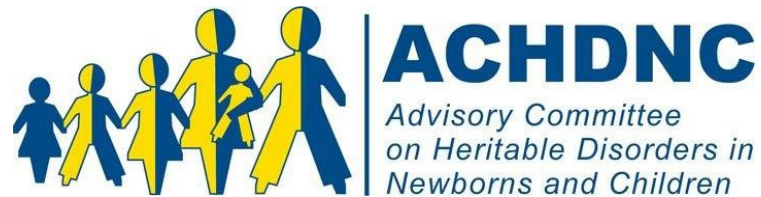


# Education and Training Workgroup Meeting Report

February 10, 2023



# Education and Training Workgroup Members

## **ACHDNC MEMBERS**

- Jane DeLuca, PhD, RN, CPNP (Chair)
- Melissa Parisi, MD, PhD National Institutes of Health
- Jannine De Mars Cody, PhD

## **ORGANIZATIONAL REPRESENTATIVES**

- Natasha Bonhomme Genetic Alliance
- Siobhan Dolan, MD, MPH March of Dimes
- Karin Downs, RN, MPH, AMCHP
- Shakira Henderson, PhD, DNP, MS, MPH, RNC-NIC, IBCLC  
Association of Women's Health, Obstetric & Neonatal Nurses
- Steven Ralston, MD, MPH  
American College of Obstetricians & Gynecologists
- Cate Walsh Vockley, MS, LCGC  
National Society of Genetic Counselors

## **MCHB**

- Loraine Swanson, MPH
- Alaina Harris, MSW, MPH

## **WORKGROUP MEMBERS**

- Barbara Ferreira, RN, BSN
- Stacy Hines-Dowell, DNP, AGN-BC
- Yvonne Kellar-Guenther, PhD
- Mary Kleyn, MS
- Keri LeBlanc, NNP, MSN, CNS
- Sylvia Mann, MS, CGC
- Jeremy Penn, PhD
- Maa-Ohui Quarmyne, MBchB MS
- Lisa M. Shook, MA, MCHES
- Samantha Vergano, MD
- Sarah Viall, MSN, PPCNP-BC

## **IN ATTENDANCE**

- Funke Akinsola
- Bob Best
- Cindy Hinton
- Ruthanne Sheller

## **TECH SUPPORT**

- Maggie McAlexander

# Proposed change in the existing structure of the Workgroups

- It was suggested that formal Workgroups dissolve in favor of smaller workgroups for specific projects
  - Discussion:
    - In some ways the E & T Workgroup has always operated in this manner
      - Small group work has often been a productive part of the workgroup
    - The downside: you can spend excess time identifying and recruiting people with specific skills taking energy away from accomplishing a task
  - E and T and has been underutilized in the past.
  - What is the impact of the work of the E and T committee?
  - We have ideas, but what goals does the ACHDNC want us to be working on?
  - **Guidance from the ACHDNC committee would be helpful**
- *Understanding what resources are available may also help guide projects*

Suggest 3 (or slightly more) top priority solutions the Committee can consider acting on to support state implementation of conditions added to the RUSP?

From this:

- Support use of existing training programs and mentorship already available
- Assure diverse and culturally tailored materials are available to families; support fostering equity
- Partner with other governmental agencies working in similar spaces (e.g. preventive task forces, maternal-child commissions etc.)
- Develop discreet goals for education and training
- Consider basic genetic and NBS education

To this:

***Partnering with governmental agencies and professional groups working in similar spaces, we will support development, distribution, and awareness of diverse and culturally focused new and existing newborn screening education programs and materials, ensuring coverage of basic genetics and newborn screening for all.***

# Educational Planning and Communication Guides

What they need to know-- "The stakeholder should know..." Stakeholder	Health reasons / benefits for screening	What screening is and when/how it is done	The general types of conditions identified by NBS	How and when will NBS results be received	The possible outcomes of NBS and respective next steps (insufficient sample, presumptive positive or borderline)	How to respond to results of newborn screening (referral, confirmatory testing, diagnostic algorithms, etc.) for personnel and healthcare providers	Special neonatal circumstances that may require modifications to the NBS process (preemie, NICU, Home Birth, etc.)	The costs of NBS assay to parents and how are they covered
Expectant parents	Y	Y	Y	Y	N	N	Y (general)	Y
New parents	Y	Y	Y	Y	Y	N	Y (if relevant)	Y
Parents of Screened Positive	Y							

What they need to know-- "The stakeholder should know..." Stakeholder	How a newborn screening sample collected from the newborn (technical aspects)	Where NBS results will reside permanently	The importance of timeliness in NBS	How healthcare providers and NBS follow-up staff should talk to parents about results	Why it is important to talk to parents about NBS	How stakeholders talk to parents about screening	Conditions in the differential diagnosis based on NBS results (clinical approach)	How stakeholders assess symptoms in newly identified newborn and determine follow-up	Variable age of onset for some identified conditions	The pattern of inheritance of conditions detected
Expectant parents	N	Y	Y	N	N	N	N	N	Y (for symptom)	N
New parents	N	Y	Y	N	N	N	N	Y (for symptom)	Y	N
Parents of Screened Positive	N									

What they need to know-- "The stakeholder should know..." Stakeholder	Condition-specific symptoms	Current condition-specific management	What is currently known about long-term health outcomes	If carrier status be detected, and if so, how will that result be returned and managed?	The costs and financial benefits of NBS	The importance of NBS for public health within the state	Policies for storage and use of dried bloodspot cards, regulations about NBS, and practices to convey this information to stakeholders	Criteria and processes for adding a condition to the NBS panel	Policy on parental consent for NBS	Availability of additional resources for stakeholders
Expectant parents	N	N	Y (for decision-making)	N	N	Y (general)	Y (general)	N	Y	Y
New parents	N	N	Y (for decision-making)	Y	N	Y (general)	Y	N	N	Y
Parents of Screened Positive	Y	Y	Y	Y	N	N	Y (targeted)	N	Y	Y
Family members of identified child (grandparents / siblings / other)	Y	Y	Y	N	N	Y (general)	Y (general)	N	N	Y
Adoptive parents (newborn / older child)	Y (general)	N	Y (newborn / N older child)	Y	N	Y	Y	N	Y (newborn) / N (older child)	Y
Foster parents (newborn / older child)	Y (general)	N	N	N	N	N	N	N	N	Y
General public (constituent)	N	N	Y	Y	Y	Y	Y (general)	Y (general)	Y (general)	Y
Disease/Condition Specific Advocates	Y	Y	Y	Y (concepts and resources)	Y	Y	Y	Y	Y	Y
Birth/ Prenatal educators	Y (general)	Y (general)	Y	Y (concepts and resources)	N	Y	Y (general)	N	Y	Y
OB / GYNs	N	N	Y (decision-making)	N	N	Y	Y (resources)	N	Y	Y
Midwives	Y (general)	N	Y (decision-making)	Y	N	Y	Y (resources)	N	Y	Y
Doulas	Y	N	Y (decision-making)	N	N	N	N	N	Y	Y
Birth nurses (OB)	Y (general)	N	Y (decision-making)	N	N	Y	Y (resources)	N	Y	Y
Pediatricians/Family practitioners/Well baby care providers/PCPs	Y	Y (general/first line)	Y	Y	N	Y	Y (resources)	Y	Y	Y
Geneticists/Biochemical geneticists	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sub-specialists (Neurologists, Endocrinologists)	Y	Y	Y	Y	N	Y	Y (resources)	Y	Y	Y
NICU Physicians/staff	Y	Y	Y	Y	Y	Y	Y (resources)	Y	Y	Y
Genetic Counselors	Y	Depends on work setting	Y	Y	Y	Y	Y	Y	Y	Y
Dietitians	Y	Y	Y	N	N	N	N	N	N	Y
Social Workers (working with positive screen patients)	N	Y	Y	N	N	Y	Y	N	Y	Y
Foster care / child protective services	Y (general)	N	N	N	N	N	N	N	N	Y
Educators for relevant professionals/trainees	Y	Y	Y	Y	Y (general)	Y	Y (general)	Y	Y	Y
Hospital Administrators/Risk Managers	N	N	Y (general)	Y (general)	Y	Y	Y	Y	Y	Y
Insurers	N	Y	Y	N	Y	N	N	Y (general)	Y (general)	Y
Phlebotomists	N	N	N	N	N	Y (general)	N	N	Y (general)	Y
Medical Assistants	N	N	N	N	N	Y (general)	N	N	N	Y
Screening laboratory staff	N	N	N	Y	N	Y	Y	Y	Y	Y
Follow up program coordinators / staff	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Researchers (bloodspot use specific; pilot study)	N	N	Y (general)	N	N	Y	Y	Y (general)	Y	Y
Legislators	N	N	Y	Y	Y	Y	Y	Y	Y	Y
Couriers	N	N	N	N	N	N	N	N	N	Y



## Communication Guide

**THIS GUIDE WILL HELP YOU EFFECTIVELY COMMUNICATE [POSITIVE]\* NEWBORN SCREENING RESULTS TO PARENTS.**



Because this type of communication is not a routine activity for the primary care provider, the information below may be used to help frame the discussion with families to improve understanding of the screening result, adherence to follow-up recommendations, and the family's overall experience with newborn screening.

Families who have had [positive]\* newborn screening results have suggested that the following key points are important in helping families cope with the uncertainty of a [positive]\* newborn screening result and understand the next steps needed to gain certainty.

- S**hare the specific [positive]\* newborn screening result and associated condition(s) with the family.
  - Help the family understand that a [positive]\* newborn screening result is serious, but that you are there to help guide them through the next steps.
- C**omprehension: Assess the family's understanding of newborn screening.
  - Assess if the family recalls and understands the process of newborn screening.
- R**emind what screening is and is not.
  - Remind the family about the purpose of newborn screening and that it is not a diagnostic test, so it is important that timely follow-up confirmatory testing be done.
- E**ngage with the family and provide information at their desired level and pace.
  - Offer to provide the family additional result-specific information provided by the state newborn screening program.
  - Discuss information using non-medical terms, at the family's pace and desired level of detail.
- E**xplore the family's emotions.
  - Explore with the family how they might use their support system or other support resources now and as they go through the diagnostic process.
  - Remember there is a wide spectrum of how families may cope with this result (anxiety to denial). Tailor your discussion to help the family hear and retain the information discussed.
- N**ext steps: Discuss a shared plan and provide resources.
  - Discuss with the family a shared plan that is concrete, specific, and includes the following:
    - Where, when, and with whom is the next appointment?
    - What testing will be considered and/or done?
    - What should they watch for in their child while they wait?
    - Who can they contact if they have additional questions or concerns?
  - Assess the family's understanding of the visit and information provided using teach-back methods, and provide valid websites for them to get more information.

\*A positive newborn screening result can also be referred to as an abnormal result, an out-of-range result, or presumptive positive result.

For more information about the Advisory Committee on Heritable Disorders in Newborns and Children, please visit <https://www.hrsa.gov/advisory-committees/heritable-disorders>

# The Past: Evaluate completed work

- What is the impact of the screening guides and other resources?
  - How can we evaluate their use?
  - Who is using them and how often, what approaches and metrics can we use to learn about this (? IP addresses)
- What does success in NBS education look like? What changes are we seeing?

# The Present: Set priorities

- Fostering community engagement
  - Using our volunteer energy for projects prioritized by communities; steered by communities
- Engaging states' NBS programs to understand needs of different groups
  - Groups we may not be reaching or who are challenging to reach
  - Check in with states programs for policies and materials on NBS education
- Use existing organizations (APHL/Genetic Alliance) and identify grantees for assistance in performing needs assessments (states' policies for example)
- Understanding parents and families' experiences; comparing families of infants who have gone through screening with positive or false positive results

# The Present: Set priorities

- Create a repository for vast NBS resources, but not reinvent the wheel
  - Evaluation of materials?
- Written materials, pamphlets tend not to get the message out; other media may do a better job (HRSA, Babies First Test- You Tube videos); Existing materials in CA, Texas and elsewhere are using You Tube.
- Creating You Tube education for NBS disorders and PSAs
  - This could be very expensive to execute
- Thinking of NBS education along the continuum of the process from OB to pediatric provider visit
- What is doable for NBS education and measurable?



# The Future: what to look at and how do we prepare?

- Education about new disorders added to the RUSP
- Providing guidance for education and understanding around genomic sequencing for NBS
  - Where is this on the horizon? Multiple companies engaged, multiple research projects

# Where to from here...

A useful framework:

- The past: evaluating outcomes to learn what works
- The present: needs assessment of what is needed now
- The future: preparing for additional conditions and *new* NBS
  
- ACHDNC vision and ideas for project-oriented work groups with the E & T committee setting priorities and acquiring funding
- Many good suggestions, but **need ongoing conversations to prioritize ideas, select potential projects, and form task groups**