



National Severe Combined Immunodeficiency (SCID) In-Person Meeting

August 8 – 9, 2017

Washington Marriott Georgetown
1221 22nd Street NW
Washington, DC 20037



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

Severe Combined Immunodeficiency (SCID) was added to the Recommended Uniform Screening Panel (RUSP) in May 2010. As of May 2017, 46 newborn screening (NBS) programs offer universal newborn screening for SCID and the remaining NBS programs continue to work towards full implementation. Supporting widespread adoption of early and accurate laboratory detection of SCID in newborns requires relationships with specialists in immunology and the development of clinical referral networks that can assist with follow-up and treatment.

PURPOSE

The purpose of this meeting is to convene SCID newborn screening stakeholders and to facilitate the strengthening of relationships between the SCID clinical network and the newborn screening community within each state. During this meeting participants will share solutions for SCID newborn screening implementation in order to support ongoing quality practices, quality data collection and interpretation across the United States. Participants will include representatives from state newborn screening laboratories, follow-up programs, and clinicians.

OBJECTIVES

- Provide input and offer expert guidance on implementation of SCID
- Share information on progress toward universal SCID newborn screening in the United States and discuss emerging challenges
- Identification of quality improvement initiatives in SCID newborn screening
- Development of interactive relationships between clinical and NBS program staff to facilitate collaboration
- Consideration of case definitions for SCID and the value of data reporting

CONTACT

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All general sessions will be located in The District.
The breakout session will be located on the same level in Quads 1-3.

8:30 – 9:00 am

Breakfast and Registration

9:00 – 9:45 am

Welcome, Introductions and Meeting Overview

- *Jelili Ojodu, MPH, NewSTEPS, Association of Public Health Laboratories*
- *Catharine Riley, PhD, MPH, Health Resources and Services Administration*
- *Marci Sontag, PhD, NewSTEPS, Colorado School of Public Health*
- *Ruthanne Sheller, MPH, NewSTEPS, Association of Public Health Laboratories*

9:45 – 10:05 am

From Birth through Follow-Up

- *Carol Johnson, Iowa Newborn Screening Follow-Up Program*

10:05 – 10:30 am

Newborn Screening for SCID in the Laboratory

- *Francis Lee, PhD, MSc, Centers for Disease Control and Prevention*

10:30 – 10:45 am

Break

10:45 – 11:00 am

Case Definitions

- *Marci Sontag, PhD, NewSTEPS, Colorado School of Public Health and*
- *Careema Yusuf, MPH, NewSTEPS, Association of Public Health Laboratories*

11:00 – 11:45 am

SCID Diagnosis

- *Jennifer Puck, MD, University of California San Francisco School of Medicine*

11:45 – 12:45 pm

Breakout Session: Challenges

12:45 – 1:45 pm

Lunch

1:45 – 2:30 pm

Report Out of Challenges

2:30 – 3:30 pm

Strengthening Clinical Referral Network

- *Lisa Kobrynski, MD, MPH, Emory University School of Medicine*

3:30 – 3:45 pm

Afternoon Break

3:45 – 5:00 pm

Looking to the Future of SCID Screening

- Multiplexing with Spinal Muscular Atrophy (SMA) Testing
 - *Mei Baker, MD, FACMG, Wisconsin State Laboratory of Hygiene*
- TREC/KREC Assay
 - *Carlos A. Saavedra-Matiz, MD, NYSDOH Wadsworth Center*
- Next Generation Sequencing in Newborn Screening for SCID in New York State
 - *Carlos A. Saavedra-Matiz, MD, NYSDOH Wadsworth Center*

5:00 – 5:15 pm

Wrap-up and Adjourn

- *Ruthanne Sheller, MPH, NewSTEPS, Association of Public Health Laboratories*

DAY 2

AGENDA

8:30 – 9:00 am

Breakfast and Arrivals

9:00 – 10:15 am

Case Presentations and Discussion

- *Susan E. Prockop, MD, Memorial Sloan Kettering Cancer Center*
- *Christine Seroogy, MD, University of Wisconsin, School of Medicine*
- *James Verbsky, MD, PhD, Medical College of Wisconsin*
- *Suzanne Skoda-Smith, MD, Seattle Children's Hospital*

10:15 – 10:30 am

Morning Break

10:30 – 11:10 am

Education

- *Jaclyn Seisman, MPH, Baby's First Test*
- *Lynn H. Albizo, Esq. and Jamie Sexton, Immune Deficiency Foundation*

11:10 – 12:00 pm

Long-Term Follow-Up

- *Charlotte Cunningham-Rundles, MD, PhD, Mount Sinai School of Medicine*
- *Tracey Bishop, BS, Genetic Disease Screening Program, California Department of Public Health*

12:00 – 1:30 pm

Networking Lunch; Identifying Next Steps with State/Regional Teams

1:30 pm

Meeting Adjourn