Neonatal Evaluation and Outcomes Network

2021 Summit
Early Cerebral palsy diagnosis
Status and management during pandemic
Premiere Program, San Antonio

Leslie-Anne Dietrich, MD

Small Beginnings PREMIEre Program Great Expectations

UT Health San Antonio

University Health System

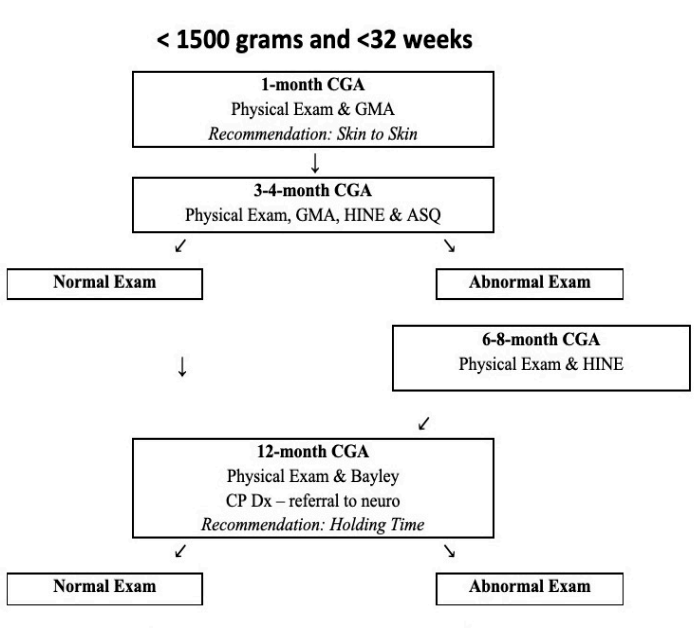
Premiere Program, UT Health San Antonio, University Health

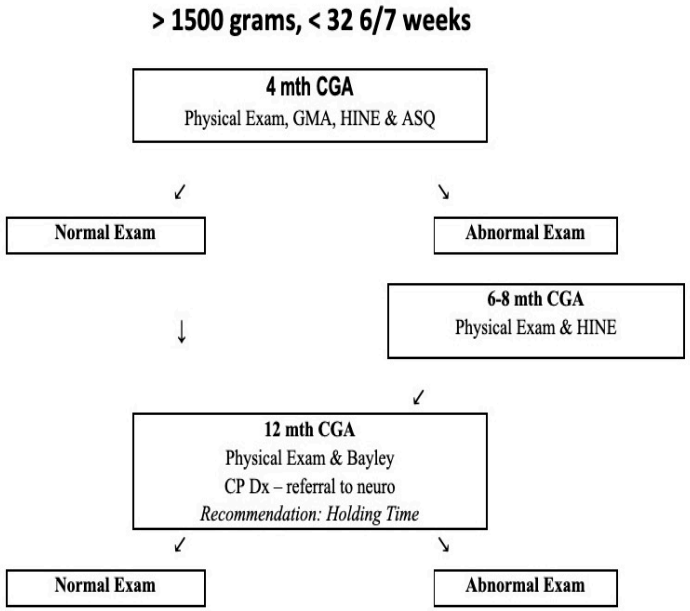
- Population served
  - ≤1500 g and/or ≤32 weeks GA
  - Infants with significant neurological compromise: HIE/cooling (include Sarnat 1 if other risk factors), stroke, meningitis
  - ECMO
  - Any patient for which the NICU team is concerned
  - Outside referrals

Follow-up practices grouped by:

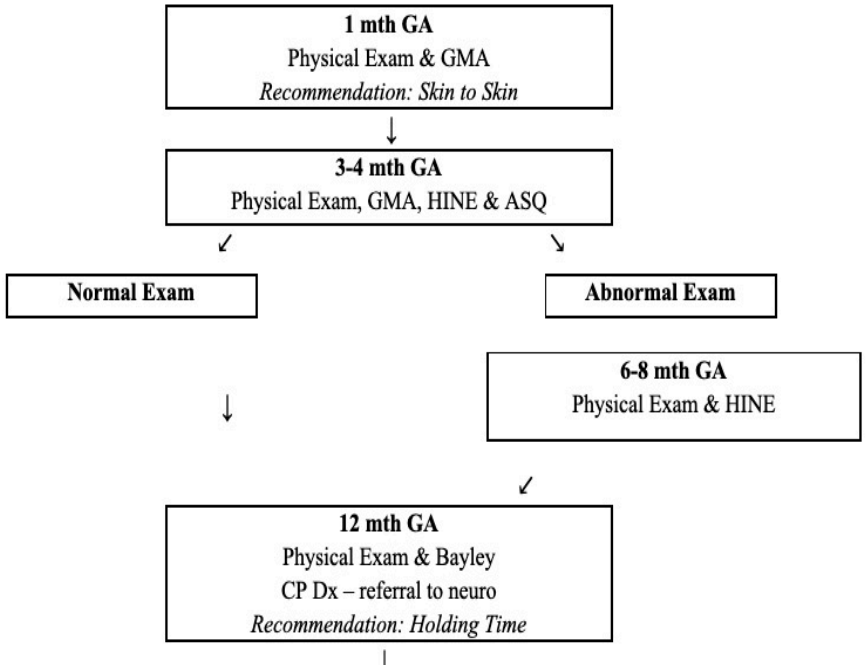
- <1500 grams and < 32 weeks PMA
- >1500 grams, < 32 weeks PMA
- Hypoxic Ischemic Encephalopathy (HIE) and/or ECMO
- Other Neuro concerns

Our site's path or protocol/algorithm to early CP diagnosis





HIE cooling/ECMO



We do the following:

- NICU (since pandemic)
  - GMA video
  - MRI as indicated
- First visit
  - 1 month GMA (as needed)
  - 3-4 months GMA, HINE

Training we have regarding GMA and HINE

- 4 in GMA
- 1 in advance GMA
- 6 HINE

How did we managed during the pandemic? Virtual visits?

- Staff to do video neonates in NICU at >35 weeks gestation to decrease first month visit
  - ECI referrals at discharge for babies <1500 grams, < 28 weeks, HIE with cooling or ECMO, babies with cystic PVL
- Request parent(s) to do home video at 1 month corrected age to share (Not successful)
- Neurodevelopmental visits:
  - Video – GMA, virtual HINE
  - Phone – ASQ, Bayley IV Social-Emotional and Adaptive Behavior Scale
  - Ages 3, 4, 5 – Vineland-3 Adaptive Scales

Our site's data with regard to early CP diagnosis since 2019:

- Numbers screened in NICU – GMA March 2020, >35 weeks
  - July-Dec, 2020 – 84 videos were done in NICU
- 3-4 month visits
  - 2019: 80 visits, 15 high risk for CP
  - 2020: 84 visits, 11 high risk for CP
    - 43 visits in-person, 5 high risk
    - 41 virtual visits, 6 high risk
- Average age at diagnosis of high risk for CP
  - 3-4 months

How we convey early diagnosis to parents?

- Family meeting during clinic that covers
  - Testing (GMA, HINE) and what that means
  - What is CP?
    - CP foundation as resource
  - Treatment
    - Referral for therapy
    - Close monitoring

What we have identified as barriers to early CP diagnosis

- No MRI
- Parents not accepting
- Getting therapy
- ECI not understanding process

Dr. Fierro and Aaron Espinoza for the San Antonio Pediatric Developmental Services

Neonatal Evaluation and Outcomes Network

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San Antonio Pediatric Developmental Services

Dr. Christine Aune, Dr. Mario Fierro, & Aaron Espinoza

San Antonio Pediatric Developmental Services

- Population served: NICU graduates
  - Congenital Heart Defects
  - HIE (Hypoxic Ischemic Encephalopathy)
  - Genetic Abnormalities
  - Prematurity
  - Drug exposure in utero
  - Community referrals for:
    - Metabolic disorders
    - Seizure disorders
    - Congenital anomalies

Follow-up practices

- **Outpatient**
  - 2 week follow-up post NICU discharge
- Mullen's – at 4, 8, 12 month
- HINE – at 2, 4, 8, 12 month
- Bayley/MCHAT – at 18-20, 24 month
- 3yo – 18 yo:
  - School readiness: BRACKEN
  - School performance / achievements
  - Behavioral Assessments

Protocol to early CP diagnosis

- NNS – NICU
- HINE – 2, 4, 8, 12 mo.
- Mullens – 4, 8, 12 mo.
- Bayley – 20-24 mo.

Did you do the following?

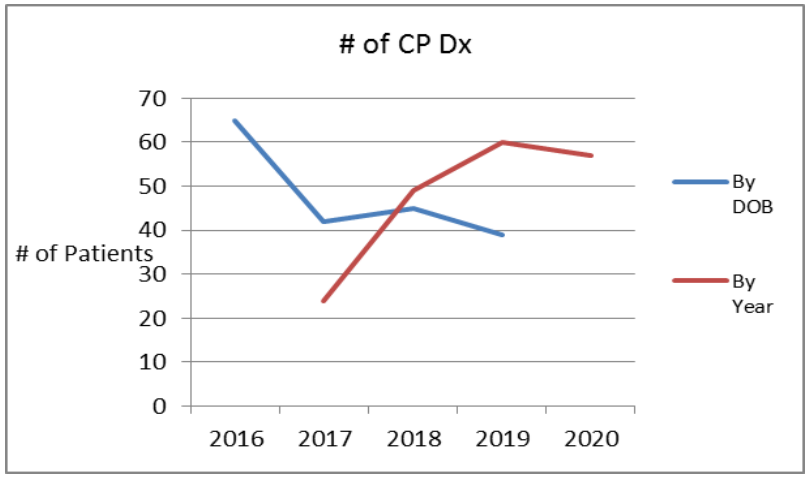
- NICU
  - TIMP
  - GMA video
  - MRI
- First visit
  - 1 month
  - 3-4 months
  - HINE

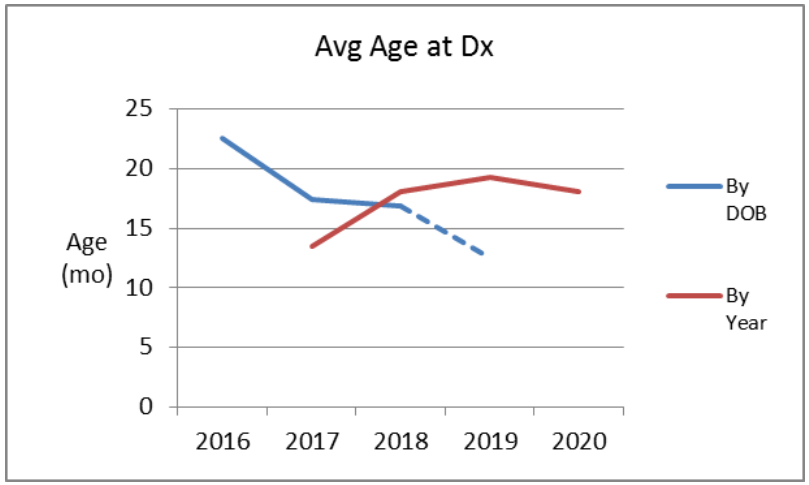
Early CP diagnosis:

- Numbers screened in NICU
  - Seen by APN/Dev. MD – 1079 in 2020
- 3-4 month visits
  - Yes if followed up
- No of high-risk for CP
  - Majority of patient population

New CP Diagnosis & Age at Diagnosis

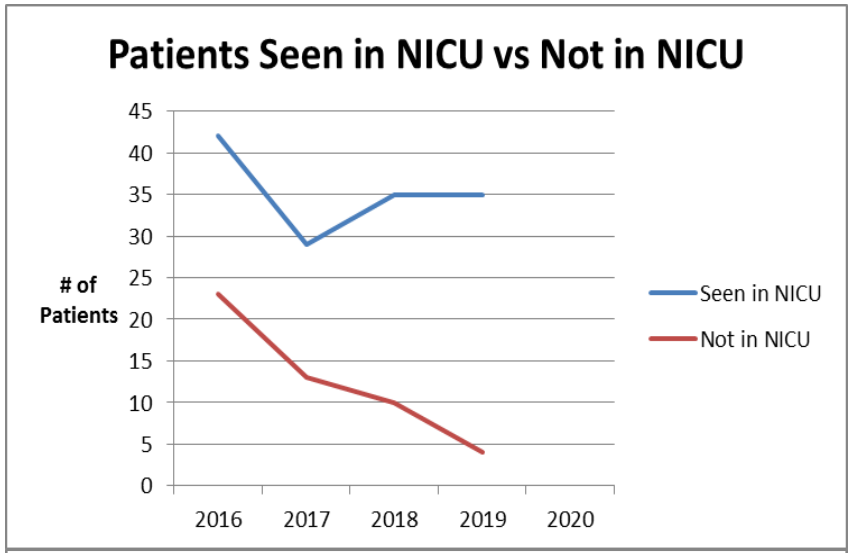
San Antonio Pediatric Developmental Services CP Data		
New CP Diagnosis by DOS	Number of Dx	Average age at Dx per year (months)
2016		
2017	24	13.5
2018	49	18.1
2019	60	19.3
2020	57	18.1
2021	3	N/A
New CP Dx by DOB	Number of Dx	Average age at Dx (Months)
2016	65	22.5
2017	42	17.4
2018	45	16.9
2019	39	12.5
2020	4	N/A

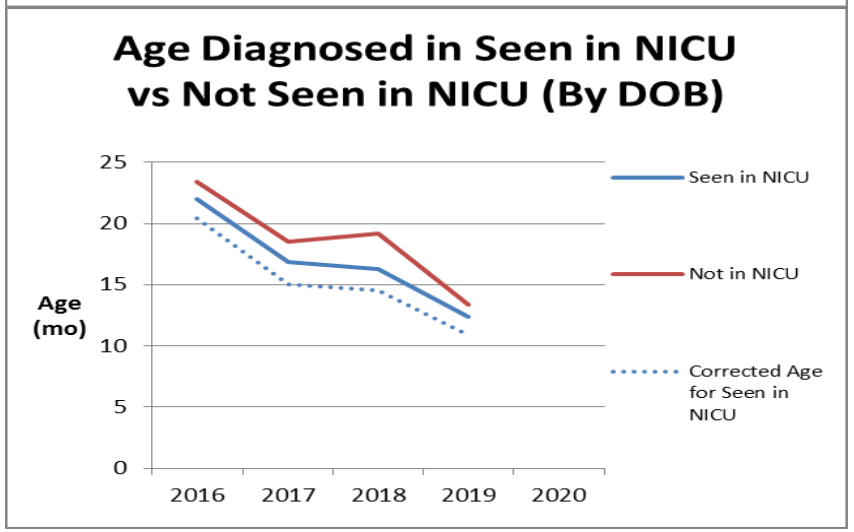




Patients Followed-up Since NICU

	Patients seen in NICU	Avg age at Dx	Avg corrected age at DX
2016	42	22	20.4
2017	29	16.9	15
2018	35	16.3	14.5
2019	35	12.4	10.9
2020	4	7.2	6.3
	Not seen in NICU	Avg age at Dx	
2016	23	23.4	
2017	13	18.5	
2018	10	19.2	
2019	4	13.4	
2020			





How do you convey early diagnosis to parents?

- Inform & educate parents, start therapies
- Follow-up
- ELAI reviewed

Needs your site have identified or barriers to early CP

- Consistent HINE testing
- Difficulties with virtual visits

Training your site has regarding GMA and HINE

- HINE trained
- No GMA training

How did you managed during the pandemic? Virtual visits?

- Yes

Dr. Yvette Johnson for the Cook Children's Hospital

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Reports by centers
(Cook Children's Hospital)

Site:

NEST (NICU Early Support and care Transition) Developmental Follow-up Clinic

Cook Children's Hospital, Fort Worth, TX

Early CP Detection Team:

Yvette R. Johnson, MD, MPH

Treka Rogers, CPNP-AC

Chelsea Sapit, CPNP-PC

Robin Grady, OTR, CNT

Kim Barber, PT, CIMI

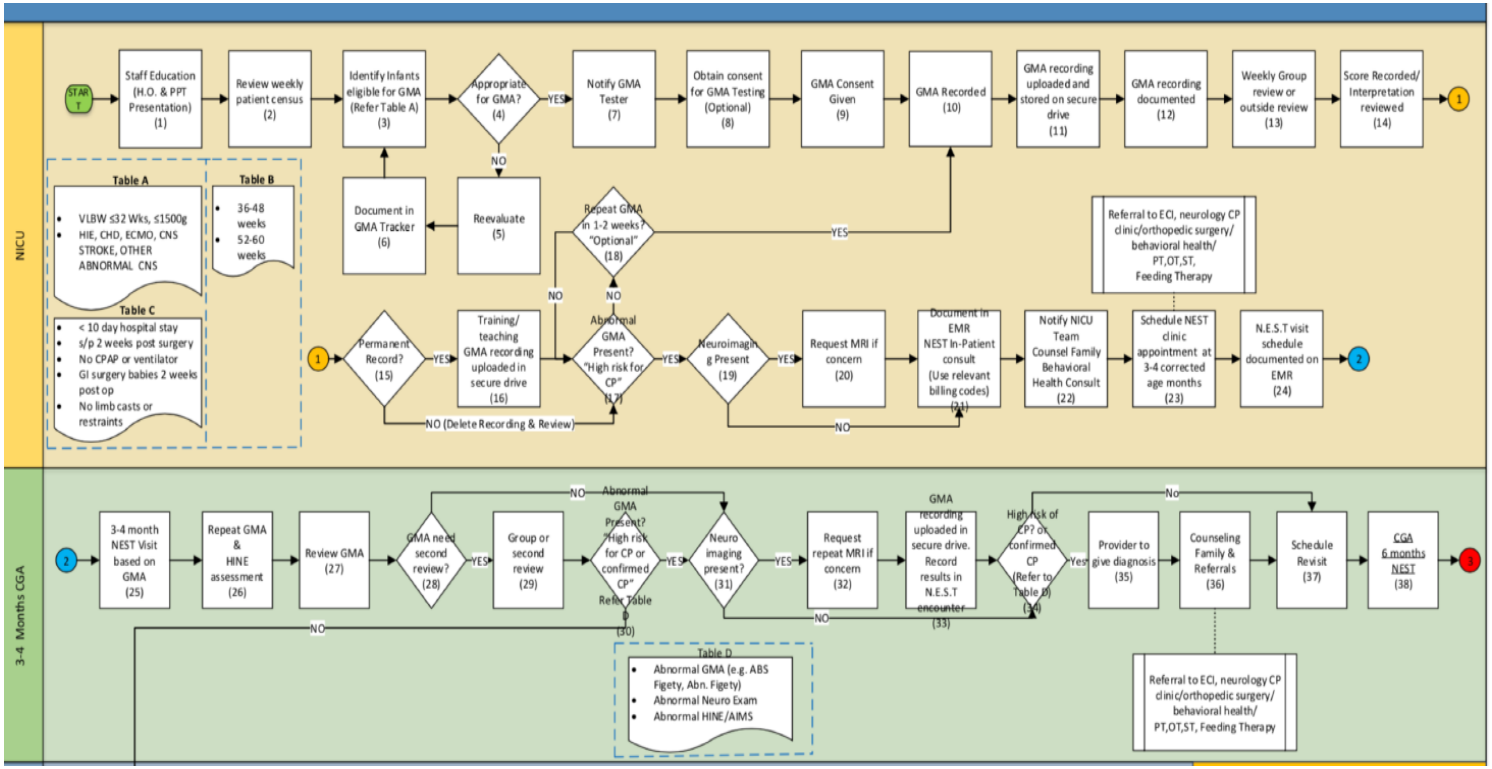
Heather Ross, PT, DPT

Betsy O'Hara, OTR, CNT

Follow-up practices

- **Target Populations:**
  - VLBW (<32 weeks', ≤1500 grams BW)
  - Hypoxic Ischemic Encephalopathy (HIE)
  - Complex Congenital Heart Disease (CHD)
    - Single Ventricle population
  - Congenital Diaphragmatic Hernia (CDH)
  - Extra Corporeal Membrane Oxygenation (ECMO)
- **Follow-up schedule:**
  - **"Early NEST":** at 3-4 months CGA
    - With abnormal NICU GMA findings
  - **"Regular NEST":** Initial appointment within 6 months (earlier as needed)
  - Follow-up appointments every 3-6 months
  - Follow-up through 5 years

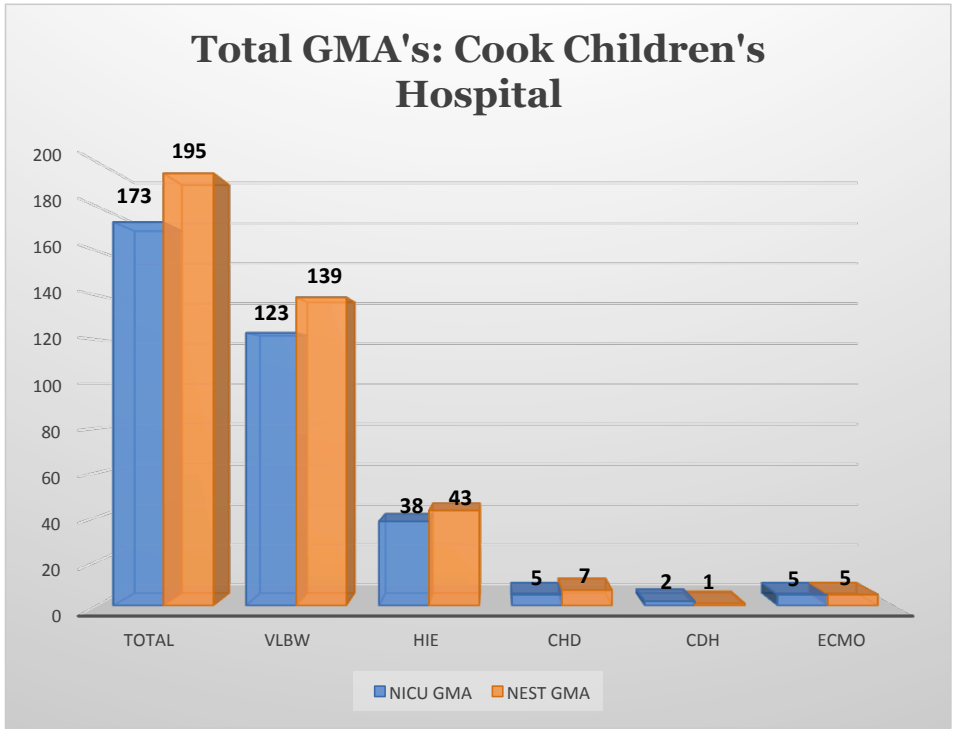
Your site's path or protocol/algorithm to early CP diagnosis

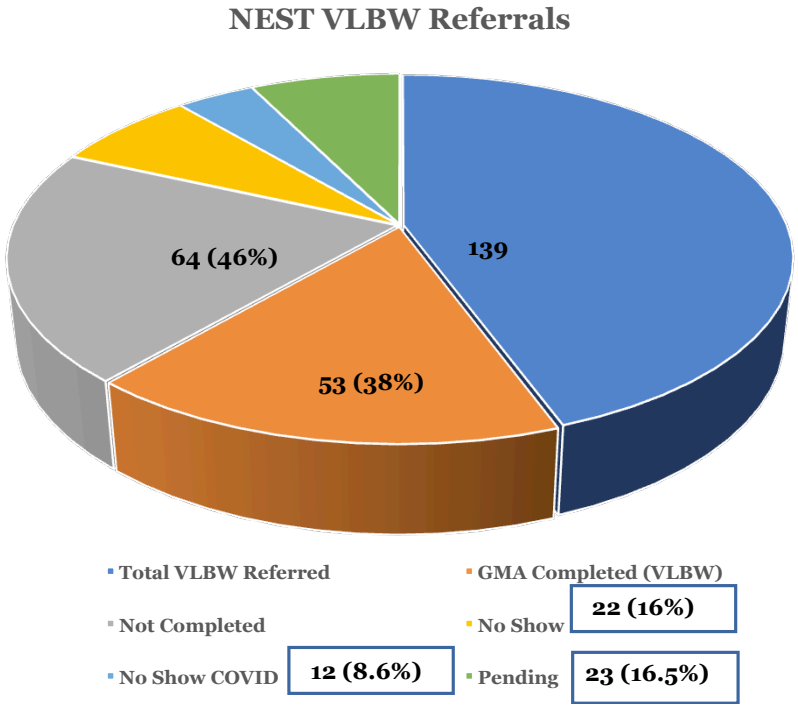


Did you do the following?

- **NICU**
  - TIMP: No
  - GMA video: Yes
  - MRI: Yes (selective)
- **First visit**
  - 1 month: Dietitian only ± Social Worker
  - 3-4 months: Yes (with abnormal NICU GMA)
  - HINE: (TBA, awaiting staff training to be completed)

Cook Children's Hospital Early CP Detection Program





GMA Findings: NICU and NEST Clinic

Location	Population	Normal (%)	Abnormal/High-Risk CP (%)	Total
NICU				
	VLBW	34	89	123
	HIE	8	30	38
	CHD	3	2	5
	CDH	1	1	2
	ECMO	1	4	5
Grand Total:				173
NEST				
	VLBW	34	19	53
	HIE	8	15	23
	CHD	3	0	3
	CDH	1	0	1
	ECMO	0	1 (inconclusive)	1
Grand Total:				81

How do you convey early diagnosis to parents?

- **NICU:**
  - Direct communication to families
    - Normal or PR findings-communicated by NICU therapist
    - Abnormal GMA findings: Telephone call from Dr. Johnson or in-person
    - Refer abnormal findings to NICU behavioral therapist (parent psychosocial support)
- **NEST:**
  - Direct communication to families by NEST physician or NP
  - Consultation to NEST behavioral therapist
  - NEST social worker and NICU Helping Hands parent liaison meet with family
  - Provide CP NOW Toolkit manual
  - Follow-up call to families within 1 week (preferred)

Needs your site have identified or barriers to early CP

- **Scheduling patients for "Early NEST" appointment from the NICU**
  - Breakdown in communication from early detection team to NICU discharge coordinator
  - Breakdown in communication between NICU discharge coordinator and NEST scheduler
  - NEST scheduler not properly "tagging patient" in schedule and EHR as needing repeat GMA
- **Process improvements have been implemented to correct the problem**
  - Improvement has been demonstrated, but still not perfect
- **COVID Crisis occurred when we had a large cluster of patients scheduled for NEST GMA and had to be converted to telephone or video telemedicine**
  - Some GMA's were done during video session
  - Developed a process to have the families upload a GMA video following standardized instructions
    - Requires uploading into Epic MyChart or send via secure email
    - New process has been initiated, but not yet fully functional

Training your site has regarding GMA and HINE

- **GMA:**
  - 7 Trained and certified
  - 4-5 awaiting training when course available
- **Advanced GMA:**
  - 6-7 expressed interest in attending a course when available
- **HINE:**
  - 1 provider trained and certified
  - 2 providers awaiting training (delayed due to COVID crisis)

How did you manage during the pandemic? Virtual visits?

- **Converted rapidly to telemedicine visits (start of pandemic)**
- **Converted to video telemedicine**
  - Within 1 month
  - Awaited system upgrade to accommodate larger bandwidth needed for full system rollout
- **Now using hybrid model:**
  - Initial visits/GMA visits: In-person only
  - Selected follow-up visits: telephone allowed selectively or parent request
  - Use of demonstration dolls to guide parents through elements of the neurological exam
  - Working on process for parents to upload videos to Epic MyChart or secure email

Kristine Tolentino-Plata for the Thrive Program at Children's Health Dallas

Neonatal Evaluation and Outcomes Network

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Status and Management during Pandemic

Thrive Program at Children's Health Dallas
University of Texas Southwestern Medical Center
and Texas Health Resources Dallas

Name of your site, location and population served

- Name of Site
  - Thrive Program
- Location
  - Children's Health Dallas
  - University of Texas Southwestern Medical Center
  - Texas Health Resources Dallas
- Population Served (*Currently accepting from Parkland Memorial Hospital, Clements, Children's Health System, and Texas Health Presbyterian Hospital)*
  - All infant with birth weight < 1500 grams
  - Infants with birth weights $\geq$ 1500 grams with specific medical conditions:
    - Hypoxic Ischemic Encephalopathy
    - Chronic Lung Disease / Bronchopulmonary Dysplasia
    - Infants requiring bowel resection / history of surgical NEC
    - Gastroschisis or Omphalocele
    - Severe (grade III or IV) intraventricular hemorrhage and/or Peri-ventricular leukomalacia
    - Infants discharged with a feeding tube (NG or G-tube)
    - Infants < 35 weeks gestational age and <3500 grams with teenage mothers
    - Other case by case basis may also be considered

Follow-up practices

- Comprehensive primary care for most:
  - Including routine health maintenance per THSteps and AAP guidelines
  - Ongoing care for acute and chronic medical problems from NICU d/c to age 5 years
  - Periodic neurodevelopmental evaluation
    - Including neuro exams at WCC visits along with developmental screening
    - Formal Bayley assessment and/or Vineland-3 at 1,2,3 years of age
    - MCHAT at 18 months and 2 years of age
    - School readiness assessment 4-5 years of age
  - Other developmental screening offered upon request
    - STAT

- Neurodevelopmental assessment only for those with other PCPs
  - Two sites: CMC THRIVE and THD THRIVE
  - HINE at 6, 12 months
  - NRN protocol neuro at 2, 3 years
  - Bayley and/or Vineland-3 at 1, 2, 3 years

Your site's path or protocol/algorithm to early CP diagnosis

- Comprehensive Care:
  - Neuro exams at WCCs during first two years
  - Developmental Screening at WCCs
  - Bayley and/or Vineland-3 at 1, 2, 3 years
- Neurodevelopmental assessment only for those with other PCPs
  - HINE at 6, 12 months
  - Bayley and/or Vineland-3 at 1, 2, 3 years

Did you do the following?

- NICU
  - MRI
- First visit
  - HINE at 6 months for Neurodevelopmental assessment only for those with other PCPs

How has your site done in the past year with regard to early CP diagnosis?

- We currently do not have retrievable data for:
  - 3-4 month visits
  - New CP diagnosis
  - No of high-risk for CP
  - Average age at diagnosis

Information can be found on each patient's chart but we will need to do manual data mining in order to retrieve data

How do you convey early diagnosis to parents?

- We do not hesitate to discuss findings of concern with families or to make referrals based on concerning findings (e.g. hypertonicity, hyperreflexia, motor impairments)

Needs your site have identified or barriers to early CP

- Debatable need to use the formal diagnosis of CP prior to 1 year old based on at risk findings
- At this point we do not have someone who can record or interpret GMA in NICU; and our outpatient GMA-certified examiner does not have inpatient privileges, so we would need to figure out a way to store and get video to her for interpret.

Training your site has regarding GMA and HINE

- MD and Developmental Specialist certified on HINE
- Have educated APPs on HINE, but they are not yet routinely using as such
- Developmental Specialist certified on GMA
- Plan to get a Neonatologist certified in the future

How did you managed during the pandemic? Virtual visits?

- Some Bayley assessments were converted to Vineland-3 to accommodate telehealth and decrease the amount of time needed to disinfect Bayley kits
- HINE was attempted for virtual visits in the beginning of the pandemic
- Well visits are scheduled in the morning while Sick visits are scheduled in the afternoon
- Neurodevelopmental visits continue to be in-person and/or through virtual visit

Thank you for the sites that reported on their data.

We are open for questions and comments.

At the end of the Summit, we will present a data collection tool to be used by Follow up centers.