



NewSTEPs New Disorders & Short Term Follow-Up National Meeting Agenda

August 25-26, 2021

Virtual



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. 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 event is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$1,500,000 with 0% financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

BACKGROUND

Pompe newborn screening was added to the Recommended Uniform Screening Panel (RUSP) in March 2015, X-Linked Adrenoleukodystrophy (X-ALD) and Mucopolysaccharidosis I (MPS I) were added in February 2016, and Spinal Muscular Atrophy (SMA) was added in July 2018. For the states that are looking to implement screening for these disorders and for other disorders that are on the horizon for RUSP nomination, such as Mucopolysaccharidosis type II (MPS II) and Guanidinoacetate methyltransferase deficiency (GAMT), newborn screening (NBS) programs may require resources and information to help improve their efficiency and expand the capacity of their laboratory and follow-up.

PURPOSE

To provide training and ideas to support NBS programs in improving efficiency, increasing knowledge, and expanding capacity.

OBJECTIVES

1. Discuss the current screening status of new and prospective disorders by illustrating state NBS experiences
2. Review tiered testing and its impact on timeliness
3. Describe new and evolving therapies for newborn screening disorders
4. Discuss strategies and identify tools to build the workforce and expand capacity for screening
5. Discuss navigating the legislative process and strategies for policymaking

CONTACT

Kshea Hale, MPH

Senior Specialist, NewSTEPS

Email: kshea.hale@aphl.org

Phone: 240-485-3842

Erin Darby, MPH, MCHES

Senior Specialist, NewSTEPS

Email: erin.darby@aphl.org

Phone: 240-485-3844

11:00 – 11:05 am

Welcome and Introductory Remarks

- Scott Becker, Association of Public Health Laboratories (APHL)
- Jelili Ojodu, Association of Public Health Laboratories (APHL)
- Mia Morrison, Health Resources & Services Administration (HRSA)

11:05 – 11:30 am

State of the States: New Disorder Newborn Screening

- Careema Yusuf, Association of Public Health Laboratories
- Amy Brower, American College of Medical Genetics and Genomics

11:30 am – 12:30 pm

Concurrent Session #1: An In-depth Look at New Disorders

* Participants will select a different Group each session. This session is for lab and follow-up staff.

Group A: RUSP LSDs- Pompe & MPS I

- Michelle Mills, Kansas Department of Health and Environment
- Christine Dorley, Tennessee Department of Health
- Amanda Ingram, Tennessee Department of Health
- George Dizikes, Tennessee Department of Health (Moderator)

Group B: Non-RUSP LSDs- MPS II and Krabbe

- Joe Orsini, New York State Department of Health
- Khaja Basheeruddin, Illinois Department of Public Health
- Joan Ehrhardt, Illinois Department of Public Health
- Patrick Hopkins, Missouri State Newborn Screening Program (Moderator)

Group C: Disorders recently added to the RUSP- X-ALD and SMA

- Rachel Lee, Texas Department of State Health Services
- Bill Hoffman, Washington State Newborn Screening Program
- Lani Culley, Washington State Newborn Screening Program
- Mei Baker, Wisconsin State Laboratory of Hygiene
- Debbie Freedenberg, Texas Department of State Health (Moderator)

Group D: On the Horizon- cCMV and GAMT

- Kim Hart, Utah Department of Health
- Jessica Dunn, Newborn Screening Ontario
- Amy Gaviglio, GTS Corporation (Moderator)

12:30 – 12:45 pm

Lunch Break

Visit our Virtual Booth (optional)



12:45 – 2:00 pm

Concurrent Session #2: An In-depth Look at New Disorders

* Participants will select a different Group each session. This session is for lab and follow-up staff.

Group A: RUSP LSDs- Pompe & MPS I

- Michelle Mills, Kansas Department of Health and Environment
- Christine Dorley, Tennessee Department of Health
- Amanda Ingham, Tennessee Department of Health
- George Dizikes, Tennessee Department of Health (Moderator)

Group B: Non-RUSP LSDs- MPS II and Krabbe

- Joe Orsini, New York State Department of Health
- Khaja Basheeruddin, Illinois Department of Public Health
- Joan Ehrhardt, Illinois Department of Public Health
- Patrick Hopkins, Missouri Sate Newborn Screening Program (Moderator)

Group C: Disorders recently added to the RUSP- X-ALD and SMA

- Rachel Lee, Texas Department of State Health Services
- Bill Hoffman, Washington State Newborn Screening Program
- Lani Culley, Washington State Newborn Screening Program
- Mei Baker, Wisconsin State Laboratory of Hygiene
- Debbie Freedenberg, Texas Department of State Health (Moderator)

Group D: On the Horizon- cCMV and GAMT

- Kim Hart, Utah Department of Health
- Jessica Dunn, Newborn Screening Ontario
- Amy Gaviglio, GTS Corporation (Moderator)

2:00 – 3:15 pm

Balancing Tiered Testing and Timeliness

- George Dizikes, Tennessee Department of Health
- Debbie Freedenberg, Texas Department of State Health
- Amy Calhoun- University of Iowa
- Patrick Hopkins, Missouri Sate Newborn Screening Program (Moderator)

3:15 – 4:20 pm

Molecular Education for Laboratory and Follow-up

- Rachel Lee, Texas Department of State Health Services
- Suzanne Cordovado, Centers for Disease Control and Prevention
- Amy Gaviglio, GTS Corporation
- Erin Darby, Association of Public Health Laboratories (Moderator)

4:20 pm

Adjourn



DRAFT AGENDA

Thursday, August 26

DAY 2

11:00 – 11:55 am

Growing and Building your Workforce

- Carol Johnson, Iowa Department of Health
- Adrienne Manning, Connecticut Newborn Screening Program
- Amy Gaviglio, GTS Corporation (Moderator)

11:55 am – 1:00 pm

New Disorder Legislation - Education Needs and Lessons Learned

- Susan Tanksley, Texas Department of State Health Services
- Peter Kyriacopoulos, Association of Public Health Laboratories
- Aaron Goldenberg, Case Western Reserve University (Moderator)

1:00 – 1:15 pm

Lunch Break

Visit our Virtual Booth (optional)

1:15 – 3:00 pm

Treatments and Therapies for Newborn Screening Conditions

- Jennifer Puck, University of California San Francisco
- Kathy Swoboda, Massachusetts General Hospital
- Priya S. Kishnani, Duke University Medical Center
- Paul Orchard, University of Minnesota
- George Dizikes, Tennessee Department of Health (Moderator)

3:00 pm

Adjourn

