

**Advisory Committee on Heritable
Disorders in Newborns and Children
Webinar Meeting
November 1-2, 2018**

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ACHDNC Business

- **Welcome**
- **Roll Call**
- **Vote – August Minutes**

COMMITTEE BUSINESS

CALL FOR COMMITTEE MEMBERS

CALL FOR WORKGROUP MEMBERS

- **Nominations for new workgroup members is open:**
 - **Education and Training Workgroup**
 - **Follow up and Treatment Workgroup**
 - **Laboratory Standards and Procedures Workgroup**

CALL FOR ORGANIZATION REPRESENTATIVES

Organizations eligible include:

Public health constituencies (state and local)

- Primary Care
- Specialty/Subspecialty
- Other federal agencies

Consumer/family organizations with a broad focus and constituencies

COMMITTEE ACTIVITIES

Review, evaluate and update, as required, the condition nomination process, evidence-based review process including impact on public health system, grading evidence and the decision matrix.

Develop processes for reviewing conditions on the RUSP and for consideration for removal of a condition from the RUSP.

COMMITTEE ACTIVITIES

Review of progress toward timeliness goals.

Review of impact of implementation of conditions recently added to RUSP on states.

COMMITTEE ACTIVITIES

New Ad-hoc Workgroup to address the overlapping issues identified through our review of risk assessment in newborn screening and interpretation of results.

FUTURE MEETINGS DATES

- February 7- 8, 2019 (in person and webcast)
- **April 23-24, 2019 – NEW DATES** (in person and webcast)
- August 1-2, 2019
- November 7-8, 2019

- Meeting dates through 2020 can be found on the Committee's website:

<https://www.hrsa.gov/advisory-committees/heritable-disorders/meetings/index.html>

MEETING TOPICS

THURSDAY, November 1, 2018

- Cerebrotendinous Xanthomatosis (CTX)
Nomination**
- Baby's First Test**
- A Panel on Education Activities in Newborn
Screening**

MEETING TOPICS

FRIDAY, November 2, 2018

- A Panel on Genomic Sequencing in Newborn Screening: Ethical, Legal, and Social Implications**
- Ethical, Legal, and Social considerations for Newborn Screening Pilot Studies**
- Updates from the Workgroups**

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 Conflicts of Interest (CIOs)

- **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 announced at the opening of a meeting.
- The Notice of Meeting in Federal Register indicated two options for public comment:
 - Oral Comments – 6 requests received
 - Submit written statements – 2 written statements received
 - Committee members receive copies of all written statements submitted
- Any further public participation will be solely at the discretion of the Chair and DFO

5600 Fishers Lane Building Info

- **Visitors only have access the Pavilion, cafeteria, restrooms, and meeting rooms.**
 - **All 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 a HRSA escort to meet you at Security to escort you in the building.**
 - **15 minutes prior to and after the lunch break ends a HRSA escort will be at the main entrance for those who need to leave and return.**
 - **For other re-entry needs, please notify a HRSA staff member or a registration team member.**

5600 Fishers Lane Building Info

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- In case of emergency please exit through the front door of 5600 Fishers Lane, cross the street, and meet on the parking pad to the left. Your escorts will have a roster and ensure everyone is accounted for.
- Please do not take any non-essential items with you if there is an evacuation, as it could delay your reentry into the building.