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# Education & Training Subcommittee Report

# Subcommittee Members

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- Natasha Bonhomme
- Colleen Buechner
- Frederick Chen
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- Timothy Geleske
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# UPDATES

- Newborn Screening Clearinghouse
  - Genetic Alliance/NNSGRC/HRSA
    - Website now active
    - 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

- Congenital Conditions Program
  - GA/HRSA/NCHPEG
- Perinatal Family Health History
  - NCHPEG/Harvard Partners/GA/MOD
- ACMGF Summer Internship Program
- SACGHS Educational Task Force

# Updates

- Genetics in Primary Care Training Institute
- Genetics and Newborn Screening Regional Collaborative Groups
- 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/NNSGRC/GA/MOD  
NCHPEG/ACMG/SACGHS/NCCRCG/NICHD
- Focus on PCP roles in NBS:
  - Response to initial out-of-range result
    - ACT Sheets / State NBS Program
  - Coordinate complete evaluation
  - Provide medical home/coordinate care
  - Educate families, healthcare workers

# 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



# Next Steps

- Residency training material through Regional Collaborative activities
- Partnership with the AAP, AAFP, ACOG and the American Board of Pediatrics
- Development of the Genetics in Primary Care Institute
- Follow-up with SACGHS