



NICU Follow-Up Clinic

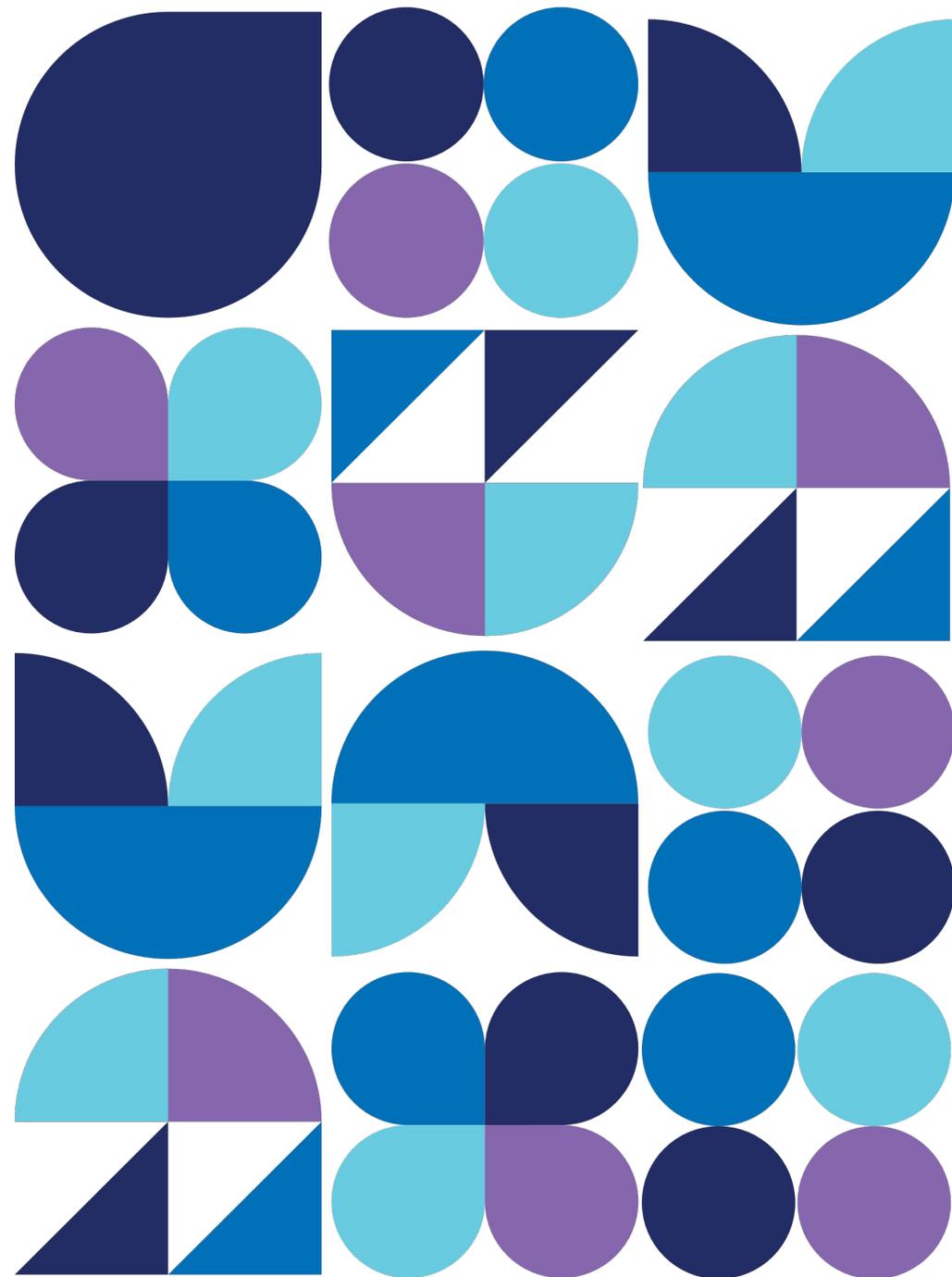
Beyond the Incubator

AAP SONPM District 8 Conference 2025

Boise, ID

Jennifer Merchant MD

Angela Fritz PT, DPT, PCS



Objectives

- Understand the criteria and purpose for our local High-Risk Pathway
- Understand the history of CP diagnosis
- Understand testing modalities now used in our pathway for early CP detection
- Early warning signs of CP in moderate risk infants

Disclosures

- None

St. Luke's NICU Follow-Up Clinic Mission since 2015 (and before):

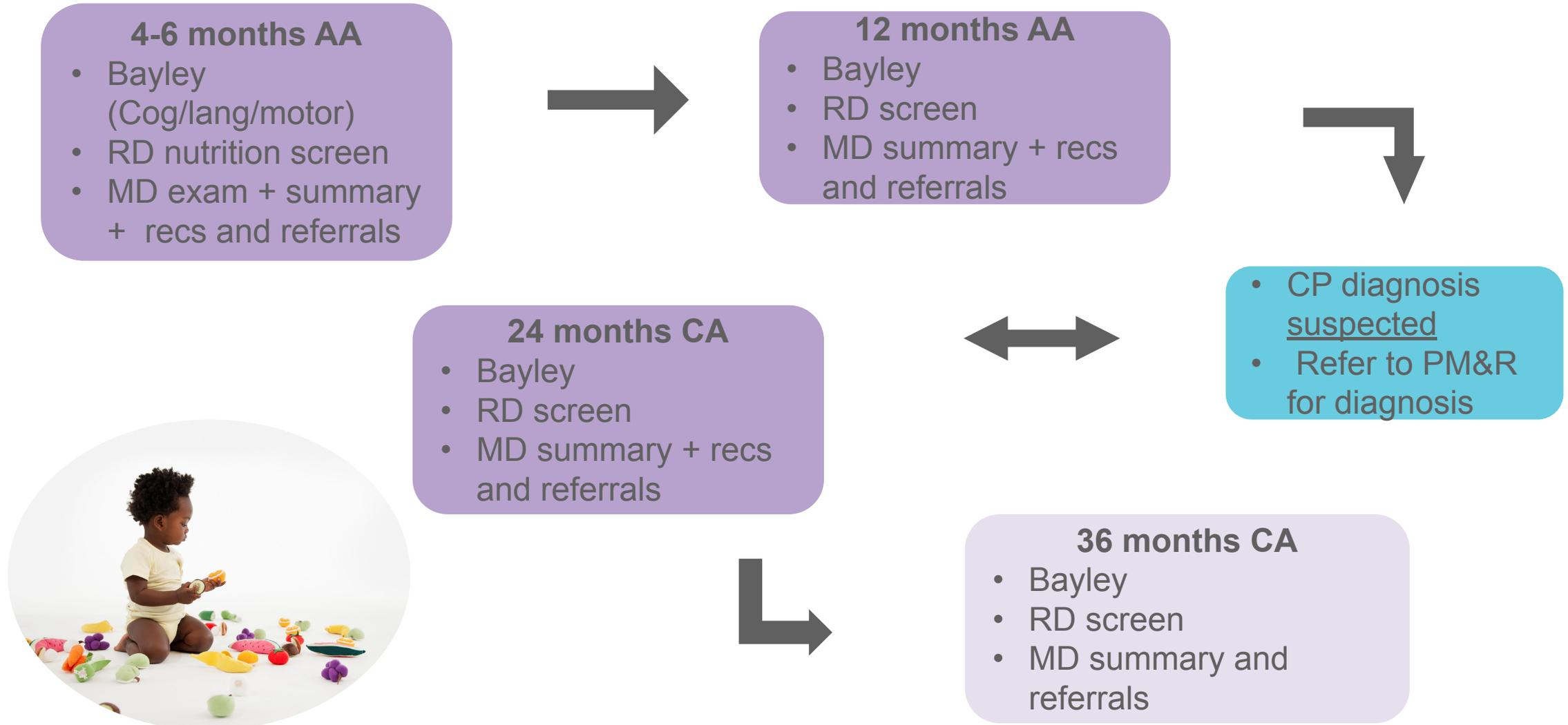
- Provide serial, multi-disciplinary, developmental and growth assessments free of charge for high-risk infants (criteria) discharged from the NICU up to 3 years of age
- Recommend interventions and place referrals as indicated to optimize developmental and growth outcomes



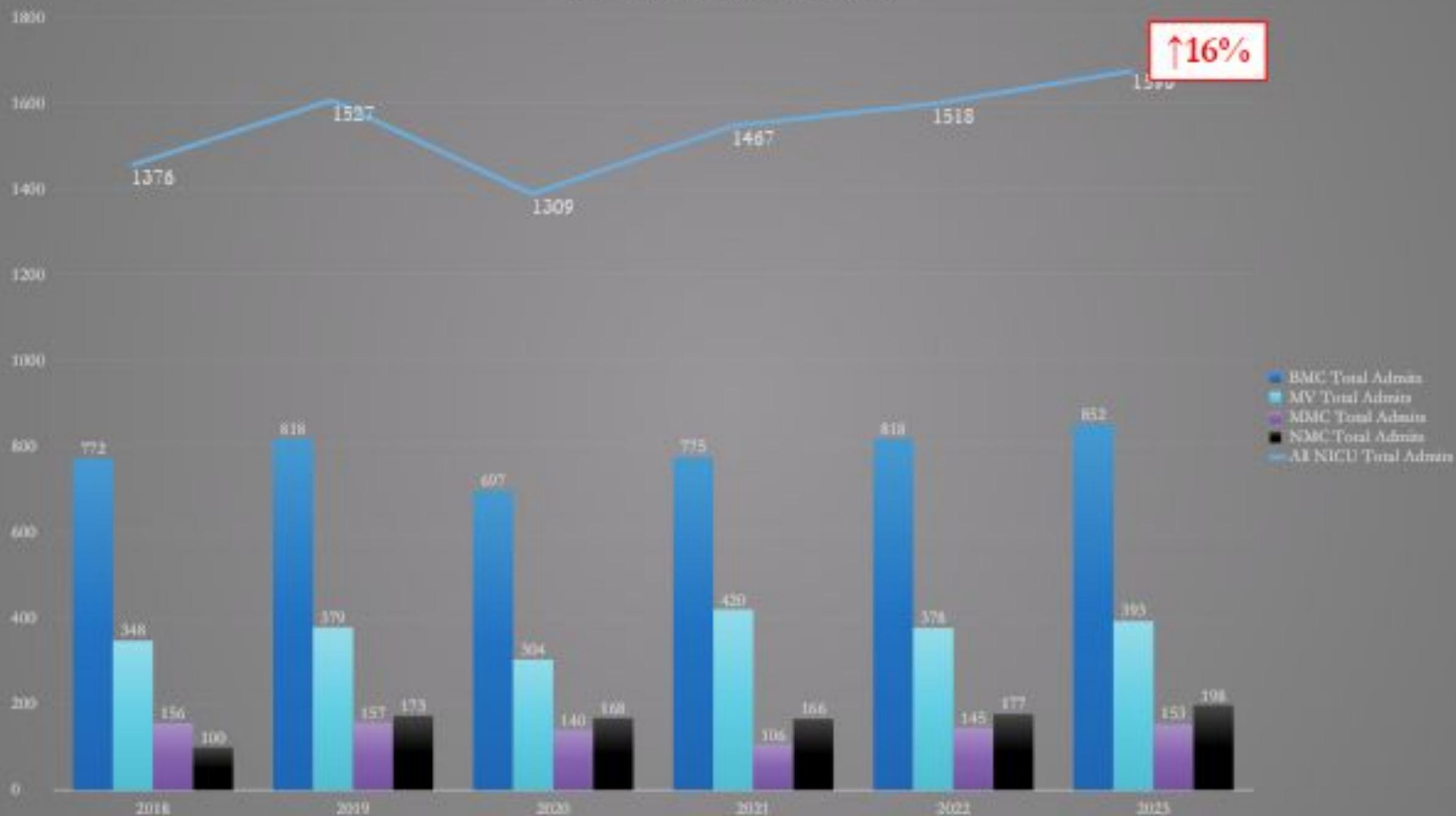
Broad NICU Follow-up Clinic Newborn Criteria

- ≤ 30 weeks gestation
- ≤ 1500 g
- **SGA (< 10%ile at birth)**
- Grade III-IV IVH
- hydrocephalus (unless spina bifida clinic)
- PVL
- Hypoxic ischemic encephalopathy (HIE) moderate & severe +/- TH
- Neonatal seizures
- **Gastroschisis**
- Congenital diaphragmatic hernia
- ECMO
- Hearing impaired requiring intervention
- Grade 3-4 ROP
- CNS or congenital infections (meningitis, CMV, herpes, toxoplasmosis not available, rubella)
- **LOS >60 days**
- Referred by Neonatology (abnormal tone, feeding problems, prolonged NG/GT support)
- Suspected syndrome without identified diagnosis

Traditional evaluation pathway



Total NICU Admissions



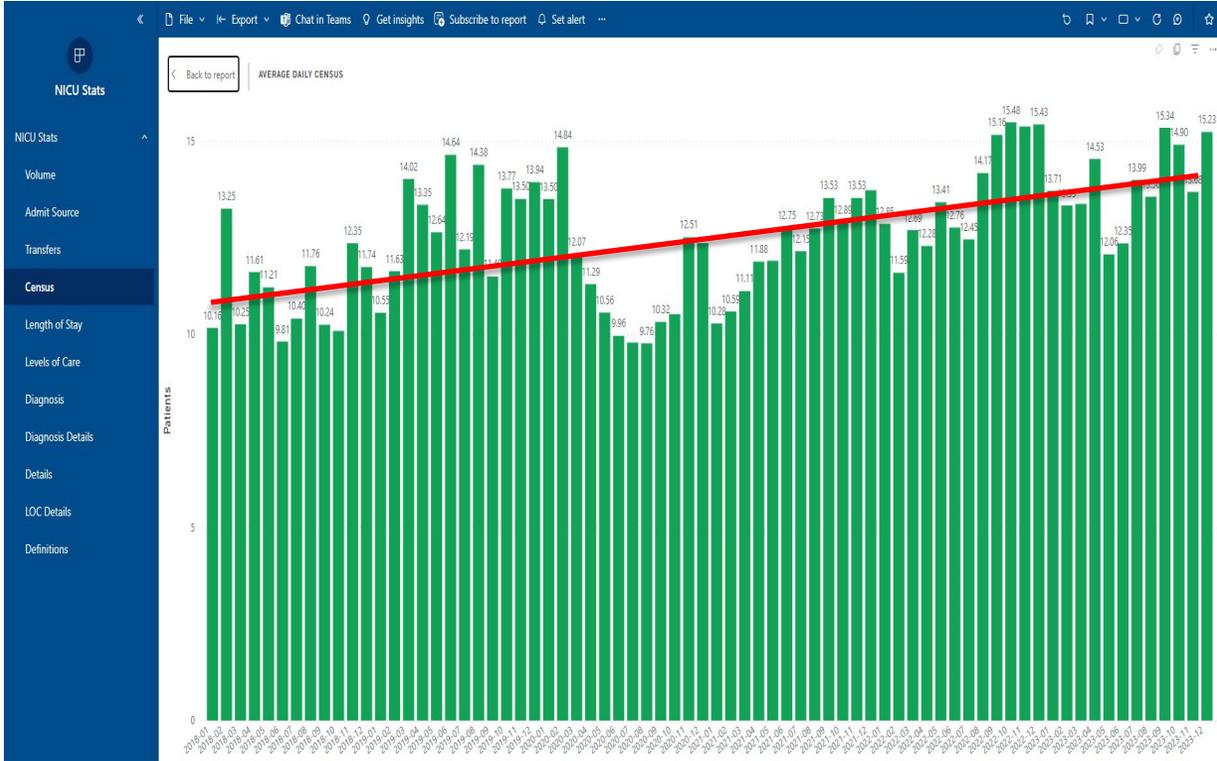
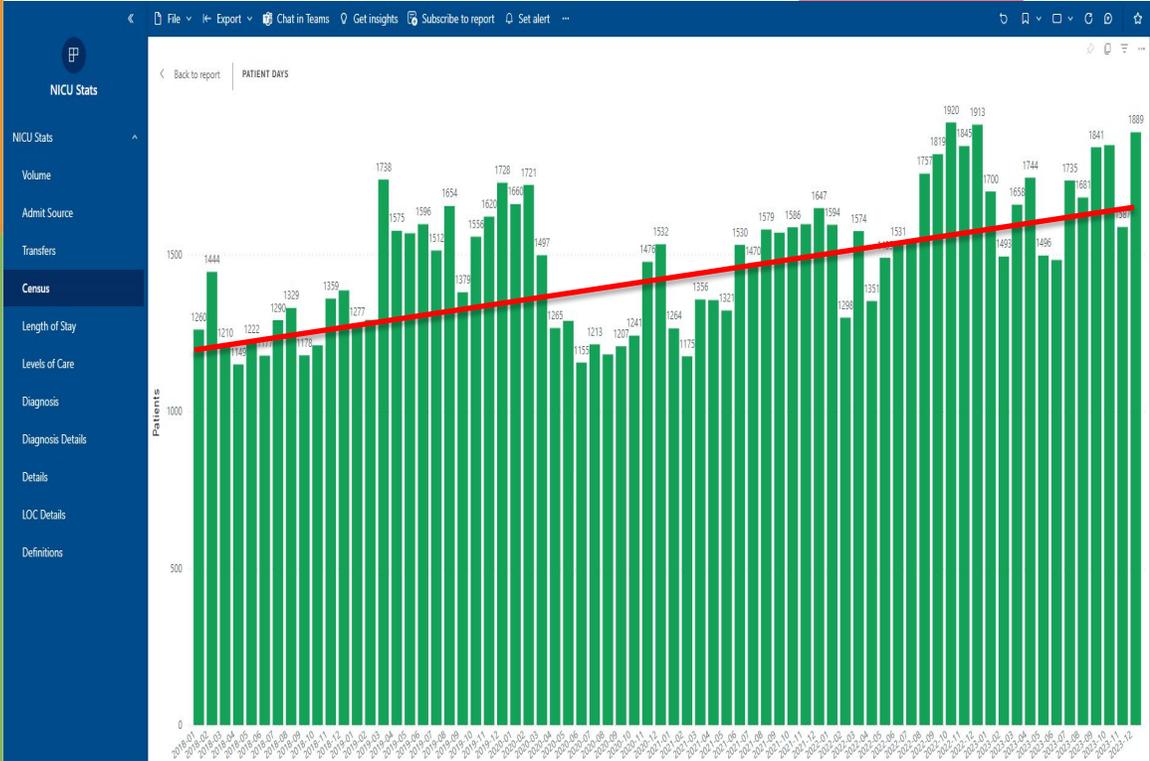
SLHS NICUs (All) 2018-2023

Patient Days

~↑↑35%

Average Daily Census

~↑↑30%



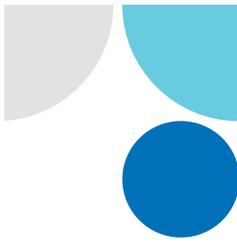


NICU PICNIC 2019

AUGUST 14TH, 2019

[VIEW GALLERY](#)

NICU Follow-Up Clinic Evolution



- *Dr. O’Riordan joined our Clinic team*
- *Added NICU Follow-up Clinic in Magic Valley*
- *Criteria tightened to capture only highest risk infants*
- *Hired a Clinic Coordinator: Jenni Sasser RN*
- *Training for therapists and providers in the GMA and HINE*
- *Visit number increased from 3 visits >> 4 visits in ~2 years*
- *Clinic capacity increased by ~25%*
- *Boise Follow-up clinic stats May 2024-May 2025*
 - *No show rate: 12%*
 - *Cancel/reschedule rate: 20%*
 - *New patients referred: ~120 (combination criteria)*
 - *Referrals made in clinic: 168 (0-10 per clinic)*



Revised NICU Follow-up Clinic Newborn Criteria

- ≤29 weeks gestation
- ≤1000 g
- Grade III-IV IVH
- hydrocephalus (unless spina bifida clinic)
- PVL
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Cerebral Palsy

“Group of permanent movement and posture disorders that limit activity and are attributed to non-progressive disturbances that occurred in the developing fetal or immature brain.”



Most
common
physical
disability in
childhood

2-3 per
1000
births

10x
higher
<32
weeks

Diagnosis
at 12-27
months

CURRENT STATE

Average age of CP diagnosis: 12-24 months or later

Activity-dependent withdrawal (learned unuse)
on injured side happens as early as 2-3
months of age

Missing out on early intervention that is key
during critical periods of development (0-3
years)





2017

Clinical Review & Education

JAMA Pediatrics | Review

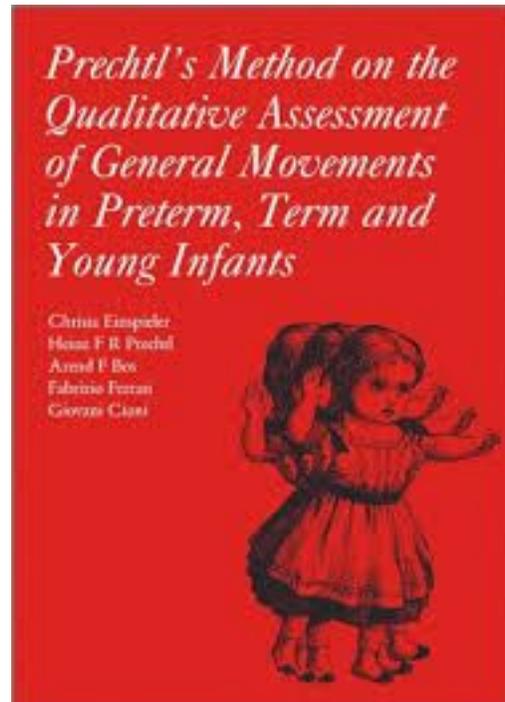
Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy Advances in Diagnosis and Treatment

Iona Novak, PhD; Cathy Morgan, PhD; Lars Adde, PhD; James Blackman, PhD; Roslyn N. Boyd, PhD; Janice Brunstrom-Hernandez, MD; Giovanni Cioni, MD; Diane Damiano, PhD; Johanna Darrah, PhD; Ann-Christin Eliasson, PhD; Linda S. de Vries, PhD; Christa Einspieler, PhD; Michael Fahey, PhD; Darcy Fehlings, PhD; Donna M. Ferriero, MD; Linda Fetters, PhD; Simona Fiori, PhD; Hans Forssberg, PhD; Andrew M. Gordon, PhD; Susan Greaves, PhD; Andrea Guzzetta, PhD; Mijna Hadders-Algra, PhD; Regina Harbourne, PhD; Angelina Kakooza-Mwesige, PhD; Petra Karlsson, PhD; Lena Krumlinde-Sundholm, PhD; Beatrice Latal, MD; Alison Loughran-Fowlds, PhD; Nathalie Maitre, PhD; Sarah McIntyre, PhD; Garey Noritz, MD; Lindsay Pennington, PhD; Domenico M. Romeo, PhD; Roberta Shepherd, PhD; Alicia J. Spittle, PhD; Marelle Thornton, DipEd; Jane Valentine, MRCP; Karen Walker, PhD; Robert White, MBA; Nadia Badawi, PhD

New testing paradigm allowing for early CP diagnosis <6 months AA

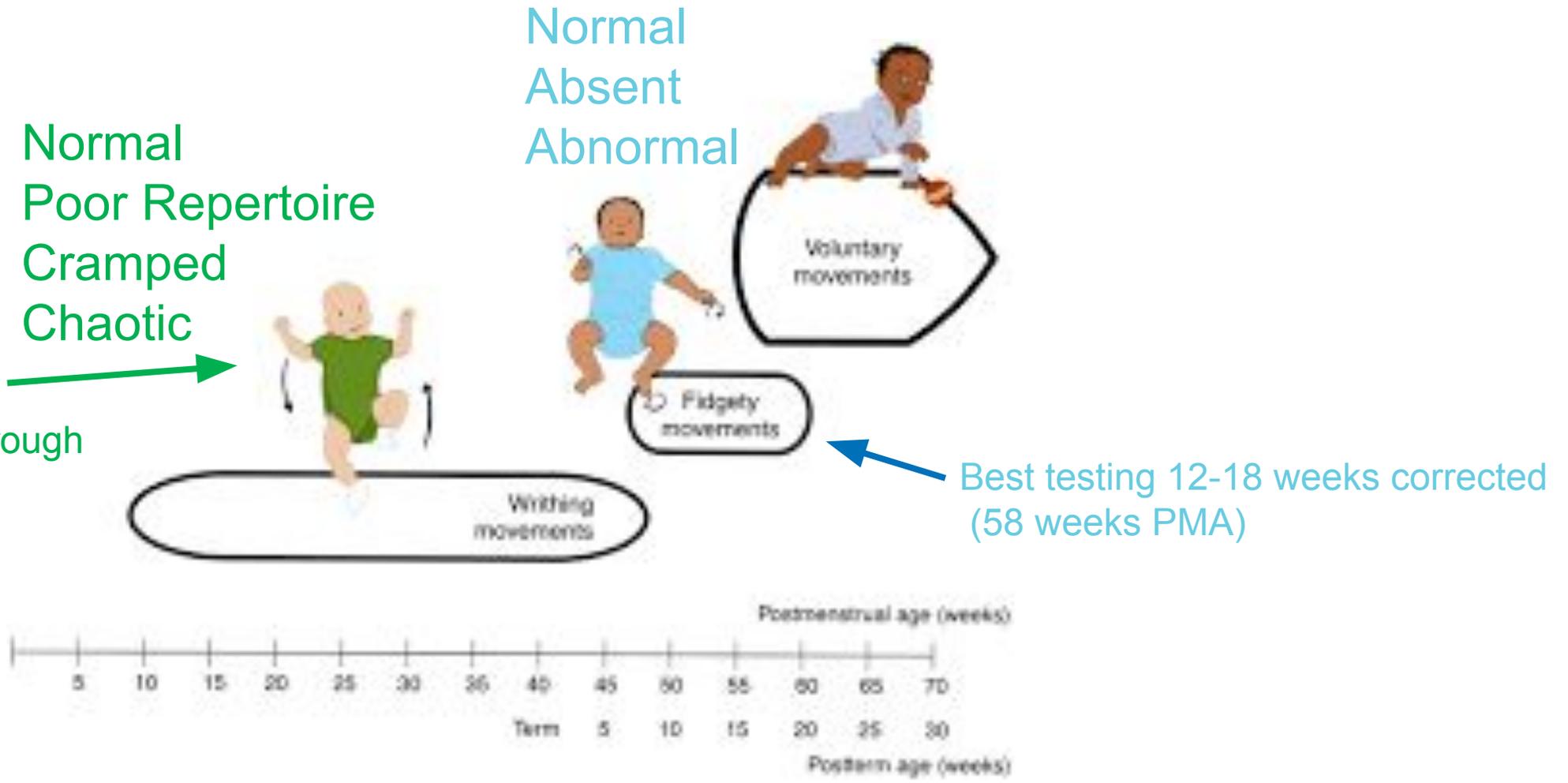
- Risk stratification
 - Neuroimaging (MRI preferred)
 - GMA - Prechtl's General Movements Assessment
 - HINE – Hammersmith Infant Neurological Exam

Prechtl's General Movement Assessment



- Begin at 9-10 weeks
- Become more complex and distinct over fetal life
- Continue into newborn postnatal age.

General movements progression



Normal
 Poor Repertoire
 Cramped
 Chaotic

Tested in NICU
 over time preterm through
 46-48 weeks PMA

Normal
 Absent
 Abnormal

Best testing 12-18 weeks corrected
 (58 weeks PMA)

Hammersmith Infant Neurological Exam (HINE)

- Developed by Lily Dubowitz
- Can be used from 2-24 months
 - 3-18 months of age validated
- 26 items; 5 domains
 - *Cranial nerve function*
 - *Posture*
 - *Quality and quantity of movement*
 - *Muscle tone*
 - *Reflexes and reactions*
- Max score 78

Score Cutoffs

3 months <57

6 Months <59

9 Months <62

12 months <65

Asymmetries >5



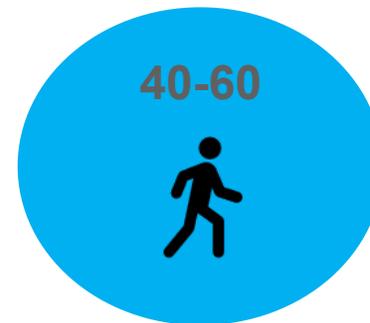
HINE

Track abnormalities to determine persistent versus transient

HINE at 3-6 months

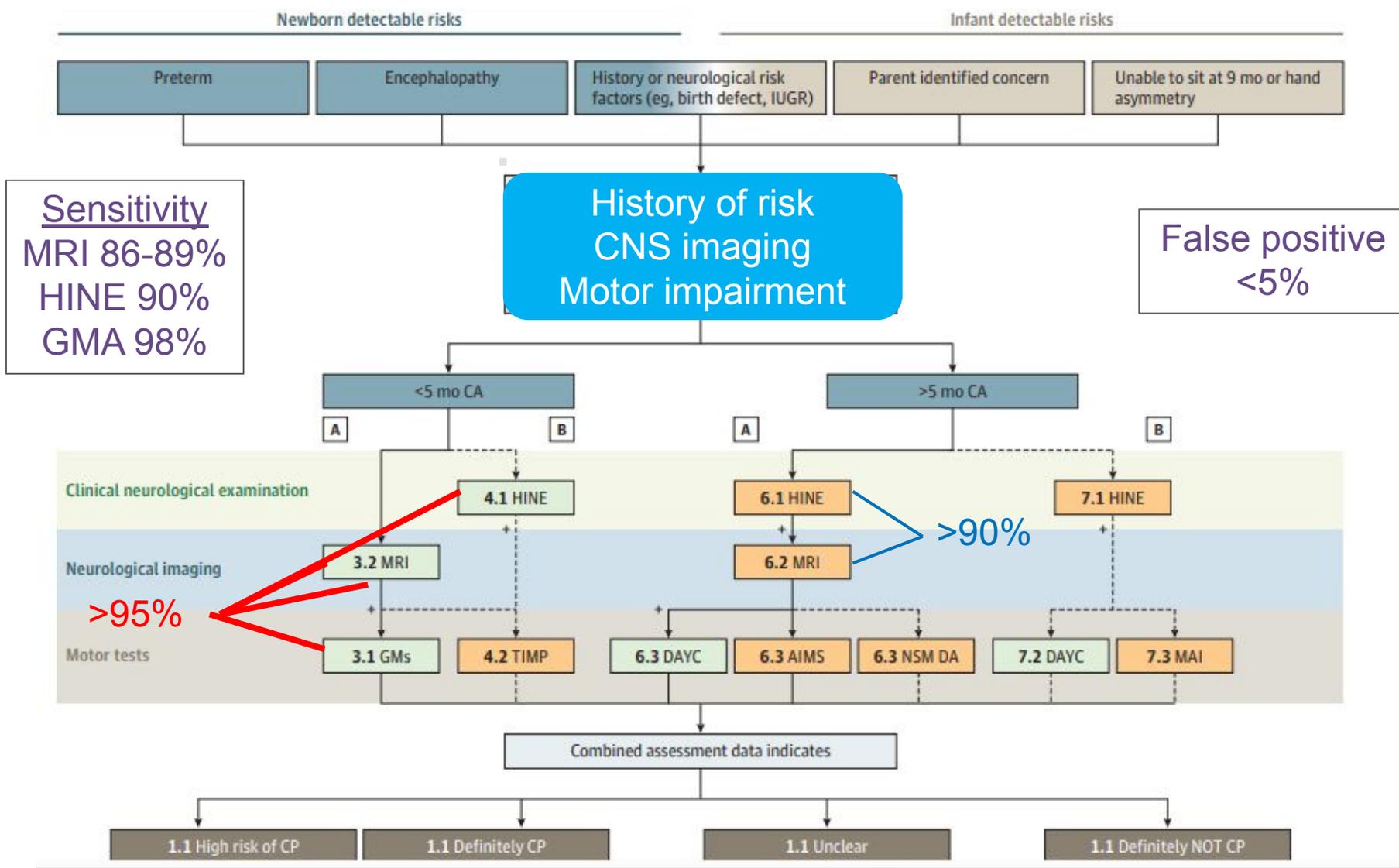


GMFCS III-V



GMFCS I-II

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





Infant-detectable Risks

Motor delays often identified by parents/PCPs

- Not sitting independently by 9 months
- Early hand preference
- Rolling to or from only one side without other explanation



WHY IT MATTERS

EARLY DIAGNOSIS RESULTS IN DIAGNOSIS-SPECIFIC EARLY INTERVENTION THAT CAN:

- Optimize infant motor and cognitive development (targeted CP intervention results in better motor and cognitive skills at 1 year compared to control)
- Prevent secondary complications (early surveillance = lower rates of hip displacement, contracture, and scoliosis)
- Enhance caregiver well-being (parents report higher rates of depression and lasting anger with prolonged diagnostic process)

IDEAL STATE

Early CP diagnosis with GMA + HINE +MRI: <6 months

Receiving early diagnoses or high-risk for CP classification is a parent priority

Intervention, especially baby CIMT for infants with unilateral CP, should start as early as possible to optimize neuroplasticity



WHAT DO PARENTS WANT?

➤ Earliest possible diagnosis

Williams et al., 2021

➤ Self-care and respite care

Guillamon et al., 2013

➤ Referrals and resources

Guillamon et al., 2013

➤ Open, honest communication
w/ team

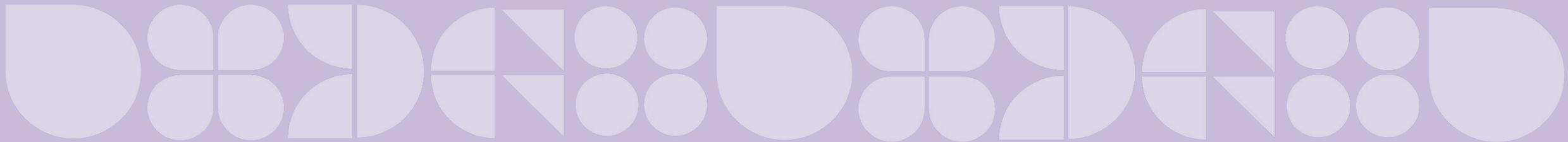
Williams et al., 2021

➤ Self efficacy & empowerment

Guillamon et al., 2013

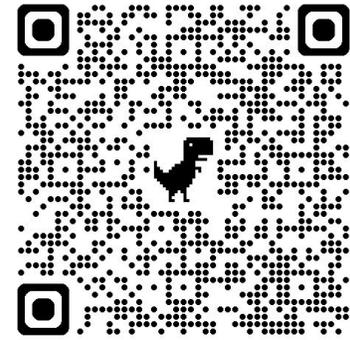


How does St. Luke's meet these new goals?





Inpatient high-risk pathway



Meet Criteria: Preterm and/or brain injury

Inpatient interventions (OT/PT/SLP)

+

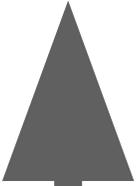
Serial HUS and/or MRI (guideline)



HUS abnormal



MRI at term



1st GMA 36 weeks or ~2 weeks after injury

+

Second GMA term (at least 2 weeks later)

+

TIMP at term



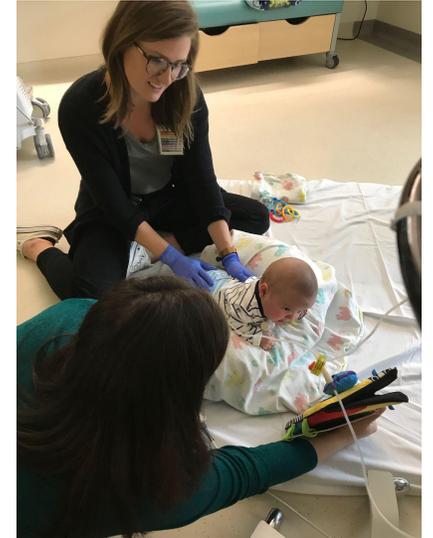
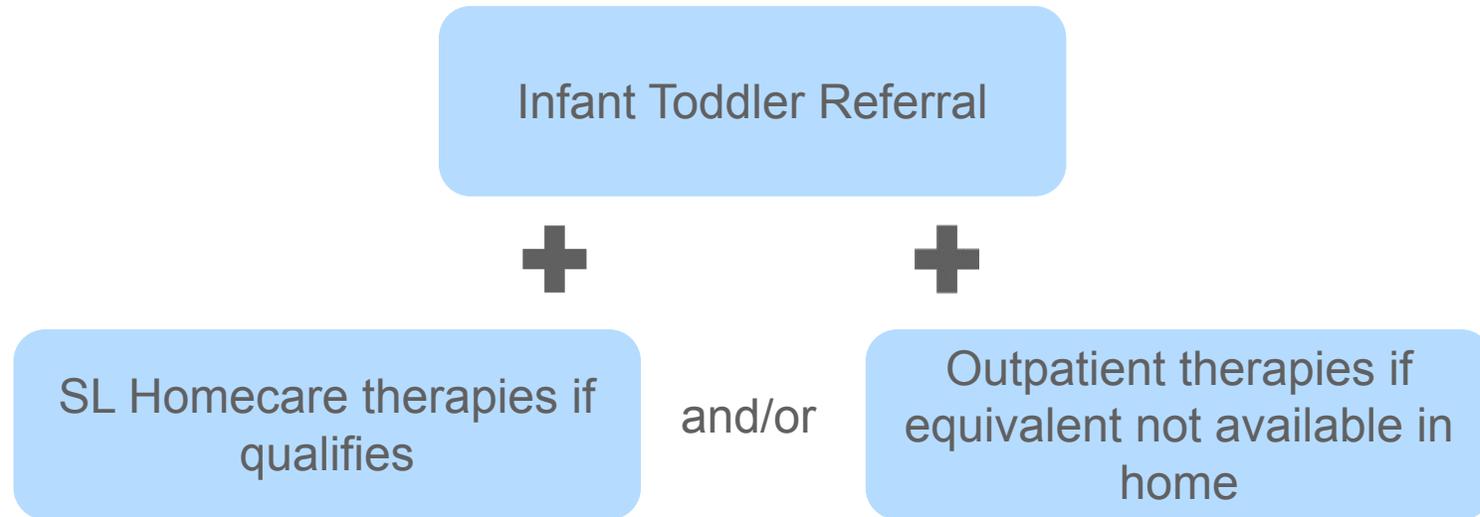
Abnormal GMA (CS, PR)



Serial GMA until 45 weeks or d/c



NICU Discharge Support and Interventions: Therapies, Sensory and Nutrition

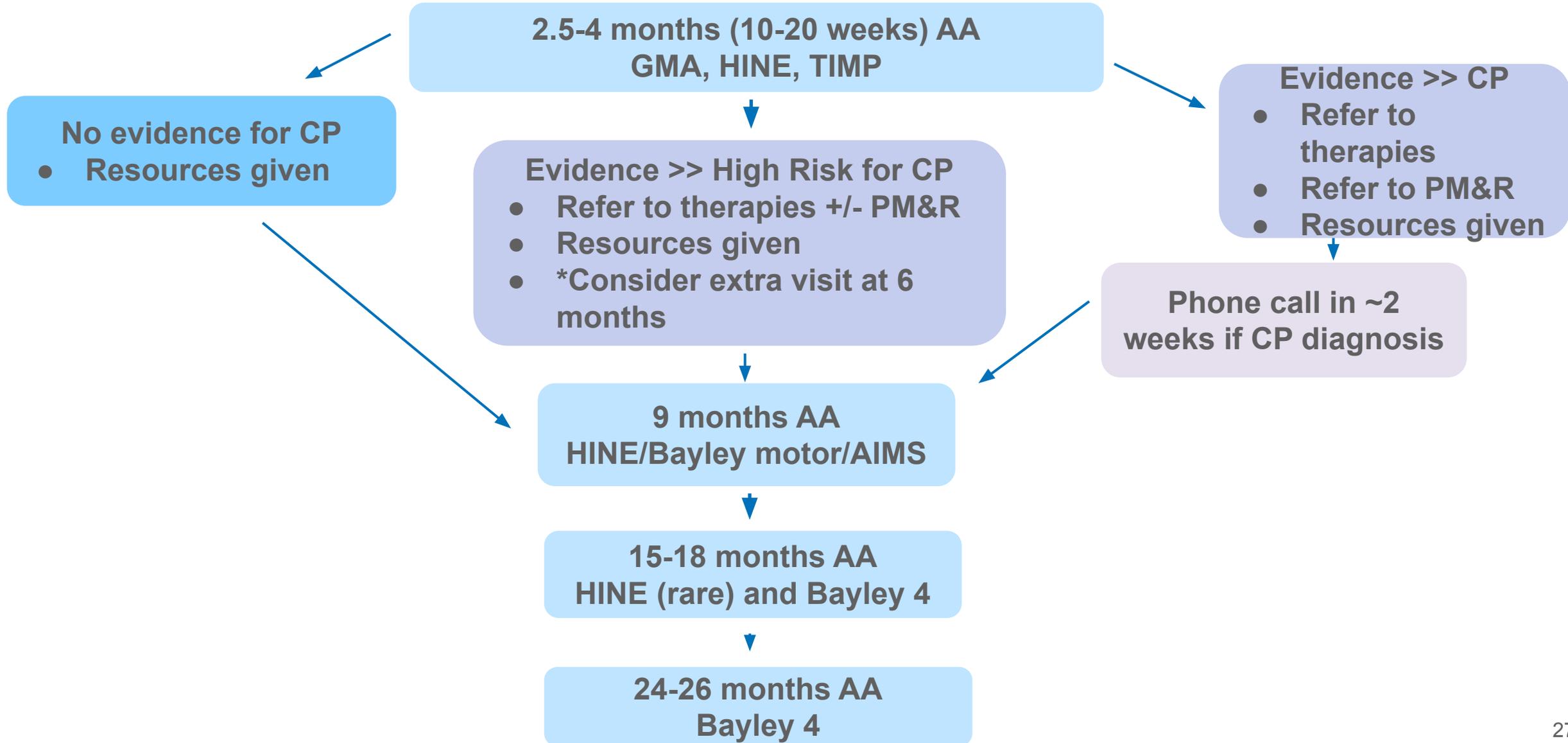


Audiology referral – due by 9 months corrected or sooner based on risk

RD referral +/- GI based on diet/risk (tube feeds, special diet, growth failure)

Ophthalmology referral (preterm)

NICU Follow-up clinic pathway



New Capabilities

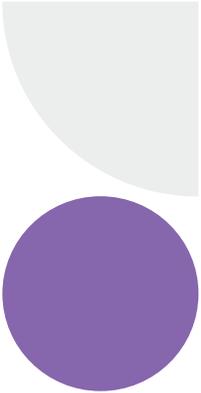
Diagnose Cerebral Palsy in the First Year (<6 months)

- Take advantage of neuroplasticity
- Access resources
- Support families





Our Mission since 2015:



- Provide serial, multi-disciplinary, developmental and growth assessments free of charge for high-risk infants discharged from the NICU
- Recommend interventions and place referrals as indicated to optimize developmental and growth outcomes





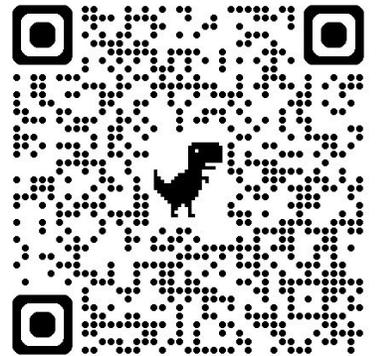
Future directions

- Collect data for QI in the NICU and accurate local antenatal counseling
- Participate in regional/national trials
- Better understand local needs to develop better models of care for medically complex infants/children

Cord Blood Treatment for Children With Cerebral Palsy: Individual Participant Data Meta-Analysis

Megan Finch-Edmondson^{1 2}, Madison C B Paton^{1 2}, Annabel Webb^{1 2},
Mahmoud Reza Ashrafi³, Remy K Blatch-Williams^{1 2}, Charles S Cox Jr⁴, Kylie Crompton⁵,
Alexandra R Griffin^{1 2}, MinYoung Kim⁶, Steven Kosmach⁴, Joanne Kurtzberg⁷,
Masoumeh Nouri⁸, Mi Ri Suh⁶, Jessica Sun⁷, Morteza Zarrabi⁹, Iona Novak¹⁰

Conclusions: UCB is safe and provides benefit for improving gross motor function in some children with CP, with higher doses associated with increased effect size. Younger participants (aged approximately <5 years) with milder CP showed increased benefit. Findings will help design future trials with precision.

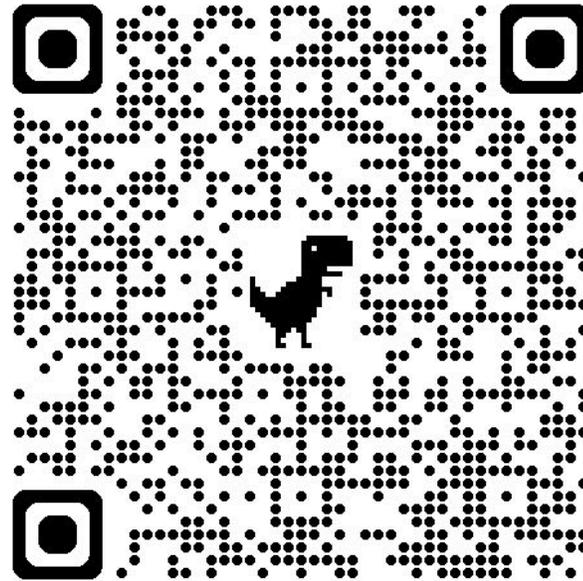


Thank you!



Back row: Declan O’Riordan MD, Sara Andrews SLP, Ashley Galloway SLP, Ashley Hirning RN , Jenni Sasser RN
Clinic Coordinator, Trish Barnes OT, Jennifer Merchant MD, Joe Hill DPT. **Front row:** Serena Arave RD, Angela Fritz
DPT, Kristen Lindsay RN. **Not pictured:** Amy Hintze RN, Emily Davis RN, Brynn Bostrom RN

NICU Follow-up clinic criteria



<https://neonatologysolutions.com/wp-content/uploads/2025/01/NICU-Follow-Up-Clin-Referral-Criteria-v.1-2-25-2.pdf>

