

Education and Training Workgroup



Catherine Wicklund, Chair
Beth Tarini, Chair

**ACHDNC MEETING
AUGUST 25-26, 2016**

AGENDA



- Relevant updates from members
- Update on Nomination Education Project
- Reviewed workgroup projects
- 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
- Dr. Kemper presented graphic and discussed next steps
 - Exploring the technological capabilities/limitations of website

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: Updates



- ACT committee members have been identified to work on this collaboration
- Natasha Bonhomme will meet with them to explore how to incorporate findings from her research into ACT sheets

**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



- Committee will assist with review of future content for ACT companion sheet
- Committee members will explore 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 1: Other Discussion



- Parent handout to be used at time of notification of positive NBS result
- Challenges
 - Dissemination to parent when needed
- Decision
 - Hold on this endeavor and focus on the practitioner/residents

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: Update



- Funding is not available to do project
- Discussed using Workgroup members' organizational relationships to encourage submission of educational materials to the NBS clearinghouse

Other Discussion: Midwife Education



- Discussed whether there is a need for us to enter space currently given yesterday's public comment
- Decided that we would wait until further information available on where we can best leverage our efforts in this space

Other Discussion: Timeliness



- Explored potential opportunities for timeliness education
- Will reach out to hospital associations
- Don suggested exploring phlebotomist associations
 - Possibly invite them to present to us in future