DEPARTMENT OF HEALTH AND HUMAN SERVICES

Establishment of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children and Notice of Meeting

AGENCY: Health Resources and Services Administration, HHS.

ACTION: Notice of establishment of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children and Notice of Meeting.

Authority: The Committee is governed by Public Health Service Act (PHS), 42 U.S.C. 217a: Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC) is to advise the Secretary of Health and Human Services 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 DACHDNC will review and report regularly on newborn and childhood screening practices, recommend improvements for newborn and childhood screening programs, as well as fulfill the list of requirements stated in the original authorizing legislation.

II. Structure

The Committee consists of fifteen (15) voting members, including the Chair. The members of the Committee were appointed by the Secretary. Membership is composed of the Chair, Special Government Employees (SGEs) and federal ex-officio members. Federal ex-officio members include the Administrator of the Health Resources and Services Administration; the Directors of the Centers for Disease Control and Prevention; the National Institutes of Health; the Agency for Healthcare Research and Quality; and the Commissioner of the Food and Drug Administration—or their designees. The Chair and other members are (a) 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; (b) experts in ethics and heritable disorders who have worked and published material in the area of public health and genetic conditions; and (c) members from the public sector who have expertise, either professional or personal, about or concerning heritable disorders in order to achieve a fairly balanced membership.

The DACHDNC also includes nonvoting liaisons or representatives from Federal Agencies, public health constituencies, advocacy organizations and medical professional societies, as determined to be necessary by the Chair and/or the Designated Federal Official, to fulfill the duties of the DACHDNC. In addition, the DACHDNC is encouraged to work closely with other relevant HHS entities that focus on reviewing scientific evidence and making recommendations on clinical preventive services.

III. First Meeting of the DACHDNC

Dates and Times: May 16, 2013, 10:00 a.m. to 2:00 p.m.

Place: Virtual via Webinar.

Purpose: The Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (Committee), as authorized by Public Health Service Act (PHS), 42 U.S.C. 217a: Advisory councils or committees, was established 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 Committee’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 HRSA-supported 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.

Agenda: The meeting will include: (1) A final report on the Pompe Condition Nomination for inclusion in the RUSP, and (2) updates on priority projects from the Committee’s subcommittees on Laboratory Standards and Procedures, Follow-up and Treatment, and Education and Training.

The Committee is expected to vote on whether or not to recommend the
SECRETARY OF HEALTH AND HUMAN SERVICES

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Announcement of Requirements and Registration for “Crowds Care for Cancer: Supporting Survivors Challenge”

AGENCY: Office of the National Coordinator for Health Information Technology, HHS.

Award Approving Official: Farzad Mostashari, National Coordinator for Health Information Technology.

ACTION: Notice.

SUMMARY: The number of cancer survivors in the United States is currently estimated at 14 million and is expected to increase significantly with the aging of the United States population. Cancer survivors may experience a host of long-term and late effects that require coordinated follow-up care after completion of primary treatment for cancer. Despite significant progress in cancer treatment, the complex, often fragmented state of end-of-treatment care may lead to harmful breakdowns in patient-provider communication and follow-up care for cancer survivors. Enabling better communication, exchange of data, and care coordination can help improve end-of-treatment consultations and care planning for cancer survivors.

Supplementary Information:

Subject of Challenge Competition

To address the needs of cancer survivors, the Office of the National Coordinator for Health Information Technology (ONC) is launching the Crowds Care for Cancer: Supporting Survivors Challenge in conjunction with the National Cancer Institute (NCI) as part of the Investing in Innovation (i2) program. This challenge aims to incentivize the development of innovative information management tools and applications that help survivors manage their transition from specialty to primary care; for example, by facilitating activities such as coordinating recommendations, appointments, and resources from patient support networks and healthcare providers involved in their care.

Submissions should help survivors use information from their providers and survivorship care plans to improve communication and coordination within their care networks that can help facilitate the planning and delivery of coordinated, high-quality, and patient-centered follow-up care. These networks often include families, friends, and members of their primary and specialty care teams. The ultimate goal of this challenge is to develop applications that will better meet the needs of cancer survivors. Finalists from Phase I will garner seed funding and publicity from ONC and NCI to assist qualified entrants in developing applications ready for solicitation of additional development resources.

DATES:

Phase I:

April 29, 2013: Crowds Care for Cancer: Supporting Survivors Challenge launch.

May 28, 2013, 11:59 p.m. PDT: Deadline for Phase I Submissions.

June 3, 2013: Up to three finalists announced, and launch of Phase II.

Phase II:

June 10, 2013: Crowdfunding portal opens platform for finalists to receive feedback and backing.

July 5, 2013: End of Crowdfunding phase.

July 12, 2013 11:59 p.m. PDT: Deadline for final development and submission of application.

July–August, 2013: Announce grand prize winner.

FOR FURTHER INFORMATION CONTACT: Abdul Shaikh, Ph.D., MHSc, Program Director, National Cancer Institute, National Institutes of Health (email: shaikhhab@mail.nih.gov; telephone: 301–594–6690); Adam Wong, Office of the National Coordinator for Health Information Technology (adam.wong@hhs.gov; 202–720–2866).


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