

Education and Training Workgroup



Beth Tarini, Chair
Jane M. DeLuca, CO-Chair

ACHDNC MEETING
AUGUST 2, 2019

Members



- Joseph Bocchini
- Natasha Bonhomme
- Jane DeLuca
- Siobhan Dolan
- Barbara Ferreira
- Amy Gaviglio
- Aaron Goldenberg
- Joyce Graff
- Stacy Hines-Dowell
- Cynthia F. Hinton
- Yvonne Kellar-Guenther
- Mary Kleyn
- Keri LeBlanc

- Sylvia Mann
- Jeremy Penn
- Cynthia M. Powell
- Maa-Ohui Quarmyne
- **Steven J. Ralston (NEW)**
- Britton Rink
- **Jacqueline Rychnovsky (NEW)**
- Lisa M. Shook
- Beth Tarini
- Samantha Vergano
- Sarah Viall
- Cate Walsh Vockley

Current Member Activities



- **Natasha Bonhomme**

- Babies' First Test- Ask an Expert- analysis of submitted questions just finished. Follow up report in Nov.

- **Sylvia Mann**

- HRSA Family Education program- needs assessment; target 1000 people (at 800) with subgroup of 200 from underrepresented groups. How do people want their information delivered? Follow up report in Nov.

Specific Projects



- We have completed our projects (Education & Communication Guides)
 - Working toward dissemination
- We are “off-cycle” - we are working with the Committee and HRSA on new initiatives/next steps

Agenda for E & T Workgroup



- **Brainstorm current gaps in the field, topics, or issues the Workgroup(s) could help address, and specific projects ideas.**
- **Provide feedback on the components of the RUSP condition nomination and evidence review process, in particular the components discussed in April and what the Committee will discuss this afternoon.**

Brainstorming Gaps and Potential Projects



- Main focus of discussion – New ideas for projects! Lively discussion!

NBS state program education

- First, do we need to know what kinds of education/materials from state programs are out there?
- States' programs education materials may need updating, but do we know if they are effective? What measures can be used?
- What are best practices in education?
- What is the reality of NBS education?
 - ✦ If someone is in crisis, what do they need to know?
 - ✦ What do providers/parents need to know as new disorders roll out?

Brainstorming NBS Education Ideas



- **Development of Multi lingual Animation NBS videos**
 - Accessible to non-English speaking parents
 - *California Dreaming example of animation*
 - Concerns: Time and expense
- **Linking NBS education materials within EMR portal**
 - Substantial coordination efforts; not all patients access portals
- **Bridging the information gap between OB and pediatrics about NBS**
 - Fragmented, unconnected healthcare systems

Comments on the RUSP



- Values may not be represented or different perspectives appreciated in smaller groups (Who comprises the “citizens’ jury”? Those with time who are not working?)
 - May be difficult – some may not be accustomed to speaking one’s mind in a group
- Public health perspectives of NBS programs may not address individual NBS issues and vice versa; concerns raised that we may be examining public health processes through lens of an individual in NBS and visa versa.

Comments on the RUSP



- There is existing and underutilized data, from the time of initiating a screening test, for evaluating effectiveness of screening, diagnostics and treatment. This would offer a critical look at public impact.
- If there disorder screening does not perform as anticipated? How to address this? Are disorders removed from the RUSP? Under what conditions should disorders be removed?

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Questions?