PSC PARTNERS
SEEKING A CURE

Patient Registry Data Curator

The Patient Registry Data Curator supports all processes associated with Patient Registry participant data. The curator will work to ensure data quality and usability in research. This includes building processes to identify inconsistencies in survey responses, and communicating with participants to resolve identified issues. The Data Curator will also support developing new surveys and preparing data for use in research. High attention to detail in handling nuanced datasets is a vital skill for this position.

About PSC Partners Seeking a Cure (PSC Partners): PSC Partners is a 501c3 non-profit patient organization. Our mission is to drive research to identify treatments and a cure for primary sclerosing cholangitis (PSC) while providing education and support for those impacted by this rare disease.

The PSC Partners Patient Registry, a key PSC Partners program, is a digital platform where data on people living with primary sclerosing cholangitis (PSC), a rare and serious disease of the bile ducts, is collected and stored. Data is primarily collected through online surveys completed by the participant living with PSC, or a qualified caregiver. The Registry currently represents over 2,700 participants from 54 countries.

Registry data is used to accelerate PSC research and advocate for the unmet needs of PSC patients. Researchers can request de-identified patient data for analysis, and the Registry supports academic and industry researchers with patient recruitment for clinical trials or studies.

Key Responsibilities

1. Review and track registry activity to identify participants who may need assistance.
2. Develop and implement new surveys on the Registry platform.
3. Build and update automated tools for performing survey and account curation tasks using Google Sheets and AppsScript or another programming language.
4. Communicate with Registry participants to answer questions from participants, and resolve issues with account creation or survey responses.
5. Maintain the Registry’s public website content, such as information on ongoing clinical trials and studies that have been made possible by the Registry.
6. Ensure compliance with FDA and EMA patient privacy requirements.
7. Monitor Registry data for progress on key performance indicators.

8. Review surveys to remove patient-identifying information before sharing with external researchers.

This role will cover a wide range of tasks and projects across patient research, communications, and education. It is an excellent opportunity for someone pursuing a career in medical research, public health, or healthcare nonprofits.

Qualifications / Required Skills

1. Bachelor's degree or higher in a quantitative or social sciences field (e.g., public health, mathematics/statistics, computer science, or psychology), OR the equivalent combination of education and experience.
2. Proficient in Microsoft Excel or Google Sheets and data processing in one or more programming languages (e.g., Java, Python, SQL, or R).
3. Excellent written and verbal communication skills, and a patient-friendly approach to communications with participants.
4. Introductory statistics coursework OR equivalent experience.
5. High attention to detail in working with nuanced data.
6. Good collaboration skills with a small team and ability to balance a wide variety of tasks.

Preferred Experience

1. Familiarity with PSC or other rare diseases or liver diseases.
2. 1-2 years experience in a research laboratory, clinic, or other related field.
3. Work experience or training to comply with HIPAA and other relevant patient data protection practices.
4. Website development skills, including HTML and Javascript.
5. Google AppsScript proficiency.
6. Basic graphic design (Canva experience a plus).
7. Statistical analysis software proficiency.

Location and Hours

Remote. Occasional travel is required for conferences and meetings, including the annual PSC Partners Patient Conference.

Full time. The work schedule is flexible outside of standing meetings held during weekdays.

Compensation & Benefits

- $52,500 to $60,000 annual salary, commensurate with experience.
- Full medical and dental benefits, PTO, sick leave, holidays, and professional development support
- Voluntary 401(k) Match Plan

Why Join PSC Partners?

- A chance to make a tangible impact on the lives of patients and families affected by rare diseases.
- Be part of a dedicated and passionate team working to make a meaningful impact on the PSC community.
- Opportunities for professional growth, including connection with research leaders and authorship on Registry-led publications

To Apply:

Please submit your application through this secure Google Form. First priority will be given to applications received by **September 21, 2025.**

Questions? Contact the hiring manager, Brian Thorsen: brian@pscpartners.org