

# Education and Training Workgroup

Chairs: Catherine Wicklund, Beth Tarini

ACHDNC Meeting

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# NBS Education Planning Guide

# Need, Purpose, and Scope:

**Need:** NBS stakeholders need access to appropriate, accurate, and informative educational resources that meet their range of educational needs.

**Purpose:** Create a Newborn Screening Educational Planning Guide that can be used by newborn screening programs to develop and improve NBS educational resources.

**Scope:** Identify important NBS content areas to consider including in relevant stakeholder group educational materials.

# Document creation and review

- Model Used:** Design of Educational Resources based on work by RW Tyler  
(Tyler, R. W. (1949). *Basic principles of curriculum and instruction*. Chicago: University of Chicago Press)
- Goal:** Educational planning tool that can be used by a range of NBS stakeholders
- Review Process:** E&T Workgroup, relevant NBS stakeholders, ACHDNC

# Next Steps

## **Potential Dissemination Strategies (after posting on HRSA website):**

- 1) NBS program listserves
- 2) Professional organizations: AAP, ACMG, NSGC, SOPHE, Regional Genetics
- 3) National Conferences: APHL NBS Symposium
- 4) Webinars
- 5) Academic publication

# Next Steps

## **For Committee Members**

- 1) Review document and provide comments back to Education & Training workgroup
- 2) Anticipated committee approval of document content at February 2018 or May 2018 meeting

# Abnormal NBS Result Communication Guide

# Need, Purpose, and Scope:

- Need:** Arose from focus group work done by Natasha Bonhomme and Dr. Carol Greene as well as anecdotal evidence from families
- Purpose:** To provide guidance to primary care providers in helping frame the initial discussion with parents about abnormal NBS results
- Scope:** Provide guidance on points of discussion *outside of result-specific information*



# Document creation and review

- Model Used:** SPIKES model for delivering high-anxiety news  
Rooted in oncology literature and genetic counseling  
Modified to be called 'SCREEN' for this purpose
- Goal:** One-page document that provides basic guidance
- Review Process:** Baby's First Test staff; primary care providers; genetic counselors; communication expert; and Education & Training workgroup members

# Next Steps

## Potential Dissemination Strategies:

- 1) Provide content to states for inclusion with abnormal result notification package
- 2) Provide content to ACMG for inclusion in ACT Sheets (as 'pre-ACT' sheet)
- 3) Provide content on NBS education sites
- 4) Consider development of AAP Maintenance of Certification (MOC) module and/or endorsement by AAP

# Next Steps

## **For Committee Members**

- 1) Review document and provide comments back to Education & Training workgroup
- 2) Anticipated committee approval of document content at February meeting

# Future Project Ideas

# Request from Committee

- Relative importance of issues presented
- Additional input on potential strategies
- Other ideas

# E&T Problems to Address

- Designing intervention strategies for optional NBS
  - Example: Optional Krabbe screening in Ohio
- Determine educational needs for NBS conditions with adult onset
- Improving educational outreach for hemoglobinopathy carrier status