

# Education and Training Workgroup



Catherine Wicklund, Chair  
Beth Tarini, Chair

**ACHDNC MEETING  
FEBRUARY 9, 2017**

# Members



- **Beth Tarini**
- **Cathy Wicklund**
- **Don Bailey**
- **Joseph Bocchini**
- **Robert Saul**
- **Joseph Biggio**
- **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 workgroup projects**
- **Discussed additional educational needs/project ideas**

# Projects



**Project 1: Create tool that provides PCPs with guidance and tips for discussing out of range and positive NBS results with parents; could be used alongside ACT sheets.**

# Project 1



- ACT committee members have been identified to work on this collaboration
- Genetic Alliance is collaborating with ACMG to determine how to incorporate research findings (Schmidt et al) into ACT sheets and/or have a separate document.

Genetics  
inMedicine

ORIGINAL RESEARCH ARTICLE

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## The impact of false-positive newborn screening results on families: a qualitative study

Johanna L. Schmidt, MPH, MGC<sup>1</sup>, Karen Castellanos-Brown, PhD<sup>2</sup>, Saltanat Childress, MSW<sup>3</sup>,  
Natasha Bonhomme, BA<sup>4</sup>, Julianne S. Oktay, PhD<sup>3</sup>, Sharon F. Terry, MA<sup>4</sup>, Penny Kyler, OT, ScD<sup>5</sup>,  
Amy Davidoff, PhD<sup>6</sup> and Carol Greene, MD<sup>7</sup>

# Project 1: Updates



- **Renamed: Communication Tool**
- **Had call with ACT committee members: Communication tool would need to go through many steps before being incorporated/added as a companion piece**
- **Will refine communication tool as a stand alone piece to be disseminated in other ways**
- **Small group will work on reviewing and revising communication tool: will invite PCPs to provide input**

# 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**
  - ✦ **Jeremy Penn presented an initial framework for discussion-a subgroup of the committee worked on further refinement of the framework and presented their work to the broader group for discussion**





# Mapping of Education Resources



- **Subgroup: Jeremy Penn, Natasha Bonhomme, Joyce Hooker, Cate Walsh Vockley, Amelia Mulford**
- **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
  - 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
  - Natasha Bonhomme (Genetic Alliance) will put together a brief summary of the project for committee members to disseminate to their relevant professional organizations
    - ✦ Cate Walsh Vockley (NSGC liaison) will work with Genetic Alliance and NSGC to determine the best way to reach genetic counselors within the organization
    - ✦ They will also connect with dietitians to determine how to reach this group

# Project 3



- **Project 3: Timeliness Education**
  - Don Bailey suggested that phlebotomists may be a group that could benefit from additional education regarding timeliness
    - ✦ Beth Tarini will research this group further and determine if this would be a relevant and reachable group: difficulty identifying a specific organization to target
  - NewSteps 360 Meeting in November
    - ✦ Committee members attending this meeting will query meeting participants to determine if there is a need for additional educational materials

# Education and Training Workgroup



**Questions?**