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.

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.

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.

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

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.

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

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

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.

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.

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.

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.

EARLY DIAGNOSIS – CEREBRAL PALSY

New guidelines for parents and caregivers when advocating for early detection and diagnosis of cerebral palsy

1. 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.

2. Early detection of severity of cerebral palsy

   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 predicted using the standardised neurological (HINE) and MRI.

3. Early detection of type of cerebral palsy

   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.

4. Early intervention

   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.

5. Early detection of associated impairments

   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.

6. Communicating the diagnosis

   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.