

State of California—Health and Human Services Agency Department of Health Care Services



EDMOND G. BROWN JR Governor

DATE: March 8, 2017

N.L.: 07-0317 Index: Medical Therapy Program

- TO: ALL CALIFORNIA CHILDREN'S SERVICES (CCS) PROGRAM COUNTY ADMINISTRATORS, MEDICAL DIRECTORS, SUPERVISING THERAPISTS, MEDICAL THERAPY UNITS, SYSTEMS OF CARE DIVISION REGIONAL OFFICE ADMINISTRATORS, MEDICAL DIRECTORS AND THERAPY CONSULTANTS
- SUBJECT: ESTABLISHMENT OF HIP SURVEILLANCE PROGRAMS IN THE CALIFORNIA CHILDREN'S SERVICES (CCS) PROGRAM, MEDICAL THERAPY PROGRAM (MTP)

I. PURPOSE

The purpose of this Numbered Letter (N.L.) is to provide county CCS Program MTPs best practice guidelines for establishing a hip surveillance program for children with Cerebral Palsy (CP). The goal of hip surveillance is to provide early screening, detection and intervention to reduce the incidence of hip dislocation and later hip reconstruction/salvage surgeries. This letter demonstrates the Systems of Care Division's (SCD) support for hip surveillance programs and the valuable service they provide for CCS MTP clients.

II. BACKGROUND

The CCS Program's MTP was established by the state legislature in 1945 to provide services to a growing population of children in the state with CP. Since that time, a number of other diagnoses have been included as medically eligible for the MTP, but the CP diagnosis remains a large portion of the overall caseload. A significant percentage of children with CP are at high risk of developing progressive hip dysplasia. This can affect a child's mobility (ability to sit, stand or ambulate), their ability to perform Activities of Daily Living (ADLs), and their overall quality of life. Research has established that early surveillance of targeted groups can minimize or eliminate the need for later limb salvaging procedures. These surgeries have a significant intrusive impact on the child/family as well as a fiscal impact on CCS Program. A correlation has been demonstrated between hip

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displacement and Gross Motor Functional Classification System (GMFCS) level in children with CP. CCS Program implemented the use of this functional classification tool in February 2014 (NL 02-0214).

There are a number of hip surveillance programs, both national and international, that share common elements in purpose and implementation. However, most current hip surveillance programs have their basis in the following two models: the Australian Academy of Cerebral Palsy and Developmental Medicine and the Swedish *UPPFÖLJNINGSPROGRAM for Cerebral Pares* (CPUP). They have completed the most comprehensive and rigorous evaluation and testing to validate their approach. In addition, Shriners Hospitals has designed a smartphone application "HipScreen" for hip surveillance that is based on the Australian model and can be used as a tool to measure a hip x-ray directly from the device.

The following are links to these hip surveillance programs/tools:

Australian: <u>https://ausacpdm.org.au/professionals/hip-surveillance/australian-hip-surveillance-guidelines/</u>

Swedish: www.cpup.se

Shriners HipScreen App: <u>http://shrinerschildrens.org/shriners-hospital-leads-collaborative-effort-for-early-detection-of-hip-disorders-in-children-with-cerebral-palsy/</u>

This policy was developed with the assistance of local county CCS MTP Physical Therapist (PTs) and Occupational Therapist (OTs) participating in the hip surveillance work group under the guidance of the Medical Therapy Program Advisory Committee (MTPAC).

III. POLICY

The SCD supports local county CCS program involvement in hip surveillance. The SCD will not make hip surveillance mandatory. At this time, county participation is optional, though firmly encouraged. The local county CCS program will also have the option of utilizing one of the models mentioned in the background based on which will best meet the county needs, program organization and demographics. However, this N.L. will outline elements that must be included in any hip surveillance program, regardless of which model the county chooses to utilize. They are as follows:

- A. Therapists in the Medical Therapy Unit (MTU) will assess and document the patient's GMFCS level score each time the child is evaluated/re-evaluated. More information regarding this function classification can be found in NL 02-0214.
- B. Therapists will consistently evaluate/document the following hip dysplasia indicators:

- 1. Hip abduction/extension ranges (especially hip abduction decreased to below 30 degrees)
- 2. Asymmetry of hip range
- 3. Reports/observation of hip pain each time the child is checked/evaluated.
- 4. Wind-swept deformity of the hip
- 5. Pelvic obliquity
- 6. Leg length discrepancy
- 7. Scoliosis progression
- 8. A decrease in function as a result of the presence of any of these indicators.

These findings will be reported to the Medical Therapy Conference (MTC) or CCS Program paneled private physician who is case managing the MTP eligible condition for evaluation and possible referral for X-ray.

- C. Family education, including written policies and procedures.
- D. Clinical exam upon initial determination of CP diagnosis, and hip X-ray as indicated by GMFCS level and hip surveillance model.
- E. Early evaluation for stander usage/program, especially for those at greatest risk for hip dislocation, GMFCS levels III-V.
- F. X-rays that show a migration percentage of less than 30 but <u>advancing</u> will require the assessment for and, when indicated, the development of a standing program and home exercise program (HEP) specifically targeted at minimizing hip migration.
- G. X-rays that show a migration percentage of 30 or greater will result in a referral to a CCS Program paneled orthopedic specialist who follows a hip surveillance protocol.
- H. Children who are part of the local county CCS Program's MTP hip surveillance and are GMFCS levels III-V shall have X-rays completed <u>not</u> less than annually between the ages of 12 months (or upon initial determination of CP diagnosis) and eight (8) years of age if the hip is deemed unstable by the managing physician.
- I. X-ray protocol (see attachment or Shriners HipScreen App) will be utilized to assure consistency in positioning for x-rays and resulting hip migration measurements. There are two versions available for use, with one being for physicians who are familiar with the hip surveillance program and one for those who are not.

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The local County CCS Program MTPs should work collaboratively with their local CCS Program paneled orthopedic surgeons in developing a hip surveillance program. Their participation/support is critical for the program to succeed. All families who participate in the hip surveillance program will receive the education support needed to accomplish the program goals. Families that are not followed in the MTC or by a CCS Program paneled private physician approved to medically case manage their child's MTP eligible condition should be educated about how to advocate for their children to complete the elements required for hip surveillance through their private insurance.

IV. IMPLEMENTATION

Research indicates that it is highly feasible to prevent dislocation of the hip and resulting hip salvage procedures in children with CP through implementation of a hip surveillance program. Any local county CCS Program MTP that decides to implement a hip surveillance program will need to develop a process that both identifies and acts on information gathered regarding a child's hip health. This includes methods of identifying at risk children, protocols for therapy evaluations, process of notification of families and physicians, X-ray procedures and tracking hip migration as well as follow-up of physician recommendations. Children who participate in a hip surveillance program must be financially eligible for CCS Program/Medi-Cal or the family will need to work with their private insurance provider to insure that X-rays and appropriate medical assessments are completed on schedule.

The CMSNet MTP Module has been modified to accept GMFCS scores and other hip surveillance data. Any county program that chooses to implement a hip surveillance program is expected to utilize the CMSNet MTP Module data collection/reporting system or, an alternative system designed to collect/report the same data identified in the CMSNet MTP Module.

If you have any questions regarding this policy, please contact Jeff Powers, PT Consultant at (916) 327-3027 or via e-mail at jeff.powers@dhcs.ca.gov. Thank you for your assistance.

Sincerely,

ORIGINAL SIGNED BY McCLELLAND

Pat McClelland, Chief Systems of Care Division Department of Health Care Services

Attachments

Cerebral Palsy Hip Surveillance X-RAY Request Form

Name:	
CCS #:	

DX: DOB:

Study Requested: Supine Anterior-Posterior Pelvis X-Ray

Positioning details:

Children should be positioned as follows:

- Pelvis horizontal
- Hips and legs in neutral adduction/abduction
- Patella pointing forward (feet may not necessarily point up)
- If a hip flexion contracture is present, position the lower legs on pillows to prevent anterior pelvic tilt and lumbar lordosis



Positioning Illustrations © Steve Dana and Vedant Kulkarni. Pelvic illustrations obtained from Australian Hip Surveillance Guidelines for Children with Cerebral Palsy 2014. www.ausacpdm.org.au/professionals/hip-surveillance

Questions? Please call

License #

Cerebral Palsy Hip Surveillance X-RAY Request Form

Name:			
CCS#:			

DOB: Diagnosis:

Study Requested: Supine Anterior-Posterior (AP) Pelvis X-Ray

Positioning details:

Children should be positioned as follows:

• Pelvis horizontal. Hips and legs in neutral adduction/abduction. Patellae pointing forward (feet may not necessarily point up). If a hip flexion contracture is present, position the lower legs on pillows to prevent anterior pelvic tilt and lumbar lordosis



Reason For Request:

Please report the **Migration Percentage (MP) for** <u>each hip</u>, defined as the percent of ossified femoral head that is not covered by the ossified acetabular roof. In the left-sided figure below, Migration Percentage = A / B x 100%.

- "H" line Hilgenreiner's horizontal line connecting open tri-radiate cartilage
 - If triradiate cartilage is closed, horizontal may be established by the alternative lines shown in the right-sided image, the Iliac Crest Line, Inter Teardrop Line, or Inter Tuberosity Line
- "P" line Perkin's perpendicular line at lateral edge of ossified acetabulum



Positioning Illustrations © Steve Dana and Vedant Kulkarni. Pelvic illustrations obtained from Australian Hip Surveillance Guidelines for Children with Cerebral Palsy 2014. <u>https://ausacpdm.org.au/professionals/hip-surveillance/australian-hip-surveillance-guidelines/</u>



Children with cerebral palsy are at a high risk of developing hip problems:

- Over one-third of children with cerebral palsy will develop hip displacement or dysplasia.
- 20% of children with moderate and severe cerebral palsy will develop a hip dislocation.
- Half of children with a hip dislocation will develop pain and problems with sitting.

Research indicates that regular examinations and screening x-rays, called "Hip Surveillance," can identify these problems in the early stages, leading to more effective treatment strategies and improved outcomes.

HipScreen is a free app to empower implementation of a hip surveillance program. It can be downloaded from the website <u>www.hipscreen.org</u>, or through the Apple App StoreTM (and soon to be released for Android phones through Google PlayTM).



Disclaimers:

- HipScreen does not store or transmit any data captured by the user. Please comply with HIPAA guidelines, and do not photograph any personally identifiable information on your device.
- Do not rely on the information from the HipScreen App as an alternative to medical advice from a doctor or other professional healthcare provider.

References:

2.Dobson F, et al. Hip surveillance in children with cerebral palsy: Impact on the surgical management of spastic hip disease. Journal of Bone and Joint Surgery [Br] 2002; 84-B:720-6.

^{1.} Cooperman DR, et al. Hip dislocation in spastic cerebral palsy: long term consequences. Journal of Pediatric Orthopaedics 1987;7:268-76.

^{3.}Hagglund G, et al. Prevention of dislocation of the hip in children with cerebral palsy: 20-year results of a population-based prevention programme. Bone Joint Journal 2014;96-B:1546-52.

^{4.} Jung NH, et al. Does hip displacement influence health-related quality of life in children with cerebral palsy? Developmental Neurorehabilitation. 2014;17(6):420-5.

Hip Surveillance is a way for your medical team to find hip problems quickly and stop them from getting worse.

<u>Hip surveillance means</u> checking your child's hips regularly and helping you get x-rays of your child's hips when your child needs them.

Why do we want to do hip surveillance?

- Children with cerebral palsy are more likely to have a hip problem, called "hip dysplasia."
- Hip dysplasia is when the thigh bone (femur) and the hip bone (pelvis) don't grow into the right shape for the hip joint to work well.
- Hip dysplasia can lead to "hip dislocation" (where the thigh bone doesn't stay tight against the bone of the pelvis anymore).



Figure adapted from: <u>http://whenithurtstomove.org/about-orthopaedics/joint-anatomy/hip/hip-dysplasia/</u> Accessed 9/7/2016.

- Hip dislocation may be painful and may lead to problems with sitting, standing, and changing clothes or diapers.
- Research has shown that children are more likely to get hip dysplasia if they are unable to move or stand.
- Researchers in Australia and Sweden have found that we can prevent hip dislocation by doing regular x-rays and hip exams.

What can I expect from hip surveillance?

- When x-rays show that there is hip dysplasia, your therapist or doctor can recommend that a specialist sees your child quickly.
- Specialists (usually surgeons) can tell you the options that may help stop hip dysplasia from becoming hip dislocation.
- By carefully watching for hip dysplasia on a regular schedule, we can give you and your child better help to keep their hips as healthy as possible.

How do we decide when your child should have a hip x-ray?

- The Gross Motor Function Classification Scale (GMFCS) is tool used all over the world to group children with cerebral palsy by their movement skills.
- The GMFCS has five levels, I through V. Children at Level I are walking, while children at Level V use a wheelchair and are unable to move themselves.
- The higher the GMFCS level, the more likely a child is to get hip dysplasia.



Graph adapted from: Soo B, Howard JJ, Boyd RN, et al. Hip displacement in cerebral palsy. J Bone Joint Surg Am. 2006 Jan;88(1):121-9.

• Children who are more likely to have hip dysplasia will need their hips checked more regularly and will need x-rays more often. (We can provide a chart to help you see when your child will need to be checked and x-rayed if you are interested).

Want more information?

We have more references on various hip surveillance programs, if you are interested.

References for Hip Surveillance Programs

AUSTRALIA: https://ausacpdm.org.au/professionals/hip-surveillance/australian-hip-surveillance-guidelines/

SWEDEN: http://cpup.se/in-english/

BRITISH COLUMBIA, CANADA: http://childhealthbc.ca/hips

UNITED KINGDOM:

- Spasticity in children and young people—Support for education and learning: practice-based implementation advice: NHS
 National Institute for Health and Clinical Excellence, September 2012: https://www.nice.org.uk/guidance/CG145
- Surveillance of Cerebral Palsy in Europe: <u>http://www.scpenetwork.eu/en/about-scpe/</u>

CALIFORNIA CENTER FOR PUBLIC HEALTH ADVOCACY:

• Surveillance to Salvage Seminar: http://shrinerschildrens.org/cphip/

SHRINERS HOSPITALS FOR CHILDREN – NORTHERN CALIFORNIA: www.hipscreen.org

RESEARCH ARTICLES:

Elkamil A, Andersen G, Hagglund G, et al. Prevalence of hip dislocation among children with cerebral palsy in regions with and without a surveillance programme: a cross sectional study in Sweden and Norway. Musculoskeletal Disorders 2011, 12:284.

Gordon GS, Simkiss DE. A systematic review of the evidence for hip surveillance in children with cerebral palsy. J Bone Joint Surg Br. 2006 Nov; 88(11):1492-6.

Hägglund G, Alriksson-Schmidt A, Lauge-Pedersen H, et al. Prevention of dislocation of the hip in children with cerebral palsy: 20-year results of a population-based prevention programme. Bone Joint J. 2014 Nov; 96-B (11):1546-52.

Hermanson M, Hagglund G, Riad J and Wagner P. Head-shaft angle is a risk factor for hip displacement in children with cerebral palsy. Acta Orthopaedica 2015, 86 (2): 229-232.

Kentish M, Wynter M, Snape N, Boyd R. Five-year outcome of state-wide hip surveillance of children and adolescents with cerebral palsy. J Pediatr Rehabil Med. 2011; 4(3):205-17.

Larnert P, Risto O, Hagglund G, Wagner P. Hip displacement in relation to age and gross motor function in children with cerebral palsy. J Child Orthop 2013, 8:129-134.

Murnaghan ML, Simpson P, Robin JG, et al. The cerebral palsy hip classification is reliable: an inter- and intra-observer reliability study. J Bone Joint Surg (Br) 2010, 92-B 436-41.

Robb JE, Hagglund G. Hip surveillance and management of the displaced hip in cerebral palsy. J Child Orthop 2013, 7:407-4138.

Shore B, Spence D, Graham H. The role for hip surveillance in children with cerebral palsy. Curr Rev Musculoskelet Med. 2012 Jun; 5(2):126-34.

Soo B, Howard JJ, Boyd RN, et al. Hip displacement in cerebral palsy. J Bone Joint Surg Am. 2006 Jan; 88(1):121-9.

Wynter M, Gibson N, Kentish M, et al. The Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care. J Pediatr Rehabil Med. 2011; 4(3):183-95.

Wynter M, Gibson N, Willoughby KL, et al. National Hip Surveillance Working Group. Australian hip surveillance guidelines for children with cerebral palsy: 5-year review. Dev Med Child Neurol. 2015 Sep;57(9):808-20.

La vigilancia de la cadera es una manera para que su equipo médico pueda encontrar rápidamente problemas de la cadera y evitar que empeoren.

La vigilancia de la cadera significa revisar regularmente las caderas de su hijo y ayudarle a obtener radiografías de las caderas de su hijo cuando su hijo las necesite.

¿Por qué queremos hacer la vigilancia de la cadera?

- Los niños con parálisis cerebral son más propensos a tener un problema de la cadera, llamado "displasia de cadera."
- La displasia de cadera es cuando el hueso del muslo (fémur) y el hueso de la cadera (pelvis) no crecen en la forma correcta para que la articulación de la cadera funcione bien.
- La displasia de cadera puede conducir a laa "dislocación de la cadera" (donde el hueso del muslo ya no permanece alineado correctamente contra el hueso de la pelvis).



Displasia de Cadera Subluxación Dislocación Figura adaptada de: http://whenithurtstomove.org/about-orthopaedics/joint-anatomy/hip/hip-dysplasia/ Accedida 9/7/2016.

La dislocación de cadera puede ser dolorosa y puede conducir a problemas en sentarse, en

parase, y en cambiar la ropa o los pañales.

- Las investigaciones han demostrado que es más probable que los niños tendrán displasia de la cadera si son incapaces de moverse o estar de pie.
- Los investigadores en Australia y Suecia han descubierto que podemos evitar la dislocación de cadera haciendo radiografías y exámenes de la cadera con regularidad.

Cadera Normal

¿Qué puedo esperar de la vigilancia de la cadera?

- Cuando las radiografías muestran que hay displasia de cadera, su terapeuta o médico puede recomendar que un especialista vea a su hijo rápidamente.
- Los especialistas (usualmente cirujanos) pueden decirle las opciones que puedan ayudar a evitar que la displasia de cadera se convierta en dislocación de cadera.
- Al vigilar atentamente la displasia de cadera en un horario regular, podemos ofrecer a usted y a su hijo mejor ayuda para mantener las caderas lo más saludables posible.

¿Cómo decidimos cuándo su hijo debe tener una radiografía de la cadera?

- La Escala de Clasificación de la Función de la Motor Gruesa (GMFCS) es una herramienta utilizada en todo el mundo para agrupar a los niños con parálisis cerebral por sus habilidades de movimiento.
- El GMFCS tiene cinco niveles, I a V. Los niños del Nivel I caminan, mientras que los niños del Nivel V usan sillas de ruedas y son incapaces de moverse por sí mismos.
- Cuanto mayor sea el nivel de GMFCS, lo más probable que un niño desarrollará displasia de la cadera.



Grafica adaptada de: Soo B, Howard JJ, Boyd RN, et al. Hip displacement in cerebral palsy. J Bone Joint Surg Am. 2006 Jan;88(1):121-9.

 Los niños que son más propensos a tener displasia de cadera necesitarán que sus caderas sean revisadas más regularmente y necesitarán radiografías con más frecuencia. (Podemos proporcionar un cuadro para ayudarle a ver cuándo su hijo necesitará ser revisado y necesitará radiografías, si está interesado).

¿Quiere más información?

Tenemos más referencias acerca de varios programas de vigilancia de cadera, si está interesado.

Referencias para Programas de Vigilancia de la Cadera

AUSTRALIA: https://ausacpdm.org.au/professionals/hip-surveillance/australian-hip-surveillance-guidelines/

SWEDEN: http://cpup.se/in-english/

UNITED KINGDOM:

- Spasticity in children and young people—Support for education and learning: practice-based implementation advice: NHS
 National Institute for Health and Clinical Excellence, September 2012: https://www.nice.org.uk/guidance/CG145
- Surveillance of Cerebral Palsy in Europe: <u>http://www.scpenetwork.eu/en/about-scpe/</u>

CALIFORNIA CENTER FOR PUBLIC HEALTH ADVOCACY:

Surveillance to Salvage Seminar: <u>http://shrinerschildrens.org/cphip/</u>

ARTÍCULOS DE INVESTIGACIÓN:

Elkamil A, Andersen G, Hagglund G, et al. Prevalence of hip dislocation among children with cerebral palsy in regions with and without a surveillance programme: a cross sectional study in Sweden and Norway. Musculoskeletal Disorders 2011, 12:284.

Gordon GS, Simkiss DE. A systematic review of the evidence for hip surveillance in children with cerebral palsy. J Bone Joint Surg Br. 2006 Nov; 88(11):1492-6.

Hägglund G, Alriksson-Schmidt A, Lauge-Pedersen H, et al. Prevention of dislocation of the hip in children with cerebral palsy: 20-year results of a population-based prevention programme. Bone Joint J. 2014 Nov; 96-B (11):1546-52.

Hermanson M, Hagglund G, Riad J and Wagner P. Head-shaft angle is a risk factor for hip displacement in children with cerebral palsy. Acta Orthopaedica 2015, 86 (2): 229-232.

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Wynter M, Gibson N, Kentish M, et al. The Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care. J Pediatr Rehabil Med. 2011; 4(3):183-95.

Wynter M, Gibson N, Willoughby KL, et al. National Hip Surveillance Working Group. Australian hip surveillance guidelines for children with cerebral palsy: 5-year review. Dev Med Child Neurol. 2015 Sep;57(9):808-20.