



NewSTEPS
A Partnership between The Colorado School of Public Health
and The Association of Public Health Laboratories™



Cystic Fibrosis Newborn Screening Quality Improvement & Timeliness Meeting

June 21-22, 2016



818 17TH Street Denver, CO 80202
303.607.9000

www.magnoliahotels.com



Welcome!

Background

Universal newborn screening for cystic fibrosis (CF) has been in place in the U.S. since January 2010, affording all children the opportunity for early diagnosis and intervention. However, significant variability exists in the implementation of CF newborn screening within each state, resulting in the median age of diagnosis ranging from 5 days of age to over 30 days of age, as reported to the Cystic Fibrosis Foundation (CFF) National Patient Registry. In parallel with decreasing age of diagnosis in the era of newborn screening, there is mounting evidence pointing to very early nutritional challenges in infants with CF. Specifically, the BONUS study, the largest, multicenter study of CF infant nutrition to date, has demonstrated that both weight and length in infants with CF is lower than their healthy counterparts for the first 12 months of life, with catch up occurring at 12 months for weight, but persistent stunting remaining at 12 months of age. Earlier intervention through *timely* newborn screening can result in improved linear growth in the first month of life, giving each infant the best opportunity for optimal lung growth and lung health.

To assist programs in improving NBS timeliness, NewSTEPS 360, a Health Resources and Services Administration (HRSA) funded initiative supports state newborn screening programs to improve timeliness in newborn screening through continuous quality improvement (CQI) technical assistance and financial means. The overarching goal of this project is to improve timeliness in newborn screening in support of the Advisory Committee on Heritable Disorders in Newborn and Children (ACHDNC) recommendations:

- 1) Presumptive positive results for time-critical conditions should be communicated immediately to the child's healthcare provider, but no later than the fifth (5) day of life.
- 2) All presumptive positive results for all other conditions should be communicated to the child's healthcare provider as soon as possible, but no later than seven (7) days of life.
- 3) All NBS results should be reported within seven (7) days of life.

NewSTEPS 360, in collaboration with the CFF, have proposed a Cystic Fibrosis Newborn Screening Timeliness Initiative with the goals of bringing together key stakeholders in CF newborn screening programs.

Meeting Purpose and Intended Audience

The purpose of this meeting is to convene CF center clinicians (physician, nurse), one laboratory specialist and one follow-up expert from each state who have significant experience with CF newborn screening, follow-up and treatment. This meeting will facilitate identification of strategies for implementation of quality improvement initiatives to assure timely newborn screening in cystic fibrosis through a partnership between CF Centers and state public health departments.

Meeting Objectives

1. Consider the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)'s recommendations on timeliness in newborn screening in the context of CF NBS quality improvement.
2. Understand data elements collected in national repositories pertaining to CF newborn screening.
3. Identify Quality Improvement initiatives in CF newborn screening.
4. Develop interactive state teams working collaboratively toward a uniform goal.



Tentative Meeting Agenda

All general sessions will be located in the Magnolia Ballroom at 817 17th Street (right across 17th St)
The Breakout sessions will be located in Larimer and Champa at the Magnolia Lounge Lower Level

Tuesday, June 21, 2016

7:30 am – 8:30 am	Breakfast & Registration <i>Hot breakfast provided at the Magnolia Lounge starting at 6:00 am</i>
8:30 am – 9:00 am	Welcome & Introductions <i>Marci Sontag, PhD & Sikha Singh, MHS, PMP</i>
9:00 am – 10:00 am	Timeliness in NBS and CF <i>Carol Johnson, RN & Susanna McColley, MD</i>
10:00 am – 10:30 am	Data Challenges <i>Marci Sontag, PhD</i>
10:30 am – 10:45 am	Morning Break
10:45 am – 11:45 am	Algorithm Breakout Session: Challenges & Goals <i>Yvonne Kellar-Guenther, PhD; Susanna McColley, MD; Suzanne Cordovado, PhD; Kathy Sabadosa, MPH; Marci Sontag, PhD; and Sarah McKasson, MPH</i>
11:45 am – 12:15 pm	Algorithm Challenges & Goals Report Out
12:15 pm – 1:15 pm	Lunch
1:15 pm – 1:45 pm	Overview of NewSTEPS 360 <i>Joshua Miller, MPH</i>
1:45 pm – 2:45 pm	State Success Stories in Improving Timeliness in NBS <ul style="list-style-type: none">• Education/Training (<i>Erica Wright, MSGC, Colorado</i>)• Courier System & Operating Hours (<i>Stan Berberich, PhD, Iowa</i>)• Health Information Technology (<i>Rachel Lee, PhD, Texas</i>)
2:45 pm – 3:00 pm	Afternoon Break
3:00 pm – 3:45 pm	State/Regional Breakout Session: Identify Problems in NBS Processes
3:45 pm – 4:15 pm	Improvements to Confirmatory Testing <i>Stacey Martiniano, MD</i>
4:15 pm – 4:45 pm	Parent Testimonial
4:45 pm – 5:00 pm	Wrap-up and Adjourn <i>Sikha Singh, MHS, PMP</i>

Wednesday, June 22, 2016

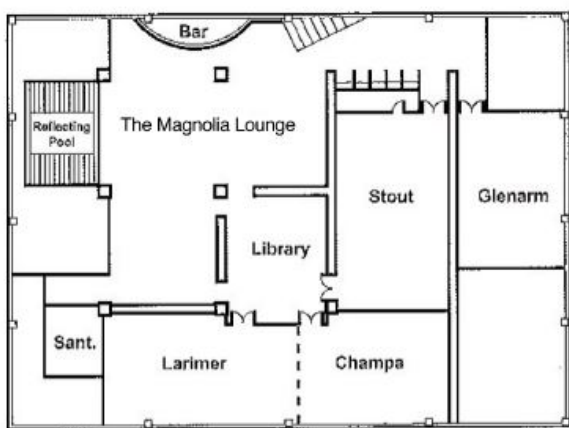
7:30 am – 8:30 am	Breakfast & Arrival <i>Hot breakfast provided at the Magnolia Lounge starting at 6:00 am</i>
8:30 am – 8:45 am	Welcome and State-Specific Solutions Summary <i>Marci Sontag, PhD and Sarah McKasson, MPH</i>
8:45 am – 9:45 am	Focus Area Breakout Session: NBS Quality Improvement Solutions <i>Marci Sontag, PhD; Yvonne Kellar-Guenther, PhD; Joshua Miller, MPH; Kathy Sabadosa, MPH; and Sikha Singh, MHS, PMP</i>
9:45 am – 10:15 am	Report out on NBS Quality Improvement
10:15 am – 10:30 am	Morning Break
10:30 am – 12:00 pm	State Model Practices in CF <ul style="list-style-type: none"> • One-screen state: Minnesota <ul style="list-style-type: none"> ○ Public Health (<i>Marc McCann, BA and Sandra Dewahl, MSCGC</i>) ○ Clinical (<i>Terri Laguna, MD, MSCS</i>) • Two-screen state: Colorado <ul style="list-style-type: none"> ○ Public Health (<i>Mark Dymerski</i>) ○ Clinical (<i>Edith Zemanick, MD, MSCS</i>) • NGS Successes in Wisconsin (<i>Mei Baker, PhD</i>)
12:00 pm – 12:30 pm	Choosing the Starting Point <i>Yvonne Kellar-Guenther, PhD</i>
12:30 pm – 1:30 pm	Working Lunch; Identifying the Plan of Action with State/Regional Teams
1:30 pm – 2:00 pm	Wrap-up & Review of Action Items <i>Marci Sontag, PhD</i>
2:00 pm	Meeting Adjourn

This event and all related activities are supported by a Cooperative Agreement (UG8MC28554) from the Health Resources and Services Administration (HRSA) with the Colorado School of Public Health in collaboration with the Association for Public Health Laboratories (APHL) and from a Newborn Quality Improvement Project Grant from the Cystic Fibrosis Foundation (SONTAG15QI0).

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Conference Center Map

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**The Magnolia Lounge
Lower Level**



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