May 2010
Washington DC

Education & Training Subcommittee Report

Subcommittee Members

- Jana Monaco*
- Tracy Trotter*
- Natasha Bonhomme
- Colleen Buechner
- Frederick Chen
- Alan Fleishman
- Timothy Geleske
- Jaimie Higgs
- Joyce Hooker
- Thomas Musci
- Deborah Rodriguez
- Andrea Williams

UPDATES

- Newborn Screening Clearinghouse
  - Natasha Bonhomme
- Genetic Alliance/NNSGRC/HRSA
  - Website active – increase accessibility to information
  - Increase awareness of NBS – all stakeholders
  - Central linkage for data/resource sharing – 2000+
  - Just-in-time and POS access for parents and providers
  - Integrate electronic health technologies:
    - Data standards and collection
    - Educational materials

Updates

- Congenital Conditions Program
  - GA/HRSA/NCHPEG *Natasha Bonhomme*
- Family History for Prenatal Providers
  - NCHPEG/Harvard Partners/GA/MOD/HRSA
    - *Joseph McInerney*
- Health Information Technology Workgroup
    - *Sharon Terry*
- Parental Attitudes in NBS
  - Consumer Task Force *Deborah Heine*

Updates

- SACGHS
- Regional Genetics and Newborn Screening Service Collaboratives
- National Newborn Screening and Genetics Resource Center
- March of Dimes Foundation
- American Academy of Pediatrics
- American College of Obstetrics & Gynecology
- American Academy of Family Physicians

Pediatrics 2008; 121;192-217

- "Advances in NBS….new challenges to PCP, both educationally and in the management of affected infants. PCPs require access to information… collaboration with local, state, and national partners is essential….to optimize the function of the NBS systems"

PCP Education

- Genetics in Primary Care Training Institute
  - HRSA contract – HRS30107 [GPCTI]
  - Advisory Board + ACNDNC
  - Development phase – 6 mo
  - Implementation of Projects/Evaluation – 42 mo
  - Final Report to ACHDNC

GPCTI

- "To increase the number of primary health care providers who are competent and confident in providing basic information about newborn screening and common genetic disorders to their patients and their families"

GPCTI

- "In regions with limited genetic expert access, to increase the number of primary health care providers who will be more knowledgeable and secure in providing care that is more comprehensive to individuals and their families with less common genetic disorders."

Targeted knowledge areas

- Genetics / genomic medicine literacy
- Clinical utility of genetic tests
- Role in newborn screening;
- How to collect, document, and act upon a family health history;
- Sources for guidelines and clinical recommendations for genetics and genomic medicine
- Methods of informing families about genetic testing and obtaining consent
- When and how to refer to a genetic counselor or geneticist

Education & Training

- *Thank you for your attention.*