

# Chan Zuckerberg Initiative

## REQUEST FOR APPLICATIONS

### Rare As One Network

**The Chan Zuckerberg Initiative invites applications from patient-led, U.S.-based 501(c)(3), advocacy organizations to develop and launch a research network for their rare disease area in partnership with clinicians and scientists.**

#### OPPORTUNITY

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 guidance from patient communities, rare disease experts, and advocacy organizations—we are launching a new program to lift up the work of patient communities. This new program—the Rare As One Project—will enable and scale a model in which patients, researchers, and clinicians work together to advance progress against their diseases.

To kick off this program, CZI is inviting patient-led, U.S.-based 501(c)(3), advocacy organizations to apply for a new, two-year grant opportunity to support the development and launch of a research network for their rare disease area in partnership with clinicians and scientists. Through the Rare As One Network Request for Applications (RFA), CZI will provide up to 10 patient organizations with funding, training, community mentorship, and capacity-building resources, and in turn, ask that they share feedback with and learn from one another, and identify how to best address the most pressing needs across a spectrum of rare diseases.

Each research community will be led by a patient organization in collaboration with researchers and clinicians. The Rare As One Network will initially focus on helping patient groups build a network of researchers, clinicians, and patients working together to align on the state of the science, the open research questions, and research priorities for their rare disease. The creation of shared research priorities will incorporate the needs of key stakeholders and help optimize research funding. Read our [Medium post](#) to learn more.

This grant program will accept Letters of Interest starting at 9 a.m. PDT Tuesday, June 11, 2019 until 5 p.m. PDT on Tuesday, July 23, 2019. After an initial round of review, a select set of organizations will be invited to submit a full application. If awarded, each grant will be up to \$450,000 total over a period of two years.

We acknowledge patient communities as the agents and architects of their own change. We hope that by continuing to connect and partner with the rare disease community, we can provide resources and tools for them to be more effective advocates for, and partners in, research. This initial round of funding is part of the Rare As One program's broader effort to strengthen community, build capacity, and promote collaboration in rare disease. The awarded groups will be a foundational cohort to create the approach, training programs, and tools for future cohorts. Please visit our [website](#) to learn more.

## ELIGIBILITY

### All grantee organizations will be evaluated based on the following criteria:

#### Minimum Criteria:

- The applicant is representing a patient-led organization focused on a rare disease, disorder, or syndrome, or group of closely related rare diseases, disorders, or syndromes.
  - *Defined as a condition affecting fewer than 200,000 people in the U.S.*
- The organization must be 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.
  - *Applicants selected to participate in the final round of review will be asked to submit valid documentation with their proposal by the deadline. This should include a copy of your most recent IRS determination letter—or the IRS letter of your fiscal sponsor—showing the organization's tax-exempt status. If your organization is fiscally sponsored, please also submit the fiscal sponsorship agreement signed between your organization and your fiscal sponsor.*
- As part of this application, the applicant must have assembled a team of at least one researcher and at least one clinician to work together with the patient organization to form a research network. This initial “network leadership team” will help build a larger network of researchers, clinicians, and patients.
  - *Please note that we require the researcher and clinician roles to be filled by two separate individuals (as opposed to a single MD-PhD).*

CZI reserves the sole right to decide if an applicant or applicant organization meet the eligibility requirements.

#### Prioritization Criteria:

- **Need for a Research Network** as demonstrated by insufficient activity within the disease area that is dedicated to the formation of shared research priorities.

- **Leadership and Organizational Focus** that reflect and adequately represent the diversity of the community served.
- **Commitment to Collaboration** as demonstrated by having a track record of joining (or attempting to join) with other groups to increase impact; awareness of existing complementary efforts and organizations and a vision for resolving any redundancy; and a desire to draw on existing community relationships and/or build new ones.
- **Patient Community-Oriented** in connecting with the population affected by the disease and in developing strategies and solutions with input from the community.
- **Potential to Advance Science** in the disease area field through engagement with the research community and creation of a research network.

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

## RFA DETAILS

### Budget

\$450,000 total costs over two years (inclusive of up to 15% indirect/overhead costs).

### Application and Review Process

The review process is a two-step process, including (1) Letter of Interest, followed by (2) Final Application from a select group of invited applicants.

### Key Dates

June 11, 2019:	Application portal opens at 9 a.m. PT to receive Letters of Interest
July 23, 2019:	Letters of Interest due by 5 p.m. PT
Late August 2019:	Earliest notification for invitation to submit full applications
Late September 2019:	Full applications due
November 2019:	Earliest notification of decisions (subject to change)
January 2020:	Earliest start date of award period (subject to change)

Awards will be two years in length with a project start date of no earlier than January 2020. Actual start date may vary, at the discretion of CZI.

## APPLICATION PROCESS

### Application Requirements

The application is a two-step process, starting with a Letter of Interest. Letters of Interest are due Tuesday, July 23, 2019 at 5 p.m. Pacific Time. Letters of Interest will be evaluated, and finalists proceeding to the next stage of review will be notified in August 2019. Invited final applications are due late September 2019.

All applications must be completed and submitted through the Chan Zuckerberg Initiative's [online grants management portal](#). We recommend that you familiarize yourself with this portal well in advance of the submission deadlines. Detailed application instructions are available on the [Chan Zuckerberg Initiative website](#).

## SELECTION PROCESS

The Chan Zuckerberg Initiative adheres to [a set of core values](#) around people, technology, collaboration, and open science in proposal selection and evaluation of progress of our grantees.

Letters of Interest will be evaluated based on the following categories:

- **Understanding of Disease Area**
  - *Does the organization have a baseline understanding of the state of the science of the disease area?*
- **Organization Mission and Structure**
  - *Are patients and the patient voice well represented in the organization's mission and leadership structure?*
- **Organization Reach**
  - *Is the organization established in a way that it is currently able (or will be able) to adequately reach and benefit the patient population affected by the disease?*
- **Network Engagement**
  - *Has the patient organization identified qualified researcher(s) and clinician(s) to support this application?*
- **Demonstrated Need for a Research Network**
  - *Does the disease area lack a coordinated research network or other effort dedicated to the development of shared research priorities?*
- **Expected Impact**
  - *Does the organization make clear how participation in this grant program will advance research and the needs of its rare disease community?*
- **Organization Leadership**
  - *Does the leader of the organization have the ability to attract resources, motivate people, and launch something new?*

The Chan Zuckerberg Initiative reserves the right to not recommend the funding of any applications. CZI does not provide feedback on decisions for unfunded proposals.

### Diversity and Equity

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. We believe the strongest teams incorporate a wide range of voices. Women, underrepresented minorities, and organizational leaders representing disease areas that disproportionately impact underrepresented communities are strongly encouraged to apply.

## 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. A detailed budget is not required at the time of submission of the Letter of Interest, but will be required for invited full applications. Funded organizations will be asked to provide a summary of budget expenditures during annual reporting.
- 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. Funded organizations will be required to participate in regular meetings and events. Key personnel of funded projects are expected to participate in grantee meetings, including annual meetings in the San Francisco Bay Area. Travel support for these 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.
- Facebook employees, including employees of any subsidiary Facebook entities, are not permitted to apply for this grant.
- **Ethical conduct:** CZI advocates the highest ethical standards for the conduct of research and for the professional and personal conduct of grantees. Grantee organizations must adopt appropriate procedures for examination of cases of scientific and personal misconduct, including harassment.
- **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 (PII)) will be considered. If you have specific questions, please contact us at [rareason@chan Zuckerberg.com](mailto:rareason@chan Zuckerberg.com).
- Unused funds may be carried over to the following year and requests for no-cost extensions will be considered.
- Indirect costs cannot exceed 15% of direct costs and must be included within the annual budget total. 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 Foundation or recommended for funding through the Chan Zuckerberg Initiative Donor-Advised Fund (DAF) at the Silicon Valley Community Foundation.
- The Chan Zuckerberg Initiative reserves the sole right to not recommend the funding of any applications.

### **CONFIDENTIALITY**

All submitted applications will be kept confidential, except as necessary for evaluation or to comply with any applicable laws. Application materials will not be returned to applicants.

### **RFA CONTACT**

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

CLOSED

# Chan Zuckerberg Initiative

## APPLICATION INSTRUCTIONS

### Rare As One Network

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 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.
- **Important Dates:** This funding opportunity will open with a Letter of Interest. All dates are subject to change.

#### Key Dates

June 11, 2019:	Application portal open at 9 a.m. PT to receive Letters of Interest
July 23, 2019:	Letters of Interest due by 5 p.m. PT
Late August 2019:	Earliest notification for invitation to submit final applications
Late September 2019:	Final applications due
November 2019:	Earliest notification of decisions (subject to change)
January 2020:	Earliest start date of award period (subject to change)

- **Application specifics:**
  - **Award Period:** Grants will be two years in duration.
  - **Budget:** The maximum budget that can be requested is \$450,000 over two years, inclusive of indirect costs. Indirect costs are limited to 15% of direct costs.

#### 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, decision-making related to grants, and analysis of our grant practices). Chan Zuckerberg Initiative will be the “data controller” 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 applications 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 [rareasone@chanzuckerberg.com](mailto:rareasone@chanzuckerberg.com).

## **SUBMITTING A LETTER OF INTEREST**

**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 program applications that CZI is hosting in SMAApply. To find the program application you are looking for, you may need to scroll down.
4. Find the program application 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, after which you will have access to the application tasks to complete. Project title is limited to 75 characters, including spaces. If you need to **edit your project title**, click on the **My Applications** link in upper right and click the green **Continue** button on the application you wish to edit. Once the application page opens, click on the three dots to the right of the application title (next to the Preview link) and select **Rename** from the dropdown menu.
  - b. The application is made up of several sections called tasks that are listed in a menu on the left side of the page. To **open a task**, click on the one you would like to work on. You can edit and complete tasks in any order. 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. All tasks must be marked as complete before submitting. To **edit a task** marked 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. 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 Review & 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. To **download your application**, click on the download link in the upper right corner. Please be mindful on any pop-up blockers that may be active in your browser that prevent/hide downloads.
  - c. Review your application in the window (or in the PDF that you have downloaded). 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 b.) to review your application before clicking submit.**
  - d. Once you are **ready to submit**, click the green **Submit Your Application** button at the bottom of the 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 [rareasone@chanzuckerberg.com](mailto:rareasone@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 [rareasone@chanzuckerberg.com](mailto:rareasone@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.

**For the purpose of the application, we will use the following terms:**

- **Patient Leader:** The person representing the patient-led organization and taking responsibility for the grant.
- **Organization:** The patient-led organization directly receiving funding.
- **Primary Researcher:** The lead researcher aiming to help develop a research network.
- **Primary Clinician:** The lead clinician aiming to help develop a research network.
- **Letter of Interest:** The first phase of this application, open to all who meet eligibility criteria.
- **Final Application:** The final phase of this application, open to a select group of invited applicants from the Letter of Interest phase.

**The Letter of Interest consists of the following sections (called ‘tasks’ in the grants portal):**

- Eligibility Questionnaire
- Patient Leader Details
- Organization Details
- Disease Area Details
- Primary Researcher Details
- Primary Clinician Details
- Short Answer Questions
- Recommendation from Primary Clinician and Primary Researcher

# SurveyMonkey Apply Letter of Interest and Full Application Contents

## Eligibility Questionnaire

In an effort to ensure your organization meets the eligibility requirements to apply, we have put together the following questionnaire. Once you have completed the questionnaire and confirmed your eligibility, the rest of the Letter of Interest will become available.

- 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.*

Select: Yes or No

- 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?\*

*Please note that organizations must be based in the U.S. Applicants selected to participate in the final round of review will be asked to submit valid documentation with their proposal by the deadline. This should include a copy of your most recent IRS determination letter showing the organization's tax-exempt status, or fiscal sponsorship agreement.*

Select: Yes or No

- As part of this application, have you identified at least one researcher and at least one clinician to work in partnership with your organization to form a research network?\*

*This initial "network leadership team" will set the foundation to build a larger network of researchers, clinicians, and patients. Please note that we require the researcher and clinician roles to be filled by at least two individuals (as opposed to a single MD-PhD).*

Select: Yes or No

If "No" is selected for any question: **Unfortunately, you are not eligible to apply for this grant program. If you think you have received this message in error, please contact us at [rareason@chan Zuckerberg.com](mailto:rareason@chan Zuckerberg.com).**

If you accidentally selected "No" for any question and would like to edit your responses after marking as complete: **At the top of the eligibility questionnaire there are three**

**dots. The eligibility questionnaire will re-open for modifications after you click on the three dots and select “Edit” from the drop down list.**

If “Yes” is selected for all questions: **Based on your answers to these questions, you are eligible to apply for this program and may proceed with your application after marking this section as complete.**

### **Patient Leader**

The Patient Leader (i.e. Executive Director, CEO, or head of organization with authority to sign on behalf of organization) will take responsibility for managing the group collaboration and be the administrative point of contact for CZI.

**Please complete all required fields. Fields in this task are required unless they are specifically noted as optional.**

- First Name\*
- Last Name\*
- Email\*
- Phone (###-###-###)\*
- Title at patient organization\*
- Time in current role (years)\*
  - Please enter a number.
- Are you currently working full-time or part-time at the organization?\*
- Select from drop down: Full time / Part time
- Are you currently paid or unpaid for your work at the organization?\*
- Select from drop down: Paid / Unpaid
- If applicable, please provide the name(s) and title(s) of any other executive patient leaders at your organization who will share responsibility for leading the research network (optional).

### **Organization Details**

This section should be completed on behalf of applicant’s patient-led, 501(c)(3), rare disease-focused advocacy organization.

**Please complete all required fields. Fields in this task are required unless they are specifically noted as optional.**

- Organization Name\*
- Organization Website\*
- Primary Address
  - Address\*, City\*, State\*, Zip\*

- Date established\*
- If applicable, please list the name of your organization's parent or partner organization (optional).\*
- Please indicate approximate percentages of your organization's operating budget for the current fiscal year from the following sources. If some of your operating budget is from other sources, please list the source in the "optional" row(s) and the corresponding percentage. Please enter "0" for any fields that do not apply.\*

Please review the below definitions before completing this task.

**Government support** includes grants made by any branch of the government.

**Foundation support** includes grants from a non-governmental entity that is established as a nonprofit corporation or a charitable trust with a principal purpose of making grants.

**Self-funded contributions** includes funds that are contributed by organizational leaders, including executive staff, directors, founders, or other key advisors.

**Individual contributions** includes funds provided by individual donors via online, mobile, direct mail, or phone donation or through individual fundraisers.

**Corporate support** includes corporate grants, in-kind donations, and matching gifts.

**Individual membership contributions** includes funds provided by members of your community who are asked to pay a monthly or annual fee to engage with your organization.

- Government\* \_\_\_\_\_ %
- Foundations\* \_\_\_\_\_ %
- Self-funded\* \_\_\_\_\_ %
- Individual Contributions\* \_\_\_\_\_ %
- Corporate\* \_\_\_\_\_ %
- Individual Membership\* \_\_\_\_\_ %
- Other (Optional): \_\_\_\_\_ % [enter source] \_\_\_\_\_

- Please provide your total operating budget for the current fiscal year.\* \$ \_\_\_\_\_
- Please indicate what percentage of your budget is currently allocated to research.\*
- Please enter the total number of paid employees (full and part-time) at your organization.\*
- Please list the roles of the paid employees at your organization.\*
- Please provide your organization's mission statement.\*
- Please enter your organization's EIN or your Fiscal Sponsor's EIN.\*
  - 9-digits, format: XX-XXXXXXX.

- Please list the names of other advocacy organizations in your organization's disease area. If there are no other advocacy organizations in your disease area, please indicate this below.\*
- Is your organization fiscally sponsored?
  - Please select  Yes or  No

If applicant selects yes, below questions appear.

- Fiscal Sponsor Organization Name\*
- Fiscal Sponsor Address
  - Address\*, City\*, State\*, Zip\*
- Fiscal Sponsor Organization Website\*
- Fiscal Sponsor Contact Information
  - First Name\*
  - Last Name\*
  - Title\*
  - Email\*
  - Phone (###-###-####)\*

### **Disease Area Details**

This section should be completed on behalf of the applicant organization's disease area of focus.

**Please complete all fields in this task; all fields are required.**

- Please enter 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.\*
  - \_\_\_\_\_
  - No references are available
- Please indicate the cause of your organization's disease/disorder of focus. If not known, please mark unknown. Please check all that are applicable.\*

- Autoimmune / Autoinflammatory diseases
- Cancer
- Environmental diseases
- Genetic diseases
- Infectious diseases
- Nutritional diseases

- Other: \_\_\_\_\_
- Unknown

- Please indicate which organs and/or tissues are affected by your organization's disease/disorder of focus. Please check all that are applicable.\*

- Blood
- Brain
- Connective tissue
- Ear, Nose, Throat
- Eye
- Heart
- Intestines
- Liver
- Kidney
- Lung
- Pancreas
- Skin
- Stomach
- Other: \_\_\_\_\_
- Unknown

- Please indicate which systems are affected by your organization's disease/disorder of focus. Please check all that are applicable.\*

- 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: \_\_\_\_\_
- Unknown

- Does the disease disproportionately affect individuals from specific communities or geographic regions?\*
- If yes, please describe. If no or unknown, please indicate this in your response.

- Please indicate the approximate number of people that are currently affected by the disease worldwide. If unknown, type unknown.\*
- Please indicate the population(s) affected by the disease\*  
Select from a drop down: Male only / Female only / Both male and female / Unknown
- Please select the age group(s) affected by the disease.\*  
Select all that apply from list: Prebirth / Infancy (Ages 0 - 1) / Child (Ages 2 - 17) / Adult (Ages 18 - 64) / Elderly (Age 65+) / Unknown
- Please indicate the typical age of onset of symptoms related to the disease.\*  
Prebirth / Infancy (Ages 0 - 1) / Child (Ages 2 - 17) / Adult (Ages 18 - 64) / Elderly (Age 65+) / Unknown
- Please indicate the typical age at diagnosis.\*  
Prebirth / Infancy (Ages 0 - 1) / Child (Ages 2 - 17) / Adult (Ages 18 - 64) / Elderly (Age 65+) / Unknown
- Please indicate the average life expectancy for those living with the disease (please enter a number and specify months/years) after onset of symptoms or select normal life expectancy or unknown.\*
  - \_\_\_\_\_
  - Normal life expectancy
  - Unknown

### **Primary Researcher Details**

Please note: If multiple researchers are already participating in the initial formation of this network, a primary researcher representing the network should be identified for the purposes of this application (with details filled in below).

**Please complete all required fields. Fields in this task are required unless they are specifically noted as optional.**

- First Name\*
- Last Name\*
- Email\*
- Title\*
- Institution Name\*
- Degree(s)\*
- Research area(s)\*
- Research website (optional)



- Institution Address
  - Address\*, City\*, State\*, Zip\*

### **Primary Clinician Details**

Please note: If multiple clinicians are already participating in the initial formation of this network, a primary clinician representing the network should be identified for the purposes of this application (with details filled in below).

**Please complete all required fields. Fields in this task are required unless they are specifically noted as optional.**

- First Name\*
- Last Name\*
- Email\*
- Title\*
- Institution Name\*
- Degree(s)\*
- Specialty\*
- Disease area(s) of focus\*
- Research website (optional)
- Institution Address\*
  - Address\*, City\*, State\*, Zip\*

### **Short Answer Questions**

Please respond to the short answer questions in this section. Each response is limited to 250 words.

**Please complete all fields in this task; all fields are required.**

#### **Disease Overview\***

Please tell us about the typical experience of patients with the disease, including age of onset (when a patient first experiences symptoms), how the disease is diagnosed (and any context about the “diagnostic path” that patients may experience), the most common symptoms, treatment options, the progression of the disease, and how the disease affects quality of life.

#### **Organization Mission and Structure\***

Please describe your organization’s mission, leadership structure (including staff, boards/committees, volunteers and advisors), and how patients participate in the governance and operations of, and activities carried out by your organization.

#### **Organization Reach\***

Where is your organization active, and how do you ensure that your organization reaches the patient population affected by the disease? What communities do you represent? Is your organization local, national, or international? If applicable to your disease area, what efforts have you undertaken to increase diversity of the communities that you reach?

### **Network Engagement\***

Please describe the expertise and capabilities of the researcher and clinician you have engaged to represent the research network funded by this grant, including why these individuals are appropriate leaders with whom to build a research network.

### **Demonstrated Need for a Research Network\***

We are hoping to learn if there is a need to develop a new research network in your organization's disease area. To the best of your knowledge, please describe the extent of research in your disease area, including any existing activity dedicated to the formation of shared research priorities.

### **Expected Impact\***

Please describe why your organization is focusing on forming a research network. What are your organization's goals for participating in this program?

### **Organization Leadership Experience\***

For patient leader(s): Please describe why you are the right person to lead the development of a research network for your disease area. Your description should highlight your motivation to carry out this work, your ability to recruit others to join your cause, and any previous experiences that support your ability to build an organization that can attract resources.

### **Request a Recommendation from Primary Clinician and Primary Researcher**

#### **Instructions to Applicant**

**Please request a recommendation from both the Primary Researcher and Primary Clinician listed on your application.** Please follow the below steps:

- Click the green **Request a Recommendation** button and a box will appear on the screen. Please enter the contact information for the **Primary Researcher**. After entering the contact details of the Primary Researcher (First name, Last name, Email), click the green **Send Request** button. Please note you **do not** need to enter a message in your request.
- Click the green **Request a Recommendation** button again and a box will appear on the screen. Please enter the contact information for the **Primary Clinician**. After entering the contact details of the Primary Clinician (First name, Last name, Email), click the green **Send Request** button. Please note that you **do not** need to include a message in your request.
- After you have requested a recommendation from both the Primary Researcher and Primary Clinician, please click the green **Mark as Complete** button.

The Primary Researcher and Primary Clinician will receive an automated email with a request to create a SurveyMonkey account to answer the recommendation questions and review the Letter of Interest. They will be asked to check a few simple questions. You may review the recommendation questions that the primary clinician and primary researcher will be required to answer [here](#) or below.

**Please note that while you will be able to submit your Letter of Interest prior to receiving responses from the Primary Researcher and Primary Clinician, both must be received for your Letter of Interest to be considered complete.**

### **Instructions to Primary Researcher and Primary Clinician**

Please confirm the following information:

I am a clinician and/or researcher with expertise in the applicant organization's disease area of focus.\*

Select Yes or No

I recommend the applicant to lead the development of a research network in partnership with other clinicians, researchers, and patients for the organization's disease area of focus.\*

Select Yes or No

I have reviewed the Letter of Interest in full.\*

Select Yes or No

If the applicant organization is selected for a final application, I will be asked to provide further information regarding the collaborative leadership of the research network and the short- and long-term goals of the research network.\*

Select Yes or No