

Committee Related Work



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Welcome

- February 2016 Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children
- Roll Call

ACHDNC Business

- **Secretarial Correspondence**
 - **MPS I Recommendations**
 - **Under review**
 - **ALD Recommendations**
 - **Under review**
 - **Committee Letter to the Secretary on the NBS Informed Consent Recommendations**
 - **Response received**
- **Comments submitted for the NPRM on Federal Policy for the Protection of Human Subjects**

Vote

**ACHDNC NOVEMBER 2015
MEETING MINUTES**

ACHDNC Subcommittees – Moving Forward

- **ACHDNC 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 tomorrow**
- **Goal**
 - **Address needs/gaps within the scope of work for the ACHDNC and do not duplicate activities**

ACHDNC Priorities

- **Pilot Study Workgroup**
- **Cost Analysis Workgroup**
 - Determine essential elements for nomination of a condition to meet 9 month deadline
- **Timeliness Workgroup**
 - Workgroups met yesterday

CY 2016 Meetings

- Feb 11-12 (Webcast and In-person)
- May 9-10 (Webcast and In-person)
- Jul 25-26 (tentative)
- Nov 3-4 (tentative)

February 2016 Meeting Topics

- Panel of experts on newborn screening long-term follow-up
- Projects for subcommittees
- Summaries of workgroup meetings

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.

Meeting Participation

- All federal committees governed by the Federal Advisory Committee Act (FACA), Public Law 92-463, as amended (5 U.S.C. App. 2), and by 41 C.F.R. Parts 101-6 and 102-3
- FACA sets the standards for the establishment, utilization, and management of Federal Advisory committees

Meeting Participation

- All Committee meetings are open to the public.
- If the public wish to participate in the discussion, the procedures for doing so are published in the Federal Register and/or announced at the opening of a meeting.
- With advance approval of the Chair or DFO, public participants may question committee members or other participants
- May submit written statements.
- Also, public participants should be advised that committee members are given copies of all written statements submitted to the public;
- Any further public participation will be solely at the discretion of the Chair and DFO

Webcast

- Remember to state your name first to ensure proper recording for the Committee transcript and minutes.