

Committee Related Work



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Welcome

- **August 2015 Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**
- **New Ex-officio Member**
 - AHRQ – Dr. Kamila Mistry
- **New Organizational Representative**
 - ACOG – Dr. Joseph Biggio
- **Roll Call**

ACHDNC Business

- **Secretarial Correspondence**
 - **HHS Acting Deputy Secretary Response**
 - **Timeliness Recommendations**
 - **MPS I is currently under review with the Department**
 - **Committee Letter to the Secretary on the NBS Informed Consent Recommendations**
 - **No response yet**

ACHDNC Priorities

- **Pilot Study Workgroup**
- **Cost Analysis Workgroup**
- **Timeliness Workgroup**
 - These workgroups will meet later today
 - These meetings are closed, however, summaries of the meetings will be presented tomorrow.
- **Determine essential elements for nomination of a condition to meet 9 month deadline**

ACHDNC Subcommittees – Moving Forward

- **During February 2016 in-person ACHDNC Meeting, subcommittees will meet to discuss priorities and potential projects on which the ACHDNC should focus**
- **Projects will be discussed, finalized and prioritized by the full Committee**
- **Goal**
 - **Address needs/gaps within the scope of work for the ACHDNC and does not duplicate activities**

Moving Forward

- **ACHDNC will hold 4 meetings per year**
 - **CY 2015**
 - Feb 12-13 (Webinar and In-person) ✓
 - May 11-12 (Webinar) ✓
 - Aug 27- 28 (Webcast and In-person)
 - Nov 2- 3 (Webinar)
 - **CY 2016 Meetings**
 - Feb 11-12 (Webcast and In-person)
 - May 9-10
 - Jul 25-26
 - Nov 3-4

August Meeting Topics

■ Day 1

- NewSTEPs presentation on the state of NBS in the U.S.
- Final Evidence Review Report on Newborn Screening for X-Linked Adrenoleukodystrophy (ALD)
- Vote on ALD

■ Day 2

- Summaries of workgroup meetings
- Updates on the implementation of SCID, CCHD, and Pompe

Committee Structure

- **ACHDNC Member Openings**
 - Received many nominations
 - New members selected, currently under review by HRSA/HHS
 - Expect terms to begin around July 2016
- **Organizational Representatives**
 - Examining ways of including more organizations
 - The process will be formalized in the ACHDNC By-laws

Ethics and COIs

- **When to recuse: In all matters likely to affect the financial interests of any organization with which you serve as an officer, director, trustee, or general partner unless you are also an employee of the organization or unless you have received a waiver from HHS authorizing them to participate.**

**VOTE –
MAY MEETING MINUTES**