

Education and Training Subcommittee



Catherine Wicklund, Chair
Beth Tarini, Co-Chair

ACHDNC MEETING
MAY 9-10, 2016

AGENDA



- Relevant updates from members
- Reviewed subcommittee projects
- Update on Nomination Education Project
- Discussed additional educational needs/project ideas

Update on Nomination Education Project



- Product: Educational guidance to groups who might be interested in preparing a nomination packet
- Genetic Alliance/NBS Clearinghouse collaborating with Dr. Kemper and his team
- Work continues and will likely be completed by December 2016
- E&T is available to review and provide suggestions

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



- Reviewed findings from the following study:

**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



- Circulated questions to consider when shaping tool's content:
 - What are the key messages that should be provided to parents of children with positive initial NBS results?
 - What pieces of information are missing from the ACT sheets?
 - What communication processes/procedures should be utilized? Which should be avoided?

Project 1



- Discussed strategies for dissemination
 - Leveraging membership alliances
 - ✦ NBS Clearinghouse
 - ✦ AAP
 - ✦ AWON
 - ✦ Regional Collaboratives
 - ✦ NSGC
 - ✦ State NBS Programs
 - ✦ etc

Project 1



- Next steps...
 - Continue to refine content with input from subcommittee members and other stakeholders
 - Connect with ACMG/ACT sheet stakeholders (and other relevant organizations) to discuss collaborative strategies

Project 2



Project 2: Educational Outreach Project

- Mapping of education resources
 - Disseminate of educational resources to target audiences that will embed them within their resources
 - Outcome: Linkages Achieved
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- Strategy: Mapping will allow us to identify gaps in available educational resources
 - Format: Matrix with characteristics deemed important – for example - audience, location, creator, mode, goals of material

Project 2



- Next Steps:
 - Need to identify audiences and goals of education
 - Leverage anticipated work of NBS Clearinghouse Resource Repository in collating multiple educational resources