

Education and Training Workgroup Members

ACHDNC MEMBERS

- Jane M. DeLuca, PhD, RN (Chair)
- Cynthia M. Powell, MD, MS, FACMG, FAAP (ACHDNC Chair)
- Natasha Bonhomme

ORGANIZATIONAL REPRESENTATIVES

- Steven J. Ralston
American College of Obstetricians & Gynecologists
- Natasha Bonhomme
Genetic Alliance
- Siobhan Dolan
March of Dimes
- **Shakira Henderson, PhD, DNP, MS, MPH, RNC-NIC, IBCLC**
Association of Women's Health, Obstetric & Neonatal Nurses
- Cate Walsh Vockley, MS, CGC
National Association of Genetic Counselors

HRSA SUPPORT

- Mabatemije Otubu

WORKGROUP MEMBERS

- Barbara Foley Ferreira, RN, BSN
- Amy Gaviglio, MS, CGC
- Aaron Goldenberg, PhD, MPH
- Joyce Graff
- 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

Education & Training Workgroup Discussion Questions

- **What range of issues related to education should the Advisory Committee consider when a condition is added to the RUSP?**
- What type of information and educational resources would be most helpful when a condition is added to the RUSP?

Education & Training Workgroup Discussion Questions

- What are we trying to achieve?
- There are many different types of learners in newborn screening. The Grid.
- Consider education early in the nomination process.
- Create a description of the nominating process for the public
- Where does education fit in the nomination process?
- Benefits and harms of screening
- Education for least informed stakeholders
- Using education to mitigate harm and support families
 - Applying the Communication Guide as part of the nomination/review process

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
Expectant parents	N	N	Y for decision-making	N	N	Y (general)
New parents	N	N	Y for decision-making	Y	N	Y (general)
Parents of Screened Positive	Y	Y	Y	Y	N	N
Family members of identified child (grandparents / siblings / other)	Y	Y	Y	N	N	Y (general)
Adoptive parents (newborn / older child)	Y (general)	N	Y (newborn) / N (older child)	Y	N	Y
Foster parents (newborn / older child)	Y (general)	N	N	N	N	N
General public (constituent)	N	N	Y	Y	Y	Y
Disease/Condition Specific Advocates	Y	Y	Y	Y (concepts and resources)	Y	Y
Birth/ Prenatal educators	Y (general)	Y (general)	Y	Y (concepts and resources)	N	Y
OB / GYNs	N	N	Y (decision-making)	N	N	Y
Midwives	Y (general)	N	Y (decision-making)	Y	N	Y
Doulas	Y	N	Y (decision-making)	N	N	N
Birth nurses (OB)	Y (general)	N	Y (decision-making)	N	N	Y
Pediatricians/Family practitioners/Well baby care providers/PCPs	Y	Y (general/first line)	Y	Y	N	Y
Geneticists/Biochemical geneticists	Y	Y	Y	Y	Y	Y

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**eiterate 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.