

Update #3 December 2014

What's been happening?

There has been a lot of activity since our last update in April of this year. The following is a brief summary of some of them.



"Funding"



- Launched e-store mid August
- 16 products (eg measures, protocols, guidelines, measurement service) are now available in the e-store
- e-store has had 46 paid transactions to Dec 8, 2014
- Hired full time business development officer (Nathan Nash)
- New business model has been designed and focuses on individual products with future efforts geared to the measurement and analysis service, webinars/training, and new digital software (eg apps).
- Ministry of Children and Youth Services (MCYS) showed interest in our service for MPOC training and measurement and analysis service for centres offering autism services in Ontario

- Grant from NeuroDevNet (\$29,488.) to support family engagement KT activities
- Sponsors for the Family Engagement Day included NeuroDevNet, Ontario Federation for Cerebral Palsy, Bloorview Research Institute, McMaster Children's Foundation, Belle Arte Photo



"Increasing Access to Information"

- Redesign of website (mid June—Dec) to make it more family friendly.
- Request for proposals have been received from 5 vendors to further redesign the website to merge the estore and website and bring more updating capabilities in-house.
- On-going social media presence (facebook/twitter)
 - \Rightarrow CanChild tweets (n=535)
 - Followers (n=1043)
 - Following (n=114)
 - \Rightarrow CanChild Facebook page likes-Dec 1,866 (an increase of 50% over the past 12 months).

- Andrea Cross and the F words team (including parents) has created the 3 minute F-words video which has led to almost 1000 views. You can still vote for this video until January 8th at CIHR's Youtube page by clicking on the 'Fwords' in Childhood Disability Video and clicking "Like": <u>https://</u> www.youtube.com/channel/ UC3rIJO4m81IXXj 9RkgK9NQ/videos
- 5732 total subscribers to the *CanChild* Today newsletter of which 471 are new subscribers from the year (January 1- Dec 8, 2014).
- 106,638 document downloads from our *CanChild* website (January 1- Dec 8, 2014).
- Media interview by TOOST radio (Seattle, Washington) about the risk of being bullied among children with disabilities (Wenonah Campbell).
- CanChild Tweet Chat (Nov) on Family Engagement (hosted by NeuroDevNet, moderated by CanChild).



 CanChild 25th Anniversary celebration Media coverage (Hamilton Spectator-June) re: F Words (Jan Willem Gorter and Kyle Chambers (youth).



- Jenn Sprung (parent advisor) co-author on paper with Camden et al (2014) on Engaging stakeholders in rehabilitation research.
- Initiated pilot project (June 2014) to launch and evaluate the use of a Parent led facebook page as an advisory for Canchild's research activities. Currently 88 members.
- KT activities in conjunction with CP-Net families- ongoing meetings, CP-Net newsletter, participation on World CP Day in "CP Family Science Day".
- Provincial Transition Research Planning Symposium (CIHR—Ontario Child Health Support unit funding) on Nov 14th, 2014 with family and youth representation among other stakeholders (over 30 participants).
- Family Engagement Day (Nov 22, 2014) attended by 69 family members, 33 children/youth and 65 professionals. Live stream attendance (n=40 unique visitors). Plans underway for a grant proposal to continue family engagement activities in 2015.
- Workshops at both the AACPDM meeting and OACRS with parents on "Partnerships in research and knowledge translation: Engaging families, service providers and researchers"

- Formation of Dutch CP-Net in the Netherlands (Mar 2014) - to improve the quality of care for children and adults with CP. Includes persons with CP, their parents and researchers working together with study participants for knowledge translation and moving evidence into practice.
- "On-Track" study team has involvement of 7 parents as active members of the research team. Family newsletters (March & Sept) have significant parent input with a column "parent to parent" written by parent members of the team. Focus groups with parents held in Summer 2014 will guide the dissemination of study results.







- Holland Bloorview/ CanChild has posted for the 2nd joint post doctoral candidate. Cora McLaren (1st recipient) received external grant funding.
- Exploring partnership with Offord Centre to explore opportunities for a joint post doctoral position.
- Job posting for full time communication/ social media person for OBI-CP-NET, NeuroDevNet KT project and CanChild general.
- Welcomed new scientists to the Canchild team- Mark Ferro, Wenonah Campbell, Briano DiRezze.

- Nihad Almarsi- visiting scholar from Jordan (6 weeks) focused on increasing knowledge translation and exchange activities
- Doreen Bartlett working with Anita Kothari and Jennifer Boyko re: a process of developing evidence briefs from the On-Track study with a view to engage in a "deliberative dialogue" with policy makers.



Holland Bloorview Research Institute:

- Quarterly meetings with Jan Willem Gorter and Tom Chau.
- Joint presentation at OACRS conference
- Reciprocal research presentations

OACRS

- New CEO (Jennifer Churchill) came for site visit July 2014
- CEO attended Canchild Family Engagement Day (Nov).
- Plan for a joint invitational conference to develop a provincial research agenda with OACRS centres, Holland Bloorview Research Institute and *CanChild*

McMaster University/Offord Centre

 meetings to discuss opportunities to strengthen collaborative research NeuroDevNet

• Partner for NeuroDevNet funding renewal (2015-2018) in relation to KT and family engagement

Community for Brain Development

 Jan Willem attended inaugural meeting in Ottawa and led KT component of this initiative-plan is to move forward with a LOI for a grant proposal



KT Publications:

- Camden, C, Shikako-Thomas, K, Nguyen, T, Graham, E, Thomas, A, Sprung, J, Morris, C & Russell, DJ. (2014) Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation. Disability and Rehabilitation. Doi 10.3109/09638288.2014.963705
- Bailey, S., Boddy, K., Briscoe, S. and Morris, C. (2014), Involving disabled children and young people as partners in research: a systematic review. Child: Care, Health and Development. doi: 10.1111/cch.12197
- Levac, D, Glegg, S, Camden, C, Rivard, LM, and Missiuna, C. (2014) Best Practice Recommendations for the Development, Implementation, and Evaluation of Online Knowledge Translation Resources in Rehabilitation. PHYS THER. Published online October 9, 2014 doi: 10.2522/ptj.20130500

- Rivard, L, Camden, C, Pollock, N, & Missiuna, C. (2014) Knowledge to Practice in Developmental Coordination Disorder: Utility of an Evidence-Based Online Module for Physical Therapists Physical & Occupational Therapy in Pediatrics, Early Online:1–17, 2014 DOI: 10.3109/01942638.2014.985414
- Camden, C., Rivard, L, Pollock, N,& Missiuna, C. (2014) Knowledge to practice in developmental coordination disorder: Impact of an evidence-based online module on physical therapists' selfreported knowledge, skills and practice. Physical & Occupational Therapy in Pediatrics (accepted)
- DeMatteo, C, Stazyk, K, Singh, S, Giglia, L, Hollenberg, R, Malcolmson, CH, Mahoney, W, Harper, JA, Missiuna, C, Law, M, & McCauley, D (2014).
 Development of a Conservative Protocol to Return Children and Youth to Activity Following Concussive Injury. Clin Pediatr. (Phila). 2014 Nov 23. pii: 0009922814558256. [Epub ahead of print]
- Zemek, R, Eady, K, Moreau, K, Farion, KJ, Solomon, B; Weiser, M & DeMatteo, C. (2014) Knowledge of paediatric concussion among front-line primary care providers. Paediatr Child Health 19(9):475 -80.

Development of a KT science resource:

• KT subsite design (led by Tram Nguyen)

Invitations for KT expertise:

- Wenonah Campbell interviewed for the American Speech Language Hearing Association on the topic of implementation science. This interview will be featured on the Clinical Research Education Library website.
- Key Note presentation by Barb Gibson for the University of Iceland & Icelandic Network on Disability Research
- BRI Cross Talk: Technology as a Mediator for Social Inclusion at Bloorview Research Institute Symposium– (Barb Gibson, panel member)

Awards:

• Mary Law received the McMaster University Innovator of the year award (2014) in recognition of commercialization success in her work with the *CanChild* team on transferring research discoveries back to society.