

Committee Related Work



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Welcome

- **November 2015 Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**
- **New Organizational Representative**
 - **AAFP – Dr. Robert Ostrander**
- **Roll Call**

ACHDNC Business

- **Secretarial Correspondence**
 - **HHS Secretary Response on MPS I**
 - **MPS I is under review by the ICC**
 - **Committee Letter to the Secretary on the NBS Informed Consent Recommendations**
 - **Under review**
 - **ALD Recommendations**
 - **Under review**

Vote

**ACHDNC AUGUST 2015
MEETING MINUTES**

ACHDNC Bylaws

- **Bylaws updated to reflect new legislative authority**

ACHDNC Bylaws – Organization Representatives

- **Allows for up to 15 organizations**
 - **Wide-ranging interests in newborn screening and heritable disorders, and whose work can inform the activities of the ACHDNC**
 - **Current 12 will remain as Org Reps**

ACHDNC Bylaws – Organization Representatives

- **Every 3 years**
 - **Reassessment of the interests, expertise, mission, relevancy and benefit provided by each organization as it relates to the ACHDNC's purpose, objectives, scope of activities and duties**
 - **Organizations will be asked to reaffirm their commitment to serving as an ACHDNC Organizational Representative**

ACHDNC Bylaws – Organization Representatives

■ *Selection of Organizational Representatives*

- Submit an application to the Designated Federal Official. The selection is based on review of the organization's subject area of expertise, mission, relevancy and benefit provided as it relates to the ACHDNC's purpose, objective, scope of activities and duties.
- More information will be available on the ACHDNC website
 - <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/>

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ACHDNC BY-LAWS 2015

ACHDNC Priorities

- **Pilot Study Workgroup**
- **Cost Analysis Workgroup**
- **Timeliness Workgroup**
 - **Workgroups met yesterday**
- **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

November Meeting Topics

- **Informed Consent, NPRM on the Common Rule and its impact on NBS**
- **Innovative Strategies for Transition Models from Pediatric to Adult Health Care**
- **Various education efforts in NBS**
- **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

Webinar

- **Members of the Public - Sound will be coming through your computer speakers, so please make sure you have your computer speakers turned ON.**
- **Committee members and org reps, your sound will be coming through your phone line, so please make sure you have your computer speakers turned OFF.**

Webinar

- Remember to state your name first to ensure proper recording for the Committee transcript and minutes. Press *0 if have any problems with your phone line.
- If time permits, a comment box will be available so that members of the public may provide input.