



CSNK2A1 Foundation Internship for PCORI Stakeholder Convening Project

Research & Stakeholder Engagement Intern

Overview

The CSNK2A1 Foundation is a 501(c)(3) nonprofit dedicated to advancing research and improving outcomes for individuals with Okur-Chung Neurodevelopmental Syndrome (OCNDS). This work is being conducted in collaboration with the CSNK2B Foundation, whose mission is to advance awareness, research, and treatment development for individuals affected by CSNK2B-related neurodevelopmental disorders.

We are seeking a **part-time Scientific Intern** to support a patient-centered research initiative that includes both virtual engagement activities and participation in a multi-stakeholder convening (virtual and in-person components). Participation in the in-person convening (December 2–4, 2026, Denver, CO) is expected; travel costs will be covered by the Foundations. This initiative is supported through a **Patient-Centered Outcomes Research Institute (PCORI) Engagement Award**, which funds stakeholder-driven efforts to build capacity for patient-centered comparative clinical effectiveness research (CER).

The project brings together stakeholders across **CSNK2A1-related neurodevelopmental disorder** (CSNK2A1 NDD, also known as Okur–Chung Neurodevelopmental Syndrome/OCNDS) and **CSNK2B-related neurodevelopmental disorder** (CSNK2B NDD, also known as Poirier–Bienvenu Neurodevelopmental Syndrome/POBINDS) communities.

This work will support the co-development of a shared research agenda and cross-community lexicon grounded in lived experience and comparative effectiveness research (CER). The project engages caregivers, clinicians, and researchers to align priorities and build infrastructure for future patient-centered research. The intern will work closely with foundation leadership and staff, as well as a network of clinicians, researchers, and caregiver stakeholders, gaining exposure to multidisciplinary collaboration in patient-centered rare disease research. This role is ideal for a student interested in rare disease, translational research, patient advocacy, and/or stakeholder-engaged research.

Timeline

- **Application Deadline: May 28, 2026**
- **Interviews: June 6–12, 2026**
- **Start Date: June 15, 2026**
- **End Date: February 28, 2027**

The intern will begin prior to key **grant-defined summer milestones** and contribute to foundational work leading into the December 2026 convening. There may be a need for extension beyond the stated end date to support manuscript development, depending on project needs and intern availability.

Compensation

\$1,000 total stipend: Paid in two installments, contingent on completion of agreed-upon deliverables:

- **\$500 (July 2026):** upon completion of initial literature synthesis, data curation, and early lexicon contributions aligned with interim reporting
 - **\$500 (February 2027):** upon completion of final deliverables, including convening synthesis, research agenda drafting, and lexicon development
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Responsibilities

- Aggregate and synthesize literature related to:
 - outcome measures in neurodevelopmental disorders
 - comparator conditions relevant to CSNK2A1 and CSNK2B NDD

- patient-centered and comparative effectiveness research (CER) frameworks
- Support development of a cross-community research lexicon
- Assist in synthesizing outputs from stakeholder engagement activities and the virtual convening
- Contribute to drafting:
 - shared patient-centered research agenda
 - summary and dissemination materials
 - manuscript content for publication
- Support coordination and administrative activities, including:
 - communicating with stakeholders (e.g., scheduling emails, follow-ups, reminders)
 - tracking completion of required participant trainings
 - collecting and organizing participant information (e.g., bios, headshots, affiliations)
 - maintaining organized records of engagement and project materials
- Collaborate with foundation staff, clinicians, and research advisors in a remote team environment

Expected Time Commitment

- Variable commitment over the course of the project, ~2–10 hours per week, depending on project phase
- Workload will fluctuate, including:
 - Lower commitment early on during onboarding and initial literature review
 - Moderate, consistent engagement during summer and early fall to support core deliverables
 - Higher-intensity periods leading up to key milestones, including:
 - virtual Q&A session
 - December 3rd in-person convening
 - major deliverable deadlines (lexicon drafts, research agenda, reporting)
- Intern should be available for:
 - periodic team meetings
 - timely communication
 - increased responsiveness during milestone-driven periods
- Remote except for the December convening; flexible scheduling, with the expectation of reliability during critical phases

Reporting & Collaboration

The intern will report to **Gabrielle Rushing, PhD**, Chief Scientific Officer, CSNK2A1 Foundation. The intern will work closely with a multidisciplinary team across both foundations, including:

- **Jennifer Sills**, President & Founder, CSNK2A1 Foundation
- **Carly Krull, PhD**, Scientific Program Associate, CSNK2A1 Foundation
- **Beth Chaffin**, Operations Manager, CSNK2A1 Foundation
- **Scott Ashley, PhD**, Scientific Director, CSNK2B Foundation
- **Denise Scott**, Executive Director, CSNK2B Foundation
- **Heather Jackson**, Board Chair, CSNK2B Foundation

Qualifications

- Currently enrolled in or recently completed a graduate-level program (Master's or PhD) in:
 - neuroscience
 - genetics
 - public health
 - psychology
 - biomedical sciences or a related field
- Demonstrated experience with:
 - reviewing and synthesizing scientific literature
 - writing in a scientific or academic context
- Strong analytical and critical thinking skills, with the ability to interpret and integrate findings across studies
- Excellent written communication skills, with attention to clarity, structure, and audience
- Ability to work independently, manage deadlines, and contribute in a remote, collaborative environment
- Interest in rare disease, neurodevelopmental disorders, or patient-centered research
- Ability to travel to Denver, CO (December 2-4th, 2026); foundation will cover travel costs

Application Requirements

- **Please submit all materials to: research@csnk2a1foundation.org by May 28th, 2026**
 - Resume or CV
 - Short statement (maximum one page) including:
 - Why this project interests you
 - Any relevant experience
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Opportunities & Learning

This internship offers hands-on experience in patient-centered rare disease research, with exposure to both scientific and stakeholder-engaged approaches. Interns will have the opportunity to:

- Develop skills in scientific literature review and synthesis, particularly in the context of rare neurodevelopmental disorders
- Gain experience with patient-centered and comparative effectiveness research (CER) frameworks
- Contribute to the development of a cross-community research lexicon and shared research agenda
- Engage with a multidisciplinary network of clinicians, researchers, and patient advocacy leaders
- Participate in the planning and synthesis of a multi-stakeholder convening
- Build experience translating complex scientific concepts into accessible, stakeholder-informed outputs
- Opportunities for authorship may be available depending on the scope and quality of contributions.
 - Authorship will be determined in accordance with standard academic guidelines (e.g., ICMJE criteria)