Advisory Committee on Heritable Disorders in Newborns and Children
February 8, 2018

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Professor and Chairman
Department of Pediatrics
Louisiana State University Health – Shreveport
ACHDNC Business

- Welcome
- Roll Call
- Vote - November Minutes
- New Organization Representative
- New Committee Website
- Call for New Committee Members
- Next Meetings
- Today’s Meeting Topics
ROLL CALL
NOVEMBER MEETING MINUTES - VOTE
ORGANIZATION REPRESENTATIVE FOR THE AMERICAN ACADEMY OF PEDIATRICS:

DR. DEBRA FREEDENBERG
NEW COMMITTEE WEBSITE

www.hrsa.gov/advisory-committees/heritable-disorders
NEW COMMITTEE MEMBERS 2018
NEXT MEETINGS

- May 10-11, 2018
- August 2-3, 2018
- November 1-2, 2018

- Meeting dates have been set up through 2020 and can be found on the Committee’s website: https://www.hrsa.gov/advisory-committees/heritable-disorders/meetings/index.html
MEETING TOPICS
WEDNESDAY, NOVEMBER 8, 2017

- Overview of Cutoff Determinations and Risk Assessment Methods used in Dried Blood Spot Newborn Screening
- SMA: Final Evidence Review Report / Committee Vote
- Follow Up and Treatment Workgroup Report: The Role of Quality Measures to Promote Long-Term Follow-up of Children Identified by Newborn Screening Programs
Advisory Committee on Heritable Disorders in Newborns and Children

- Established under the Public Health Service Act, Title XI, § 1109 (42 U.S.C. 300b-10), as amended by the Newborn Screening Saves Lives Reauthorization Act of 2014 (P.L. 113-240)

- 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
Ethics and COIs

- Advisory to the Secretary of HHS
- Inquiries about the Committee
- 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 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.
  - The Notice of Meeting in Federal Register indicated two options for public comment:
    - Request to make oral comments at the meeting
      - Public Comments are scheduled to take place between 9:50am – 10:30am
    - Submit written statements
      - Committee members receive copies of all written statements submitted
      - No written statements have been received for the February 8th meeting
  - Any further public participation will be solely at the discretion of the Chair and DFO
Visitors only have access to the 5th floor of the building (Pavilion, cafeteria, restrooms, and meeting rooms).
- All other areas of the facility are restricted and require an escort by a HRSA staff member. No exceptions.

If you need to leave and re-enter, you will be required to go through security screening again and will require an escort to meet you at Security to escort you in the building.
- 15 minutes prior to and after the lunch break has ended a HRSA escort will be at the main entrance to those who need to leave and come back after lunch.
- For other re-entry needs, please notify a HRSA staff member or a registration team member.