

Severe Combined Immunodeficiency (SCID) In-Person Meeting

Date: July 30-31, 2015

Location:

Bethesda North Marriott Hotel & Conference Center
5701 Marinelli Road
North Bethesda, MD 20852
(301) 822-9200

<http://www.marriott.com/hotels/travel/wasbn-bethesda-north-marriott-hotel-and-conference-center/>

Background:

Severe Combined Immunodeficiency (SCID) newborn screening was added to the Recommended Uniform Screening Panel (RUSP) in May 2010. The implementation of SCID screening at the state level has been steady and yet 20 states continue to face barriers to universal screening of SCID as of April 1, 2015. Current challenges faced by states newborn screening programs in implementing SCID screening include (1) integration of new technology within the lab, (2) laboratory staffing to conduct tests, (3) clinical follow-up capacity and resources, (4) funding for personnel, equipment, education, and (5) legislative or statutory approval. The goal of this meeting is to provide an open forum to discuss these challenges, share experiences, and identify strategies for moving all programs toward full SCID implementation.

Meeting Purpose and Intended Audience:

The purpose of this meeting is to convene Health Resources and Services Administration (HRSA) SCID grantees and non-grantees who support the implementation of new disorders added to RUSP, as well as pertinent partners and stakeholders who have significant experience with implementing SCID to screening panels in their respective jurisdictions.

Objectives:

1. Participants will provide input and offer expert guidance to attendees on implementation of SCID.
2. Identification of Quality Improvement initiatives for SCID implementation.
3. Development of key components of a strategic template consisting of model practices and quality improvement initiatives for implementation of new disorders within newborn screening programs.

Contact Person:

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Meeting Day 1	
Time	SCID In-Person Meeting Agenda
8:30 am - 9:00 am	Arrival and Continental Breakfast
9:00 am - 9:30 am	Welcome and Introductions: Jelili Ojodu, MPH <ul style="list-style-type: none"> Health Resources and Services Administration (HRSA) Welcome: Joan Scott, MS, CGC Overview of Meeting: Marci Sontag, PhD
9:30 am - 10:30 am	State of SCID NBS in the United States: Marci Sontag, PhD <ul style="list-style-type: none"> State of SCID Newborn Screening Looking to the Future Legislative Session: Lessons Learned from North Carolina: Scott J. Zimmerman, DrPH, MPH, HCLD (ABB)
10:30 am - 11:15 am	Challenges: Legislation/Approval/Fee Increases (small work groups)
11:15 am - 12:00 pm	Report out from small groups
12:00 pm - 1:00 pm	Lunch
1:00 pm - 2:30 pm	SCID Implementation Successes and Challenges Update <ul style="list-style-type: none"> Technology Overview, Centers for Disease Control and Prevention: Francis Lee, MSc, PhD Lessons from Wisconsin: Mei Baker, MD, FACMG Lessons from New York: Michele Caggana, ScD, FACMG Lessons from Massachusetts: Anne Comeau, PhD
2:30 pm - 3:15 pm	Challenges: Laboratory Interpretation and Short Term Follow-Up (small work groups)
3:15 pm - 3:30 pm	Break
3:30 pm - 4:15 pm	Report out from small groups
4:15 pm - 4:30 pm	Action Item Review and Wrap Up: Marci Sontag, PhD

Meeting Day 2	
Time	SCID In-Person Meeting Agenda
8:00 am - 8:30 am	Arrival and Continental Breakfast
8:30 am - 9:15 am	Family Perspective and Education <ul style="list-style-type: none"> Advocacy, Parent Perspective and Education, Genetic Alliance: Natasha Bonhomme Health Literacy, March of Dimes: Ed McCabe, MD, PhD Educational Resources, Immune Deficiency Foundation: Marcia Boyle, MS
9:15 am - 10:00 am	Challenges: Education/Information Dissemination (small work groups)
10:00 am - 10:15 am	Break
10:15 am - 10:45 am	Report out from small groups
10:45 am - 12:15pm	Clinical Management <ul style="list-style-type: none"> Clinical Manifestations of SCID: Lisa Kobrynski, MD, MPH Confirmatory Testing Following a Positive Diagnosis: Francisco Bonilla, MD PhD Treatment Plan: Rebecca Buckley, MD
12:15 pm - 12:45 pm	Parent and Community Engagement: Barbara Ballard
12:45 pm - 1:00 pm	Action Item Review and Wrap Up: Marci Sontag, PhD
1:00 pm - 2:00 pm	Lunch
2:00 pm	Adjourn