

September 2009

Bethesda, MD

Education & Training Subcommittee Report

Subcommittee Members

- Jana Monaco*
- Tracy Trotter*
- Natasha Bonhomme
- Colleen Buechner
- Frederick Chen
- Alan Fleishman
- Timothy Geleske
- Gregory Hawkins
- Joyce Hooker
- Thomas Musci
- Andrea Williams

UPDATES

- Newborn Screening Clearinghouse
 - HRSA – Genetic Services Branch
 - NNSGRC
 - Genetic Alliance
 - Increase awareness of NBS – all stakeholders
 - Central linkage for data/resource sharing
 - Just-in-time and POS access for parents and providers
 - Integrate electronic health technologies:
 - Data standards and collection
 - Educational materials

Updates

- Genetics and Newborn Screening Regional Collaborative Groups
- Genetic Alliance
- 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

- Partners:
AAP/AAFP/ACOG/NHGRI/NNCGRC/GA
- Focus on PCP roles in NBS:
 - Response to initial out-of-range result
 - ACT Sheets / State NBS Program
 - False out-of-range result
 - Coordinate complete evaluation
 - Provide medical home/coordinate care
 - Educate families, healthcare workers

Collaboration in Education

- E&T Subcommittee to serve in an advisory capacity to current groups involved in both PCP and public/family education:
 - NHGRI, NNSGRC, Genetic Alliance, NCCRCG, NCHPEG, Academies, and others
 - Avoid duplication / enhance collaboration

PCP Education

▣ NHGRI

- “Developing a Blueprint for Primary Care Physician Education in Genomic Education”
 - June 2009

▣ ACNDNC

- MCH roundtable on day two [30 participants]
- Specific educational needs and barriers
- Report for publication prepared by Alex Kemper

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

Barriers to Educating Primary Care Providers

- Lack of time
- Lack of geneticists to train primary care providers, especially those already in practice
- Lack of enthusiasm
 - Poor genetics and genomic medicine literacy
 - Lack of certainty and confidence
 - Concerns about relevance to child health care

Educational Interventions

- Develop educational curriculum for residency training programs.
- Assuring that board certification exams assess basic literacy in genetics and genomic medicine
- CME on the practical aspects of incorporating genetics and genomic medicine into primary care
- Promote participation in genetics and genomic medicine-related educational activities through the maintenance of board certification process
- Create a website that would organize both clinical recommendations and practical office tools (e.g., family health history forms, risk questionnaires)

Genetics in Primary Care Training Institute

- “Learning collaborative”
 - Pair physicians from busy primary care practices with expert in genetics and genomic medicine
 - All PCPs attend a conference to define opportunities for genetics in primary care
 - Develop specific one-year projects
 - Participate in frequent calls to review progress
 - Meet at the end of a year to share results
 - Institute to formally evaluate project impact

Next Steps

- Residency training material through RC activities
- Partnership with the American Board of Pediatrics
- Development of the Learning Collaboratives
- Follow-up MCH meeting

Public Education

- Need for increased public awareness of the NBS system