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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)

Date and Time: April 19, 2013, 9:30 a.m. to 3:00 p.m.

Place: Virtual via Webinar

Status: The meeting is open to the public. Pre-registration is required. 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) a policy paper report on the impact of recommendations related to sickle cell trait testing; (2) a presentation on the Affordable Care Act and the impact on individuals with heritable disorders; (3) a presentation by the Agency for Healthcare Research and Quality regarding the processes behind the U.S. Preventive Services Task Force review process; and (4) project reports on screening for Tyrosinemia Type I and Point of Care Screening and Lessons Learned.

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. All comments, whether oral or written, are part of the official Committee record and will be available for public inspection and copying. Individuals who wish to make public comments are required to register for the webinar and email Lisa Vasquez (lvasquez@hrsa.gov) by April 10, 2013. The public comment period is scheduled for the morning of April 19, 2013. Written comments should be emailed to Lisa Vasquez (lvasquez@hrsa.gov) by April 10, 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 the designated federal officer (DFO), 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://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders.

Dated: March 11, 2013

Bahar Niakan

Director, Division of Policy and Information Coordination

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