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
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
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 the 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
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
<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Benefits of screening</th>
<th>What screening is done</th>
<th>How results will be received</th>
<th>Cost</th>
<th>Overview of conditions screened</th>
<th>Results and next steps (if presumptive positive)</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expectant parents</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Why it is important to talk to parents about screening</td>
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<tr>
<td>New parents</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>How to do screening</td>
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<tr>
<td>OB / GYN</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>What to do with the results (where to refer, confirmatory tests to order, etc.)</td>
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<td>Midwives</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>What conditions are screened and what conditions are not</td>
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<tr>
<td>Birth nurses</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Cost / benefit for states</td>
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<td>Pediatricians / Well baby care providers</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Importance of NBS for public health and health of the state</td>
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<td>Y</td>
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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
Questions?