Education and Training Subcommittee Report

SACHDNC Advisory Committee Meeting
May 17-18, 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

Current E&T Subcommittee Members

- SACHDNC Members
  - Don Bailey (chair)
  - Stephen McDonough
  - Joe Bocchini
  - Catherine Wicklund
  - Jeffrey Botkin
- Organization Representatives to SACHDNC
  - Frederick Chen (AAFP)
  - Beth Tarini (co-chair) (AAP)
  - ***Nancy Rose (ACOG)***
  - Mary Willis (DoD)
  - Joe Leigh Simpson (MoD)
  - Natasha Bonhomme (GA)
- Federally-Funded Grantees
  - Joyce Hooker (Regional Collaboratives)
  - Colleen Buechner (NNSGRC)
- Consultant Members
  - ***Emily Drake (birthing facility)***
  - ***Jeremy Penn (parent)***
  - Cate Vockley (genetic counselor)
  - ***Joan Scott (professional training)***
  - Deborah Rodriquez (state lab)
  - Jacque Waggoner (parent)

Goals for May 2012 meeting

- Review ongoing activities and updates from organizations and projects
- Hear a preliminary report about whether states collect data on newborn screening refusals and whether state policies affect refusal rates
- Discuss potential collaboration with the Condition Review Group to provide guidance for advocacy groups and others regarding the nomination and review process.
- Review findings and initial recommendations from the recent NBS Awareness Campaign Strategy Summit Meeting
- Discuss awareness activities planned in association with the2013 50th anniversary of newborn screening

Newborn Screening Awareness Activities

- Phase I media scan completed (report presented at prior SACHDNC meeting)
- April 26-27 Convened a strategy session to discuss strategies to inform and educate the public about newborn screening
  - Focus
  - Audiences
  - Messages
- 50th Anniversary plans
  - CDC – APHL taking major responsibility
  - Media scan and strategy session are being used to help inform the planning process
  - Wide range of interesting activities currently in planning stage

Genetic Alliance Updates

- Consumer Task Force is active
  - Promote newborn screening at the local level
  - Identify "on the ground" problems that might compromise the benefits of newborn screening
  - Help inform continued development of *Baby's First Test* website
- Successful Challenge Award Review Cycle
  - A number of interesting applications submitted
  - 6 new awards funded: List available on Genetic Alliance website
  - Primary focus: developing and evaluating the effects of educational materials
    - Videos
    - Social media
    - Print materials
    - Web-based applications

Newborn Screening Refusals: Policies and Practices (Lewis, Goldberg, Therrell)

- Conducted an email survey of 50 state labs and D.C.
  - Do you track the # of individual parent refusals for newborn screening (in contrast to comparing the # of screening samples received per year with # of births)?
  - What types of information do you collect on those refusals?
- 41% (21 states) do not track refusals
- Only 14 (27%) track reasons for refusals
- A better system to track and report refusals at the national would be useful surveillance information and would allow monitoring of trends
- Studies of the reasons for parent refusals and how those vary across settings or time would be very informative

Collaboration with Condition Review Group

- 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
- Several activities discussed
  - Create short, plain language summaries of evidence reviews
  - Provide "blueprint" for future nominators
  - Improve information on SACHDNC website
  - Create a "lessons learned" case study book for future nominators
  - Have a point person to help nominators navigate the process

Other Brief Reports

- Continued implementation of activities in the Genetics and Primary Care
  - 3-year (June 2011 – May 2014) cooperative agreement to American Academy of Pediatrics
  - Goal: to increase Primary Care Provider knowledge and skills in providing genetic-based services.
- ACOG
  - Variety of activities underway
  - Nancy Rose developing manuscript to provide further guidance for implementing ACOG recommendations regarding NBS information
- Family History for Prenatal Providers
  - Discussion deferred, possible SACHDNC presentation at next meeting

Priority 1: Enhance our ability to track, provide input on, and facilitate integration of national initiatives and committee-initiated activities

- Goals for the next year
  - Work with professional organizations to identify priorities for newborn screening awareness efforts
  - Conduct scan to determine major education and training needs that extend into areas other than newborn screening: goal within 1 year to have identified one major E&T goal that addresses a need related to genetic and metabolic disorders outside the newborn screening arena.

Priority 2: Promote newborn screening awareness among the public and professionals

- Continue to 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

Priority 3: Provide better guidance for advocacy groups and others regarding the nomination and review process

- Collaborate with the Condition Review Group to develop public-friendly summaries of previously conducted evidence reviews
- Create a subcommittee to recommend strategies for supporting nominators and advocacy groups
  - Increase clarity of nomination and review process
  - Provide guidance for "getting your condition ready for nomination and review"
  - Feedback on next steps
    - For nominated conditions deemed "not ready for review"
    - For reviewed conditions that are not approved for addition to RUSP