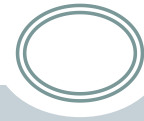


Education and Training Workgroup



Catherine Wicklund, Chair
Beth Tarini, Chair

ACHDNC MEETING
MAY 11, 2017

Members



- **Beth Tarini**
- **Cathy Wicklund**
- **Don Bailey**
- **Joseph Bocchini**
- **Robert Saul**
- **Adam Kanis**
- **Natasha Bonhomme**
- **Cate Walsh Vockley**

- **Pamela Clark**
- **Emily Drake**
- **Amy Gaviglio**
- **Aaron Goldenberg**
- **Joyce Graff**
- **Stacy Hines-Dowell**
- **Joyce Hooker**
- **Keri LeBlanc**
- **Jeremy Penn**
- **Lisa Shook**

AGENDA



- **Introductions of new member and relevant updates from members**
- **Reviewed current workgroup projects**
- **Discussed additional educational needs/project ideas**

Projects



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

Small Workgroup:

- **Lead: Amy Gaviglio**
- **David Flannery**
- **Alisha Kheen**
- **Cathy Wicklund**
- **Natasha Bonhomme**
- **Amelia Mulford**
- **Lisa Shook**

Projects



- Will utilize existing resources from previous focus groups and best practices for communication.
- Once finalized the document will be submitted to ACMG for approval to be linked to existing ACT sheets.
- Document will also be disseminated in alternative ways.

Project 2: Educational Outreach Projects



Project 2a: Mapping of education resources

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

Small workgroup:

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

Mapping of Education Resources



- **Discussion points**
 - Current NBS paradigm or potential movement into age of molecular medicine?
 - Return of carrier results (ROR in genomic sequencing)?
 - Both may warrant a broader discussion with the ACHDNC Committee

Mapping of Education Resources



- **Next steps**
 - Continue to refine framework with input of E&T Workgroup
 - Reach out to key stakeholders to solicit feedback
 - Determine how to utilize framework:
 - ✦ Apply to existing educational resources to identify gaps?
 - ✦ Subgroup will brainstorm next steps: how to use framework? Dissemination?

Project 2



- Project 2b:
 - Discussed using Workgroup members' organizational relationships to encourage submission of educational materials to the NBS clearinghouse

Education and Training Workgroup



Questions?