



REQUEST FOR APPLICATIONS

Rare As One Network (Cycle 4)

Biohub invites patient-led rare disease organizations focused on rare respiratory disorders, rare immune dysregulation disorders, and rare sarcomas to apply to join the Rare As One Network. Through three-year grants, selected organizations will strengthen their organizational and scientific capacity; engage their patient communities; expand collaborative research, clinical, and therapeutic-development networks; convene key stakeholders and develop patient-prioritized collaborative research and therapeutic-development agendas; and work across diseases to identify shared priorities and advance collaborative activities, resources, studies, or proposals.

Learn about our Rare As One grantees from [Cycle 1](#), [Cycle 2](#), and [Cycle 3](#), and view the Network's [Cycle 1 Impact Report](#) and [Cycle 2 Impact Report](#).

Opportunity

Overview

Biohub believes that patients and families affected by rare diseases are powerful leaders of research. Through the Rare As One Network, Biohub supports patient-led organizations in building the organizational capacity, scientific expertise, partnerships, and infrastructure needed to advance research in their disease areas. Since its launch in 2018, the Network has grown to include nearly 100 patient-led organizations that are centering patient priorities as they establish collaborative research networks; develop registries, natural history studies, biobanks, disease models, and other essential resources; build centers of excellence; and support - and in some cases, even sponsor - their own clinical trials. Together, they are transforming historically disparate and fragmented communities into coordinated research fields capable of accelerating progress toward diagnoses, treatments, and cures.

The first two cycles of Rare As One brought together organizations working across many different rare diseases. Cycle 3 introduced a cohort model, organizing participating organizations into ciliopathy, channelopathy, and inborn-errors-of-metabolism cohorts so they could strengthen their individual disease fields while also working on scientific questions and barriers shared across related diseases. Cycle 4 will build on this approach through three additional disease-focused cohorts:

- Rare respiratory disorders
- Rare immune dysregulation disorders
- Rare sarcomas

These areas encompass many distinct diseases, but organizations within each cohort may share relevant biology, research needs, infrastructure gaps, translational barriers, or therapeutic opportunities. Bringing them together can allow communities to learn from one another, develop common approaches, and pursue work that would be difficult for any single rare disease organization to undertake alone.

Through this RFA, Biohub will provide support for patient-led organizations to receive grants of \$600,000 total costs over three years and join the Rare As One Network.

Each selected organization will pursue seven common grant objectives:

1. Build the organization's organizational and scientific capacity to lead and sustain research in its disease area.
2. Engage the patient community and incorporate patient perspectives into research activities, including the identification of research priorities, meaningful outcomes, acceptable risks, and unmet needs.
3. Develop or expand a collaborative research network that includes researchers working in the disease and related fields, clinicians, academic and industry therapeutic developers, and other partners needed to advance the field.
4. Convene patients, researchers, clinicians, industry, and other relevant stakeholders, typically in Year 2 or 3 and after completing appropriate community-engagement activities.
5. Develop or update a patient-prioritized collaborative research and therapeutic development agenda informed by community priorities and perspectives gathered through the organization's community engagement and convening activities.
6. Participate actively in the relevant disease cohort and broader Rare As One Network and contribute, as appropriate, to the cohort's identification and advancement of at least one shared activity, project, resource, or collaborative proposal that can advance multiple diseases, address shared barriers, or unlock cross-disease opportunities.
7. Advance therapeutic development by identifying and assessing promising therapeutic opportunities - including opportunities to repurpose existing drugs - addressing stage-appropriate scientific and translational gaps, and building the evidence, tools, capabilities, and partnerships needed to move potential therapies toward patients.

Biohub will provide flexible grant funding, organizational and scientific trainings and capacity-building support and opportunities for peer learning and collaboration. Support may address areas such as leadership, staffing, governance, fundraising, finance and operations, community engagement, research strategy, data and biospecimen stewardship, biomarkers and endpoints, regulatory considerations, clinical-trial readiness, and therapeutic development. Organizations will complete an organizational maturity assessment at the beginning of the grant period and participate in training selected to address their areas of greatest need or potential for growth.

Cycle 4 will place a strong emphasis on building organizations' capacity to identify, assess, and pursue pathways from research to therapeutic development. Applicants are not required to have an existing therapeutic program or mature scientific infrastructure. The program is intended to

support organizations at different stages - from those building foundational research capabilities to those preparing to assess or advance specific diagnostic or therapeutic opportunities. Each grantee will allocate grant funds across four areas: organizational and scientific capacity building; a multi-stakeholder convening; approved scientific and translational activities, tools, and infrastructure that advance research and therapeutic development; and patient and research community engagement or other approved purposes. Specific activities and allocations within these areas will vary according to the organization's stage and priorities and will be governed by the applicable allocation parameters and approved grant budget.

Cohort and Network participation are central components of this opportunity. Selected organizations will participate in regular calls, training, peer-learning activities, working groups, and convenings. They will be expected to share their experiences and approaches, learn from other patient-led organizations, and contribute to identifying common priorities and developing shared activities. During Year 1, each cohort will map shared priorities, existing assets, gaps, and opportunities and define at least one shared activity or project to advance during the grant period. Examples could include developing common data or biospecimen standards, connecting existing datasets, biobanks, or disease models, pursuing a comparative study across diseases, developing a shared tool or resource, or preparing a collaborative proposal for external funding. Individual organizations will not be expected to participate in every activity but will be expected to contribute to shared work where appropriate. The grants are intended in part to provide organizations with the staffing and operational capacity needed to participate meaningfully in this work.

Where patient-community priorities, scientific opportunities, and available capabilities align, participation may also create opportunities to explore relationships with Biohub scientists or external research and therapeutic-development partners.

Application Specifics

Detailed application instructions are provided in the [section below](#). All applications must be completed and submitted through our online grants management portal (<https://apply.chanzuckerberg.com>).

Key Dates

October 29, 2026	Application portal opens
December 15, 2026	Applications due by 2:00 p.m. Pacific Time
April 2027	Earliest notification of decisions (subject to change)
May 1, 2027	Expected start date (subject to change)

Award period and start date: Awards will be three years in duration, with an expected start date of May 1, 2027.

Budget: Awards will provide **\$600,000 in total costs over three years** (inclusive of up to 15% indirect costs), \$200,000 total costs per year. Indirect costs may not exceed 15% of direct costs.

Continued annual funding will be subject to satisfactory progress toward the approved grant objectives and milestones; spending consistent with the approved budget; timely completion of reporting and annual review requirements; completion of the organizational maturity assessment and following that, completion of at least two trainings addressing areas of greatest need; participation in at least 50% of required Network-wide and subcohort calls during each grant year; participation by the grant lead and at least one board member in the required annual review and designated board calls; responsible stewardship of data and biospecimens, where applicable; and compliance with all other grant terms and applicable legal, financial, privacy, consent, regulatory, and institutional requirements.

Use of grant funds

Grant funds may be used to support the following areas:

1. Organizational and scientific capacity building;
2. A multistakeholder convening;
3. Approved scientific and translational activities, tools, and infrastructure that advance research and therapeutic development; and
4. Meaningful engagement of affected patient and research communities and other approved activities that advance the grant objectives.

Applicants will be required to submit a high-level three-year budget. Based on experience from prior Rare As One cohorts, Biohub generally expects budgets to reflect the distribution below.

Additional guidance is listed in the [Detailed Application Instructions](#)

- **Approximately 30–40%** for organizational and scientific capacity building.
- **Approximately 10–20%** for planning and holding a multistakeholder convening.
- **Up to approximately 40%** for approved scientific and translational activities, tools, and infrastructure that advance research and therapeutic development.
- **Generally up to 20%** for meaningful engagement of patient and research communities or other approved activities that advance the grant objectives.

These ranges are intended to promote balanced investment across the grant objectives, not to prescribe an identical budget for every organization. Applicants may propose a different distribution when justified by their stage, existing capacity and infrastructure, community priorities, or proposed activities and should briefly explain any material variation. All expenditures will remain subject to the approved grant budget, charitable-purpose requirements, and any applicable legal, privacy, consent, regulatory, and institutional approvals. Biohub may work with finalists to clarify or revise proposed budgets before making final funding recommendations.

Eligibility

To be eligible to apply, an organization must meet all of the following requirements:

- **Represent an eligible rare disease and area of focus:** Focus on a rare disease, condition, or syndrome—or a group of closely related rare diseases—that affects fewer

than 200,000 people in the United States, consistent with the federal definition of a rare disease, **and** falls within one of the following areas:

- **Rare respiratory disorders:** Rare diseases in which dysfunction of the lungs, airways, pulmonary vasculature, respiratory muscles, or other components of the respiratory system is a defining feature or a major driver of morbidity, mortality, diagnosis, monitoring, or therapeutic development. Multisystem diseases may be eligible when respiratory involvement is central to the affected community's unmet needs and research priorities; diseases in which respiratory symptoms are only incidental or an uncommon secondary complication will not generally be eligible.
- **Rare immune dysregulation disorders:** Rare diseases in which disrupted immune recognition, signaling or regulation is a defining feature or a major driver of morbidity, mortality, diagnosis, monitoring or therapeutic development. These include monogenic immune dysregulation and autoimmunity, autoinflammatory diseases and interferonopathies, rare acquired autoimmune diseases, and immunodeficiencies with related defects in immune recognition, signaling or regulation. Multisystem diseases may be eligible when immune dysregulation is central to the affected community's unmet needs and research priorities; diseases in which immune involvement is incidental or an uncommon secondary complication will not generally be eligible.
- **Rare sarcomas:** Rare malignant tumors that arise in bone or soft or connective tissues, including muscle, fat, cartilage, blood vessels, nerves, fibrous tissue, and other supporting tissues. The cohort will include sarcomas affecting patients of all ages, with an emphasis on subtypes that arise primarily in children and adolescents and rare pediatric presentations of subtypes more commonly diagnosed in adults. Eligible sarcomas may arise at any anatomical site and may be defined by their histologic, clinical, or molecular features. They may include sarcomas driven by oncogenic gene fusions, recurrent mutations, gene amplification or loss, epigenetic alterations, or complex genomic changes, as well as sarcomas for which no recurrent molecular driver has been identified. Cancers that originate outside bone or soft or connective tissue are not eligible solely because they carry an oncogenic fusion or have metastasized to bone or soft tissue.
- **Be a nonprofit organization:** Be recognized by the Internal Revenue Service as a tax-exempt organization under Section 501(c)(3) of the Internal Revenue Code or, for organizations based outside the United States, hold an equivalent nonprofit or charitable status. The organization must maintain this status throughout the grant period. Grants will be awarded to eligible organizations, not to individuals.
- **Be patient-, parent-, or family-led:** Patients, parents, family members, or others directly affected by the disease must hold meaningful leadership and decision-making authority through the organization's executive leadership, governing board, and/or core leadership team. Organizations may also include leaders without lived experience who bring expertise needed to strengthen and advance the organization.
- **Serve a broader affected community and advance research:** Work on behalf of a broader community of people affected by the disease and demonstrate a commitment to

advancing research toward improved understanding, diagnosis, care, treatments, or cures for that community.

- **Have an annual budget of less than \$10 million USD** averaged over a two year period.
- Meta employees, including employees of any subsidiary Meta entities, as well as employees of Chan Zuckerberg Initiative, LLC and Biohub, are not permitted to apply.
- Biohub reserves the sole right to decide if an applicant and applicant organization meet the eligibility requirements, and reserves the right to request budget changes prior to award.
- Biohub welcomes applications from any country, provided the proposed work is compliant with the U.S. Treasury Department's Office of Foreign Asset Control (OFAC) sanctions program. Prior to award, all applications will be reviewed for compliance with the OFAC sanctions program, the U.S. Department of Commerce's export administration regulations, the Foreign Corrupt Practices Act (FCPA), any other applicable U.S. laws and regulations, and any corresponding laws and regulations in the country where the applicant is based. All grant agreements will require the grantee to comply with these laws and regulations. For additional information, please refer to the [U.S. Treasury Department's resources](#), the International Trade Administration's [website on U.S. Export Controls](#), and the Department of Justice's [website on the FCPA](#).
- While applicants from all countries are welcome to apply, because of required ongoing compliance with U.S. sanctions and export controls, an applicant's funding eligibility may need to be reassessed if the applicable laws and regulations change at any time. Even if an applicant is eligible to receive funding at the time the application is reviewed, the applicant's status may change later in the process or during the grant term.

Prior-funding and applicant exclusions

- Organizations that have previously received funding through the following multi-year CZI/Biohub Science grant programs are **not** eligible to apply:
 - Rare As One Network Cycle 1
 - Rare As One Network Cycle 2
 - Organizations that received only a [one-time Cycle 2 award of \\$50,000](#) remain eligible to apply.
 - Rare As One Network Cycle 3
- Organizations that were funded through the following programs are eligible to apply if they meet the other eligibility criteria:
 - Patient-Partnered Collaborations for Single-Cell Analysis of Rare Inflammatory Pediatric Disease
 - Patient-Partnered Collaborations for Rare Neurodegenerative Disease

For questions about eligibility for this award or the application process, please contact us in advance of the proposal deadline at sciencegrants@chanzuckerberg.com.

Selection Process and Evaluation Criteria

Biohub will use a multistage review process to identify organizations that demonstrate strong potential to benefit from the opportunity, achieve the grant objectives, participate meaningfully in

the Rare As One Network, and contribute to a collaborative subcohort. Review will be based on the required short-answer responses, proposed budget, and other requested application materials. Applicants and disease fields are not expected to have mature capabilities or infrastructure in every area. Selection will balance readiness and need: competitive applicants should demonstrate sufficient leadership, capacity, and momentum to use the grant effectively while identifying gaps that flexible funding, training, advising, and Network support can realistically address.

Unsolicited attachments, supplemental materials, and letters of support will not be considered. Existing or potential relationships with Biohub, perceived alignment with a particular Biohub scientist or project, and access to specific data, biospecimens, or other research assets will not confer an advantage.

Applications will be assessed using the following criteria:

- **Patient-led governance and community accountability:** Meaningful leadership by patients, family members, and others directly affected by the disease, together with clear accountability to the broader affected community. The review will assess whether people with lived experience hold meaningful authority over the organization's strategy, priorities, and decisions and whether its direction reflects the community's needs, rather than solely the interests of an individual or family. As organizations mature, they may—and generally are expected to—include non-affected leaders who bring relevant professional, scientific, operational, or other expertise, while maintaining meaningful decision-making authority for people with lived experience.
- **Organizational and scientific leadership capacity:** A strong and credible organizational and research leadership team with the judgment, relevant experience, available capacity, and commitment needed to lead the disease field, achieve the grant objectives, use flexible multi-year support effectively, manage the award responsibly, and engage the organization's board.
- **Ongoing community engagement and patient-centered research:** A demonstrated commitment and credible approach to engaging a meaningful and representative portion of the affected community throughout the grant period. The review will consider how the organization currently listens to and communicates with its broader community and how patients will help identify unmet needs, meaningful outcomes, acceptable risks, and research priorities; shape research activities; and receive information about progress and results. The organization should also demonstrate how community priorities will inform its multistakeholder convening and patient-prioritized collaborative research and therapeutic development agenda.
- **Readiness, need, and potential for growth:** A balanced combination of existing organizational and scientific strengths that position the organization to make progress and clearly identified capacity gaps that Rare As One funding, required training, tailored advising, and Network support can realistically help fill. The review will consider the organization's vision for growth; its capacity-building priorities; and whether its proposed activities, investments, and budget align with its identified needs and goals.
- **Disease-field and therapeutic-development network:** The ability or potential to build or expand a collaborative network that includes researchers, clinicians, academic

therapeutic developers, biotechnology and pharmaceutical companies, and other partners needed to advance the field. The review will consider the strength and gaps of the organization's relationships within its disease area and across related diseases and disease classes, and the potential for this network to align around patient-prioritized research, develop needed infrastructure, and advance therapeutic opportunities.

- **Disease-specific scientific and translational opportunity:** Significant unmet need and a credible opportunity to advance the applicant's own disease field. The review will consider the field's current stage and most important gaps; opportunities to improve data, biospecimens, models, diagnosis, patient stratification, biomarkers, outcome measures, endpoints, trial readiness, therapeutic development, or other research infrastructure; and how grant support could enable meaningful progress toward patient-prioritized scientific and therapeutic goals. Indicators of readiness may include an engaged scientific advisory board, research agenda or roadmap, registry, natural history study, biobank, disease models, research partnerships, or therapeutic programs. These assets are not all required if the applicant demonstrates a credible plan and the potential to develop them through the grant.
- **Network participation and peer learning:** A willingness and demonstrated capacity to make participation in the Rare As One Network a meaningful part of the grant by engaging consistently in calls, convenings, working groups, training, and peer-learning activities. The review will consider whether the organization is prepared both to learn from other organizations and to share its challenges, approaches, experience, and resources, including its capacity and willingness to meet the required attendance threshold.
- **Subcohort fit, contribution, and cross-disease potential:** The review will consider the perspectives, community knowledge, disease-specific experience, research and clinical relationships, practical lessons, and other strengths the organization could contribute. Where relevant, reviewers may also consider existing data, biospecimens, models, tools, or research infrastructure that could inform shared work. Reviewers will assess the cohort activities that interest the applicant, its complementarity with other strong applicants, and the potential for the resulting subcohort to pursue shared priorities or joint projects that advance multiple diseases, address common barriers, or unlock opportunities involving common standards, comparative studies, shared infrastructure, therapeutic development, or basket trials.
- **Responsible stewardship:** A commitment to responsible data and biospecimen practices, where applicable, including appropriate consent, privacy, representation, provenance, governance, access, and return of value to participating communities.

Final funding decisions will reflect both the assessment of individual applicants and the goal of building strong, complementary, and collaborative subcohorts. All funding decisions are at Biohub's discretion.

Policies

Please see our policies listed in the [Institutional Approval Form](#), which must be reviewed and signed as part of the application process.

- **Use of funds and approved scope:** Grant funds must be used for the charitable purposes, objectives, activities, and budget approved by Biohub.
- **Budget management:** Grantees must monitor spending against the approved budget and required allocation framework throughout the grant period. Material changes to the approved budget, activities, or allocation of funds will require advance written approval from Biohub.
- **Reporting and continued funding:** Financial statements and progress reports will be required annually. Specific reporting requirements and deliverables will be described in the award agreement. Continued annual funding will be subject to satisfactory progress toward approved objectives and milestones; spending consistent with the approved budget and required allocations; completion of required reporting, assessments, training, annual reviews, and board participation; participation in at least 50% of required Network-wide and subcohort calls during each grant year; active participation in Network and subcohort activities; and compliance with all other grant terms.
- **Carryover, extensions, and changes in scope:** Unused grant funds may be carried over to the following grant year. Requests for no-cost extensions will be considered at the end of the overall grant period upon receipt and review of the required annual report. Changes in organizational control or leadership and material changes to the approved work or budget may require prior written approval from Biohub.
- **Data Access:** Any data, biospecimens, and research assets curated or generated using Biohub grant funding must be made publicly available under an open license (preferably CC0 or CC BY/CC BY-SA), with controlled access allowed only for data that needs protection under privacy rules such as HIPAA and HITECH.

Use of Generative Artificial Intelligence (AI) Tools

We support the use of generative artificial intelligence (AI) tools to facilitate the drafting and preparation of grant proposals and to support grant reviews in ways that ensure the integrity and confidentiality of the grantmaking process, protect user privacy, and preserve the individual accountability and responsibility of each applicant and reviewer. Please read our [full guidelines](#) on AI for grant applicants.

Confidentiality

Generally, Biohub will treat submitted applications and related materials as confidential (and will use such materials solely for the purposes of administering and evaluating applications, managing awards, and other related operational and compliance activities). Access to application materials will be limited to Biohub personnel, affiliated entities, external reviewers, advisors, and service providers who have a need-to-know basis for these purposes and who are subject to confidentiality obligations. Biohub may disclose application materials: (i) as required by applicable law, regulation, legal process, or governmental request; or (ii) to enforce Biohub's legal rights. Biohub may publish or otherwise disclose non-confidential, high-level information about applications (e.g., project titles, abstracts, general areas of research, and aggregate statistics). For applications selected for funding, Biohub may publicly share summaries of funded projects and outcomes. Application materials will not be returned.

Personal Data

As part of the application process, you may provide personal data (e.g., names, contact details, professional information, and biographical information). You should only provide personal data that is necessary for the application and that you are authorized to share. We will use and store such personal data for grant-related purposes (e.g., administering and evaluating applications; managing grants and related communications; compliance, legal, and reporting obligations; and improving grantmaking processes in a de-identified or aggregated manner where feasible). The Chan Zuckerberg Initiative Foundation, Chan Zuckerberg Initiative, LLC (collectively “CZI”) and Chan Zuckerberg Biohub, Inc. will act as independent or joint controllers, as applicable, for personal data processed in connection with your application. Such data may be transferred to and/or processed in countries other than your country of residence, including the United States. Where required, appropriate safeguards will be used to protect such transfers. Personal data may be shared with reviewers, advisors, collaborators, service providers, authorities, or other third parties where required by law. Personal data will be retained only for as long as necessary to fulfill the purposes described above, including for recordkeeping, reporting, and legal compliance. If you have any questions or concerns regarding our privacy practices, the collection or use of personal data, or data subject requests (e.g., to access, correct, delete, or restrict the use of your personal data), you may contact us at privacy@chanzuckerberg.com.

Detailed Application Instructions

All applications must be submitted through this portal: <https://apply.chanzuckerberg.com>.

Deadline extensions will not be granted.

To complete and submit an application:

1. Go to <https://apply.chanzuckerberg.com>.
2. Register and/or log in.
3. Click on the **Programs** link in the upper right corner.
4. Find the **Rare As One Network (Cycle 4) RFA** and click **More**.
5. Click the green **Apply** button in the upper right corner.
6. Enter the title of your application. The project title is limited to 60 characters, including spaces.
7. Complete the sections below and **submit them no later than 2:00 p.m. Pacific Time on December 15, 2027**.

Applicants are encouraged to create or verify their accounts and complete the eligibility questionnaire well before the application deadline. The remainder of the application will become available only after the organization confirms that it meets the eligibility requirements. The application should be submitted by the proposed Patient Organization Lead, who must be affiliated with the applicant organization and will serve as the administrative contact. Grant funds will be awarded to the eligible organization, not to an individual.

The application consists of the following sections (called tasks in the grant portal): Eligibility, Patient Organization Lead, Patient-Led Organization, Proposed Grant Budget,

Disease Area Detail, Existing Research Resources and Infrastructure, and Short Answer Questions.

Eligibility: To confirm that your organization meets the eligibility requirements, the eligibility questionnaire must be completed first. Once you have completed the questionnaire and confirmed your eligibility, the remainder of the application will become available. **We strongly recommend completing the eligibility questionnaire well before the submission deadline. No deadline extensions will be granted.**

○ **Eligibility Questions (Yes/No):**

- Do patients, parents, family members, or others directly affected by the disease hold meaningful leadership and decision-making authority through the organization's executive leadership, governing board, and/or core leadership team?
- Does your organization work on behalf of a broader community of people affected by the disease and demonstrate a commitment to advancing research toward improved understanding, diagnosis, care, treatments, or cures for that community?
- Is your organization focused on a rare disease, condition, or syndrome - or a group of closely related rare diseases - that affects fewer than 200,000 people in the United States, consistent with the federal definition of a rare disease?
- Does your organization represent a disease that falls within one of the following three Cycle 4 areas?
 - **Rare respiratory disorders:** Rare diseases in which dysfunction of the lungs, airways, pulmonary vasculature, respiratory muscles, or other components of the respiratory system is a defining feature or a major driver of morbidity, mortality, diagnosis, monitoring, or therapeutic development. Multisystem diseases may be eligible when respiratory involvement is central to the affected community's unmet needs and research priorities; diseases in which respiratory symptoms are only incidental or an uncommon secondary complication will not generally be eligible.
 - **Rare immune dysregulation disorders:** Rare diseases in which disrupted immune recognition, signaling or regulation is a defining feature or a major driver of morbidity, mortality, diagnosis, monitoring or therapeutic development. These include monogenic immune dysregulation and autoimmunity, autoinflammatory diseases and interferonopathies, rare acquired autoimmune diseases, and immunodeficiencies with related defects in immune recognition, signaling or regulation. Multisystem diseases may be eligible when immune dysregulation is central to the affected community's unmet needs and research priorities; diseases in which immune involvement is incidental or an uncommon secondary complication will not generally be eligible.
 - **Rare sarcomas:** Rare malignant tumors that arise in bone or soft or connective tissues, including muscle, fat, cartilage, blood vessels, nerves,

fibrous tissue, and other supporting tissues. The cohort will include sarcomas affecting patients of all ages, with an emphasis on subtypes that arise primarily in children and adolescents and rare pediatric presentations of subtypes more commonly diagnosed in adults. Eligible sarcomas may arise at any anatomical site and may be defined by their histologic, clinical, or molecular features. They may include sarcomas driven by oncogenic gene fusions, recurrent mutations, gene amplification or loss, epigenetic alterations, or complex genomic changes, as well as sarcomas for which no recurrent molecular driver has been identified. Cancers that originate outside bone or soft or connective tissue are not eligible solely because they carry an oncogenic fusion or have metastasized to bone or soft tissue.

- 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? For non-U.S. organizations, is your organization considered a nonprofit/charitable patient-led rare disease organization (equivalent to a U.S.-based 501(c)(3))?
- Does your organization have an annual budget of less than \$10 million USD averaged over a two-year period?
- Does your organization acknowledge that any data, biospecimens, and research assets generated or curated using Biohub grant funding must adhere to Biohub's Data Access policy as stated in the grant agreement (see the [Institutional Approval Form](#))?
- Has your organization previously received funding through any of the following multi-year CZI/Biohub Science grant programs?
 - Rare As One Network Cycle 1
 - Rare As One Network Cycle 2
 - Organizations that received only a one-time Cycle 2 award of \$50,000 remain eligible.
 - Rare As One Network Cycle 3

Patient Organization Lead: the information entered in this section should relate to the proposed Patient Organization Lead—for example, the Executive Director, CEO, or head of the organization—who will take primary responsibility for the grant.

- Name and email, automatically populated. To edit this information, click your name in the upper-right corner and select **My Account**.
- Organization.
- Title or position: CEO/Executive Director, Board Member, Science Officer/Scientific Director, or Other (please specify).
- Paid or unpaid position.
- Connection to the disease area: Patient, Parent of Patient, Caregiver, Relative of an Affected Person, No Personal Connection to the Disease Area, or Other. Applicants selecting **Other** should provide additional information.
- Upload a PDF of the Patient Organization Lead's resume.

- If another member of the organization will serve as the administrative contact—including reviewing and responding to Biohub communications, distributing information within the organization, or preparing and submitting grant reports—provide that person’s name, title, and email. This field is optional.

Patient-Led Organization

- Enter the organization’s name/Street address/City/State/Country/Website/Year established.
- Will the organization be applying with a fiscal sponsor? (Yes/No) If yes, provide:
 - Fiscal Sponsor Organization Name
 - Fiscal Sponsor Street address/City/State/Country/Website
 - Fiscal Sponsor Contact Information
 - First name, Last name, Title/Position, Email
- Enter the organization’s Employer Identification Number (EIN), as assigned by the Internal Revenue Service in the 9-digit format (XX-XXXXXXX; 10 characters total). If there will be a fiscally sponsored organization, please enter the EIN of the fiscal sponsor. Foreign organizations or others who do not have an EIN should enter 44-4444444.
- List the name and contact information for the person to discuss press releases and media.
 - First name, Last name, Title/Position, Email
- Indicate the number of employees at the organization, including the Patient Organization Lead.
- Complete the table with the following information for each employee (up to a maximum of 10). **Please include the Patient Organization Lead and Administrative Contact (if different) in this section.** You may need to use the scroll bar at the bottom of the table to scroll right to view and 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
- Share the organization’s mission or mission statement (maximum of 75 words).
- Mark all regions in which the organization provides support/engages in activities. Check all that apply.
 - Local, U.S., North America, South America, Africa, Asia, Europe, Australia
- Describe which portions of the affected population the organization represents:
 - All ages, Pediatric only, Adult only, Other (please specify)
- Are other patient organizations working directly in the same disease area? (Yes/No)
 - If Yes:
 - List the names of other patient organizations directly involved in the disease area your organization represents.
 - Describe how your organization differentiates itself from and/or collaborates with 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).

- Other than the grant programs addressed in the eligibility questionnaire, has the organization previously received funding or financial support from CZI or Biohub? (Yes/No)
 - If Yes, provide the program name, amount, award period, and purpose.
- Organization Financial Information: provide the following information as a singular PDF upload. If the organization receiving the funds is a fiscal sponsor, please provide items 1-4 for both the patient-led organization and the fiscal sponsor.
 - 1) Audited Financial Statements (if available): include the most recent fiscal year; if audited financials are not available, provide the unaudited version
 - 2) Organization Operating Budget - include:
 - a. Current Fiscal Year Organization Budget (required); and
 - b. Forecasted Organization Budget which covers the duration of the potential grant (only if available)
 - 3) Organization Size (required): provide the number of full-time employees employed by your organization, as of the current date
 - 4) Project list of funders (required): High-level only, total funding, confirmed vs. unconfirmed for the specific project for all years of the grant
- Budget % allocated to research: Indicate the percentage of the organization's current budget allocated to research-related activities, including direct research funding, development of research-enabling infrastructure, and scientific convenings.
- [Institutional Approval Form](#): upload as a single PDF. This form should be reviewed and signed by a person authorized to sign on behalf of your organization. **These policies are non-negotiable, so this form should be signed only if the organization can comply with the stated terms.**

Proposed Grant Budget: Upload a one-page, high-level draft budget in PDF format showing \$600,000 USD in total costs over three years (\$200,000 per year), inclusive of any indirect costs.

- For each budget category, show the proposed amount by grant year, three-year total, percentage of the total grant, and a brief description of the planned expense.
- The budget should align with the needs, priorities, proposed investments, and uses of grant support described in the short-answer responses. It will be evaluated alongside those responses for consistency.
- The budget should generally reflect the following framework. These ranges are guidance rather than absolute requirements. Applicants may propose a different distribution based on their stage, needs, priorities, proposed work, and existing infrastructure but should briefly explain any material variation. Every budget must support the required convening and meaningful engagement of the affected community throughout the grant period.
 - **Approximately 30% to 40% — organizational and scientific capacity building:** Funds may support staff, consultants, training, technology, systems, and tools that strengthen the organization's capabilities. Examples include executive or scientific leadership; fundraising capacity; board development and governance; finance and operations; communications and community engagement; research strategy and scientific advising; project management;

partnership development; and organizational capabilities related to data, biospecimens, regulatory strategy, intellectual property, clinical research, or therapeutic development.

- **Approximately 10% to 20% — multistakeholder convening:** Funds may support planning and holding the required convening of patients, researchers, clinicians, biotechnology and pharmaceutical companies, academic therapeutic developers, and other relevant partners. Allowable expenses may include meeting planning and facilitation; venue and audiovisual costs; participant travel and lodging; accessibility accommodations; interpretation; support for patient and caregiver participation; development of meeting materials; and documentation and dissemination of outcomes. The convening should inform or advance a shared, patient-prioritized collaborative research and therapeutic development agenda and help identify the data, biospecimen, model, clinical, and other infrastructure needed to pursue it.
- **Up to 40% — approved scientific and translational activities, tools, and infrastructure:** Funds may support scientific and translational activities and the planning, development, improvement, harmonization, or responsible sharing of research resources that advance research and therapeutic development. Examples include registries; natural history studies; data generation, curation, or harmonization; biobanks and biospecimen strategies; animal models; patient-derived cell lines; iPSCs; organoids; assays; biomarkers; outcome measures; endpoints; trial-readiness tools; respiratory-disease models and delivery-relevant tools; longitudinal immune data, immunophenotyping, and biospecimen resources; and sarcoma tissue, models, and clinical or molecular datasets, including fusion-annotated resources where relevant. These investments should be designed to benefit multiple researchers, institutions, or related disease communities whenever feasible.
- **Any remaining funds, generally up to 20% — community engagement and other approved grant activities:** Funds may support surveys, focus groups, listening sessions, patient or caregiver advisory groups, accessible communications, dissemination of research progress and results, participation in Rare As One Network activities, and other approved expenses that advance the grant objectives. Every budget must include an identifiable investment in meaningful engagement of the affected community throughout the grant period.
- The proposed allocations must total 100% of the requested grant amount. Each expense may be assigned to only one budget category. The suggested percentage ranges apply to the total grant amount, including indirect costs, and indirect costs should not be treated as a separate fifth category. Spending may vary across grant years; for example, capacity-building activities may be concentrated in Year 1 and the convening may occur in Year 2 or 3.
- Grant funds may not be used to: provide clinical care or pay for patient treatment; directly fund clinical trials, interventional research, or drug or therapeutic manufacturing; support a stand-alone therapeutic-development program outside the approved grant scope; pay for activities or expenses already funded by another source; engage in

prohibited lobbying, political-campaign activity, or commercial activity; or support costs that are inconsistent with the approved charitable purposes, activities, or budget.

- Indirect costs are limited to 15% of direct costs. Indirect costs may not be assessed on capital equipment or subcontracts, although subcontractors may include indirect costs of up to 15% of their own direct costs.
- International grantees must use grant funds exclusively for activities conducted outside the United States.

Disease Area Detail

- **Disease or disease group**
 - Provide the name of the rare disease, condition, syndrome, cancer, or group of closely related diseases that your organization represents. Write out all acronyms at first use. If your organization represents more than three closely related diseases, please name them and briefly explain what makes the diseases a coherent group for the purposes of your organization's work (maximum of 100 words).
 - If the disease is included in a recognized rare-disease ontology or database—such as [GARD](#), [Orphanet](#), or [Mondo](#)—provide the relevant link.
- **Cycle 4 Subcohort**
 - Select the **one primary Cycle 4 subcohort** to which your organization is applying:
 - **Rare respiratory disorders:** Rare diseases in which dysfunction of the lungs, airways, pulmonary circulation, respiratory muscles, or other components of the respiratory system is a defining feature or a major driver of morbidity, mortality, diagnosis, monitoring, or therapeutic development. Multisystem diseases may be eligible when respiratory involvement is central to the affected community's unmet needs and research priorities; diseases in which respiratory symptoms are only incidental or an uncommon secondary complication will not generally be eligible.
 - **Rare immune dysregulation disorders:** Rare diseases in which disrupted immune recognition, signaling or regulation is a defining feature or a major driver of morbidity, mortality, diagnosis, monitoring or therapeutic development. These include monogenic immune dysregulation and autoimmunity, autoinflammatory diseases and interferonopathies, rare acquired autoimmune diseases, and immunodeficiencies with related defects in immune recognition, signaling or regulation. Multisystem diseases may be eligible when immune dysregulation is central to the affected community's unmet needs and research priorities; diseases in which immune involvement is incidental or an uncommon secondary complication will not generally be eligible.
 - **Rare sarcomas:** Rare malignant tumors that arise in bone or soft or connective tissues, including muscle, fat, cartilage, blood vessels, nerves, fibrous tissue, and other supporting tissues. The cohort will include sarcomas affecting patients of all ages, with an emphasis on subtypes

that arise primarily in children and adolescents and rare pediatric presentations of subtypes more commonly diagnosed in adults. Eligible sarcomas may arise at any anatomical site and may be defined by their histologic, clinical, or molecular features. They may include sarcomas driven by oncogenic gene fusions, recurrent mutations, gene amplification or loss, epigenetic alterations, or complex genomic changes, as well as sarcomas for which no recurrent molecular driver has been identified. Cancers that originate outside bone or soft or connective tissue are not eligible solely because they carry an oncogenic fusion or have metastasized to bone or soft tissue.

- **Rare respiratory or rare immune dysregulation subcohort applicants only:** identify the principal respiratory manifestations or form of immune dysfunction or dysregulation associated with the disease. For immune disorders, identify any known genetic causes, immune targets or signaling defects, distinguishing established findings from suspected mechanisms. Briefly explain how that component is a defining feature or a major driver of morbidity, mortality, diagnosis, monitoring, or therapeutic development (maximum of 75 words).
 - **Rare sarcoma subcohort applicants only:** identify the sarcoma type, subtype, or patient population represented and describe its defining histologic, clinical, and molecular features. Include any known oncogenic fusion or other characteristic molecular alteration and, where relevant, the evidence that it is a defining feature or central driver of the sarcoma. If your organization serves a broader cancer population, explain how it represents and engages the relevant sarcoma population (maximum of 75 words).
 - Provide up to three links to peer-reviewed publications or authoritative scientific sources demonstrating that the disease meets the definition of the selected subcohort.
 - If your disease also has meaningful scientific relevance to another Cycle 4 subcohort, identify the secondary area and briefly explain the overlap. Your application will still be reviewed and, if selected, assigned principally within the primary subcohort chosen above. (Optional; maximum of 50 words)
- **Patient Experience and Disease Course:** briefly describe what it is like to live with the disease, including its most consequential symptoms or clinical manifestations, typical course, and effects on quality of life and daily functioning. Describe current treatment options and the most important needs they leave unmet. Note important differences by subtype, age, genotype or other molecular features, disease stage, or other factors (maximum of 150 words).
 - **Affected body systems, organs, and tissues**
 - Indicate the body system(s) affected by the disease your organization focuses on. Check all that apply:
 - Cardiovascular / Circulatory, Digestive, Endocrine, Hematopoietic / Lymphatic / Immune, Integumentary / Exocrine, Metabolic, Muscular /

Skeletal, Nervous / Sensory, Renal / Urinary / Excretory, Reproductive, Respiratory, Other (please specify), Unknown.

- Indicate which organs and/or tissues are affected by the disease your organization focuses on. Check all that apply. Sarcoma applicants should select the tissue and anatomical site or sites in which the primary tumor typically arises, not sites affected only by metastasis. If the primary site varies or is unknown, indicate this under “Other.”
 - Adrenal glands, Airways (bronchi and bronchioles), Bile ducts, Bladder, Blood, Blood vessels (veins, arteries), Bone marrow, Bones, Bowel, Brain, Breasts, Connective tissue / joints, Ductus deferens, Ears, Esophagus, Eyes, Fallopian tubes, Gallbladder, Head and neck, Heart, Intestines, Kidneys, Limbs, Liver, Lungs, Lymph fluid, nodes, ducts, vessels, Mediastinum, Mouth / teeth, Muscles, Nerves, Nose, Ovaries, Pancreas, Parathyroid, Penis, Peritoneum, Pleura, Prostate gland, Pulmonary blood vessels, Respiratory muscles, Retroperitoneum, Salivary glands, Scrotum, Sinuses, Skin, Soft tissue, Spinal cord, Spleen, Stomach, Testes, Thymus, Throat, Thyroid, Trachea, Ureters / urethra, Uterus, Vagina, Vulva, Other (please specify), Unknown.
- **Demographic and clinical characteristics**
 - Indicate the sex(es) of those affected by the disease. Check all that apply:
 - Male, Female, Intersex, Unknown
 - 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
- **Diagnosis and outcomes**
 - What is the average age of diagnosis of an individual diagnosed with the disease? If this answer is dependent on subtype, please explain in the provided text box (maximum of 50 words).
 - 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, Depends on subtype
 - **Rare respiratory and rare immune dysregulation disorder applicants only:** What is the average life expectancy of an individual with the disease? If this answer is dependent on subtype, please explain in the provided text box (maximum of 50 words).
 - 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, Depends on subtype
 - **Sarcoma applicants only:** Provide the best available estimate of overall survival, progression-free survival, or another clinically relevant survival measure, including the measure, time period, and relevant patient population, subtype, or disease stage. If no reliable information is available, enter Unknown (maximum: 75 words).

- Indicate, if known, the average length of time in years that passes between initial symptoms of the disease appearing and diagnosis. If unknown, please mark unknown. If this answer is dependent on subtype, please explain in the provided text box (maximum of 50 words).
 - Less than one year, 1 to 5 years, 5+ to 10 years, 10+ years, Unknown, Depends on subtype
- Indicate the typical method(s) of diagnosis of the disease. Check all that apply:
 - Clinical diagnosis, Neurological exam, Imaging, Genetic test, Blood test, Urine test, Biopsy, Metabolic test, Electrophysiological test, Pulmonary-function or other respiratory testing, Immunologic testing, functional immune assays, or immunophenotyping, Pathology or histology, Immunohistochemistry, Molecular profiling or next-generation sequencing, RNA sequencing, Fluorescence in situ hybridization, Reverse-transcription polymerase chain reaction, Cytogenetic or karyotype analysis, Bone-marrow evaluation, Other (please specify).
- **Prevalence and incidence**
 - Indicate the prevalence of the disease (i.e. the approximate number of people believed to have the disease).
 - In the country where your organization is based:
 - Less than 10, 11-50, 51-100, 101-1000, 1001-10,000, 10,000+, Unknown
 - Beyond the country where your organization is based:
 - Less than 10, 11-50, 51-100, 101-1000, 1001-10,000, 10,000+, Unknown
 - **Sarcoma applicants only:** If you identified a recurrent oncogenic fusion above, provide the estimated number or percentage of patients whose tumors carry it. Include the relevant population, geography, and source where known. If no reliable estimate is available, enter Unknown (maximum of 50 words).
 - Indicate the incidence of the disease (i.e. the approximate number of new cases identified per 100,000 people in a given year):
 - In the country where your organization is based:
 - Less than 10, 11-50, 51-100, 101-1000, 1001-10,000, 10,000+, Unknown
 - Beyond the country where your organization is based:
 - Less than 10, 11-50, 51-100, 101-1000, 1001-10,000, 10,000+, Unknown
 - Describe whether there are global regions or ethnic or racial populations with higher-than-average prevalence or incidence rates (maximum of 75 words).

Existing Research Resources and Infrastructure: Please identify up to five of the most important existing resources that currently support research or therapeutic development in your disease area and briefly describe their current status, ownership or management, access, and any formal role patients or patient organizations have in decisions about their use. Examples may include patient registries; natural history studies or longitudinal clinical cohorts; biobanks

and other biospecimen collections; clinical, genomic, molecular, imaging, or other data repositories; patient-derived cell lines, iPSCs, organoids, animal models, or other disease models; diagnostic or research assays; biomarkers; outcome measures or endpoints; research agendas or roadmaps; and other trial-readiness resources. *This question is intended to help Biohub understand the existing disease landscape and will not be used as a selection criterion. Applicants are not expected to have developed or control these resources* (maximum of 150 words).

Short Answer Questions: We recognize that every patient-led organization and disease field has its own history, strengths, needs, and goals. These questions are intended to help us understand what your organization and community have built to date, what you hope to accomplish, and where Rare As One funding, training, advising, and Network participation could be most valuable. Organizations and disease fields are not expected to have mature capabilities or infrastructure in every area.

The headings of the short-answer questions correspond to the principal criteria that reviewers will use to evaluate applications. Reviewers will consider your organization's readiness to make progress, its potential to benefit from the opportunity, and the perspectives and experience it could bring to the Network, including both its current strengths and the gaps that Rare As One could realistically help address. Applicants should therefore respond directly and candidly and provide specific examples wherever possible.

1. Patient-led governance

- Describe how patients, family members, and others directly affected by the disease are represented in your organization's governance and hold meaningful authority over its strategy, priorities, and decisions. Identify the governing or leadership roles held by people with lived experience and describe the types of decisions they help make (maximum of 125 words).

2. Organizational and scientific leadership capacity

- Describe the organizational and scientific leadership team that would be responsible for achieving the grant objectives. Explain the relevant experience, skills, available capacity, and commitment of staff, board members, scientific advisors, and other key leaders. Provide one or more specific examples that demonstrate the team's ability to execute significant organizational or research-related work. If participation in the grant would require your organization to hire or add staff capacity, describe the type of role and capabilities you would expect to add (maximum of 200 words).

3. Readiness, need, and potential for growth

- Describe the organizational and scientific strengths that currently position your organization to make progress and the most important capacity gaps limiting its ability to lead and sustain research. Explain how flexible funding, required training, tailored advising, and Network support would help address those gaps and what meaningful changes in the organization's capacity you would seek to achieve during the three-year grant period. Identify the principal capacity-building investments you would prioritize within the required 30%–40% budget allocation, such as staffing, governance, fundraising, operations, scientific advising, or

research strategy. The priorities described here should be reflected in your proposed budget (maximum of 250 words).

4. Ongoing community engagement and patient-centered research

- Describe how your organization currently engages a meaningful and representative portion of the affected community. Include the approaches you have used, such as surveys, focus groups, advisory groups, listening sessions, or other methods; what you learned; and how those findings have influenced your organization's research priorities or activities (maximum of 150 words).
- Two related grant requirements are: (1) holding a multi-stakeholder convening - typically in Year 2 or 3 - that brings together patients, researchers, clinicians, industry, and other relevant participants; and (2) developing or updating a patient-prioritized collaborative research and therapeutic development agenda. Explain how you would engage the community throughout the grant period to identify unmet needs, meaningful outcomes, acceptable risks, and research priorities; inform these two activities and other research efforts; and communicate progress and results (maximum of 200 words).

5. Potential to develop and expand the disease-field and therapeutic-development network

- Describe the current research, clinical, and therapeutic-development network in your disease area, including any centers of excellence, specialized clinical or research sites, or formal consortia, and your organization's role within it (maximum of 125 words).
- Identify the most important gaps in the network, including missing expertise, disciplines, relationships, or geographic representation. Explain how your organization would use the grant to develop or expand the network, including connections with researchers and partners working in related diseases or broader scientific fields, and align participants around patient-prioritized research and therapeutic-development needs (maximum of 125 words).

6. Disease-specific scientific and translational opportunity

- Describe the most important scientific and translational gaps and opportunities in your disease area, including those related to data, biospecimens, disease models, diagnosis, patient stratification, biomarkers, outcome measures, endpoints, trial readiness, research infrastructure, or the identification, assessment, or advancement of potential therapies. Explain what your organization could realistically accomplish during the three-year grant period and how the program's funding, training, advising, and Network support could help advance patient-prioritized scientific and therapeutic goals (maximum of 250 words).

7. Rare As One Network participation and peer learning

- Describe why your organization wants to join the Rare As One Network and how it would make Network participation a meaningful part of the grant. Explain how your organization would ensure that it has the staff time and leadership capacity needed to participate consistently in required calls (meeting the 50% attendance requirement), trainings (including two required trainings), convenings, and other collaborative or peer learning opportunities. Provide examples of knowledge,

approaches, experience, or resources your organization could share with other patient-led organizations and areas in which it would particularly benefit from peer learning (maximum of 200 words).

8. Subcohort fit, contribution, and cross-disease potential

- Recognizing that the final composition of the subcohort is not yet known, describe one or more shared biological mechanisms, scientific questions, translational barriers, infrastructure needs, or therapeutic opportunities that could be pursued across diseases, what such collaboration could achieve, what concrete shared output could realistically be advanced during the grant period, and which potential cohort activities most align with your community's interests. Describe the knowledge, experience, relationships, resources (such as relevant data, biospecimens, models, tools, or research infrastructure), or other strengths your organization could contribute to this work (maximum of 250 words).

9. Responsible stewardship of data, biospecimens, and research assets

- If applicable, describe your organization's current or planned approach to the responsible stewardship of patient data, biospecimens, disease models, and other research assets relevant to its proposed activities. Address, as applicable, consent, privacy, governance, access, responsible sharing, and return of information or other value to participating communities. If your organization has not yet developed these practices, identify the most important gaps and describe how grant support and training could help address them. Organizations will not be required to contribute data or samples to Biohub or to any shared repository as a condition of receiving a grant. **However, any data, biospecimens, and research assets curated or generated using Biohub grant funding must adhere to Biohub data access requirements as stated in the grant agreement** (see the [Institutional Approval Form](#)) (maximum of 100 words).

The formatting and component requirements, including any word and/or page limits indicated above, will be enforced by the review team. Any submitted materials that exceed the word and page limits or do not follow the requirements will not be considered during the application review process.

RFA Contact

For administrative and programmatic inquiries or questions pertaining to this RFA, please contact sciencegrants@chanzuckerberg.com. For technical assistance with SMAApply, please click on the information "i" link in the upper right corner at <https://apply.chanzuckerberg.com>.