



Education and Training Subcommittee Report

- ▶ SACHDNC Advisory Committee Meeting
- ▶ September 14, 2012

Subcommittee Charge

- ▶ Review existing educational and training resources, identify gaps, and make recommendations regarding five groups:
 - ▶ Parents and the public
 - ▶ Parents
 - ▶ The public
 - ▶ Health professionals
 - ▶ Health professionals
 - ▶ Screening program staff
 - ▶ Hospital/birthing facility staff
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Goals for September 2012 meeting

- ▶ Review ongoing activities and updates from member organizations
 - ▶ Priority projects
 - ▶ Review progress to date
 - ▶ Identify next steps/goals for January 2012 meeting
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▶ **Priority projects**

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Member Organizations Updates

▶ AAP

- ▶ EQIPP NBS quality improvement program/course – *Newborn Screening: Evaluate and Improve Your Practice*
- ▶ Genetics in Primary Care Institute (GPCI)
 - ▶ Quality improvement initiative
 - ▶ *Genetic Literacy in Primary Care Colloquium*
 - ▶ Pediatric family history tool

▶ NCHPEG

- ▶ Prenatal Family History Tool
 - ▶ Collaboration with AAP on development of pediatric tool
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Priority A: Track, provide input on, and facilitate integration of national initiatives and committee-initiated activities

Priority A Project

▶ Aims

- ▶ Conduct scan to determine major education and training needs that extend into areas other than newborn screening
- ▶ Using a prototype condition, identify major education and training gaps

▶ Objectives

- ▶ Identify one heritable condition that is not part of the RUSP and for which screening and treatment most likely would occur at a later point in child development
 - ▶ In partnership with professional and parent organizations, identify major education and training needs for that condition
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Priority A Project

- ▶ **First Step: Create a list of possible prototype disorders**
 - ▶ Prototype characteristics
 - ▶ Not currently on/or previously considered for RUSP
 - ▶ Specific heritable condition (e.g., not “developmental disorders”)
 - ▶ Specific genetic etiology known
 - ▶ Availability of screening procedures
 - ▶ Effectiveness of screening to prevent costly diagnostic odyssey
 - ▶ May – Sept 2012: Solicited input from members of the Education & Training, Long-term Follow-Up, and Laboratory Standards Subcommittees, SACHNDNC members, Regional Collaboratives
 - ▶ Sept 2012: Create and present list Committee for additional input
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List of Possible Prototype Conditions

- ▶ Duchenne muscular dystrophy
 - ▶ Ehlers-Danlos Type IV
 - ▶ Familial adenomatous polyposis (FAP)
 - ▶ Fanconi's anemia
 - ▶ Fragile X
 - ▶ Friedreich's ataxia
 - ▶ Long QT syndrome
 - ▶ Marfan syndrome
 - ▶ Turner syndrome
 - ▶ Wilson's disease
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Priority B: Promote newborn screening awareness among the public and professionals

Priority B Project: Overall Objectives

- ▶ Support and provide input on the 2013 Newborn Screening Awareness Campaign plans and activities
 - ▶ How can/should the SACHDNC be involved in each of the various activities being planned?
 - ▶ Develop an action plan with specific objectives regarding professional practices in newborn screening awareness
 - ▶ What changes in professional practice would most likely result in increased public awareness about NBS and how can we make those happen?
 - ▶ Identify potential partner(s) to develop a plan to inform state legislators about the SACHDNC and evidence review process
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Priority B Project: Sept 2012

- ▶ CDC-APHL 50th Anniversary plans
 - ▶ APHL-NBS Symposium meeting in May 2013
 - ▶ Book documenting achievements in NBS
 - ▶ DC celebration event to coincide with Sept 2013 SACHDNC, will include “Day on the Hill”
 - ▶ Traveling exhibit of NBS history
 - ▶ Social media messaging
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Priority B Project: Sept 2012

- ▶ Subcommittee Discussion/Next Steps: 2013
 - ▶ Value of advocacy groups in spreading awareness
 - ▶ Need for messages (e.g., press releases, statistics) that can be used by member organizations to increase awareness of NBS in a standardized way

 - ▶ Subcommittee Discussion/Next Steps: *After* 2013
 - ▶ Create a toolkit for individual states to use when they celebrate their 50th anniversary
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Priority C: Provide better guidance for advocacy groups and others regarding the nomination and review process

Priority C

- ▶ **Problems to be solved**
 - ▶ Increase public transparency for what we do and the rationale for decisions made
 - ▶ Provide feedback to nominators regarding next steps
 - ▶ Support future nominators in preparing successful application packages
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Priority C Project

- ▶ Collaborate with Condition Review Group to develop public-friendly website information
 - ▶ Start with public-friendly summary of evidence review summary

 - ▶ Discussion/Next steps
 - ▶ Seek clarity on technical constraints on revisions to SACHDNC website
 - ▶ Work on harnessing potential of SACHDNC and NBS Clearinghouse websites to disseminate material
 - ▶ Create subcommittee to assist with creation of public-friendly documents, starting with a past review
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