

Education and Training Workgroup



Beth Tarini, Chair
Cynthia Powell, CO-Chair

ACHDNC MEETING
AUGUST 2, 2018

Members



- **Beth Tarini**
- **Cynthia Powell**
- **Joseph Bocchini**
- **Yvonne Kellar-Guenther**
- **Sarah Viall**
- **Mary Klein**
- **Barbara Ferreira**
- **Amy Gaviglio**
- **Aaron Goldenberg**

- **Stacy Hines-Dowell**
- **Siobhan Dolan**
- **Keri LeBlanc**
- **Jeremy Penn**
- **Adam Kanis**
- **Natasha Bonhomme**
- **Cate Walsh Vockley**
- **Britton Rink**
- **Joyce Graff**

Announcements



- **Welcome to Cynthia Powell, new co-chair**
- **Thank you to Cathy Wicklund, former co-chair**

Current Projects: Communication Guide



- **Final stages**
 - Discussed getting feedback from Pediatric Residents and Genetic Residents.
 - Working to link to ACT Sheet.
 - Identify most effective way to get it to the states, especially the end users.
 - ✦ List serve?
 - ✦ APHL?
 - ✦ Media options?
 - ✦ Other?

Current Projects: Education Guide



- **Final stages**
 - Will be posted on the Committee's website
 - Workgroup would like a way to validate/evaluate the guide as well as have a way to track or monitor usability (number of visits to the page, number of downloads?) and be able to thank users for their use and feedback.
 - ✦ Survey Monkey as a tool to collect feedback/comments?
 - ✦ Ask for their email address when they download the document and then follow up with them a week or two later send them an email asking for comments.
 - ✦ Work with HRSA to determine options given this a Committee product and will be posted on the Committee's website.
 - Need to fine tune introduction to target the end user, including more background and direction with regard to how to use the guide.
 - ✦ Status: drafting revised introduction

Brainstorm Projects: Provider Education



- **Problem**: Issues with communicating the limitations of newborn screening.
- **Target-Who**: Providers (generalist and specialist) – educating the providers on the limitations of newborn screening results (e.g. the possibility of a false negative). Providers can then better inform families.
- **Target-How**: North American Metabolic Academy

Brainstorm Projects: Public Education



- **Problem**: Explaining that a negative screening does not mean you do not have the disease
- **Target-Who**: Public – prenatal, postnatal, child, adult
- **Challenges**: Newborn screening is complex and nuanced.
- **Target-How**: Get focus groups of parents involved in this issue.

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Questions?