

September 2011
Washington DC

Education & Training Subcommittee

PAST, PRESENT & FUTURE

Subcommittee History

- Established by SACHDNC – January 2005
 -to review existing educational and training resources, identify gaps, and make recommendations regarding NBS to five groups:
 - Health Professionals
 - Parents
 - Screening program staff
 - Hospital/birthing facility staff
 - The Public

First meeting – April 2005

- Jennifer L. Howse, PhD – Chair
 - President, March of Dimes
- E. Stephen Edwards, MD
 - Past president, American Academy of Pediatrics
- William J. Becker, DO, MPH
 - Director, Public Health Laboratories - Ohio
- Gregory A. Hawkins, PhD
 - Center for Genomics – Wake Forest University

E&T Subcommittee Chairs

- Jennifer L. Howse, PhD
- William J. Becker, DO, MPH
- Gregory A. Hawkins, PhD
- Jana Monaco, PaD
- Tracy L. Trotter, MD
- Don Bailey, PhD, MEd

Current E&T Subcommittee Members

- Don Bailey*
- Tracy Trotter*
- Joseph Bocchini
- Natasha Bonhomme
- Colleen Buechner
- Frederick Chen
- Alan Fleishman
- Timothy Geleske
- Jaimie Higgs
- W. Allen Hogge
- Joyce Hooker
- Jana Monaco
- Deborah Rodriguez
- Cate Walsh Vockley
- Jacque Waggoner
- Andrea Williams
- Mary Willis

PAST

- Established ongoing dialogue on NBS issues with the major primary care professional organizations – ACOG, AAP and AAFP
- Expanded SC membership to include:
 - Parents
 - NBS program staff
 - Nurses
 - Genetic counselors

PAST

- Compiled listing of vetted websites with genetic/NBS resources.
- Facilitated the establishment of a national NBS Repository of educational material for all targets in multiple languages.
 - NNSGRC
 - Genetic Alliance
 - NLM
 - NCC/RC

PAST & PRESENT

- Provides input and feedback to numerous organizations who are developing educational programs in genetics and NBS:
 - March of Dimes
 - Genetic Alliance
 - NCHPEG
 - SACGHS
 - AAP, ACOG, AAFP
 - Regional Collaboratives

PAST

- Workshop on Genetic Education Topics in Maternal & Child Health....as a subset of..
- Developing a Blueprint for Primary Care Physician Education in Genomic Education
 - Convened by NHGRI/HRSA in June 2009
 - 30 representatives of PCP organizations
 - Knowledge areas
 - Barriers of educating PCPs
 - Possible educational interventions

RECENT PAST

- Summary and recommendations of the “Blueprint” meeting published in Genetics in Medicine – Feb 2010
- SACHDNC approved E&T recommendation
 - Develop a plan for a “Learning Collaborative – Genetics in Primary Care Training Institute”

FUTURE

- Genetics in Primary Care Institute contract awarded to American Academy of Pediatrics
 - Robert Saul, MD and Beth Tarini, MD – Med Directors
 - Improve provision of quality genetic-based medicine and services across the lifespan.
 - Pair genetics experts with 20 practices [3 members]
 - Mobilize a community of learners.
 - Technical assistance center.
 - Assess and address residency training needs

PRESENT UPDATES

- **Newborn Screening Clearinghouse**
 - *Natasha Bonhomme*
 - Genetic Alliance/HRSA
 - “BabysFirstTest.org” – launched Sept 7, 2011
 - Consumer Task Force – one year programs
 - Challenge Awards – application due October 30
 - Blogs and Twitter lists

Updates

- NBSC Challenge Awards

Engage the community and bridge NBSC with existing programs – outreach, engagement, and educational efforts.

- Awardees – April 1, 2011 – reports on BFT
 - March of Dimes
 - NYMAC
 - Hawaii Dept of Health
 - APHL

Updates

- Family History for Prenatal Providers
 - NCHPEG/Harvard Partners/GA/MOD/HRSA
 - *Emily Edelman*
- Regional Genetics and Newborn Screening Service Collaboratives – **[NYMAC]**
 - *Deborah Rodriguez*
- NNSGRC
 - *Colleen Buechner*
- Congenital Conditions Program
 - *Natasha Bonhomme*

Updates

- ACMG/NBSTRN
 - Michael Watson, MD
- American Academy of Pediatrics
 - Timothy Geleske, MD
- American Academy of Family Physicians
 - Frederick Chen, MD
- American College of Obstetrics & Gynecology
 - William Hogge, MD

S. 1858

- Newborn Screening Saves Lives Act of 2007
 - Sec 4, 5H
 - “The Advisory Committee on Heritable Disorders in Newborns and Children shall include recommendations, advice, or information dealing with public and provider awareness and education.”

National NBS Awareness Campaign

- Phase 1. Planning & Strategy Development
 - Media/environmental scan
 - Stakeholder analysis
 - Understand current messaging and resources
 - Identify information gaps
 - Define specific audiences
 - Facilitated “Strategy Summit”
 - Review analysis and solidify goals
 - Define priorities and target audiences

Jennifer Nichols

FUTURE DIRECTIONS

- There is continued need for E&T SubCommittee.
- Should we address implementation...or new SubC?
- Would benefit from increased ACOG participation.
- Consideration of additional nursing representation.
- Genetics training initiatives – include NBS.
- As SACHDNC expands beyond NBS, should E&T charge change?
- Collaboration with Evidence Review Group to produce guidance for groups nominating disorders.

Education & Training



- *Thank you for your attention.*