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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

# Advisory Committee on Heritable Disorders in Newborns and Children

## Request for Nominations

**AGENCY**: Health Resources and Services Administration, HHS.

**ACTION**: Notice of request for nominations.

**SUMMARY:** The Health Resources and Services Administration (HRSA) is seeking nominations of qualified candidates to be considered for appointment as members of the Advisory Committee on Heritable Disorders in Newborns and Children (Committee). The Committee provides advice, recommendations, and technical information about aspects of heritable disorders and newborn and childhood screening to the Secretary of Health and Human Services. HRSA is seeking nominations of qualified candidates to fill three positions on the Committee.

**AUTHORITY:** Section 1111 of the Public Health Service (PHS) Act, Title XI, § 1111(g)(1) (42 U.S.C. 300b-10(g)(1)), as amended by the Newborn Screening Saves Lives Reauthorization Act of 2014. The Committee is governed by the Federal Advisory Committee Act (FACA), as amended (5 U.S.C. App.), and 41 CFR part 102-3 and 41 CFR part 102-3, which set forth standards for the formation and use of advisory committees.

**DATES:** Written nominations for membership on the Committee must be received on or before **[INSERT DATE 30 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER]**.

**ADDRESSES:** Nomination packages must be submitted electronically as email attachments to Ms. Lisa M. Vasquez, Genetic Services Branch, Maternal and Child Health Bureau, Health Resources and Services Administration, lvasquez@hrsa.gov.

**FOR FURTHER INFORMATION CONTACT:** Ms. Lisa Vasquez, Genetic Services Branch, Maternal and Child Health Bureau, HRSA, at lvasquez@hrsa.gov or (301) 443-4948. A copy of the Committee Charter and list of the current membership can be obtained by accessing the Advisory Committee website at http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders.

**SUPPLEMENTARY INFORMATION:**

The Committee is chartered under section 1111 of the Public Health Service (PHS) Act, 42 U.S.C. 300b-10, as amended by the Newborn Screening Saves Lives Reauthorization Act of 2015 (Act). The Committee was established in 2003 to advise the Secretary of the U.S. Department of Health and Human Services regarding newborn screening tests, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having or at risk for heritable disorders. In addition, the Committee provides advice and recommendations to the Secretary concerning the grants and projects authorized under section 1109 of the PHS Act and technical information to develop policies and priorities for grants, including those 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 Committee is governed by the provisions of Pub. L. 92-463, as amended (5 U.S.C. App. 2), and 41 CFR part 102-3, which set forth standards for the formation and use of advisory committees. The Committee reviews and reports regularly on newborn and childhood screening practices for heritable disorders, recommends improvements in the national newborn and childhood heritable screening programs, and recommends conditions for inclusion in the Recommended Uniform Screening Panel (RUSP). The Committee's recommendations regarding additional conditions/inherited disorders for screening that have been adopted by the Secretary are included in the RUSP and constitute 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 and group and individual health insurance issuers are required to cover screenings included in the HRSA-supported comprehensive guidelines without charging a co-payment, co-insurance, or deductible for plan years (i.e., in the individual market, policy years) beginning on or after the date that is 1 year from the Secretary's adoption of the condition for screening.

NOMINATIONS: HRSA is requesting nominations to fill three (3) positions for voting members to serve on the Committee. Nominations of potential candidates for consideration are being sought for individuals who are medical, technical, public health, or scientific professionals with special expertise in the field of heritable disorders or in providing screening, counseling, testing, or specialty services for newborns and children at risk for heritable disorders; who have expertise in ethics (i.e., bioethics) and infectious diseases and who have worked and published material in the area of newborn screening; members of the public having special expertise about or concern with heritable disorders; or members from such federal agencies, public health constituencies, and medical professional societies as determined to be necessary by the Secretary. Interested applicants may self-nominate or be nominated by another individual and/or organization.

Individuals selected for appointment to the Committee will be invited to serve for up to 4 years. Members who are not federal officers or permanent federal employees are appointed as special government employees and receive a stipend and reimbursement for per diem and any travel expenses incurred for attending Committee meetings and/or conducting other business on behalf of the Committee, as authorized by section 5 U.S.C.

5703 for persons employed intermittently in government service. Members who are officers or employees of the United States Government shall not receive additional compensation for service on the Committee, but receive per diem and travel expenses incurred for attending Committee meetings and/or conducting other business on behalf of the Committee. Nominees will be invited to serve during calendar year 2016.

The following information must be included in the package of materials submitted for each individual being nominated for consideration: (1) a statement that clearly states the name and affiliation of the nominee, the basis for the nomination (i.e., specific attributes such as expertise in bioethics, evidence review, public health, laboratory, maternal and child health, or clinical expertise in heritable disorders, which qualify the nominee for service in this capacity), and that the nominee is willing to serve as a member of the Committee; (2) the nominee's name, address, and daytime telephone number and the home/or work address, telephone number, and email address; and (3) a current copy of the nominee's curriculum vitae. Nomination packages may be summited directly by the individual being nominated or by the person/organization recommending the candidate.

The Department of Health and Human Services will make every effort to ensure that the membership of the Committee is fairly balanced in terms of points of view represented. Every effort is made to ensure that individuals from a broad representation of geographic areas, gender, ethnic and minority groups, as well as individuals with disabilities are given consideration for membership. Appointments shall be made without discrimination

on the basis of age, ethnicity, gender, sexual orientation, and cultural, religious, or socioeconomic status.

Individuals who are selected to be considered for appointment will be required to provide detailed information regarding their financial holdings, consultancies, and research grants or contracts. Disclosure of this information is necessary in order to determine if the selected candidate is involved in any activity that may pose a potential conflict with the official duties to be performed as a member of the Committee.

Jackie Painter,

Director,

Division of the Executive Secretariat.

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