Key Stakeholder Colorado Premature Infant
And Follow Up Meeting:
Assuring Premature Infant Follow Up through a Medical Home
Summary and Report (10-24-12)

"Infants born preterm with low birth weight who require neonatal intensive care, experience a much higher rate of hospital readmission and death during the first year after birth compared with healthy term infants. Careful preparation for discharge and good follow-up after discharge may reduce these risks. It takes time for the family of a high-risk infant to prepare to care for their infant in a home setting and to obtain the necessary support services and mobilize community resources." American Academy of Pediatrics, Committee on Fetus and Newborn. Hospital discharge of the high-risk neonate. Pediatrics. 2008. 122(5): 1119.

We would like to acknowledge MedImmune Advocacy for support of the
Key Stakeholder Colorado Premature Infant Summit
Stakeholder Colorado Premature Infant Summit and Follow-Up Meeting:
Assuring Premature Infant Follow Up through a Medical Home

Summary

The Key Stakeholder Colorado Premature Infant Summit convened on May 18, 2012. Invited key stakeholders included participants from health policy, family organizations, physician provider organizations, health care, education, foundations, and community organizations connected with the Colorado Medical Home Initiative and/or the follow up needs of families of premature infants. Prior to the Summit, all participants were provided with the document *Colorado Premature and Late Premature Infants: Did you Know?* to assure their awareness of the data regarding the number of infants born prematurely in Colorado, their health issues, as well as the impact of prematurity on the family and health care system as a result re-hospitalization and ongoing health, support services, and educational needs.

The goal of the Summit was to "optimize the health and developmental outcomes of premature and high risk infants and their families by sharing best practices and systems of care that support the transition home from the NICU and hospital to the medical home and supportive community based services." A discussion was facilitated after three presentations that highlighted the needs of premature infants and their families. *The Toolkit for the Follow-Up Care of Premature Infants* was also presented as a resource to assure a smooth transition from hospital home and community. The facilitated discussion led to the identification of six priority areas with related Action Steps in each area. The priority areas include:

- **Disseminate Best Practice** including the *Toolkit for Follow-up Care of the Premature Infants* to identified provider organizations.
- **Develop and implement parent support services** for parents of premature infants and high risk infants
- **Increase availability and access to educational programs** for health care professionals regarding the needs of premature infants and high risk infants and their families
- **Develop connected data systems** to better understand the Colorado population of premature and high risk infants and their needs
- **Include the needs of premature and high risk infants and their families in policy discussion and decisions**
- **Follow up with the Summit Participants in 3 months regarding the progress of the Action Items**

On September 28, 2012 Key Stakeholders and additional key participants were brought back together for a Follow-Up Meeting to report on progress on the Action Steps. The major accomplishment reported was a partnership with the Colorado Perinatal Care Council to continue working together through calendar year 2013. Additional activities were identified for each of the Action Steps and are reported later in this report.
Key Stakeholder Colorado Premature Infant Summit and Follow-Up Meeting:
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Summary and Report

On May 18, 2012, the Colorado Department of Public Health (CDPHE), the Health Care Program for Children with Special Needs (HCP) and Special Kids, Special Care, a 501(c)3, convened the Key Stakeholder Colorado Premature Infant Summit: Assuring Premature Infant Follow Up through a Medical Home. The goal of this Summit was to "optimize the health and developmental outcomes of premature and high risk infants and their families by sharing best practices and systems of care that support the transition home from the NICU and hospital to the medical home and supportive community based services."

The need for the Summit arose out of the recognition among health care professionals and families of the unique needs of parents of premature and late premature infants that are not being addressed in current policies and priorities for Colorado families. In June of 2011, the Colorado Department of Public Health and Environment (CDPHE) Health Care Program for Children with Special Needs (HCP) staff brought together a committee representing public health, Children's Hospital Colorado, the University of Colorado, and Special Kids, Special Care to determine how to increase awareness and address the needs of Colorado families with premature and late premature infants after discharge home from the hospital. In January of 2012, a small grant was obtained from MedImmune Advocacy by Special Kids, Special Care to convene the Summit in May of 2012. The Planning Committee identified key stakeholders that represented health policy, families, physician provider organizations, health care providers and educators, foundations, and community organizations connected with the Colorado Medical Home Initiative and/or the follow up needs of families of premature infants. Prior to the Summit all participants were provided with the document Colorado Premature and Late Premature Infants: Did you Know? to assure their awareness of the data regarding the number of infants born prematurely in Colorado, their health issues, as well as the impact of prematurity on the family and health care system as a result re-hospitalization and ongoing health, support services, and educational needs.

Participants included:

Summit Objectives were to:

- Understand the causes of premature and late premature births, the impact of a preterm birth on the family after discharge, the costs of re-hospitalization, and the impact on health care and education costs after reviewing the Premature Infant Fact Sheet: Did You Know?
- Understand how a premature infant’s regulatory disorders influence the hospital to home transition for the family, re-hospitalization, and premature infant follow up needs.
- Discuss hospital discharge and follow up guidelines for premature infants by utilizing the Toolkit for Follow-Up Care of the Premature Infant.
- Prioritize next steps in meeting the follow up needs of premature and late premature infants and their families.
- Implement coordinated strategies to carry out the recommendations of the Key Stakeholder Premature Infant Summit.

Presentations at the Summit included:

- Coming Home from the NICU: A Parent Perspective – Amy Brunner, mother of Griffin
- Regulatory disorders that affect preterm infant outcomes: Re-hospitalization, growth, and development - Joy Browne, PhD
- Addressing Premature Infant Follow-Up Guidelines: Toolkit for Follow-up Care of the Premature Infant - Veena R. Kumar, MD, MPH
- Facilitated Discussion:

A facilitated group discussion led to the identification of priority next steps in meeting the needs of premature and late premature infants and their families as well as coordinated strategies to carry out the Summit recommendations. In addition, the terms Neonate and Infant and Toddler with Special Health Care Needs was introduced based on the 2007 White Paper by Browne and Deloian. As a result it was recognized that the more inclusive term premature or high risk infants would be the focus for the priorities and next steps.

Priorities, Next Steps, and Actions Identified Included:

- Dissemination of Best Practice such as the Toolkit for Follow-up Care of the Premature Infants.
  - Colorado Academy of Family Physicians will review and disseminate to their members
  - Rural Health organizations will explore working with AHEC to hold a Webinar on the Toolkit
  - Colorado AAP will explore dissemination of the Toolkit
  - Colorado Perinatal Council will explore sharing the Summit information and sharing of the Toolkit
  - Early Intervention Colorado will look further into how the Toolkit might be a resource for them
  - CDPHE Maternal and Children Health and HCP will disseminate the Toolkit to their HCP staff through a Webinar
  - Colorado NAPNAP (National Association of Pediatric Nurse Practitioners) will explore strategies for sharing information about the Toolkit.
Increase Parent Support Options and Access for Parents of Premature Infants
  - A small group will meet to explore available resources, identify needed resources, and develop new resources such as parent support groups
  - Reinstitute efforts to inform families and assist families in applying for SSI Disability while infants are in the NICU to avoid unnecessary extreme hospital bills
  - Develop a supplement for the Tool Kit to assure that financial needs and parental mental health needs are identified and addressed in primary care

Increase Availability and Access to Educational Programs for Health Professionals regarding the needs of premature and high risk infants and their families
  - Volunteers identified for the Planning Committee of the Colorado Fall Interdisciplinary Institute
  - Explore options to develop additional webinars on the health care needed by and challenges of premature infants and their families
  - Reach out to OB physicians and providers to engage them in educational efforts and collaboration to assure that families of premature infants are connected to needed services

Develop Connected Data Systems to better understand the Colorado population of premature and high risk infants and their needs
  - Explore strategies to connect different data systems available in Colorado so that data can be collected and analyzed on the status of premature and high risk infants
  - Revise and publish the 2007 White Paper by Browne and Deloian that introduced specific definitions of neonates with special health care needs and infants and toddlers with special health care needs the rationale for these definitions, available data on this population in Colorado, and specific recommendations for addressing the needs of this population

Include the Needs of Premature and High Risk Infants and their Families in Policy Decisions
  - Forward information about the Summit and the Toolkit to the Colorado Children’s Campaign staff
  - Include information about the needs of premature infants and their families in the Early Childhood Colorado yearly agenda
  - Request information about how other states are including the needs of premature infants and their families in their policy agendas

Follow up with the Summit Participants in 3 months regarding the progress of the Action Items
  - Volunteers identified to participant as a possible Steering Committee
  - A Summit Summary and Report will be sent out to the participants and made available on the CDPHE Website
Summary and Report

Action Steps Reported

1. FOLLOW UP WITH PARTICIPANTS ON ACTION STEPS
   - Follow Up Meeting – September 28, 2012

2. IDENTIFY AND DISSEMINATE BEST PRACTICES through the Tool Kit for the Follow Up of Premature Infants:
   - May 2012: Colorado Academy of Family Physicians
   - July 2012: Colorado National Assoc. of Pediatric Nurse Practitioners (NAPNAP)
   - September 2012: AWHONN and FRANN – Transition to Home and Follow Up for Preterm Infants - Exhibitor
   - October 2012: Riverton WY – Children’s Special Health MCH Educational Conference

3. DEVELOP HEALTH PROFESSIONAL EDUCATION PROGRAMS regarding the needs of premature and high risk infants
   - October 2012 – JFK HCP Webinar Series: NICU Follow Up
   - March 15, 2013 - Babies 101: Supporting Feeding, Sleep, and Consoling in Premature, Late Premature, and High Risk Infants – Joy Browne
   - Fall 2013 - Colorado Interdisciplinary Institute on Premature and High Risk Infants – pending funding support
   - Browne & Deloian White Paper Publication – In progress

4. DEVELOP AND DISSEMINATE PARENT SUPPORT strategies and tools
   - Collaboration with Denver Health and Hospital Systems on NICU – Home Parent Support System.
   - Explore Convening Colorado Grant from the Colorado Trust to convene 1 or more focus groups of parents of premature and high risk infants to inform and educate us about the types of supports and resources they would find most helpful as they transition home from the hospital.

Next Steps/Future Suggestions

1. FOLLOW UP WITH PARTICIPANTS ON THE ACTION STEPS
   - Include Additional Partners
     - Healthy Mothers, Healthy Babies – Helene Kent
     - Prenatal and Maternal state efforts/representation
     - March of Dimes (MOD)
     - Behavioral Health Organizations
     - AAP Legislative Committee representation

2. IDENTIFY AND DISSEMINATE BEST PRACTICES through the Tool Kit for the Follow Up of Premature Infants:
   - Include PCP’s in planning
   - Review billing code guidelines for screening,
   - Collaborate with ABCD on outreach
   - Identify gaps and barriers in obtaining services after risk assessment and Maternal Depression
   - Consents – develop consent for check off to allow better communication and collaboration among providers

3. DEVELOP HEALTH PROFESSIONAL EDUCATION PROGRAMS regarding the needs of premature and high risk infants
   - Find out what information do high school/college students receive about substance use and pregnancy, collaborate on PSA’s
   - Include educational opportunities on interviewing regarding maternal substance use and maternal depression and available resources.

4. DEVELOP AND DISSEMINATE PARENT SUPPORT strategies and tools
   - Identify evidenced based practice models
   - MOD has program for the NICU but not for after discharge
   - Hand to Hold (on line support services
   - Submit Convening Colorado Grant to develop Parent Focus Groups to inform systems efforts
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**Report Continued**

**Action Steps Reported**

5. **INCREASE AWARENESS THROUGH HEALTH POLICY** of the needs of premature/high risk infants and their families
   - Follow the Re-authorization of the Premature Infant Act -

6. **DEVELOP A DATA SYSTEM** about infants and toddlers with special health care needs. **Objective:** To develop comprehensive, coordinated systems of care for preterm and other high-risk infants in CO, we need to know more information about this population.
   **Goals:**
   1. Understand existing and needed data sources
   2. Empirically describe this population using existing (and new) data sources
   3. Develop a system to describe and monitor outcomes
   **Questions:**
   - What data systems exist to describe the epidemiology of high-risk infants? What are the strengths and limitations of each?
   - What are the medical, social, and developmental characteristics of high-risk infants in CO?
   - What is the health and/or developmental service utilization of this population? What are their long-term outcomes?
   **Progress**
   Contact with EI Colorado staff for fiscal accountability and data coordination to determine current available data:
   - Established conditions
   - Reason for referral and referral source
   - If IFSP was written and when
   - Types and duration of EI services family is receiving
   **Plans:**
   1. Data query in CO EI system to describe:
      A) medical and developmental characteristics of high-risk infants referred to EI
      B) Types and duration of EI services
   2. Explore other available data sets (e.g. Children’s Hospital)
   3. Determine meaningful outcomes and explore existing and new data sources to determine, for example (these are only suggested possibilities):
      A) short and long-term effectiveness of existing developmental services
      B) potential gaps in service delivery
      C) family perceptions and needs over time

**Next Steps/ Future Suggestions**

5. **INCREASE AWARENESS THROUGH HEALTH POLICY** of the needs of premature/high risk infants and their families
   - Evaluate pay for services – prevention and follow up
   - Pay for success
   - Human capital investment
   - Economic value for health care
   - Collect testimony from families
   - Document the cost of re-hospitalization
   - Denial of maternal health – access?

6. **DEVELOP A DATA SYSTEM** about infants and toddlers with special health care needs
   - Look at Kaiser data systems and outcomes for guidance
   - Consider using models for improving outcomes (e.g. seat belt use)
   - Use national models for improving outcomes (e.g. seat belt use)
   - EMR – look at maternal data on substance use and encourage consistent use of interview questions
   - Continue efforts of early identification across agencies, organizations, and systems (Dept of Ed, CDPHE, Dept HHS)
   - Link child health information as with the Immunization Registry
   - CDC and MCHB/MCH Colorado – what data is available from them on infant morbidity/mortality
   - Develop risk assessment criteria to be used – maternal and infant (see White Paper for Newborns and Infants/Toddlers
   - Explore web based data systems – e.g. Colorado Perinatal Care Council efforts w/ hospitals
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The Key Stakeholder Colorado Premature Infant Summit Planning Committee would like to thank the following organizations and agencies and individuals for their participation in the Summit.

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