



**Holland Bloorview**  
Kids Rehabilitation Hospital

**SickKids**

Thames Valley  
Children's Centre

 **Laurentian University**  
**Université Laurentienne**

**ERINOAKIDS**  
Centre for Treatment and Development



**McMaster Children's Hospital**



**McMaster University**

Inspiring Innovation and Discovery

**Making Research  
Relevant to Families**

**We want to hear from you!**

**Baycrest**

**CHEO**

**University Health Network**



**UNIVERSITY of TORONTO**



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**Hotel Dieu HOSPITAL**

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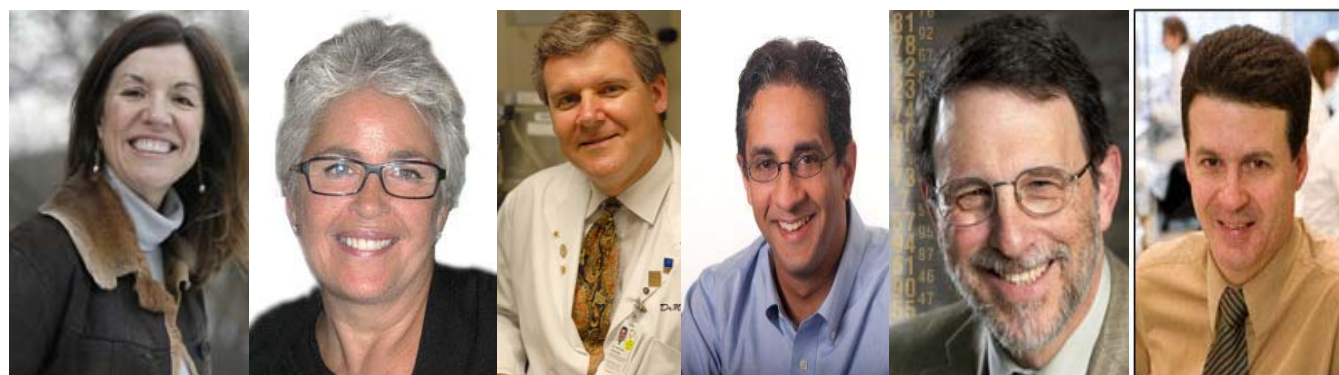
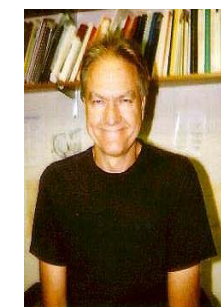
## Agenda

1. Introductions
2. Overview of CP-NET
3. Building a Parent/Family Advisory Group
4. Getting the Right Information to the Right People at the Right Time
5. Research Priorities & Future Directions





Ontario Brain Institute  
Childhood Cerebral Palsy Integrated Neuroscience  
Discovery Network (CP-NET)  
Investigator Group





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**CP-NET Organizations**

- Holland Bloorview Kids Rehabilitation Hospital (lead)
- The Hospital for Sick Children
- The University of Toronto
- Toronto Western Hospital, University Health Network
- Robarts Research Institute, University of Western Ontario
- McMaster Children's Hospital, Hamilton Health Sciences
- McMaster University
- Child Development Centre, Hotel Dieu Hospital
- Queen's University
- Children's Treatment Centre, Health Sciences North
- Laurentian University
- Grandview Children's Centre
- ErinoakKids Centre for Treatment and Development
- Children's Hospital of Eastern Ontario, University of Ottawa
- Thames Valley Children's Centre
- Rotman Research Institute, Baycrest



## CP-NET Investigators

Dr. Darcy Fehlings (Lead) – Holland Bloorview Kids Rehabilitation Hospital

Dr. Gabrielle deVeber – SickKids

Dr. Michael Fehlings – Toronto Western Hospital, University Health Network

Dr. Ravi Menon – Rotman Research Institute, University of Western Ontario

Dr. Peter Rosenbaum – McMaster University

Dr. Stephen Scherer – SickKids

Dr. Elaine Biddiss – Holland Bloorview Kids Rehabilitation Hospital

Dr. Craig Campbell – Thames Valley Children's Centre, London Health Sciences Centre

Dr. Tom Chau – Holland Bloorview Kids Rehabilitation Hospital

Dr. Robert Chen – Toronto Western Hospital, University Health Network

Dr. Jan Willem Gorter – McMaster Children's Hospital, McMaster University

Dr. Mark Henkelman – SickKids

Dr. Carolyn Hunt – Grandview Children's Centre

Dr. Anne Kawamura – Holland Bloorview Kids Rehabilitation Hospital

Dr. Marie Kim – ErinoakKids Centre for Treatment & Development

Dr. Anna McCormick - Children's Hospital of Eastern Ontario, University of Ottawa

Dr. Ronit Mesterman - McMaster Children's Hospital, McMaster University

Dr. Cindi Morsehead – University of Toronto

Dr. Sean Murray – Health Sciences North

Dr. Andrew Paterson – SickKids

Dr. Lucie Pelland – Queen's University

Dr. Dawa Samdup – Child Development Centre, Hotel Dieu Hospital

Dr. Stephen Scott – Queen's University

Dr. Manohar Shroff – SickKids

Dr. Margot Taylor – SickKids

Dr. Derek van der Kooy – University of Toronto

Dr. Richard Wintle – SickKids

Dr. Virginia Wright – Holland Bloorview Kids Rehabilitation Hospital

Dr. Nancy Young – Laurentian University

Ms. Lauren Switzer – CP-NET Project Manager – Holland Bloorview Kids Rehabilitation Hospital

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**OBI CP-NET Industrial Partners**

- |                            |                    |
|----------------------------|--------------------|
| Electronic Arts            | Siemens Healthcare |
| BKIN Technologies          | XLR Imaging        |
| Gesture Tek                | Sangamo Inc        |
| Cell Cure Neuroscience Ltd | Covidien Inc.      |
| Northern Digital           | Allergan Inc.      |
| Hocoma Inc                 | Stem Cells Inc.    |

**OBI CP-Net Patient Advocacy Organization Partners**

- CanChild Centre
- NeuroDevNet
- Ontario Federation for CP
- OACRS
- Heart and Stroke Foundation of Ontario
- Parents for Children with Hemiplegic CP

**Baycrest**

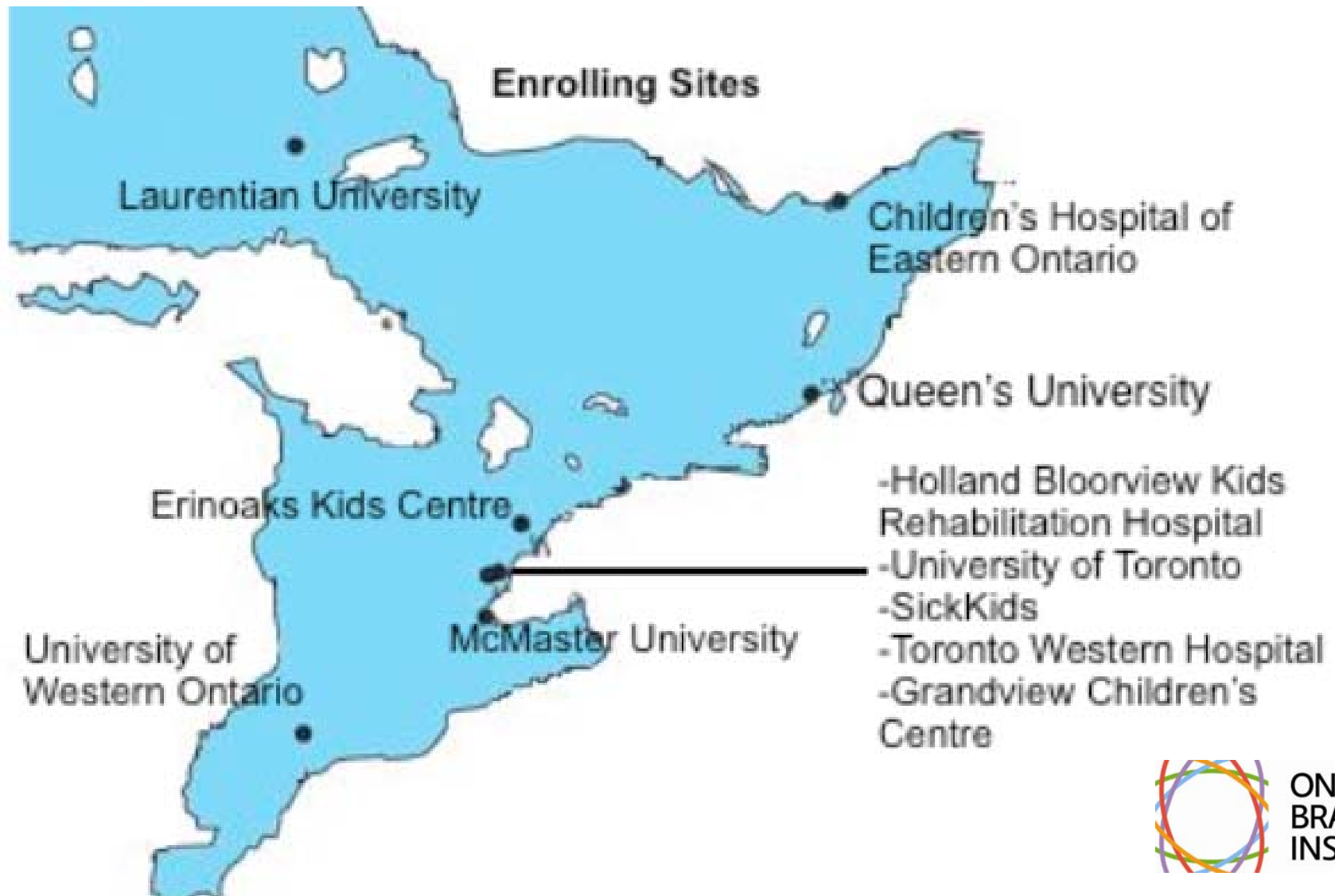
University  
Health  
Network

OBI CP-Net Vision: to transform care for children with CP and their families by accelerating the development of new neuroscience treatments

## Databases

Research Themes	Clinical Risk Factors	Genomics	Neuro-Developmental	Neuro-Imaging
1) Neuro-Developmental Patterns				
2) Genomics				
3) Constraint Therapy				
4) Technology Innovation				

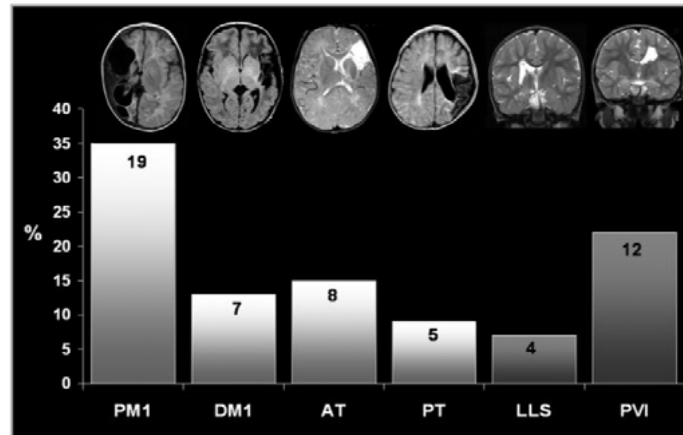
# Sites Involved





# Research Themes

## 1. Predicting developmental outcomes based on images of the brain



Adam Kirton, MD, MSc, FRCPC,<sup>1</sup> Gabrielle deVeber, MD, MHSc, *Ann Neurol* 2008;63:436–443

## 2. Role of Genetics in Hemiplegic CP

- Special genetic testing to discover genetic risk factors for hemiplegic CP

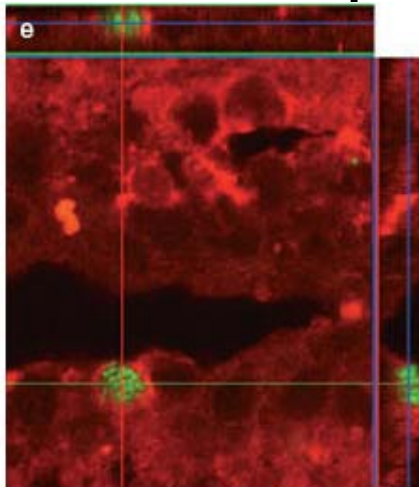
## Research Theme 3: Constraint Therapy

- 3a) Can we predict when Constraint Therapy will have the most benefit by looking at images of the brain?



## Research Theme 3: Constraint Therapy

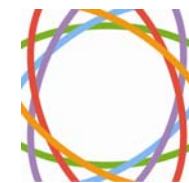
3b. Looking at the molecular and cellular mechanisms of Constraint Therapy in mice with focus on stem-cells. Can the information in mice tell us something about kids with hemiplegic CP?



DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

ORIGINAL ARTICLE

**Effects of constraint-induced movement therapy on neurogenesis and functional recovery after early hypoxic-ischemic injury in mice**



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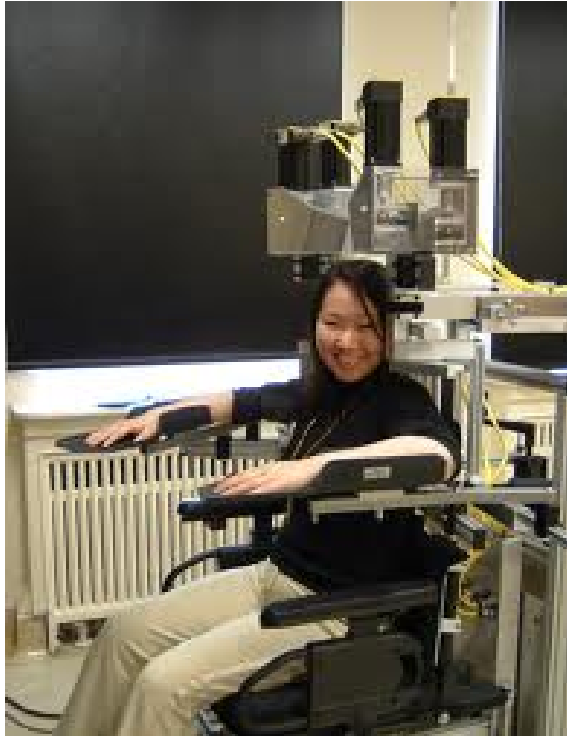
# Theme 4: Developing Technological Innovations for Neuro-Rehabilitation

## a. Virtual Reality Therapy (Kinect)



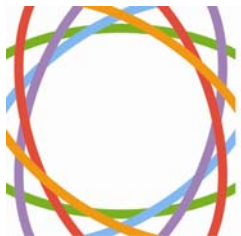
## b. Robotics-Assisted Gait Training (Lokomat)





## c. Robotic Upper-Limb Proprioception (Kinarm)

## d. Transcranial Magnetic Stimulation (TMS)



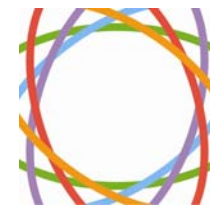
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# Building a Parent/Family Group

- Purpose of the Parent/Family Group?
  - Provide input into research initiatives
  - Communication of results & resources available
  - Actively recruit other parents into group
  - Put together support groups for parents & kids
  - Identify/organize conferences/workshops/seminars
  - Focal point for questions and discussion
  - Advocacy for government funding to support future research



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# Building a Parent/Family Group

- **Process behind Parent/Family Group**
  - Meeting frequency, location, how (in person, online, etc)
  - Time-commitment
  - How to communicate (email, website, meetings, etc)
  - Membership (how many? How to recruit members?)
  - Roles & Responsibilities
  - Subcommittees



# Building a Parent/Family Group

- Next Steps & Support for Building Parent/Family Group?
  - Set next meeting date?
  - Recruit additional members?
  - Finalize & circulate purpose & process?
  - Get examples from other Parent Advisory Groups?
  - Support & training from Holland Bloorview's Family Leadership Program?

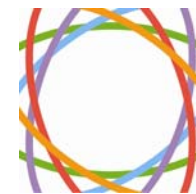


# Getting the Right Information to the Right People

- From this study (OBI CP-NET):
  - What type of information are families interested in knowing?
  - In what format or formats should this information be presented?
  - What can we do to ensure that families are able to find this information when they need/want it?

# Types of Information People Want

- Ideas from the Parent Panel (June 27, 2011):
  - early identification of cerebral palsy (signs parents may look for)
  - treatment options available
  - understanding how/when children with hemiplegia might reach important developmental milestones
  - Do you have other ideas?

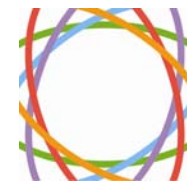


# Accessing Information?

- Report mailed to people's homes
- Internet: e.g., Holland-Bloorview and *CanChild* websites?
- Social Media (Facebook & Twitter)
- eNewsletter
- Through support groups or networks, treatment centres

# Format of the Information?

- Written Communication
  - Via Internet
    - Reports like Keeping Current or “In Brief”
  - Via Brochure/Hard Copy
- Discussion Forum
- Online Workshop
- YouTube Video
- Presentation
- Other?



# Research Priorities: What are your thoughts??