December 2018 Newsletter

CHILD HEALTH BC
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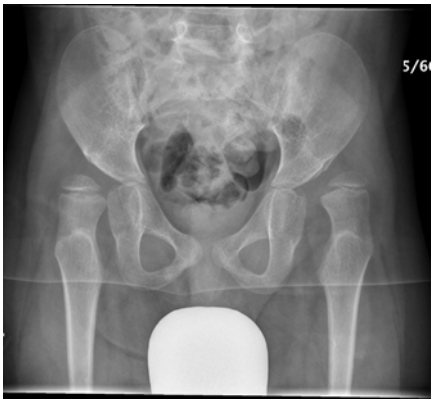
HIP SURVEILLANCE PROGRAM

for Children with Cerebral Palsy



The **Child Health BC Hip Surveillance Program for Children with Cerebral Palsy** aims to ensure that all children in BC with cerebral palsy (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.

Within this newsletter:

A Shorter, Simpler Clinical Exam

In 2018, the clinical exam requirements were reduced to reflect recommendations for hip surveillance established by a group of international experts from Australia, Scotland, the United States, and Canada, including our team from the Child Health BC Hip Surveillance Program. Measurements of spastic catch (R1) and hip flexion contracture (Modified Thomas test), as well as questions related to care and function, were removed. The updated clinical exam now includes:

- Gross Motor Function Classification System (GMFCS)
- Unilateral or bilateral motor distribution
- If unilateral, presence of Group IV gait pattern
- Hip abduction range of motion (R2)
- Assessment of pain during clinical exam
- Question for the child/caregiver about hip pain

Though not required, we also ask that you identify a child's Manual Ability Classification System (MACS) (aged 4-18 years) or Mini-MACS (age 1-4 years) level and Communication Function Classification System (CFCS) level. This helps us better understand the child's function. For more information about these classification systems, please see page 3. In 2019, the program's e-learning module will be updated to reflect these changes and will include new information about the MACS and CFCS.

Enrollment Fast Facts:

As of October 31, 2018:

- 781 children enrolled
- 46% of the estimated children, aged 2-5, with CP in BC
- 44% of the estimated children, aged 6-12, with CP in BC
- 207 (27%) children have been discharged

Thank you to everyone who has enrolled a child in the program and completed clinical exams when we've requested.

Need Help Getting Started?

Visit our website and open the Launch Checklist for a step by step guide on how to get started
www.childhealthbc.ca/hips

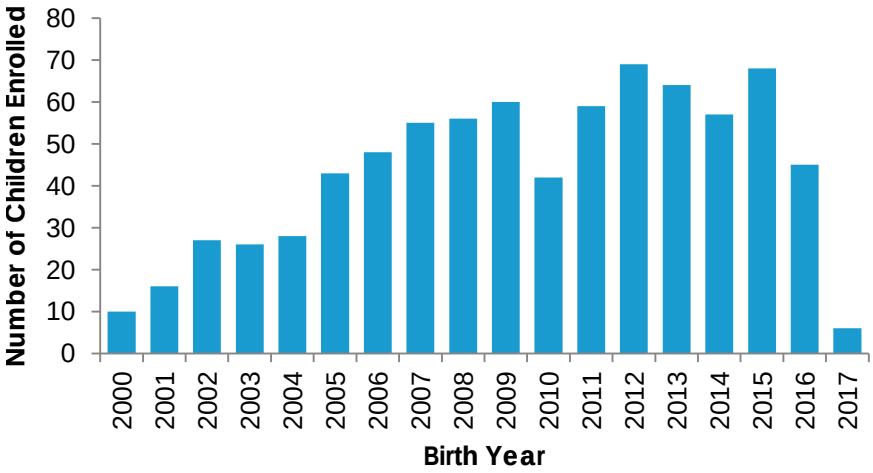
or

contact Stacey at
hips@cw.bc.ca or
1-888-300-3088 ext. 4099

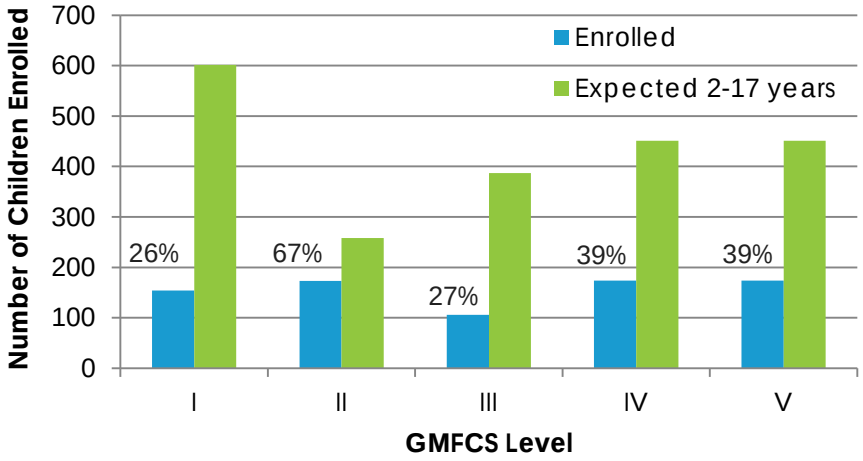
PROVINCIAL ENROLLMENT

We do not know how many children in BC have CP. In a 2008 study completed in Ontario, the prevalence of CP was 2.68 per 1000 live births (Gorter el al., *Dev Med Child Neurol*, 2008; 46: 461-467). Using this prevalence rate and BC population data, we can estimate how many children with CP are in the province and in each region.

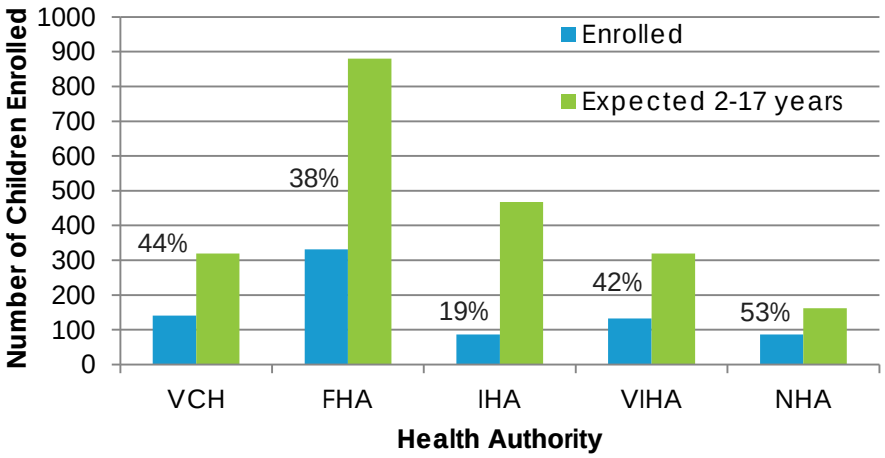
We estimate that 36% of children with CP born between 2000 and 2016 have been enrolled in the program. This graph shows the number of children enrolled by birth year. Our aim is to identify children with hip displacement early. When considering children born 2013 to 2016 (age 2-5 years), 46% of the expected children with CP in BC have been enrolled.



Children at GMFCS levels III, IV, and V are at highest risk of displacement. Shown are the number of children expected by GMFCS and the number enrolled.



Enrollment varies by region, ranging from 19% in the Interior to 53% in the North. Within each Health Authority, regional differences are also significant. Watch for more detailed geographic comparisons of enrollment in the spring edition of this newsletter.



RESOURCES:

- Find Information about different surgeries for hip displacement and how to prepare your client's for surgery on the BC Children's Hospital website at: www.bcchildrens.ca/orthocpclinic
- Are you receiving our dictations? If not, add your name by calling 604-806-9696 or emailing transcriptionalerts2@vch.ca. When you call, ask to have your name added to the "database for dictations".
- Visit our program website: www.childhealthbc.ca/hips to find all of our family and clinician resources.

Manual Ability Classification System

The Manual Ability Classification System (MACS) describes how children with CP use their hands in daily activities. There are 5 levels and classification is based on the child's self-initiated ability to handle objects and need for assistance or adaptions. The MACS can be used for children aged 4 – 18 years and the Mini-MACS for children aged 1 – 4 years of age. Both the MACS and mini-MACS are available for download, free of charge, on the MACS website: www.macs.nu/.

Determining a child's MACS level can be completed in only a few minutes. It is best completed by someone who knows the child. The child, parents, or teachers can be asked questions focusing on the child's ability to handle objects in daily activities. Questions may include the type of objects the child handles, in what situations, and how much help is required. Classification is based on the child's usual performance, not their best ability. The child's overall ability to handle objects is considered, not each hand separately. In the User Instructions, you will find descriptions of the characteristics for each of the five levels.

Communication Function Classification System

The Communication Function Classification System (CFCS) describes everyday communication performance in children with CP. Consistent with the GMFCS and MACS, there are 5 levels. Classification is based on how the child usually takes part in everyday situations requiring communication, regardless of communication method. The CFCS can be used for children aged 2 – 18 years. It is available for download, free of charge, on the CFCS website: www.cfcs.us/.

Determining a child's CFCS level takes only a few minutes. The CFCS is best completed by someone who knows the child. Classification is based on the child's usual performance, not their best ability or potential. All methods of communication are considered when selecting a CFCS level, including use of speech, gestures, behaviors, eye gaze, facial expressions, and augmentative and alternative communication. The child's performance as a sender and receiver of communication, the pace of communication, and whether the conversational partner is familiar or unfamiliar are considered. The User Instructions provides descriptions for each of the five levels.

GMFCS describes gross motor function only and does not predict function in other areas. By also using the MACS and CFCS, the overall functioning of the child can be described.

Hip Surveillance: The Basics

- Clinical exam findings are a poor indicator of hip displacement. Both clinical exams and x-rays are necessary.
- Displacement is often silent. In some cases, there are no signs until the hip is fully dislocated.
- Risk of hip displacement is directly related to a child's motor function (GMFCS level).
- Children with spasticity, hyperkinetic movement disorders (e.g. dystonia), and hypotonic are all affected.
- Hip displacement can start early, as young as age 1 or 2 years.
- Children can (and should) be enrolled as soon as they are suspected of having CP; a diagnosis is not required.
- CP is an umbrella term and includes a wide array of etiologies.
- A physician's referral is NOT required for a child to be enrolled in the Child Health BC Hip Surveillance Program.
- Children at GMFCS levels III, IV, and V are at highest risk of hip displacement; they are followed until skeletal maturity.
- Most children with hemiplegia are at low risk (GMFCS level I and II) and are discharged at age 5 (GMFCS level I) or age 10 (level II). Children with a group IV hemiplegic gait pattern require monitoring until skeletal maturity. Look for a hip that is flexed, adducted, and internally rotated.
- Migration percentage (MP) is the proportion of the femoral head outside of the lateral edge of the acetabulum. When MP > 30%, a child be referred to a pediatric orthopaedic surgeon.
- Surveillance occurs close to home; only if there is a concern will a child be referred to a pediatric orthopaedic surgeon.
- Children can be referred to a pediatric orthopaedic surgeon in Vancouver, Victoria, Prince George, New Westminster, Calgary or Edmonton – whichever is closest to home.

Happy Holidays!

From our team to yours, wishing everyone a happy holiday season and all the best in 2019!

(L to R) Kishore Mulpuri, Medical Lead, Jennifer Farr, Program Assistant, Stacey Miller, Coordinator

Need more program materials?

Contact us if you need additional clinician booklets, family booklets, Quick Guide posters, or our new "EARLY" poster (see page 3).

Updated family booklets in Simplified and Traditional Chinese, Punjabi, Korean, and Arabic will be available in January 2019. Please let us know if you would like copies!

Visit our website: www.childhealthbc.ca/hips to find all of our family and clinician resources.

Questions, thoughts, comments, concerns....we want to hear from you. Contact Stacey or Jennifer at hips@cw.bc.ca or 1-888-300-3088 ext. 4099.