Azrieli CHILD-BRIGHT Fellowship Program

Project Summary

Genome-wide sequencing (GWS) has emerged as an important diagnostic test to facilitate diagnoses for patients with many brain-based developmental disabilities and other genetic conditions. This testing is essential to **timely diagnosis** and care and is widely available in the UK and the US. **Access in Canada is limited**. To begin to address this challenge, ***Genome-wide Sequencing Ontario (GSO: https://gsontario.ca)*** was developed to provide high-quality and timely GWS for residents of Ontario.

Currently, access to GSO is limited to patients assessed by a medical geneticist. However, there are long wait times to access geneticists and many families who are eligible for GWS are cared for by other providers (e.g. developmental pediatricians, neurologists). "Mainstreaming" models of care enable non-genetics providers to order genetic testing themselves, saving families the step of waiting for a referral to genetics. Therefore, using a multi-phase, mixed methods design, the GRIP Study will:

1. Explore barriers and facilitators to the uptake of GWS among non-geneticist providers to inform the development of a mainstreaming model of care.
2. Leverage patient, provider, and laboratory partnerships to co-design, test, and implement a mainstreaming model of care with and for patients with brain-based developmental disabilities and other genetic conditions.
3. Determine the clinical, patient and implementation outcomes of the mainstreamed model of care to inform related activities across Canada.

The candidate will join a diverse multi-disciplinary team and be involved in all facets of this project. This includes protocol development, study design, participant recruitment, data collection, data analysis, manuscript preparation, and core strategies related to knowledge translation, patient engagement, and equity, diversity, and inclusion.

Position Description

- Lead aspects of Aims 2 and 3 of the GRIP Study, such as protocol development, protocol refinement, project management, etc.
- Assist with development and implementation of process and outcome measurement strategy
- Assist with development and implementation of patient and provider-facing education/training materials.
- Develop informed consent documents based on regulations, REB consent templates. and institutional requirements. Submit to REB and coordinate revisions. Assist P.I. with annual approval process and amend protocols and consents as required.
- Conduct literature reviews and keep current with study literature.
- Assist with database design, ensure the quality of the database and supervise database cleaning. Perform/assist with data entry and analysis, including planning.
- Develop and monitor study timelines.
- Confirm eligibility of patient, obtain consent, enrol study participants.
- Perform data collection via medical record review, structured surveys, qualitative interviews
- Perform/support quantitative and qualitative analyses of data

- Assist with strategies related to patient engagement, equity, diversity, inclusion, and knowledge mobilization, including preparation of a range of evidence-informed knowledge mobilization strategies to share findings with lay and academic audiences and support the uptake of new knowledge (e.g. reports, presentations, and manuscripts).
- Present work at internal, local, national, and international meetings/conferences
- Engage in management and administrative duties as needed.

Qualifications & Requirements

- A PhD degree in health services research, health policy, implementation science or a related field.
- Experience in implementation science is an asset.
- Experience in genetics/genomics or genetic counselling is an asset.
- Experience/proficiency with quantitative and qualitative data analysis.
- Exceptional written and verbal communication skills.
- Track record indicating ability to conduct scholarly work, prepare publications, and manage research projects.
- Experience preparing and submitting REB applications.
- Demonstrated organizational and problem-solving skills.
- Demonstrated ability to be self-motivated and self-directed.
- Excellent computer skills (strong knowledge of Microsoft Word, Excel, PowerPoint, and data collection platforms such as REDCap).
- Ability to work independently and within a team.
- Ability to work in a fast-paced environment and meet deadlines.
- Ability to pay close attention to detail while maintaining view of the larger scope.
- Applicant must be based in Ontario; hybrid work options may be considered.

About Host Institution

The Hospital for Sick Children (SickKids) is one of the world's largest paediatric academic health science centres, renowned for research achievements and vast supportive infrastructure. The selected candidate will have the opportunity to work remotely or onsite at the state-of-the-art SickKids Research Institute. The selected candidate will work closely with Dr. Robin Hayeems, Scientist, Child Health Evaluative Sciences at SickKids Research Institute and an extensive and diverse leadership team affiliated with ***Genome-wide Sequencing Ontario***.

Expected Duration

Please provide any details regarding anticipated start and end-dates. Do note that the PDF funding opportunity will commit to one year of support, which will be revisited near the conclusion of the term.

Start date is flexible based on the needs of the selected candidate. Expected duration is one year with potential to extend.

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Application Instructions

Submit a detailed CV and cover letter (both in PDF) outlining your background and experience through the online submission form. If you have any questions, please contact us at pierre.zwiegers@child-bright.ca.