

# Early Detection of Infants at High Risk for Cerebral Palsy

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## What is the Concern?

- ❑ Cerebral Palsy (CP) is the most common physical disability
- ❑ 2.3 children in every 1,000 in US
- ❑ Typically diagnosed at **age 2 years** or later for milder cases
- ❑ The cause of CP is unclear in about 80% <sup>1</sup>

## Why is Delayed Identification a Problem?

- ❑ Little to no intervention during the critical period of brain plasticity
  - *Corticospinal tract changes occur before 12 months of age*
- ❑ Intervention services and surveillance occurs late or with less intensity
- ❑ Focused intervention – specific evidence-based practices are available
- ❑ *Strong recommendation against “Wait and See”*

## What is the Advantage of Early Detection?

- ❑ Infant can receive diagnostic-specific early intervention to optimize neuroplasticity, prevent complications and reduce impairments
- ❑ Ongoing diagnostic monitoring and surveillance can be provided

## Parents tell us

- ❑ Research has shown that parents prefer to know early rather than late <sup>2</sup>
- ❑ Risk – Delayed diagnosis is harmful as parents are more likely to experience depression / anger
- ❑ Benefits – Early detection allows for
  - Parent participation in intervention as well as coping and emotional support
  - Potential financial support and services

## How is Early Identification of Risk Possible?

- ❑ An infant's motor impairment can now be detected very early and accurately with standardized tools.
  - Hammersmith Infant Neurological Examination (HINE)
  - HINE score <57 at 3 mos is 96% predictive of CP <sup>3</sup>
  - General Movement Assessment (GMA)
  - GMA is 95-98% predictive of CP <sup>3</sup>
- ❑ *The most accurate method for early detection of CP with newborn detectable risks and age <5 months is to use a standardized assessment of movements and neuroimaging and history taking about risk factors. Strong recommendations based on high quality evidence <sup>4</sup>*

## Implementation of Risk Detection

### Program

#### UTAH

- ❑ Programmatic QI initiative involving Neuro NICU Steering Committee and Neonatal Follow-up Program (NFP)
- ❑ Training on the GMA and HINE supported and provided by the Cerebral Palsy Foundation
- ❑ Several PDSA cycles to implement process change
- ❑ Key personnel: NICU therapists, Pediatric Neurologist on NeuroNICU Steering Committee, NP in NFP, therapists, and Medical Director of NFP, Nurse Coordinator in NFP

#### NEW MEXICO

- ❑ Interagency and interdisciplinary task force meeting monthly
- ❑ Task force developed mission, goals and objectives
- ❑ Task force members completed literature review and members pursued training in screening tools –UTAH LEND HINE training
- ❑ Task force members beginning to educate workforce
- ❑ Met with legislative committee to advocate for funding

#### References:

1. Nelson, KB. Causative factors in cerebral palsy. Clin Obstet gynecol.2008;51(4):749-762.
2. Baird G, McConachie H, Scrutton D. Parents' perceptions of disclosure of the diagnosis of cerebral palsy. Arch Dis Child 2000; 83: 475-80.
3. Novak, I., Morgan, C., Adde, L., et al. Early accurate diagnosis and early intervention in cerebral palsy: Advances in diagnosis and treatment. JAMA Pediatr. 2017; 171(9): 897-907.
4. Novak, I., Morgan, C., Adde, L., Brunstrom-Hernandez, J., Blackman, J., et al. (2017). Early detection and diagnosis of cerebral palsy and “high-risk of cerebral palsy”. International Clinical Practice Guideline.

