It isn’t a Sprint…

It’s a Marathon!
Helping NICU Graduates Achieve Their Greatest Potential

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Objectives

• Discuss importance of developmental care

• Highlight common medical problems of NICU graduates

• Identify measures of long-term neonatal outcomes

• Evaluate purpose of Cleveland Clinic Children’s NICU Follow-up Clinic
The Hard Facts

- Survival rate of VLBW infants is reported to be ~85%

- Pulmonary Morbidity
- Poor neuro-development
- 15-25% Disability
Factors affecting morbidity and mortality

**Biologic**
- Birthweight & Prematurity
- Sex
- PPROM
- Maternal sepsis
- Brain white matter injury

**Environmental**
- Education of mother
- SES
- Family
- NICU & early practices
Difficulties at School Age

- Visual-motor integration
- Language performance
- Behavior
- Attention
- ↓IQ
Interventions to decrease NICU stress

Optimal Neuro-Development

Developmental Care
Early (LBW Preterm)

- Increased risk of “poor health-related” outcomes during their birth hospitalization
- Increased health care utilization during their first year
- Increased cost

Late Preterm Infants: Birth Outcomes and Health Care Utilization in the First Year- Pediatrics July 2010
School Age (ELBW Preterm)

- Serious Cognitive Impairment - 40%
- Serious Functional Disability - 45%

Neurodevelopmental Disability Through 11 Years of Age in Children Born Before 26 Weeks of Gestation - Pediatrics August 2009
Adult (ELBW Preterm)

- Asthma
- Insulin resistance
- Lower bone density
- Hypertension
- Sleep disordered breathing
- Cognitive issues
- Neurosensory impairment
- Psychological disorders

Adult Outcomes of Extremely Preterm (<28 wks)
Pediatrics August 2010
Adult (ELBW Preterm)

- Poorer school function, completion
- Self reported- No difference in quality of life
- Better work performance
- Less risk taking (drugs, sex)

Adult Outcomes of Extremely Preterm (<28 wks)
Pediatrics August 2010
Former 25 wk BW: 2 pounds
College freshman
Now: 215 pounds
The Challenge of Parental Thinking

The shift from NICU to home requires a shift in thinking…

Infant is receiving intensive care

Infant is receiving primary care
Purpose of NICU Follow-up

- Review neonatal history
- Medical follow-up
- DME management
- Medication management
- Medical home coordination
- Service coordination
- Developmental testing
ESTABLISH a medical home for NICU graduates & high infants

EVALUATE & treat complex medical conditions

ENSURE compliance to subspecialty evaluations & therapy services

EDUCATE parents about unique services & financial assistance available

ENCOURAGE individual & family counseling when needed

EMPOWER parents to better advocate for their children
Purpose of NICU Follow-up

- Referrals
- Smooth transition to Home
- COMPLIANCE vs REALITY
- Reassurance
Common Medical Problems in Preterm Infants
Growth

- Conditions associated with Poor Growth
  - Chronic lung disease
  - Environmental compromise
  - Malabsorption
  - Intracranial hemorrhage
  - Congenital anomalies
Nutrition and Growth

- Chronic undernutrition and poor growth
- Preterm formula improves IQ and decrease rates of CP
- Nutritional deficits not typically resolved prior to hospital discharge
Growth Curves & Catch Up Growth

• Use the infant’s corrected age until at least 18 months of age

• Greatest during the 1st 4 months of life

• Head circumference → weight → length
Caloric Supplementation

- Flat or decelerating curve
- Infant is unable to take enough volume
- Infant is fluid restricted
Catch Up Growth

• Head growth at 8 months corrected age is one of the best predictors

• Slowing of head growth at 5 to 6 months is an ominous sign

• If catch up growth has not occurred by 18 months, consider referral
Gastroesophageal Reflux

- Mild GER in 40-65% of healthy term infants

- Natural history of physiologic GER – disappearance of symptoms by 2 years of age
Is GER Worse in Preemies?

- Frequency and duration of mild physiologic reflux is LESS in preterm infants
  - Jeffrey and Page 1995 & Kohelet et al. 2004

- Pathologic GER:
  - 6-7% term vs. 3-10% VLBW
Risk Factors for GERD

- Prematurity
  - Medications
  - Intubation
  - BPD
  - OG/NG
- Perinatal depression
- Sepsis
- Congenital anomalies
- ECMO
- Neurologic impairment
Miscellaneous

• Umbilical hernias
Miscellaneous

• Umbilical hernias

• Inguinal hernias
Miscellaneous

• Umbilical hernias
• Inguinal hernias
• Skull abnormalities
Figure – This 8-month-old infant has on a typical orthotic cranial molding helmet used for treatment of positional plagiocephaly.
Miscellaneous

- Umbilical hernias
- Inguinal hernias
- Skull abnormalities
- Torticollis
Prematurity and Dental Care

Endotracheal Intubation

- Enamel Defects
- Delayed Eruption

↓ Crown Size
- Cavity Defects
Retinopathy of Prematurity

- Disorder of abnormal vascular proliferation of the infant retina
- Second most common cause of blindness
- Incidence
Risk Factors for Hearing Loss

- Parental concern
- Family history
- Genetic syndromes
- Postnatal infection
- In-utero infection
- Hyperbilirubinemia
- PPHN
- ECMO
- Ototoxic medications
Screening for Hearing Loss

- Initial hearing screen before discharge
- If ≤ 32 weeks, consider retest at 12 months
- If risk factors, recheck q 6 months until 3 years of age
Cerebral Palsy

- Leading cause of childhood disabilities
- Prevalence of cerebral palsy is 3.3 children per 1,000 live births.
- Risk 20 times greater in VLBW infants
- Importance of the neuro exam
Associated Problems with CP

- Audiologic
- Communication problems
- Developmental delays
- Poor feeding and growth
Associated Problems with CP

- Neurologic
- Ophthalmologic
- Orthopedic
- Respiratory
CP screening – The Pearls

- Irritability
Pearls for Autism

- Deficits in social skills, language skills or behavior
- Frequent tantrums or intolerance to change
- No babbling by 9 months
- No pointing or gestures by 12 months
Pearls for Autism

• Lack of orientation to name by 12 months of age

• No single words by 16 months

• Lack of pretend or symbolic play by 18 months

• No spontaneous, meaningful two-word phrases by 24 months

• Any loss of any language or social skills at any age
Creating the Medical Home for High Risk Infants
# Risk Factors for Developmental & Behavioral Problems

<table>
<thead>
<tr>
<th>Prenatal</th>
<th>Postnatal</th>
</tr>
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<tbody>
<tr>
<td>Lower BW</td>
<td>Seizures</td>
</tr>
<tr>
<td>Lower GA</td>
<td>IVH, WMI, PVL</td>
</tr>
<tr>
<td>IUGR</td>
<td>CLD</td>
</tr>
<tr>
<td>Male</td>
<td>Prolonged ventilation</td>
</tr>
<tr>
<td></td>
<td>Infection</td>
</tr>
<tr>
<td></td>
<td>Feeding problems</td>
</tr>
<tr>
<td></td>
<td>ECMO</td>
</tr>
<tr>
<td></td>
<td>Low SES</td>
</tr>
<tr>
<td></td>
<td>Maternal depression</td>
</tr>
<tr>
<td>Disability</td>
<td>Prevalence</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>10-20%</td>
</tr>
<tr>
<td>CP</td>
<td>5-21%</td>
</tr>
<tr>
<td>Blindness</td>
<td>2-11%</td>
</tr>
<tr>
<td>Deafness</td>
<td>1-3%</td>
</tr>
<tr>
<td>Motor delay</td>
<td>24%</td>
</tr>
<tr>
<td>Language problems</td>
<td>23-42%</td>
</tr>
<tr>
<td>ADHD</td>
<td>7-10%</td>
</tr>
<tr>
<td>Need for special education</td>
<td>9-28%</td>
</tr>
<tr>
<td>Psychological/behavioral problems</td>
<td>25%</td>
</tr>
</tbody>
</table>

*Wolke D: Arch Dis Child 1998*
Pearls on Outcomes

- More disabilities with lower BW and lower GA
- Cognitive more common than motor deficits
- Up to 50% born at ≤25 wks may have no disability over the 1st 3 years of life
- Deficits may not manifest until school age
Supporting Parents of Premature Infants
“Wished for Baby”

- Parents are “premature parents”
- Poor interactions between parent and preterm baby
Behavior of Premature Infant

- Hypersensitivity to social and environmental stimulation
- Task of self regulation
  - Compromised
  - Limited in duration
Specific Behavioral Issues

- Sensory Integration
- Temperament
- Attachment disorders
- Sleep
- Crying and colic
- Vulnerable child syndrome
Anticipatory Guidance for the Preterm Infant

- Sleep Issues
- Touching and Handling
- Feeding Problems
- Excessive Crying
- Chronologic vs. Corrected Age
- Relationship based care for the family
Early Intervention

- Individuals with Disabilities Education Act (2004)

Developmental services focus on:
- Physical
- Cognitive
- Communication
- Social or emotional
- Adaptive
Neurodevelopmental problems

- Learning and language delays
- Developmental screening is CRITICAL up to 2 years corrected age
Why Measure Outcomes…

Continuous Improvement

Clinical Outcomes

Patient Experience
“Long Term” Neonatal Outcome Measurements

- Physical
- Morbidity
- Quality of Life
- Mortality
- Parent Satisfaction
- Bayley Scale of Infant Development (BSID)
What is a BSID-III?

- Bayley Scales of Infant Development-third edition (BSID-III)
  - Standardized assessment
  - Ages 1-42 months
What does a BSID-III Assess?

- Cognition
- Language
- Motor
- Social-emotional and adaptive skills
BSID-III

- Raw scores → scaled scores and composite scores
- Determines a child's level of functional performance
BSID-III

- Composite scores
  - 85 – 115  Average
  - < 85 – Slightly below average
  - < 70 – Below average

- Percentile ranks and age equivalents are also determined
Interpreting BSID scores

• Determine if there are concerns for developmental delays

• Initiate Therapy services
  • PT, OT, Speech and EI

• Predicts school performance and readiness at 24 mo CA
Case Review – Neonatal History

- Female
- GA: 24 weeks
- Pregnancy complications: Quad reduction to twins, oligohydramnios, PPROM, abruption
- Delivery by C-section
- Apgars: 7\(^1\) and 7\(^5\)
- BW: 530 grams
Case Review – Hospital Course

- Apnea of prematurity
- RDS/CLD
- PDA
- Sepsis
- Anemia of prematurity
- ROP
- Feeding problem
- Hyperbilirubinemia
- Elevated alkaline phosphatase
- HUS wnl
- Hearing screen passed
- Newborn screen low risk
Cognitive Skills

- Explores objects
- Finds hidden objects
- Looks at correct picture
- Imitates gestures
- Pushes object on wheels
- Takes objects out of containers
Language Skills

- Responds to no and simple requests
- Uses simple gestures
- Says dada and mama
- Uses exclamations
- Tries to imitate words
- Begins using objects correctly
- Attends to simple play routines
- Recognizes familiar words
- Vocalizes
- Begins to use one word approximations
- Points to objects
Gross Motor Skills

- Gets to sitting position without assistance
- Crawls
- Assumes hands-and-knees position
- Gets from sitting to crawling
- Pulls self up to stand
- Walks holding on to furniture
- Begins to stand alone for a few seconds
- Occasionally sits down with control
Fine Motor Skills

- Pincer grasp
- Releases objects voluntarily
- Finger feeds self
- Isolates index finger
- Turns pages of a book
- Lifts a cup by its handle
- Brings objects to midline
# BSID-III Results

## Age 12 mo, 8 mo CA:

<table>
<thead>
<tr>
<th>Composite Score</th>
<th>%ile Rank</th>
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<tbody>
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<td>Cognitive</td>
<td>85</td>
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<tr>
<td>Language</td>
<td>91</td>
</tr>
<tr>
<td>Motor</td>
<td>110</td>
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</table>

## Age 18 mo, 14 mo CA:

<table>
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<th>Composite Score</th>
<th>%ile Rank</th>
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<tbody>
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<td>Language</td>
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</tr>
<tr>
<td>Motor</td>
<td>85</td>
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</table>
Our Assessment

• Functioning at the 9-10 month level

• Growth was <3rd %ile

Recommendations

• Continue HMG & 1x mo therapy
• Increase therapy services
• Audiology consult
• Pediasure + Carnation for growth
Baby Girl B.

- Born at 40 weeks with presumed pneumonia and pneumothorax requiring chest tube placement
- Hypotonia with respiratory insufficiency
- Apnea
Baby Girl B.

- LOS 40 days
- Bayley at 24 mo:

<table>
<thead>
<tr>
<th>Composite Score</th>
<th>%ile Rank</th>
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</thead>
<tbody>
<tr>
<td>Cognitive</td>
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<td>Language</td>
<td>56</td>
</tr>
<tr>
<td>Motor</td>
<td>46</td>
</tr>
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Early Power Mobility

• Independent mobility associated with advances in motor, social, emotional, language, cognitive, and perceptual development

• Motor impairments associated with global social and cognitive delays

• Early power mobility reduces barriers to exploration and advances the general development
Who has a driver’s permit so far…

- 22 5/7 week infant with normal HUS and CLD with resultant trach, vent, and GT dependence
- 26 week infant with severe IUGR and FTT
- 30 week infant with PVL
- 31 week infant with IVH and resultant CP
- 31 week infant with Trisomy 13
- Term infant with generalized hypotonia, etiology unknown
- Term infant with X-linked centronuclear myopathy and resultant trach, vent and GT dependence
- Term infant with congenital hydrocephalus s/p VP shunt with acquired Chiari malformation, tethered cord s/p repair, Klippel–Feil anomaly, VACTERL association, and FTT
- Term infant with multiple pterygoid syndrome, Escobar type with resultant trach, vent, and GT dependence
Baby Girl I.

- 26 weeks
- IUGR
- BW 477 grams
- LOS 114 days

- Required PT, OT and ST after hospital discharge
Developmental Testing

- BSID- III was performed at 10 mo CA:

<table>
<thead>
<tr>
<th>Composite Score</th>
<th>%ile Rank</th>
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<tbody>
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<td>Cognitive</td>
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<td>Language</td>
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<tr>
<td>Motor</td>
<td>67</td>
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</table>

- BSID- III was performed at 18 mo CA:

<table>
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<th>Composite Score</th>
<th>%ile Rank</th>
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<tbody>
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<td>Cognitive</td>
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<tr>
<td>Language</td>
<td>83</td>
</tr>
<tr>
<td>LMotor</td>
<td>61</td>
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</table>
After power mobility was initiated

BSID- III was performed at 24 mo CA:

<table>
<thead>
<tr>
<th></th>
<th>Composite Score</th>
<th>%ile Rank</th>
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<tbody>
<tr>
<td>Cognitive</td>
<td>110</td>
<td>75</td>
</tr>
<tr>
<td>Language</td>
<td>97</td>
<td>42</td>
</tr>
<tr>
<td>Motor</td>
<td>76</td>
<td>5 (fine motor &gt;&gt;&gt; gross motor)</td>
</tr>
</tbody>
</table>
Baby Boy A.

- 35 weeks
- Complicated Neonatal Course due to CPAM
- s/p HFOV and iNO
- BW 2561 g
- Discharge weight 3525 g
- LOS 60 days
## Developmental Testing

- BSID-III was performed at 8.5 mo CA:

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<th>Composite Score</th>
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<tbody>
<tr>
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<td>Language</td>
<td>106</td>
</tr>
<tr>
<td>Motor</td>
<td>110</td>
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</tbody>
</table>

- BSID-III was performed at 20 mo CA:

<table>
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<tr>
<th>Composite Score</th>
<th>%ile Rank</th>
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</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>115</td>
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<tr>
<td>Language</td>
<td>103</td>
</tr>
<tr>
<td>Motor</td>
<td>91</td>
</tr>
</tbody>
</table>
Baby Girl L.

- 26 weeks with BW 570 grams
- Prolonged NICU stay
  - LOS 120 days
  - Discharge weight 3000 grams
- Complicated but predictable NICU Course
- Age at exam: 12.5 mo = 9 mo CA
### BSID at 1 year of age

<table>
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<th>Composite Score</th>
<th>%ile Rank</th>
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</thead>
<tbody>
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<tr>
<td>Language</td>
<td>127</td>
</tr>
<tr>
<td>Motor</td>
<td>107</td>
</tr>
</tbody>
</table>
NICU Follow-up Clinic Schedule

- Hillcrest – every Thursday
  - 5 Bayleys per clinic

- Fairview – 1st, 3rd, & 5th Tuesdays of the month
  - 4 Bayleys per clinic with additional testing throughout the week

- CCCHR – 2nd and 4th Tuesdays of the month
  - 5 Bayleys per clinic

- 2 Bayleys every Thursday available at TSE
Conclusions

- Purpose of the NICU Follow-up Program is to:
  - Provide ongoing evaluations and management of medical problems
  - Assess for neurodevelopmental impairments

- Goal is to optimize neurodevelopmental outcome and overall quality of life

- Promote compliancy, therapy services, and follow-up for neurodevelopmental disorder
Questions?
Thank You!