

Education and Training Subcommittee Report



Don Bailey, Chair
Beth Tarini, Co-Chair

SACHDNC MEETING
APRIL 19, 2013

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) Catherine Wicklund
- Stephen McDonough Jeffrey Botkin
- Joe Bocchini

- **Organization Representatives to SACHDNC**

- Frederick Chen (AAFP) TBD (DoD)
- Beth Tarini (co-chair) (AAP) Natasha Bonhomme (GA)
- Nancy Rose (ACOG) Lisa Bujno (AMCHP)
- Cate Vockley (NSGC)

- **Federally-Funded Grantees**

- Joyce Hooker (Regional Collaboratives)

- **Consultant Members**

- Emily Drake (birthing facility) Joan Scott (professional training)
- Jeremy Penn (parent) Deborah Rodriguez (state lab)
- Jacque Waggoner (parent)

Priority A: Track, provide input on, and facilitate integration of national education & training initiatives



- **Project**

- 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

- **Rationale**

- The SACHDNC is charged with advising the Secretary about aspects of newborn and childhood screening....
- Exploratory work is needed to understand the challenges inherent in future attempts to make national recommendations regarding childhood screening

Childhood Screening Prototype Review Timeline



- Summer, 2012 Exemplar conditions nominated
- September, 2012 SACHDNC feedback
- Fall, 2012 Informal rating of conditions
- January, 2013 Three exemplar conditions selected
 - fragile X syndrome
 - long QT syndrome
 - Wilson's disease
- Summer, 2013 Review GEDDI draft for overlap/implications
- Fall, 2013 Input from stakeholders
- Winter, 2014 Report to SACHDNC regarding lessons learned and possible next steps

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



- **Project**
 - Support and provide input on the 2013 Newborn Screening Awareness Campaign plans and activities
 - Identify ongoing strategies for NBS awareness after 2013

Campaign Activities



- NBS Exhibits
- 2013 NBSGT/ISNS Meeting – May 5-10
- Website/ PSAs
- Coffee table and e-book
- Educational brochures
- Media coverage
- DC Reception and Awards Ceremony
- Social media outreach



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



- **Project**

- Collaborate with the Condition Review Group to develop public-friendly summaries of previously conducted evidence reviews as well as evidence review nominations that have not gone forward

Collaboration with Condition Review Group



- **Problems to be solved**
 - Increase public transparency for what we do and the rationale for decisions made
 - Support future nominators in preparing successful application packages
- **Activities**
 - 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

Condition Review Guidance Timeline



- Summer, 2012 SACHDNC report of activity timeline
- Fall-Spring, 2013 Draft documents prepared by Atlas Research
- Summer, 2013 CRW and E&T document revision
- September, 2013 Draft document to SACHDNC