DEPARTMENT OF HEALTH AND HUMAN SERVICES

Secretary's Advisory Committee on Heritable Disorders in Newborns and Children
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March 23, 2010

The Honorable Kathleen Sebelius
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Sebelius:

The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) is charged with advising the Secretary of the Department of Health and Human Services in areas relevant to heritable conditions in newborns and children such as newborn and child screening, counseling, or health care services for newborns and children having or at risk for heritable disorders.

In September 2009, I wrote to update you on various SACHDNC activities, including a White Paper on how health care reform might improve the quality and efficiency of public health newborn screening programs and equal access to those services for the benefit of the families that they serve. That report is now complete and is submitted for your information, review and consideration.

SACHDNC chose to evaluate the newborn screening system's needs because, despite more than four decades of impressive growth and refinement in this field, the delivery of newborn screening and ongoing follow-up services across the United States remains substantially variable depending on place of birth. The reasons behind this disparity—issues related to public financing, payment systems, administrative inefficiencies and insurance coverage—mirror problems cited in ongoing discussions among policymakers about the need for systemic improvements to the entire U.S. public health system.

To address the multiple barriers to newborn screening system improvement, the SACHDNC makes the following recommendations to the Secretary of the Department of Health and Human Services:

1. Encourage the Centers for Medicare and Medicaid Services to convene an expert panel to examine coding changes to streamline the billing process for newborn screening services and to put forth recommendations that enhance the standardization of health care transactions.

2. Encourage the Centers for Medicare and Medicaid Services to develop and pilot a payment method for an integrated system of care coordination through the medical home framework for children diagnosed with heritable and congenital disorders as a result of screening.

3. Encourage the adoption and further definition of the Newborn Screening Use Case within the Department's health information exchange endeavors, specifically encouraging the Centers for Medicare and Medicaid Services to make use of the Newborn Screening Use Case when defining "meaningful use" of Electronic Health Records and the Office of the National Coordinator for Health Information Technology to further facilitate the adoption of the Newborn Screening Use Case.

4. Support, as allowable, the closure of gaps in insurance coverage for medical foods and foods modified to be low in protein, as recommended by the Committee in April, 2009.

In conclusion, please know that the Committee stands ready to be of service to you to help strengthen newborn screening programs.

Sincerely yours,

R. Rodney Howell, M.D.
Chairperson