

Advisory Committee on Heritable Disorders in Newborns and Children November 8-9, 2017



Joseph A. Bocchini, Jr. MD

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

ACHDNC Business

Welcome

New Committee Members

Roll Call

Vote - August Minutes

Welcome New Members

Susan Berry, MD

Cynthia Powell, MD

Scott Shone, PhD

Laura Kavanagh, MPP

ROLL CALL

AUGUST MEETING MINUTES - VOTE

ACHDNC Business

Next Meetings

- February 8-9, 2018
- May 10-11, 2018
- Meeting dates have been set up through 2020 and can be found on the Committee's website
<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/upcomingmeetings.html>

Workgroup Openings

- Currently accepting nominations for the following workgroups:
 - Education and Training
 - Follow-up and Treatment
 - Laboratory Standards and Procedures
- Self-nominations should include a statement of interest and your CV or Résumé
- Nominations must be emailed to Alaina Harris (email: aharris@hrsa.gov) by November 20, 2017

New Committee Members 2018

- Call for nominations will be announced in the Federal Register next year.

Meeting Topics

Wednesday, November 8, 2017

- **Working Toward Newborn Screening Timeliness Goals**
- **Implications of Detecting Carriers Through Newborn Screening**
- **SMA Evidence Review – Phase 2 Report**

Meeting Topics

Thursday, November 9, 2017

- **Workgroup Updates**
 - **Follow-up and Treatment**
 - **Education and Training**
 - **Laboratory Standards and Procedures**
- **Prioritizing 2018 Workgroup Activities**
- **Clinical and Public Health Impact of SCID Screening**

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.
 - Request to make oral comments at the meeting
 - Submit written statements
 - Committee members are given copies of all written statements submitted
- Any further public participation will be solely at the discretion of the Chair and DFO
 - Public participants may ask questions of committee members, presenters, or other participants only with prior approval of the Chair or DFO

5600 Fishers Lane Building Info

- **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.