

Education and Training Workgroup



Catherine Wicklund, Chair
Beth Tarini, Chair

**ACHDNC MEETING
NOVEMBER 3, 2016**

AGENDA



- 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 positive NBS results with parents; could be used alongside ACT sheets.

Project 1



- ACT committee members have been identified to work on this collaboration
- Natasha Bonhomme 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, MGC¹, Karen Castellanos-Brown, PhD², Saltanat Childress, MSW³,
Natasha Bonhomme, BA⁴, Julianne S. Oktay, PhD³, Sharon F. Terry, MA⁴, Penny Kyler, OT, ScD⁵,
Amy Davidoff, PhD⁶ and Carol Greene, MD⁷

Project 1: Next Steps



- Draft document to be presented at February meeting
- Depending on outcome, committee will decide if an additional document is needed to address communication strategies and/or psychosocial impact
- Committee members currently exploring potential to incorporate content into other projects
 - AAP resident education project
 - Pediatric resident education curriculum
 - Existing American Board of Pediatrics Maintenance of Certification (MOC) projects

Project 2



Project 2: Educational Outreach Projects

- Project 2a: Mapping of education resources
- Original project: Mapping of education materials with dissemination to target audiences that will embed them within their resources
- Mapping will allow the identification of gaps in available educational resources
- Lack of funding to support an extensive project to map education resources

Project 2



- Current objective: Develop a matrix with relevant stakeholders and topics that would be important for stakeholder to know regarding NBS
 - Jeremy Penn presented an initial framework for discussion-a subgroup of the committee will work on further refinement of the framework to present to the broader group for discussion
 - After further development: present to various state working groups to determine specific state needs

Project 2



- Project 2b:
 - Discussed using Workgroup members' organizational relationships to encourage submission of educational materials to the NBS clearinghouse
 - Natasha 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 Natasha 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
 - ✦ Consider inviting this group to present regarding their role in NBS
 - 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

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Questions?