Education and Training Subcommittee Report

Don Bailey, Chair Beth Tarini, Co-Chair

DACHDNC MEETING
MAY 16, 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

Roll Call and Updates from Subcommittee Members

DACHDNC Members

Don Bailey (chair)

Catherine Wicklund

Stephen McDonough

Jeffrey Botkin

Joe Bocchini

Organization Representatives to DACHDNC

Frederick Chen (AAFP)
 Adam Kanis (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)

Proposed Request to DACHDNC Chair

- <u>FACT</u>: When our subcommittee cannot meet inperson with key constituents, it compromises our ability to effectively accomplish our mission
- **REQUEST**: We ask the DACHDNC chair to urge the Secretary in the strongest possible terms to reinstate in-person committee meetings

<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 DACHDNC (Committee) website
- Create a "lessons learned" case study book for future nominators

Original Condition Review Guidance Timeline

• Summer, 2012

Committee 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 Committee

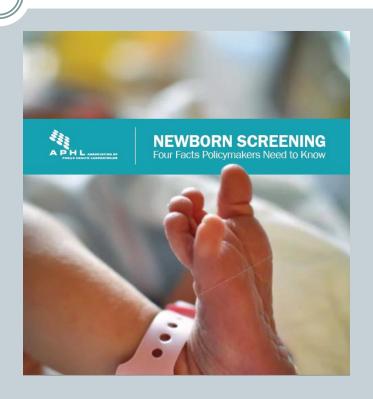
<u>Priority B</u>: Promote newborn screening awareness among the public and professionals

Current activities

- 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



QUESTION: What should be the focus of our post-campaign awareness activities?

- Our focus thus far has been on promoting awareness among the general public and professionals
- What is the most pressing awareness need in the next few years?

POSSIBLE THEME: "Cross-state harmonization of screening targets."

• What is the problem that needs to be solved?

- Not all states have established the RUSP as their primary screening protocol
- Cross-state discrepancies in screening were the focus of several major campaigns and initiatives about 10 years ago
- National harmonization has been a fundamental goal of the committee since its inception, to assure that every child has access to the same screening in every state
- Should we again focus on cross-state harmonization as our public awareness goal and how should we go about achieving it?

<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

Childhood Screening Prototype Review Timeline

January, 2013 Three exemplar conditions selected

-- fragile X syndrome

-- long QT syndrome

-- Wilson's disease

May 2013 Agree on questions to address and discuss FX

Review GEDDI draft for overlap/implications

September, 2013 Long QT syndrome review

Summer 2013

Jan/Feb, 2014

Wilson's disease & preliminary report

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?