

The logo for the Neonatal Evaluation and Outcomes Network (neo.n) features the lowercase letters 'neo.n' in a blue, rounded, sans-serif font. The 'o' is a solid circle, and the 'n' is a simple vertical bar with a rounded top.

Neonatal Evaluation and Outcomes Network



Alice K. Gong, M.D.

WILLIAM AND RITA HEAD DISTINGUISHED CHAIR IN
DEVELOPMENTAL AND ENVIRONMENTAL NEONATOLOGY

Professor of Pediatrics

UT Health San Antonio

<http://neonatal-net.org/>



TCHMB Summit: Making Quality Improvement Local

Provided by Texas Children's Hospital

February 26th, 27th, 28th, 2020 | Austin, TX | Wednesday: 1:00 pm- 5:00 pm

Thursday & Friday: 8:30 am-5:30pm

CONTINUING MEDICAL EDUCATION (CME) ACCREDITATION

Texas Children's Hospital (TCH) is accredited by the Texas Medical Association to provide continuing medical education for physicians.

CREDIT DESIGNATION

Texas Children's Hospital designates this live activity for a maximum of 17 *AMA PRA Category 1 Credits*™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

CME transcripts available upon request via email:

cme@texaschildrens.org
Please note this survey and certificate retrieval closes 7 days after the activity date

LEARNING OUTCOME(S)

At the conclusion of this continuing professional development activity, the participant will be able to enhance care to reduce global and national maternal mortality by actively participation in the learning activity and intent to change practice on the post activity evaluation.

Objectives:

- Disseminate evidence based best practices content to impact in the reduction of maternal mortality and morbidity rate at local, national and global level
- Discuss concerns, issues and initiatives related to the health, wellbeing and safety of maternal and fetal quality improvements.
- Describe how safety bundles can impact the reduction in disparities in maternal and fetal health outcomes.

CONFLICTS OF INTEREST

Explanation: A conflict of interest occurs when an individual has an opportunity to affect or impact educational content with which he or she may have a commercial interest or a potentially biasing relationship of a financial nature. All planners and presenters/authors/content reviewers must disclose the presence or absence of a conflict of interest relative to this activity. All potential conflicts are resolved prior to the planning, implementation, or evaluation of the continuing nursing education activity. All activity planning committee members and presenters/authors/content reviewers have submitted Conflict of Interest Disclosure forms.

[The activity's Nurse Planner has determined that the following planning committee member(s) and/or presenter(s)/author(s)/content reviewer(s) have a conflict of interest. Those conflicts of interest have been appropriately resolved.]

- Michael Speer, MD, Intellectual Property (patient rights, royalty payments): UpToDate, Walters Kluwer Health

CONTINUING NURSING PROFESSIONAL DEV ELOPMENT

Texas Children's Hospital is an approved provider with commendation of continuing nursing education by the Texas Nurses Association - Approver, an accredited approver with distinction, by the American Nurses Credentialing Center's Commission on Accreditation.

REQUIREMENTS FOR SUCCESSFUL COMPLETION

To receive contact hours for this continuing education activity, the participant must:

- Attend at least one entire day of the two day educational activity
- Sign in to the educational activity
- Complete a participant evaluation online at :

<https://tch-redcap.texaschildrens.org/REDCap/surveys/>

Code: C4PMD9MXP

Once successful completion has been verified, a "Certificate of Successful Completion" will be awarded for 17 contact hour(s). For web link issues, email cne@texaschildrens.org

Joint Provider Statement: This CNE activity has been jointly provided by Texas Children's Hospital collaboratively with:

The Texas Collaborative for Healthy Mothers and Babies (TCHMB).

Objectives

1. Learn about long-term benefits of following-up with all NICU survivors
2. Understand how follow-up programs can help with early diagnosis of Cerebral Palsy
3. Discuss best practices for a robust NICU follow-up program

Prematurity

- IOM describes prematurity as a common complex condition from multiple gene-environmental interactions that lead to several final pathophysiological pathways resulting in early birth
 - Factors include maternal medical conditions, genetics, environmental exposures, assisted reproductive technology, behavior and psychosocial factors, neighborhood and social characteristics
 - Prior preterm birth is strongest risk factor
 - Pathways include inflammation, uterine distention, deteriorating fetal or maternal health
- Preterm outcome studies have reported higher rates of cerebral palsy (CP), intellectual disability, sensory impairment in survivor.
 - Recent studies describe school and behavior problems such as learning disabilities, language, visual-perceptual and attention deficits

This year, in addition to monitoring progress on key indicators, Report Cards include selected state actions to improve maternal and infant health. Premature birth and its complications are the largest contributors to infant death in the U.S., and preterm birth rates have been increasing for four years. Prematurity grades are assigned by comparing the 2018 preterm birth rate to March of Dimes' goal of 8.1 percent by 2020. While it's not yet possible to assign grades for maternal health indicators given the available data, it's clear that rates of maternal death and morbidity are unacceptably high. Maternal health complications, and the social determinants of health, affect the health and survival of both mom and baby. Highlighted on the second page are selected actions available to states to help improve maternal and infant health.

TEXAS

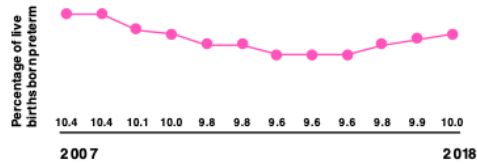
D

PREMATURITY GRADE

PRETERM BIRTH RATE 10.8%

UNITED STATES

PREMATURITY GRADE **C** PRETERM BIRTH RATE **10.0%**



PRETERM BIRTH RATES AND GRADES BY STATE



GRADE	PRETERM BIRTH RATE RANGE	SCORING CRITERIA
A	Preterm birth rate less than or equal to 7.7 percent.	
A-	Preterm birth rate of 7.8 percent to 8.1 percent.	
B+	Preterm birth rate of 8.2 percent to 8.5 percent.	
B	Preterm birth rate of 8.6 percent to 8.9 percent.	
B-	Preterm birth rate of 9.0 percent to 9.2 percent.	
C+	Preterm birth rate of 9.3 percent to 9.6 percent.	
C	Preterm birth rate of 9.7 percent to 10.0 percent.	
C-	Preterm birth rate of 10.1 percent to 10.3 percent.	
D+	Preterm birth rate of 10.4 percent to 10.7 percent.	
D	Preterm birth rate of 10.8 percent to 11.0 percent.	
D-	Preterm birth rate of 11.1 percent to 11.4 percent.	
F	Preterm birth rate greater than or equal to 11.5 percent.	

Puerto Rico is not included in the United States total. Preterm is less than 37 completed weeks of gestation, based on obstetric estimate of gestational age. Source: Preterm Birth rates are from the National Center for Health Statistics, 2018 final natality data. Grades assigned by March of Dimes Perinatal Data Center. © 2019 March of Dimes.

Child Health Inequities

- Social determinants follow social gradient that risk adverse outcome increases with increasing disadvantages.
- Inequities in child health are dependent on exposure to risk and protective factors
 - Exposure is influenced by mother's exposure to risk and protective factors in her own childhood and in pregnancy so that infants are likely born low birth weight, premature and at risk for disability, such as cerebral palsy
- Intergenerational effects contribute to next generation.
- Addressing inequities, societies achieve better health and developmental outcomes
 - Spillover effect on other nonhealthy outcomes

Clinically Significant Stress is major risk factor for preterm birth

- Grappling with serious mental and physical illnesses in self or close family
- Income, food, housing insecurity
- Complicated grief
- Unsafe working conditions
- Threat of gun or police violence
- Lack of access to health care and child care
- Lack of social safety net
- Lack of sense of safety

NICU

- Children born prematurely or sick are cared for by health care providers who have special training and equipment around-the-clock until physiologic stability and have the ability to transition to home care.

Why NICU follow up?

- Improve survival means more survivors with complex needs
 - Multidisciplinary needs
 - Medical, rehabilitative, psychological, social service
- Pediatricians and Family practitioners have less experience with advances in NICU care
- ELBW have high use special outpatient services
- Parent support
- Liaison with community physicians and agencies
- Early identification of developmental disabilities, referral to appropriate agencies
- Poor compliance -> higher rates of disability, lower IQ scores
 - Less access to required ancillary services

AAP Policy: Hospital Discharge of the High-Risk Neonate

Committee on Fetus and Newborn

Pediatrics November 2008, 122 (5) 1119-1126; DOI: <https://doi.org/10.1542/peds.2008-2174>

- Who?:

- Preterm infant
- Infant with special health care needs or technology dependence
- Risk due to family issues
- Anticipated early death

- When?:

- physiologic stability – oral feeding to support appropriate growth, ability to maintain normal body temperature, sufficiently mature respiratory control
- Parents received necessary teaching and demonstrate mastery of essential knowledge and skills.
- Arrangements for follow up

- What needs to happen for transition of care?
 - Individualized home-care plan developed with input from all appropriate disciplines
 - Identification and preparation of in-home caregivers
 - Knowledge of basic infant care
 - Plan for nutritional care and medication administration
 - List of required equipment, supplies, accessible source
 - Primary care physician (medical home) mobilized, initial appointment made
 - Review of hospital course, unresolved medical problems identified, plans for follow up and treatment

- What needs to happen for transition of care?
 - Community support services
 - Specific appointments with pediatric medical and surgical subspecialists as needed
 - Emergency care and transport plan
 - Financial ability to ensure capability to finance home-care costs.
 - Plan for periodic developmental evaluation
 - Follow-up for eye and hearing
 - Car seat evaluation

Medical home

- Approach to providing comprehensive primary care
 - Access and coordinate specialty care, other health care, educational services, in- and out-of-home care, family support
 - Home care services required physician's order
 - Updates plan of care based upon feedback from other members of team

From a parent perspective:

“When we were discharged from the NICU, the doctors kept telling me that I should treat Mira like a “normal” baby. She didn’t need intensive care anymore... She was medically stable...But my anxiety level was still in the stratosphere...I didn’t know how to just let go of the two months of intensive care that were my introduction to being a mother. Prematurity doesn’t end at discharge...

For premature babies, the cascade of development is disrupted at the very beginning... Being in an incubator, even carefully positioned with the best developmental care in the world is not the same as ‘an in-utero’ experience... Premature infants have to find their own cascade.”

Goal of neurodevelopmental follow-up

- Support all at risk babies by identifying problems as early as possible and providing treatments and therapies to promote and support their development and improved outcomes
- Measure of success: families linked to all support services they need after baby is discharged. Things do change after discharge.
- Identify interventions that contribute to improved outcomes
- Help parents decipher all the information.

What is Home care?

- Rehabilitative (PT, OT, SLP)
- Implementing plans of care (coordinating home med equipment, pharmacy, supplies)
- Personal care
- Administration of prescribed medication/therapies (IV nutrition, antibiotics, fluids)
- Respiratory support, CPAP, BiPAP, vent
- Tracheostomy care
- Complex medical and surgical care
- Mobility assistance and transfers
- Educating, training, supporting family
- Hospice

Parents' role at times

- Use of enteral feeding tubes
- Tracheostomy care
- Respiratory treatments and supports
- Wound care
- IV line care
- Medication management
- CPR

Very preterm ELBW Infants have multiple service needs between hospital discharge and 18-22 mo CA

- Visiting Nurse - 58.7%
- OT or PT - 59.9%
- Speech therapy - 33.7%
- Early Intervention - 55.7%
- Social Worker - 25.6%
- Subspecialty care - 68.8%
- Missed opportunities for referral to ECI
- 34% “high concern” infants not referred to ECI

“Every premature baby should get access to developmental care and therapies as they grow, if they need them. We were quite lucky in this regard: Not only did we qualify for our NICU’s excellent follow-up clinic, but Mira also automatically qualified for Early Intervention because she had been born weighing less than 1,000 grams.”

NICU care is very profitable for hospitals so most hospitals want one. Follow-up care is not, so not all hospitals will allocate money for a follow up program.

Neurodevelopmental Domains Affected

- Cognitive deficits
- Motor deficits
 - Gross motor – developmental coordination disorder (16%)
 - DCD associated w/ poorer academic performance (Roberts, DMCN 2011)
 - Fine motor (71%)
 - Cerebral palsy
- Sensory impairments
 - Vision: visual-motor integration /spatial skills (10-20%)
 - Hearing
- Behavioral and psychological problems

Minor Neurodevelopmental Difficulties: High prevalence, low severity dysfunction

- Cognitive
 - Mean IQ 8-14 points lower than Full term
 - Borderline intelligence – IQ 70-84
 - 750-1500 g (20%)
 - < 750 g (33%)
 - < 1000 g (22%) [Gargus, et al. Pediatrics 2009]
- Learning deficits
 - 45% - 65% v. 11% Full term
 - Reading, comprehension, written output, abstract thinking, math skills
 - Memory tasks and processing speed

Minor Neurodevelopmental Difficulties: High prevalence, low severity dysfunction

- ADHD, behavioral social problems
- Executive function deficits
 - Planning
 - Organizing
 - Problem solving
 - Working memory – retrieval
 - Inhibition
 - Attention
- Related to abnormalities neural connectivity involving cortical dorsal stream – parietal, frontal, hippocampal areas

Challenges in Predicting Outcomes

- Available studies/data may not be relevant to current NICU practices and patient population
- Gestational Age vs. birthweight
- Single center vs. MCT trial vs. population-based vs. national
- Varied Assessment tools
- Length of follow-up – age at assessment
- Difficulty in determining the independent effects of biologic vs. environmental factors
- Must often piece together information from various studies to provide families with information that is meaningful and helpful

Minimal age for reliable neurodevelopmental prognosis

- 129 ELBW born between 1993 and 1998 followed to age 6-10 years
- At last follow up exam, 17% showed major impairment
 - 9% CP
 - 42% minor impairment
 - 41% normal
- Longitudinal analysis of cases without CP
 - Assessments at term equivalent correct 49% of cases
 - At 12 mo cCA, prognosis correct in 59%
 - At 3 years, 70% correct
- CP can be confirmed at 2 years with sufficiently reliability

Voss, W. Acta Paediatr, 2007

Impact on Family up to 2 years post NICU discharge

- Greater impact on Family scores (worse effects on family function) were associated with ≥ 3 unpaid hours/week off from work, increase debt, financial worry, unsafe home environment and social isolation.
- Lower parent emotional scores (greater impact) were associated with social isolation, unpaid time off, financial worry, unsafe home
 - Higher parent scores were associated with early intervention and Medicaid.

Lakshmanan et al, Health and Quality of Life Outcomes, 2017

Insurance: It matters!

- $\frac{3}{4}$ Pediatric home health paid by Medicaid
 - Comprehensive home health benefits
 - Part-time or intermittent nursing
 - Home health aide
 - Medical supplies and equipment
 - PT, OT, ST
 - Low payment
- State CHIP
 - 36 states, only 1 does not cover home health services
- Private health insurance
 - Authorization when it is perceived to be cost-effective alternative to hospitalization or outpatient treatment
- Non-group plan
 - Seldom get home health coverage
 - Title V for children with special health care needs

Public Benefits

- Low income families with low birth weight infants may qualify for Supplemental Security (SSI)
 - <1200 grams, < 33 weeks gestation
 - <1500 grams, < 34 weeks
 - <1700 grams, < 35 weeks
 - <1870 grams, < 36 weeks
 - < 2 kg, 37-40 weeks
 - Qualification in 3 ways
 - Under listing for low birth weight as long as child is < 6 months old
 - another listed medical condition
 - Functionally equaling a listed condition
 - Periodic continuing disability reviews (CDRs)



Cerebral Palsy – most common physical disability of childhood

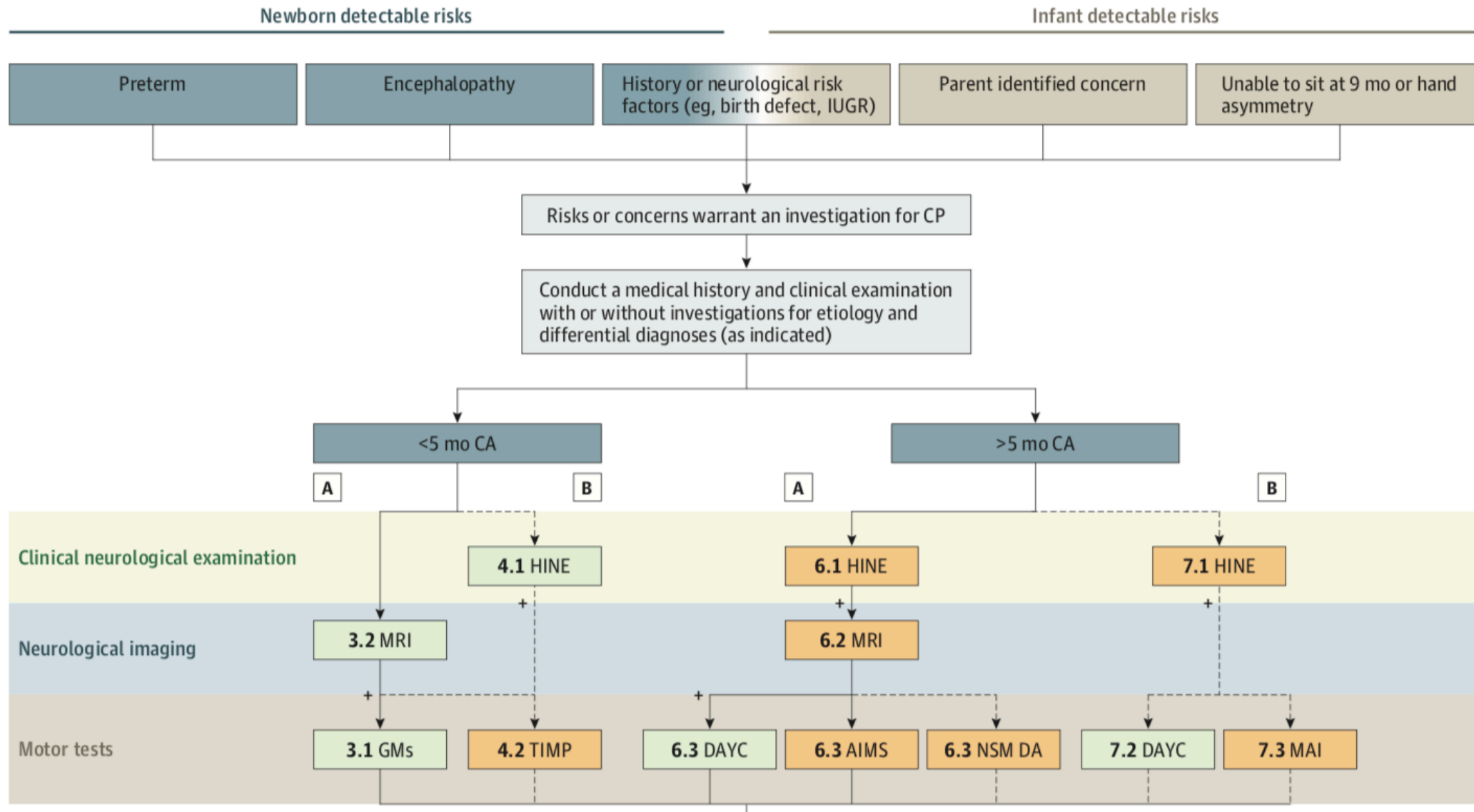
- Cerebral palsy is a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.
 - Diagnosis typically made between 12-24 months
- 4 motor types
 - Spasticity (85-91%)
 - Unilateral (hemiplegia) 38%
 - Bilateral (diplegia, lower > upper) 37%
 - Quadriplegia 24%
 - Dyskinesia (4-7%)
 - Ataxia (4-6%)
 - Hypotonia (2%)

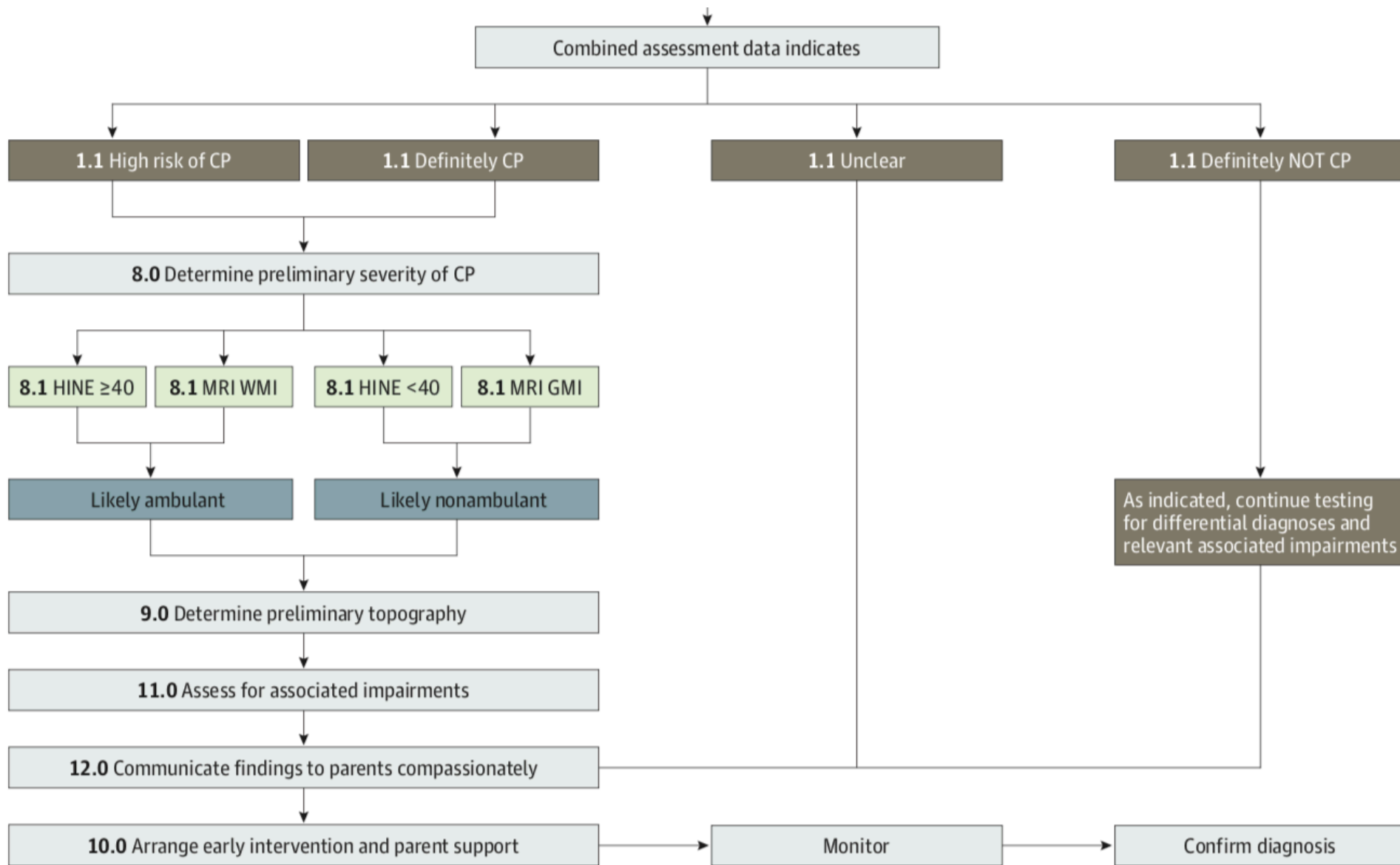
Rosenbaum P, Dev Med Child Neurol, 2008
Novak, I, et al. JAMA Pediatr, 2017

Early diagnosis of CP: 3 tools

- Neonatal MRI (86-89% sensitivity)
- Prechtl Qualitative Assessment of General Movements, GMs (98% sensitivity)
- Hammersmith Infant Neurological Examination, HINE (90% sensitivity)
- High quality evidence indicates that a trajectory of abnormal GMs or HINE scores, in combination with abnormal MRI, producing congruent findings is more accurate than individual clinical assessments in isolation.

Figure. Algorithm for Early Diagnosis of Cerebral Palsy or High Risk of Cerebral Palsy



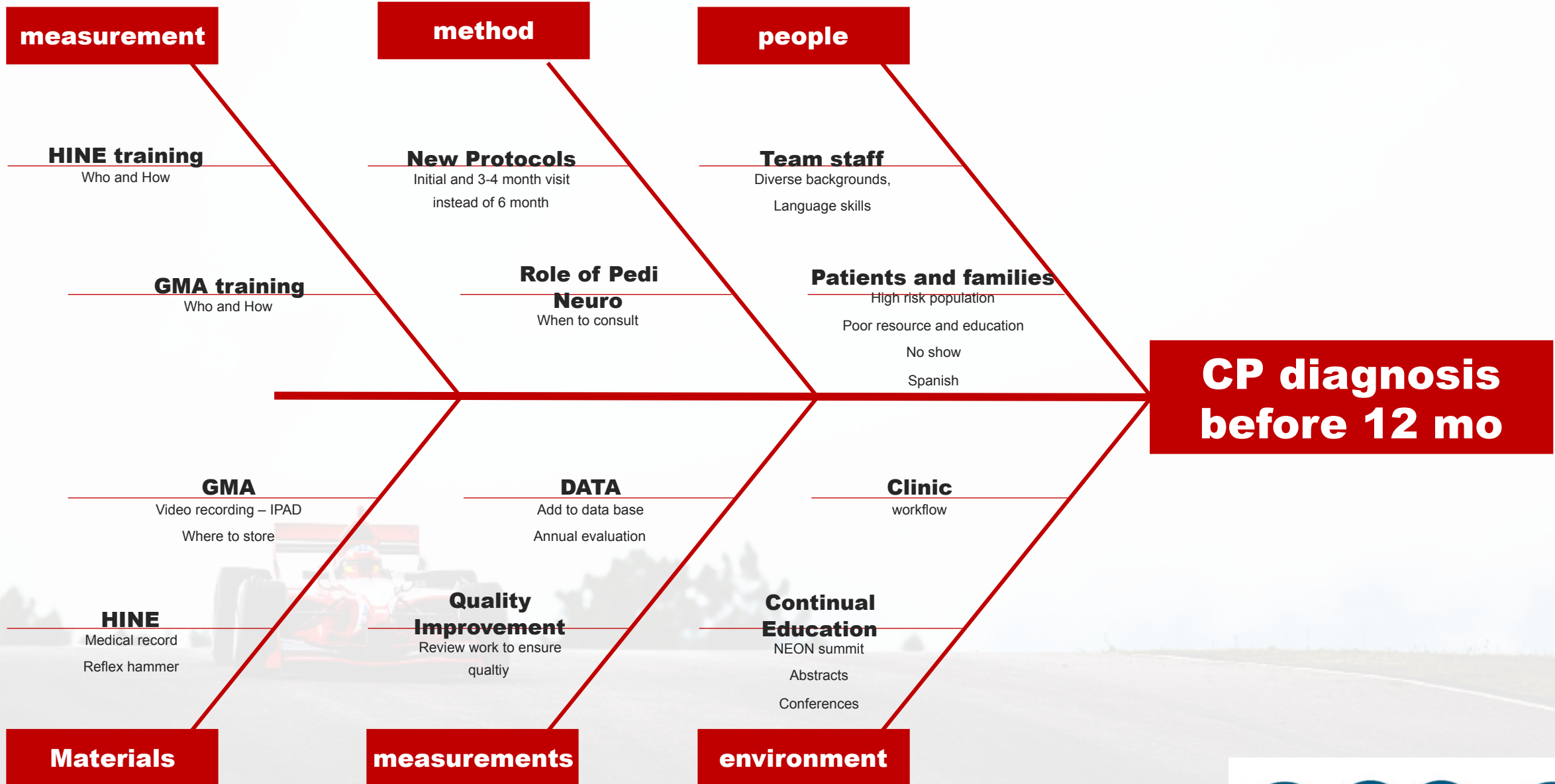


Why?

- Brain development and refinement of motor system continues postnatally and is driven by cortical activity
- Infants who do not use their motor cortex risk losing cortical connections and dedicated function
- Infant motor behavior, via discovery and interaction with environment controls and generates growth and development of muscles, ligament, bone, and ongoing development of neuromotor system.
- CP-specific early intervention maximizes neuroplasticity and minimizes deleterious modifications to muscle and bone growth and development.

Evidence for therapy

- Hemiplegic CP with early constraint-induced movement therapy (CIMT) have better hand function than controls
- Regular surveillance and interventions have decreased rates of hip displacement, contracture and scoliosis in infants with bilateral CP
- GAME – Goals-Activity-Motor Enrichment – early, intense, enriched, task-specific, training-based intervention at home have provided better motor and cognitive skills than those with usual care
- Larger replication RCTs underway





Why a follow up collaborative?

- Traditional reliance of clinical practice on randomized clinical trials has led to large numbers of underpowered trials, making less impact on population outcomes
- New trial strategies such as comparative effectiveness trials, routinely collected data sets may help to more effectively clarify importance of small detailed steps
- Learning from differences and ensuring we gather potentially better practices into individually clinical strategies in well-planned services are important goals.

Development is a continuum, build on earlier development

- We have a responsibility to better understand the protective factors beyond the neonatal period that modify the trajectory of general and organ specific health of people born preterm and thus overcoming the potential negative consequences.

Communities of Practice (COP)

- Groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an on-going basis.
- Wenger: COP model: 5 stages, 3 key dimensions (domain, community, practice)
 - Potential
 - Coalescing
 - Maturing
 - Stewardship
 - Transformation
- NEON as a COP
 - Not enough evidence to guide post-discharge care of NICU survivors

NEON

- 5 annual summits
 - Rotated to different follow up program hosts around the state
- Goal to establish evidence for best practices and standardized care for NICU survivors so that all can reach maximal potential
- Created distribution lists and member roster
- Formed executive committee to maintain momentum (lack of funds for a coordinator)
- Logic model to map out theory of change
- Collaborative group to advocate for support for follow-up services
- Follow up practices reliant on expert opinion
- Need infrastructure to establish a share database to help determine evidence-based practices.

Survey of constituents 2016

- 16 programs
 - 8 private; 8 academic
 - 3828 initial visits infants $\leq 32 \frac{6}{7}$ weeks
- Barriers to follow up
 - Financial problems
 - Insurance denials
 - Transportation
 - Insufficient clinic staff
 - Scheduling
 - Unsupportive Pediatricians

Early identification of cerebral palsy

- Single data-driven project quality improvement project
- Base line data from 7 sites
- Groups to get GMA and HINE training

Long term goals

- Secure funding
- Centers of excellence for NICU follow-up care and services
- State-wide NICU follow-up database to benchmark long-term outcomes, to guide quality improvement and improve long-term neurodevelopmental and health outcomes of NICU survivors.

Bibliography

- Behrman RE, Stith Butler A, editors. Institute of Medicine Committee on Understanding Premature Birth and Assuring Healthy Outcomes Board on Health Sciences Outcomes: Preterm Birth: Causes, Consequences, and Prevention. Washington DC: The National Academies Press; 2007.
- American Academy of Pediatrics, Committee on Fetus and Newborn. Clinical report: hospital discharge of the high-risk neonate. *Pediatrics*. 2008;122(5):1119–1126. Reaffirmed May 2011
- Hintz SR, Kendrick DE, Vohr BR, et al. Community Supports after surviving extremely low-birth-weight, extremely preterm birth. *Special Outpatient Services in Early Childhood. Arch Pediatr Adolesc Med*. 2008;162(8):748-755. doi:10.1001/archpedi.162.8.748.
- DiGregorio, Sarah. *Early, An Intimate History of Premature Birth and What It Teaches Us About Being Human*, 2020, Harper Collins Publisher, NYC.
- Voss W, Neubauer A-P, Wachtendorf M, et al. Neurodevelopmental outcome in extremely low birth weight infants: what is the minimum age for reliable developmental prognosis? *Acta Paediatr*. 2007; 96 (3), 342-7.
- Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006 [published correction appears in *Dev Med Child Neurol*. 2007;49(6):480]. *Dev Med Child Neurol Suppl*. 2007;109:8-14.
- 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. doi:10.1001/jamapediatrics.2017.1689.
- Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database Syst Rev*. 2015;11:CD005495
- Eliasson AC, Holmefur M. The influence of early modified constraint-induced movement therapy training on the longitudinal development of hand function in children with unilateral cerebral palsy. *Dev Med Child Neurol*. 2015;57(1):89-94.
- Elkamil AI, Andersen GL, Hägglund G, Lamvik T, Skranes J, Vik T. 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. *BMC Musculoskelet Disord*. 2011;12:284.
- Morgan C, Novak I, Dale RC, Guzzetta A, Badawi N. Single blind randomised controlled trial of GAME (Goals–Activity–Motor Enrichment) in infants at high risk of cerebral palsy. *Res Dev Disabil*. 2016;55:256-267.
- <https://www.disabilitybenefitscenter.org/faq/SSI-benefits-premature-children>
- Lakshmanan A, Agni M, Lieu T, et al. The impact of preterm birth <37 weeks on parents and families: a cross-sectional study in the 2 years after discharge from the neonatal intensive care unit. *Health and Quality of Life Outcomes*. (2017) 15:38. DOI 10.1186/s12955-017-0602-3.
- Cummings JJ, Marlow N. Reducing variations in neonatal outcomes: look at practices, systems, and the patient. *Pediatrics*. 2018. 14(5):e20180402.
- Raju TNK, Buist AS, Blaisdell CJ, Moxey-Mims M, Saigal S. Adults born preterm: a review of general health and system-specific outcomes. *Acta Paediatr*. 2017; 106(9): 1409-1437.
- Uchitel J, Alden E, Bhutta ZA, et al. *The Rights of Children for Optimal Development and Nurturing Care*. *Pediatrics*. 2019;144(6): e20190487
- Wenger E, *Communities of Learning*, 2004, Cambridge University Press, United Kingdom.

Thank you!

- Questions?

