Neonatal Passport to Facilitate Post-discharge Care

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Disclosure

• I have no relevant financial relationships with the manufacturer of any commercial products and/or providers of commercial services discussed in this CME activity.

• I do not intend to discuss any unapproved or investigational use of a commercial product or devise in my presentation.

At the end of this talk participants should be able to:

• Evaluate a former preterm infant’s medical complications and risk factors for disability
• Formulate a plan for longitudinal infant assessment and developmental support
• Recognize and address the complex subspecialty needs of a preterm baby.

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)

March of Dimes Peristats: March 2015

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
## 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

## 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 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.

## Oxygen

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

Neonatal Research Network Data 2011

## Vision

- Infants with immature retinas at discharge must be followed by ophthalmology until the retina is fully vascularized: 50 weeks CGA

- 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

Quinn et al. Ophthalmology 1998
AAP Eye examinations in infants, children, and young adults by pediatricians. Pediatrics. 2003

## 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

# 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.

AAP Committee on Infectious Diseases: Red Book 2012

# Synagis (Palivizumab)

- **Guidelines as of July 2014**
- **Who gets it?**
  - 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

# Nutrition

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


# Breastmilk Fortification

- A 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).


# 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


# 2 Year Rehospitalization/Operations

- ≤27 weeks
- 50% rehospitalization 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
Discharge Services at 18-22mo Corrected Age

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<th># of services</th>
<th>≤24wk</th>
<th>25wk</th>
<th>26wk</th>
<th>27wk</th>
<th>Total</th>
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<td>4.1%</td>
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<td>37.7%</td>
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</tr>
<tr>
<td>6-7</td>
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<td>20.5%</td>
<td>15.9%</td>
<td>12.9%</td>
<td>19.1%</td>
</tr>
</tbody>
</table>


Comprehensive Follow-Up Care

- 887 infants participated in a single center randomized controlled trial
  - Comprehensive Care vs. Routine Care
- Comprehensive care provided 5 days a week and included all acute care.
- Intercity population
- 95% follow-up at 1 year of age

Broyles et al. JAMA 2000

Broyles et al. JAMA 2000

| Table 3. Deaths, Life-Threatening Illnesses, and Pediatric Intensive Carea |
| --- | --- | --- | --- | --- | --- |
| Comprehensive-Care Group (n = 259) | Routine-Care Group (n = 260) | Relative Risk (95% Confidence Interval) | P Value |
| Total infants unknown whether alive at 1-y adjusted age | 9 | 28 | 0.32 (0.13-0.69) | .001 |
| Total known deaths | 11 | 13 | 0.83 (0.38-1.83) | .68 |
| Total infants with life-threatening illnesses | 30 | 62 | 0.49 (0.29-0.83) | .001 |
| Total infants admitted for intensive care | 25 | 52 | 0.43 (0.27-0.67) | <.001 |
| Total life-threatening illnesses | 33 | 63 | <.001 |
| Total admissions | 23 | 53 | .003 |
| Total intensive care days | 254 | 440 | .002 |

Broyles et al. JAMA 2000

| Table 4. Estimated Hospital Costs From Nursery Discharge to 1-Year Adjusted Agea |
| --- | --- | --- |
| Costs, Mean (SD), $ |
| Comprehensive-Care Group | Routine-Care Group |
| Outpatient costs | 1251 (807) | 917 (773) |
| All outpatient | 2748 (1415) | 2901 (1493) |
| Inpatient costs | 296 (1750) | 1371 (4843) |
| All inpatient | 3517 (1465) | 6992 (3414) |
| Total cost | 122% (15.62%) | 201% (12.39%) |

For the 198 comprehensive-care infants and 177 routine-care infants from January 1, 1996, and March 31, 1996. Data are presented in 1996 dollars.

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

Special Equipment

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

Neonatal Research Network Data 2011
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 and breast-feeding should be advocated by pediatricians and lactation resources should be made available
- 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.

Medical Passports

- Medical passports are an established method of improving care in high risk patient populations such as diabetes, heart disease, and inflammatory bowel disease.
- A neonatal passport is a tool that can be used to improve parents’ understanding of the critical healthcare needs of their child.

The Neonatal Passport

- Objective
  - To assess utilization of a neonatal passport to educate families on the critical healthcare needs of a very preterm infant after initial hospital discharge

CATCH Grant

- Community Access To Child Health (CATCH)

  **MISSION:** CATCH supports pediatricians to collaborate within their communities so that all children have access to needed health services and a medical home.

  All pediatricians are eligible to apply regardless of employment setting or retirement status.

  Outreach must be to the community at large, not to practice or clinic patients only.

  All initiatives should incorporate screening for or connecting children to medical homes and available insurance programs.

I was born before my due date

If you count my age from my due date instead of from the day I was actually born, this is called my adjusted age.

Knowing my adjusted age helps my mom to watch for changes in my growth and to know from when I am learning to do new things.

My mom was pregnant for 27 weeks.

My due date was January 1, 2015.

My birthday is October 1, 2014.

I went home from the hospital on November 14, 2014.

My adjusted age when I went home from the hospital was 39 weeks.
Useful Resources

- [www.preemietoolkit.com](http://www.preemietoolkit.com)
- *Primary Care of the Premature Infant*, D Brodsky and MA Ouellette
- Nutritional Care of Preterm Infants
- AAP