DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Proposed Establishment of the Advisory Committee on Heritable Disorders in Newborns and Children

AGENCY: Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

ACTION: Proposed Establishment of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC or Committee).

SUMMARY: In accordance with the Federal Advisory Committee Act (FACA) and section 1111 of the Public Health Service (PHS) Act, HHS announces the establishment of the ACHDNC as a discretionary advisory committee.

FOR FURTHER INFORMATION CONTACT: Mia Morrison (DFO), Maternal and Child Health Bureau, HRSA, 5600 Fishers Lane, Rockville, Maryland 20857; 301-443-2521; or mmorrison@hrsa.gov.

SUPPLEMENTARY INFORMATION: The ACHDNC provides advice and recommendations to the Secretary of HHS on policy, program development, and other matters of significance concerning certain activities described in section 1111 of the PHS Act (42 U.S.C. § 300b-10), as further described below. The ACHDNC is also governed by the provisions of the FACA, as amended (5 U.S.C. App.), which sets forth standards for the formation and use of advisory committees. The ACHDNC advises the Secretary of HHS about aspects of newborn and childhood screening and technical information for the development of policies and priorities that
will enhance the ability of the state and local health agencies to provide for newborn and child screening, counseling, and health care services for newborns and children having, or at risk for, heritable disorders. The ACHDNC will review and report regularly on newborn and childhood screening practices, recommend improvements in the national newborn and childhood screening programs, and fulfill responsibilities described in section 1111 of the PHS Act. In addition, the ACHDNC’s recommendations regarding inclusion of additional conditions for screening, following adoption by the Secretary of HHS, are considered evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA through the Recommended Uniform Screening Panel (RUSP) pursuant to section 2713 of the PHS Act (42 U.S.C. § 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services 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.

Notice of Establishment: In accordance with the FACA and section 1111 of the PHS Act, (42 U.S.C. § 300b-10) the Secretary of HHS announces the proposed establishment of the ACHDNC.

It has been determined that the formation of the ACHDNC is in the public interest in connection with the performance of duties imposed on the Department of Health and Human Services by law. A copy of the ACHDNC charter can be accessed on the ACHDNC website once available. A copy of the charter also can be obtained, once available, by accessing the FACA database that
is maintained by the Committee Management Secretariat of the General Services Administration. The website address for this database is http://www.facadatabase.gov/.

Maria G. Button,

Director, Executive Secretariat.

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