Holtz Children's Hospital
UM/JACKSON MEMORIAL MEDICAL CENTER

Medical Follow-up of the High-Risk NICU Graduate

UNIVERSITY OF MIAMI

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Early Steps Team

Objectives

- To review the transition process for high-risk infants from the NICU to a pediatric medical home
- To identify the common medical conditions seen in high-risk infants in the follow-up clinic
- To determine appropriate medical sub-specialty and neurodevelopmental follow-up of high-risk infants

"Hospital Discharge of the High-Risk Neonate" AAP Guidelines- *Pediatrics* 2008

- High-risk neonate defined:
  - Preterm infants
  - Infants with special health care needs or dependence on technology
  - Infants with anticipated early death

Teamwork is Key to Success

- **NICU Discharge Planning Team**
  - Family
  - Case manager or Social Worker
  - Nursing (Manager or Educator)
  - Physicians (Neonatologists, Specialists)
  - Community Service Representatives (Home Health, Child Protective Services, Neurodevelopmental follow-up programs)
  - Primary Health Care Physician (Identified and sent a discharge summary)

- **NICU Follow-up Team**
  - Family ←→ Primary Care Physician
  - Pediatric Medical or Surgical Subspecialists
  - Neurodevelopmental follow-up clinic
    - Neonatologist or Developmental Pediatrician
    - Psychologist
    - Dietician
    - Physical, Occupational, and Speech therapists
    - Case Manager or Social Worker

Role of the Primary Care Physician

- Health Care Maintenance
  - Assessment of Growth and Nutrition
  - Safety Education (Car seat, Back to Sleep)
  - Prevention of Infection (Routine immunizations, RSV prophylaxis, Flu vaccine)
  - Vision and Hearing Evaluation
  - Neurodevelopmental Assessments
  - Referral to medical subspecialists and other community programs

Common Medical Disorders

- Growth Failure
- Anemia of Prematurity
- Apnea and Bradycardia
- Chronic Lung Disease
- Gastrointestinal diseases (GERD, NEC, SBS)
- CNS disorders (Complications of IVH, PVL, Seizures)
- Eye problems (ROP, myopia, amblyopia)
- Hearing problems (hearing loss)

Nutrition of the Preterm Infant

- Breast milk +/- fortifier versus specialized formula
  - Benefits of breast milk
    - Nutritional- whey protein; carbohydrates and lipids
    - Gastrointestinal- easily digestible, faster gastric emptying
    - Immunological- secretory IgA
    - Developmental- higher IQ, long-chain polyunsaturated fatty acids
    - Psychological-improved mother-infant attachment
  - Challenges of breast milk
    - Provision of adequate caloric and nutritional intake
    - Establishing and maintaining milk supply
    - Transitioning from gavage feeding to breast feeding

Growth Failure

- Definition: growth < 20g per day
- Associated with Feeding difficulties
  - Poor suck and swallow coordination (Severe Perinatal Asphyxia)
  - GERD
  - Increased work of breathing in CHD or BPD
- Can also be associated with other medical conditions:
  - Prematurity or SGA
  - Short Bowel Syndrome
  - Chronic Renal disease
  - Inborn Errors of Metabolism
  - Chromosomal or Major Malformation Syndromes

Assessment of Growth

- Infant needs assessment if growth rate is in the lower percentiles, growth curve flattens or decelerates
- Maximize nutritional support and perform diagnostics to determine underlying etiology
- Referral to an Endocrinologist, Gastroenterologist, and/or Dietician if no obvious cause

Anemia of Prematurity

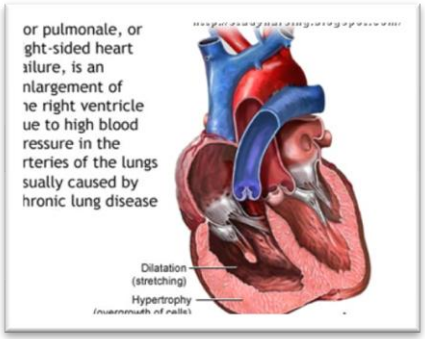
- Most common problem in premature infants
- Hemoglobin concentrations decrease more rapidly in premature infants especially ELBW
- Be aware of hemolytic issues (Rh and ABO incompatibility) as chronic anemia can be a subtle finding
- Closely follow Hemoglobin, Hematocrits, and reticulocyte counts until they stabilize (usually at 3-6 months old in ELBW)
- Treatment: Iron supplementation (or transfusion only in severe cases)

Apnea and Bradycardia

- Causes include:
  - Immature central regulation of breathing
  - Obstruction due to immature airway reflexes
  - Delayed coordination of sucking, swallowing, and breathing responses
- When presents or persists after NICU discharge consider profound anemia, GERD, hypoxia or bronchospasm related to CLD, viral infections, and seizures
- Home apnea monitoring- discontinued after 4 to 8 week period of no clinical apnea, no cyanotic episodes, and no history of monitor alarms
- Re-hospitalization may be indicated if ALTE occurs at home

Chronic Lung Disease

- Definition:
  - Typical radiographic appearance of cystic emphysema and fibrosis **or** subtle changes of diffuse interstitial edema with an oxygen requirement at 36th week post-conceptual age.
- Cardiopulmonary complications of CLD post-discharge:
  - Cor-pulmonale, hypoxemia, or hypercarbia



Chronic Lung Disease

- Follow-up with a Pulmonology Specialist
- Treatment:
  - Home oxygen therapy requires close monitoring
  - Inhaled bronchodilators +/- steroids
  - Oral corticosteroids
  - Diuretics (Furosemide, Aldactone, Diuril)
  - Maximize nutrition (120-150 kcal/kg/day)
  - RSV immune prophylaxis

Gastroesophageal Reflux

- Clinical Symptoms include:
  - Repeated regurgitation or emesis after feedings
  - Fussiness or painful crying during or after feedings

- May be a residual finding associated with esophageal or duodenal atresia, diaphragmatic hernia, HIE brain injury, prematurity +/- CLD

- Evaluation and follow-up with Gastroenterologist as needed

Gastroesophageal Reflux

- Medical therapy
  - H2-receptor blockers or proton-pump inhibitors
  - Thickened feedings
  - Positioning to facilitate gastric emptying

- Surgical therapy
  - If severe and associated with HIE, then gastric fundoplication may be indicated

Necrotizing Enterocolitis

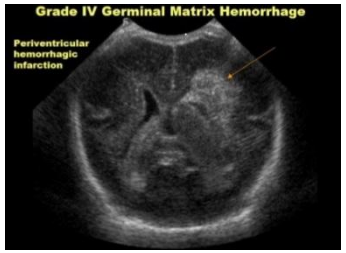
- Occurs in the second to third week of life in premature, formula-fed infants
- Intestinal tract damage ranging from mucosal injury to full-thickness necrosis and perforation.
- NEC affects 10% of infants with BW<1500g with mortality rates of 50% or more depending on severity
- May also occur in term and near-term babies.

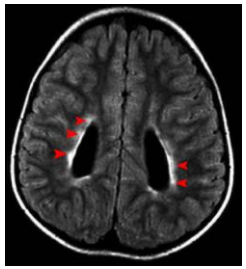
Short Bowel Syndrome

- Close follow-up by PCP, Gastroenterologist and Pediatric Surgeon
- Can develop Dumping Syndrome (increased ostomy output or severe diarrhea with GI infection) causing dehydration and electrolyte imbalance.
- Associated with poor growth
- When TPN must be given in the home, there is an increased risk of catheter or gut-related bacteremia.
- Post surgical complications may include scarring resulting in partial or complete bowel obstruction.

CNS Disorders

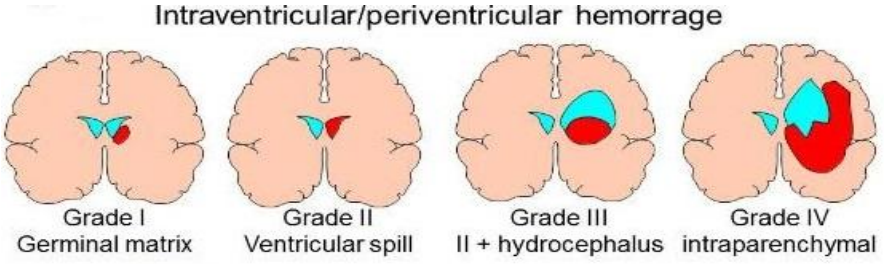
- Most common and serious CNS disorders in premature infants
  - Post-hemorrhagic hydrocephalus
  - Post-meningitic hydrocephalus
  - Periventricular leukomalacia
  - Seizures
- Place NICU graduates at high risk for poor long-term neurologic outcomes
- Brain ultrasounds are routinely used for screening. Brain MRI prior to NICU discharge is increasingly becoming standard of care





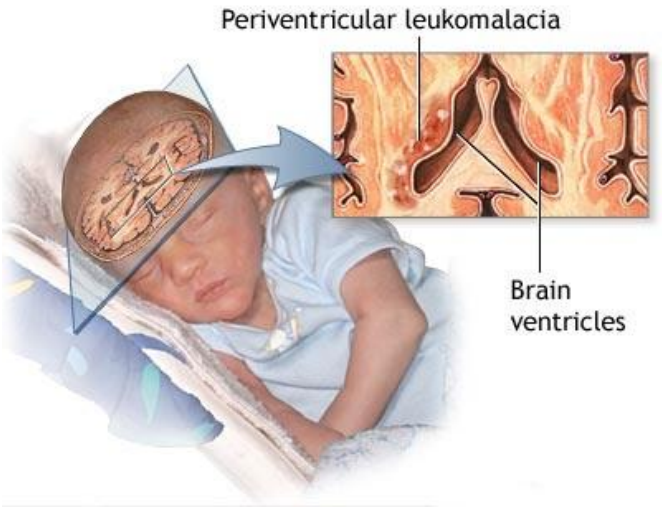
Post Hemorrhagic Complications

- Grade III and IV intraventricular hemorrhages are associated with least favorable neurodevelopmental results
- Grade I and II may also have poor neurologic outcomes
- IVH leads to post hemorrhagic hydrocephalus in 35% ELBW infants
  - Rapid progression may result in VP shunt placement
  - After VP shunt in place, need to monitor for infection or malfunction
- Intracortical hemorrhage→cerebral infarction→cerebral or cerebellar porencephaly
- The risk of these conditions are inversely proportional to gestational age.



Periventricular Leukomalacia

- Etiology: ischemic infarction of white matter adjacent to lateral ventricles
- Associated medical conditions include:
  - Antenatal or Intrapartum hemorrhages
  - Chorioamnionitis
  - Postnatal sepsis and NEC
  - CSF infections
  - IVH
  - Life threatening apnea and bradycardia
  - Cardiopulmonary arrest



PVL is highly associated with Cerebral Palsy

Neonatal Seizures

- Neurodevelopmental outcomes related to underlying etiology
- Some causes include:
  - Hypoxic Ischemic Injury
  - Direct Cerebral trauma
  - Intracranial hemorrhage
  - Metabolic abnormalities
  - Malformations
  - Infections

- Evaluation and Treatment
  - Neurology consult
  - Anticonvulsants:
    - Phenobarbital
    - Keppra
    - Dilantin
- If EEG is negative, then anticonvulsants are discontinued prior to NICU discharge or shortly after by Neurology
  - Monitor for reoccurrence after stopping

Vision Problems

- Blindness is the most devastating consequence of ROP
- ROP association with oxygen therapy, degree of prematurity and infections
- NICU screening and follow-up by retinal specialist until retinas are fully vascularized (usually 44-48 weeks post conception)
- Laser surgery or Avastin therapy when at risk for retinal detachment
- Screening for refractive disorders and amblyopia at 6 months post NICU discharge, 2-3 years old, before kindergarten, during grade school and in adolescence.
- Infants with ROP are at higher risk of having myopia, amblyopia and later glaucoma. PCP to screen for strabismus.

Hearing Problems

- Incidence of hearing loss is higher in NICU graduates
- Contributing factors: hypoxia, certain drugs, infections.
- Congenital or Acquired CMV infection associated with progressive hearing loss.
- Universal newborn hearing screening
- Referral to Audiology and ENT specialist as needed

Summary

- NICU graduates require close medical and neurodevelopmental follow-up
- A team approach is required for successful transition from NICU to home
- The risk of most medical conditions that affect premature infants is inversely proportional to gestational age
- The Primary Care Physician plays a key role in the health care maintenance of preterm and other high-risk infants
- Early and appropriate referral to medical subspecialists and other community developmental and educational programs help to maximize long term outcome