

Seeking Parent Partners for Project About Assessing Pain in Children with Brain-Based Developmental Disabilities



About the project

Pain is a very personal experience making it hard for others to know how much pain someone is experiencing. We often rely on the child or person in pain to tell us how much it hurts to inform decisions about treatment; but this is particularly difficult when children cannot talk or who communicate in other ways. While there are many established ways of assessing pain, most of these have been designed for typically developing children who can verbally report their pain.

The goal of this project is to make recommendations about the best ways of assessing pain in children with brain-based developmental disabilities. We will do this by reviewing the scientific literature to identify and evaluate existing measures for assessing pain in children with brain-based developmental disabilities. This information will be used to: (1) identify areas in need of more research or if new measures need to be developed; and (2) to make recommendations based on the science about which measures should be used by health professionals and caregivers/families to assess pain in children with brain-based developmental disabilities.

As a parent partner and member of the research team, you would be working with researchers/ health professional at the Alberta Children's Hospital/University of Calgary, BC Children's Hospital/University of British Columbia, and the University of Guelph. The lead researcher is a psychologist named Dr. Katie Birnie. The project is funded by the Chronic Pain Network (<http://www.cpn-rdc.ca>). Solutions for Kids in Pain (SKIP; www.kidsinpain.ca) is a project partner.

Opportunity: We are looking for 2 parents of youth with brain-based developmental disabilities who live with pain. You will be involved as an equal member of the research team with a chance to contribute to how we design, conduct, and share about the review with others.

- **How much time will it take?** The project will take 8-12 months.
- **Start date:** November 2020
- **What would I be asked to do?**
 - Willing and able to participate in monthly team meetings
 - Meetings would be with other parent partner, researchers, and health professionals
 - Respond to emails
 - Reading and providing feedback on written documents
 - Involved in co-creating infographics, plain language summaries, policy brief
 - Opportunities to co-present in webinars
 - Opportunities to co-author a scientific article, if of interest
- **Is it suitable for a beginner?** Some prior experience partnering on a research team would be beneficial, but is not necessary.
- **Can it be done from home?** Yes. You would just need a computer.
- **Compensation:** \$1,000 CAD honorarium

Who should I contact if I'm interested or have questions:

Name: Katie Birnie

Email: kathryn.birnie@ucalgary.ca

Role: Main researcher

Please contact before November 1, 2020.

