

Education and Training Subcommittee



Catherine Wicklund, Chair
Beth Tarini, Co-Chair

SACHDNC MEETING
SEPTEMBER 11-12, 2014

AGENDA



- Introductions and “2-minute updates” from committee members
- Final summary and next steps regarding Priorities

Priority A



Track, provide input on, and facilitate integration of national education and training initiatives

Priority A: Project Review



- Identify heritable conditions that are not part of the RUSP and for which screening and treatment most likely would occur at a later point in child development
 - Heritable conditions were chosen to represent a variety of clinical characteristics (age of presentation, age of diagnosis, clinical morbidity, etc)
- In partnership with professional and parent organizations, identify major education and training needs for each condition

Six Questions for Each Condition



- What is the typical pattern of identification of children with this condition?
- What problems exist with the current pattern of identification, problems that could be ameliorated to some extent by earlier identification?
- Would population screening outside of the newborn period be at all feasible or desirable?
- In the absence of population screening, what could be the likely best case scenario for earlier identification?
- What level of effort would be required to substantially change the current paradigm – minimal, moderate, substantial, or heroic?
- Which stakeholder groups would need to be engaged in any discussions about altering current practice?

Priority A: Final Steps



- Summarize major issues/themes that have emerged from this work: Complete
- Provide the Committee with a 2-page summary of the project: Ongoing
- Don Bailey/Beth Tarini: Discuss possibility of writing a white paper summarizing the work of this initiative and discussing the role of public health in childhood screening versus the role of practice guidelines

Priority B Initiatives Completed



Promote newborn screening awareness among the public and professionals

Priority C



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

Priority C Initiatives



- Public-friendly summary document of SACHDNC process (Nominations): Collaboration with Condition Review Group
 - Interview of advocates to identify important issues
 - Next steps: continued development TBD

Priority C: Current Effort



- Development of a glossary of terms to be incorporated into SACHDNC website
 - Revise the glossary to appropriate reading level: Jeremy Penn/Cate Walsh Vockley
- Work on implementation logistics
 - Identify appropriate location (e.g., SACHDNC website or Clearinghouse)

Next Steps



- Priority A and B objectives have been completed
- Developed short questionnaire on current trends and barriers to NBS to start discussion on needs and gaps within the E&T Subcommittee

Preliminary Needs Assessment



- What are the three most important issues facing newborn screening today?
- What are the three most important issues facing education and training about newborn screening today?
- In your own words, describe where newborn screening is today.
- What are the three biggest obstacles facing education and training regarding newborn screening?
- What are the biggest barriers we need to overcome with regard to newborn screening?
- What skills sets, current connections, and experiences do you bring to the table ?

Preliminary Themes



- Where do the most serious issues happen in the system: rare conditions and the challenges of educating stakeholders
- Education about and impact of false positives on parents
- Overwhelmed state health departments: lack of funding, vulnerability, IT needs, negative media attention
- Issues in general with the current infrastructure
- How to educate the public? What are the key relevant messages? How to utilize parents/public?

Preliminary Themes



- PCP access to specialists (just in time)
 - Are there ways to model access after other critical issues i.e. infectious disease/HIV etc.
- Timeliness issues
 - Education regarding timeliness and its impact?
- Genetics workforce issues:
 - Number, diversity
- Education needs regarding genome/exome sequencing?

Preliminary Needs Assessment



- **Committee wants to be mindful of:**
 - Where we can have the most impact? Influence?
 - Continue to be aware of other organizations' efforts and not be repetitive in our efforts
 - Where do heritable disorders in general fit into the work of the committee?
- **Await input from Committee on new priorities/projects**