Timing is Everything:

First Annual New Mexico Virtual Conference on Cerebral Palsy and Neurodevelopmental Disorders

The Referral Process: Why, To Whom, & How

November 7, 2020

Gerri Duran, MS, OT/L, UNM Developmental Care Program

Sandy Heimerl, DPT, Associate Professor, Dept. of Pediatrics

A little about us…

We Have Nothing to Disclose

Why refer?

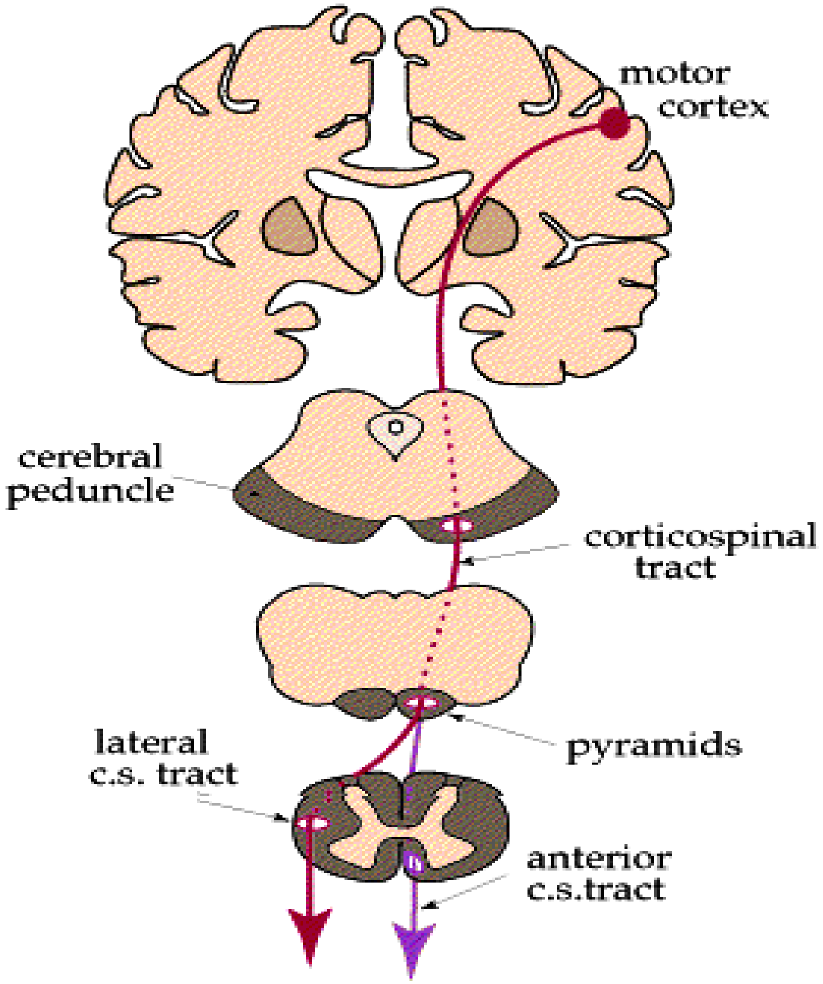
What is the Concern?

- Cerebral Palsy is the most common physical disability
- 1 in 345 children in the US, Equates to approximately 76 infants born / yr. in NM
- Typically diagnosed at **age 2 years** or later for milder cases
- ***50% of children with CP do not have identifiable risk factors and are under the care of general or pediatric practitioner***

Why is early detection important?

Corticospinal tract – **the** principle motor system for voluntary motion of limbs

- Upper motor neurons with cell bodies in primary motor cortex and axons traveling through brainstem into spinal cord
- Spinal cord synapse with lower motor neurons – innervate skeletal muscle



Why is Early Detection Important?

Corticospinal Tract & Neuroplasticity

- ☐ Rapid increase in growth & maturation from birth to 1 year, then levels off between 1-2 years.
- ☐ Early motor interventions aiming to influence corticospinal tract most effective early – **Before 2 years of age**
- ☐ **Critical period missed with late identification**

(Braga et al. 2015)

Why is Early Detection Important?

- CP intervention using intense, motor learning task-specific approaches plus environmental enrichment optimizes plasticity and improves motor and cognitive outcomes.
- Early, regular monitoring and treatment for musculoskeletal complications can prevent the onset of hip dislocation, scoliosis and contracture.
- Parents experience more depression and stress when dissatisfied with diagnostic process. Families prefer early diagnosis.
- <u>Wait and see</u> approach precludes infant from accessing supports and services and negatively impacts child and family.

http://www.aacpdm.org/publications/care-pathways/early-detection

Why is Delayed Identification a Problem?

- Less ability to mitigate brain injury occurs if:
  - Little-to-no intervention during the critical period of brain plasticity Intervention
  - Services occur late or with less intensity
- Specific evidence-based practices are warranted

When Early Signs Prompting Referral for Specialist Evaluation for CP

- Persistent fisting of the hands past 4 months
- Persistent head lag beyond 4 months
- Stiffness or tightness in the legs between 6-12 months

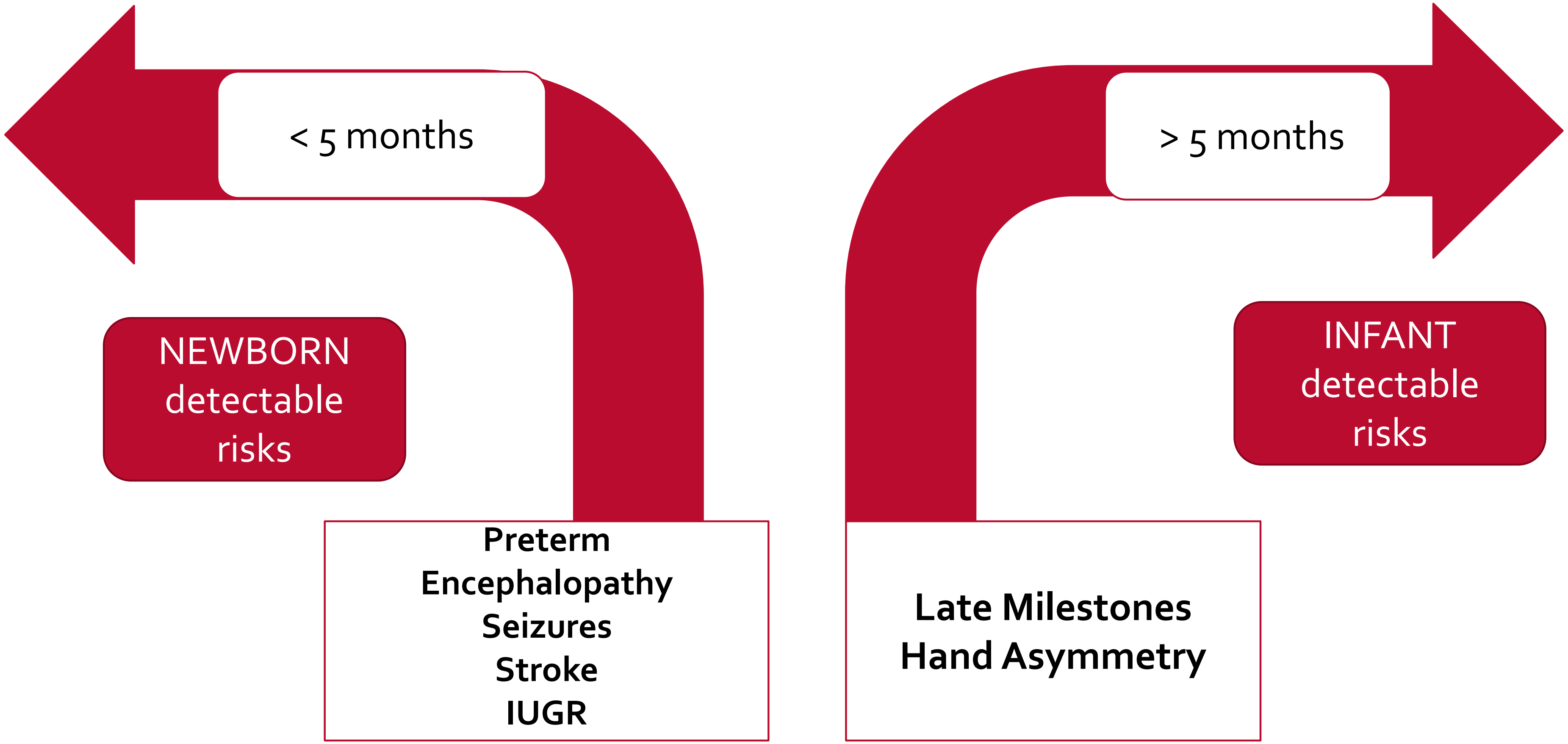
Why is There an Advantage with Early Identification?

- If identified as “High Risk for CP” at 3 - 6 months, the infant can receive diagnostic-specific intervention to optimize neuroplasticity and reduce impairments
- Ongoing medical monitoring and surveillance can be provided to prevent secondary problems
- While learning their child is at high risk is extremely difficult, research has shown that parents prefer to know early rather than late

Why Optimize Neuroplasticity

Because neuroscience research demonstrates intensive, repetitive, task-specific, exercise should commence within the first 12 months of life to optimize neuroplasticity.

Two Risk Pathways



< 5 months

NEWBORN detectable risks

Preterm
Encephalopathy
Seizures
Stroke
IUGR

> 5 months

INFANT detectable risks

Late Milestones
Hand Asymmetry

Decision Tree for Early Identification of Motor Disorder

Signs Prompting Physical Therapy or Occupational Therapy Evaluation before 6 months of age

Signs Prompting Physical Therapy or Occupational Therapy Evaluation after 6 months of age

INFANTS < 6 MONTHS WITH KNOWN RISK s	INFANTS < 6 MONTHS W/O KNOWN RISK	INFANTS > 6 months All signs prior to 6 mos. would prompt referral in addition these signs
Prematurity	Persistent orientation of head to one side beyond 4-months	Inability to sit independently by 9-months
Encephalopathy	Persistent fisting of hands past 4 months	Inability to take weight through flat feet when supported in standing
Stroke or Intraventricular Hemorrhage	Persistent head lag beyond 4 months	Hand function asymmetry -strong preference of one hand
Intrauterine Growth Restriction	Feeding issues	**Parental concern**
Parental concern	Stiffness/tightness in legs	
	Parental concern	

How is Accurate Detection Now Possible?

How is Early Identification of Risk Possible?

- An infant’s motor impairment can now be detected very early and accurately with standardized tools.
- The *General Movement Assessment* (GMA)
- The *Hammersmith Infant Neurological Examination* (HINE) is a relatively simple and quick assessment tool for infants 3 -24 months. It has high predictive ability (about 90%)

When and Who Can Administer GMA and HINE?

We have New Mexico OTs, PTs & physicians who are trained in the administration of the GMA and the HINE

- Prechtl General Movement Assessment (**GMA**)
  - Age Range: birth- 5 months
  - Requires 3-5 minute video of baby in diaper
  - Subsequent Scoring of video
  - Can be predictive of risk for CP
- Hammersmith Infant Neurological Examination (**HINE**)
  - Age Range: (2) 3 months to 24 months
  - Takes 5-15 minutes (with practice)
  - NOT a developmental milestone evaluation
  - Can be predictive of neuromotor disorders including CP and hemiplegia

General Movements

GMA looks at abnormal quality and quantity of movement

Writhing Movements:

Birth to approx. 8 weeks PCA

- Normal
- Poor Repertoire
- Cramped Synchronized
- Chaotic

Fidgety Movements

3-5 months

- Normal
- Abnormal
- Absent

Cramped synchronized movements https://www.youtube.com/watch?v=LSa4jENxgLk

Normal fidgety movements (mis-labeled in video heading) https://www.youtube.com/watch?v=XrVZmG9KSxo

GMA Compared to MRI

Bosanquet M, et.al, 2013; Spittle AJ, et al, 2009; Spittle et al., 2008; Spittle AJ, et al., 2013;Ferrari F, et al., 2002)

GMA	**MRI**
Sensitivity*	Sensitivity
93-100%	60-100%
Specificity**	Specificity
82-100%	89-99%

* **sensitivity** correctly identifies a true positive rate

** **specificity** correctly identifies a true negative rate

Hammersmith Infant Neurological Examination (HINE)

90% predictive of CP

For Infants 2-24 months adjusted age

Assesses

- Cranial nerve function,
- Posture,
- Quality and quantity of movement,
- Muscle tone,
- Reflexes & reactions

- Standardized and scorable clinical neurological examination of infants between 2 and 24 months
- 26 Items
- Each item scored individually with (0, 1, 2, or 3) with a global score adding the scores of all individual items (range from 0-78)
- Scoring Form with instructions for performing the test and diagrams to aid in scoring

How? Early detection after 9 months

- Inability to sit by 9 months
- Inability to take weight through heels and forefoot
- Hand function asymmetry

How? Who? Entry into Services via Early Intervention (EI)

- Providers **AND** Parents can refer
  - BUT, **Family Infant Toddler Early Intervention (FIT/EI)** is a Voluntary Program and Parents MUST agree!
- Birth – 3 years
- Federal/State Program (paid for with tax dollars)
- FIT/EI is within the **Early Childhood Care and Education Program**

https://nmhealth.org/about/ddsd/pgsv/fit/

How can EI programs access therapists who can provide GMA and/or HINE?

- UNM Developmental Continuity Care Program can be added to EI agency’s IFSP and GMA and/or HINE can be provided via ZOOM
  - DCCP (505) 272-1097
- https://hsc.unm.edu/medicine/departments/pediatrics/divisions/neonatology/dev-care.html
- Other EI agencies can provide same services but an MOU needs to be completed e.g. MECCA would need an MOU with Inspirations
- UNM Early Childhood Evaluation Program can provide diagnostic evaluation and/or complete the HINE. (505) 272-9846
- http://www.cdd.unm.edu/clinics/early-childhood-evaluations.html

How can EI programs access therapists who can provide GMA and/or HINE?

- IT IS NOT OKAY to simply provide evaluations without therapeutic follow-up.
- THIS is why the CP Task Force is providing concomitant educational programs that offer information about evidence based practices (EBP)
- AND, EBP includes knowing how to speak with families about concerns in a compassionate, realistic manner

To Whom? Other Resources

- Refer for outpatient PT or OT at community-based clinics – this will require an RX for insurances to cover

- FIT/EI services **and** outpatient clinic can **both** serve children

http://www.cdd.unm.edu/other-disability-programs/information-network/index.html

When do you ask for an MRI?

- Can use an MRI to confirm a diagnosis BUT, remember, a “clean” MRI does not r/o CP as CP is a **clinical** dx
- If request an MRI, provide concerns for radiologist to examine
  - E.g. Bebe walks on toes; Bebe uses right more than left
- NM does not have a pediatric neuroradiologist.
  - Consider asking how much it would cost to have MRI sent to a Children’s Hospital that has a pediatric neuroradiologist
- To Sedate or Not to Sedate?
  - Discuss all risks if you sedate under 2 years of age

When do you refer to a Neurologist?

- Many providers will not diagnosis CP and will refer to a neurologist
- If this is the case, therapies should not wait for a dx!
- Work with the bebe/family on the clinical aspects that bebe is showing!
- Regardless of dx, if a bebe has an asymmetry or a motor delay, provide therapy that is EBP

When do you refer to the UNM CP Clinic?

When you need a dx.

- Margaret Armstrong, MD, pediatrician at UNM CP Clinic
  - One of the “Founders” of the CP Task Force
  - Trained in the HINE
  - Will recommend specific therapies
  - Dr. Armstrong does dx CP – CP is one of her specialties!!
- First visit is face-to-face
- Offers comprehensive approach and multi-disciplinary
  - SW
  - Seating
  - Hip surveillance
  - Nutrition
  - Additional referrals
- Catching-up but still a wait list

How to Talk ~~Communicate~~ **With** ~~to~~ Parents

How the diagnosis is communicated – From Parents

- Tone positive: “Be honest, realistic, hopeful.”
- Language: Adapted to parent “Start with simple words and offer numbers if a parent wants more details”—“we shouldn't need a translator, just an interpreter if it is a different language.”
- Specific to disorder and child: “Don't be too general or use platitudes.”
- High-risk for CP: Acceptable diagnosis “We understand that the conversation will continue, and diagnosis may be revisited.”

Byrne, et al., 2019

How do we share our concerns with parents?

We take our time

We sit down

We structure a conversation when parent has additional support e.g. partner, spouse, another parent

We do not rush

We ask for questions and we provide answers as many times as necessary

We communicate hopeful reality

We listen

We allow silence

We encourage timely interventions

We commend them on taking the time to bring their precious child to us

We plan for a follow-up contact and ask when they would like to re-connect

NEW MEXICO
Early Childhood
Education & Care Department

CENTER FOR
DEVELOPMENT
& DISABILITY

Resources

APS

LAS CRUCES
PUBLIC SCHOOLS

- Refer to FIT Early Intervention (birth to 3) https://nmhealth.org/about/ddsd/pgsv/fit/
- Refer to public schools Child Find (>3yrs.)

http://www.cdd.unm.edu/infonet/pdfs/tipsheets/early-childhood-pdfs/child-find-developmental-screenings-for-children-ages-3-4.pdf

- UNM CDD Information Network

http://www.cdd.unm.edu/other-disability-programs/information-network/resource-portal/babynet.html

Take-Aways

(Carry-outs during COVID…)

- Through careful observation, examination and listening to parents, motor delays and disorder can be identified early
- If atypical motor development is identified – refer for intervention and to medical specialist for possible diagnosis
- Continue to develop your capacity and network in order to support families

When we accept a referral for therapy, evaluation, or intervention

- There is an understanding by parents/providers that we shall use EBP
- Our task force goal is to develop capacity in Health Care Providers, Therapists, and Developmental Specialists to:
  - Know when to refer
  - Know what evaluations are evidence-based
  - Know what interventions are evidence-based
  - Know how to complete evidence-based evaluations and interventions
  - Build capacity throughout the state
  - Network when we need consultation and collaboration

Other Resources

- **Cerebral Palsy Foundation**
  - **https://www.yourcpf.org/**
- **American Academy of Cerebral Palsy and Developmental Medicine (AACPDM)**
  - http://www.aacpdm.org/publications/care-pathways/early-detection
- **American Academy of Pediatrics – Providing a Primary Care Medical Home for Children with CP**
  - https://pediatrics.aappublications.org/content/128/5/e1321
- **Learn the Signs Act Early – Centers for Disease Control** - includes developmental tracker APP
  - https://www.cdc.gov/ncbddd/actearly/index.html

Questions?
Thank you.

Sandy Heimerl, DPT
Center for Development and Disability
Early Childhood Evaluation Program
sheimerl@salud.unm.edu

Gerri Duran, MS, OT/L
UNM Developmental Care Program
gduran@salud.unm.edu