



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

Notice of Meeting

In accordance with section 10(a)(2) of the Federal Advisory Committee Act (Public Law 92-463, codified at 5 U.S.C. App. 2), notice is hereby given of the following meeting:

Name: Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC)

Dates and Times: January 31, 2013, 9:30 a.m. to 5:00 p.m.
February 1, 2013, 9:30 a.m. to 1:15 p.m.

Place: Virtual via Webinar

Status: The meeting is open to the public. For more information on registration and webinar details, please visit the SACHDNC website:

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

Purpose: The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC), as authorized by Public Law 106-310, which added section 1111 of the Public Health Service Act, codified at 42 U.S.C. 300b-10, was established by Congress to

advise the Secretary of the Department of Health and Human Services regarding 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. The SACHDNC's recommendations regarding additional conditions/inherited disorders for screening that have been adopted by the Secretary are included in the Recommended Uniform Screening Panel (RUSP) that constitutes part of the comprehensive guidelines supported by the Health Resources and Services Administration. Pursuant to section 2713 of the Public Health Service Act, codified at 42 U.S.C. 300gg-13, non-grandfathered health plans are required to cover screenings included in the 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 SACHDNC also provides advice and recommendations concerning grants and projects authorized under section 1109 of the Public Health Service Act (42 U.S.C. 300b-8).

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; (4) updates on priority projects from the Advisory Committee's subcommittees on Laboratory Standards and Procedures, Follow-up and Treatment, and Education and Training; (5) a presentation on the Duchenne Muscular Dystrophy Newborn Screening Symposium; (6) a final workgroup report on carrier screening; and (7) a presentation on the National Institutes of Health's Genomic Sequencing and Newborn Screening Disorders Initiative.

Tentatively, the SACHDNC is expected to vote on: (1) a finalized report regarding genetic carrier screening (i.e., testing to identify individuals who may be at increased risk of carrying one or more gene mutations that could result in having children affected with an inherited genetic disorder); and (2) application of the Condition Review Decision Matrix.

Proposed agenda items are subject to change as priorities dictate. The agenda, webinar information, Committee Roster, Charter, presentations, and meeting materials are located on 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 (ivasquez@hrsa.gov) by Thursday, January 17, 2013. 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, professional or business affiliation, type of expertise (i.e., parent, 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: Anyone interested in obtaining other relevant information should contact Patrick Stephens, Maternal and Child Health Bureau, Health Resources and Services Administration, Room 18A-19, Parklawn Building, 5600 Fishers Lane, Rockville, Maryland 20857; telephone: 301-443-1080; email: pstephens@hrsa.gov.

More information on the Advisory Committee is available at <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Dated: December 28, 2012

Bahar Niakan

Director, Division of Policy and Information Coordination

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