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
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:

**ORIGINAL RESEARCH ARTICLE**

**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: Educational Outreach Project

- Mapping of education resources
- Disseminate of educational resources to target audiences that will embed them within their resources
- Outcome: Linkages Achieved

- 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
Next Steps:

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