



### **Job Description: HI Global Registry Manager**

**Company 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 toward 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:** The HI Global Registry (HIGR) Manager is a half-time position that reports to the CHI Executive Director. The HIGR Manager will also work closely with CHI's Board and Research Committee, THE HIGR Steering Committee, HI families and patient advocates, scientific and medical personnel from academic medical centers and biopharmaceutical companies.

**Location:** The HIGR Manager will work remotely from home with limited travel.

The primary objectives of the Registry are to:

- Provide a convenient online platform for participants (or caregivers) to self-report cases of congenital hyperinsulinism (HI) in order to document the natural history and outcomes of individuals with HI
- Improve knowledge of global prevalence of HI and any associated co-morbidities
- Better understand the role of timely diagnosis of HI on patient developmental outcomes
- Better understand the patient health outcomes of different HI treatment options, settings and provider types.
- Identify both positive and negative effects related to different HI treatment options.
- Support the evolving standards of care for HI patients using natural history and outcome information from a global perspective.

The successful candidate for this position will manage the operational aspects of HIGR under the supervision of the CHI Executive Director and in collaboration with the HIGR study investigators, the HIGR Steering Committee, and the CHI Research and Development Committee (The HIGR Leadership Team).

Responsibilities:

#### **Project management**

- Work with the HIGR leadership team to establish and fulfill the strategic objectives of the Registry program
- Develop and manage HIGR, including working with the platform vendor on ongoing functional and technical enhancements
- Work effectively with the HIGR vendor team to maintain high functional performance and to implement ongoing system enhancements

- Manage the HIGR budget
- Ensure all stakeholders needs are met; troubleshoot all problems and provide a positive experience for all stakeholders

### **HI Global Registry development, communication and coordination**

- Work with the HIGR Leadership Team to identify specific data to be collected
- Work with the HIGR Leadership Team to develop and update governance protocols
- Work with participants who need guidance on completing surveys
- Coordinate and facilitate HIGR Steering Committee meetings
- Coordinate and facilitate communication with and documents for the Institutional Review Board (IRB)
- Create data reports for CHI use, patients, families, physicians, and scientific researchers
- Develop education and training materials for patients, families, physicians, and scientific researchers, outreach programs and internal and external communications
- Conduct outreach programs
- Develop and manage a process that ensures maximum patient participation in the registry
- Develop and manage a process that ensures consistent participation by physicians and scientific researchers
- Work with the HIGR leadership team to develop and implement consent forms, privacy policy and other explanatory material
- Work with the HIGR leadership team on regulatory, confidentiality and/or ethical issues related to the Registry
- Perform other related tasks as assigned

### **Requirements/Qualifications**

The ideal candidate is an excellent communicator who has worked successfully on data projects and is familiar with the work of patient support organizations, academic medical centers and biopharmaceutical companies.

- BA, BS, or BSN required
- Understanding of clinical trials, registries and related experience
- Ability to work closely with information technology specialists
- Experience with data projects
- Excellent verbal and written communication skills
- Ability to adapt to a dynamic work environment
- Ability to work independently with minimal supervision
- Proficiency with Excel, Microsoft Word, PowerPoint, and Outlook
- Proficiency posting to social media sites like Facebook, Twitter, and Instagram

### **Preferred qualifications:**

- Advanced degree (MA, MS, MPH, MSN, CNP)
- Experience managing a patient registry
- Knowledge of medical terminology to oversee verification of patient-entered data and/or submitted test results
- Grant writing experience

If the above job description and requirements are a good match with your interests and qualifications and you are interested in the position, please send a cover letter and resume to [jobs@congenitalhi.org](mailto:jobs@congenitalhi.org). CHI is an equal opportunity Employer.