EI After NICU Discharge: “Where Should We Begin?”

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Objectives/Topics

- Prematurity
- Correcting for prematurity
- Nutritional needs
- Issues that we see most frequently in SBC
- Why we recommend following until they are 2 y/o (even when they are doing okay)
- Head Shape
- Parental stress & trauma
- HIE
  - Cooling
- Who makes our focused vs. generalized NICU attention?

Disclosure

- We have no relevant financial relationships with the manufacturer of any commercial products and/or providers of commercial services discussed in this CME activity.
- We do not intend to discuss any unapproved or investigative use of a commercial product or devise in this presentation.

Factors Associated with Preterm Labor and Delivery

- Maternal History:
  - Chronic disease
  - Diabetes
  - Cardio. disease
  - Underweight (preconception)
  - Smoking
  - Previous preterm labor
  - African American Race
  - Low socioeconomic status
  - Reproductive tract anomalies
  - Age extremes

- Current Pregnancy:
  - Inadequate weight gain
  - Acute Maternal Illness
  - PIH
  - UTI
  - Infection
  - PROM
  - Multiple gestation

- Fetal Factors:
  - Fetal anomalies
  - Fetal demise
  - Infection
United States Stats as of 2015

- ~4 million births per year
  - Gestational age
    - 9.6% are preterm (<37 weeks gestation)
      - 7% late preterm (34-36 6/7 weeks)
      - 2.6% (<34 weeks)
  - Weight
    - Low Birth Weight (<2500g):
      - ~8% of annual births
      - ~90% (~288,000) of these infants survive to discharge
        ~ 1/3 will need specialty services

Impact in Numbers as of 2014

- Average Week in New Mexico
  - 521 births
  - 59 preterm births
  - 8 very preterm
  - 45 Low Birth Weight (LBW)
  - 7 Very Low Birth Weight (VLBW)

30 week AGA Female

Discharge Criteria

- Infant Readiness
- Family and Home Environmental Readiness
- Community and Health Care System Readiness

Our goal is to discharge a stable baby, NOT a term healthy newborn

AAP, Committee on Fetus and Newborn. Pediatrics. 2008
77 days later……Now what?

Medical Home

• The primary care provider who provides the family of a premature infant with
  – Routine healthcare maintenance
  – Anticipatory guidance
  – Coordination of multiple specialty evaluations,
  – Family advocacy and support
  – Assessment of neurodevelopment or behavioral issues

Outpatient Management

• Evaluation of Growth and Nutrition
• Vision and Hearing Screening
• Ongoing Preventative Care
• Developmental Progress
• Close monitoring of common medical problems of the preterm infant

Growth

• Poor postnatal growth is a major cause of morbidity in the preterm population
  – Most develop a significant nutrient deficit in the first weeks of life that is not replaced before hospital discharge (even when recommended dietary intakes are met)
  – Not much is known about the nutritional status of these infants post-discharge and best practice is still largely unknown

Carlson SE: Nutrition of the preterm infant: scientific basis and practical guidelines, ed 3. 2005
Growth Patterns

• Head growth frequently exceeds weight gain and linear growth
• Many have a disproportionate increase in weight for length in the early months after discharge, especially VLBW
  – This should not be used as evidence for restriction of intake
• Accelerated growth patterns usually normalize between 1 & 2 years of age

Human Milk

• The optimal choice, but...
  – Deficient in calcium, phosphorous, and vitamin D for bone mineralization and protein for adequate growth
  – Human milk fortifiers add these factors
    • At higher volumes it requires close monitoring as potential for inappropriate vitamin intake
  – Transitioning from fortified human milk to exclusive human milk and/or something in between
    – No best practice available
    – No good studies available
    – Needs to be individualized with close follow-up

Fortification?

• Only 2 studies
• Fortification did NOT effect duration of BF
• No difference in Bayley II scores

Post-Discharge Recommendations

• Needs may be met by human milk, human milk supplemented with post-discharge or term formula, or exclusively post-discharge or term formula
• An individualized approach is essential
• Human milk is preferred for preterm infants; breast-feeding should be advocated by pediatricians and lactation resources should be made available

O'Connor et al. JPEN 2012

Nzegwu & Ehrenkranz. Clinics of Perinatology 2014
**Post-Discharge Recommendations**

- A discharge nutritional plan should be discussed among the health care team, parents, and if possible the outpatient care provider.
- Close monitoring of growth parameters using validated growth curves and nutritional intake should be assessed at discharge and every 2-4 weeks thereafter, until stable weight gain is established.

**Nutrition**

- By the time of discharge, prematurely born infants generally are feeding ad lib with good total volume intake.

**Fortification**

- 24-32 weeks gestation infants randomized to either exclusive breastfeeding or breastfeeding with fortification
  - Fortification of breastmilk had no significant effect on duration of breastfeeding.
  - Growth was also not significantly different between the two groups (secondary outcome).

**Fortification**

- Fortifying human milk while in the NICU is important
- For the majority of NICU graduates there must be a clear and strong indication before changing a breastfed infant’s diet to any alternative
- With either strategy, close follow-up should be done to ensure adequate growth and bone mineralization

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*Nzegwu & Ehrenkranz, Clinics of Perinatology 2014
2017 FIT Annual Meeting
19

*Nzegwu & Ehrenkranz, Clinics of Perinatology 2014
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19

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21

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21

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22

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23
Formulas

- VLBW infants should remain on nutrient enriched post-discharge formulas (transitional) until at least 9 months CGA
  - Standard caloric content: 22kcal/oz
  - Preterm infants need to consume at least as much formula per day as their term-born peers.
  - If growth exceeds 2 birth percentile lines or if weight/length exceeds 90%, 20cal/oz term infant formula may be considered earlier

Other Formulas

- No role for the use of low-iron formulas
- Soy protein-based formula not recommended for preterm infants weighing < 1800 grams
  - Lacking in sufficient calcium, phosphorous and protein
  - The presence of phytates (soy) decreases bioavailability of mineral absorption in the gut

Calcium, Phosphorous, and Vitamin D Intakes at 160ml/kg/day

<table>
<thead>
<tr>
<th></th>
<th>2013 AAP Recommendation For Infants &lt;2kg</th>
<th>Human Milk (20 kcal/oz)</th>
<th>Fortified Human Milk (24 kcal/oz)</th>
<th>Preterm Formula (24 kcal/oz)</th>
<th>Transitional Formula (22 kcal/oz)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calcium (mg/kg)</td>
<td>150-220</td>
<td>37</td>
<td>184-218</td>
<td>210-234</td>
<td>125-144</td>
</tr>
<tr>
<td>Phosphorous (mg/kg)</td>
<td>75-140</td>
<td>21</td>
<td>102-125</td>
<td>107-130</td>
<td>74-80</td>
</tr>
<tr>
<td>Vitamin D (IU/day)</td>
<td>200-400</td>
<td>2.4</td>
<td>283-379</td>
<td>290-468</td>
<td>125-127</td>
</tr>
</tbody>
</table>

Risk Factors for Bone Disease

- Population at highest risk for bone disease
  - <27 weeks gestation and BW < 1000gm
    - 80% of mineral deposition occurs in the third trimester
  - Long term TPN need—4-5 weeks
    - Aggravates the mineral deficit that a preterm infant starts with
    - Treatment with medications known to affect bone or vitamin D metabolism (diuretics, methylxanthines, glucocorticoids, antiepileptics)
    - History of severe complications—NEC, BPD, liver disease, multiple episodes of infection
    - Failure to tolerate formula or HMFs with high mineral content
    - Poor weight gain
- Still need to be concerned about the entire VLBW population and those ≤ 32 weeks

Lewis: https://www.preemietoolkit.com/pdfs/E_PhysicalExaminationAssessment/Recommendations-for-Postdischarge.pdf
Bone Mineralization: Vitamin D, Calcium and Phosphorous

• For exclusively breastfed VLBWs
  — Recommend measurement of alkaline phosphatase at 2-4 weeks post discharge
    • For levels > 800 IU/L, need close follow-up
    • For levels > 1000 IU/L, consider supplementation
      — Alternative: consider changing to some feeds with transitional formula
  — Maintain normal Ca and Phos
    • Supplementation with 2-3 feeds of a transitional formula will enhance mineral intake
    • Recommend following until at least 6 months CGA if normal

Iron Supplementation

• Breast Fed
  — 2 mg/kg/day from 1 month through 12 months—current AAP recommendations
    • Tsang et al. continue to recommend 2-4 mg/kg/day for ELBW and VLBW

• Formula Fed
  — Only iron fortified formulas are recommended
  — Transitional formulas provide ~ 1.8 mg/kg/d at 150ml/kg/day—additional supplementation is indicated to meet the recommended 2-4 mg/kg/d
  — Screening hematocrit at 2-4 weeks post-discharge is recommended with ongoing close monitoring

Close Follow-Up

• At discharge the preterm infant is usually just meeting a set growth guideline
  — Typically 3-5 days of good weight gain while on ad lib feeds.
• First follow-up appointment is usually arranged for 48-72 hours after discharge.

Our goal is to discharge a stable baby, NOT a term healthy newborn

Food Introduction

• Introduction of foods should occur at a schedule consistent with a term baby, using the infant’s CGA
  — VLBW infant’s should wait until 6 months CGA
Vision and Hearing

Retinopathy of Prematurity

- 2nd most common cause of childhood blindness
- Affects up to 80% of VLBW, ELBW and sick premature infants
- Presents at 32 weeks CGA, peaks at 38-40 weeks CGA, and begins to regress by 46 weeks CGA
- Infants with immature retinas at discharge must be followed by ophthalmology until the retina is fully vascularized: 50 weeks CGA
- If untreated, can lead to retinal detachment and blindness


Vision

- Increased risk for:
  - Myopia (16%)
  - Strabismus (13-25%)
  - Amblyopia
- Recommended that all premature infants be evaluated by an ophthalmologist at 6-12 months CGA and then yearly


NMSBVI

- Should be consulted as a part of a child’s IFSP team if any concerns arise OR if there has been a history of any of the risk factors noted on their Screening Tool.
Hearing

- 2-4 per 100 infants <32 weeks’ gestation will develop some degree of hearing loss.
- A normal hearing screen prior to discharge does not preclude delayed onset or acquired hearing loss
  - Infants who pass the neonatal screening but have a risk factor should have at least 1 diagnostic audiology assessment by 1 year of age

When to do Hearing Evaluations Beyond Discharge

- Risk factors associated with permanent congenital, delayed onset, or progressive hearing loss
  - Caregiver concern for hearing, speech, language or developmental delay
  - Family history of permanent childhood hearing loss
  - NICU stay > 5 days
  - History of ECMO, assisted ventilation, exposure to ototoxic medications or loop diuretics, and hyperbilirubinemia requiring exchange transfusion
  - Postnatal infections associated with hearing loss
  - Congenital infections: CMV, Herpes, Rubella, Syphilis, toxoplasmosis

Ongoing Preventative Care

- Standard Immunizations
  - Preterm infants should receive full immunizations based upon their chronological age consistent with the schedule and dose recommended for normal full-term infants


2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs

AAP Committee on Infectious Diseases: Red Book 2012
Rotavirus

• AAP recommends initial vaccination at or following discharge if clinically stable and between 6 and 15 weeks of (chronological) age
• Live vaccine
  — Need to know your NICU’s policy
• More than half of ELBW infants are ineligible due to age at discharge from the NICU.
• Recent study suggests it may be safe to give in the NICU

AAP Committee on Infectious Diseases: Immunization in special circumstances. Red Book 2012

Synagis (Palivizumab)

• New guidelines as of July 2014
• Who gets it this season?
  — All infants born at 29 0/7 weeks or less who are younger than 12 months at start of season
  — Any preterm infant less than 32 0/7 weeks with CLD, defined as:
    • Requirement of >21% oxygen for at least the first 28 days after birth

Committee on Infectious Diseases and Bronchiolitis Guidelines Committee. Pediatrics 2014

Developmental Progress

• Use until the infant reaches 24-36 months
• Use for all developmental milestones, including introduction of foods
• The only schedule that should follow the preterm infant’s chronological age is their immunization schedule

Committee on Infectious Diseases and Bronchiolitis Guidelines Committee. Pediatrics 2014
Correction for Gestational Age

- AAP recommends correction until at least age 2 and most until age 3
  - Consider the percentage of prematurity
    - Baby born at 28 weeks at age 2 years is 12%
    - Baby born at 24 weeker at age 3 years is 10%

Neurological Differences

- When corrected to term the extremely preterm infant’s brain
  - Reduced gray matter volume
  - Increased cerebrospinal fluid
  - Males have significantly lower white matter volumes in specific areas
- These findings persist to school age and are associated with learning challenges


Perinatal/Neonatal Risk Factors

- Prenatal
- Prematurity
- Intrauterine growth
- Condition at birth
- Neonatal complications
- Neurological structure
- Socioeconomic status

Perinatal/Neonatal Risk Factors

- Risk: Increased likelihood of disability
- Risk ≠ disability
- Many who have disability do not have risk
- Some risk factors carry a higher risk of disability than others.
- More risk factors will lead to an additive effect
### Surveillance, Screening, & Evaluation

- **Surveillance**: the process of recognizing children who may be at risk of developmental delays.
- **Screening**: the use of standardized tools to identify and refine recognized risk.
- **Evaluation**: a complex process aimed at identifying specific developmental disorders that are affecting a child.

### Developmental Surveillance

- **Why**
  - Large numbers of children with disabilities are not identified until school age.
  - Can be highly sensitive and detect even a subtle delay in developmental domain.

### AAP Recommendation Screening

- In the **absence** of risk or concerns
  - 9, 18, and 30 months
- If surveillance identifies risk then additional screening is needed
- Surveillance should be continued even if screening does not indicate a risk of delay.

### Surveillance

- **5 areas**
  - Eliciting and attending to the parents’ concerns
  - Documenting and maintaining a developmental history
  - Making accurate observations
  - Identifying risk and protective factors
  - Maintaining an accurate record of documenting the process and findings
Long-term Outcome?

- Complex interplay
  - Biologic: serves as the strongest predictor of long-term function and development as the child recovers from perinatal and prenatal insults.
  - Genetic and Environmental: accounts for more of the variations seen in cognitive development.
- In most preterm children a positive environment can ameliorate many biologic risk factors.

Perinatal Mood and Anxiety Disorders (PMAD)

Factors That May Impact Risk

- Changes in Hormonal levels
- High Risk Pregnancies
- Complications/Difficult birth
- History of Depression
  - PMAD with a previous pregnancy (risk: 30-50%)
- Feelings of Isolation
- Lack of Sleep
- Social/environmental stressors

2013: Exposed in pain: Danielle Haines of Phoenix, Arizona, shared this image of herself three days postpartum with her son Ocean, describing in detail how she experienced anxiety and depression after birth. 

http://www.dailymail.co.uk/femail/article-3237618/I-rong-Mother-posts-devastating-image-sobbing-cradling-newborn-baby-shed-light-realities-postpartum-depression.html#ixzz4Oxt5tZdB
Statistics

- Up to 80% of women will experience “Baby Blues” (NIMH)
- Prevalence: 10-20% of women will experience a PMAD, half will begin experiencing symptoms during pregnancy
- Suicide is one of the most common causes of maternal death in the first year post-delivery in the developed world (WHO, 2016)
- About 18% of women will experience a traumatic birth (i.e., birth complications, hemorrhaging, hx of sexual abuse)...5-9% will develop PTSD

Impact of PPMD

- Mother
- Baby
  - https://www.youtube.com/watch?v=BTqgPIT0sZg
  - https://www.youtube.com/watch?v=6czxW4R9w2g
- Overall Development
  - Cognitive
  - Social Emotional
  - Long Term outcomes (All development unfolds from the primary relationships)
- Family

Depression and Anxiety Symptoms

- Feeling “down”
- Feelings of guilt
- Low self-esteem/sense of worthlessness
- Low energy
- Changes in appetite
- Scary Thoughts
- Sleep disruptions

- Excessive worry
- Hypervigilence
- Agitation
- GI disturbances
- “Can’t shut mind down”
- Sleep disturbances

What are the Perinatal Mood Disorders

- Depression
- Anxiety
- Bipolar Disorder
- Obsessive Compulsive Disorder
- Post Traumatic Stress Disorder
- Psychosis
How do you ask about this?

Think about how the mom and dad are already feeling
Not accusatory
Affirming
Letting them know what is available
Letting them know that you are NOT saying that they are “depressed and anxious”

Early Intervention

• New Mexico’s EI eligibility criteria is based on:
  1. Established conditions
  2. Identified developmental delay, OR
  3. Risk
     • Biomedical Risk
     • Environmental Risk

Close monitoring of common medical problems of the preterm infant

Dental Care

• ~ 2/3 of VLBW infants have dental enamel defects
• May have delay in tooth eruption
  – Full complement should be present by 2 years
• Decreased tooth crown size
• If history of prolonged intubation:
  – V-shaped palates, palatal groove, posterior cross bites, deformed incisal edges, and missing teeth
• Initial evaluation based on risk:
  – As early as 6 months of age, 6 month after the first tooth erupts, and no later than 12 months of age

Eastman et al. Newborn Infant Nursing review-2003
### 2 Year Re-hospitalization/Operations ≤27 weeks

- 50% re-hospitalization rate
  - Mean is 1.9 times, Median 1
- 1/3 received an operation
  - 30% Hernia repair
  - 25% Tubes
  - 15% G-tube
  - 15% Bronch
  - 3% Eye Surgery

Neonatal Research Network Data 2011

### 2 Year Re-hospitalization/Operations ≤27 weeks

- Oxygen
  - 7% with oxygen requirement at age 2
  - 2% on Vent or CPAP

Neonatal Research Network Data 2011

### 2 Year Re-hospitalization/Operations ≤27 weeks

- 12% Cerebral Palsy
  - 6% mild
  - 6% moderate/severe
- 11% require special equipment
  - 86% braces/orthotics
  - 19% walker

Neonatal Research Network Data 2011

### Follow-Up Care Delivery
AAP Recommendations on Follow-Up Care of the High-Risk Infant

- There are currently no standardized guidelines for provision of follow-up services for high-risk infants in tertiary care centers.

- Experience in follow-up care is required for all neonatal-perinatal medicine fellows....

Follow-Up Care

- Neonatal follow-up programs (such as Special Baby Clinic) have been developed to survey the outcome of high-risk infants.
  - Does not address the specialized health needs related to the preterm infants pulmonary, gastrointestinal, nutritional, and neurologic problems.
  - Does not address acute illnesses or complications that may quickly become life threatening.

New Mexico Follow-Up Care

- Currently we don’t have comprehensive care for high-risk neonates
- UNMH’s NICU represents all regions of the State
  - 80% Medicaid
  - 2% No insurance
  - 50-60% from outside of Bernalillo County
- More than 1/3 of births are to residents in rural and semi-rural areas
- Preterm birth is more common in rural areas.
- 10.4% of children with special health care needs are without a usual source of care

Useful Resources

- [www.premietoolkit.com](http://www.premietoolkit.com)
- *Primary Care of the Premature Infant*, D Brodsky and MA Ouellette
- Nutritional Care of Preterm Infants
- AAP
• Hypoxic-ischemic injury: important cause of perinatally acquired brain injury in full-term infants.
• The best predictor of mortality and long-term outcome following perinatal injury is presence of neonatal encephalopathy.
• Moderate encephalopathy: risk of death <10% and as many as 1/3 of survivors have physical disabilities.
• Severe encephalopathy: mortality as much as 60% and many, if not all, survivors are handicapped.

Benefit of induced hypothermia (cooling) in post-asphyxia encephalopathy has been proven in high-quality randomized controlled trials to be safe.
• In addition, it reduces incidence of death and disability at 18-22 months of age.
• Current evidence does not support cooling of infants with mild hypoxic-ischemic encephalopathy (HIE) or those born before 35 weeks.
• Long term monitoring is very, very important.

Intraventricular hemorrhage (IVH)
• IVH is a significant risk factor for Cerebral Palsy.
• It is most common in premature babies
  – especially those who have experienced respiratory distress syndrome,
  – collapsed lung,
  – or high blood pressure.
• IVH occurs most frequently in the first 48 hours after birth and decreases in likelihood as baby ages.

www.cerebralpalsy.org

IVH
• Changes in blood pressure can also cause delicate infant blood vessels to rupture.
• Ventilatory support
  – although great care taken to prevent rupture, it is possible baby can breathe out of sync with the ventilator causing increased pressure in the lungs and brain.

www.cerebralpalsy.org
Grades of IVH

- Intraventricular hemorrhage is categorized into four grades (Grades I through IV) of increasing severity.
- Grades I and II usually involve a small amount of bleeding contained in the ventricles and do not normally cause long-term problems.

IVH

- Grades III and IV
  - More substantial bleeding which leading to swelling or obstruction in the brain.
  - The swelling and obstruction, in turn, can lead to a hydrocephalus, which causes dangerous pressure and may require surgical procedures to relieve.

What are the risk factors for intraventricular hemorrhage?

- Placental blood clots
- Malformed or weak blood vessels in the brain
- Blood-clotting abnormalities
- Maternal high blood pressure (hypertension)
- Maternal infection
- Pelvic inflammatory disease
- Shaken baby syndrome
- Head injury

We are growing brains in the NICU
Synactive Theory

- Infant’s communication is via his/her behavior
- Behavior represents the hierarchical integration of his subsystems
- Focuses on the unique way that each baby processes the environment at any given time
- Subsystems are
  - interdependent
  - hierarchical
  - mature sequentially

Systems and the NICU

- Essential ‘properties’ of the child can be considered when looking at “the interactions and relationships among the parts.”
  - Muscle stiffness; cognition; medical condition; personality
- But, when we look at the child merely as a ‘24-weeker’ we lose sight of the fact that “these parts are not isolated and the nature of the whole is always different from the mere sum of its parts”
- This is someone’s baby

Nippling

- Misconception of nippling and breastfeeding
- Flow of milk/formula
- Cue-based and Infant-driven
### Plagiocephaly/Torticollis

- NICU positioning
  - Gravity
  - Preference
  - Medical needs
- Back-to-sleep
- Huge problems in f/u

### Plagiocephaly/Torticollis

- AAP
- Common condition
  - ¼ of U.S. infants w/ some degree of positional plagiocephaly.
  - The incidence has increased since AAP Back to Sleep campaign in 1994 (to prevent SIDS)

### What to do about it?

- Ask your motor therapist
- Ask your pediatrician
- Do not wait to address it
- Positioning
- Best approach?
  - PREVENTION
### What to do about it?

- **Helmet**
  - Still need attention to the shortened muscles
- **Think about the words that you use**
  - Lengthening vs. shortening
  - Active vs. passive responses of muscles

### Recommendations (Congress of Neurological Surgeons, 2016)

1. *[Physical] therapy recommended over repositioning education alone for reducing prevalence of infantile positional plagiocephaly in infants 7 weeks of age.*  
   *(Strength of recommendation: Level I [high clinical certainty].)*

2. *[Physical] therapy is as effective for the treatment of positional plagiocephaly and recommended over the use of a positioning pillow in order to ensure a safe sleeping environment and comply with AAP recommendations.*  
   *(Strength of recommendation: Level I)*

### Recommendations- Helmet Therapy (Congress of Neurological Surgeons, 2016)

[Physical] therapy is an additional intervention often utilized with more significant deformity and/or torticollis to speed the rate of correction.

Torticollis commonly associated w/ more severe cases of plagiocephaly, due to even longer periods of time spent laying in the same position w/ pressure on the flattened skull surface.

[Physical] therapy serves to treat both the torticollis and the resultant positional plagiocephaly.
2. Helmet therapy recommended for infants with moderate to severe plagiocephaly presenting at an advanced age. (Strength of Recommendation: Level II – uncertain clinical certainty)

3. For infant either at advanced age (usually > 8 months) w/ significant deformity or who presents at younger age, (~6 months of age) who failed to respond to repositioning/therapy, a cranial orthosis (molding helmet) is more effective, compared to conservative therapy, especially if asymmetry is severe, and provided that helmet therapy is applied during the appropriate period of infancy.

3. (cont) In general, infants with a more severe presenting deformity, & infants helmeted early in infancy, tend to yield better outcomes (such as correction and even normalization) of head shape.
### Special Baby Clinic

- Appointments made pre-d/c Women’s & Pres (the latter for some insurances)
- UNMH made at d/c
- Staffed by
  - Neonatologist
  - Therapist
  - SW/Family therapist
- Younger than 1 year

### Misc.

- Invitation to SBC
- Invitation to place us on your IFSPs if you think that a consult/E & A would be helpful