

# Improving Timeliness in Newborn Screening: The Story Behind the Story

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**Babies  
SAVED!**



Providing Education



Implementing HIT Systems



**NBS Results  
Getting to Doctors  
FASTER**



Improving Lab Workflows



**State Labs  
Testing NBS  
Samples  
SOONER**



Increasing Lab Hours



Expanding Courier Services



**NBS Samples  
Collected  
EARLIER**

**NBS Samples  
Arriving to  
State Labs  
FASTER**



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

*Improving timeliness across the newborn screening (NBS) system to assure that more babies are saved. For more information, watch this [video](#).*

# Timely newborn screening is critical



**ASK AN EXPERT**  
Have a question that's not answered on Baby's First Test? Send it to our experts.


**ASK A QUESTION**

**Blog & News**  
FAMILY STORIES  
**A Mom's Public Comment to the SACHDNC**  
February 10, 2012 at 10:02pm by Kristine Brite McCormick | [comments](#)

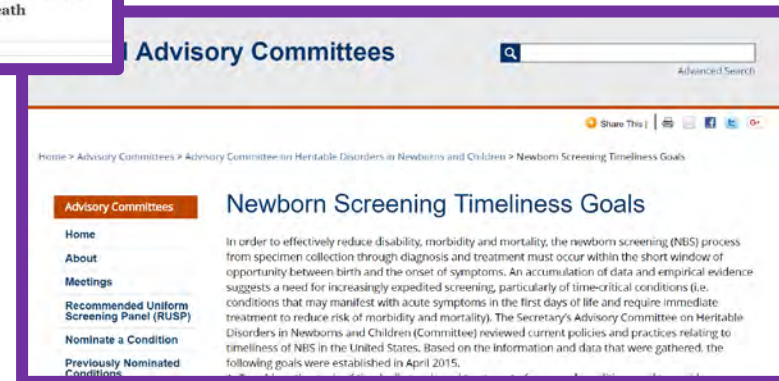
At each Secretary's Advisory Committee on Heritable Disorders in Newborns and Children meeting, there is an opportunity for members of the public to share their thoughts and experiences about **newborn screening**. This past January Ms. Kristine Brite McCormick, one of our **Challenge Award** recipients, was present to share the story of her



**Deadly Delays**  
The nation's newborn screening programs depend on speed and accuracy to save babies from rare... But thousands of lengthy lab tests, deadly delays are ignored and failures are hidden from public view — while babies and their families suffer.



**Delays at hospitals across the country undermine newborn screening programs, putting babies at risk of disability and death**  
By Ellen Gabler of the Journal Sentinel staff



**Advisory Committees**

Home > Advisory Committees > Advisory Committee on Heritable Disorders in Newborns and Children > Newborn Screening Timeliness Goals

**Advisory Committees**

- Home
- About
- Meetings
- Recommended Uniform Screening Panel (RUSP)
- Nominate a Condition
- Previously Nominated Conditions

### Newborn Screening Timeliness Goals

In order to effectively reduce disability, morbidity and mortality, the newborn screening (NBS) process from specimen collection through diagnosis and treatment must occur within the short window of opportunity between birth and the onset of symptoms. An accumulation of data and empirical evidence suggests a need for increasingly expedited screening, particularly of time-critical conditions (i.e. conditions that may manifest with acute symptoms in the first days of life and require immediate treatment to reduce risk of morbidity and mortality). The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (Committee) reviewed current policies and practices relating to timeliness of NBS in the United States. Based on the information and data that were gathered, the following goals were established in April 2015.

# Funding Opportunity

- Health Resources and Services Administration (HRSA), Maternal Child Health Bureau (MCHB), Genetic Services Branch
  - NBS Timeliness Mini CoIN (Collaborative Improvement and Innovation Network)
  - Timeliness Quality Improvement Initiative


# Timeliness Mini CoIN Overview

- Design
  - 2014-2015
  - Eight Programs Participated, 5 members on each team (including hospital representative)
  - No direct state funding
  - Continuous Quality Improvement (CQI) techniques and apply to local projects
  - Connection
    - One in person-meeting,
    - Monthly coaching calls
    - Monthly webinars
    - Focus on virtual engagement
  - Lessons learned that have broad applicability



# Newborn Screening Mini CoIN - Lessons Learned

Sondi from AZ



Number 6.  
Don't forget  
maintenance.  
Maintaining  
timeliness is just  
as hard as  
getting it to  
happen.

Video developed by programs participating in the CoIN Pilot Program

# Following up on success...



- HRSA Newborn Screening Timeliness Quality Improvement Initiative
  - Three years of funding
    - CQI Training
    - State Based Projects
  - Twenty-four programs encompassing 28 states were funded
  - Collaboration

# Each team chose their own focus area





# Improvements in timeliness!

- November 2017 presentation to ACHDNC highlighted interim success
- It takes a village.... of unsung heroes





# Unsung Superheroes



Save



Share



# Timeliness Toolkit for Expanding Newborn Screening Services

Laboratory Practice

Follow-Up

Policy

Timeliness

Toolkit

Model Practices

Educational Tools

## Introduction

The toolkit for expanding newborn screening services was developed by NewSTEPS 360, a collaboration between the Colorado School of Public Health (CoSPH) and the Association of Public Health Laboratories to support states to make improvements in their courier and newborn screening (NBS) laboratory operations. It is designed to assist state NBS programs, advocates, legal, and public health professionals to shape appropriate policies and communicate the value of weekend and holiday courier and laboratory operations in order to improve timeliness in newborn screening.



### Are you an NBS advocate?

We recommend you look at the Policy Guide (Section 2) and Communication Guide (Section 5) of this toolkit.

# Final 360 in person meeting: April 2018



- Networking
- Sharing ideas and solutions
- Skill-building
  - Budgeting
  - Building process maps
  - Story-telling

# Video production skill-building

- Dual purpose:
  - Inexpensive video production
  - Custom video to thank newborn screening professionals





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# Closing of meeting



# Thank You





# Acknowledgments

- Families involved in the video
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- NewSTEPs 360 Teams
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  - Association of Public Health Laboratories
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