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

Summit Summary and Report

"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 thank MedImmune Advocacy for support of the Key Stakeholder Colorado Premature Infant Summit
Key Stakeholder Colorado Premature Infant Summit
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 the *Toolkit for Follow-up Care of the Premature Infants* to identified provider organizations.
- Increase support options and access for parents of premature 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.

The Key Stakeholder Colorado Premature Infant Summit was supported by an event grant from MedImmune Advocacy
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On May 18, 2012, the Colorado Department of Public Health (CDPHE), the Health Care Program for Children with Special Needs (HCP) and 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 *Colorado Premature and Late Premature Infants: 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, PCNS-BC
- 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 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.
o 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
  o A small group will meet to explore available resources, identify needed resources, and develop new resources such as parent support groups.
  o 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.
  o 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 care professionals regarding the needs of premature infants and high risk infants and their families
  o Volunteers identified for the Planning Committee of the Colorado Fall Interdisciplinary Institute.
  o Explore options to develop additional webinars on the health care needed by and challenges of premature infants and their families.
  o 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
  o 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 infant.s
  o 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 needs of premature infants and their families in policy discussion and decisions
  o Forward information about the Summit and the Toolkit to the Colorado Children's Campaign staff.
  o Include information about the needs of premature infants and their families in the Early Childhood Colorado yearly agenda.
  o 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
  o Volunteers identified to participant as a possible Steering Committee
  o A Summit Summary and Report will be sent out to the participants and made available on the CDPHE Website.
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Participants
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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Attachment A – The Key Stakeholder Colorado Premature Infant Summit Action Items and Next Steps

Attachment B – Colorado Premature and Late Premature Infants: Did You Know?
# Key Stakeholder Colorado Premature Infant Summit

**Assuring Premature Infant Follow Up through a Medical Home**

**Actions Items and Next Steps**

<table>
<thead>
<tr>
<th>Summit Themes:</th>
<th>Action Items</th>
<th>Primary Contact Person Participants</th>
<th>Follow Up/Status</th>
</tr>
</thead>
</table>
| Summit Follow Up                          | 1. Report back to participants and Summit Planning Committee                                                                                                                                                  | Barbara Deloian  
Jane Gerberding  
Yvonne Kellar-Guenther   | Participants will receive a Summit Summary Report by the end of June and it will be posted to the CDPHE web site. Dissemination to others will be encouraged. |
|                                           | 2. Participate in future systems of care planning efforts based on recommendations of the Summit - Develop a planning/steering committee to follow up on the action items of the Summit | Jane Gerberding  
Barbara Deloian  
Ayelet Talmi  
Laura Pickler  
Beth McManus  
Norma Patterson  
Peter Hulac   | Due by about August 18, 2012                                                                                                                          |
|                                           | 3. Follow up after the with participants in about 3 months                                                                                                                                                   | Steering Committee                                                                                   | Resume effort of the original "Assuring a Medical Home for NICU Babies" workgroup/taskforce/steering committee                                     |
|                                           | 4. Identify lead in this initiative                                                                                                                                                                          | Jane West  
Christy Blakely  
Barbara Deloian  
Gina Robinson   |                                                                                                                                                    |
|                                           |                                                                                                                                                                                                             |                                                                                                     |                                                                                                                                                                                                            |
| Policy Development                        | 1. Forward information from the Summit and the Tool Kit to the Colorado Children's Campaign                                                                                                                  | Hanna Nichols                                                                                         | Jane Gerberding will follow up and ask them to put on yearly agenda                                                                                                                                |
|                                           | 2. Ask Lt. Gov/Early Childhood to place this on their yearly agenda                                                                                                                                          | Jane Gerberding                                                                                       |                                                                                                                                                                                                            |
|                                           | 3. Identify what other states are doing on behalf of premature and high risk infants                                                                                                                        | Angela McCoy  
Barbara Deloian                                                                                   | Barbara can survey NAPNAP members                                                                                                               |
| Development and Dissemination of Parent Supports | 1. Explore options to develop parent supports                                                                                                                                                                  | Jane West  
Christy Blakely  
Barbara Deloian  
Gina Robinson   | Jane West brought together Barbara and Christy for initial discussion on developing parent support groups.                                               |
<p>|                                           | 2. Assure families know about SSI                                                                                                                                                                             |                                                                                                     |                                                                                                                                                                                                            |
|                                           | 3. Develop resource for the Tool Kit about SSI for families                                                                                                                                                   |                                                                                                     |                                                                                                                                                                                                            |</p>
<table>
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<th>Follow Up/Status</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disseminate the Tool Kit for the Follow Up Care of Premature Infants</strong></td>
<td>1. Colorado Academy of Family Physicians will review and disseminate to members</td>
<td>Laura Pickler, MD, Chet Cedars, MD</td>
<td>Completed by 6/7/12. e-mail to members with a link to the Toolkit and explanation about use.</td>
</tr>
<tr>
<td></td>
<td>2. Coordinate with AHEC to hold a Webinar on the Tool Kit for rural health providers</td>
<td>Michelle Mills, Laura Pickler</td>
<td>Laura will talk with Jack Westfall AHEC Director, and Michele about Webinar. Question if it can be stored.</td>
</tr>
<tr>
<td></td>
<td>3. Colorado AAP – may disseminate but not sure now</td>
<td>Rachel Write, MD</td>
<td>Barbara will follow up with Rachel Write</td>
</tr>
<tr>
<td></td>
<td>4. Colorado Prenatal Council - presentation</td>
<td>Jane Gerberding, Peter Hulac</td>
<td>Jane has been asked to present in August 2012</td>
</tr>
<tr>
<td></td>
<td>5. MCH – HCP will hold a Webinar to disseminate to HCP staff</td>
<td>Rachel Hudson</td>
<td>Jane will work with Rachel</td>
</tr>
<tr>
<td></td>
<td>6. Share Tool Kit with EIC</td>
<td>Stacy Kennedy</td>
<td>To be confirmed</td>
</tr>
<tr>
<td></td>
<td>7. Share information about the Toolkit with Colorado NAPNAP</td>
<td>Barbara Deloian</td>
<td></td>
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| **Data System Development on Infants and Toddler with Special Health Care Needs** | 1. Develop data connections, collection, & analysis for description of infants with special health care needs and costs | Beth McMannus, Joy Browne, Barbara Deloian, Ayelet Talmi, Peter Hulac, MD, Rachel Write, MD | Barbara will follow up with Beth and Joy |
| | 2. Revise, publish, and disseminate the 2007 White Paper to establish a definition of Infants and Toddlers with special health care needs | | Barbara will follow up with Joy |

| **Health Care Professional Education and Engagement** | 1. Colorado Rocky Mt. Fall Institute on Infants Born at Risk | Barbara Deloian, Renee Charlifue-Smith, Beth McManus | Barbara will confirm Planning Committee, date, and corporate sponsors and community partners |
| | 2. Develop Webinars to share information on the health and development needs of premature and high risk infants | Barbara Deloian, Jane Gerberding, Laura Pickler, Michele Mills | Consider the development of Webinar on possible topics and available resources |
| | 3. Reach out to OB Docs to share available resources for families | Peter Hulac, Jane Gerberding, Barbara Deloian | Connection through the Perinatal Council Possible contact with Denver Health to engage OB physicians |
Every year 7,000–8,000 preterm, late-preterm, and low birth weight infants are born in Colorado.

- The percent of preterm births (births before 37 weeks gestation) in Colorado is highest for Black infants (17.1%), followed by Native Americans (13.6%), Hispanics (11.8%), Asians/Pacific Islander (10.7%), and Whites (10.9%). NVS Preliminary Report November 2011.
- The percent of low birth weight infants (<2500 grams) is highest for Black infants (13.5%), followed by Asian/Pacific Islander (8.5%), Native Americans (7.6%), Whites (7.1%), Hispanics (7.0%). NVS Preliminary Report November 2011.
- The United States Healthy People 2020 goal is to reduce preterm births to less than 9.6% of live births.

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 in accessing health care services.

- Premature births related to health disparities include poverty, single motherhood, mothers less than 20 years old, unintended pregnancy and lack of prenatal care.
- Interventions with mothers are needed after a baby’s birth that will reduce the chance of a second premature or low birth weight baby since the health risk factors associated with preterm births do not resolve with the birth of a baby. Health risks include history of a preterm birth or low birth weight baby, unintended pregnancy, infections, diabetes, obesity and hypertension as well as life style concerns such as smoking, alcohol, and drug abuse.
- In addition, thirty percent of women who have an unintended pregnancy will have a second unintended pregnancy and seventy percent of women with a second unintended pregnancy will have a third unintended pregnancy. Those with an unintended pregnancy are more likely to have preterm infants.

Preterm infants have more regulatory problems due to their medical fragility and neuro-developmental immaturity. This immaturity and physiologic disorganization results in re-admissions for jaundice, respiratory illnesses, and poor growth and feeding disorders.

- Neuro-developmental immaturity also results in increased irritability, crying, and disorganized sleep patterns causing greater challenges for parents. Long term, these regulatory problems frequently result in developmental delays and attachment relationship difficulties.
- Without parent support and anticipatory guidance regulatory disorders can affect preschool and school readiness.
- Mothers of premature infants experience more stress resulting in mental health issues such as depression and anxiety.
- Premature infants are often at greater risk for child abuse and neglect due to parent stress dealing with feeding and crying.

Preterm and late preterm infants (32 – 37 weeks gestation) are more likely to be re-admitted to the hospital after discharge and require additional community support and services.

- Premature infants have an increased need for health services due to complex medical conditions that include respiratory, neurologic, cardiac, gastrointestinal, and vision and hearing problems.
- The cost of preterm and low birth weight births averages $58,000.00 compared with the average term infant cost of $4,300.
- Late premature infants, who account for about 75% of all preterm births, have a greater rate of re-hospitalization and health care utilization resulting in an increase in total health care costs compared to term infants. Late preterm infant's re-hospitalization costs can range as high as $43,628.00 for respiratory failure even for late preterm infants hospitalized longer after birth. Strategies for reducing morbidity and associated costs are needed especially because these differences in health care costs persist throughout the first year of life. Unfortunately these costs are generally not appreciated.
- Premature infants also have an increased need for early intervention services due to developmental issues. Early intervention cost an estimated $611 million for this population with additional costs for special education services.
- The Institute of Medicine estimates that the total cost to the United States for infants born prematurely is 26 billion dollars a year.
References

**Articles:**


The Academy of Breastfeeding Medicine. ABM Clinical protocol #10 Breastfeeding the late preterm infant (34 0/7 to 36 6/7 weeks gestation (First Revision June 2011). *Breastfeeding Medicine.* 2011; 6(3): 151-156.


**Web Sites:**
