



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

Dates and Times: January 26, 2012, 8:30 a.m. to 5:00 p.m.
January 27, 2012, 8:30 a.m. to 3:30 p.m.

Place: Park Hyatt Hotel
1201 24th Street, N.W.
Washington, D.C. 20037

Status: The meeting will be open to the public, but attendance will be limited by the space available. Participants are asked to register for the meeting by going to the registration website at <http://altarum.cvent.com/event/sachdncjan2012>. The registration deadline is Monday, January 23, 2012. Individuals who need special assistance, such as sign language interpretation or other reasonable accommodations, should indicate their needs on the registration website. The deadline for special accommodation requests is Tuesday, January 24, 2012. If there are

technical problems gaining access to the website, please contact Maureen Ball, Meetings Coordinator, at conferences@altarum.org.

Purpose: The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (Advisory Committee), 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 in connection with 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. Recommendations for screenings that are adopted by the Secretary are included in the Recommended Uniform Screening Panel (RUSP), which forms a 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 provided for in the Comprehensive Guidelines without charging a co-payment, co-insurance, or deductible for plan years (in the individual market these are known as policy years) beginning on or after the date that is one year from the Secretary's adoption of a screening(s). The Advisory Committee 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) an orientation for all new Committee members including overviews of the Department of Health and Human Services, the Health Resources and Services Administration (HRSA), and the Maternal and Child Health Bureau; (2) the history of the Advisory Committee; (3) an overview of the authorizing legislation for the Advisory Committee; (4) updates from the Nomination and Prioritization workgroup, Public Health Impact Matrix

workgroup and the Evidence Review workgroup; and (5) presentations on the continued work and reports of the Advisory Committee's subcommittees: Laboratory Standards and Procedures; Follow-up and Treatment; and Education and Training. Tentatively, the Advisory Committee is expected to review and/or vote on the following items: (1) forwarding the 22q11 condition nomination package to the Evidence Review Workgroup for further evaluation; (2) reviewing the draft Public Health Impact Matrix; (3) forwarding the Hyperbilirubinemia condition nomination to the Public Health Impact Workgroup for further evaluation; (4) reviewing the report on Linking Birth Certificates and Serial Numbers; and (5) reviewing the report on Implementing Point of Care Newborn Screening.

Proposed agenda items are subject to change as priorities dictate. The Agenda, Committee Roster and Charter, presentations, and meeting materials can be found at the home page of the Advisory Committee's website at <http://www.hrsa.gov/heritabledisorderscommittee/>.

Public Comments: Members of the public can submit written comments and/or present oral comments during the public comment periods of the meeting. Time for public comments has been scheduled to occur during the afternoon of January 26, 2012. Those individuals who want to make oral comments are requested to register online by Monday, January 23, 2012 at <http://altarum.cvent.com/event/sachdncjan2012>. In order to be considered, written comments should be emailed no later than Tuesday, January 24, 2012. All comments, whether oral or written, should contain the name, address, telephone number, and any professional or business affiliation of the author. Groups having similar interests are requested to combine their comments and present them through a single representative. Submit written comments to Maureen Ball, Meetings Coordinator, Conference and Meetings Management, Altarum Institute, 1200 18th Street, N.W., Suite 700, Washington, D.C. 20036. Comments may also be faxed (202-

785-3083) or emailed (conferences@altarum.org). If you have additional questions regarding the submission of comments, please contact Ms. Ball at 202-828-5100.

Contact Person: Anyone interested in obtaining other relevant information should contact or write to Debi Sarkar, 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: dsarkar@hrsa.gov. More information on the Advisory Committee is available at <http://mchb.hrsa.gov/heritabledisorderscommittee>.

Dated: December 2, 2011

Reva Harris

Acting Director, Division of Policy and Information Coordination

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