

Education & Training Subcommittee Report

ACHDGDNC

December 19, 2006



Education and Training Subcommittee Charges

- Review existing educational and training resources for health professionals, parents, screening program staff, hospital/birthing facility staff and the public
- Identify deficiencies and make recommendations for action regarding the five groups

Current Focus

(December 6th Conf. Call)

- In the past, the Sub-Committee had focused on creating a communication plan to increase the awareness of NBS.
- One key topic came from the conf. call.
 - Before we focus on a strong campaign, are the resources in place?
 - Are the current resources working and adequate?
 - Parent resources
 - Healthcare provider resources

What NBS Resources Are Already Available?

In 2005, a number of NBS educational materials were distributed/made available to healthcare providers and parents

- ACT sheets
 - NBS materials produced by Terry Davis
 - Material from AAP, ACOG, and AAFP
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- Several key questions
 - Where the materials received?
 - If so, how were they used?
 - What was the response of healthcare providers and parents to the NBS material?
 - Are the materials sufficient to reinforce education between the healthcare providers and parents?
 - What improvements are needed?

Stages of the NBS Education Process

- In addition to the question of effectiveness of the NBS materials, at what point are the NBS materials most effective in aiding communication between the healthcare providers and parents (or vice versa) the importance of NBS.
 - Pre-natal (Front-end education)
 - Post-natal (Backend education)

Current Assessment of Prenatal and Postnatal NBS Education

- Based on current and proposed studies by AAP (example: Anne Gramiak presentation) and examples of published studies**, evaluation of the postnatal (backend) education process is already occurring.
- Assessment of the prenatal (front-end) education process, however, is inadequate and should be the focus of the Sub-Committee.

**Kemper et al. Primary Care Physicians' Attitudes Regarding Follow-up Care for Children with Positive Newborn Screening Results *Pediatrics* (2006) 118:1836-1841.

Prenatal Education Recommendation

- That the full ACHDGDNC Advisory Committee endorse the Sub-Committee emphasis on prenatal education by creating a mechanism to assess the healthcare provider-parent prenatal education process.

Preamble to the Following Recommendation

- The ACHDGDNC Education and Training Sub-Committee recommends that the ACHDGDNC Committee formally endorse prenatal education for parents, with emphasis on prenatal education that occurs within the health care provider-patient relationship, and by the professional organization and entities most frequently involved in prenatal education, such as AOG, AAP AAFP, hospitals, birthing centers, clinics and midwives.
- The fundamental message communicated should be consistent with current HRSA materials such that no new educational materials need to be created.

Formal Recommendation

- The ACHDGDNC Education and Training Subcommittee recommends that the full ACHDGDNC Advisory Committee endorse the following proposal:

“That the Dept of Health and Human Services Secretary develop and fund a mechanism to study the distribution of existing newborn screening educational material and acquisition of knowledge about newborn screening by expectant parents in the context of the clinician-patient relationship.”

Components of the Study

- The study should focus on prenatal education, with a target of the third trimester
- The study should be hypothesis driven
- The study should be completed within one year
- Evaluation of currently available material should be encompassed in the study. No new material should be created for the study
- Need to assess different methods of learning by parents
- Need to assess the methods of information transfer between the healthcare providers and parents
- Could use a geographical component to implement the study. For example, the use of Regional Genetics group resources or selecting a representative city with sufficient defined resources (large OB hospital)

Future Agenda Items

- Consideration of the postnatal (back-end) NBS education process
- Revisit the Sub-Committee communication plan
 - Getting the “message” out about NBS

Questions