April 13, 2011

R. Rodney Howell, M.D.
Committee Chairperson
Secretary’s Advisory Committee on Heritable Disorders
in Newborns and Children
5600 Fishers Lane, Room 18A19
Rockville, MD 20857

Dear Dr. Howell:

Thank you for your recent letter regarding the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children’s (Committee) briefing paper on "Considerations and Recommendations for a National Policy Regarding the Retention and Use of Dried Blood Spot Specimens After Newborn Screening" and corresponding recommendations. I appreciate the Committee’s review and analysis of issues related to the research and use of residual newborn screening blood specimens to advance science and the clinical care for newborns and children.

At this time, the Committee recommendations are not ready for adoption. Therefore, I am referring the Committee’s report, Considerations and Recommendations for a National Policy Regarding the Retention and Use of Dried Blood Spot Specimens After Newborn Screening, to the Interagency Coordinating Committee on Newborn and Child Screening (ICC) for its review and input regarding possible future implementation of the recommendations. The use of the ICC allows a more formal engagement of the Office for Human Research Protections and Office for Civil Rights, along with the federal agencies assigned to the ICC by its authorizing legislation. I will encourage the ICC to submit a report with recommendations for appropriate Departmental action by June 1, 2012.

Please accept my personal thanks to you, the members, and the organizational representatives of the Committee for your valuable work to improve the health of our nation’s infants and children.

Sincerely,

/s/

Kathleen Sebelius