



CHI Research and Policy Associate Job Description

Nonprofit overview: Congenital Hyperinsulinism International (CHI) is a leading organization dedicated to improving the lives of children with congenital hyperinsulinism (HI). HI is a life-threatening disorder that causes dangerously low blood sugar levels due to the over-production of insulin. Prolonged or severe low blood sugar can cause seizures, brain damage, and even death. CHI supports research towards better treatments and a cure, advocates for timely diagnosis and improved standards of care and supports people living with HI every step of the way.

Position summary: Joining the CHI team as a research and policy associate is a great opportunity to participate in exciting and impactful research and advocacy projects in the rare disease space. The program coordinator will work together with CHI staff to support projects related to research, advocacy, and awareness. The CHI research and policy associate will report to the research and policy director.

Location: The CHI research and policy associate will work remotely from home with limited travel. A preference will be given to individuals who live near Montclair, NJ, western MA, northern CT, Washington, DC, or CA, though other locations will be considered for the right candidate.

Responsibilities:

- Support engagement and recruitment for the HI Global Registry (HIGR) utilizing best-practices for registry recruitment.
- Complete the NIH Human Subjects Research training to learn about ethical research best practices.
- Contribute to data analysis and research projects for the HIGR and the collaborative research network.
- Help the CHI staff plan and execute major events including conferences (virtual and in-person) and the Sugar Soiree.
- Support projects associated with the collaborative research network, including stakeholder communication and disseminating project documentation.
- Create surveys, forms, and applications using Submittable, SurveyMonkey, or other software to support research, the Centers of Excellence Program, and other programs as needed.
- Contribute to the program evaluation for the Centers of Excellence Program and the collaborative research network.
- Collaborate with CHI staff and other stakeholders to develop effective ways to communicate the importance of participating in the HIGR.
- Assist on-going advocacy and awareness projects and help launch new projects to increase public awareness for CHI.
- Support other projects and initiatives as needed based on CHI priorities.

Requirements/qualifications:

- A bachelor's or bachelor's and master's degree in public health, communications, public affairs, policy, genetics, health sciences, or another relevant degree and/or experience.

- Strong interest in HI, rare diseases, research, genetics, medicine, policy, or advocacy.
- Familiarity with the HI or rare disease patient experience or a willingness to learn relevant medical terminology.
- Ability to work collaboratively with individuals in a remote work environment.
- Capacity to adapt to a dynamic work environment.
- Strong self-guided work habits and ability to track multiple simultaneous projects.
- Excellent knowledge of Excel, Microsoft Word, and PowerPoint.
- Good verbal and written communication skills.
- A positive attitude and enthusiasm for learning new skills, terminology, and concepts.

CHI is an Equal Opportunity Employer. We respect and seek to empower each individual and support the diverse cultures, perspectives, skills and experiences within our workforce.