



NewSTEPS Short Term Follow-Up National Meeting Draft Agenda

May 12-13, 2020

Renaissance Seattle Hotel
515 Madison Street
Seattle, WA 98104



NewSTEPS

A Program of the Association of Public Health Laboratories™

This meeting is sponsored by the Association of Public Health Laboratories

About NewSTEPS

NewSTEPS (Newborn Screening Technical assistance and Evaluation Program) is a program of the Association of Public Health Laboratories in collaboration with the Colorado School of Public Health. It 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.

Consent to Use Photographic Images

Registration and attendance at or participation in APHL Meetings and other activities constitutes an agreement by the registrant to APHL's use and distribution (both now and in the future) of the registrant's or attendee's image or voice, without compensation, in photographs, videotapes, electronic reproductions and audiotapes of such events and activities.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number #U22MC24078 for \$1,500,000. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

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 national 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 follow-up newborn screening.

OBJECTIVES

1. Facilitate the building of cross-cutting partnerships to improve outcomes.
2. Provide input, guidance and technical assistance on follow-up in newborn screening.
3. Provide an arena in which follow-up staff can network and collaborate on quality improvement efforts.

CONTACT

Erin Darby, MPH, MCHES
Senior Specialist, NewSTEPs
Email: erin.darby@aphl.org
Phone: 240.485.3844

DAY 1

AGENDA

Tuesday, May 12

8:00 – 8:30 am

Arrival/Breakfast

8:30 – 9:30 am

Welcome and Introductory Remarks (Visions)

- Jelili Ojodu, Association of Public Health Laboratories (APHL)

Meeting Overview and Ice Breaker: John Thompson and Carol Johnson

- John Thompson, Washington Newborn Screening Program Director
- Carol Johnson, Iowa Newborn Screening Follow-Up Coordinator

9:30 – 1:00 pm

SESSION A: Parents Consortium (Visions)

Speakers and Moderators: TBD

1:00 – 2:00 pm

Lunch (provided)

Visit our Help Desk to explore the NewSTEPS website, Data Repository and update your state profile

2:00 – 3:00 pm

SESSION B: Introduction to Breakouts: Quality Assurance, Health Information Technology, Laboratory and Follow-Up Collaborations

3:00 – 4:30 pm

ROTATING ROUNDTABLES

- **Quality Assurance** (Visions)
Fran Altmaier, Arizona Department of Health Services and Carol Johnson, Iowa Department of Public Health
- **Health Information Technology** (Vista I)
Brendan Reilly, Texas Department of State Health Services and Amy Gaviglio, APHL
- **Laboratory and Follow-Up Collaborations** (Vista II)
Joe Orsini, New York Department of Health and John Thompson, Washington State Department of Health

4:30 – 5:00 pm

Day 1 Wrap Up and Adjourn

- John Thompson, Washington Newborn Screening Program Director
- Carol Johnson, Iowa Newborn Screening Follow-Up Coordinator

DAY 2

AGENDA

Wednesday, May 13

8:00 – 8:30 am

Breakfast

Visit our Help Desk to explore the NewSTEPS website, Data Repository and update your state profile

8:30 – 9:00 am

Welcome and Recap of Day 1 (Visions)

9:00 – 10:30 am

SESSION C: Data Partnerships and Data Systems (Visions)

Speaker: TBD

10:30 - 10:45 am

BREAK

10:45 - 12:00 pm

SESSION D: Internal Improvements within Newborn Screening Programs (Visions)

Speaker: TBD

12:00 – 1:30 pm

Working Lunch – Lessons Learned

Visit our Help Desk to explore the NewSTEPS website, Data Repository and update your state profile

1:30 – 2:00 pm

What Is Next? (Visions)

John Thompson and Carol Johnson

Wrap Up and Action Items

2:00 pm

Meeting Adjourn



VENUE MAP

Renaissance Seattle Hotel

