New guidelines for parents and caregivers

when advocating for early detection and diagnosis of cerebral palsy

1 Diagnosis of cerebral palsy (CP) can and should be made as early as possible. It can often be made under 6 months of age. If it cannot be made with certainty, the interim 'high risk' of cerebral palsy should be given.

MOTOR DYSFUNCTION + ABNORMAL NEURO IMAGING + CLINICAL HISTORY

2 Scientific tests should be carried out to detect risk of cerebral palsy in all infants who are born prematurely, infants admitted to a neonatal intensive care unit (NICU) and infants with neonatal encephalopathy and infants with birth defects.

Early detection before 5 months (corrected age for prematurity)

The most accurate tools to detect the risk of cerebral palsy are the combination of brain MRI, Prechtl's Qualitative General Movements Assessment (GMs) and talking to families about risk factors.

MOTOR DYSFUNCTION + ABNORMAL NEURO IMAGING

3 The General Movements Assessment (GMs) is a video assessment of your baby lying on their back, which can be assessed by certified scorers for risk of cerebral palsy. The video can be taken from birth up to 20 weeks corrected age.

MOTOR DYSFUNCTION

A brain MRI can be ordered by a doctor. In very young babies it can be performed during sleep without the need for sedation.

ABNORMAL NEURO IMAGING

When the General Movements (GMs) assessment or MRI is not available (such as countries with limited resources) a specific neurological examination called the Hammersmith Infant Neurological Examination (HINE) is most predictive of cerebral palsy. In addition, a specific test of your baby's posture and movement skills, the Test of Infant Motor Performance (TIMP), is also recommended.

STANDARDISED NEURO EXAM + MOTOR DYSFUNCTION

4 The HINE can be performed and scored by a doctor or experienced clinician.

STANDARDISED NEURO EXAM

The TIMP can be performed and scored by an experienced clinician.

MOTOR DYSFUNCTION

Early detection after 5 months (corrected age for prematurity)

Accurate early detection of 'high-risk' of cerebral palsy in those aged 5–24 months can and should still occur as soon as possible, but different diagnostic tools are required.

5 Any infant with:
(a) inability to sit independently by 9 months; or
(b) hand function asymmetry: strong early preference for one side; or
(c) inability to take weight with feet flat on the floor
should receive standardised investigations for cerebral palsy.

6 The most accurate tools to predict cerebral palsy after 5 months corrected age along with talking to families about risk factors, are MRI and HINE neurological examination.

STANDARDISED NEURO EXAM + ABNORMAL NEURO IMAGING

Specific tests of movement and development called the Developmental Assessment of Young Children (DAYC) and the Alberta Infant Motor Scale (AIMS) are also recommended and can be performed and scored by experienced clinicians.

MOTOR DYSFUNCTION

Adapted with permission from: Novak et al 2017. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy. *JAMA Pediatr.* 2017;171(9):897-907. doi:10. 1001/jamapediatrics.2017.1689 Available from: http://jamanetwork.com/journals/jamapediatrics/article-abstract/2636588

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7 If MRI is not available or safe, the Hammersmith Infant Neurological Examination (HINE) is strongly recommended.

STANDARDISED NEURO EXAM

Specific movement development assessments called the DAYC and Motor Assessment of Infants (MAI) are also recommended.

ABNORMAL NEURO IMAGING

Early assessment of severity of cerebral palsy

The Gross Motor Function Classification System (GMFCS), is the most accurate tool for assessing severity of cerebral palsy, and is best used in children over the age of 2 years.

8 Clinicians should be cautious of prognosis of severity under the age of 2 years and should always use standardised tools. Severity in children under 2 years is more accurately predicated using the standardised neurological (HINE) and MRI.

STANDARDISED NEURO EXAM + ABNORMAL NEURO IMAGING

Early detection of type of cerebral palsy

9 In a child under 2 years, it can be difficult to predict what type of cerebral palsy is present (e.g. spastic or dystonic) and what bodily movement control may be affected.

It is important to try to identify if both sides of the body are affected (bilateral) or predominantly one (unilateral), as the early intervention and types of surveillance required will be different.

Early intervention

10 A diagnosis of cerebral palsy should always be followed by referral to cerebral palsy specific early intervention. Parent concern is a valid reason to trigger formal diagnostic investigations and referral for early intervention.

Early detection of associated impairments

11 A diagnosis of cerebral palsy or high risk of cerebral palsy should always include standardised medical investigations for associated problems such as sleep disorders, vision impairment, hearing impairment and epilepsy.

Communicating the diagnosis

12 It is common for parents to experience grief and loss at the time of receiving a diagnosis or notification of high risk of cerebral palsy. Your multidisciplinary team will support the diagnosis through tailored communication and the facilitation of ongoing parent supports as you begin your journey into early intervention.

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Cerebral Palsy ALLIANCE

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