

**Announcement:** The 29<sup>th</sup> meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) will be held as a webinar on January 31, 2013 from 9:30 am to 5:00 pm and February 1, 2013, 9:30 am to 1:15 pm

**Registration: To attend this webinar meeting, you must register by 5 P.M. Eastern Time, Thursday, January 17, 2013.**

**Registration is at:** [https://hrsa.connectsolutions.com/sachdnc\\_event/event/registration.html](https://hrsa.connectsolutions.com/sachdnc_event/event/registration.html)

Individuals who need special assistance, such as sign language interpretation or other reasonable accommodations, should indicate their needs on the registration website.

**Agenda:** The meeting will include: (1) updates on state implementation of newborn screening for Critical Congenital Heart Disease (CCHD) and Severe Combined Immunodeficiency Disorder (SCID); (2) update on the Pompe Condition Nomination; (3) update on application of the SACHDNC Condition Review Matrix; (3) updates on priority projects from the Advisory Committee's subcommittees on Laboratory Standards and Procedures, Follow-up and Treatment, and Education and Training; (4) a presentation on the Duchenne Muscular Dystrophy Newborn Screening Symposium; (5) a final workgroup report on carrier screening; and (6) a presentation on the National Institutes of Health's Genomic Sequencing and Newborn Screening Disorders Initiative.

Proposed agenda items are subject to change as priorities dictate. Available materials from past and future meetings, as well as the Committee Roster and Charter, are located at the Advisory Committee's website at <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>

**Public Comments:** Members of the public can submit written comments and/or register to present oral comments during the public comment period of the meeting. All comments, whether oral or written, are part of the official Committee record and will be available for public inspection and copying. Advanced registration is required to present oral comments or submit written comments. Individuals who wish to make public comments are required to email Lisa Vasquez ([lvasquez@hrsa.gov](mailto:lvasquez@hrsa.gov)) by Thursday, January 17, 2013. At this time, the public comment period is scheduled for the morning of January 31, 2013.

Written comments should identify the individual's name, address, email, telephone number, organizational affiliation, type of expertise (i.e., parent, advocacy group, researcher, clinician, public health, etc.) and the topic/subject matter of comment. 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.

**Contact Person:**

Patrick Stephens

HRSA MCHB Genetic Services Branch

5600 Fishers Lane, Room 18A-19 Rockville, Maryland 20857

Telephone: (301) 443-1080; Email: [pstephens@hrsa.gov](mailto:pstephens@hrsa.gov)