will not be used to make final grant funding decisions.** All responses will be shared only with limited personnel, who will use that information only for the purposes described in this paragraph.

If you have any additional questions about why we ask this, what we do with the data, or to share suggestions for improvement, please reach out to [sciencegrants@chanzuckerberg.com](mailto:sciencegrants@chanzuckerberg.com).

The information below may be entered for the Patient Leader. **Please note that completing the below is voluntary, and demographic information will not be used to make final grant funding decisions.**

- What is your race/ethnicity? (optional)
- What is the year of your last academic degree? (optional)
- What is your gender? (optional)
- Are you transgender? (optional)
- Are you a member of the LGBTQ community? (optional)
- Do you have one or more disabilities? Please specify (optional)
  
- **Patient-Led Organization:**
  - Please enter your Organization's Name/Street address/City/State/Website/Year established.
  - Will your organization be applying with a fiscal sponsor? (Yes/no) If yes:
    - Fiscal Sponsor Organization Name
    - Fiscal Sponsor street address/City/State/Website
    - Fiscal Sponsor Contact Information
      - First name, Last name, Title/Position, Email.
  - Please enter your organization's Employer Identification Number (EIN), as assigned by the Internal Revenue Service in the 9-digit format (XX-XXXXXXX; 10 characters total). If you are a fiscally sponsored organization, please enter the Tax ID of your fiscal sponsor.
  - Please list the name and contact information for the person to discuss press releases and media.
    - First name, Last name, Title/Position, Email.
  - Please indicate the number of employees at your organization, including the Applicant/Patient Leader and then complete the table with the following information for each employee (up to a maximum of 10). **Please include the Applicant/Patient Leader in this section.** You may need to use the scroll bar at the bottom of the table to scroll right to view and to complete all fields. Alternatively, you can tab to move through and complete the fields. For each employee, please enter:
    - Name, Title/Role, Full-time/Part-time, Paid/Unpaid, Years in Role
  - Please share your organization's mission/mission statement (maximum of 75 words).
  - Please mark all regions in which your organization is active. Check all that apply.
    - Local, U.S., North America, South America, Africa, Asia, Europe, Australia
  - Please describe which portions of the disease population your organization represents.
    - All, Pediatric only, Adult only, Other (please specify)
  - Are there other advocacy organizations working directly in the disease area your organization represents? (Yes/No)

- If Yes:
      - Please list the names of other advocacy organizations directly involved in the disease area your organization represents.
      - Please describe how your organization differentiates itself from these other organization(s) (i.e. in terms of mission/structure, involvement in research, services provided, etc.), how your organization contributes to or complements the work and efforts of other organizations, and how your organization ensures that its work is not duplicative (maximum of 150 words).
  - Budget:
    - Please provide your total operating budget for the current fiscal year in U.S. dollars.
    - Please indicate what percentage of your budget is currently allocated to research (including funding research directly, the development of research-enabling infrastructure, etc.).
- **Disease Area Details:** This section should be completed on behalf of the applicant organization's disease area of focus.
  - Please provide the name of your organization's rare disease, disorder, or syndrome, or group of closely related rare diseases, disorders, or syndromes of focus.
  - Please provide a published reference (link to a peer-reviewed paper or website) for your disease area or indicate if no references are available.
  - Please indicate the cause of the disease your organization focuses on. If not known, please mark unknown. Check all that apply:
    - Autoimmune/Autoinflammatory diseases, Cancer, Environmental diseases, Genetic diseases, Infectious diseases, Nutritional diseases, Other (please specify), Unknown
  - Please indicate which organs and/or tissues are affected by the disease your organization focuses on. Check all that apply:
    - Blood, Brain, Connective tissue, Ear/Nose/Throat, Eye, Heart, Intestines, Liver, Kidney, Lung, Pancreas, Skin, Stomach, Other (please specify), Unknown
  - Please indicate which systems are affected by the disease your organization focuses on. Check all that apply:
    - Circulatory system, Digestive system, Endocrine system, Integumentary/Exocrine system, Lymphatic system/Immune system, Metabolic system, Muscular system, Nervous system, Renal/Urinary/Excretory system, Reproductive systems, Respiratory system, Skeletal system, Other (please specify), Unknown
  - Please indicate the sex(es) of those affected by the disease. Check all that apply:
    - Male, Female, Both male and female, Intersex, Unknown

- Please select the age group(s) affected by symptoms of the disease. Check all that apply:
  - Pre-birth, Infancy (Ages 0 to 1), Early childhood (1+ to 5), Middle childhood (6 to 11), Teen (12 to 17), Adult (18 to 65), Elderly (65+), Unknown
- What is the average age of diagnosis of an individual diagnosed with the disease? If this answer is dependent on sub-type, please explain (50 characters).
- What is the average life expectancy (age) of an individual with the disease? If this answer is dependent on sub-type, please explain (50 characters).
  - \_\_\_\_ years, Unknown
- Please indicate, if known, the average length of time that passes between initial symptoms of the disease appearing and before a diagnosis is obtained. If unknown, please mark unknown. If this answer is dependent on sub-type, please explain (50 characters).
  - Less than one year, 1 to 5 years, 5+ to 10 years, 10+ years, Unknown
- Please indicate the typical method(s) of diagnosis of the disease. Check all that apply:
  - Genetic testing, Clinical diagnosis, Imaging, Other (please specify)
- To the best of your knowledge, are the majority of those living with the disease currently diagnosed?
  - Yes.
  - No. If no, please describe what percent of the affected population is believed to be undiagnosed. Are certain groups/subpopulations within the disease area undiagnosed? Does this vary by geography? (maximum of 75 words)
  - If unknown, please mark unknown.
- Please indicate, if known, the approximate number of individuals that have received an accurate diagnosis of the disease. Please indicate if this number refers to the worldwide disease population or U.S. only. If unknown, please mark unknown.
- Please indicate the prevalence of the disease (i.e. the approximate number of people believed to have the disease). Please indicate if this number refers to the worldwide disease population or U.S. only. If unknown, please mark unknown.
- Please indicate the incidence of the disease (i.e. the approximate number of new cases of the disease identified over the course of a year). Please indicate if this number refers to the worldwide disease population or U.S. only. If unknown, please mark unknown.
- Please describe if there are global regions, ethnic, or racial groups in which there are higher than average prevalence/incidence rates (maximum of 75 words).
- Please tell us about the typical experience of patients with the disease, the most common symptoms, any treatment options, the progression of the disease, and how the disease affects quality of life (maximum of 150 words).

- **Short Answer Questions:**

- **Need For A Patient-Led Collaborative Research Network:** The overall goal of the grant is to help organizations develop or build upon a patient-led collaborative research network in their disease area in order to better address diagnostic challenges and advance research towards treatments and cures. In order to help us understand the need for a patient-led research network in your disease area, please answer the following questions:
  - Please describe the current state of the research community in your organization's disease area of focus and why there is a need for the development or expansion of a research network (maximum of 200 words).
  - Please describe the role that your organization currently plays in the research community (maximum of 150 words).
  - How would you describe what a patient-led collaborative research network is (maximum of 100 words)?
  - How does your organization envisage developing/expanding a patient-led research network (maximum of 150 words)?
  - What role do you see the patient voice playing in the research agenda, and how would you work to incorporate it (maximum of 150 words)?
  - How would your organization approach engaging the research community and patients to develop and execute on shared research priorities (maximum of 150 words)?
- **Potential Impact Of A Patient-Led Research Network In Improving Research and Diagnosis:**
  - Please describe the diagnostic challenges in the disease area, including any systemic barriers to diagnosis (i.e. diagnostics not covered by insurance, lack of access to expert centers, etc.) and any scientific barriers (maximum of 200 words).
  - Please describe—to the extent known—current scientific research priorities and areas of focus with regard to diagnosis in the disease area, and how the development of a patient-led collaborative research network could facilitate progress in those areas (maximum of 150 words).
  - Please describe how you think the development/expansion of a patient-led collaborative research network would advance research more broadly and ultimately contribute to improved understanding of the disease and the development of treatments and cures in the disease area your organization represents (maximum of 200 words).
  - Please describe any challenges specifically related to representation or equity that affect research progress in your disease area and how a patient-led collaborative research network could address them (maximum of 150 words).

- **Leadership Strengths:**
  - Please describe your motivation for creating and/or leading this organization (maximum of 200 words).
  - Please describe why you and your team are positioned to lead the development of a research network for your disease area. This could include your ability to recruit others to join your cause, any previous experiences that support your ability to build an organization and develop a research network, the representation of individuals from groups that are underrepresented in your disease area in your leadership team, and the combined motivations and strengths of your team that will be relevant to this work (maximum of 200 words).
- **Commitment to Collaboration:**
  - Please describe the role that you see collaboration playing in strengthening your organization's work (maximum 150 words).
  - Please describe two key collaborations your organization has engaged in and their impact (maximum 200 words).
- **Community Representation:**
  - Please describe how your organization reflects the interests of the patient community and is inclusive of and responsive to the patient community in its governance, outreach, and other organizational activities (maximum of 200 words).
  - Please describe what steps you are taking as an organization to improve your efforts with regard to diversity, equity, and inclusion. This could include efforts to diversify your leadership team, and your current or planned efforts to reach and serve patients, families, and others affected by the disease who identify as members of groups that are underrepresented or marginalized in science (maximum of 200 words).
- **Organization Needs:**
  - Please describe what you see as your organization's greatest challenges and most pressing needs (maximum 200 words).
  - Please describe how participation in this program would help you address those challenges/needs (maximum 200 words).
  - Please describe in what ways you think that your organization would benefit from engagement with the other organizations in the RAO Network (maximum 150 words).

## QUESTIONS?

For administrative and programmatic inquiries pertaining to this RFA, please contact [sciencegrants@chanzuckerberg.com](mailto:sciencegrants@chanzuckerberg.com). For technical assistance with SMaply, please contact [support@smapply.io](mailto:support@smapply.io) or while logged into SMaply, click on the information "i" link in the upper right corner and submit a help request ticket.