



Short Term Follow-Up Stakeholders Meeting Agenda

May 17-18, 2018

Bethesda North Marriott Hotel & Conference Center
5701 Marinelli Rd
Rockville, MD 20852



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.

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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 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 short- and long-term follow-up newborn screening.

OBJECTIVES

1. Provide input, guidance and technical assistance on follow-up in newborn screening.
2. Identify needs and offer technical assistance related to molecular literacy in short term follow-up.
3. Provide an arena in which follow-up staff can network and collaborate on quality improvement efforts.

CONTACT

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8:30 – 9:00 am	<p>Arrival/Breakfast</p>
9:00 – 10:00 am	<p>Welcome and Introductions (Brookside A&B)</p> <ul style="list-style-type: none"> • Jelili Ojodu, Association of Public Health Laboratories (APHL) • Andrea Matthews, Health Resources and Services Administration (HRSA) <p>Meeting Overview and Ice Breaker: John Thompson and Carol Johnson</p> <ul style="list-style-type: none"> • John Thompson, Washington Newborn Screening Program Director • Carol Johnson, Iowa Newborn Screening Follow-Up Coordinator
10:00 – 11:00 am	<p>Education: External (Brookside A&B)</p> <p>Natasha Bonhomme, Genetic Alliance</p> <ul style="list-style-type: none"> • Educating providers, families, and legislators • Existing educational tools • Needs assessment/gap analysis
11:00 am – 12:00 pm	<p>Education: Internal (Brookside A&B)</p> <p>State Spotlights</p> <ul style="list-style-type: none"> • Sharing Family Stories – Son-di Aponte & Fran Altmaier, Arizona • Integrating Laboratory and Follow-Up Staff – Christen Crews, Virginia • Hospital Staff Education Programs – Ashley Comer, Iowa
12:00 – 1:00 pm	<p>Lunch (provided)</p> <p><i>Visit our Help Desk to explore the NewSTEPS website, Data Repository and update your state profile</i></p>
1:00 – 3:00 pm	<p>Be Prepared!</p> <p>Skill Building Break Out Sessions Pick 2</p> <ul style="list-style-type: none"> • Emergency Planning: Continuity of Operations Plan (COOP) (Middlebrook) Christen Crews, Virginia & Jelili Ojodu, NewSTEPS <i>Attendees will discuss topics such as continuity of operations, finding a family in a disaster, and including your program in state emergency planning</i> • Stakeholder Education (Brookside A&B) Amy Gaviglio, Minnesota & John Thompson, Washington <i>Attendees will discuss topics such as teaching others how follow-up works, facilitating discussions about needed resources, ensuring adequate resources for full staffing, and working with families, family advocates, and legislators</i> • Preparing your Elevator Pitch (Timberlawn) Yvonne Kellar-Guenther NewSTEPS, & Carol Johnson, Iowa <i>Attendees will develop an elevator pitch for their program, prepare talking points, and learn how to promote short-term follow-up</i>
3:00 – 3:15 pm	<p>Break</p> <p><i>Visit our Help Desk to explore the NewSTEPS website, Data Repository and update your state profile</i></p>
3:15 – 5:00 pm	<p>Creating Program Standards and Systems Panel Discussion (Brookside A&B)</p> <ul style="list-style-type: none"> • Sara Denniston, Oregon - Standard Operating Procedures & Cross Training • Joyal Meyer, North Dakota - Hiring: Barriers and Successes • Cindy Ingham, Vermont - Succession Planning • Sarah Bradley, New York - Shadowing Programs
5:00 pm	<p>Day 1 Adjourn</p>



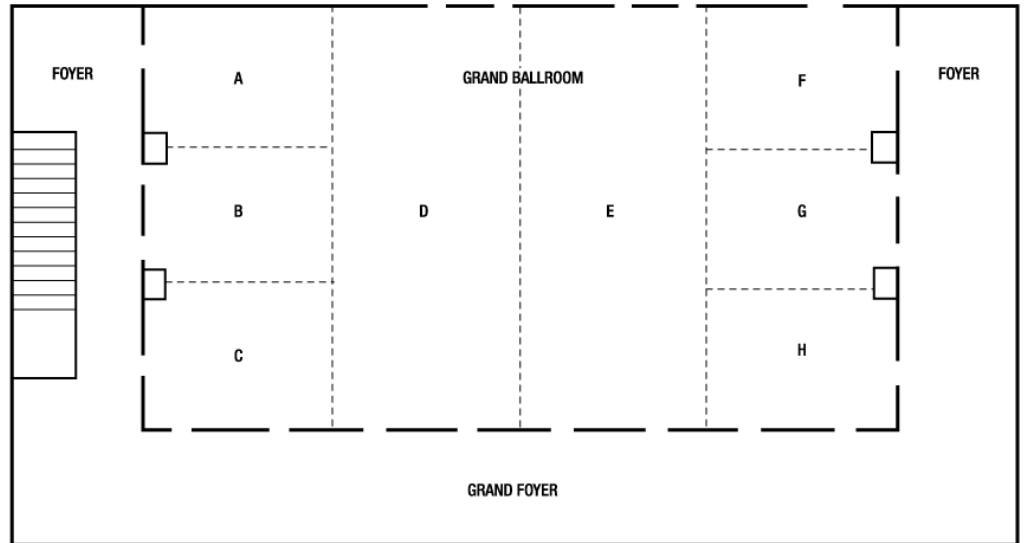
8:30 – 9:00 am	Breakfast <i>Visit our Help Desk to explore the NewSTEPS website, Data Repository and update your state profile</i>
9:00 – 10:00 am	Welcome – “Meet Me for 3” (Brookside A&B) Speed Meeting Icebreaker and Networking Activity
10:00 am– 12:00 pm	Choose Your Own Adventure! Roundtable Discussions Pick 2 <ul style="list-style-type: none">• Molecular Literacy (Brookside A&B: 10:00 am-11:00 am & 11:00 am-12:00 pm) <i>John Thompson, Washington</i> <i>Attendees will explore what resources are available for training follow-up staff in molecular techniques and interpretation of genetic testing results and identify what technical support is needed in the community</i>• Laboratory Information Management System (LIMS) User Groups (Forest Glen: 10:00 am-11:00 am) <i>Attendees will break out by user group (Neometrics, PerkinElmer, and other vendors or “home-brew” systems) to share how they use the systems to accomplish their daily work and program goals</i>• Size Matters: Program Size Challenges & Successes (Forest Glen: 11:00 am-12:00 pm) <i>Attendees will break out into groups based on program size to discuss challenges of small, medium, and large programs</i><ul style="list-style-type: none">○ <i>Small: Sarah Groeneveld, South Dakota</i>○ <i>Medium: Mary Kleyn, Michigan</i>○ <i>Large: Robin Thomas, California & Dusty Edwards, Florida</i>
12:00 – 1:30 pm	Working Lunch – Lessons Learned <i>Visit our Help Desk to explore the NewSTEPS website, Data Repository and update your state profile</i>
1:30 – 2:00 pm	What’s Next? John Thompson and Carol Johnson Wrap Up and Action Items
2:00 pm	Meeting Adjourn



VENUE MAP

Bethesda North Marriott Hotel & Conference Center

MAIN LEVEL



LOWER LEVEL

