

A Call for Using Checklists in Infants at High Risk for Cerebral Palsy

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Faith Kim, MD, and Nathalie Maitre, MD, PhD, NeoReviews Authors

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In the January 2024 issue of *NeoReviews*, we wrote a Perspectives piece titled “A Call for Early Detection of Cerebral Palsy” (10.1542/neo.25-1-e1). The article highlights the history behind early cerebral palsy (CP) detection and provides evidence for validated tools that can be used in NICUs and high-risk infant follow-up programs. Historically, disclosure of a diagnosis even when suspected was often delayed due to multiple barriers, ranging from lack of biomarkers to perceived stigma associated with an incurable diagnosis. However, there is an overall positive perception of early detection by parents, granting them more timely psychological support and an earlier start to seek out interventions to improve their child’s developmental trajectory during a critical period of neuroplasticity. As briefly mentioned at the end of our article, in order to facilitate earlier conversations with families when considering CP, the Early CP Detection and Intervention Network and the Canadian Neonatal Follow-Up Network published a 2022 consensus statement advocating for the use of a “high-risk for CP (HRCP)” designation in two scenarios: 1) an assessment was not performed or had a negative result but other data suggested CP; 2) evaluation of a child for the first time before two years suggests CP, but no previous concerns or assessments are available.¹

Essential components that should be considered for the designation are complex, and situations in which it is applied can be fraught with the pressures of a busy clinical practice, vulnerable patients, and families still impacted by early trauma. Therefore, we proposed a checklist for structured guidance, to ensure a

consistent and accurate designation given the importance of family conversations and the need for responsible healthcare resource utilization that follow.

Checklists are used daily in various industries and are essential to quality improvement. Dr. Atul Gawande has written extensively about checklist use in medicine to promote safe and efficient knowledge implementation worldwide. Checklists that consider multiple steps of a process (such as follow-through) decrease human error, especially when systems are complex and under pressure.² This is exactly the case for HRCP designation or CP diagnosis in clinic. This can be a daunting experience, particularly for those starting to implement early CP detection.

HRCP discussions with families remain crucial conversations, even for experienced providers.³ Thus, a checklist (Figure 1) provides a systematic approach to a complex, multifaceted process and serves as a communication tool amongst members of interdisciplinary teams. The checklist has three sections:

- Situation 1: Infant with newborn attributable risks—those likely cared for in NICUs with known risk factors.
- Situation 2: Infant with infant attributable risks—those with no established risk factors in the neonatal period, usually referred later when pediatricians or other providers observe developmental concerns.
- Situation 3: When to consider converting from a HRCP designation to a CP diagnosis.

We acknowledge that every family is different, and conversations should be individualized to meet families where they happen to be at the time. This checklist is a simple and limited guide during a time of medical and emotional complexity. We hope it helps support our teams, as we strive to ensure consistent, high-quality, compassionate care.

SITUATION 1 – INFANT WITH NEWBORN ATTRIBUTABLE RISKS	
Consider diagnosis of cerebral palsy (CP) if 6 criteria present (including clinical history) Consider high risk for cerebral palsy (HRCP) designation if 4 criteria + clinical history present (missing 1 diagnostic element) Note MRI OR positive genetic testing for condition count as a single criterion	
☒ Clinical history consistent e.g. prematurity, fetal growth restriction, birth asphyxia, intrauterine drug exposure	☐ Neuroimaging e.g. brain MRI or ultrasound with findings consistent with hypoxic-ischemic encephalopathy, grade 3-4 intraventricular hemorrhage, hydrocephalus, stroke, periventricular leukomalacia, sequelae of infection
☐ Neurological exam consistent e.g. hypertonia, dystonia, head lag, absent parachute reflex in infant >12 months, hyperreflexia	☐ QR if MRI unremarkable then genetic testing consistent e.g. Lesch-Nyhan syndrome
☐ Motor function impaired e.g. clinical therapist impression, tests (e.g. TIMP, AIMS, NSMDA) showing delay or impairment	☐ GMA e.g. cramped synchronized (suggestive of spastic CP), absent fidgety
	☐ HINE scores consistent e.g. Total score for age below expected cut-offs, asymmetry score age 9 months
SITUATION 2 – INFANT WITH ONLY INFANT ATTRIBUTABLE RISKS/FIRST EVALUATION	
Consider HRCP designation if 4 criteria present (missing 1 diagnostic element) Note MRI OR positive genetic testing for condition count as a single criterion	
☐ Neurological exam consistent e.g. hypertonia, dystonia, head lag, absent parachute reflex in infant >12 months, hyperreflexia	☐ Neuroimaging e.g. brain MRI or ultrasound with findings consistent with hypoxic-ischemic encephalopathy, grade 3-4 intraventricular hemorrhage, hydrocephalus, stroke, periventricular leukomalacia, sequelae of infection
☐ Motor function impaired e.g. clinical therapist impression, tests (e.g. TIMP, AIMS, NSMDA) showing delay or impairment	☐ QR if MRI unremarkable then genetic testing consistent
☐ HINE scores consistent e.g. Total score for age below expected cut-offs, asymmetry score age 9 months	☐ GMA e.g. cramped synchronized (suggestive of spastic CP), absent fidgety
SITUATION 3 – CONVERTING FROM HRCP TO CP	
Consider conversion to CP diagnosis if 4 criteria present	
☐ Repeat Neurological Examination consistent between visits	☐ Motor function impaired and not improving without intervention
☐ Neuroimaging consistent OR Genetic testing consistent	☐ Repeat HINE scores consistently below cut-offs or asymmetry score > 5 at 9 months

Figure 1. High Risk for Cerebral Palsy Designation Checklist: Many elements are involved in the diagnosis of cerebral palsy (CP) and high risk for CP (HRCP) designation. This checklist may help with the decision to use the term HRCP, or choose a follow-up per your clinic's protocols. Test of Infant Motor Performance (TIMP), Alberta Infant Motor Scale (AIMS), Neuro-sensory Motor Developmental Assessment (NSMDA).

This document was created by Dr F. Kim, MD, and Professor N. Maitre, MD, PhD, for the Cerebral Palsy Foundation based on the published consensus statement in *J. Pediatric Rehabilitation Medicine* (2022)

References

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