Supporting Medically Fragile Infants Transition from the NICU to a Medical Home
October 25, 2012
Jane Gerberding
Barbara Delolan

Objectives
➢ Describe Colorado’s premature, late premature, and medically at risk infant population.
➢ Review the Actions Steps that have been identified by the Colorado Key Stakeholder Premature Infant Summit in May 2012.
➢ Describe several local implementation efforts that support premature and medically fragile infant’s transition from the NICU to a medical home, including their partners, challenges, and success.

Supporting a Medical Home Approach for the Premature and Medically Fragile Infant

Key Stakeholder Colorado Premature Infant Summit May 2012 and Summit Follow Up September 2012

Background and Action Steps

Colorado’s At Risk Infant Population

Every year 7,000 – 8,000 preterm, late preterm and low birth weight infants are born in Colorado

<table>
<thead>
<tr>
<th>Preterm Births (&lt;= 37 Weeks Gestation)</th>
<th>Low Birth Weight (LBW) Births (&lt;= 2500 grams)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black Infants (17.1%)</td>
<td>Black Infants (13.5%)</td>
</tr>
<tr>
<td>Native American Infants (13.6%)</td>
<td>Asian/Pacific Islander (8.5%)</td>
</tr>
<tr>
<td>Hispanic Infants (11.8%)</td>
<td>Native American Infants (7.6%)</td>
</tr>
<tr>
<td>Asian/Pacific Islander (10.7%)</td>
<td>White Infants (7.1%)</td>
</tr>
<tr>
<td>White Infants (10.9%)</td>
<td>Hispanic Infants (7.9%)</td>
</tr>
</tbody>
</table>

Source: NVS Preliminary Report 2011
Preterm infants may be born to any mother, but they are more likely to be born to mothers who experience unintended pregnancies and health disparities.

- Health disparities include poverty, single motherhood, mothers less than 20 years, unintended pregnancy, and lack of prenatal care.
- Health risks associated with a preterm birth do not resolve with the birth of the baby. Interventions after the birth of a baby are needed to reduce the chance of a second premature birth.

30% of women who have an unintended pregnancy will have a 2nd unintended pregnancy, and 70% of women with a second unintended pregnancy will have a 3rd unintended pregnancy.

Interventions after the birth of a baby are needed to reduce the chance of a second premature birth.

Source: Institute of Medicine of the National Academies. Preterm Birth: Causes, Consequences, and Prevention

Preterm and late preterm infants (32 – 37 weeks gestational age) costs are greater because they are more likely to be re-admitted to the hospital after discharge and require additional community supports.

- The cost of preterm and LBW births averages $58,000 compared with average term infant cost of $4,300.
- Late preterm infants account for about 75% of all preterm infants and have a higher rate of re-hospitalization than term infants resulting in higher overall costs.
- Strategies for reducing morbidity and associated costs are needed because the costs for health care persist throughout the first year of life and these costs are not appreciated.
- The Institute of Medicine estimates that the total cost to the US for infants born prematurely is 26 billion dollars.

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

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
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 501(c) 3
- 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

**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 and vetted by the AAP and AAFP.

**Includes 6 sections:**
- Introduction
- Discharge Planning
- Outpatient Follow-up Care
- Parent/Caregiver Information
- Tools
- Resources

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.

http://www.nichq.org/resources/Premature_Infant_FollowUp_Toolkit.html
1. Disseminate Best Practices to healthcare providers in Colorado
   - Disseminate the Tool Kit for the Follow Up of Premature Infants
     http://www.nichq.org/resources/Premature_Infant_FollowUp_Toolkit.html

2. Develop Health Professional Educational Programs regarding the needs of premature and high-risk infants
3. Develop and Disseminate Parent Support strategies and tools
4. Increase Awareness through Health Policy of the needs of premature, high-risk infants and their families
5. Develop a Data System about infants and toddlers with special health care needs

Intervention # 8 – Coordinating NICU discharge planning
- Involve families in defining planning and coordinating medical home outside of the NICU
- Provide written and oral communication of follow-up instructions at discharge
- Increase communication between discharge team and accepting community organizations
- Identify specific community resources for families including resources to resolve outstanding health care issues at the time of discharge

Intervention # 9 – Optimizing follow-up care of high-risk infants
- 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

Colorado Current State Wide Efforts
- Colorado Perinatal Care Council – presentation of the Premature Infant Summit and Action Steps in August 2012 by the CO Premature Infant/NICU Committee has resulted in a formal partnership through calendar year 2013.
- Premature Infants Summit Action Steps Follow Up Meeting – September 28, 2012
- Special Kids, Special Care 501(c)3 – fundraising efforts to provide Family Support Grants and Health Support Services for families of premature and high-risk infants and toddlers and support educational programs for health professionals
- Colorado Maternal Child Health 2011–2015 Nine Priorities alignment – Improve Perinatal Depression Screening #2 - Reduce Barriers to a Medical Home Approach #6
- Serving Families Impacted by Prenatal Substance Use – Dr. Kathryn Wells and Dr. Sharon Langendoefer

Premature Infant Summit Action Steps

Colorado Local Community Supports for Parents of Medically Fragile Infants
- Boulder County Public Health
- Mesa County Public Health
- Tri-County Public Health
- Kaiser Permanente – Perinatal Home Care Program and Care Coordination Program and
- Larimer County Public Health
- Others?
- Early Intervention Colorado (EIC)
- North Metro Community Services (Adams CO) – special training for EIC providers who see premature infants through EIC
- Developmental Pathways – contract for RN consultation for high-risk infants
Discussion

What other opportunities are available based on the Premature Infant Summit Action Steps and current Colorado efforts?

Thank you for coming

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