

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



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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

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Advisory Committee on Heritable Disorders in Newborns and Children

UPCOMING MEETING

UPDATE: the previously scheduled two day meeting will now be a one day meeting held on February 8, 2018.

For up-to-date information about the status of this meeting, please visit <http://www.achdncmeetings.org/>.

Dates and Times

February 8, 2018, 8:30 a.m. to 3:00 p.m. ET

Location (In-Person)

Health Resources and Services Administration
5600 Fishers Lane
5th Floor Pavilion
Rockville, MD 20857

Registration Deadline:

Monday, February 5, 2018, 12:00 PM ET

Registration:

For technical problems gaining access to the [registration website](#), please email Morgan Pinckney.

Public Comments:

To submit written comments or request time for an oral comment at the meeting, please [register online](#) by January 31, 2018 by 12:00 pm EST. To ensure all individuals who have registered and requested time for oral comments are accommodated, the allocated time for comments may be limited. Individuals associated with groups or who plan to provide comments on similar topics may be asked to combine their comments and present them through a single representative. No audiovisual presentations are permitted.

Contact:

For additional information, questions on public comments, or individuals who need special assistance, please email Ann Ferrero.

The mission of the Advisory Committee on Heritable Disorders in Newborns and Children is to reduce morbidity and mortality in newborns and children who have, or are at risk for, heritable disorders. The Advisory Committee on Heritable Disorders in Newborns and Children (Committee) was 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).

The Committee recommends that every newborn screening program include a Uniform Screening Panel (PDF - 12 MB)* that screens for 34 core disorders and 26 secondary disorders; the disorders' selection was based on the *Newborn Screening: Towards a Uniform Screening Panel and System* (PDF - 191 KB).

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**

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.**