



THE SECRETARY OF HEALTH AND HUMAN SERVICES
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March 1, 2010

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in Newborns and Children
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Dear Dr. Howell:

Thank you for your letter providing an update on the activities of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (the Committee) and for your service as the Committee's Chairperson. I understand that three recommendations were made during your September 2009 meeting.

The first recommendation was to not add Krabbe Disease to the Committee's Recommended Screening Panel and to move forward the consideration of the nomination of Hemoglobin H disease (Alpha Thalassemia) for formal external evidence review. I adopt the Committee's recommendation to not add Krabbe Disease to the Recommended Uniform Screening Panel at this time, and I look forward to evaluating the Evidence Review Report on Hemoglobin H disease once made available.

The second recommendation was to develop and fund an initiative to establish a "Learning Collaborative" in genetics and primary care training. I adopt this recommendation. It has been reviewed by the Health Resources and Services Administration (HRSA), and they are establishing a project that pairs representatives from primary care practices with genetics and genomic medicine expertise through the formation of a Genetics in Primary Care Training Institute. This project would be funded as a Special Project of Regional and National Significance by the Maternal and Child Health Bureau at HRSA.

The final recommendation was to provide additional resources to increase public awareness of the newborn screening system. I adopt this recommendation. I agree that the public, especially parents and pediatric providers, need to be well-informed about newborn screening and the newborn screening system. The newly funded Clearinghouse for Newborn Screening Information and Resources will bring needed resources to newborn screening education by establishing and maintaining a central clearinghouse of current educational and family support services information, which will include materials, research, and data on newborn screening.

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I look forward to receiving the work of the Committee regarding the two policy papers: *Considerations and Recommendations for a National Policy Regarding the Retention and Use of Dried Bloodspots* and *Newborn Screening and Health Care Reform*. These papers may help guide us in deliberations concerning research and health care reform. In addition, I encourage the Committee to seek formal public comments on the *Considerations and Recommendations for a National Policy Regarding the Retention and Use of Dried Bloodspots*.

I appreciate your and the Committee members' valuable work to improve the health of our Nation's infants and children.

Sincerely,

Kathleen Sebelius