

Activities Report

ACHDGDNC

October 21, 2005

E & T 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

E & T Subcommittee Composition Changes

- Association Members:
 - AAFP Dr Kahn
 - AAP Dr Edwards
 - ACOG Dr Gregg
- Parent TBD
- NBS program K. Velasquez (CA)
- Birth Facility G. Johannes (OH)
- Nursing/midwives TBD

Update on Association Partners Education Activities - AAFP

- Annual Clinical Focus Genomics
- Series of 8 programs NBS is up now
- 19 partner organizations contributed
- Designed for Providers, but likely could be used with NBS Program/Birth Center staff
- www.aafp.org
- E & T subcommittee will review

Update on Association Partners Education Activities AAP

- NBS Parent & Provider materials release perhaps early Nov 2005
- Dr T. Davis (MCHB/LSU) project
- Evaluation of materials Survey
- Clinical report on NBS & Medical Home
 - Policy statements

Update on Association Partners Education Activities - ACOG & NICHD

- HRSA/LSU NBS educational template project (Dr Davis)
- Federal agencies developing materials
 - Anticipate update at next SAC mtg

Other Business

- Alternate avenues for distribution of printed resources to general public
 - Assoc of librarians, Genetic & Rare Disease grp toll free line
- Other groups to consider:
 - Illiterate, disabled, deaf or blind persons
- Consider asking Google about the order of information provided when you type "newborn screening" into search engine

Other Business

- PSA's from the SAC for parents & providers
- Parents importance of NBS (general)
- Providers importance of emerging national recommendations for NBS
 - Thru assoc partners and/or MOD
- Pending HHS Secretary approval

Other Ideas for E & T SC

- Training needs ongoing discussion
 - State programs, Laboratians, Providers & residents, HCP's
 - Overlap with other SC's
- Consider a National Spokesman for NBS
- Coordination of information being developed

Next Steps

- Regular conference calls
- Assignment to review the AAFP program
- Review HRSA/LSU materials when available
- Invite Donna Wms to next SAC as consultant for presentation to SC

