

SCID In-Person Meeting Presentations

Brief summaries of each of the presentations presented during the in-person Severe Combined Immunodeficiency (SCID) meeting of July 2015 are found below. The purpose of the meeting was to convene Health Resources and Services Administration (HRSA) SCID grantees and non-grantees who support the implementation of new disorders added to Recommended Uniform Screening Panel (RUSP), as well as pertinent partners and stakeholders who have significant experience with implementing SCID to screening panels in their respective jurisdictions.

The presenters are listed in order of appearance during the SCID in-person meeting. For additional details please contact Ruthanne.salsbury@aphl.org.

State of SCID NBS in the United States

Marci Sontag, PhD: [*Severe Combined Immunodeficiency Newborn Screening Implementation*](#)

Dr. Marci Sontag, Associate Director of NewSTEPS, reviewed the foundation for and progression of SCID newborn screening in the United States. Dr. Sontag stressed the value of entering SCID data in the [NewsSTEPS National Data Repository](#) for newborn screening.

Scott J. Zimmerman, DrPH, MPH, HCLD (ABB): [*“Legislative Session – SCID Implementation: Lessons Learned from North Carolina*](#)

Dr. Scott Zimmerman, State Laboratory Director of the North Carolina State Laboratory of Public Health (NCSLPH), discussed the history of testing at the NCSLPH. The challenges of implementing SCID newborn screening in North Carolina and possible solutions to these barriers were discussed.

SCID Implementation Successes and Challenges Update

Francis Lee, MSc, PhD: [*Newborn Screening for Severe Combined Immunodeficiency \(SCID\)*](#)

Dr. Francis Lee, Research Microbiologist at the Centers for Disease Control and Prevention, provided an overview of the technical and scientific support offered by the CDC including consultations, trainings and access to reference materials.

Mei Baker, MD, FACMG: [*SCID Implementation Successes and Challenges: Lessons from Wisconsin*](#)

Dr. Mei Baker, Co-Director of the Newborn Screening Laboratory at the Wisconsin State Laboratory of Hygiene (WSLH), discussed the timeline and progression of SCID newborn screening in Wisconsin.

Michele Caggana, ScD, FACMG: [*SCID Screening – Challenges are Inevitable*](#)

Dr. Michele Caggana, Director of the Wadsworth Center Newborn Screening Program, reviewed the history and progression of SCID newborn screening in New York.

Anne Comeau, ScD, FACMG: [*Newborn Screening for SCID: New England Update*](#)

Dr. Anne Comeau, Deputy Director of the New England Newborn Screening Program, provided recent statistics regarding SCID newborn screening in New England.

Family Perspective and Education

Natasha Bonhomme: [*Advocacy, Parent Perspectives, and Education*](#)

Ms. Natasha Bonhomme, Vice President of Strategic Development at Genetic Alliance, stressed the importance of grassroots and state level advocacy as well strategies for spreading awareness about newborn screening through social media, healthcare providers, trusted communities, etc.

Ed McCabe, MD, PhD: [*March of Dimes: Health Literacy, Advocacy, and Quality Improvement*](#)

Dr. Ed McCabe, Senior Vice President and Chief Medical Officer at the March of Dimes Foundation, provided an overview of the March of Dimes Foundation's educational resources, advocacy and government affairs and quality improvement initiatives.

Marcia Boyle, MS: [*Educational Resources*](#)

Ms. Marcia Boyle, President and Founder of the Immune Deficiency Foundation (IDF), presented an outline of the IDF's SCID Newborn Screening Campaign and reviewed the resources and services offered through the IDF. During this presentation, Ms. Boyle shared a [powerful video](#) recently produced by the IDF that highlights a success story and provides valuable tools to help others cope with the challenges of SCID.

Clinical Management

Lisa Kobrynski, MD, MPH: [*Severe Combined Immunodeficiency Clinical Manifestations*](#)

Dr. Lisa Kobrynski, Pediatric Allergy and Immunology Specialist at Children's Healthcare of Atlanta and Marcus Professor at the Emory University School of Medicine, provided an overview of the definitions and clinical presentations associated with SCID.

Francisco Bonilla, MD PhD: [*Confirmatory Testing Following a Positive SCID Newborn Screen*](#)

Dr. Francisco Bonilla, Allergy Immunology Specialist at Boston Children's Hospital and Associate Professor at Harvard Medical School, reviewed the various outcomes of SCID following an abnormal SCID newborn screen.

Rebecca Buckley, MD: [*SCID: Treatment Plan, Long-Term Outcomes, and Quality of Life Data*](#)

Dr. Rebecca Buckley, Allergy and Immunology Specialist, Pediatric Allergy and Immunology Specialist, Pediatric Bone Marrow Transplant Specialist, and Pediatric Medical Genetics Specialist at Duke University Medical Center, presented an overview of common characteristics, treatments, long-term outcomes and quality of life data for SCID as well addressed concerns for the future.

Parent and Community Engagement

Barbara Ballard: [*A Parent's Experience*](#)

Ms. Barbara Ballard, a parent advocate for SCID and member of the Immune Deficiency Foundation Board of Trustees, SCID Angels for Life Executive Board, and SCID Family Network (SCID.net), shared her personal experience, beginning with the birth of her son and continuing until present day. During her presentation, Ms. Ballard discussed the importance of early detection, complications and costs arising from late diagnosis, and resources available to families.

Action Item Review and Wrap Up

Marci Sontag, PhD: [*SCID National Conversation Summary*](#)

Dr. Marci Sontag, Associate Director of NewSTEPS, provided a summary of solution oriented themes discussed and reported out by small work groups throughout the meeting.