



Billing Code: 4165-15

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

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

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

ACTION: Notice of Request for Nominations of Non-Voting Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) members to serve as representatives of organizations or interest groups.

SUMMARY: HRSA is requesting applications to fill three (3) vacancies for non-voting organizational representatives on the SACHDNC.

AUTHORITY: Section 1111 of the Public Health Service (PHS) Act, 42 U.S.C. 300b-10, as amended. The SACHDNC also is governed by the provisions of Public Law 92-463, as amended (5 U.S.C. App. 2), and 41 CFR Part 102-3, which sets forth standards for the formation and use of advisory committees.

DATE: The agency must receive written applications from nominees (including a letter of support from an appropriate official of the organization with which affiliated) or the nominee's organization, on or before August 1, 2012.

ADDRESS: Submit written applications to Sara Copeland, M.D., Designated Federal Official (DFO), SACHDNC; and, Chief, Genetic Services Branch, Maternal and Child Health Bureau, Health Resources and Services Administration, Room 18A-19, Parklawn Building, 5600 Fishers Lane, Rockville, Maryland 20857. Applications may also be sent to Screening@hrsa.hhs.gov.

FOR FURTHER INFORMATION CONTACT: Debi Sarkar, M.P.H., Genetic Services Branch, Maternal and Child Health Bureau, HRSA, at dsarkar@hrsa.gov or (301) 443-1080. A copy of the SACHDNC Charter and list of the current membership may be obtained by contacting Ms. Sarkar or by accessing the SACHDNC website at <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/>.

SUPPLEMENTAL INFORMATION: The SACHDNC is directed to review and report regularly on newborn and childhood screening practices for heritable disorders and recommend improvements in the national newborn and childhood heritable screening programs.

The SACHDNC provides the Secretary with recommendations, advice, and technical information regarding the application of technologies, policies, guidelines, and standards for: (a) effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders; and (b) enhancing 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.

Specifically, HRSA is requesting applications for three (3) non-voting organizational representatives to serve on the SACHDNC: two (2) at large representatives of a public health constituency, medical professional society or national advocacy organization and one (1) representative of a public health professional organization. Non-voting representatives provide a perspective unique to the SACHDNC based on their organizations' or interest groups' subject area of expertise, and each nominee selection is based on the organization's/interest group's mission and relevancy to the SACHDNC's purpose (e.g., primary care, pediatrics, newborn screening, genetics and other relevant specialty expertise). Eligible organizations should represent broad constituencies affected or impacted by the work of the SACHDNC, as noted in the SACHDNC Charter.

Applicants eligible for consideration include representatives of the following organizations: (a) medical, technical, public health, or scientific organizations with special expertise in the field of heritable disorders or (b) organizations that provide screening, counseling, testing, or specialty services for newborns and children at risk for heritable disorders. Organizations will also be chosen based on perspectives and expertise not currently represented, or with expiring terms, that serve to increase the knowledge base of the SACHDNC.

Applicants are requested to submit a written application to the DFO. Applications must contain the following:

- Letter of nomination stating the organization's:
 - Name and mission statement;

- Outline of the perspective and expertise provided by the nominated organization and why this perspective and expertise would benefit the SACHDNC; and
- Description of how the SACHDNC's work affects and/or impacts the nominated organization and its constituency.
- Contact information: point of contact name, address, telephone number, and website of the organization;
- Portfolio of organizational projects, programs and products that are of importance to the SACHDNC's work;
- Organization's commitment to provide expert input into the decision-making process of the SACHDNC;
- Organization's detailed information concerning any possible conflicts of interest relative to both the organization and the proposed organizational representative (e.g., current or anticipated employment, consultancies, research grants, or contracts);
- Organization's commitment to support a representative to attend all SACHDNC meetings;
- Organization's commitment to ensure active contribution to and dissemination of SACHDNC activities and recommendations to its representative constituencies;
- Statement affirming that the organization: (a) wishes to serve as a representative to the SACHDNC, and (b) has no conflict of interest that would preclude informing the SACHDNC in a fair and balanced manner;

- Organization's description clearly identifying how the organizational perspective and expertise would serve to increase the knowledge base of the SACHDNC; and
- SACHDNC's professional impact on the organization and its stakeholders.

Please submit written nominations no later than August 1, 2012. The two (2) at large organizational representatives will be invited to contribute to the SACHDNC for terms of not more than 2 years with an opportunity to re-apply to serve after the 2-year term has expired. The public health professional organization will be invited to have a representative contribute to the SACHDNC for terms of not more than 4 years with an opportunity to re-apply to serve after the 4-year term has expired. Selected organizations will have their representatives begin serving their term in January 2013.

Whenever possible, organizational representatives to the SACHDNC shall have expertise in dealing with heritable disorders and genetic diseases affecting racially, ethnically, and geographically diverse populations of newborns served by State newborn screening programs. HHS will ensure that SACHDNC members equitably reflect geographical location and gender distribution, provided that Committee effectiveness would not be impaired. Appointments shall be made without regard to age, ethnicity, gender, or sexual orientation, and cultural, religious, or socioeconomic status.

Dated: June 7, 2012

Reva Harris

Acting Director, Division of Policy and Information Coordination

[FR Doc. 2012-14499 Filed 06/13/2012 at 8:45 am; Publication Date: 06/14/2012]