

May 2011
Washington DC

Education & Training Subcommittee Report

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

UPDATES

■ Newborn Screening Clearinghouse

- *Natasha Bonhomme*
- Genetic Alliance/HRSA
 - Beta Website active – nbsclearinghouse.org
 - User guide [PDF and Web page]
 - Condition specific information
 - NLM portal, GARD, NCBI, Disease InfoSearch
 - ACTion sheets
 - Blog posts
 - HRSA Genetics Collaboratives, Immune Deficiency Foundation
 - “BabysFirstTest.org” – to launch Sept 2011

Updates

- Beta site analysis – BabysFirstTest.org
 - Blenderbox.com
 - 1808 visits last 3 months
 - 65% new [unique users]
 - No real PR until Sept
 - Multiple Twitter lists
 - Materials WG and Public Education WG

Updates

- NBSC Challenge Awards
 - Engage the community and bridge NBSC with existing programs – outreach, engagement, and educational efforts.
 - Awardees – April 1, 2011 [6 mo projects]
 - March of Dimes
 - NYMAC
 - Hawaii Dept of Health
 - APHL

Updates

- **GA / NBSC – QUALITY INDICATORS**
- Genetic Alliance
- APHL
- CDC
- HRSA

- Report in September 2011

Updates

- Family History for Prenatal Providers
 - NCHPEG/Harvard Partners/GA/MOD/HRSA
 - *Alaina Harris*
- Regional Genetics and Newborn Screening Service Collaboratives – [**SERC projects**]
 - *Brian Pike*
- Genetics in Primary Care Institute
 - *Tracy Trotter*
- NNSGRC
 - *Colleen Buechner*
- Congenital Conditions Program
 - *Natasha Bonhomme*

Updates

- ACMGF Summer Genetics Scholar Program
 - Barry Thompson
- Preserving the Future of Newborn Screening
 - Kelly Leight
- Saving Babies Through Screening Foundation
 - Jill Levy-Fisch
 - Cate Walsh-Vockley

Updates

- 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

Tracy Trotter / Alaina Harris

Education & Training



- *Thank you for your attention.*