May 21, 2010

R. Rodney Howell, M.D.
Committee Chairperson
Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children
Professor, Department in Newborns and Children
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Dear Dr. Howell:

Thank you for your letter regarding the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children’s (SACHDNC) recommendation to initiate appropriate action to facilitate adoption of the SACHDNC’s Recommended Uniform Screening Panel, and your second letter recommending the addition of Severe Combined Immunodeficiency Disorder (SCID) as a core condition to the SACHDNC’s Recommended Uniform Screening Panel, as well as the addition of related T-cell lymphocyte deficiencies to the list of secondary targets as a comprehensive entity.

1. SACHDNC’s Recommended Uniform Screening Panel

The Secretary adopts the Committee’s recommendations to adopt the SACHDNC’s Recommended Uniform Screening Panel (screen for the identified 29 core conditions; report on the identified 25 secondary conditions) as a national standard for newborn screening programs and facilitate the adoption of the SACHDNC’s Recommended Uniform Screening Panel by all State newborn screening programs.

2. SACHDNC’s Recommendations Concerning the addition of SCID to the Recommended Uniform Screening Panel

The Secretary also adopts the Committee’s recommendation to adopt the SACHDNC’s addition of SCID as a core condition to the Recommended Uniform Screening Panel, and related T-cell lymphocyte deficiencies to the list of secondary targets as a comprehensive entity as a national standard and affirms the SACHDNC’s updated Recommended Uniform Screening Panel to screen for 30 core conditions and report 26 secondary conditions.

In addition, I request that the SACHDNC submit a report in May 2011 on the status of States’ implementation of this recommendation, including the surveillance activities to be conducted through the Newborn Screening Translational Research Network. Adopting these SACHDNC recommendations will provide the federal guidance necessary to assist States to voluntarily bring...
their newborn screening programs into alignment with the most up-to-date research, technology, laboratory and public health standards and practices.

Please accept my appreciation to you, and the members of the SACHDNC, for all your efforts to improve the health of our Nation’s infants and children.

Sincerely,

Kathleen Sebelius