COMING OUT OF THE OVEN TOO SOON

Neurodevelopmental Follow-up of the NICU Graduate

Theodore E. Atkinson, M.D., FAAP,
NeuroDevelopmental Pediatrics
Medical Director of High Risk Infant & Cardiac Developmental Clinics
Michael R. Boh Center for Child Development
Ochsner Hospital for Children

Financial Disclosures

- Nothing to disclose

Objectives

- Review statistics and data on the incidence of preterm birth
- Review causes of preterm birth
- Review and discuss morbidities of prematurity which contribute to developmental delays
- Review follow-up clinics and their role in the early diagnosis of Cerebral Palsy
- Discuss feeding issues common in NICU graduates

The Ingredients of a good cake from scratch

Good Cake Ingredients from the box

Outcome of staying in the oven

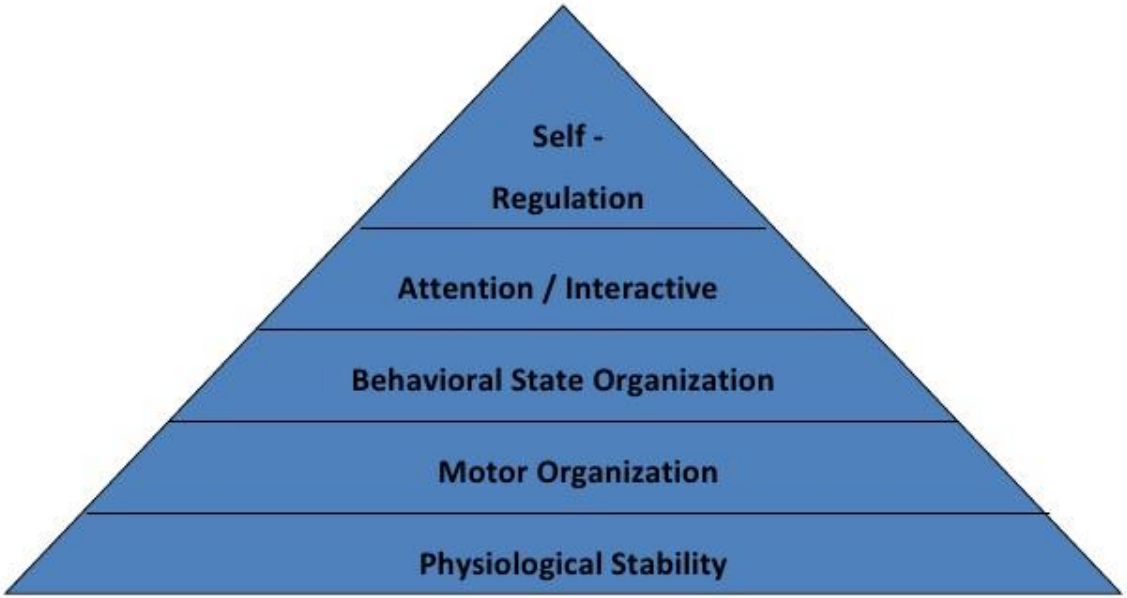
Best New Orleans cake

Best New Orleans cake

The Term Newborn (a Gerber baby)

To Be a Term Newborn

Synactive Theory of Infant Development
Heidelise Als



Hierarchical interaction and interdependency of five subsystems

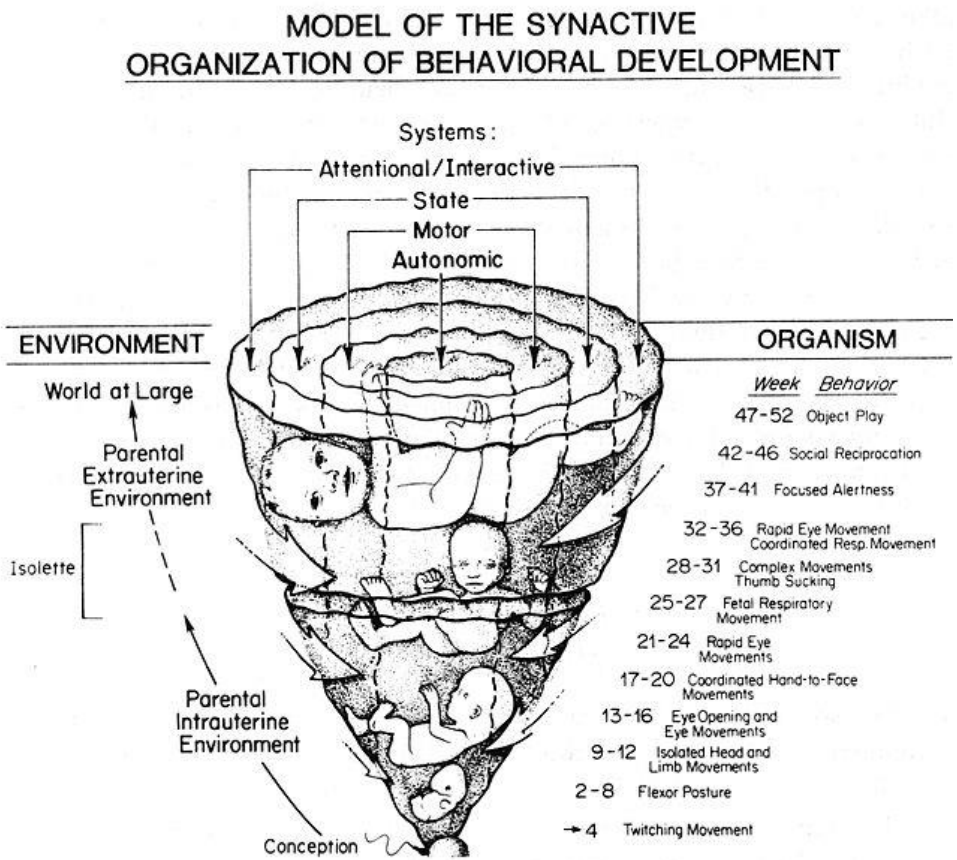
Coming out the oven too soon

Unbaked Cake

Unbaked Cake

The Preterm Infant

To be a Term Newborn 2



The process of subsystem interaction (how the five subsystems work together or influence each other) is what is meant by the term "synaction." This synaction is combined with the infant's continuous interaction with the environment to formulate the "Synactive Theory of Infant Development."

Signs of stress, by subsystem, seen in preterm or full term infants in the NICU

- **Autonomic Signs of Stress**
  Color changes (pallor, flushing (turning red), and cyanosis (turning blue)
  Changes in vital signs (heart rate, respiratory rate, blood pressure (BP), pulse ox rate)
  Visceral responses (vomiting, gagging, hiccups, passing gas); Sneezing or Yawning
- **Motor Signs of Stress**
  Generalized hypotonia (limp, decreased resistance to moving of the infant's extremities)
  Frantic flailing movements; Finger splaying (holding fingers spread wide apart)
  Hyperextension of extremities (arms or legs extended straight out almost in a locked position)
- **State Signs of Stress**
  Diffuse sleep states (lots of twitching, grimacing, not resting peacefully)
  Glassy-eyed (appears to be "tuning out")
  Gaze aversion (cuts eyes to the side trying not to look at what is in front of them)
  Staring (a locked gaze, usually wide open eyes)
  Panicked look; Irritability (hard to console)
- **Attention/Interaction Signs of Stress**
  Infant will demonstrate stress signals of the autonomic, motor and state systems
  Inability to integrate with other sensory input (can't look and face, listen to talking and suck a bottle at the same time)
- **Self-Regulatory Behaviors** - these are attempts to deal with stress and regain control
  Change in position
  Hand-to-mouth; Grasping
  Sucking Visual locking Hand clasping

Too soon

General problems in premature infants

- Feeding: (IV – Gavage)
- Temperature control: (incubator-heated bed)
- Respiratory control: apneas, Respiratory support CPAP, Artificial ventilation
- Immature lungs – lack of surfactant: Oxygen suppl, Respiratory support (CPAP, ventilator)
- Immature brain: brain hemorrhage and cysts
- Immunology: risk of infections ⇧ (antibiotics)
- Organ injury (Brain, Eye, Lung, Intestine, Skin
- Long term consequences

Risk for Developmental Problems

A collection of causes

TABLE 1.

Infants at High Risk of Neurodevelopmental Impairments Admitted to the Neonatal Intensive Care Unit

Medical/ biological risk factors

- Prematurity: higher risk <28 weeks GA; moderate risk <32 weeks GA
- Lower BW: higher risk <1,000 g; moderate risk <1,500 g
- Brain abnormalities: intraventricular hemorrhage grade III or IV, cystic or periventricular leukomalacia
- Necrotizing enterocolitis
- Chronic lung disease
- Neonatal encephalopathy
- Encephalitis, meningitis, sepsis
- Postnatal steroids
- Surgical intervention
- Abnormal neurologic/neurobehavioral examination at term age

Family/environmental factors

- Low socioeconomic status
- Low maternal education
- Single parent
- Drugs/alcohol, smoking, substance abuse
- No prenatal care
- Environmental stress

Abbreviations: BW, birth weight; GA, gestational age.
Adapted from Doyle et al.[1] and Wang et al.[3]

Epidemiology of Prematurity

- Preterm birth is a major cause of death and a significant cause of long-term loss of human potential amongst its survivors worldwide.
- Complications of preterm birth are the single largest direct cause of neonatal deaths, responsible for 35% of the world's 3.1 million deaths per year, and 2nd most common cause of under-5 deaths, after pneumonia.
- In almost all high- and medium-income countries of the world, preterm birth is the leading cause of childhood death.

Prematurity: Epidemiology

BORN TOO SOON

Just over 11% of live births worldwide are pre-term — before 37 weeks of gestation — and premature birth is the second largest cause of child deaths in under-fives. The medical risks increase with the extent of prematurity; neuroscientists now think that some effects on brain development may last into adulthood.

22 WEEKS
Some hospitals now try to save babies born as early as 22 weeks.

22–32 WEEKS
One long-term study found that up to half of children born in this window have some neurodevelop-mental problem at age five.

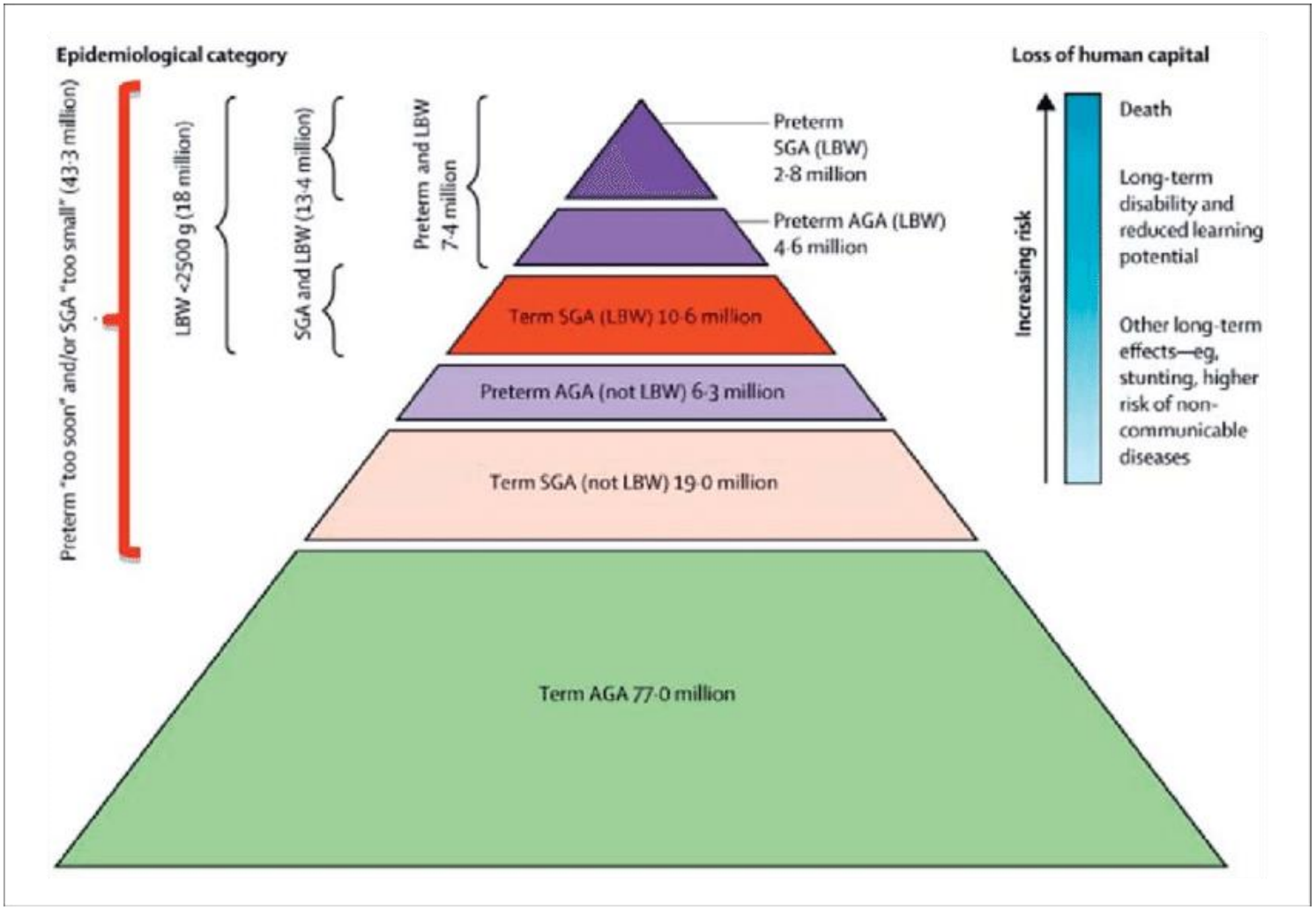
23–39 WEEKS
Brain-scanning studies point to atypical structural and functional connections in the brains of premature infants.

24 WEEKS
50% chance of survival with neonatal intensive care in most high-income countries.

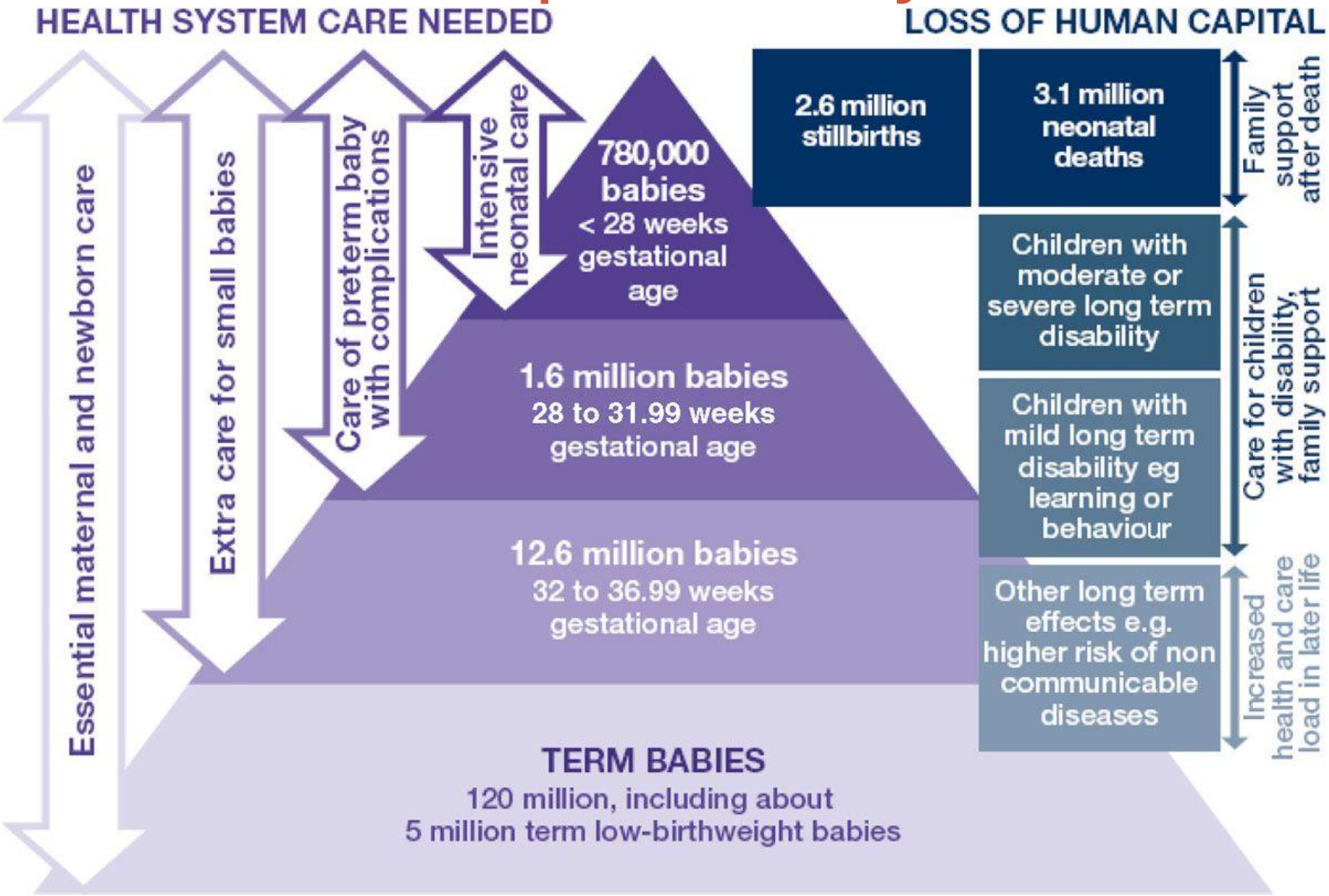
26 WEEKS
Cerebral palsy affects around 10% of very pre-term babies, but 18% of those born at 26 weeks.

34 WEEKS
50% chance of survival with neonatal intensive care in many low-income countries.

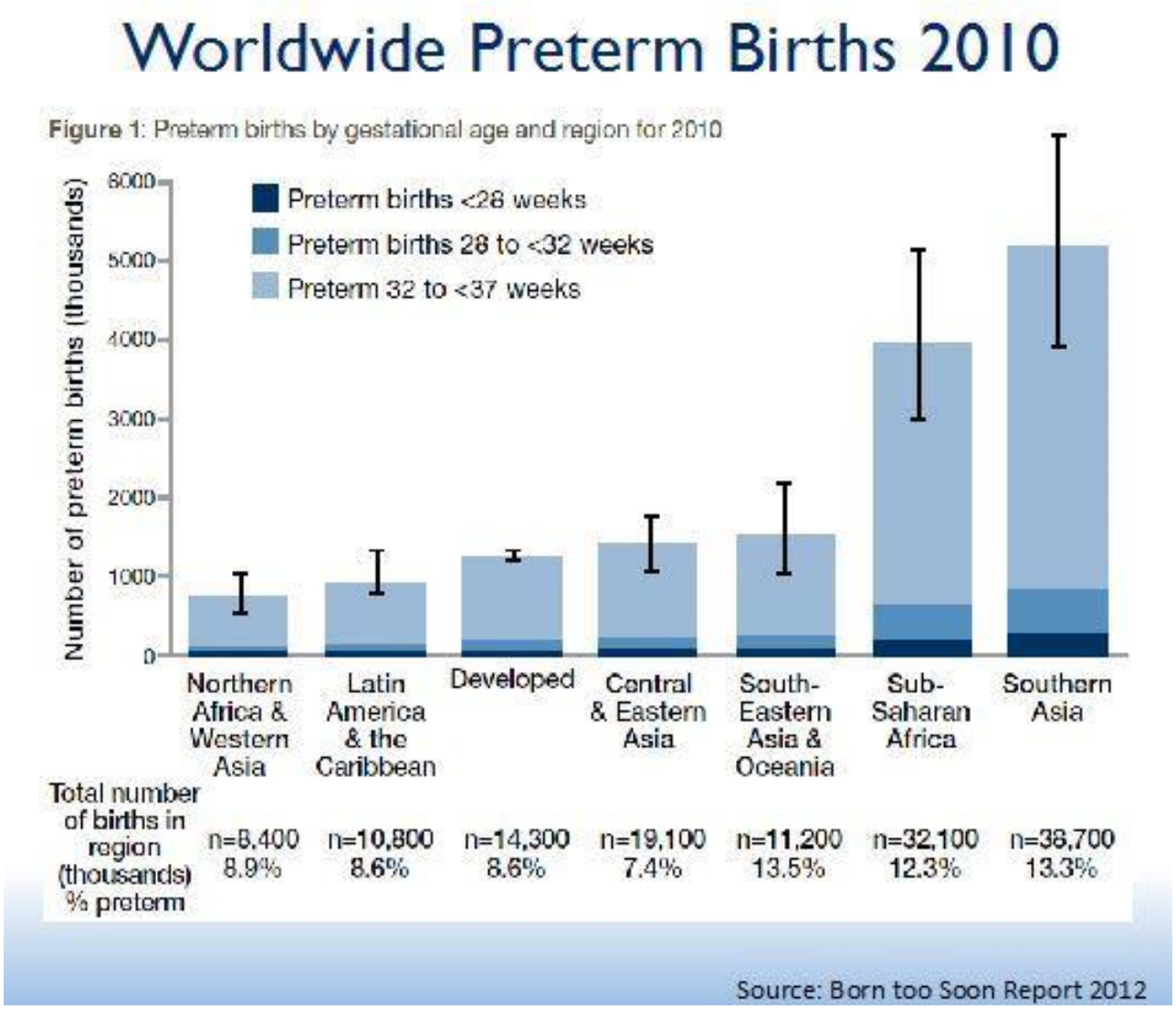
Premie Epidemiology



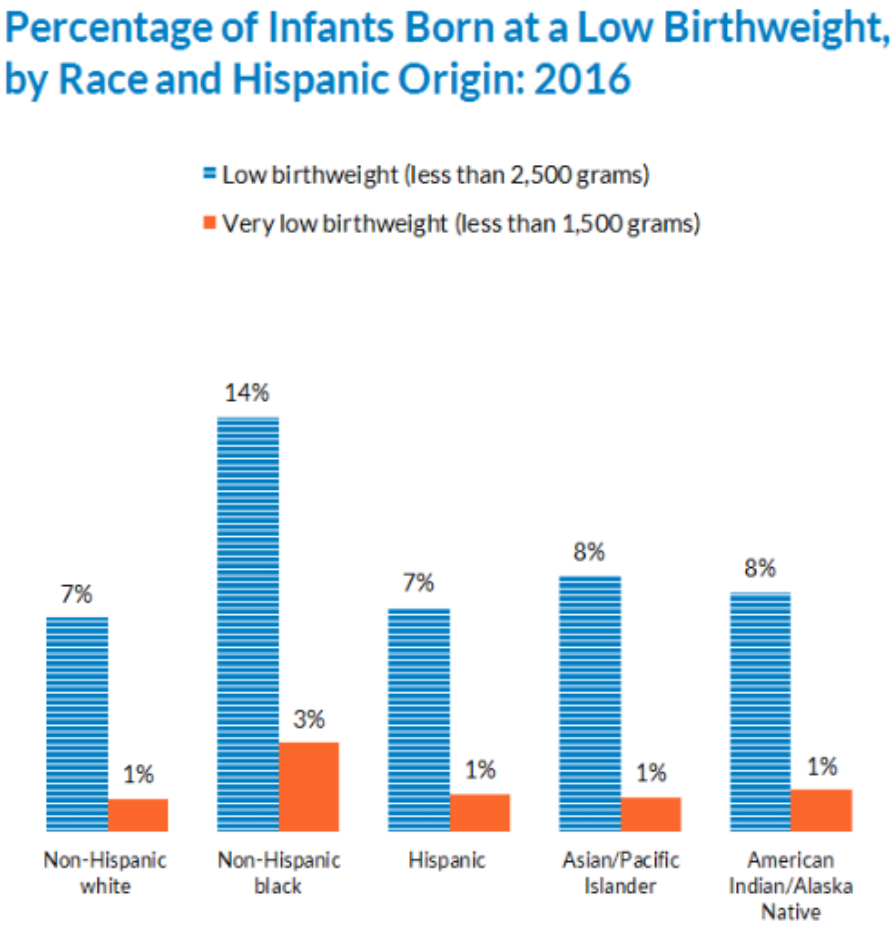
Human Cost of prematurity



Preterm Births Worldwide 1



Prematurity in USA



Source: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics. (2018). CDC WONDER [Data tool]. Retrieved from http://wonder.cdc.gov/natality-current.html.

childtrends.org

Premie: definiton

MICRO-PREEMIE
A baby born weighing less than 1 pound, 12 ounces (800 grams) or before 26 weeks gestation.

VERY PREMATURE
A baby born between 27 and 30 weeks gestation. A baby born at 27 weeks weighs around 2 lbs 3 oz; a baby born at 30 weeks weighs around 3lbs 3 oz.

MODERATELY PREMATURE
A baby born between about 31 and 34 weeks gestational age. They usually weigh between about 3 1/2 to 5 pounds.

LATE PRETERM
A baby born between 34 and 37 weeks gestation. They are also called near term and are usually weigh between 5 to 7 pounds.

Because all babies and circumstances are different, these are not exact weights. Your preemie could weigh more or less.

Preemie Support And Awareness

Prematurity & Low Birth Weight

Gestational Age

LPT: between 34 weeks and 36 weeks + 6 days

VPT: ≤32 weeks

EPT: ≤28 weeks

Birthweight

LBW: <2,500 g (5 lb, 8 oz.)

VLBW: <1,500 g (3 lb, 4 oz.)

ELBW: <1,000 g (2 lb, 3 oz.)

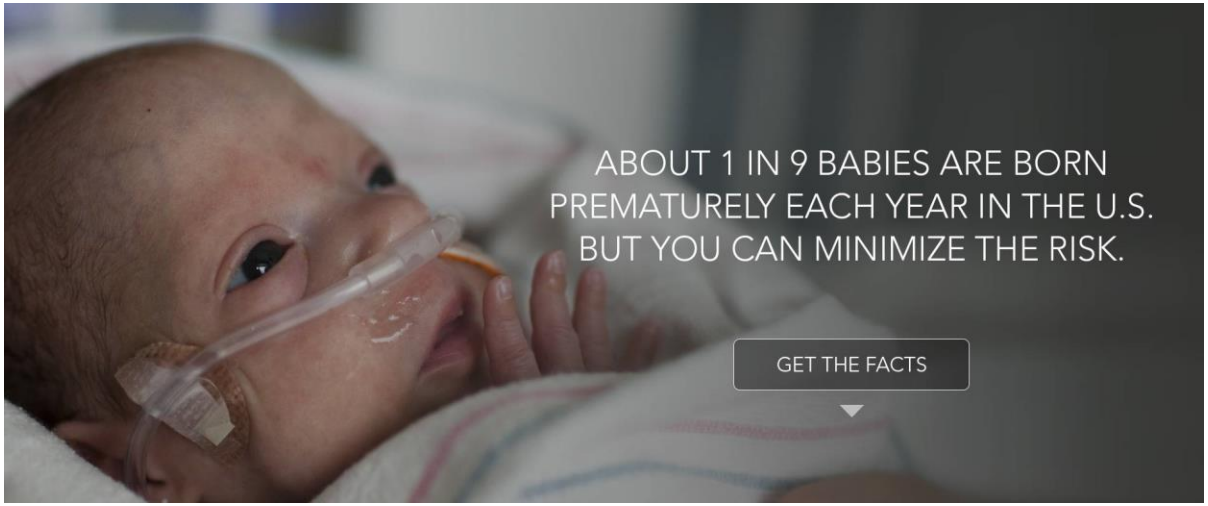
ELBW: extremely low birthweight; EPT: extremely preterm; LBW: low birthweight; LPT: late preterm; VLBW: very low birthweight; VPT: very preterm.

Source: Reference 1.

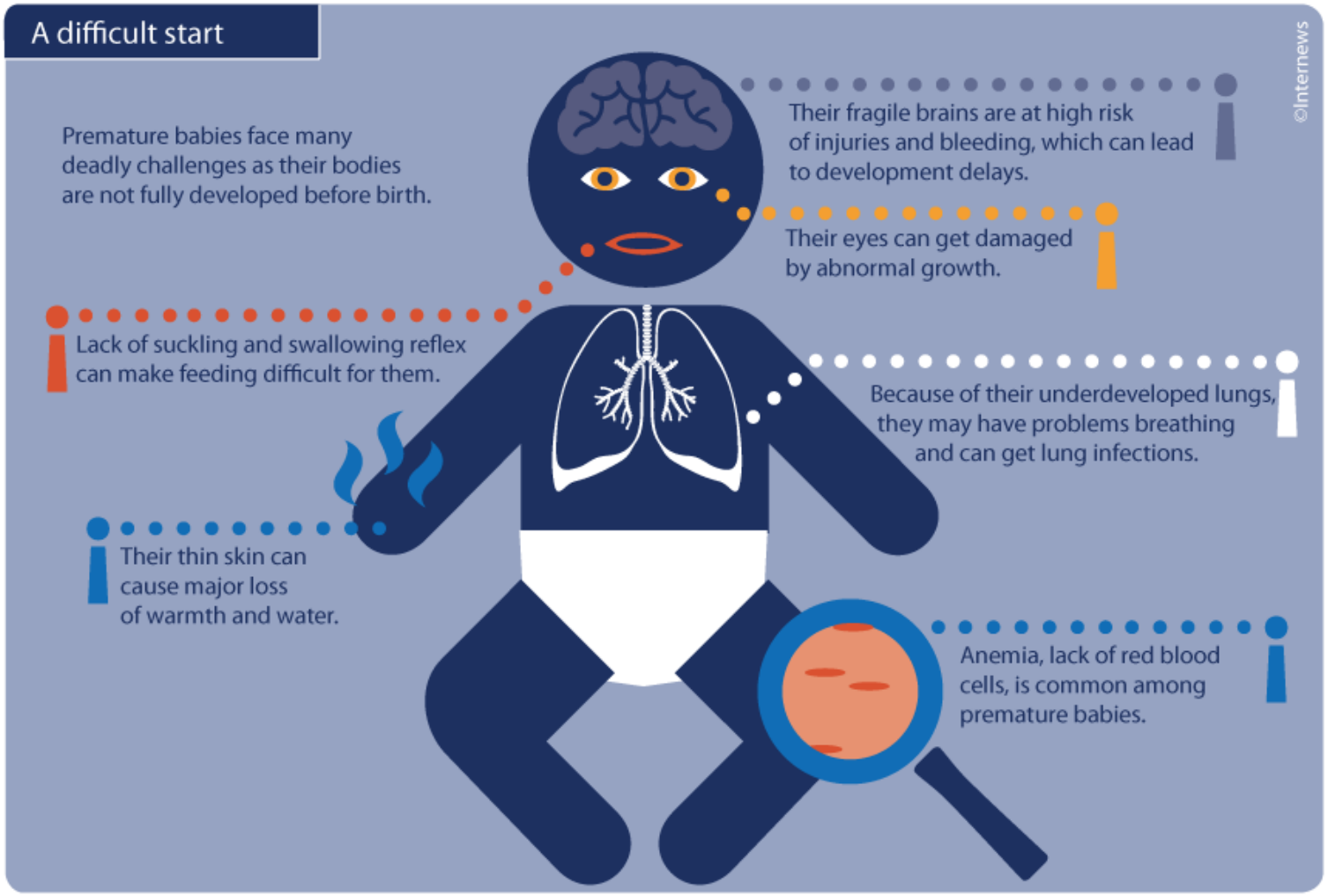
NICU admissions

For Ochsner Baptist, which had approximately 3300 deliveries in 2018, this would equate to 375 newborns per year.

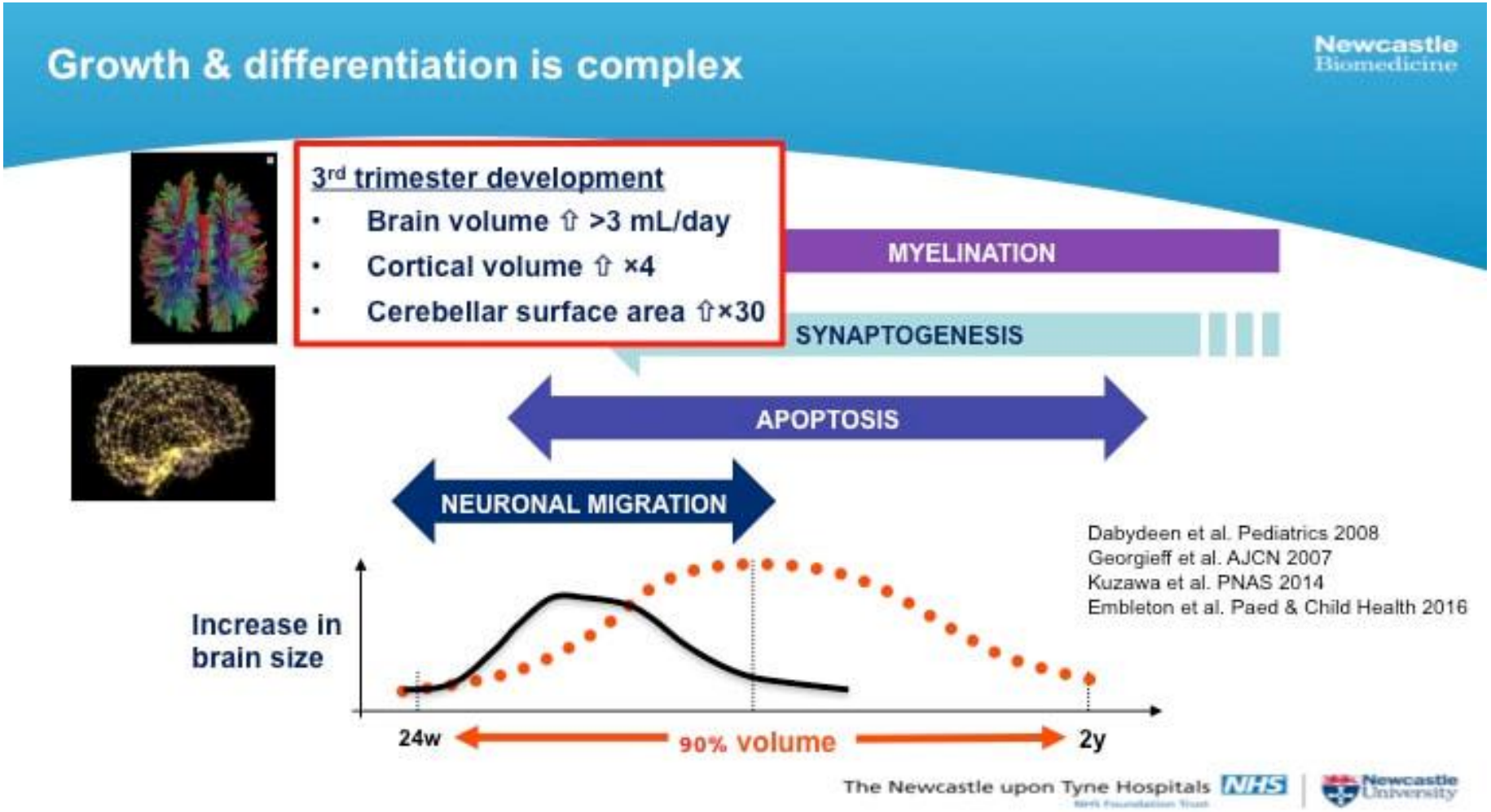
We have set up our HRNB followup clinic to accommodate this number.



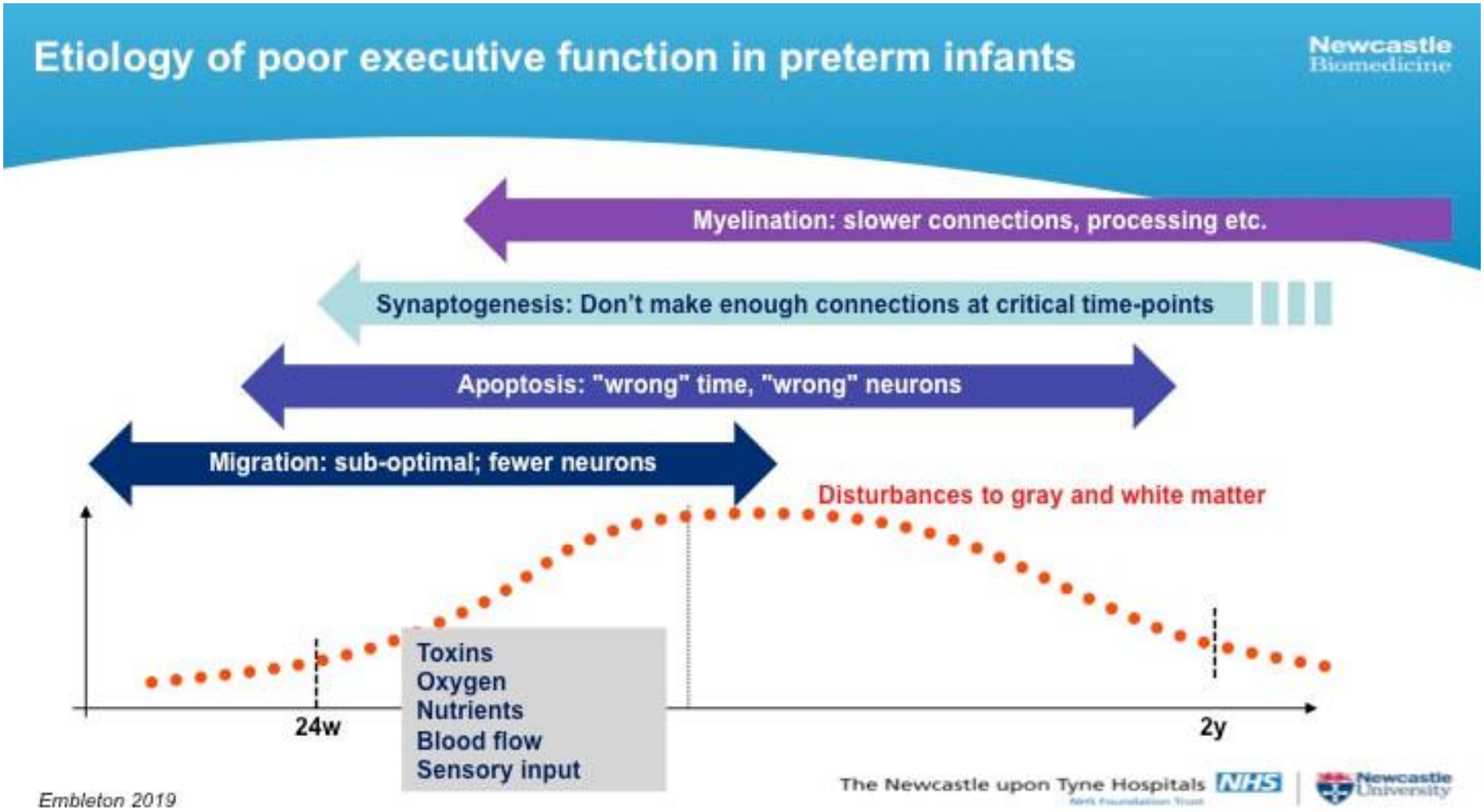
Why Premies have problems



Why Premies have Developmental Problems 1



Why Premies have Developmental Problems 2



Specific Causes of Neurodevelopmental Problems

- Prematurity
- Antepartum hemorrhage
- Complications of multiple pregnancy
- Genetic disorders
- Intrauerine infection; for example, chorioamnionitis, funisitis, villitis, cytomegalovirus, toxoplasmosis
- Intrapartum fever
- Intrauterine growth restriction
- Maternal and fetal coagulopathies
- Multiple congenital anomalies
- Maternal disease; for example, hypothyroidism, diabetes, drug abuse, severe pre-eclampsia, viral illness
- Placental pathology; for example, major infarction, thrombotic vasculopathy
- Tight nuchal cord
- Childhood causes
- Other causes; for example, fetal hemorrhage, rhesus disease.

Premie Problems

Neuro-Developmental Evaluation

- Most premature infants will experience temporary delays in development, this is due to:
  - Prolonged hospitalization.
  - Impact of medical condition.
- The impact of prematurity in preterm infants without neurologic insult lessens over time

Goal of HRIF Programs

- Provide early identification and referral of neurodevelopmental delays and impairments to preterm infants or those with perinatal insults contributing to their developmental vulnerability.
- Serve as referral centers for general providers who have identified delays on routine screenings.
- Providers in HRIF can further support diagnoses, provide a mechanism for better understanding of disorders, help define prognoses, monitor longitudinal history of a disease and document the effects of interventions.

from Implementation of the HINE in a HRIF program. Maitre, NL et al. Ped Neuro 65, (2016), 31-38

High Risk Infant Follow-up: Why?

Prematurity and Developmental Disability

	Prevalence per 1000 children by Gestational Age				
	20-23 wk	24-28 wk	29-32 wk	33-36 wk	>37 wk
Cerebral Palsy	49.9	49.9	16.7	3.2	1.3
Mental Retardation	76.0	60.9	27.2	12.9	6.8
Hearing Loss	14.3	6.3	1.9	1.0	0.7
Vision Impairment	11.9	16.1	2.9	1.0	0.5

Developmental disabilities by gestational age among survivors to age 3

gapps

Preterm Birth: Causes, Consequences, and Prevention. IOM; Behrman RE, Butler AS, editors. Wahington DC: National Academies Press: 2007.

HRIF: for Early Detection

Prevalence of Significant Disabilities in VLBW

Mental retardation	10-20%
CP	5-21%
Blindness	2-11%
Deafness	1-3%
Motor delay	24%
Language problems	23-42%
ADHD	7-10%
Need for special education	9-28%
Psychological/behavioral problems	25%

Our Current Team

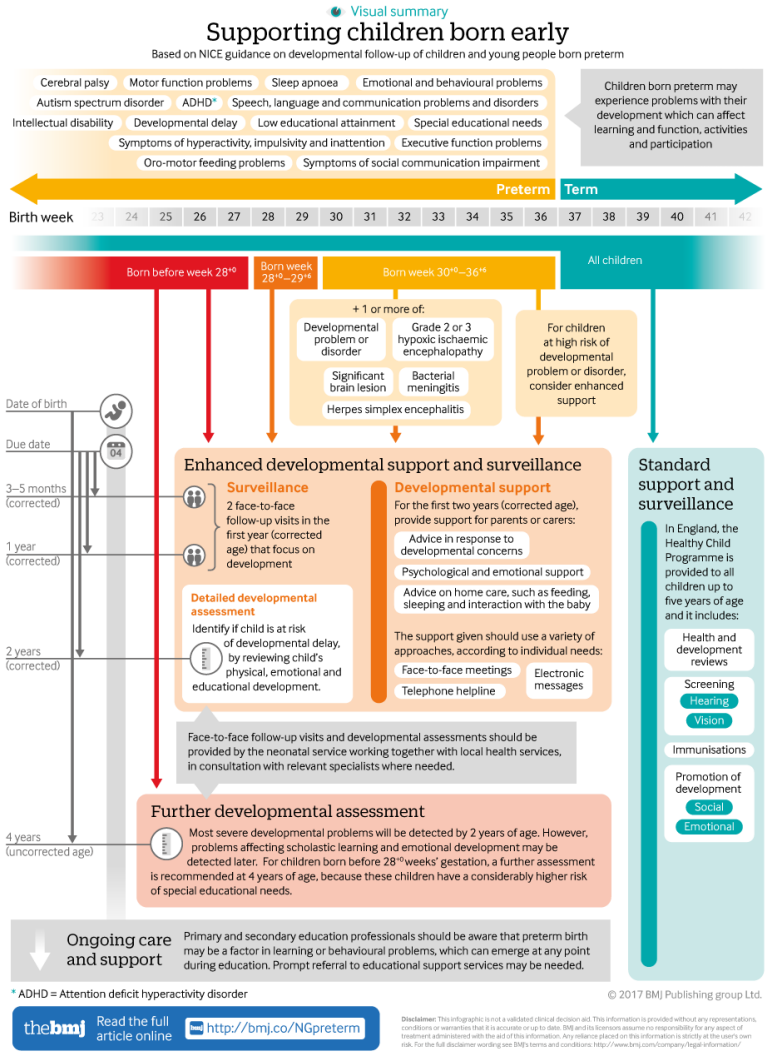
- NeuroDevelopmental Pediatrician or Nurse Practitioner
- Social Worker
- Speech Language Pathologist
- Occupational Therapy
- Physical Therapy

Recommended Follow-up of High Risk Infants

	AGES AT ASSESSMENT											
	2–6 WEEKS	3–4 MONTHS	8 MONTHS	12 MONTHS	15–18 MONTHS	24 MONTHS	36 MONTHS	4–5 YEARS[a]	6–8 YEARS[b]	12–14 YEARS	TRANSITION TO ADULT	ADULT
Child												
Physical health												
General health	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++
Growth	+++	+++	+++	+++	++	++	++	++	++	+++[c]	++[d]	++[d]
Feeding problems	+++	++	++	++	+	+	+	0	0	0	0	0
Special senses	+++	++	++	+	+	+	+	+	+	+	+	+
Neurological	+++	+++	+++	+++	+++	+++	++	++	+	+	+	+
Motor skills	+	++	++	+++	+++	+++	+++	+++	+++	++	+	+
Blood pressure/ CVS	UR	UR	UR	UR	UR	+/–	+/–	++	+++	+++	+++	+++
Respiratory health	+++	+++	+++	+++	+++	+++	++	++	+++	+++	+++	+++
Daily functioning	++	++	++	++	++	++	+++	+++	+++	+++	+++	+++
Learning and cognition												
Development/ cognitive function	++	++	++	++	+++	+++	+++	+++	+++	+++	++	++
Language	+	++	+++[e]	+++[e]	+++[e]	+++[e]	+++	+++	+++	+	0	0
Preacademic skills	0	0	0	0	0	0	+	+++	++	0	0	0
Academic progress	0	0	0	0	0	0	0	0	+++	+++	+++	++[f]
Mental health												
Behavior	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++
Social skills	+	+	++[e]	+++[e]	+++[e]	+++[e]	+++[e]	+++	+++	+++	+++	+++
Psychopathology	0	0	0	+[e]	+[e]	++[e]	++[e]	++	+++	+++	+++	+++
Risk-taking	0	0	0	0	0	0	0	0	0	++	+++	+++
Family												
Parental mental health	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++
Caregiver-child interaction	+++	+++	+++	+++	+++	+++	+++	++	+	+	+	0
Family function	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++
Siblings	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++

[a]Prior to school entry.
[b]1–2 years after starting school.
[c]Growth 12–14 years includes normal pubertal development.
[d]Overweight/obesity an ongoing issue.
[e]Relevant to early presentation of autism spectrum disorder.
[f]Ongoing life learning.
0, Does not apply; + to +++, reflects relative importance; +/–, of dubious value; *CVS*, cardiovascular system; *UR*, unreliable.
Shaded areas represent a suggested minimal checklist for busy clinicians.
From Doyle LW, Anderson PJ, Battin M, et al. Long term follow up of high risk children: who, why and how? *BMC Pediatr.* 2014;14:279.

Follow-up Purpose



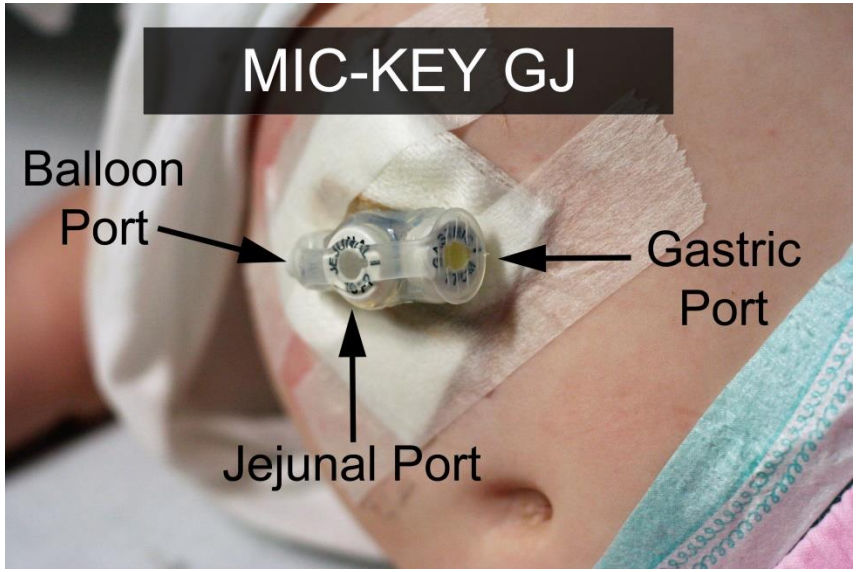
2 Major Areas of our Focus: NeuroDevelopment & Feeding

Preterm Brain Injury: Long Term Effects

- **Motor**
  - Hypotonia (initially)
  - Hypertonia
    - Cerebral palsy
      - Spastic diplegia
  - Delays
    - Gross
    - Fine
- **Cognitive**
  - Delays
  - Mental retardation
- **Speech/Language**
  - Delays
    - Expressive
    - Receptive

gapps

Wood N, et al. Neurologic and developmental disability after extremely preterm birth: The EPICure study group. *N Eng J Med*. 2000; 343(6):378.
Baron I, et al. Late preterm birth: A review of medical and neuropsychological childhood outcomes. *Neuropsych Rev*. 2012; 22:438.



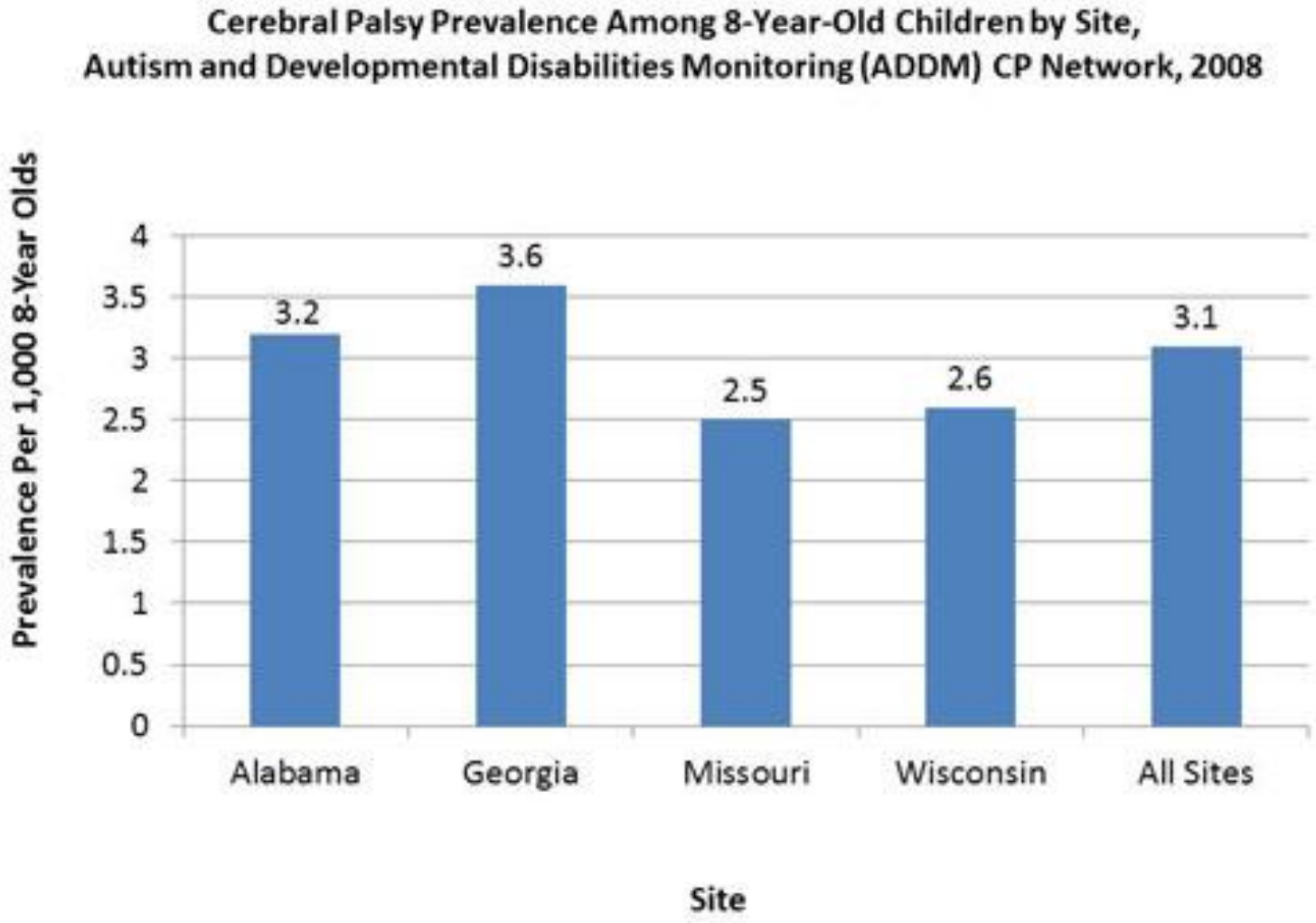
Definition of Cerebral Palsy

Cerebral Palsy

4

- Definition: Global term for a group of disorder which effect movement and muscle coordination which is nonprogressive in nature.
- Incidence: 2-3 children per 1,000
  - Increasing in the US→ increased survival of premature infants
- Etiology: Multifactorial
  - Damage to a developing brain
- Risk Factors:
  - Preterm Birth
  - Birth Asphyxia 6-20%
  - Hypoxia Ischemic encephalopathy(HIE)

Occurrence of CP



Signs of Cerebral Palsy

Table 3. Frequency of abnormal neurological signs in newborns with andwithout IPVH.

	Without IPVH		With IPVH	
Abnormal signs	Abnormal	Suspicious	Abnormal	Suspicious
Trunk hypotonia and fallen head	4	-	6	-
Flexor tonus UE>LE*	3	3	7	5
Abnormal head control	9	7	8	8
Tremor and startles	2	1	6	2
Thumb adduction	1	-	8	4
Abnormal Moro reflex	-	-	2	1
Asymmetry	2	1	8	3
Abnormal eye movement	1	-	5	1
Poor orientation	2	1	8	4
Irritability	3	4	4	4

*UE > LE, upper extremities / lower extremities

Evidence of CP:
Persistence of Primitive Reflexes

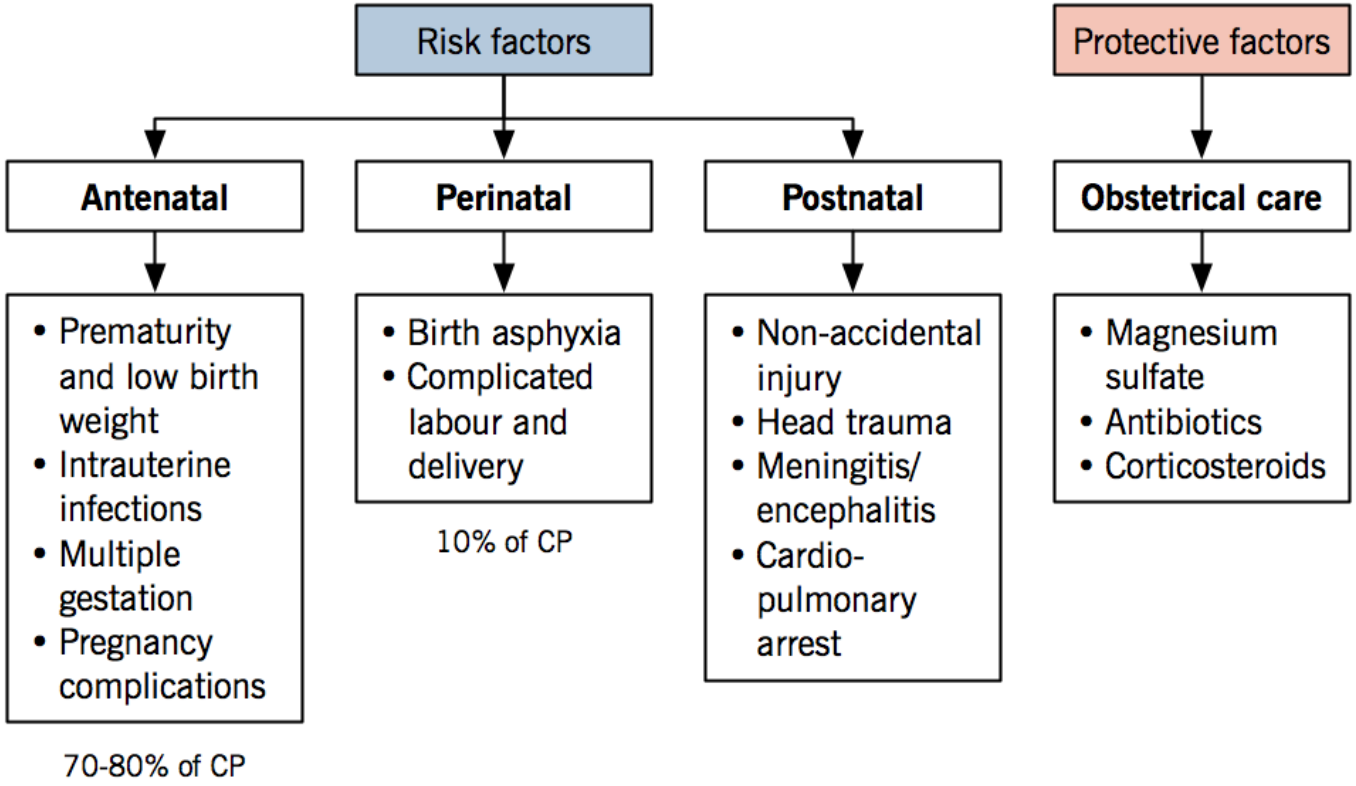
Table 1. Normal Developmental Reflexes (Modified From Swaiman)[15]

Reflex	Appearance Age	Disappearance Age, mo
Adductor spread of knee jerk	Birth	7-8
Moro	Birth	5-6
Palmar grasp	Birth	6
Planter grasp	Birth	9-10
Routing	Birth	3
Tonic neck response	Birth	5-6

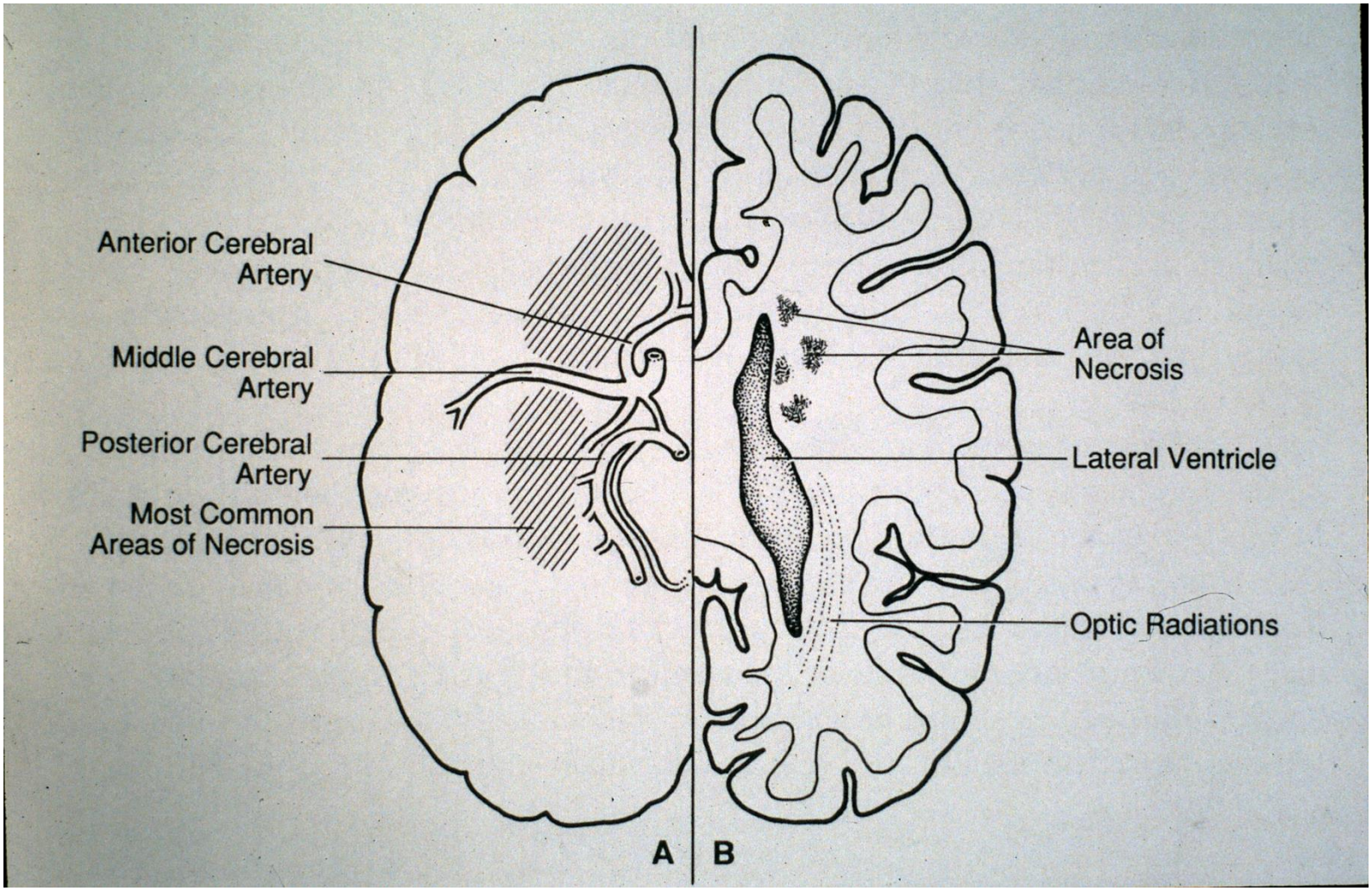
CEREBRAL PALSY

Risk factors for development of cerebral palsy

Risk factors can be divided by time period into antenatal, perinatal, and postnatal factors. The majority of the risk occurs in the antenatal period. Prematurity is a significant risk factor, predisposing to development of periventricular leukomalacia (PVL). Prudent obstetrical care, with management of preeclampsia (magnesium), infections (antibiotics), and preterm labour (corticosteroids), can help reduce the risk of CP.



Brain Bleeds



Brain Bleeds

Diagnosis of IVH:

as the clinical signs are non specific, its recommended that preterm infants less than 32 wks to be evaluated with real-time cranial US,

infants less than 1000gm: 1st 3-7 days,

1-1.5 kg: 7-14 days, all at risk : follow up 36-40 wk age

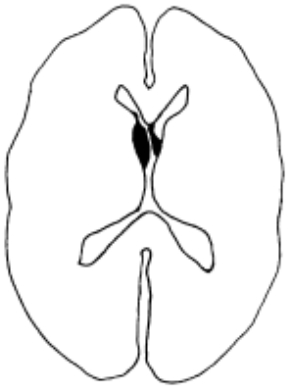
10-15% of LBW infants with IVH develop hydrocephalus

MRI is a more sensitive tool for evaluation of extensive periventricular injury and may be more predictive of adverse long-term outcome. CT or, more reliably, diffusion-weighted MRI is indicated for term infants in whom brain injury or stroke is suspected

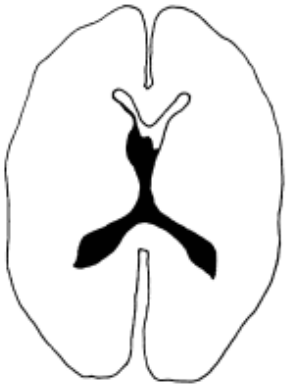
Brain Bleeds

Grades of intraventricular hemorrhage
(cross-section view of the brain)

Grade I: bleeding near ventricle

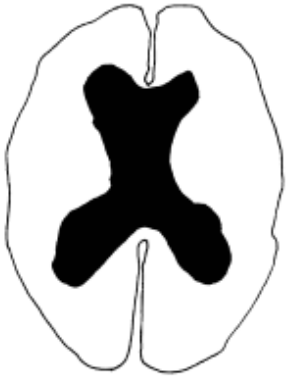


Grade II: Blood in ventricle

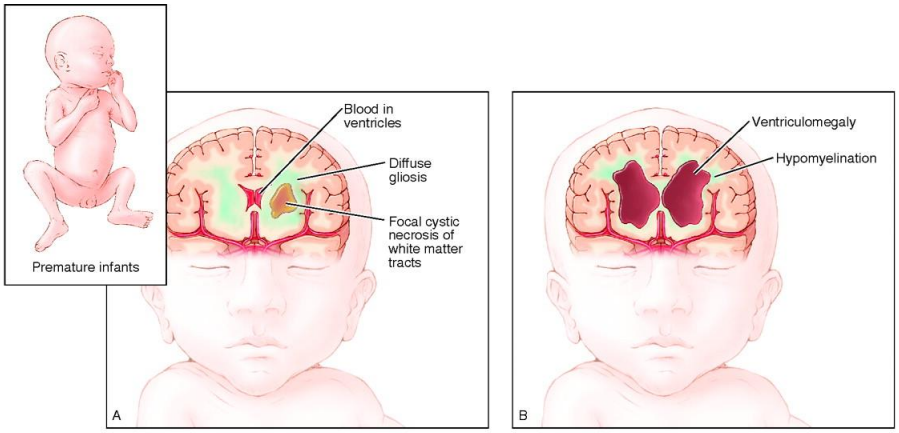


Grade III: Enlarged ventricle

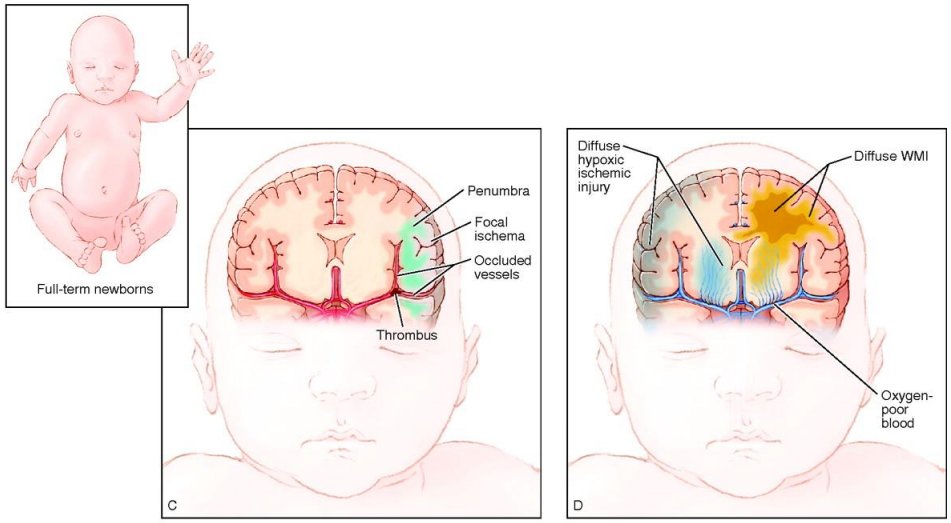
Grade IV: Enlarged ventricle with blood in brain tissue



Cerebral Palsy

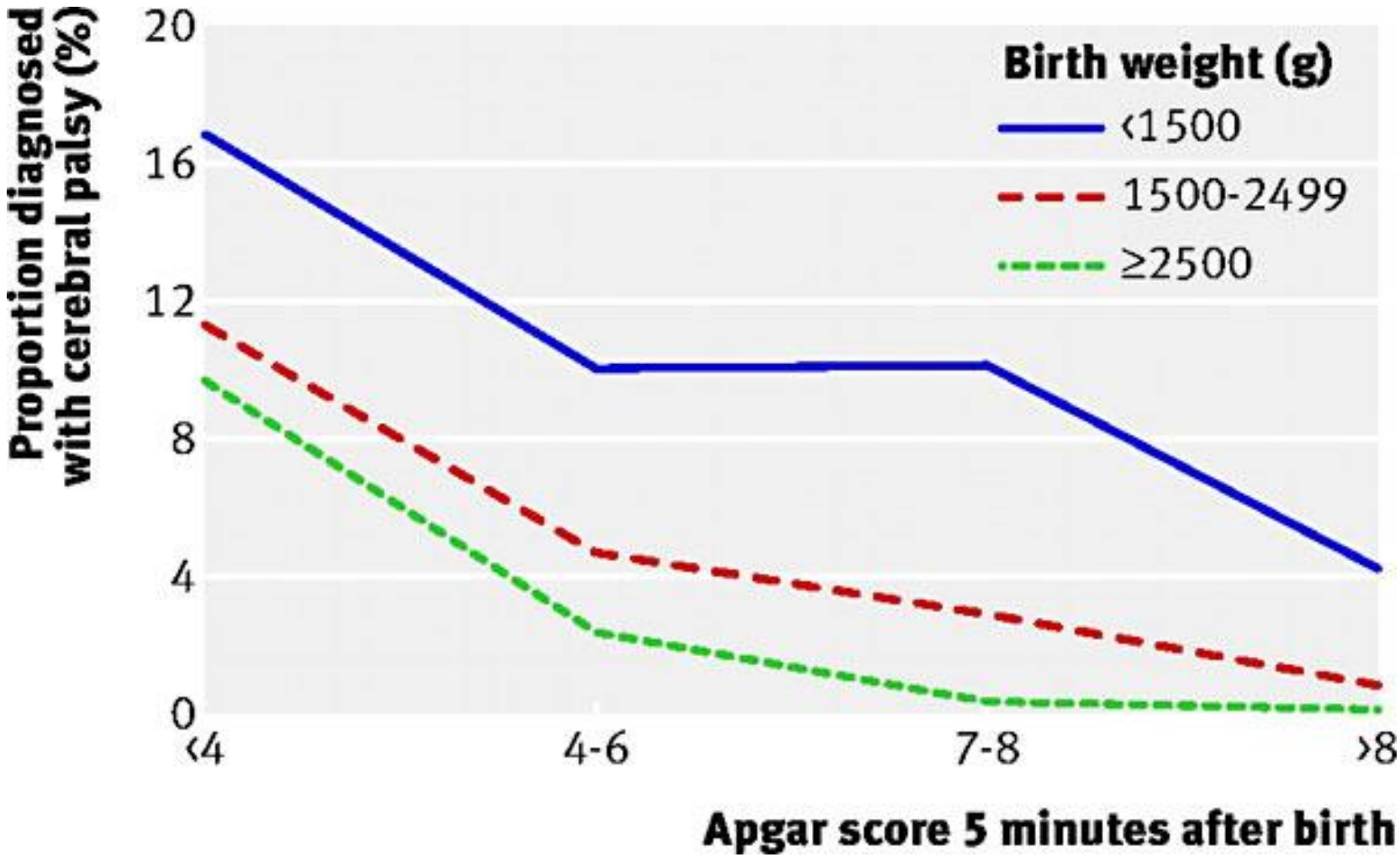


Cerebral palsy and periventricular leukomalacia



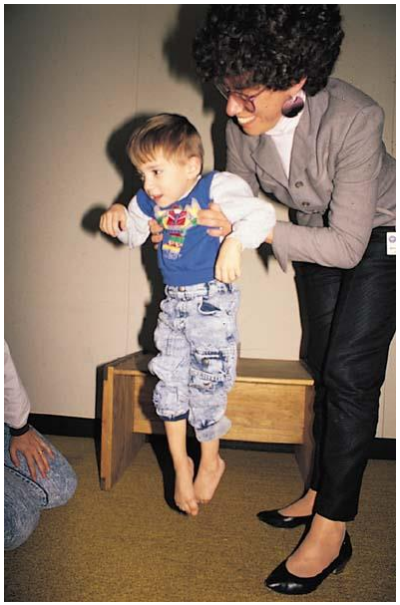
Neonatal stroke **Hypoxic ischemic encephalopathy**

Cerebral Palsy: relation to Apgar Score



Cerebral Palsy: When to Diagnosis

- CP describes the most common physical disability in childhood
- Occurs in 1 in 500 live births
- Historically, the diagnosis has been made between age 12 and 24 months, but can now be made before 6 months corrected age



Early Diagnosis of Cerebral Palsy

Diagnosis

WORLD CEREBRAL PALSY DAY OCTOBER 6

CP can sometimes now be diagnosed early, so interventions can start as soon as possible

Babies can now be assessed as being at 'high risk of cerebral palsy' as early as 3-5 months of age.

The most sensitive tools are:

- General Movements Assessment in babies <20 weeks (corrected) - 95% predictive
- Neuroimaging
- Hammersmith Infant Neurological Assessment (HINE) - 90% predictive

See *CP: Diagnosis and Treatment* poster at www.worldcpday.org

Early Diagnosis of Cerebral Palsy

Table 2. Clinical Signs Indicating Motor Type and Topography in Infants

Unilateral Spastic Hemiplegia	Bilateral Spastic Diplegia	Bilateral Spastic Quadriplegia	Dyskinesia	Ataxia
GMs[34]				
• Poor repertoire or cramped synchronized GMs, followed by absent fidgety movements plus an asymmetry in segmental movements (eg, wrist or hand). Note that some cases of hemiplegic CP may be missed by GMs	• Cramped synchronized GMs, followed by absent fidgety movements	• Early onset and long duration of cramped synchronized GMs, followed by absent fidgety movements	• Poor repertoire GMs, followed by absent fidgety movements with circular arm movements and finger spreading	• Unknown
MRI[35,36]				
• Focal vascular insults (24%) • Malformations (13%) • Unilateral hemorrhage (grade IV) with porencephaly • Lesions in the parietal white matter involving the trigone • Middle cerebral artery stroke with asymmetry of myelination of the PLIC	• Bilateral white matter injury (31%-60%) • Cystic PVL (grade II-III) with sparse or absent myelination of the PLIC • Moderate to severe white matter injury (also known as PVE)	• Gray matter injury (34%) • Malformations (16%) • Cystic PVL (grade III) with absent myelination of the PLIC • Severe white matter injury with or without deep nuclear gray matter	• Gray matter injury (21%) with thalamic and lentiform nuclear injury	• Malformations (18%) • Normal imaging (24%-57%) • Cerebellar injury
HINE Scores[37]				
50-73	<50	<50 <40 GMFCS level IV-V	<50	Unknown
Motor Tests				
• Asymmetrical hand preference • Stuck in floor sitting (ie, unable to transition out of sitting) • Cruises or steps consistently in one direction or with the same leg always leading • Reduced variation in motor behavior	• Good hand function compared with lower limb function • Dislike or avoidance of floor sitting • Weight bears on toes • Reduced variation in motor behavior	• Head lag • Persistent rounded back in supported sitting • Bilateral fisted hands • Slow to reach and grasp with either hand • Reduced variation in motor behavior	• Twisting arm or neck postures on voluntary movement (may be painful) • Finds midline play difficult, prefers toys positioned at shoulder width • Switches hands during reaching task • Requires a lot of extra time to initiate movement • Voluntary movement and emotion worsens postures • Reduced variation in motor behavior	• Nonspecific

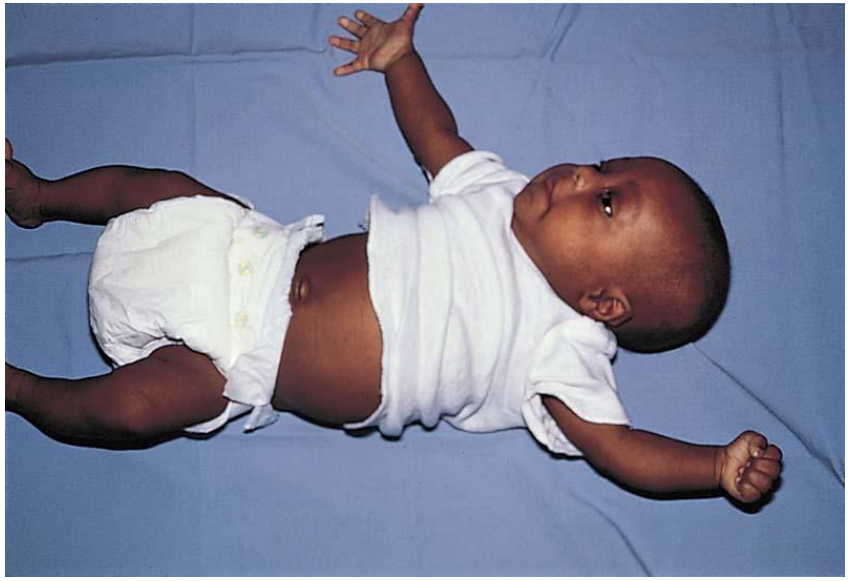
Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; GMs, Prechtl Qualitative Assessment of General Movements; HINE, Hammersmith Infant Neurological Examination; MRI, magnetic resonance imaging; PLIC, posterior limb internal capsule; PVE, periventricular echogenicity; PVL, periventricular leukomalacia.

Early Diagnosis of CP

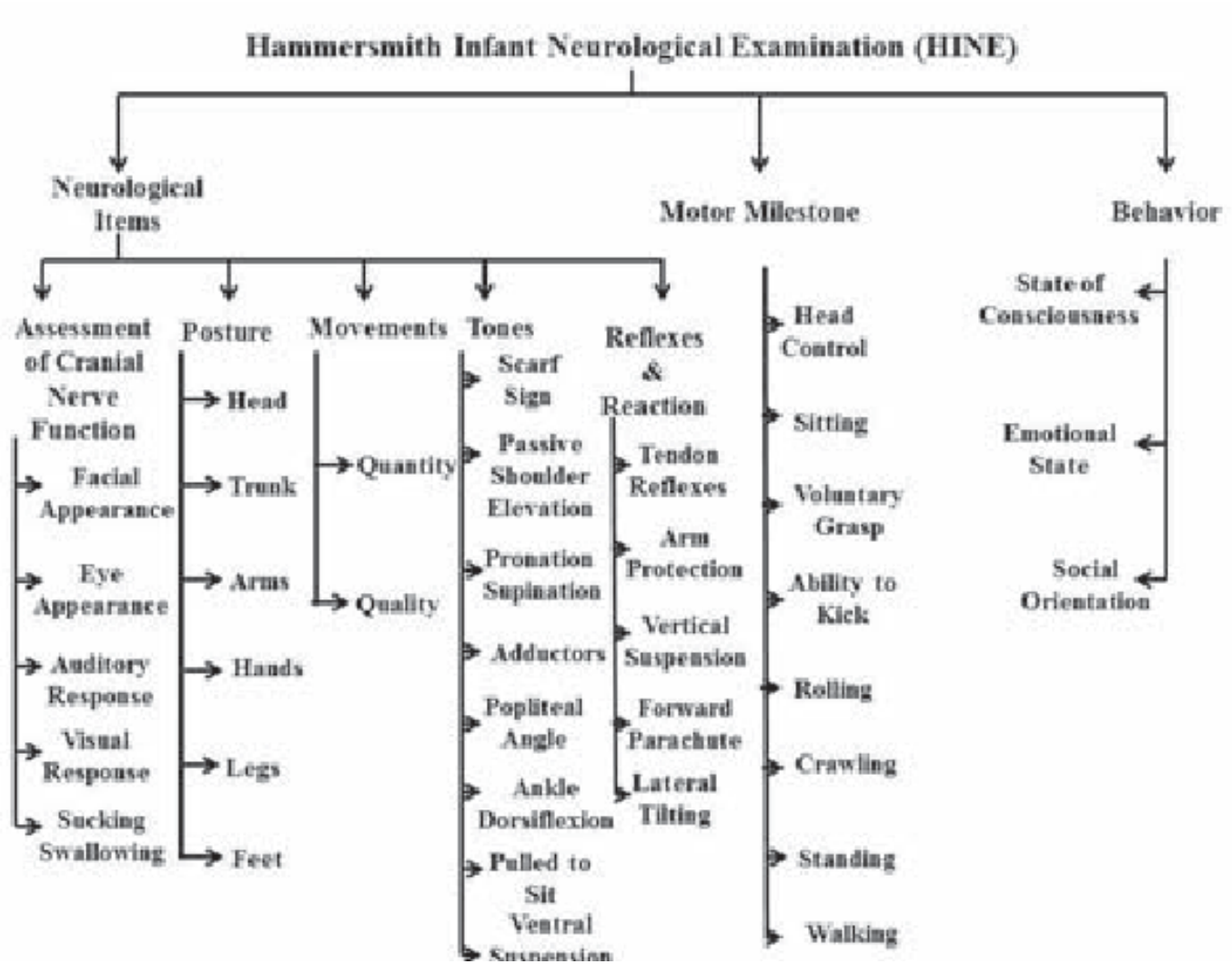
University of CINCINNATI | COLLEGE OF ALLIED HEALTH SCIENCES

What is the Hammersmith Infant Neurological Examination?

- It is a simple and scoreable assessment designed for evaluating after the neonatal period in infants between 2 months and 24 months of age.
- Includes 26 items that assess different aspects of neurological examinations such as cranial nerves, posture, movements, tone and reflexes. (Romeo, D. M., Ricci, D., Brogna, C., & Mercuri, E. , 2015).

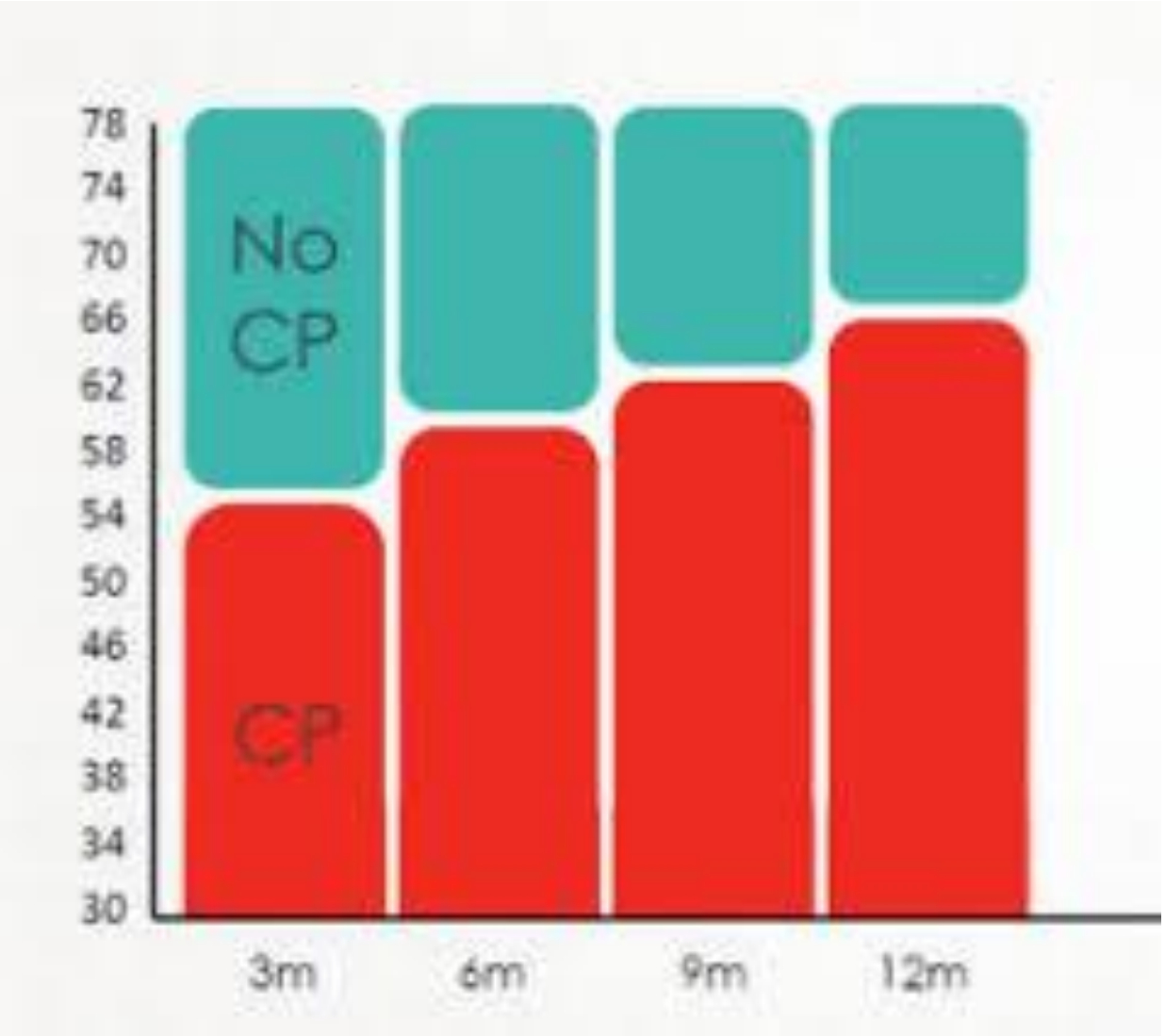


CP, Early Diagnosis



Hammersmith Infant Neurological Examination (HINE)

Cerebral Palsy based on HINE score



To Diagnosis Cerebral Palsy

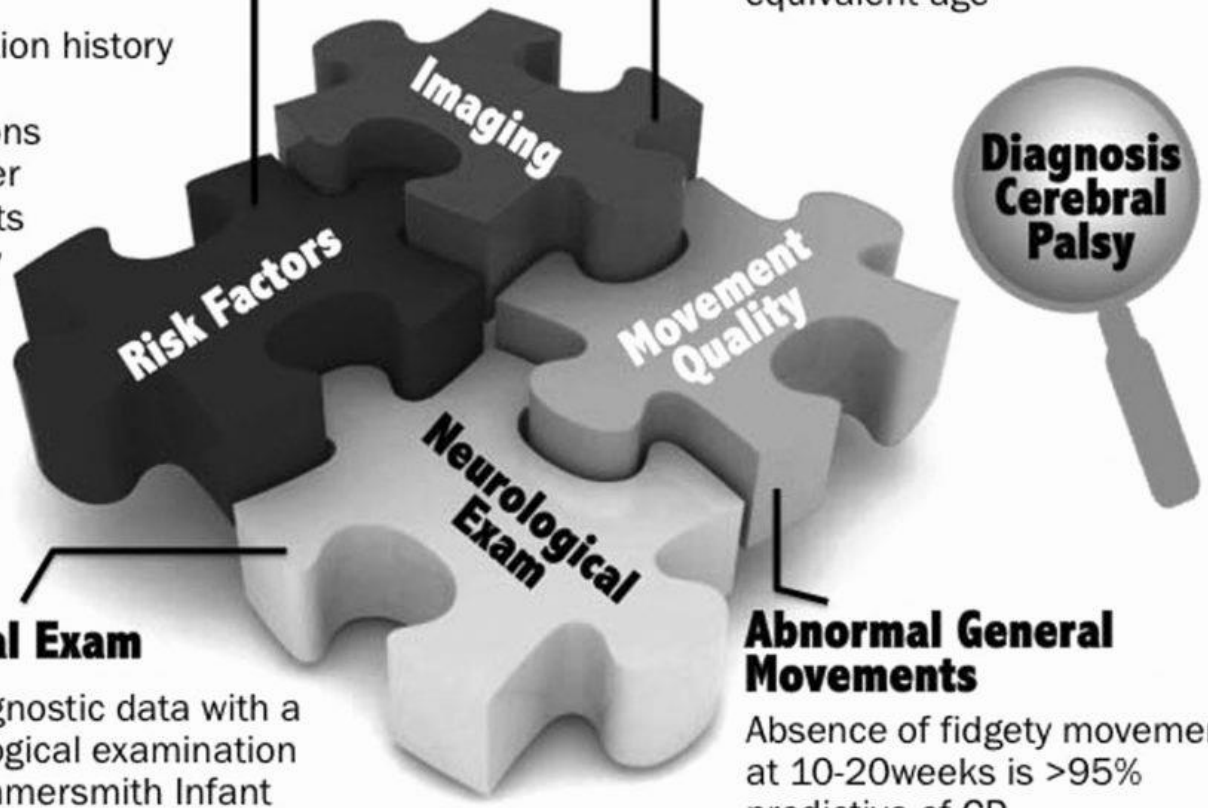
Risk Factors

Take a medical history to identify risk factors, including:

- ✓ Preconception history
- ✓ Pregnancy complications
- ✓ Male gender
- ✓ Birth defects
- ✓ Brain injury
- ✓ Multiples
- ✓ Genetics

Abnormal Imaging

If a brain injury is presumed or suspected take an MRI at term equivalent age



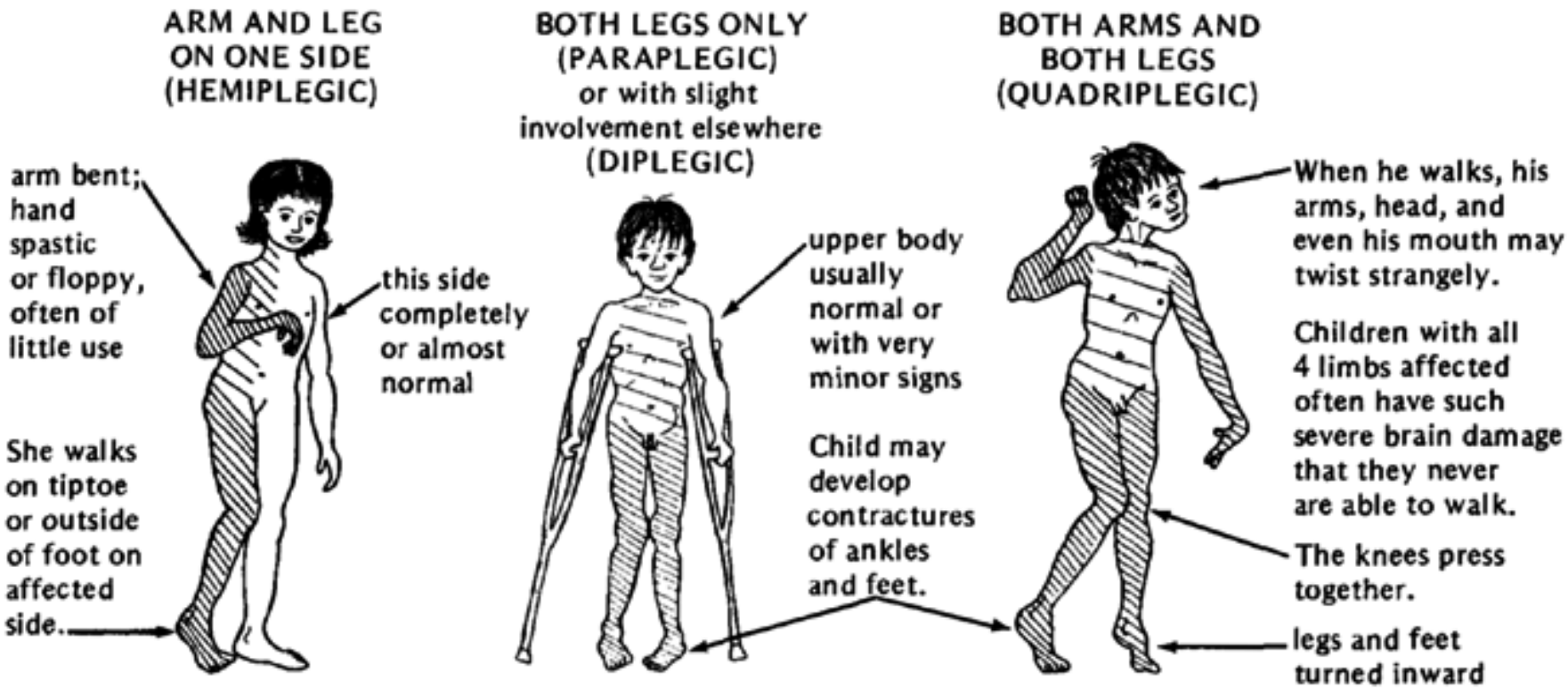
Abnormal Neurological Exam

Pair other diagnostic data with a formal neurological examination using the Hammersmith Infant Neurological Assessment (HINE)

Abnormal General Movements

Absence of fidgety movement at 10-20weeks is >95% predictive of CP

Cerebral Palsy, Types



CP-will the child walk?

TABLE 7E-3 ■ Prognosis for Ambulation of Children with Cerebral Palsy, Based on Postural Reactions and Primitive Reflexes[48]

When the child is at least 12 months old, score one point for each of the following primitive reflexes if obligatory:

- Asymmetrical tonic neck reflex
- Symmetrical tonic neck reflex
- Moro
- Neck righting
- Extensor thrust

Score one point for each of the following postural reactions if absent:

- Foot placement
- Parachute

Prognosis for ambulation:

- 0 points = good
- 1 point = guarded
- 2+ points = poor

From Rothstein JM, Roy SH, Wolf SL: Rehabilitation Specialist's Handbook, 3rd ed. Philadelphia: FA Davis, 2005, p 577.

Feeding Issues

Feeding Issues: Why?

Problems of Preterm

Physiological Handicaps :

- Poor co-ordination of sucking & swallowing (<33 wks)
- Weak Gag reflex (aspiration)
- Lax esophageal sphincter
- Small gastric capacity
- Gastroparesis & intestinal hypomotility

Biochemical handicaps :

- High energy & micronutrient requirement.
- Higher fluid requirement
- Increase need for proteins, minerals & vitamins
- Relative deficiency of bile acids & lactase

Saili A et al, J Neonatol July-Sept 2002

Feeding Problems:

- **Feeding and digestive problems:** Premature infants often cannot drink from the breast or a bottle at birth, and may be fed with IV fluids or through a tube in the nose or mouth for several weeks.
- These early feeding challenges can cause long-term feeding difficulties, including food refusal and slow growth.
- Severe cases of necrotizing enterocolitis may require bowel surgery.
- Gastroesophageal reflux disease, is another problem that premature babies may have as they grow.

Items that Impact Feeding

Table 2 Possible interruptions to oral feeding development associated with illness and medical treatment.

PRIMARY CONDITION	INTERVENTION	OUTCOMES
PREMATURITY Premature: 1. Anatomical and physiological development (cardiac, respiratory, gastrointestinal systems) 2. Neurological development (reflexes, tone, coordination)	ARTIFICIAL FEEDING Enteral nutrition (gavage feeds) 1. Nasogastric (NG) 2. Orogastric (OG) 3. Gastrostomy 4. Transpyloric (TP) 5. Jejunostomy Parenteral nutrition	PRIMARY CONDITION PERSISTS TO SOME DEGREE 1. Ongoing morbidity 2. Energy imbalance
MORBIDITY Impairment of: 1. Major body systems (neurological, cardiac, respiratory, gastrointestinal systems) 2. Swallowing mechanism (oral region, pharynx, larynx, oesophagus)	OTHER INTERVENTIONS Intubation (and/or suctioning) 1. Orotracheal 2. Nasotracheal 3. Via tracheostomy	EFFECTS OF INTERVENTION Immediate 1. Local irritation of swallowing mechanism 2. Obstruction of swallowing mechanism 3. Injury to swallow mechanism 4. Altered breathing Long-term 5. Disuse of muscles involved in swallowing 6. Altered sensitivity in swallowing mechanism
OTHER ISSUES Physiological instability 1. Altered alertness/ state 2. Poor endurance 3. Altered appetite (medication, reduced gastric emptying, constipation) Altered nutritional and energy requirements 1. Increased energy requirements (morbidity, such as cardiac and respiratory disease) 2. Increased energy losses (poor absorption, gastro-oesophageal reflux) 3. Low nutritional stores	VARIABLES 1. Age when intervention started 2. Duration of intervention 3. Frequency of intervention 4. Total vs. supplemental tube feeding (i.e. opportunity for any oral experience) 5. Route for tube feeding (via oral/ nasal cavity or directly into gut) 6. Rate of tube feeding (bolus or continuous) 7. Type of feed offered 8. Positioning during feeds	INTERRUPTED DEVELOPMENT FOR INFANTS 1. Delayed development of oral-motor skills 2. Defensive oral behaviour/ food/ fluid aversion 3. Reduced association between feeding and reduction of hunger 4. Lack of mealtime routines 5. Limited exposure to tastes/ textures/ feeding utensils 6. Altered bonding opportunities with parents 7. Reduced parental confidence in feeding infant
REASONS FOR COMMENCING INTERVENTION 1. Risk of aspiration 2. Risk of inadequate growth		

UNDERSTANDING

Nutrition in the NICU

Babies need the right nutrition to grow and develop. In the NICU, there are several different ways to feed a baby. How your baby is fed depends on his/her age, weight, and medical condition. There are two main ways of feeding: **enteral** and **parenteral**. Talk to your health care team about which way is right for your baby

Enteral Nutrition

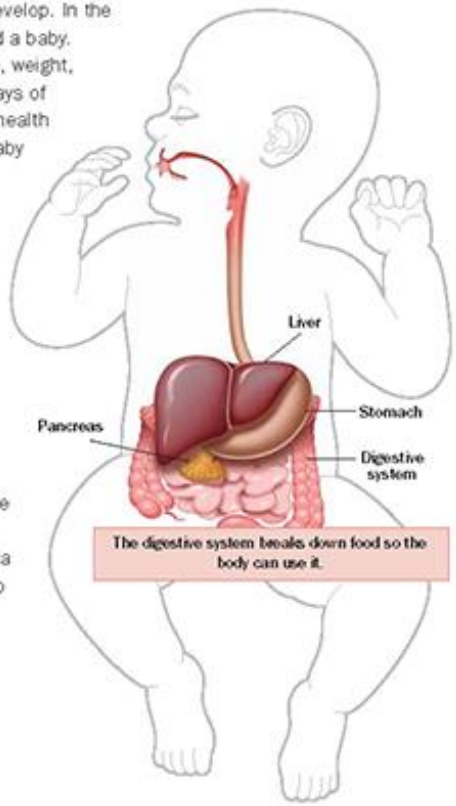
Feeding by mouth

Some babies in the NICU are ready to eat by mouth as soon as they are born. These babies may be fed breast milk or formula. In either case, babies in the NICU often need extra supplements to get the calories, vitamins, and minerals they need.

Feeding by tube

Babies with working **digestive systems** who are unable to feed by mouth may need to be fed by tube. The tube carries breast milk or formula directly into the baby's stomach. There are two main types of feeding tubes:

- Tubes that go through the baby's mouth (**orogastric** or OG tubes)
- Tubes that go through the baby's nose (**nasogastric** or NG tubes)



The digestive system breaks down food so the body can use it.

When is tube feeding used?

Tube feeding is most often used in premature babies. The ability to coordinate sucking, swallowing, and breathing doesn't usually develop until 34 to 36 weeks' gestational age. Tube feeding is also used for babies with medical problems that make feeding by mouth difficult.

How long will my baby be fed by tube?

If the baby is premature, tube feeding will be used until the baby is capable of eating by mouth. If the baby has a medical problem, tube feeding will be used as long as needed.

Deciding on a Gastrostomy

- As a general rule, PEG feeding should be considered if it is expected that the patient's nutritional intake is likely to be qualitatively or quantitatively inadequate for a period exceeding 2–3 weeks.
- The central question to be answered is whether PEG feeding is likely to improve or maintain the patient's quality of life?
- Placement of a PEG-tube should always be for medical reasons and not for administrative convenience—saving time, money or manpower—nor is a PEG tube a substitute for good nursing care

Indications for Gastrostomy

- **The primary aim of enteral tube feeding is to avoid further loss of body weight, to correct significant nutritional deficiencies, to rehydrate the patient, to promote growth in children with growth retardation, and to stop the related deterioration of the quality of life of the patient due to inadequate oral nutritional intake.**

ESPEN Guidelines on artificial enteral nutrition—Percutaneous endoscopic gastrostomy (PEG). Clinical Nutrition (2005) 24, 848–861

- **Oncological disorders (stenosing tumours in the ear, nose and throat region or the upper gastrointestinal tract; PEG tubes may be used palliatively in inoperable cases or placed prior to surgery, radiotherapy or chemotherapy and removed when the patient has recovered and has a reliable and adequate oral intake.**
- **Neurological disorders (dysphagic states after cerebrovascular stroke or craniocerebral trauma, and in patients with cerebral tumours, bulbar paralysis, Parkinson's disease, amyotrophic lateral sclerosis, cerebral palsy).**
- **Other clinical conditions (wasting in AIDS, short bowel syndrome, reconstructive facial surgery, prolonged coma, polytrauma, Crohns disease, cystic fibrosis, chronic renal failure, congenital abnormalities, e.g. tracheo-oesophageal fistula).**

Indications for enteral tube feeding in paediatric patients

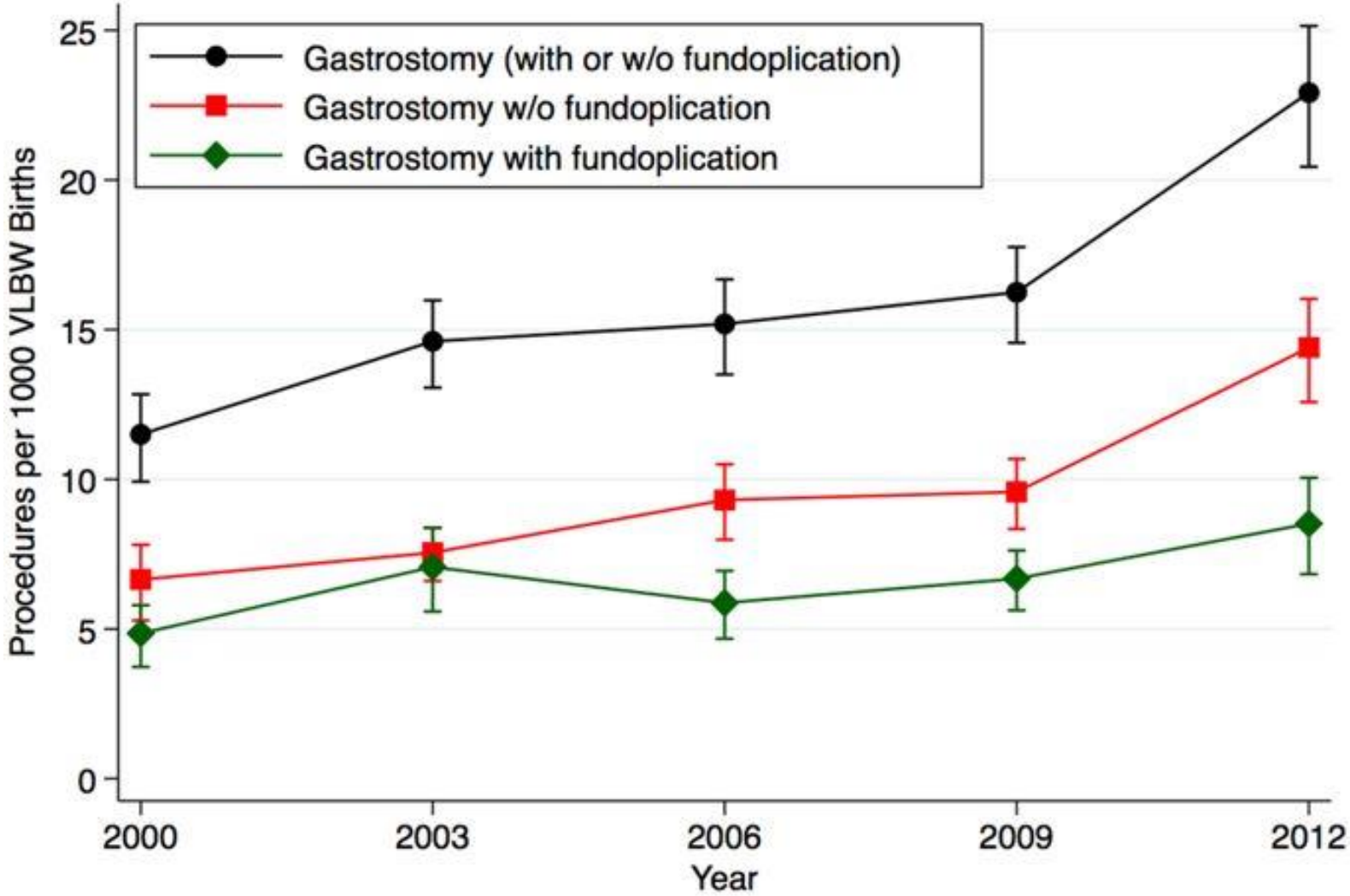
Table 1

Incapacity or limited ability to eat: Suck–swallow dysfunction (for example, prematurity, neurological disorders, discoordinated swallowing) Congenital abnormalities (for example, craniofacial malformations, oesophageal atresia, tracheo-oesophageal fistulae).

Inability to meet requirements by oral intake: Fatigue and muscle weakness (for example, cardiac disease, respiratory disease) Increased metabolic needs (for example, trauma, burns, sepsis, cystic fibrosis, congenital heart disease, multiple organ failure)

- **Increased nutritional losses:** Impaired digestion (for example, pancreatic insufficiency, enzyme deficiencies) Impaired absorption (for example, intestinal resection, mucosal damage or inflammation). Excess gastrointestinal losses (for example, high-output fistulae, protein-losing enteropathy, chronic diarrhoea)
- **Altered metabolism/primary disease management:** Inborn error of fasting adaptation (for example, hyperinsulinaemia, glycogen storage disease, defects in gluconeogenesis) Impaired organ function (for example, renal disease, liver disease, pulmonary disease)

Surgical Intervention for GI Issues



Rates with 95% CI

Reasons for Feeding Aversions

- In neonates and infants who have never been orally fed from birth and in those for whom tube feeding lasts for a longer period (from 6 weeks to over 1 year), however, without any progressive oral stimulation programme, the reintroduction of oral feeding can be an ordeal for the child and the caregiver alike.
- The absence or involution of the afferent sensory input (tactile, olfactory and taste) from the oro-pharynx, which normally occurs during oral feeding, means that, when attempts are made to start oral feeding, the presence of food in the mouth is likely to be misinterpreted as a noxious stimulus and to stimulate the gag reflex and lead to oro-aversion.

Return to Oral Feedings

- Thus, early oral stimulation is a crucial component of feeding management in the exclusively tube-fed neonate and intraoral massage, for instance, has been shown to be useful in inhibiting the gag reflex and helping it to mature into an adult pattern (Senez et al., 1996).

Gastrostomy tube feeding: When to start, what to feed, how to stop. F Gottrand and PB Sullivan. European Journal of Clinical Nutrition (2010) 64, S17–S21

Let them Eat

- When a decision is made to begin the process of normalizing feeding, this will be more successful if approached as a multi-disciplinary process. The speech and language therapist will provide oral stimulation and deal with eating-related maladaptive behaviour, such as grimacing, mouth closure and gagging. The dietitian will advise on food texture and consistency and assist in the development of a behavioural feeding plan.
- Managing feeding problems and especially weaning a child off tube feeding are major challenges for the parents and for all health workers involved, including dietitians, speech therapists, psychologists, nurses and **Paediatricians. (yes, you all are in charge of this).**

Ibid

Getting to Eating

Your Baby's Development	Texture of Food
Sits with support	• pureed, mashed foods • semi-solid foods
Sits on own	• soft mashed foods without lumps
Crawls	• ground or soft mashed foods with tiny soft noticeable lumps • foods with soft texture • crunchy foods that dissolve (such as baby biscuits or crackers)
Walks with assistance	• coarsely chopped foods, including foods with noticeable pieces • foods with soft to moderate texture • toddler foods • bite-sized pieces of food • finger foods

Makes the transition to the family diet at about 12 months of age.

Our Teams

- Early Feeding issues (HRIF clinic)

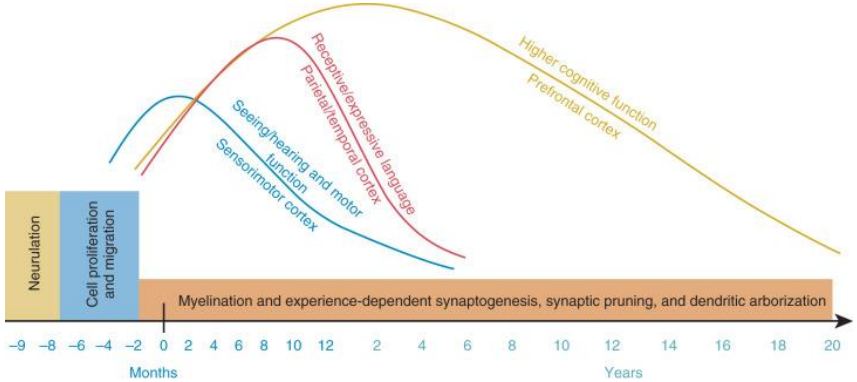
  Speech Pathology
  Occupational Therapy
Consultations with:
Nutrition
Gastroenterology
?ENT

- Late Feeding issues (Ex-premie, CHD, ASD, sensory issues)

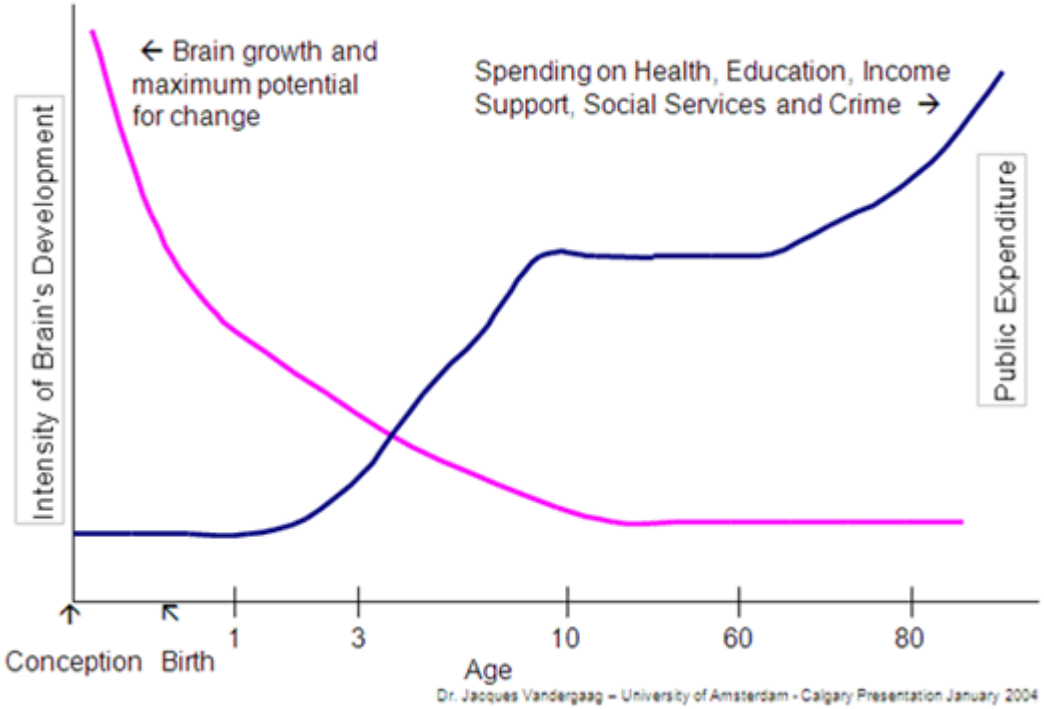
  Speech Pathology
  Occupational Therapy
Clinical Psychology
Consultations with:
Nutrition
Gastroenterology
?ENT

Our Goal– the Finished Cake

Have your cake and eat it too

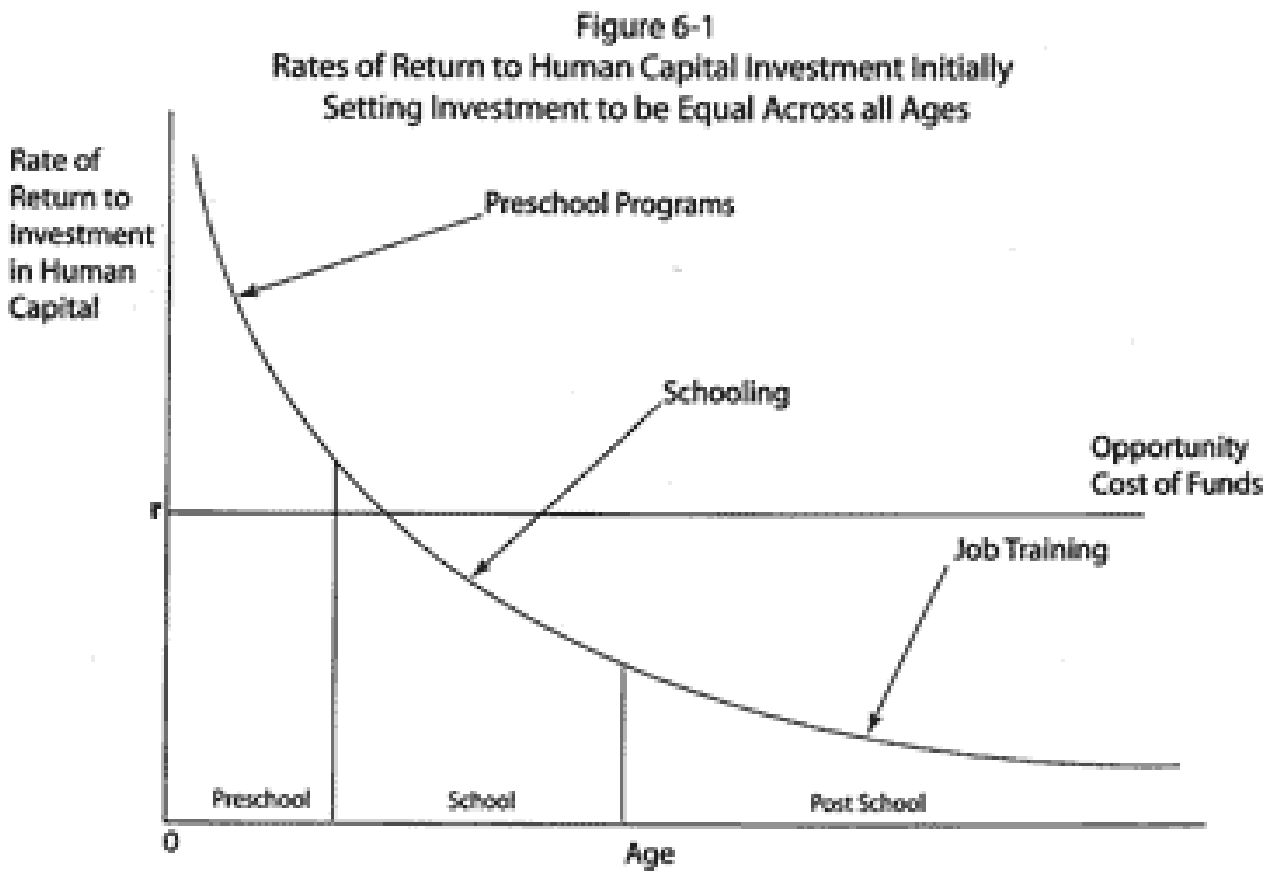


Why Refer & Evaluate



- ROLE OF EARLY INTERVENTION

Early Intervention Saves $$'s



Rates of Return to Human Capital Investment Initially Setting Investment to be Equal Across all Ages

REFERENCES

- Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy. Novak,I et al. JAMA Pediatr, 2017;17(9): 897-907.
- Use of the Hammersmith Infant Neurological Examination in infants with cerebral palsy: a critical review of the literature. Romeo, DM et al. DMCN, 2016; 58:240-245.
- Gastrostomy tube feeding: When to start, what to feed, how to stop. F Gottrand and PB Sullivan. European Journal of Clinical Nutrition (2010) 64, S17–S21
- Born Too Soon: The global epidemiology of 15 million preterm births. Blencowe et al. Reprod Health, 2013; 10(Suppl 1), S2.
- Cerebral Palsy-Don't Delay. McIntyre S et al. Dev Dis Res Rev, 2011; 17:124-129.
- Implementation of the HINE in a HRIF program. Maitre, NL et al. Ped Neuro 65, (2016), 31-38.
- A Pediatrician's Guide to Caring for the Complex NICU Graduate. Billimoria,ZC & Kamat,D. Pediatr Ann. 2014;43(9):369-372.