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)

o 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 Rodriquez (state lab)

Jacque Waggoner (parent)

<u>Priority A</u>: 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 <u>and</u> 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

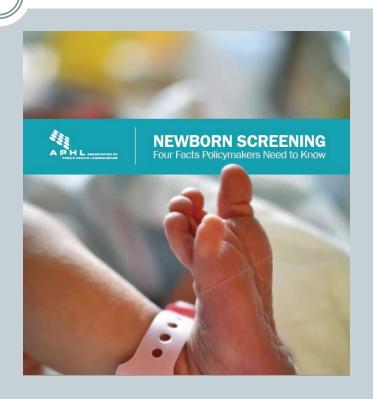
<u>Priority B</u>: Promote newborn screening awareness among the public and professionals

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



<u>Priority C</u>: 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