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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Meeting of the 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 about a meeting of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). This meeting will be open to the public but advance registration is required.

Information regarding the ACHDNC can be found at

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

DATE: The meeting will be held on February 9, 2017, from 9:00 a.m. to 5:00 p.m. EST.

ADDRESSES: This meeting will be a webinar. The public can join the meeting by registering in advance. The registration link is available at

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/>. The registration deadline is February 6, 2017, 11:59 p.m. Eastern Time.

FOR FURTHER INFORMATION CONTACT: Anyone requesting information regarding the ACHDNC should contact Alaina Harris, Maternal and Child Health Bureau (MCHB), HRSA, Room 18W66, 5600 Fishers Lane, Rockville, Maryland 20857; email: aharris@hrsa.gov.

SUPPLEMENTARY INFORMATION: ACHDNC, as authorized by the Public Health Service Act (PHS), Title XI, § 1111 (42 U.S.C. 300b-10), was established to advise the Secretary of HHS about 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 recommendations regarding additional conditions/inherited disorders for screening that have been adopted by the Secretary are included in the Recommended Uniform Screening Panel and constitute part of the comprehensive guidelines supported by HRSA. Pursuant to section 2713 of the PHS, codified at 42 U.S.C. 300gg-13, 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 1 year from the Secretary's adoption of the condition for screening.

ACHDNC will hear presentations and discussions on topics related to 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. ACHDNC will also hear updates from the Laboratory Standards and Procedures workgroup, Follow-up and Treatment workgroup, and Education and Training workgroup. Agenda items are subject to changes as priorities indicate. ACHDNC will not be voting on a proposed addition of a

condition to the Recommended Uniform Screening Panel. The detailed meeting agenda, and any changes to the start and end times, will be available 2 days prior to the meeting on the ACHDNC 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 ACHDNC record. Advance registration is required to submit written comments and/or present oral comments. Written comments must be submitted by February 6, 2017, 11:59 p.m. EST to be included in the February meeting briefing book. Written comments should identify the individual's name, address, email, telephone number, professional or business affiliation, type of expertise (i.e., parent, researcher, clinician, public health, etc.), and the topic/subject matter of comments.

Individuals who wish to provide oral comments must register by February 6, 2017, 11:59 p.m. EST. To ensure that all individuals who have registered to make oral comments can be accommodated, time may be allocated per speaker. 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 Alaina Harris, MCHB, HRSA; email: aharris@hrsa.gov.

Individuals who need special assistance, such as sign language interpretation or other reasonable accommodations, should notify Alaina Harris at aharris@hrsa.gov at least 10 days prior to the meeting.

Jason E. Bennett

Director, Division of the Executive Secretariat

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