## November 2017 Newsletter



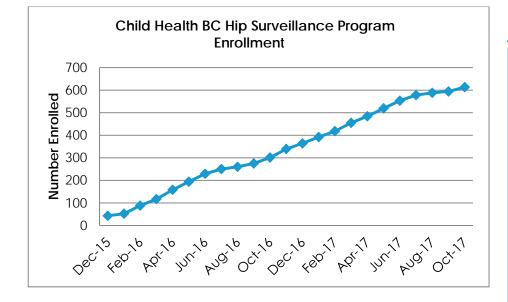
save on foods for Children with Cerebral Palsy

The **Child Health BC Hip Surveillance Program for Children with Cerebral Palsy**, the first in North America, has now been enrolling children, province wide, for more than 1 year! Within this newsletter, you'll find 1) an update on how we're doing with enrollment by region, 2) answers to commonly asked questions, and 3) information on changes coming to the surveillance guidelines based on international consensus work.

Watch for quarterly newsletters! If you have questions, you'd like us to address, email us at <u>hips@cw.bc.ca</u> or call us at 604-875-2345 (toll free 1-888-300-3088), extension 4099.

#### **Provincial Enrollment**

Enrollment began in the Orthopaedic Clinic at BC Children's Hospital in September 2015. Two test sites, Prince George and Victoria, were added in February 2016. Full provincial launch was completed in August 2016. See page 2 for more information on how your region is doing with enrollment.





#### **Enrollment Fast Facts:**

#### As of October 31, 2017:

- 612 children enrolled
- 30% of the estimated children, aged 2-17, with CP in BC
- 136 (22%) discharged
- 12% of children enrolled by their community PTs have been referred to a pediatric orthopaedic surgeon.

Thank you to all those who have enrolled children in the program and completed clinical exams! The program relies on the collaboration between community therapists and the Hip Surveillance team.

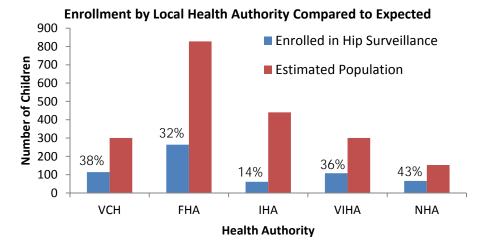
#### **Our Aim**

The Child Health BC Hip Surveillance Program For Children with Cerebral Palsy aims to ensure that all BC children with CP receive appropriate screening and are referred to a pediatric orthopaedic surgeon at the appropriate time to minimize or prevent complications associated with hip dislocations.

# **REGIONAL ENROLLMENT**

## How does enrollment compare by Health Authority?

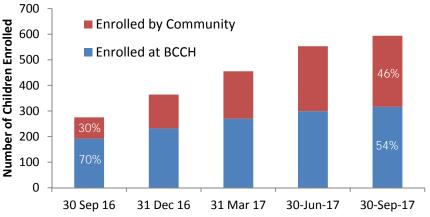
Enrollment varies by Health Authority, ranging between 14% (Interior Health Authority) and 43% (Northern Health Authority). This is based on the number of children with CP estimated to live in each region (for birth years 2000-2015) based on prevalence data and regional populations.



#### Who is enrolling children?

Since the start of province wide enrollment, referrals from community therapists have outpaced enrollments from the Orthopaedic CP Clinic at BCCH. This is the desired outcome. In the future, referrals should originate from the community. The goal of hip surveillance is to enroll children before they are seen in Orthopaedics.

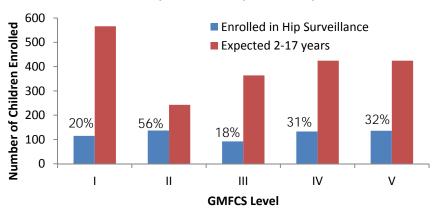




#### Which children are being enrolled?

Estimates of the number of children at each GMFCS level are based on the distribution of GMFCS levels in a population of Ontario children with CP. Enrollment of children at GMFCS levels III to V, who are at highest risk for displacement, ranges between 18% (level III) and 32% (level V) of the number of children with CP that are estimated to be in BC.

**Enrollment by GMFCS Compared to Expected** 



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#### **CLINICAL REMINDERS**

Clinical exam findings are a poor indicator of hip displacement; a radiograph is required to assess hip displacement. **Please ensure families are aware x-rays will be required.** If families have questions about x-rays, radiation exposure, or x-ray frequency, please have them contact us. We are happy to answer their questions.

For children at GMFCS levels III, IV, and V, and those with a Type IV hemiplegic gait, hip surveillance continues until the child has reached skeletal maturity. Children at GMFCS levels I and II may be discharged earlier (age 5 and 10 years, respectively).

Only children with a migration percentage greater than 30%, those with decreased hip abduction range of motion, and/or hip pain, will be referred to a pediatric orthopaedic surgeon as part of hip surveillance.

## RESOURCES

Resources are available on at www.childhealthbc.ca/hips.

- Online Learning Module (Winner of the 2017 Fred P. Sage Award from the American Academy of Cerebral Palsy and Developmental Medicine)
- Launch Checklist
- Clinical Exam Instructions
- Frequently Asked Questions
- Family Booklets (translated in 5 languages)
- Clinician Booklets

### UPDATED SURVEILLANCE GUIDELINES

A group of international experts from Australia, Scotland, the United States, and Canada, including the team from the Child Health BC Hip Surveillance Program, worked together to develop the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) Care Pathway on Hip Surveillance. Consensus was reached based on the available research evidence and expert opinion. Based on this work, the Child Health BC Hip Surveillance Program's Advisory Committee has approved changes to BC's Consensus. Below are the highlighted changes:

#### Clinical Exam:

We will no longer ask therapists to measure a child's R1 hip abduction value, have removed the modified Thomas test, and removed 2 of the clinical questions.

We will continue to ask you to assess GMFCS level, Type IV hemiplegic gait, and hip abduction end range of motion as well as now asking you to assess for pain during the clinical exam.

## **Radiographs:**

Children at GMFCS level I no longer require radiographs but should still be enrolled and receive clinical exams at enrollment, age 3, and age 5 years.

Children at GMFCS level II now receive clinical exams and x-rays at enrollment, age 5, and age 10 years plus clinical exams at age 3 and age 8 years.

■ Children at GMFCS levels IV and V may have the frequency of their hip x-rays reduced to annually from 6 months prior to age 6 if their migration percentage is less than 30% and has been stable over a period of 2 years.

# WATCH FOR UPDATED QUICK GUIDES AND RESOURCES IN EARLY 2018!

If your client has lost their x-ray requisition, please contact us and we'll be happy to send them a new requisition.

# THERAPIST QUESTIONS

Please email us at <u>hips@cw.bc.ca</u> with your questions.

# Do I need to enroll children seen in Orthopaedics Clinic at BC Children's Hospital?

Yes, please enroll kids even when they are seen in Orthopaedics. The physiotherapists in the Orthopaedic CP Clinic do their best to enroll children as they come to clinic but they are unable to see all children.

# After the kids are enrolled, are the repeat clinical exams up to us community therapists or is that just the initial exam to get them enrolled?

You will be asked to do clinical exams which occur as often as twice per year or as infrequently as once every 24 months. We will fax a request asking that you complete a clinical exam. We now aim to send you the request 8 weeks in advance of it being due. If the child is due to be seen in Orthopaedics at BCCH when the clinical exam is due, you will not be asked to complete it.

# My client does not have a diagnosis of cerebral palsy (CP) but I think they should be enrolled. What should I do?

A diagnosis of CP is not required for a child to be enrolled. If a child may have CP or has a diagnosis consistent with the definition of CP (even if they have not been given the diagnosis of CP), please enroll the child. Select the most appropriate box under Diagnosis on the clinical exam form: CP, Suspected CP, or Other. Children should be enrolled while investigations are being undertaken to determine the cause of their motor impairment. If in doubt, contact us (hips@cw.bc.ca) to discuss enrollment.

#### Should children receiving care in Alberta be enrolled?

Yes, we have worked out a process for exchanging information and ensuring x-rays are not duplicated with colleagues in Calgary and are in the process of doing the same for children seen in Edmonton. Enrollment in the program will ensure children are not lost to follow up.

We have heard from therapists that their clients are not being given a diagnosis of CP. We understand this can make discussing the Hip Surveillance Program with the child's parents challenging. We are currently working to learn more about how children in BC are diagnosed with CP. Stay tuned to hear more.



## HOW DOES IT WORK?

**Step 1**: PT provides and reviews caregiver booklet with caregiver

**Step 2**: PT completes the Enrollment Package with family

**Step 3**: PT faxes forms to Hip Surveillance Program Coordinator (604-875-2387).

The Coordinator will review the enrollment forms and determine if an x-ray is needed. If an x-ray is due, an x-ray requisition will be mailed to the family. Results and recommendations are mailed to the child's family, PT, and physician(s).

## HOW DO I GET STARTED?

1. Visit our website: www.childhealthbc.ca/hips.

2. Open the Launch Checklist.

3. Follow the steps to learn all you need to know about the Child Health BC Hip Surveillance Program.

BC Children's Hospital, Orthopaedics, 4480 Oak Street, Vancouver, BC, V6H 3V4 Telephone: 604-875-2345 (toll free 1-888-300-3088), ext. 4099 • Fax: 604-875-2387 Email: <u>hips@cw.bc.ca</u> Website: www.childhealthbc.ca/hips

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