

Education and Training Workgroup



Catherine Wicklund, Chair
Beth Tarini, Chair

ACHDNC MEETING
AUGUST 4, 2017

Members



- **Beth Tarini**
- **Cathy Wicklund**
- **Joseph Bocchini**
- **Adam Kanis**
- **Natasha Bonhomme**
- **Cate Walsh Vockley**
- **Lisa Shook**
- **Siobhan Dolan**
- **Britton Rink**
- **Emily Drake**
- **Amy Gaviglio**
- **Aaron Goldenberg**
- **Joyce Graff**
- **Stacy Hines-Dowell**
- **Joyce Hooker**
- **Keri LeBlanc**
- **Jeremy Penn**

AGENDA



- **Introductions of new members and relevant updates from members**
- **Reviewed current workgroup projects**
 - Matrix/Curriculum Map
 - Communication Aid
- **Discussed additional educational needs/project ideas**
 - Optional Krabbe testing in specific states
 - Provider/Public education on interpreting NBS results, including results within normal range (Practice level and/or professional societies, resident education)
 - ✦ Screening results are not diagnostic

Projects: Communication Aid



Project 1: Create document that provides guidance to providers on how to discuss the initial out of range NBS results with parents.

- **Workgroup:**
 - Lead: Amy Gaviglio
 - Cathy Wicklund
 - Natasha Bonhomme
 - Amelia Mulford
 - Lisa Shook

Projects: Communication Aid



- **Will utilize existing resources from previous focus groups and best practices for communication.**
 - Draft developed by working group
 - Reviewed by E&T workgroup: edits/revisions will be made and sent back to workgroup for further review

Project: Communication Aid



Next Steps:

- Feedback will be solicited from PCPs, along with preferred methods of dissemination
- Once finalized the document will be submitted to the entire committee for review and comments
- Once approved by committee it will be submitted to ACMG for approval to be linked to existing ACT sheets
- Document will also be disseminated in alternative ways: yet to be determined

Projects: Matrix/Curriculum Map



Project 2: Develop a matrix with relevant stakeholders and topics that would be important for stakeholders to know regarding NBS

- **Workgroup:**
 - Leads: Jeremy Penn, Cate Walsh Vockley
 - Natasha Bonhomme
 - Joyce Hooker
 - Aaron Goldenberg
 - Amelia Mulford
 - Beth Tarini

Projects: Matrix/Curriculum Map



- **Matrix has been renamed: NBS Educational Planning Guide**
 - Planning guide has been further developed by working group
 - Guide presented to invited stakeholders at the Baby's First Test Summit for input
 - Baby's First Test: three parent workgroups have incorporated the guide in their discussion and will provide feedback
 - Graduate student (working with Aaron Goldenberg) is using the categories the Workgroup presented to the Committee in May as guide to review a subset of educational brochures

Project: NBS Educational Planning Guide



- **Next steps:**
 - Further refinement by working group based on feedback
 - Key stakeholder review: Identify stakeholders who have not given feedback and target them for review of the guide
 - Follow up with Aaron regarding graduate student project and outcomes
 - Once guide has been reviewed by stakeholders, will present guide to committee for review and feedback
 - Create list of potential partners to help with dissemination
 - ✦ Prioritize list

Additional Educational Projects



- Further exploration of states that have incorporated screening for Krabbe as an optional screen
- Educational opportunities for NBS Cutoff/In range results
 - Amy Gaviglio and Sue Berry are working on project regarding normal/in range NBS results
 - Will wait to see how their project evolves and determine how the E&T workgroup can contribute

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Questions?