



# The Canadian Cerebral Palsy Registry, BC Division

## Learning Objectives:

- ▶ To review current enrollment in the CP Registry (nationally and provincially) and compare by GMFCS and region in BC
- ▶ To describe the results of two publications:
  - ▶ Current referral practices for diagnosis and interventions for children with cerebral palsy.: a national environmental scan
  - ▶ Family centred health care for children with cerebral palsy
- ▶ How to register children diagnosed with CP





# Canadian Cerebral Palsy Registry

- ▶ The Canadian CP Registry is a voluntary, confidential nation-wide collection of non-identifying medical and social information about children with CP and their families
- ▶ Serve to provide a national profile of children with CP, identify potential risk factors, collect epidemiologic data, provide an infrastructure for researcher conducting population based studies on CP which may lead to improvement in the overall care of children with CP





## Team members

Co-Directors: Dr. Michael Shevell & Dr. Maryam Oskoui

National Coordinator: Nafisa Husein, BSc, MSc

Co-PIs:

Dr. Ram Mishaal (British Columbia)

Dr. Adam Kirton (Calgary)

Dr. Darcy Fehlings (Toronto)

Dr. John Andersen (Edmonton)

Dr. Annette majnemer (Montreal)

Dr. David Buckley (Newfoundland) Dr. Ellen Wood (Nova Scotia)





## Basic status information from the Canadian CP Registry database May 2021

- ▶ Overall records in the database: 2,773
  - ▶ Consented participants with CP: 2235
  - ▶ Refusals: 313
  - ▶ Unavailable participants: 109
  - ▶ Withdrawals: 3
  - ▶ Non-CP cases: 72
  - ▶ Net yet processed; 41





## Current Registrations per birth year in BC (consented participants) May 2021

Health Authority	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Fraser	19	16	9	10	9	4	4	2	0	0	73
Vancouver Coastal	14	4	5	7	7	2	1	1	0	0	41
Interior	10	4	6	4	4	2	2	0	2	1	35
Northern	5	1	7	1	3	2	3	1	0	0	23
Vancouver Island	8	6	7	3	4	2	1	0	1	0	32
	56	31	34	25	27	12	11	4	3	1	204



## GMFCS levels

### ► Canada

I	II	III	IV	V	Unknown	Unavailable
925	326	236	267	274	51	41
43.63%	15.38%	11.13%	12.59%	12.92%	2.41%	1.93%

### ► BC

I	II	III	IV	V	Unknown	Unavailable
49	49	14	34	28	9	21
24.04%	24.02%	6.09%	16.67%	13.73%	4.41%	10.29%





- ▶ Articles published using data from the National Cerebral Palsy Registry



# Current Referral Practices for Diagnosis and Intervention for Children With Cerebral Palsy: A National Environmental Scan

Boychuck Z, Andersen J, Fehlings D, Kirton A, Oskoui M, Shevell M, Majnemer A, PROMPT Group. J Pediatr, Jan 2020

## Objective:

- ▶ Describe current physician referral practices with respect to age at referral
  - ▶ to medical specialists for initial diagnosis of CP
  - ▶ to rehab specialists for intervention
- ▶ To identify factors associated with delayed referrals





# Sources of Information

- ▶ Canadian CP Registry database:
  - ▶ National environmental scan produced 455 children born between 2008-2011 from 4 sites (Edmonton, Calgary, Toronto, Montreal)
  - ▶ Information was extracted from the registry and explored
    - ▶ sociodemographic, birth history, CP profile
- ▶ Medical chart reviewed for age at:
  - ▶ Referral by a physician to a medical specialist for diagnoses of CP
  - ▶ Diagnosis of CP
  - ▶ Referral to a rehab specialist and initiation of treatment



# Results

Age at referral:

- ▶ For diagnosis of CP
  - ▶ median age was 16 months
- ▶ To rehab specialists for intervention
  - ▶ median age was 10 months



# Results

Factors associated with delayed referrals:

- ▶ Lower maternal education
- ▶ Mild severity of dysfunction
- ▶ Type of CP
- ▶ Early discharge after birth



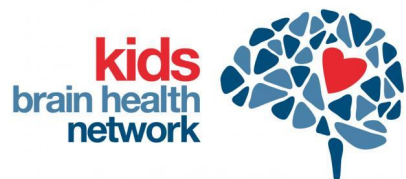
- ▶ One possible factor contributing to the delayed referrals from primary care providers is that knowledge of the early clinical features associated with increased risk of CP may differ



Highlights the need for improved awareness of early motor signs and attributes of milder CP subtypes

International expert recommendations of clinical features to prompt referral for diagnostic assessment of cerebral palsy

Zachary Boychuck John Andersen André Bussi eres Darcy Fehlings Adam Kirton Patricia Li Maryam Oskoui Charo Rodriguez Michael Shevell Laurie Snider Annette Majnemer  
The Prompt Group. *Developmental Medicine & Child Neurology* 2020, 62:89-96



# Sunny Hill Health Centre: Early CP diagnosis initiative

## The Goals:

- ▶ Make Diagnosis of CP in BC, as early as possible, as recommended by the 2017 international guidelines, and by the Early Diagnosis working group of the BC Cerebral Palsy Advisory Committee
- ▶ Provide families and caregivers with consistent resources and information

## 2 arms:

- ▶ SHHC Early CP Diagnosis clinic
  - ▶ Assess all neonates “at high risk” for CP, as determined by the BCCPAC by 6 months of age
  - ▶ Launch date: Fall 2021
- ▶ Community level
  - ▶ Knowledge Translation and support by SHHC for earlier diagnosis by community teams and pediatricians
  - ▶ Planned for 2022

## Family-centred health care for children with cerebral palsy

Shevell M, Oskoui M, Wood E, Kirton A, van Rensburg E, Buckley D, Ng P, Majnemer A. Dev Med Child Neurol, Oct 2018

AIM: to identify characteristics of young children with cerebral palsy (CP), and intrinsic and extrinsic factors, that may be associated with parental perceptions regarding family-centred health care services.

Method: Utilized Canadian Cerebral Palsy Registry (CCPR)

- ▶ Participants recruited through 4 locations (Newfoundland, Nova Scotia, southern Alberta, and BC), children were born between 2008 and 2014



# Parents completed the Measure of Processes of Care (MPOC-56)

- ▶ Assesses parents perceptions of the care receive by their children, evaluating specifically the family-centeredness of the behaviours of health service providers using a Likert scale 1 (never) to 7 (to a great extent) with respect to 56 items
- ▶ Items grouped into subscales
  - ▶ Enabling and partnership
  - ▶ Providing general information
  - ▶ Providing specific information about the child
  - ▶ Coordinated and comprehensive care for the child and family
  - ▶ Respectful and support care





Postulated that *intrinsic* and *extrinsic* factors potentially might be associated with MPOC subscale scores:

- ▶ Intrinsic factors related to the child's CP, sex, or gestation age
- ▶ Extrinsic factors such as provincial residence, demographic information and rehab services



## Results

- ▶ 336 parents were approached for recruitment in the CCPR and asked to fill out the MPOC-56, 282 parents were included as they completed all subscales in the MPOC-56
- ▶ Subscale scores were high, median of 6.0
  - ▶ Respectful and Supportive Care was highest, median of 6.3
  - ▶ Providing General Information was lower, median of 4.8
    - ▶ Paternal educational attainment beyond high-school was associated with a significantly lower score 4.6
    - ▶ No differences identified for maternal education attainment and annual household income
  - ▶ Providing specific information about the child, median 6
    - ▶ Lower score associated with a higher household income (5.6)
- ▶ CP Subtype, GMFCS level and presence of comorbidities did not relate significant with any median scores



## Results

- ▶ Sociodemographic factors were associated with parental perceptions of family-centred care
- ▶ Factors intrinsic to the child's CP were not associated with parental perceptions



## Take away:

High scores on the MPOC imply that:

- ▶ We are embracing family centred care
- ▶ Involved families are positively affirming this
- ▶ Factors intrinsic to the child's CP characteristics appear not to be associated with parental perceptions



- ▶ Analysis implies that higher socio-economic status leads to great parent expectation for information
  - ▶ Need to consider increasing the amount of information provided
- ▶ Meeting the expectations of high socio-economic status families and all families could be:
  - ▶ Outlining family needs at the beginning of the therapeutic relationship
  - ▶ Target appropriate services and delivery to enhance family-centredness



# Who are we looking for?

- Children with diagnosis of CP
- Children born on or after January 1<sup>st</sup>, 2009



# The Canadian Cerebral Palsy Registry, BC Division



- ▶ Health care professionals can introduce the study, and obtain a signed “consent to contact” form and fax to project coordinator
- ▶ Family can also contact project coordinator directly




<http://www.bcchildrens.ca/our-research/participate/sunny-hill-health-centre/cerebral-palsy-registry>

The screenshot shows the BC Children's Hospital website. At the top left is the logo. A navigation bar contains links for 'Our Services', 'Health Info', 'Our Research', 'About', 'Contact', 'Health Professionals', 'Careers', and 'Donate'. Below this is a breadcrumb trail: 'Our Research / Participate / Sunny Hill Health Centre / Cerebral Palsy Registry'. The main heading is 'Cerebral Palsy Registry'. A sub-heading reads: 'We are creating a national registry of information about children with cerebral palsy.' Below this are three buttons: 'About', 'Register', and 'FAQs'. A paragraph explains that the registry is part of the Canadian Cerebral Palsy Registry, a confidential nationwide collection. Another paragraph states that the information is held in a secure database and is non-identifiable. A section titled 'Who are we looking for?' lists two criteria: children with a diagnosis of Cerebral Palsy (CP) and children born on or after January 1, 2009. On the right side, there is a 'In this section' list with four items: 'Sunny Hill Health Centre', 'Cerebral Palsy Registry', 'POWER Mobility Toolkit', and 'Seated Postural Control Measure'. Below this is a 'Contact us' section for Dr. Ram Mishaal, Principal Investigator, with contact information: 604-453-8354 and [ram.mishaal@cw.bc.ca](mailto:ram.mishaal@cw.bc.ca). The bottom right corner features the BC Children's Hospital logo and the text 'Provincial Health Services Authority'.

**BC Children's Hospital**

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## Cerebral Palsy Registry

We are creating a national registry of information about children with cerebral palsy.

[About](#) [Register](#) [FAQs](#)

The Cerebral Palsy Registry (BC Division) is a part of the Canadian Cerebral Palsy Registry, a confidential, nationwide collection of information about people with cerebral palsy in Canada.

The information collected is held in a secure database and is non-identifiable. This will be the first national cerebral palsy registry in North America.

### Who are we looking for?

- Children with a diagnosis of Cerebral Palsy (CP)
- Children born on or after January 1, 2009

**In this section**

- Sunny Hill Health Centre
- Cerebral Palsy Registry
- POWER Mobility Toolkit
- Seated Postural Control Measure

**Contact us**

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**BC Children's Hospital**  
Provincial Health Services Authority





## The Canadian Cerebral Palsy Registry

Links to these publications and others as well as resources on Cerebral Palsy can be found at: <https://www.cpreistry.ca/>

### Contact:

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Thankyou

**kids**  
brain health  
network

