

# Education and Training Workgroup



**Beth Tarini, Chair**  
**Cynthia Powell, CO-Chair**

**ACHDNC MEETING**  
**NOVEMBER 2, 2018**

# Members



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

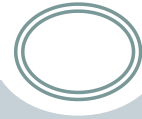
- **Stacy Hines-Dowell**
- **Siobhan Dolan**
- **Keri LeBlanc**
- **Jeremy Penn**
- **Adam Kanis**
- **Natasha Bonhomme**
- **Cate Walsh Vockley**
- **Britton Rink**
- **Joyce Graff**

# Current Member Activities



- **Yvonne Kellar-Guenther, NewSteps: Video tutorial, midwife-client discussions about NBS**
- **Cindy Powell: Early check project, voluntary screening in NC for Fragile X, SMA**
- **Cate Walsh Vockley: educational materials, NSGC**
- **Natasha Bonhomme: NBS Family Education Project**
- **Sue Barry, Amy Gaviglio, & Midwest Region: MOC4 Module for NBS**

# Current Member Activities



- **Masters Thesis, Amy Gaviglio's GC student: Newborn screening report design and content to improve parent and provider understanding**
- **Jeremy Penn: Parents' preferences for NBS result communication structure**
- **Beth Tarini: R01 post-screening harms**
- **Masters Thesis, Aaron Goldenberg: Content analysis of state NBS Educational materials**

# Current Projects: Communication Guide

- Discussed yesterday

The screenshot displays the website for the Federal Advisory Committees under the Health Resources & Services Administration. The page features a dark blue header with the organization's name and a search bar. Below the header, the main content area is titled "Federal Advisory Committees" and includes a search bar and a "Share This" button. A breadcrumb trail indicates the current location: Home > Advisory Committees > Advisory Committee on Heritable Disorders in Newborns and Children > Reports. A left-hand navigation menu lists various sections, with "Advisory Committees" highlighted in orange. The main content area is titled "Reports" and includes a sub-section for "Reports to Congress" with three links to annual reports from 2011 to 2017. Below this, there is a section for "Other Committee Reports" with a sub-section for "2018" containing two links to communication guides.

Health Resources & Services Administration Explore +

## Federal Advisory Committees

Advanced Search

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Home > Advisory Committees > Advisory Committee on Heritable Disorders in Newborns and Children > Reports

- Advisory Committees**
- Home
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- Recommended Uniform Screening Panel (RUSP)
- Nominate a Condition
- Previously Nominated Conditions
- Reports**
- Recommendations
- Newborn Screening Timeliness Goals

## Reports

### Reports to Congress

The Advisory Committee on Heritable Disorders in Newborns and Children Report to Congress 2013 – 2017 (PDF - 512 KB)

Secretary's Advisory Committee on Heritable Disorders in Newborns and Children 2013 Annual Report (PDF - 678 KB)

Secretary's Advisory Committee on Heritable Disorders in Newborns and Children 2012 Annual Report (PDF - 642 KB)

Secretary's Advisory Committee on Heritable Disorders in Newborns and Children 2011 Annual Report to Congress (PDF - 871 KB)

### Other Committee Reports

The Federal Advisory Committee on Heritable Disorders in Newborns and Children periodically produces white papers and reports to the Secretary of the U.S. Department of Health and Human Services. Along with providing their recommendations, these reports and papers address the mission of the committee, to reduce morbidity and mortality in newborns and children who have, or are at risk for, heritable disorders.

#### 2018

Communication guide for clinicians and providers to help frame the initial notification and discussion with parents about positive/abnormal/out-of-range newborn screening results (PDF - 290 KB)

The Role of Quality Measures to Promote Long-Term Follow-up of Children Identified by Newborn Screening Programs (PDF - 1.13 MB)

# Current Projects: Education Guide



- **Discussed yesterday**

# Ad-Hoc WG NBS Results Education



- **Issues for Ad-hoc group to consider:**
  - Definition and harmonization of terminology used by lab
  - Including communication of providers to parents in goals may be too great to tackle
  - Precision of action items

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**Questions?**