

# SCID National Conversation

July 30-31, 2015

Discussion Summary



**NewSTEPS**

A Program of the Association of Public Health Laboratories™

# Legislation/Approval/Fee Increases

## Solution Oriented Themes

Be proactive, not reactive

- Messaging: educate and engage state legislators early and often.
- Harness partnerships and utilize your champions
- Public Health Authority: ensure legislation is not limiting (include fee increases); create a role for PH in legislative process
- Perform pilot testing in tandem with lengthy rule-making process.

Appeal to  
Advocates/Partners

- Identify and engage collaborators who can advocate for you (APHL, MOD, IDF, JMF, AMCHP, ASTHO, BFT, etc.)
- Harness activities of APHL Legal and Legislative Issues in NBS Workgroup
- Relationship building using non-traditional approaches (social media)

Be Informed

- Know costs, resources, staffing, technology, workforce requirements associated with implementing NBS for disorder.
- Have an elevator speech- be able to share this information on NBS and disorder specific activities.
- Share resources (repository for model practices; don't reinvent the wheel)

# Laboratory

## Solution Oriented Themes

Garner broad support and limit duplication of efforts

- Share model practices (benefit from what other states have done)
- Encourage public health leadership to understand the unique functions of molecular NBS and associated LIMS requirements

Recognize Molecular Requirements

- Benefit from experiences of others in implementing unidirectional workflow, PCR, training, etc.
- Utilize APHL Molecular Assessment Program (MAP), Molecular workshops and associated resources, including CDC experts.
- Utilize NewSTEPS SCID Expert Evaluators: Caggana, Baker and Comeau
- Implement collection of quality indicators to review/track quality practices

Recognize unique challenges associated with low birth-weight and NICU Babies

- Low birth-weight, pre-term and transfused babies with low TREC numbers will benefit from unique solutions such as engaging in early dialogue with immunologists, perform period evaluation of cut-offs, perform flow cytometry in lieu of repeat screen, etc.
- Transfusion of packed red blood cells should not result impact screening results. The exceptions are following an exchange transfusion or after cardiac surgery.
- Recognize situations where newborns with congenital heart abnormalities or multiple congenital defects may not require additional screening/testing for SCID; contact physician to clarify clinical status.
- Understanding clinical scenario to characterize whether additional testing needs to be performed.

Ensure Timeliness and Laboratory Efficiencies

- Point of care testing to measure lymphocytes
- Efficiencies in workflow and considerations related to sharing space with other molecular programs; identifying creative solutions

# Short Term Follow-Up

## Solution Oriented Themes

Clarify path from screening to diagnosis	<ul style="list-style-type: none"><li>• Perform confirmatory testing within 24 hours</li><li>• Involve both laboratory and follow-up staff to develop a 'critical list' of items that need to be addressed that occur between laboratory and follow-up, but are necessary to confirm a diagnosis.*</li><li>• Develop a system of care prior to initiating SCID screening; this would be a centralized checklist.*</li></ul>
Ensure integrity of results and interpretation	<ul style="list-style-type: none"><li>• Setting and maintaining accurate cut-offs requires investing time to repeat tests and analyze assay results.</li><li>• Thresholds may vary between programs.</li></ul>
Develop processes to minimize False positives/False Negatives	<ul style="list-style-type: none"><li>• Clarify procedures/pathways for performing confirmatory testing.</li><li>• Maintain stringent controls; maintain contact information.</li><li>• Perform flow cytometry in lieu of repeat screen when first specimen is abnormal.</li></ul>
Continue conversation	<ul style="list-style-type: none"><li>• Forum needed for Short Term Follow-up staff (national SCID webinar topics dedicated to this).</li></ul>

\*Potential action item for NewSTEPS Short Term Follow Up workgroup

# Education and Information Dissemination

## Solution Oriented Themes

Know your audience	<ul style="list-style-type: none"><li>• Physicians receiving results following abnormal newborn screen</li><li>• Parents</li><li>• General pediatricians</li><li>• Public</li><li>• Translate scientific knowledge in an effective way</li></ul>
Don't reinvent the wheel	<ul style="list-style-type: none"><li>• Streamline</li><li>• Have a process (information sheets, check-lists, fact sheets, grand rounds)</li><li>• Use existing resources (NewSTEPs, Baby's First Test, Immune Deficiency Foundation, Jeffery Modell Foundation, ACMG ACT Sheets etc.)</li></ul>
Build relationships	<ul style="list-style-type: none"><li>• With hospitals</li><li>• Within rural areas (boots on the ground)</li></ul>
Assess NBS Literacy	<ul style="list-style-type: none"><li>• Identify vehicles to perform outreach and information dissemination, including face to face meetings and social media.</li><li>• Involve all stakeholders (advocacy and interest groups)</li><li>• Be cognizant of level of language and linguistic culture</li></ul>