

Announcement: The next meeting of the Advisory Committee on Heritable Disorders in Newborns and Children will be held on Thursday, August 27, 2015 from 8:30am to 3:30pm and Friday, August 28, 2015 from 9:00am to 12:30pm. The meeting will be held at 5635 Fishers Lane, Rockville, Maryland 20857. The meeting will also be webcasted.

Registration: The meeting will be open to the public with in-person attendance limited to space availability. Participants have the option of viewing the meeting via webcasting. Whether attending the meeting in-person or via webcast, **all** participants must register in advance at <https://www.blsmeetings.net/ACHDNCAugust2015>. **The registration deadline has been extended to Friday, August 21, 2015, 11:59 PM Eastern Time.** For technical problems gaining access to the registration website, please email Anthony Rodell at arodell@seamoncorporation.com

Agenda: Agenda items include: (1) a final evidence review report on Adrenoleukodystrophy (ALD) Condition Nomination for inclusion on the RUSP, (2) a presentation by the Newborn Screening Technical assistance and Evaluation Program on their activities and data repository, (3) updates on the implementation of Severe Combined Immunodeficiency, Critical Congenital Heart Disease, and Pompe Disease, (4) updates from workgroups focused on cost analysis in newborn screening, newborn screening timeliness, and pilot studies for evidence based reviews of conditions. Following the final evidence review report on ALD, the Committee is expected to vote on whether or not to recommend to the Secretary the addition of ALD to the RUSP.

Agenda items may be subject to change as necessary or appropriate. The agenda, webinar information, and other meeting materials will be located on the Committee's website: <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Public Comments: Members of the public may present oral comments and/or submit written comments. Comments are part of the official Committee record. Public comment periods are tentatively scheduled for August 27 and 28, 2015. Advance registration is required <https://www.blsmeetings.net/ACHDNCAugust2015>. **The deadline to register for public comments and/or submit written comments is Friday, August 21, 2015, 11:59 PM Eastern Time.**

Written comments must be received by the deadline in order to be included in the August 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. 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 questions on public comments, please contact Lisa Vasquez at lvasquez@hrsa.gov.

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