



Pain Detectives: Optimizing the Management of Pain and Irritability of Unknown Origin in Children with Severe Neurological Impairment

Katherine Ketchum¹ Bruce Carleton^{1, 2} Tammie Dewan³ Liisa Holsti^{1, 9} Vithya Gnanakumar⁴ Julia Orkin^{5, 6} Anamaria Richardson¹ Christina Vadeboncoeur^{7, 8} Tim Oberlander^{1, 2} Hal Siden^{1, 2}

¹British Columbia Children's Hospital Research Institute, Vancouver, Canada ²Department of Pediatrics, University of British Columbia, Vancouver, Canada
³Department of Pediatrics, University of Calgary, Calgary, Canada ⁴University of Calgary, Physical Medicine and Rehabilitation, Alberta Children's Hospital, Calgary, Canada
⁵Department of Pediatrics, University of Toronto, Toronto, Canada ⁶Complex Care, Hospital for Sick Children, Toronto, Canada
⁷Department of Pediatrics, University of Ottawa, Ottawa, Canada ⁸Palliative Medicine, Children's Hospital of Eastern Ontario, Ottawa, Canada
⁹Department of Occupational Science and Occupational Therapy, University of British Columbia, Vancouver, Canada



Background

Children with severe neurological impairment (SNI) are typically non-verbal, non-mobile and cognitively impaired. Often these children experience pain-like sensations on a daily basis. These sensations are termed Pain and Irritability of Unknown Origin (PIUO). Given its complex nature, PIUO is difficult to treat. Children with SNI exhibit ambiguous pain signals, and physicians have no standardized method for investigating PIUO. Our goal is to improve the assessment and treatment of pain and irritability in children with complex health conditions and multiple disabilities who have limited communication and cognition. These children are amongst the most vulnerable seen in any hospital or clinic.

Pain in the most commonly reported symptom in children with SNI

Objectives

Our plan is to evaluate the effectiveness of an integrated clinical pathway (i.e. a sequential order of standardized evaluation steps) for managing unexplained pain and irritability in children with complex conditions and limited communication. We are also interested in potential correlations between a child's pain level and parent/caregiver well-being.

Procedure

Step 1 begins with a detailed History and Physical Examination (Hx&PE). This includes a pain history and a recording of previous assessments and treatments directed towards pain. The history will include a record of medications, surgical interventions and physical and behavioural interventions from allopathic and alternative/complementary approaches.

If pain persists or remains unidentified → Step 2

Step 2 consists of a series of screening tests.

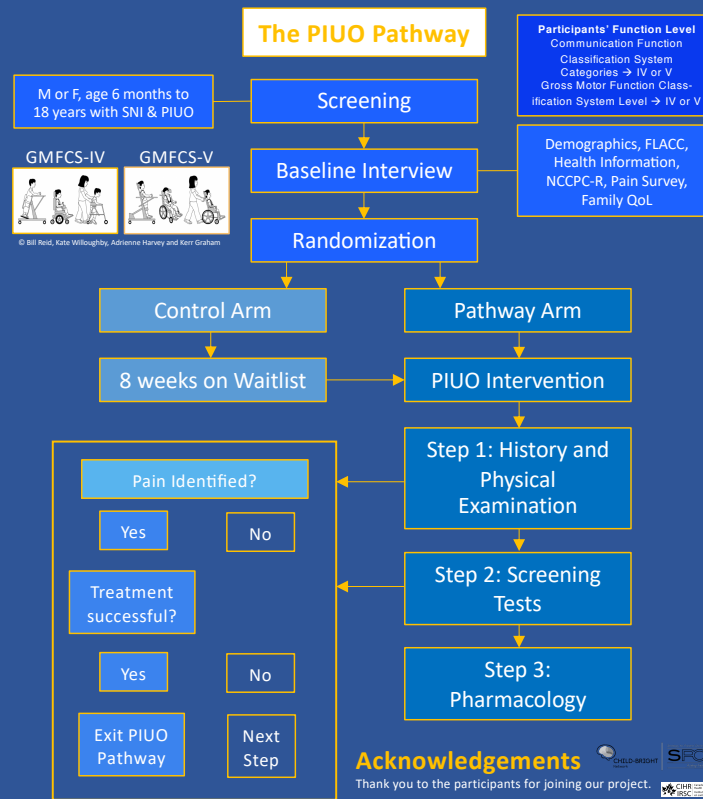
1. Ultrasound – abdominal
2. Urinalysis
3. Gastric pH (if G-tube present)
4. Bloodwork



Photo used with permission from family.

References

1. Ståhle-Öberg L, Fjellman-Wiklund A. Parents' experience of pain in children with cerebral palsy and multiple disabilities – An interview study. *Adv Physiother*. 2009;11(3):137-144. doi:10.1080/14038190902906318.
2. Bajelidze G, Belthur MV, Littleton AG, Dabney KW, Miller F. Diagnostic evaluation using whole-body technetium bone scan in children with cerebral palsy and pain. *J Pediatr Orthop*. 2008;28(1):112-117. doi:10.1097/BPO.0b013e3181558bc1.
3. Siden HB, Carleton BC, Oberlander TF. Physician variability in treating pain and irritability of unknown origin in children with severe neurological impairment. *Pain Res Manag J Can Pain Soc J Société Can Pour Trait Douleur*. 2013;18(5):243-248.



Children with SNI

Severe neurological impairment in children can manifest from a variety of causes. Some examples are listed below.

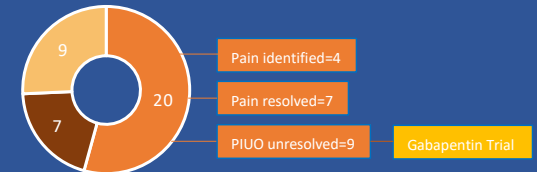
- | | | |
|----------------|------------------------|------------------------|
| Rett Syndrome | Traumatic Brain Injury | Sanfilippo Syndrome |
| Krabbe Disease | Dravet Syndrome | Adrenoleukodystrophy |
| Cerebral Palsy | Aicardi Syndrome | Unknown disease origin |

Preliminary Results

Of the 20 participants who have completed the PIUO Pathway, four have had their pain origins identified. Seven participants have had their PIUO resolved. Nine participants were discontinued (due to health issues, withdrawn permission or death). Seven participants are active in the pathway.

The PIUO Pathway is deemed a **success** if the participant scores in lowest two categories of Pain Survey (little or no pain) on 2 consecutive visits or if the source of the participant's pain is identified.

36 PIUO Participants



Completed Active Discontinued



Future Directions

Our team will continue recruiting until 120 children have completed the PIUO Pathway. The preliminary results indicate that many children will complete the PIUO Pathway without being relieved of their PIUO. To address this issue, our team will be conducting a novel randomized controlled trial investigating the efficacy of **gabapentin** in treating pain and irritability in children with severe neurological impairment.

Acknowledgements

Thank you to the participants for joining our project.

Funding provided by the CHILD-BRIGHT Network, SPOR and CIHR.

