



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Service Administration

Advisory Committee on Heritable Disorders in Newborns and Children

AGENCY: Health Resources and Service Administration (HRSA), Department of Health and Human Services (HHS).

ACTION: Notice of Meeting.

SUMMARY: In accordance with the Federal Advisory Committee Act, notice is hereby given that a meeting is scheduled for the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). This meeting will be open to the public but advance registration is required. Please register online at <http://www.achdncmeetings.org/> by 12:00 p.m. Eastern Time on November 6, 2017. Information about the ACHDNC can be obtained by accessing the following website:

<https://www.hrsa.gov/advisorycommittees/mchbadvisory/heritableisorders/index.html>.

DATES: The meeting will be held on Wednesday, November 8, 2017, 9:30 a.m. to 5:00 p.m. Eastern Time and Thursday, November 9, 2017, 9:30 a.m. to 3:00 p.m. Eastern Time (meeting times are tentative).

ADDRESSES: This meeting will be held in-person at 5600 Fishers Lane, 5th Floor Pavilion, Rockville, MD 20857. The meeting will also be accessible via Webcast. Instructions on how to access the meeting via Webcast will be provided upon registration. Please note, the 5600 Fishers Lane building requires security screening on entry. Visitors must provide a driver's license, passport, or other form of government-issued photo identification to be granted entry into the facility. Non-US Citizens planning to attend in person will need to provide additional information to HRSA by October 24, 2017, 12:00 p.m. Eastern Time. Please see contact information below.

FOR FURTHER INFORMATION CONTACT: Anyone requesting information regarding the ACHDNC should contact Ann Ferrero, Maternal and Child Health Bureau (MCHB), HRSA, in one of three ways: 1) send a request to the following address: Ann Ferrero, MCHB, HRSA 5600 Fishers Lane, Room 18N100C, Rockville, MD 20857; 2) call 301-443-3999; or 3) send an email to: AFerrero@hrsa.gov.

SUPPLEMENTARY INFORMATION: The ACHDNC provides advice to the Secretary of HHS on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. In addition, ACHDNC's recommendations regarding inclusion of additional conditions and inherited disorders for screening which have been adopted by the Secretary are then included in the Recommended Uniform Screening Panel (RUSP). Conditions listed on the RUSP constitute part of the comprehensive preventive health guidelines supported by HRSA for infants and children under section 2713 of the Public Health Service Act, codified at 42 U.S.C. 300gg-13. Under this provision, non-grandfathered health plans are required to

cover screenings included in the HRSA-supported comprehensive guidelines without charging a co-payment, co-insurance, or deductible for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

The meeting agenda will include: (1) an update on states' progress toward the newborn screening timeliness goals outlined by the Committee; (2) a presentation on phase 2 of the spinal muscular atrophy evidence review; (3) presentations on newborn screening topics such as the clinical and public health impact of Severe Combined Immunodeficiency (SCID), carrier status in the context of newborn screening, and a review of long term follow up in newborn screening; and (4) updates from the Laboratory Standards and Procedures workgroup, Follow-up and Treatment workgroup, and Education and Training workgroup. The Committee will not be voting on a proposed addition of a condition to the RUSP. Agenda items are subject to change. The final meeting agenda will be available 2 days prior to the meeting on the Committee's website: <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Members of the public will have the opportunity to provide comments. All comments are part of the official Committee record. To submit written comments or request time for an oral comment at the meeting, please register online by 11:59 p.m. Eastern Time on November 2, 2017, at <http://www.achdncmeetings.org/>. 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. Written comments should identify the individual's name, address, email, telephone number, professional or organization affiliation, background or

area of expertise (i.e., parent, family member, researcher, clinician, public health, etc.) and the topic/subject matter.

Individuals who plan to attend and need special assistance, such as sign language interpretation or other reasonable accommodations, should notify Ann Ferrero using the address and phone number above at least 10 days prior to the meeting.

Amy McNulty,
Acting Director, Division of the Executive Secretariat.
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