Education Activities Panel

Presented to the Advisory Committee on Heritable Disorders in Newborns and Children

November 1, 2018

Moderator: Beth Tarini, MD, MS

Goal of the Panel

- Highlight the critical role of education in NBS
- Feature the achievements and ongoing activities in NBS education
- Foster discussion and spark ideas for future collaborations/projects

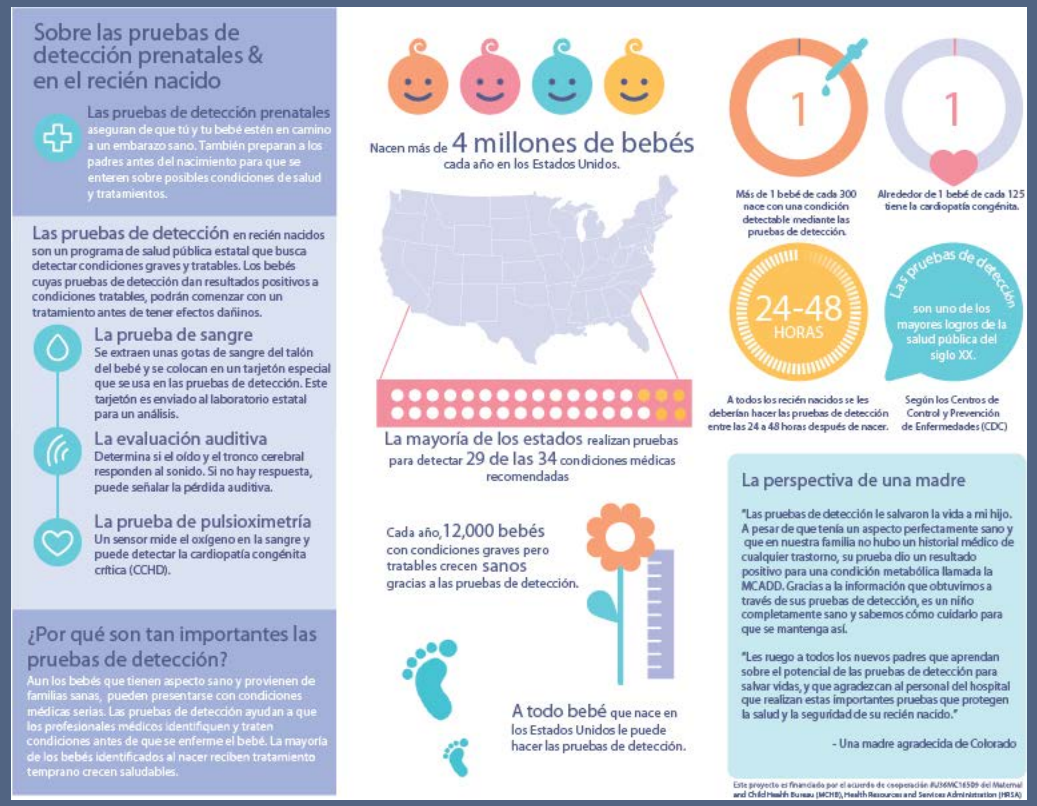
Background

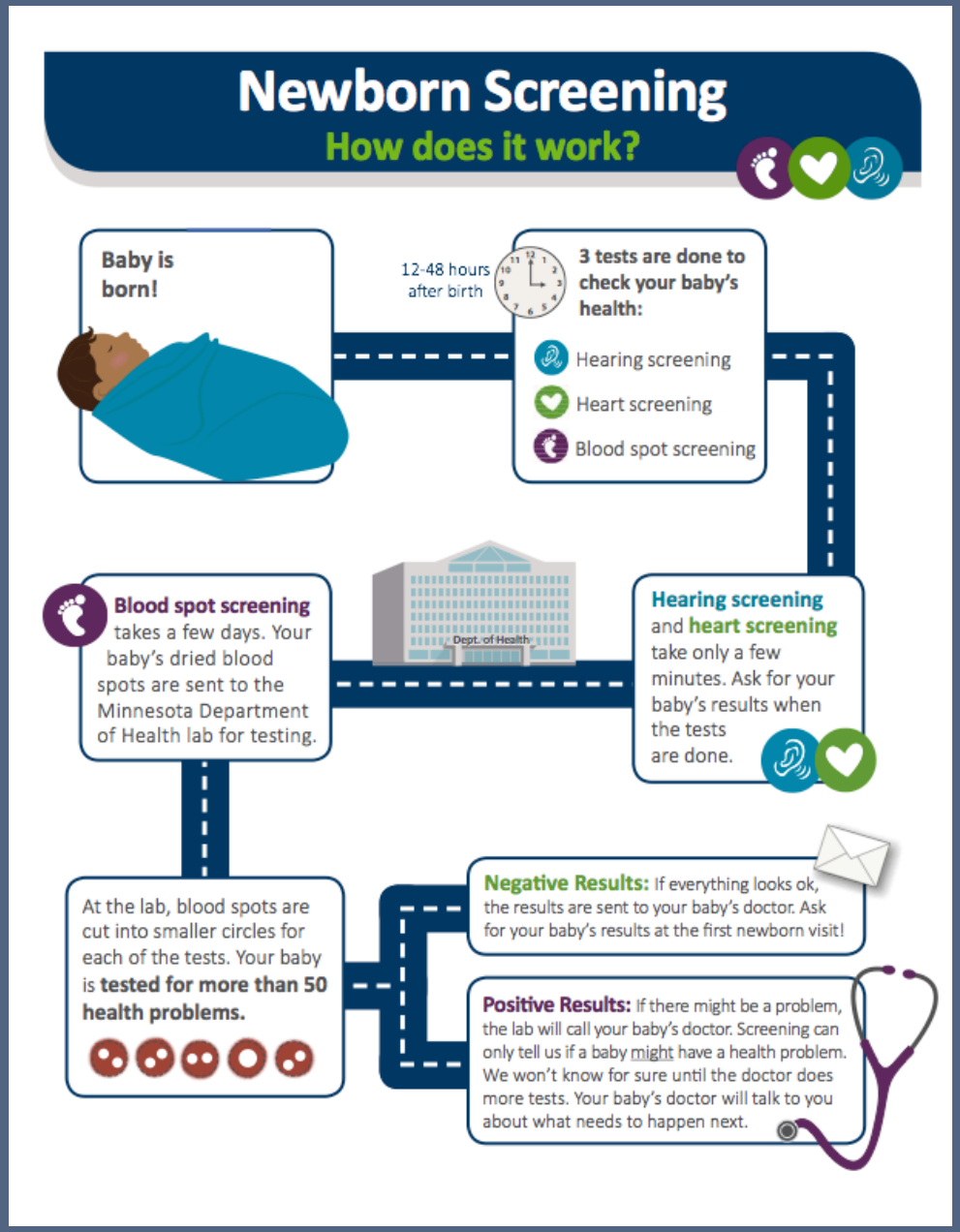
Educate

- *To provide with information*
- *To train by formal instruction and supervised practice especially in a skill, trade, or profession*

-Merriam-Webster

Role of Education in NBS





Serving the Family From Birth to the Medical Home

Newborn Screening: A Blueprint for the Future

A Call for a National Agenda on

ABBREVIATIONS. PKU, phenylketonuria; AAP, American Academy of Pediatrics; MCHB, Maternal and Child Health Bureau ARC, Association for Retarded Citizens; MCH, maternal and child health (programs); CDC, Centers for Disease Control and Prevention; HRSA, Health Resources and Services Administration CSHCN, Children With Special Health Care Needs; CORN, Council of Regional Networks for Genetic Services; NAS, National Academy of Sciences; IOM, Institute of Medicine; HHS, US Department of Health and Human Services; NIH, National Institutes of Health; AHRQ, Agency for Healthcare Research and Quality APHL, Association of Public Health Laboratories; SACGT, Secretary's Advisory Committee on Genetic Testing; CLIA, Clinical Laboratory Improvement Amendments; HCFA, Health Care Financing Administration; NSQAP, Newborn Screening Quality Assurance Program; WIC, Supplemental Nutrition Program for Women, Infants, and Children; HEDIS, Health Plan Employer Data and Information Set; NBAC, National Bioethics Advisory Commission; IRB, institutional review board; OTA, US Congress Office of Technology Assessment; SSI, Supplemental Security Income; SCHIP, State Children's Health Insurance Program; HIPAA Health Insurance Portability and Accountability Act; ERISA, Employee Retirement and Income Security Act; EPSDT, Early and Periodic Screening, Diagnosis, and Treatment (program).

I. BACKGROUND

Newborn screening in the United States is a public health program aimed at the early identification of conditions for which early and timely interventions can lead to the elimination or reduction of associated mortality, morbidity, and disabilities. This screening takes place within the context of a newborn screening system, and involves the following components: screening, short-term follow-up, diagnosis, treatment/management, and evaluation. Inherent to each of these components is an education process.

ACHDNC

Commentary | Published: 15 January 2010

A blueprint for maternal and child health primary care physician education in medical genetics and genomic medicine: Recommendations of the United States Secretary for Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children

Alex R Kemper ✉, Tracy L Trotter, Michele A Lloyd-Puryear, Penny Kyler, W Gregory Feero & R Rodney Howell

Genetics in Medicine **12**, 77–80 (2010) | Download Citation ⬇

ACHDNC: Education & Training Workgroup

- 1 of 3 ACHDNC Workgroups
- Instrumental in garnering interest and support for funding of the Genetics and Primary Care Institute
  - Mission of the Genetics in Primary Care Institute (GPCI): to increase primary care provider (PCP) knowledge and skills in providing genetic-based services
- Diverse membership spans organizations, disciplines, NBS stakeholders

E&T Workgroup: Recent Projects

ACHDNC
Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

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.

Share 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.

Comprehension: Assess the family's understanding of newborn screening.
- Assess if the family recalls and understands the process of newborn screening.

Reiterate 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.

Engage 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.

Explore 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.

Next 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

Link: https://www.hrsa.gov/advisory-committees/heritable-disorders/resources

E&T Workgroup: Recent Projects

NBS Education Learning Goals

Stakeholders

NBS Education Planning Guide

What they need to know→ "The stakeholder should know..." Stakeholder↓	Health reasons / benefits for screenin	What screening is and when / how it is done	The general types of conditions identified by NBS	How and when will NBS results will be receive	The possible outcomes of NBS and respective next steps (insufficient sample, presumptive positive or borderlin	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	How a newborn screening sample collected from the newborn (technical aspects)	Where NBS results will reside permanentl y	The importanc e of timeliness in NBS	How healthcare providers and NBS follow-up staff should talk to parents about results
Expectant parents	Y	Y	Y	Y	N	N	Y (general)	Y	N	Y	Y	N
New parents	Y	Y	Y	Y	Y	N	Y (if relevant)	Y	N	Y	Y	N
Parents of Screened Positive	Y	Y	Y	Y	Y	N/A	Y (preemie and NICU)	Y	N	Y	Y	N
Family members of identified child (grandparents / siblings / other)	Y	Y	N	Y (general)	Y (general)	N	N	N	N	Y	Y	N
Adoptive parents (newborn / older child)	Y (newborn) / N (older child)	Y	Y	Y (newborn) / N (older child)	Y	N	N	Y	N	Y	Y	N
Foster parents (newborn / older child)	Y (newborn) / N (older child)	Y	Y	Y (newborn) / N (older child)	Y (general)	N	N	N	N	Y	Y	N
General public (constituent)	Y	Y	N	Y (general)	Y (general)	N	Y (general)	Y (general)	N	Y	Y	N
Disease/Condition Specific Advocates	Y	Y	Y	Y	Y (general)	Y	Y (general)	Y	N	Y	Y	Y (focus on referrals, key messages, and support)
Birth/ Prenatal educators	Y	Y	Y	Y	Y (general)	N	Y (general)	Y (general)	Y (general)	Y (general)	Y	N
OB / GYNs	Y	Y	Y	Y	Y (general)	N	Y	Y	N	Y	Y	N
Midwives	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y	Y
Doulas	Y	Y	Y	Y	Y (next steps)	Y	Y (general)	Y	N	Y	Y	N
Birth nurses (OB)	Y	Y	Y	Y	Y (next steps)	N	Y	Y	Y	Y	Y	N
Pediatricians/Family practitioners/Well baby care providers/PCPs	Y	Y	Y	Y	Y	Y	Y	Y	Second Screen States?	Y	Y	Y
Geneticists/Biochemical geneticists	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Link: https://www.hrsa.gov/advisory-committees/heritable-disorders/resources

ACHDNC: New Ad-hoc Workgroup

- Joint effort - Committee Members, Education and Training Workgroup members, and Laboratory Standards and Procedures Workgroup members
- Address opportunities and challenges related to interpretation of newborn screening results
  - Communicating the strengths and limitations of newborn screening results
  - Educating different audiences – providers, parents, and the public

Panel Presentations

- **Jaclyn Seisman, MPH, Assistant Director of Maternal & Child Health, Genetic Alliance**
  - Summary from the Education and Engagement Summit
- **Debra Freedenberg, MD, PhD, Medical Director, NBS and Genetics, Texas Dept of State Health Services**
  - Creation of X-ALD education materials - retrospective comparison of the process used with the framework developed post Summit
- **Susan Berry, MD, Committee Member, Professor & Director of Division of Genetics and Metabolism, University of Minnesota**
  - Development (who, what, why, how) of the “Newborn Screening: More Than a PKU Screen" educational tool – using it in the field
- **Kim Piper, RN, Executive Officer, Center for Congenital & Inherited Disorders, Iowa**
  - Using a Deliberative Community Engagement process to inform Iowa’s NBS Program processes and education efforts
- **Q&A/Discussion**