Knowledge Translation and Stakeholder Engagement Initiatives by the Cerebral Palsy Integrated Neuroscience Discovery Network

Alice Kelen Soper[1,2,3,4], Dayle McCauley[1,2,4], Heather Shearer[2,5,6], Richard Wintle[2,7,8], Jan Willem Gorter[1,2,4], Manda Krpan Mesic[2], Brenda Agnew[2], Rosarie Coughlan[2], Kinga Pozniak[1,2,4], Amanda St. Dennis[2], Crystal Chin[2], Darcy Fehlings[2,5,9], Peter Rosenbaum[1,2,4]

[1]Department of Pediatrics, McMaster University, [2]The Cerebral Palsy Integrated Neuroscience Discovery Network, [3]School of Rehabilitation Science, McMaster University, [4]CanChild Centre for Childhood Disability Research, Hamilton, [5]Holland Bloorview Kids Rehabilitation Hospital, Toronto, [6]Faculty of Health Sciences, Ontario Tech University, Oshawa, [7]The Hospital for Sick Children, [8]The Centre for Applied Genomics, [9]Department of Pediatrics, University of Toronto, Canada

Background

The Cerebral Palsy Integrated Neuroscience Discovery Network (CP-NET), funded by the Ontario Brain Institute (OBI), addresses several research themes:

- Brain and development
- Individual and family
- Cerebral palsy (CP) community

CP-NET's efforts include dissemination of research findings to people with CP, families, clinicians, and policymakers.

Objectives

1 Knowledge Translation

To disseminate current research findings relevant to people with CP and their families.

2 Stakeholder Engagement

To actively engage patient and family stakeholder perspectives in evidence-based research planning and outcomes.

Methods

To ensure that the CP community receives relevant information and awareness of knowledge translation and engagement opportunities, a Stakeholder Advisory Committee was formed when CP-NET began in 2011. All CP-NET KT activities are determined by the committee and are evaluated for their impact and reach.

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#DOHaD2022

Results

CP-NET includes the following knowledge translation activities and stakeholder engagement initiatives:

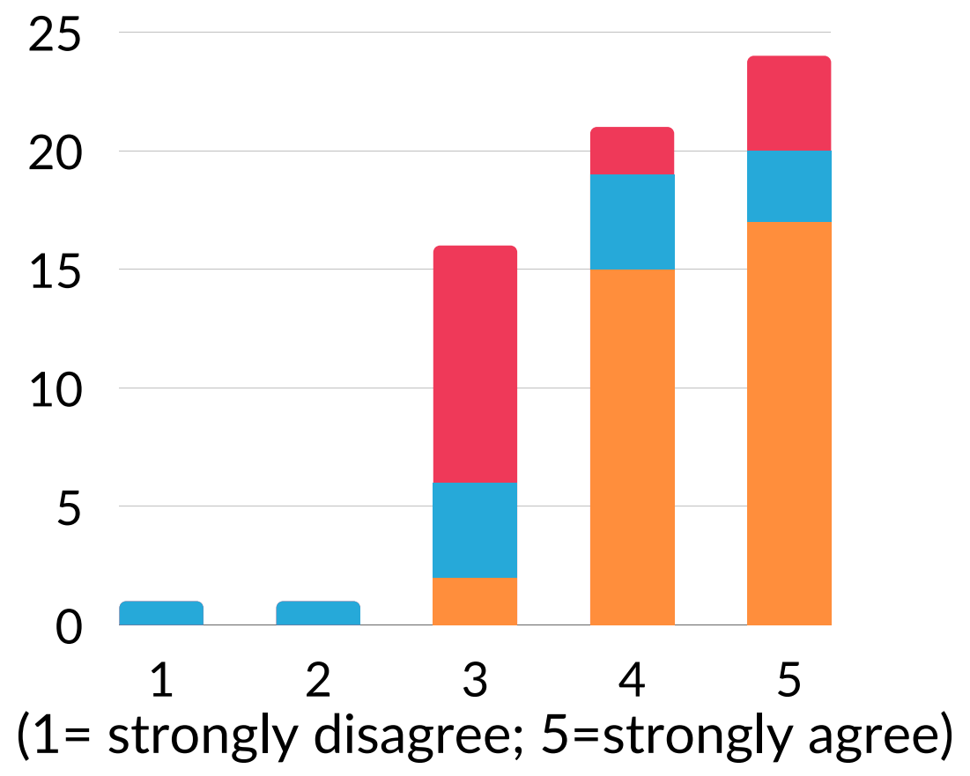
Knowledge Translation Activities

Educational Meetings

The annual **CP-NET Science and Family Day** (SAFD) celebrates World CP Day, bringing together individuals with CP, families, clinicians, and researchers.

The **Meet the Expert Series** provides opportunities to engage in conversation with clinicians, researchers, and community experts. In 2022, three were hosted on:

- 🟥 Neurotechnology
- 🟦 Transition from pediatric to adult care
- 🟧 Baby constraint induced movement therapy (CIMT)



Attendees' perceived **increase in knowledge** about neurotechnology, transition from pediatric to adult health care, and baby CIMT

Educational Materials

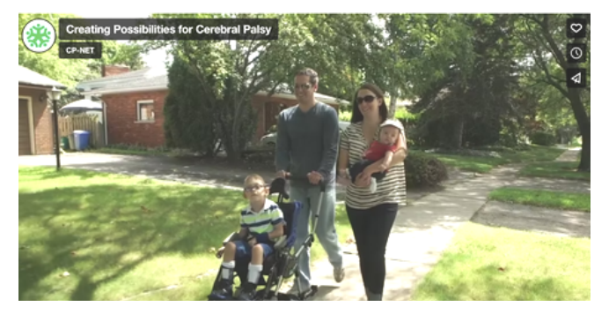
CP-NET develops online **webinars** that are attended live and recorded. Topics include:

- Hip surveillance
- Mental health for people living with CP

Four **videos** developed by CP-NET have included topics on communication, technology, the 'F-words for Child Development', and creating possibilities for people with CP. The videos have been viewed >33,800 times.

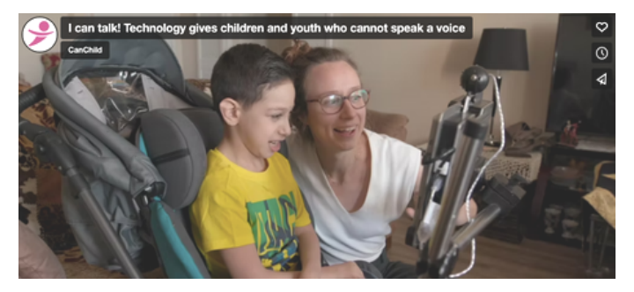
The 'F-words' for Child Development

Creating Possibilities for Cerebral Palsy



Discover CP-NET

Communication Technology

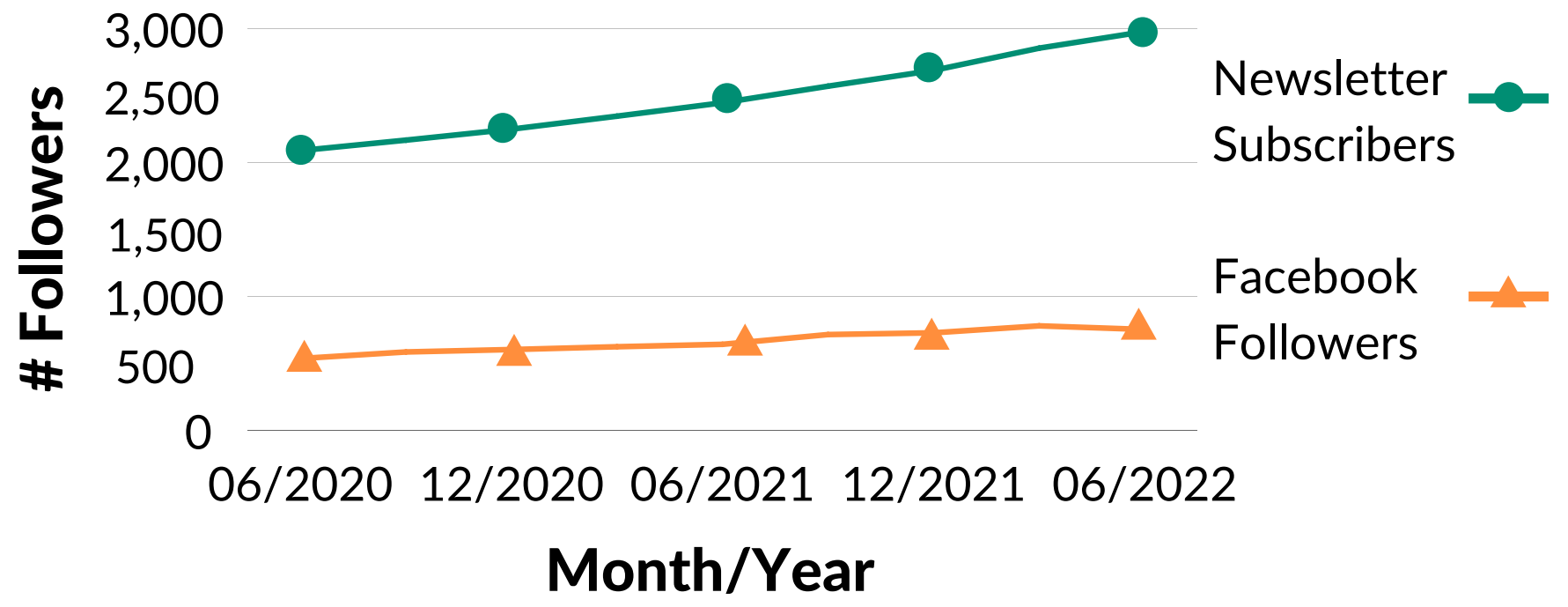


Scan the QR Code to view the videos:

Social Media

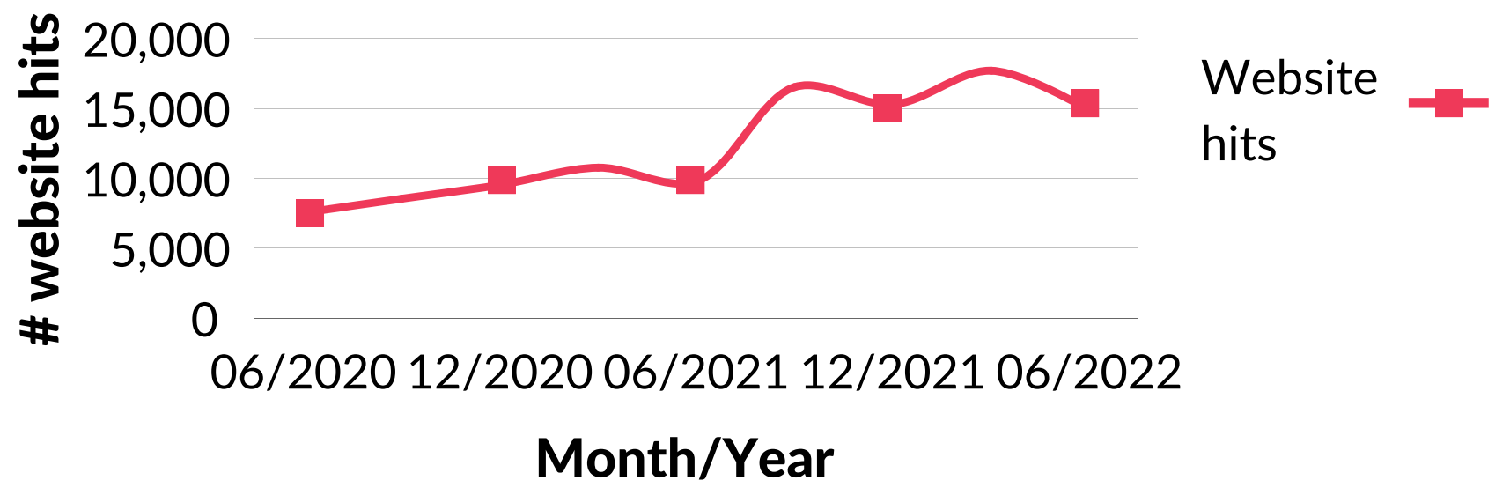
CP-NET **Facebook Page** and **newsletter** (>2,850 subscribers) feature community profiles, upcoming events, videos, and lay summaries of publications.

CP-NET social media



CP-NET **website**, developed with the Stakeholder Advisory Committee, houses videos, webinars, community profiles, and information on CP-NET research projects.

CP-NET website hits



Stakeholder Engagement Initiatives

Opportunities for Stakeholder Engagement

CP-NET stakeholders initiated and are co-investigators on a project to address training needs of youth with disabilities who want to partner in research (Youth Engagement in Research (YER)). They also contribute to the OBI Patient Advisory Committee and advise on grant applications.

> *Participating in the YER project made me feel valued as a person and as a disabled person. It was also an opportunity to put to use my university education in Child and Youth and Disability Studies.*

Stakeholder Advisory Committee

Meets quarterly to support research priorities and future directions in CP research and is composed of individuals with CP, clinician scientists, and parents.

> *This group is very open to discussing how to address knowledge gaps in CP research and, as a parent, I appreciate being able to provide my perspective.*

Conclusion

It is essential to have stakeholder involvement in the research process from the outset through to dissemination. This ensures relevance, potential uptake, and mutual learning.

To this end, CP-NET will continue to work with diverse stakeholders, explore our members' needs to inform research priorities, and be a model for stakeholder engagement committees.

> *Being a stakeholder means having a chance to be a key player in a project that will impact other stakeholders in the future.*

Acknowledgements

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CP-NET
Childhood Cerebral Palsy Discovery Network

Holland Bloorview
Kids Rehabilitation Hospital

SickKids

CanChild

McMaster University

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