

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)
- 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)

Proposed Request to DACHDNC Chair



- **FACT**: When our subcommittee cannot meet in-person 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

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 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

Priority B: 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?

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

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**
- **Summer 2013** **Review GEDDI draft for overlap/implications**
- **September, 2013** **Long QT syndrome review**
- **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?