

# Education & Training Subcommittee Report

*ACHDGDNC*

Sept 18, 2007

# Current Focus

- **Communication Plan**
  - **Guiding plan for the Sub-committee on Education and Training**
- **Proposal to Study the Response and Utilization Of NBS Education Material**
- **Proposal to Develop a Repository for NBS Education Material**

# Communication Plan

The Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (ACHDGDNC) was established to advise and guide the Secretary of the Department of Health and Human Services regarding the most appropriate application of universal newborn screening tests, technologies, policies, guidelines and programs for effectively reducing morbidity and mortality in newborns and children having or at risk for heritable disorders.

The ACHDGDNC established the Education and Training Subcommittee (E&T) to provide assistance in reviewing current newborn screening educational and training resources and programs for health professionals, affected families, screening program staff, hospital/birthing facility staff and the public. By evaluating existing resources and identifying gaps, the Subcommittee will make recommendations on current and future Federal programs targeting these five groups.

This communication plan is a working document to provide guidance towards accomplishing the E&T program goals.

# Communication Plan

- This communication plan outlines a newborn screening public education program formulated as a result of (1) recommendations presented at the Education and Training Subcommittee meetings June 2005-June 2007; (2) planning documents produced by NICHD staff ; (3) E&T subcommittee deliberations; and (4) other papers. The plan describes the development of a public education program for five primary target audiences: health professionals, affected families, screening program staff, hospital/birthing facility staff, and the public
- In developing the plan further, the E&T subcommittee will identify current education efforts and the most critical gaps in public knowledge, attitudes, and practices. The E and T subcommittee also will seek to use the AC resources most effectively; tasks outlined in this document will be prioritized according to need, opportunities for collaboration, and potential impact

# Recognition of Education Resource Materials

Many federal agencies, states and national organizations have developed materials focusing on newborn screening, including

- Health Resources and Services Administration
- Centers for Disease Control and Prevention
- Agency for Healthcare Research and Quality
- National Institutes of Health
  - National Library of Medicine
  - National Human Genome Research Institute
- The Office of Rare Diseases

# Program Goals

- Phase 1: Raise awareness of NBS
- Phase 2: Increase knowledge, attitudes, and practice
- Phase 3: Sustain the education process

# Partnerships and Target Audience

## Partnerships

- Health professional organizations
- Family advocacy groups
- Screening programs
- Federal and State agencies
- Hospital/birthing centers
- Community based organizations
- Academic institutions
- Corporate sector
- Others

## Target Audiences

- General public
- Families
- Healthcare providers
- Physicians
- Primary care: Ped, FP, OB
- Specialists: Genetics, other
- Nurses (NP and others)
- Public health
- Others (SW, OT, PT, Genetic Counselors)

# Proposal to Study the Response and Utilization Of NBS Education Material

## Background:

At the December 2006 meeting, the Subcommittee on Education and Training drafted a letter requesting that the Secretary approve and authorize a funding mechanism to study the response and utilization of NBS material that had been previously distributed to healthcare professionals.

“Dept of Health and Human Services develop and fund a mechanism to study the distribution of existing NBS materials and acquisition of knowledge about NBS by expectant parents in the context of the healthcare provider-patient relationship”.

In anticipation of approval, the Subcommittee has drafted guidelines for the proposal, broadly outlining the specifics and expectation of the study.

# Proposal to Study the Response and Utilization Of NBS Education Material

## Methods:

- The study should be hypothesis driven and focus on NBS education material that have been used in prenatal education and provider post natal education with a Target of evaluating how the NBS material was utilized.
- We want the evaluations to address the response of expectant parents to educational materials (i.e. literacy materials disseminated by AAP, ACOG, and AAFP, state newborn screening programs, and interactions with obstetricians, midwives and family physicians) provided as part of their prenatal care
- We also want to address the response by pediatricians and family physicians to educational materials (i.e. ACT sheets).
- The goals of this study should be a clear evaluation of the different methods of teaching utilized by the healthcare provider, the methods of learning demonstrated by the parents, and the methods utilized to transfer the NBS material between the healthcare providers and the parents.
- The outcome of the study will be a complete assessment of the education process with recommendations on how to improve the current NBS education material, recommendations on how the NBS education material is communicated and used by healthcare providers and expectant parents, and recommendations on the best mode of transferring the NBS education material between the healthcare provider and the parents.

# Proposal to Study the Response and Utilization Of NBS Education Material

## Participants:

It is anticipated that two study sites will be evaluated by this study mechanism. The number of participants used in the study should be provide enough statistical power to make the necessary conclusions needed and should encompass a significant population base representing an equitable ethnic representation of the country. The study should be performed within a single geographical region that will consist of a representative city with sufficiently defined resources, such as a city that is served by a large obstetrics hospital. It is expected that the study will also make use of resources from the Regional Genetics Collaborative responsible for that geographical area. .

## Timeline:

It is expected that the study should be completed within two years, with initial period of FY 2008 to develop the methodologies to perform the study followed by a one year evaluation and data analysis period in FY 2009.

# Proposal to Develop a Repository or NBS Education Material

- Based on the recommendation made at the May 2007 ACHDGDNC meeting, the Subcommittee on Education and Training has started to develop and revise proposal guidelines on develop of a national repository for NBS education material. This repository would contain NBS education material translated into other languages, focusing on ethnic and cultural aspects which make the NBS material pertinent to specific groups.
- In discussions with Dr. Brad Therrell from the Nation Newborn Screening and Genetics Resource Center, the Subcommittee has decided that the best use of resources would be to host the repository at the NNSGRC, making use of the current GEMS database, which current serves as a internet based portal to NBS educational material.
- The Subcommittee also recommends the development of criteria for deposition of NBS material into the repository based on guidelines developed by the Western Collaborative (Dr. Kathleen Velasquez). For translated material, these criteria would include:
  - relevant community testing
  - relevant field testing
  - and back translation

# Proposal to Develop a Repository or NBS Education Material

The Subcommittee on Education and Training recognizes the importance of proper development of these guidelines and methods for developing the repository.

Therefore the Subcommittee requests permission to have a one day planning meeting to discuss the specific guidelines for developing the repository. This meeting should occur prior to the Jan 2008 meeting of the ACHDGDNC, and should include representatives from the Subcommittee on Education and Training, HRSA, and the NNSGRC. We propose that the meeting be held in the Washington DC area.

# Questions