



BILLING CODE: 4165-15

## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Health Resources and Services Administration**

#### **Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services 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 of the following meeting for the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). The meeting will be open to the public but advance registration is required. The online registration deadline is Thursday, May 4, 2017, 5:00 p.m. Eastern Time. Please check the website for additional guidance and registration information. The registration link is <http://www.achdncmeetings.org/>. Information about the agenda for this meeting can be obtained by accessing the following website:

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

**DATES:** The meeting will be held on May 11, 2017, 9:00 a.m. to 5:00 p.m. and May 12, 2017, 9:00 a.m. to 3:00 p.m.

**ADDRESSES:** This meeting will be held in-person and by webcast. The address for the meeting is 5600 Fishers Lane, 5<sup>th</sup> Floor Pavilion, Rockville, MD 20857. Webcast information will be emailed to you after you register.

**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 Ann Ferrero, MCHB, HRSA 5600 Fishers Lane, Room 18N100C, Rockville, Maryland 20857; 2) call 301-443-3999 or 3) send an email to: AFerrero@hrsa.gov. More information on the Advisory Committee is available at the Advisory Committee's website, provided above.

**SUPPLEMENTARY INFORMATION:** The ACHDNC, as authorized by Public Health Service Act, Title XI, § 1111 (42 U.S.C. 300b-10), 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 guidelines supported by HRSA for infants, children, and adolescents. Pursuant to section 2713 of the Public Health Service Act, codified at 42 U.S.C. 300gg-13, non-grandfathered health plans and health insurance issuers 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 will include: (1) presentations and discussion on the process of identifying and following up on out of range newborn screening results; (2) a presentation on newborn screening quality assurance programs; (3) presentations on the clinical and public health impact of Critical Congenital Heart Defects screening; (4) discussion and possible vote on a report on Medical Foods for Inborn Errors of Metabolism; (5) a presentation, discussion, and possible vote on whether to move a nomination forward to evidence review for spinal muscular atrophy (SMA);

and (6) 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. The final meeting agenda will be available two (2) days prior to the meeting on the Committee's website: <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Members of the public may submit written and/or present oral comments at the meeting. All comments are part of the official Committee record. Advance registration is required to submit written comments and/or present oral comments. Written comments must be submitted by April 28, 2017, 12:00 p.m. Eastern Time to be included in the May meeting briefing book. 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 wish to provide oral comments must register by Thursday, May 4, 2017, 5:00 p.m. Eastern Time. To ensure that all individuals who have registered to make oral comments can be accommodated, the allocated time may be limited. Individuals who are associated with groups or have similar interests may be requested to combine their comments and present them through a single representative. No audiovisual presentations are permitted. For additional information or questions on public comments, please contact Ann Ferrero, MCHB, HRSA; email: [AFerrero@hrsa.gov](mailto:AFerrero@hrsa.gov).

The 5600 Fishers Lane building requires a security screening on entry. To facilitate your access to the building, please contact Ann Ferrero at 301-443-3999. Individuals who plan to attend and need special assistance, such as sign language interpretation or other reasonable accommodations, should notify Ann Ferrero, MCHB, HRSA; email: [AFerrero@hrsa.gov](mailto:AFerrero@hrsa.gov), at least 10 days prior to the meeting.

**Jason E. Bennett,**

*Director,*

*Division of the Executive Secretariat.*

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