Assuring Premature Infant Follow Up through a Medical Home
Key Stakeholder Premature Infant Summit
Held on May 18, 2012

Jane Gerberding
Barbara Deloian
Overview

How It Began?

- Assuring NICU Follow Up through a Medical Home Committee
- CDPHE staff, University of Colorado, School of Medicine faculty, Special Kids, Special Care non-profit, and MedImmune
Background

- **HR 2679 – Preemie Reauthorization Act.**
  - To reduce preterm labor and delivery and the risk of pregnancy related deaths and complications due to pregnancy, and to reduce infant mortality due to prematurity.

- **Public Law 111–148 – Patient Protection and Affordable Care Act**
  - Section 2703, (h) (4) health home services – (iii) comprehensive transitional care, including appropriate follow-up from inpatient to other settings, (iv) patient and family support, (v) referral to community and social support services, if relevant.
Colorado Premature and Late Premature Infants: Did You Know?

- Approximately 7,000 preterm infants are born in Colorado every year.
- Preterm infants may be born to any mother, but are more likely to be born to mothers who experience health disparities in accessing health care services.
- Preterm infants are more likely to re-admitted to the hospital after discharge and require additional community support services resulting in increased health and educational costs.
- Preterm infants and late preterm infants have more regulatory problems due to their medical fragility and that result in hospital re-admissions and challenges for their parents.
Meaning of:

- Crying
- Sleeping
- Eating/feeding

“…crying, feeding and sleeping problems indicate shared difficulties of the infant to regulate or inhibit ongoing behavior, expressed in difficulties to self-soothe, fall asleep unaided, or to overcome neophobia to try new foods”

Schmid, et al., 2011

Slide and information provided by Joy Browne
Persistent crying, sleeping and eating problems in infancy predict
- Cognitive outcomes
- Behavioral outcomes
- Mental health outcomes

The risk is higher when an infant is dysregulated in more than one area

The earlier born children were more likely to have multiple dysregulatory problems

Feeding contributes substantially to the overall dysregulation.
Support is Needed for Parents to Enable Them to Care for Their Infant

Parents have the most significant impact on the child’s outcome once home. They provide:

- The essential environments in which infants grow
- The constant relationship in their child’s life
- Regulation through relationships and caregiving

Parents help the infant regulate:

- Bio-physical processes (temperature, heart rate, and respirations)
- Arousal and sleep
- Body movements
- Interaction with others
- Eating
- Self soothing

Slide and information provided by Joy Browne
Heckman, 2009 Economics and Human Biology 7, 1–6
The Antenatal Investment Hypothesis

Slide and information provided by Joy Browne
An Ecobiodevelopmental Framework for Early Childhood Policies and Programs

Policy and Program Levers for Innovation
- Primary Health Care
- Public Health
- Child Care and Early Education
- Child Welfare
- Early Intervention
- Family Economic Stability
- Community Development
- Private Sector Actions

Caregiver and Community Capacities
- Time and Commitment
- Financial, Psychological, and Institutional Resources
- Skills and Knowledge

Foundations of Healthy Development
- Stable, Responsive Relationships
- Safe, Supportive Environments
- Appropriate Nutrition

Biology of Health and Development
- Cumulative Over Time
  - Gene-Environment Interaction
  - Physiological Adaptations or Disruptions
  - Embedded During Sensitive Periods

Outcomes in Lifelong Well-Being
- Health-Related Behaviors
- Educational Achievement and Economic Productivity
- Physical and Mental Health

Ecology

Biology

Health and Development
Key Stakeholder Premature Infant Summit Overview

Purpose:
To provide recommendations to optimize the health and developmental outcomes of premature and late premature infants through systems of care that support the medical home approach and have the potential to reduce related health care system costs in Colorado.
Planning Committee

- Colorado Department of Public Health and Environment (CDPHE)
  - Maternal and Child Health (MCH) Health Care Program for Children with Special Needs (HCP)
  - Denver – (HCP)
  - Tri–County Health Department – HCP
- Children’s Hospital Colorado – HCP Liaison
- Special Kids, Special Care, Inc
- Family Medicine and Pediatric Genetics University of Colorado

Support from MedImmune Advocacy
Participants

- Colorado Academy of Pediatrics (AAP)
- Colorado Academy of Family Physicians (CAFP)
- Colorado Children’s Campaign
- Colorado Rural Health Centers
- Colorado Trust
- CDPHE – MPH
- Early Childhood Councils/Lt. Governor’s Office
- Early Intervention Colorado
- Family Voices
- JFK Partners, University of Colorado
- Health Care Policy and Finance
- Pediatric Leadership Council
- Perinatal Care Council
- WONDERBabies
Tool Kit for the Follow Up of Premature Infants

http://www.nichq.org/resources/Premature_Infant_FollowUp_Toolkit.html

- **Goal:** help improve the care and outcomes of premature infants.

- **Purpose:** to assist in the transition of the premature infant from hospital to outpatient care, to facilitate accurate transfer of pertinent patient information and to help provide evidence-based practical measures for consideration in the care of the premature infant.
  - A multidisciplinary, electronic, interactive toolkit with a web-based interface developed over the 5 years with NICHQ and MedImmune.
Provides age-specific information about the unique needs of premature infants, birth to 12 months (corrected age)

Intended to provide a resource and facilitate the care of the premature infant by general pediatric and family physicians and other health care providers.
Follow-up Care of the Premature Infant: Discharge Checklist

Immunization History

<table>
<thead>
<tr>
<th>Date(s) 1</th>
<th>Hep B</th>
<th>DTaP</th>
<th>IPV</th>
<th>Hb</th>
<th>PCV</th>
<th>Rotavirus</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Risk Assessment for Severe RSV Disease

<table>
<thead>
<tr>
<th>High Risk for Severe RSV Disease</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>RSV Qualification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prematurity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CLD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Screening

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Date</th>
</tr>
</thead>
</table>

Feeding and Medication

<table>
<thead>
<tr>
<th>Breastfeeding</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Express Breastmilk by Bottle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formula</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gavage</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volume per Feeding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Iron</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elemental Iron Dose (mg/kg/day)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamins</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caloric Supplements</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount</td>
<td></td>
<td>Cal / oz</td>
</tr>
</tbody>
</table>

Medication

<table>
<thead>
<tr>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
</table>

Discharge Diagnoses

Referrals / Follow-up Appointments

<table>
<thead>
<tr>
<th>Referral / Follow-up</th>
<th>Date</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Pediatrician</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identified Physician Specialist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visiting Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ophthalmology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical / Occupational Therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lactation Consultant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Intervention Program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial / Insurance Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This form is not intended to be a comprehensive list of all patient information. Information or evaluations not included or addressed in this form should always be considered. This form is not intended to be a substitute for the independent clinical judgment of the healthcare provider. Healthcare providers completing the form are ultimately responsible for ensuring the accuracy of the medical documentation for individual patients.

CONFIDENTIAL: This form is intended for internal use only. This form may contain individually identifiable health information and is therefore subject to all applicable privacy laws and regulations.

© 2012 Medimmune 10529-22462 This Toolkit was created by Medimmune in collaboration with the National Initiative for Children's Healthcare Quality (NICHQ)
Action Items from the Summit

1. Disseminate the Tool Kit to health care providers in Colorado
2. Develop a data system about infants and toddlers with special health care needs
3. Develop educational programs for health professionals regarding the needs of premature and high risk infants
4. Increase awareness of the needs of premature/high risk infants and their families through policy development
5. Develop and disseminate parent supports.
6. Follow-up with participants on progress towards Action Items
NICHQ Neonatal Improvement Project
(National Institute for Children’s Healthcare Quality)

- Maternal Risk Reduction
- Antenatal Practices
- Immediate Postnatal Practices
- Neonatal Intensive Care Unit Practices
  - Intervention # 8  Coordinating NICU discharge planning
  - Intervention # 9 Optimizing follow-up care of high-risk infants.
Intervention # 8 – Coordinating NICU discharge planning

• Involve families in defining planning and coordinating ongoing evaluative and preventive care in the process of establishing a medical home outside of the NICU.

• Provide written and oral communication of follow-up instructions to families at discharge. Assess family understanding: including understanding of the need for continued care.

• Increase communication between discharge team and accepting community organizations (e.g. Pediatrician in the community, level II nursery, MCH Coordinator, LCSW, EIP) to ensure optimal follow-up care of infant.

• Identify specific community resources for the families including resources required to resolve outstanding health care issues at the time of discharge.
NICHQ Neonatal Improvement Project
(National Institute for Children’s Healthcare Quality)

✓ Intervention # 9 – Optimizing follow-up care of high-risk infants
  • Increase communication between discharge team and accepting community organization
  • Increase communication between discharge team and accepting community organizations (e.g. Pediatrician in the community, level II nursery, MCH Coordinator, LCSW, EIP) to ensure optimal follow-up care of infant.
  • Adopt quality of care indicators for the neuro-developmental follow-up of (< 1500 grams) children.
  • Ensure a process for developmental surveillance and screening. Develop or adopt a system within the NICU to monitor and report follow-up rate and developmental outcomes.
  • Align billing/reimbursement to encourage follow-up services.
Current Colorado Efforts

- **State Wide Efforts**
  - Summit Action Items and Follow Up – Tool Kit dissemination; parent support development; Interdisciplinary Institute (2013)
  - Special Kids, Special Care 501(c)3 – fundraising efforts to provide innovative health support services for families of premature and high-risk infants and toddlers.

- **Local Health Department Efforts**
  - Tri–county – Special Infant Project (SIP) HV by PHN’s
  - Boulder – surveillance for premature infants
  - Larimer – hospital contract with HCP for referrals

- **Early Intervention Colorado**
  - Adams County – North Metro Premature Infant Project – special training for EIC providers who see premature infants through EIC
Action Items from the Summit Questions

1. Disseminate the Tool Kit
2. Development data system for identification/ tracking
3. Develop educational programs for health care professionals
4. Develop supportive state wide policy for families
5. Develop parent supports systems after discharge
6. Action Item Follow-up with Key Stakeholders
Where are the opportunities for alignment with the Premature Infant Summit Action Items identified and the Colorado Perinatal Care Council?
Thank you

- Dr. Peter Hulac
- Colorado Perinatal Care Council
Contact Information

Jane Gerberding, RN, BSN
Nurse Consultant
Colorado Department of Public Health and Environment
Children with Special Health Care Needs Program
Phone: 303-692-2024
E-mail: jane.gerberding@state.co.us

Barbara Deloian, PhD, RN, CPNP, IBCLC
President/CEO
Special Kids, Special Care Inc
Phone: 720-480-5367
E-mail: bdeloian@earthlink.net