



ACHDNC
*Secretary's Advisory Committee
on Heritable Disorders in
Newborns and Children*

Advisory Committee on Heritable Disorders in Newborns and Children Meeting

September 24, 2019

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DEPARTMENT OF PEDIATRICS



ACHDNC Business

- **Welcome**
- **Roll Call**
- **Vote – August 2019 Minutes**

ACHDNC REPORT

MEDICAL FOODS FOR INBORN ERRORS OF METABOLISM: THE CRITICAL NEED TO IMPROVE PATIENT ACCESS



MEETING TOPICS

Tuesday, September 24, 2019

- Data Interoperability in Newborn Screening: State Experiences
- Review of the RUSP Condition Nomination and Evidence Review Process: Public Health System Impact Assessment



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** – 2 requests received. Public Comments are schedule for 10:45am today.
 - **Written Statements** – 1 written statement received. Committee members were provided a copy of the written statement prior to the meeting.
- Any further public participation will be solely at the discretion of the Chair and DFO.

Webinar Instructions

- **Members of the Public**
 - Audio will come through your computer speakers.
 - There is also a call in option. The number is listed on the screen.
- **Committee Members and Organization Representatives**
 - Audio will come through your phone line. Please make sure you have your computer speakers turned OFF.
 - Please speak clearly and 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.
 - In order to facilitate discussion, please use the “Raise Hand” feature in Adobe Connect when wanting to make comments or ask questions.
- **Technical Difficulties**
 - Try re-opening the webinar using a different browser.
 - If you still have technical issues, please refer to the contact information provided in the registration confirmation email you received.

