



# Short Term Follow-Up Stakeholders Meeting Agenda

October 25-26, 2016

Hyatt Regency Orlando Airport Hotel

Orlando, FL



**NewSTEPS**

A Program of The Association of Public Health Laboratories®

## **This meeting is jointly sponsored by NewSTEPs and the Cystic Fibrosis Foundation**

### **About NewSTEPs:**

NewSTEPs (Newborn Screening Technical assistance and Evaluation Program) is a national newborn screening program designed to provide data, technical assistance, and training to newborn screening programs across the country and to assist states with quality improvement initiatives. NewSTEPs is a comprehensive resource center for state newborn screening programs and stakeholders.

### **About the Cystic Fibrosis Foundation:**

The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatment and ensuring access to high-quality, specialized care.

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## BACKGROUND

A critical component to the success of all newborn screening systems is ensuring that all infants receive appropriate testing and care. Short Term Follow-Up entails the process of ensuring that all newborns are screened, that an appropriate follow-up caregiver is informed of results, that confirmatory testing has been completed, that the newborn has received a diagnosis and, if necessary, treatment.

## PURPOSE

The purpose of this meeting is to convene newborn screening personnel involved with short- and long- term follow-up under the leadership of the NewSTEPs Short Term Follow-Up Workgroup. Participants will share solutions for short- and long- term follow-up newborn screening.

## OBJECTIVES

1. Provide input and offer expert guidance on challenges in follow-up
2. Identify Quality Improvement initiatives for follow-up
3. Develop a toolkit of solutions to common barriers identified

## CONTACT

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8:30–9:00 am	Arrival/Breakfast (Continental Ballroom 7 & 8)
9:00–10:30 am	Welcome and Introductions <ul style="list-style-type: none"><li>• <i>Jelili Ojodu, Association of Public Health Laboratories</i></li><li>• <i>John Thompson, Washington Newborn Screening Program Director</i></li><li>• <i>Carol Johnson, Iowa Newborn Screening Follow-Up Coordinator</i></li></ul> Meeting Overview and Ice Breaker: <i>John Thompson and Carol Johnson</i>
10:30 am–Noon	Keynote Addresses  Building a Learning Network: If you want to go fast, go alone; If you want to go far, go together <i>Kathryn Sabadosa, The Dartmouth Institute for Health Policy &amp; Clinical Practice</i>  The Critical Importance of Communication in Fostering Quality Short Term Follow-Up <ul style="list-style-type: none"><li>• <i>Jelili Ojodu, Association of Public Health Laboratories</i></li><li>• <i>John Thompson, Washington Newborn Screening Program Director</i></li><li>• <i>Carol Johnson, Iowa Newborn Screening Follow-Up Coordinator</i></li></ul> Strategies for Newborn Screening Communication Peter Deveaux, Infant Screening Coordinator, Winnie Palmer Hospital  Questions and Answers: Open Discussion
12:15–1:00 pm	Lunch (provided)
1:00–2:00 pm	False Negatives: Small Group Breakouts Many challenges are related to false negative results. Discussion will include ways to ascertain false negatives and strategies to reduce the number of false negatives.
2:00–2:15 pm	Report out of challenges and strategies for reduction of false negatives
2:15- 2:30 pm	Break
2:30- 4:00 pm	Co-Location of Laboratory and Follow-Up OR Funding Challenges: Small Group Breakouts <ul style="list-style-type: none"><li>• Co-Location Breakout: Discussion on benefits and challenges for various models</li><li>• Funding Challenges Breakout: Discussion of different funding structures and the unique challenges to ensure adequate funding.</li></ul>
4:00–4:40 pm	Report out of Challenges and Strategies from Co-Location and Funding Breakouts. <ul style="list-style-type: none"><li>• Lessons from Co-location groups</li><li>• Lessons from Funding groups</li></ul>
4:40- 5:00 pm	Wrap Up: John Thompson and Carol Johnson <ul style="list-style-type: none"><li>• Discussion</li><li>• Action Items</li><li>• Adjourn</li></ul>

## DAY 2

## AGENDA

7:00-8:00 am

Breakfast

8:00-8:30 am

Travel to Hyatt Regency Orlando Convention Center  
(transportation provided; meet in Hyatt Regency Airport lobby)

9:00 am–Noon

Participate in Cystic Fibrosis Quality Improvement Meeting  
(Hyatt Regency Orlando Convention Center)

Noon–1:00 pm

Lunch (provided)

Additional Challenges and Strategies for Short Term Follow-Up: Open Discussion

1:00-2:00 pm

What's Next? John Thompson and Carol Johnson

- Wrap Up and Action Items

2:00 pm

Adjourn

## RESOURCES

[www.newsteps.org](http://www.newsteps.org)

**Short Term Follow-Up Website:**

<https://www.newsteps.org/quality-practice-resources/short-term-follow>

**Short Term Follow-Up Bi-Monthly Technical Assistance Webinars:**

<https://www.newsteps.org/quality-practice-resources/stfu-technical-assistance-webinars#overlay-context=short-term-follow>

# NOTES

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