THE PIUO STUDY:

OPTIMIZING THE MANAGEMENT OF PAIN AND IRRITABILITY OF UNKNOWN ORIGIN IN CHILDREN WITH SEVERE NEUROLOGICAL IMPAIRMENT

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BACKGROUND

Some children with SNI, who are non-verbal and non-mobile, experience pain and irritability of unknown origin, also known as PIUO. They cannot tell their caregivers where it hurts and families are left frustrated with inconsistent and ineffective care provided to them by many different specialist teams.

The PIUO Pathway is a standardized approach to assessing and treating PIUO. **We wanted to know:**

- Can we identify pain sources?
- Can we improve pain control?
- Can we increase quality of life?
- Is the pathway useful for clinicians?

THE PIUO PATHWAY

1.Hx&PE, directed testing

2.Screenings
(urinary, gastric, abdominal, bloodwork)

3.Pharmacology

It is not always possible to find a source for PIUO. But we know now that even when it is not possible to diagnose the problem or when PIUO persist beyond our assessments, **participants in the PIUO study derive benefit from the relationship they are able to build with a dedicated RN and MD team.** They feel validated in their parental expertise with their child's complex condition, they feel supported in managing their child's pain and they welcome the holistic, family centred approach to treatment.

CHILD-BRIGHT
Network

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

RECRUITMENT CHALLENGES

The COVID-19 pandemic hampered our recruitment, but there are other challenges:

- Parents already burdened by the demands of their child's health care weigh the cost/benefits of research participation carefully
- Families living outside of city centres have difficulty accessing hospital based research
- Complex care clinics across the country are meeting previously unmet needs of our population

TEAM CONSTELLATION

Our participants meet a multidisciplinary clinical team as well as a multidisciplinary research team in the PIUO Study, including parent partners. Ongoing and future activities birthed from our Child-Bright affiliation are informed by a POR lens and include the establishment of a journal club for parents of medically complex children and a library of patient voices; reimagining research strategies based of parents' participation experiences and implementation of the PIUO pathway among community providers.

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