



# Beyond the Bloodspot: Education and Engagement Summit

Presented to the Advisory Committee on Heritable  
Disorders in Newborns and Children  
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# Summit Task Force

- Pat Blake, *State Hygienic Laboratory at the University of Iowa*
- Jordann Coleman, *Family Member/Consumer Task Force Member*
- Siobhan Dolan, MD, MPH, *Albert Einstein College of Medicine*
- Amy Gaviglio, MS, LCGC, *Minnesota Department of Health*
- Aaron Goldenberg, PhD, MPH, *Case Western Reserve University*
- Carol Greene, MD, *University of Maryland*
- Stacy Hines-Dowell, DNP, AGN-BC, FNP-BC, *St. Jude Children's Research Hospital*
- Alex Kemper, MD, MPH, MS, *Nationwide Children's Hospital*
- Melanie Lockhart, *March of Dimes*
- Patrice Milos, PhD, *Medley Genomics*
- Michele Puryear, MD, PhD, *Parent Project Muscular Dystrophy*
- Louisa Stark, PhD, *Genetic Science Learning Center, University of Utah*
- Beth Tarini, MD, MS, FAAP, *University of Iowa*

*Special thanks to the 2017 cohort of Consumer Task Force members for serving as family leaders during the Summit*

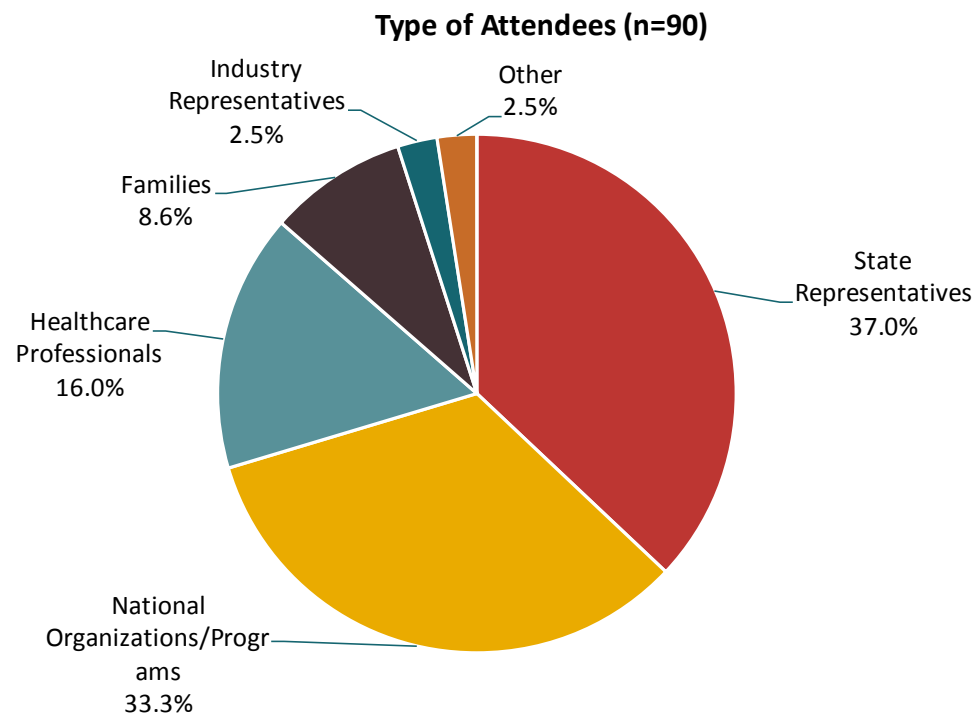
# Beyond *the* Bloodspot: Education and Engagement Summit

June 5 - 6, 2017



Washington, DC

- 107 registrants
- 90 attendees
- 30 representatives from 22 states
- At least one state from each of the seven regional genetics networks



# Organizational Representation

- American College of Nurse-Midwives
- American College of Medical Genetics and Genomics
- Association of Maternal and Child Health Programs
- Association of Public Health Laboratories
- Association of Women's Health, Obstetric, and Neonatal Nurses
- UNC Center for Maternal and Infant Health
- Family Voices National
- Health Resources and Services Administration
- March of Dimes
- Muscular Dystrophy Association
- North Carolina Healthy Start Foundation
- National Center for Education in Maternal and Child Health
- National Center for Hearing Assessment and Management
- National Society of Genetic Counselors
- Parent Project Muscular Dystrophy
- RTI International
- Text4baby/Zero to Three

# Goals of the Summit

- Identify and evaluate best practices to improve family and healthcare provider *understanding* of newborn screening
- Identify best practices to increase family and healthcare provider *involvement* in the newborn screening system
- *Evaluate* family and healthcare provider involvement in the newborn screening system



# Range of Topics

- Engaging families
- Priority/target populations
- Educating in a crisis
- Training and communications with healthcare providers
- Short-term follow-up
- Priority setting in education
- New disorders
- Best practices continuum
- NBS touchpoints (*awareness vs education vs training vs. engagement*)
- Access issues
- Privacy and autonomy in public health

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## Name of Workshop:

*Identify the why. Why does this matter? What is need, problem, or opportunity for improvement?*

*Identify the what. What is the potential best practice? What is the expected benefit or value of this practice?*

*Identify the who. Who is the target? Who are the stakeholder/partners that are/need to be involved?*

*Identify the how. How is it being implemented? How is it being evaluated?*





How does it fit within the continuum of best practices? \*

## Cutting Edge Practice

- Innovative solution to an evolving issue
- Aligns with experimental evidence inside and outside of field/public health
- Perceived benefit to target population
- Early signs of success and commitment to ongoing evaluation

## Emerging Practice

- Based on guidelines, protocols, standards or preferred practice patterns that have been proven to lead to effective outcomes
- Incorporates a process of continual quality improvement
- Accumulates and applies knowledge about what is working and not working in different situations/contexts
- Incorporates lessons learned, feedback and analysis to lead toward improvement in outcomes
- Has an evaluation in place but does not yet have evaluation data available to demonstrate positive outcomes

## Promising Practice

- Fulfills criteria of an emerging practice
- Strong quantitative data showing positive outcomes
- Strong qualitative data showing positive outcomes
- Does not yet have enough research of replication to support generalizable positive outcomes

## Best Practice

- Reviewed and substantiated by experts in the field
- Is replicable, and produces desirable results in a variety of settings
- Clearly links positive effects to the programs/practice being evaluated

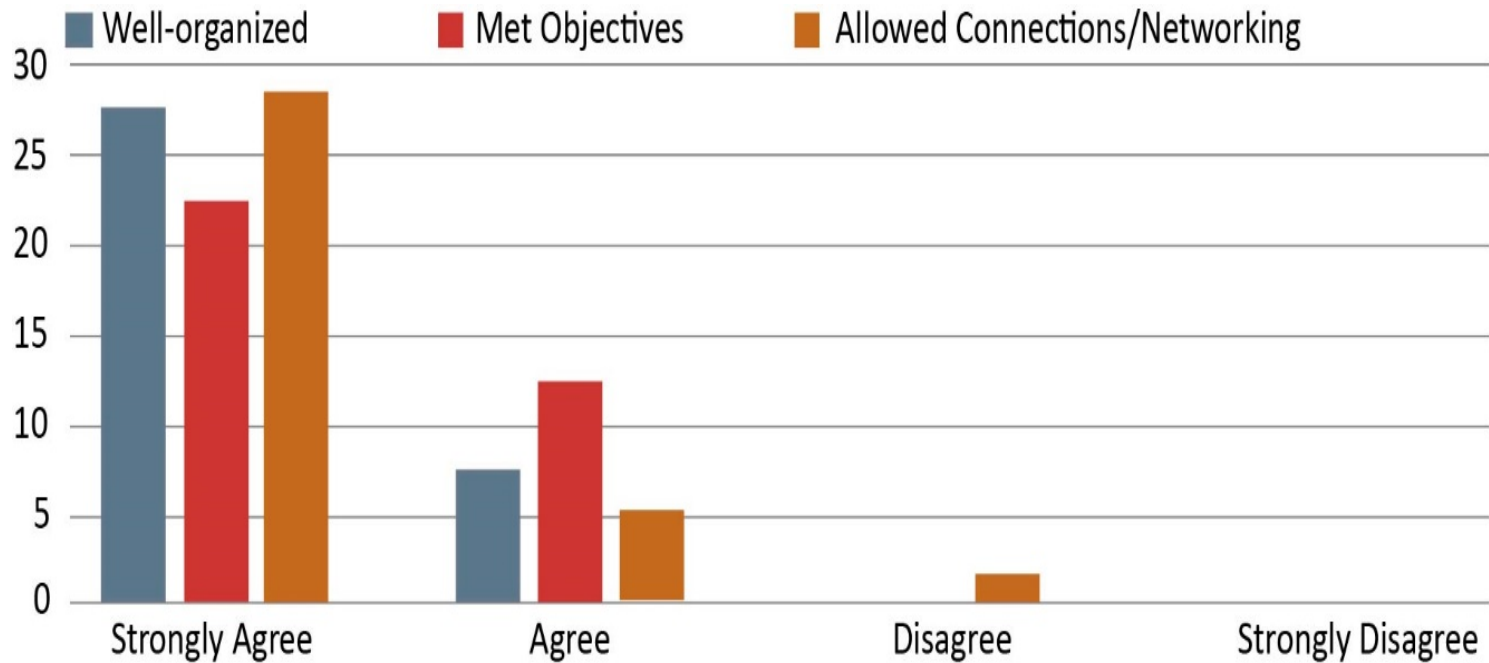
\*Association of Maternal & Child Health Programs (AMCHP). *AMCHP's Best Practices*. 2017.



# Attendee Response

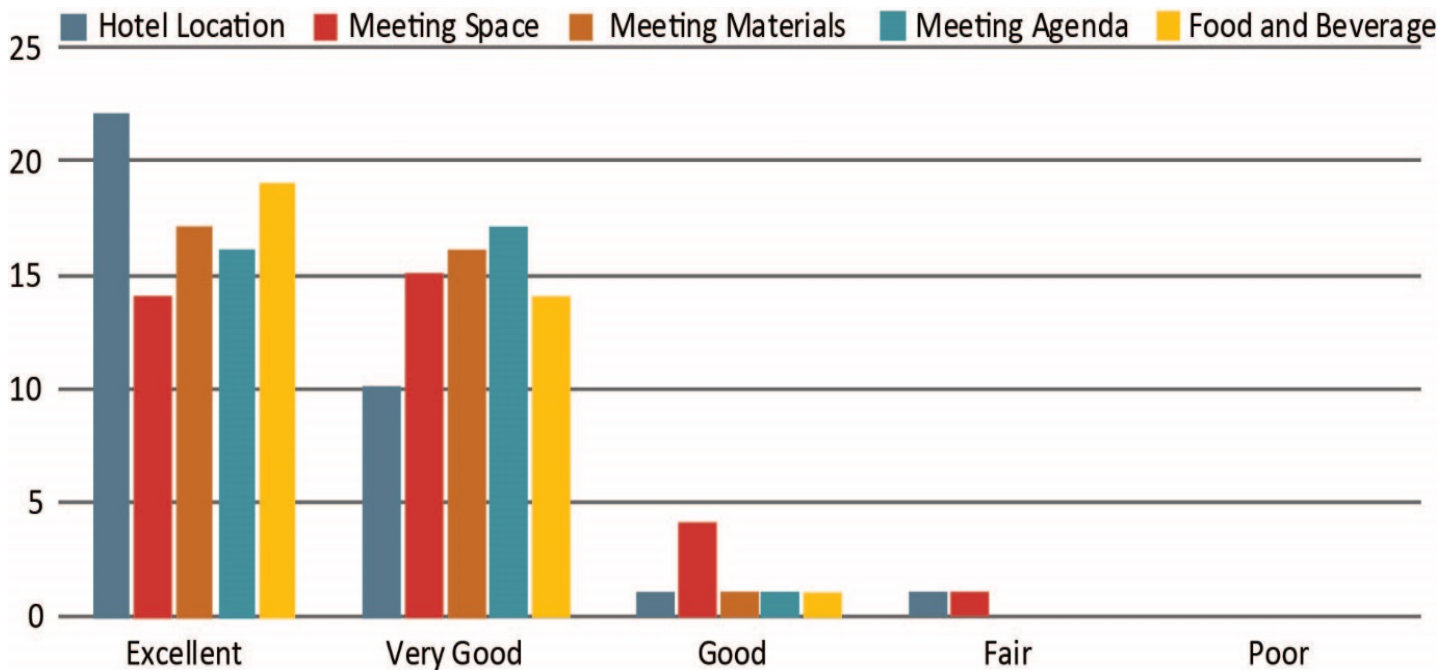
*“NBS people have not necessarily been taught to teach.”*

*— Summit attendee*



# Attendee Response

*“This was, hands down, one of the best conferences that I have attended—breadth, depth, expertise.” — Summit attendee*



# More Reactions

*“What I appreciated most was the mixture of people – the families were very powerful, and it was great to have them there alongside the state programs and clinicians.”*

*“The Summit helped me see what other potential partnerships are out there.”*

*“I hope there are more educational summits; I thought it was a great meeting and well organized/planned. Having other people there besides NBS staff was educational for NBS people.”*

*“NBS people have not necessarily been taught to teach.”*

*“It is heartwarming to see how seriously the Genetic Alliance takes the role of families.”*

*“Great summit. Thought provoking, educational and enlightening.”*



# Benefits of Summit

## **A focus on education**

*“...That it was focused on education and the challenges to not only identifying or producing material but the challenges faced on how to get these materials into the hands of the individuals who need them.”*

## **Ability to connect with diverse audiences**

*“Seeing the different groups (healthcare professionals, parents, policy advisors, newborn screening laboratory personnel, etc.) come together to discuss issues/concerns that impact the overall NBS process.”*

## **Networking**

*“It brought together individuals with very different experiences since everyone was from all areas around the country and from different NBS related backgrounds.”*



# Learning and Takeaways

## Attendees

- Benefits of education and its top challenges
- Effective communication strategies
- The different players in engagement/education and how they share the same goals

## Facilitators

- Involve target audiences in material development and evaluate materials
- Better equip providers to have discussions with families
- Connect with partners to conserve limited resources



# Behavior

*“[I have] more confidence in highlighting the importance of building up the education, training, engagement, and awareness efforts of the state program and therefore also prioritizing honing my skills in those activities.”*

*“I learned other methods to be a better advocate for my patients.”*

- **Confidence to make education and engagement an organizational priority**
- **Potential for connection and collaboration**
- **Better engagement of consumers in the development and evaluation of materials**

# Results

*“[Continue] to expand who is at the table for these discussions so that each program can have a voice, make progress, and be aware of efforts/ideas/activities... education always seems to take a back seat...”*

*“I hope there are more educational summits; I thought it was a great meeting and well organized/planned.”*

- **Primary theme was that the Summit served as a place to bring together diverse groups to connect and share**
- **Baby’s First Test was important as a point of connection for various stakeholders in education and engagement**
  - Provide more opportunities like the Summit
  - Develop more materials/resources
  - Technical assistance



# In Conclusion...

- Indicated tremendous need for resource and strategy sharing
- Increasing need for a process toward best practices/more guided approach to education
- Summit did not reach all its intended goals (i.e. identifying and evaluation best practices) but showcased a more accurate representation of where people are starting in education and engagement
- Summit provided a space for diverse groups to connect and share
- Summit inspired confidence in communicating the benefits and importance of education and engagement

# Summit Outcomes

- Summit Monograph
  - Information on educational and health communications models/frameworks
  - Concludes with Baby's First Test's Newborn Screening Educational Best Practices Framework
  - Designed and disseminated by December 2018
- State Work Group
  - "More Than a PKU Screen" Fact Sheet
  - Plain Language Recommendations for Reporting NBS Results Fact Sheet
- Best Practices Work Group
  - Newborn Screening Educational Best Practices Framework

# State Work Group Members

- Amy Gaviglio, MS, LCGC, *Minnesota Department of Health*
- Sondi Aponte, *Arizona Department of Health*
- Erin Bonzon, MSW, MSPH, *DC Department of Health*
- Marie Burlette, RN, BSN, MPH, *Connecticut Department of Health*
- Ashley Comer, *State Hygienic Laboratory at the University of Iowa*
- Patti Constant, MPH, *Minnesota Department of Health*
- Karen Eveans, MD, *Nebraska Department of Health*
- Shannon Harrison, RN, BSN, LCCE, *Illinois Department of Health*
- Tami Horeweski, MS, CHES, *Wisconsin Department of Health*
- Sylvia Mann, MS, CGC, *Hawaii Department of Health*
- Joyal Meyer, RN, MSN, *North Dakota Department of Health*
- Emily Phillips, *University of Iowa*
- Heather Pint, RN, PHN, *Minnesota Department of Health*
- Deborah Rodriguez, RN, MPH, CPH, *New York Department of Health*
- Lisa Shook, MA, MCHES, CCP, *Cincinnati Children's Hospital*
- Kristen Thompson, MPH, *Michigan Department of Health*

**Guidelines**

**Plain Language Recommendations for Reporting Newborn Screening Results**

Screening results should be conveyed in a simple and direct manner.

**1. SUMMARIZE THE RESULTS**

Screening results should be conveyed in a simple and direct manner.

**2. LANGUAGE RECOMMENDATIONS**

Clearly and concisely state the meaning of results.

**3. RISK TERMINOLOGY IS RECOMMENDED**

Screening results should be conveyed in a simple and direct manner.

**4. DESIGN RECOMMENDATIONS**

Abnormal results should stand out from other results.

Condition	Phrase	Results
Galactosemia	Galactosemia Galactosemia	High Risk of Liver Failure
Cystic Fibrosis	Communication Communication	Low Risk of Respiratory Failure
Hypothyroidism	Thyroid (Hormone) Thyroid (Hormone)	Intermediate Risk (Hormone)

**babys**

**Fact Sheet**

**Newborn Screening: More Than a PKU Screen**

Newborn screening (NBS) began in the 1950s with a screen for Phenylketonuria (PKU). But over the years, NBS has expanded to screen babies for many conditions.

**REMEMBER:**

State and national health programs have activated and widely use the term **NEWBORN SCREEN** to refer to the collection group of conditions screened for at birth. References to the "PKU test" should be updated to **NEWBORN SCREEN** including any language found in brochures, reporting systems, or in daily use.

**A STATE NBS STORY**

**NEW WORDS MATTER**

A fact sheet was created to help clarify the term "Newborn Screening" and to help state health officials communicate more effectively with the public.

**WHY IS THIS IMPORTANT TO REMEMBER?**

Being a new parent of a child with an abnormal newborn screen can be overwhelming. It is important to provide consistent, accurate information to families about the newborn screening process to minimize anxiety, confusion, and frustration.

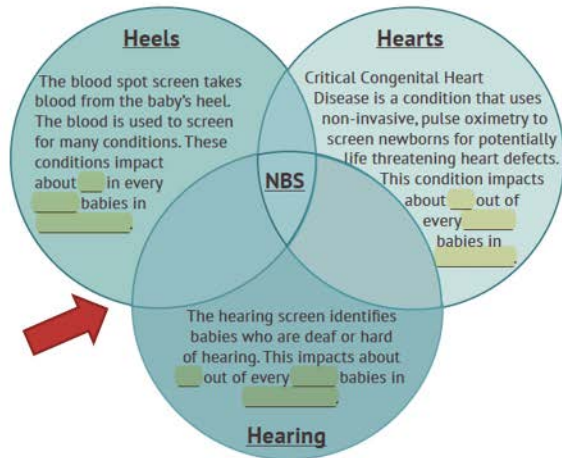
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## Newborn Screening: More Than a PKU Screen

**Newborn screening (NBS)** began in the 1960s with a screen for Phenylketonuria (PKU), but over the years, NBS has expanded to screen babies for many conditions. Despite this growth, many healthcare professionals still use the term "PKU test". With more conditions added to newborn screening panels, this term is no longer accurate and is confusing for parents and clinicians.

### REMEMBER:

State and national health programs have accepted and widely use the term **NEWBORN SCREEN** to refer to the collective group of conditions screened for at birth. References to the 'PKU test' should be updated to **NEWBORN SCREEN** - including any language found in textbooks, reporting systems, or in daily use.



### WHY IS THIS IMPORTANT TO REMEMBER?

Being a new parent of a child with an abnormal newborn screen can be overwhelming. It is important to **provide consistent, accurate information** to families about the newborn screening process to minimize anxiety, confusion and misinformation.

If you have further questions about newborn screening or the conditions screened in your state, please visit [BabysFirstTest.org](http://BabysFirstTest.org)

### A STATE NBS STORY:

#### WHY YOUR WORDS MATTER

A family received an urgent call informing them that their child needed follow-up for an abnormal newborn screen. Arriving at the lab, a staffer came up to them and said "You must be the people here for the **PKU test**!" Returning home, this family spent all weekend researching PKU. Arriving at the metabolic clinic, they were surprised to find their newborn was not suspected of having PKU at all. Instead, their child was actually at risk for an entirely different condition.

Clinic staff had to spend a lot of time helping the family "unlearn" all the information they had gathered, a time-consuming task which **could have been avoided had the correct terminology for newborn screening been used from the beginning**. Iowa NBS staff have been discussing this issue for several years now in their presentations to perinatal staff. After presentations, staff will often say, "We didn't know we weren't supposed to say PKU test".

#### What can we learn from this story?

1. The term 'newborn screen' should be used in place of PKU test.
2. Using the incorrect terminology for newborn screening is a important issue in clinical practice.
3. Using the term PKU test has tangible consequences.
4. Using inaccurate terminology may lead to incorrect follow-up testing.

- As of mid-October 2018, fact sheet tested by Michigan NBS program

- Do you call the newborn screen a PKU screen?
- After reading this handout, do you recognize the importance of refraining from calling it a PKU screen?
- Do you think this 'More than a PKU Screen' Handout would be useful for health care providers who collect the newborn screen in your hospital?
- 31 returned surveys
  - All positive feedback, extremely well-received
- More events scheduled

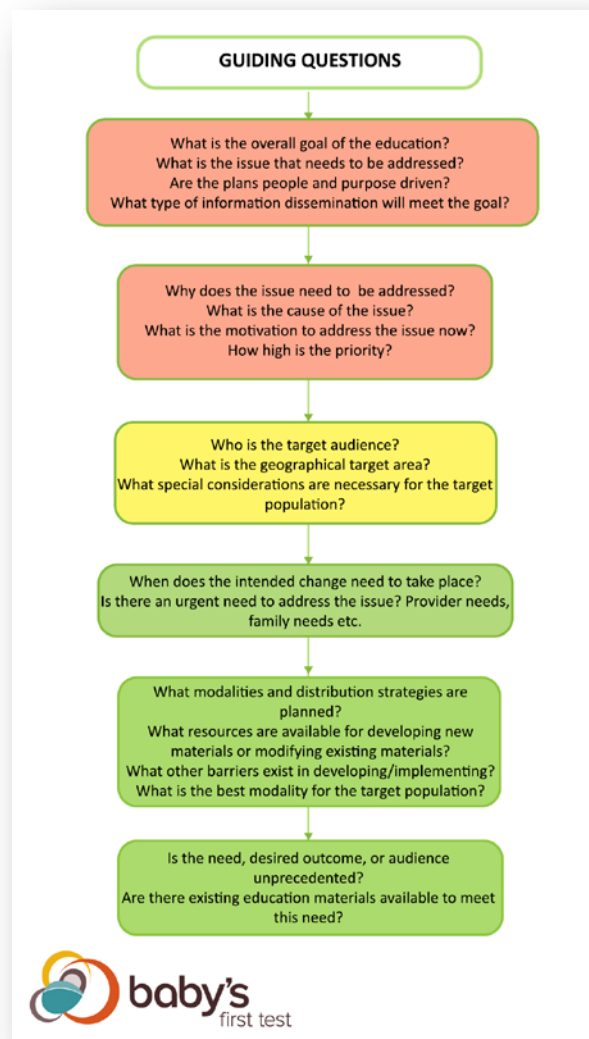
# Best Practices Work Group

## Co-Chairs

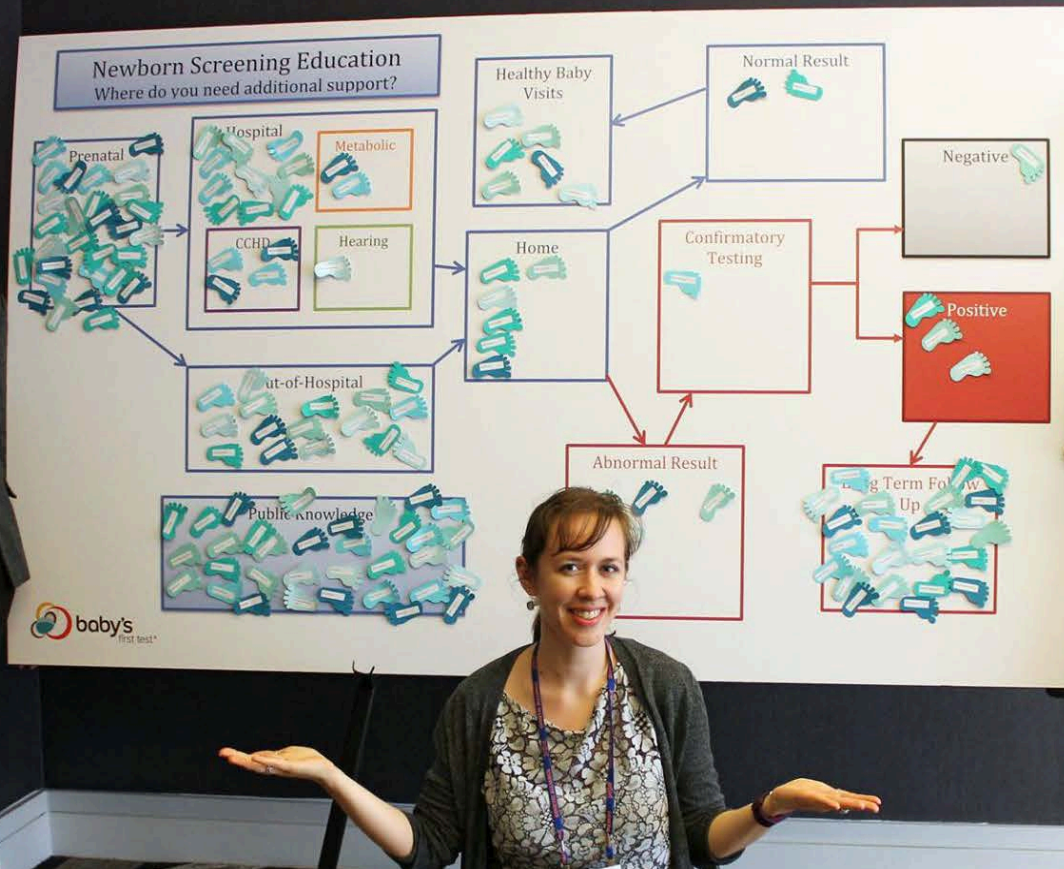
- Aaron Goldenberg, PhD, MPH, *Case Western Reserve University*
- Keri LeBlanc, MSN, NNP, CNS, *Rady Children's Hospital, Newborn Screening Program*

## Members

- Siobhan Dolan, MD, MPH, *Albert Einstein College of Medicine*
- Debbie Freedenberg, MD, PhD, *Texas Department of Health*
- Amy Gaviglio, MS, LCGC, *Minnesota Department of Health*
- Carol Johnson, *University of Iowa*
- Carrie Langbo, MS, CGC, *Michigan Department of Health*
- Scott Shone, PhD, *RTI International*
- Louisa Stark, PhD, *Genetic Science Learning Center, University of Utah*



*Guiding Questions to NBS Educational Best Practices Framework (2018)*



## Acknowledgements

- Expecting Health Staff
- Summit Task Force
- Consumer Task Force members
- Health Resources and Services Administration

# Questions?



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