



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Secretary's Advisory Committee on Heritable
Disorders in Newborns and Children
5600 Fishers Lane, Room 18A19
Rockville, Maryland 20857

May 19, 2011

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

Dear Secretary Sebelius:

In January 2010, the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (Committee) recommended that Severe Combined Immunodeficiency Disorder (SCID) be added to the Recommended Uniform Screening Panel (RUSP). You accepted the Committee's recommendation on May 21, 2010 and SCID was added to the RUSP. At that time you also requested that the Committee submit a report in May 2011 on the status of State's implementation of screening for SCID, including the surveillance activities to be conducted through the Newborn Screening Translational Research Network (NBSTRN). I am pleased to submit the enclosed report, *Newborn Screening for Severe Combined Immunodeficiency*. The report summarizes the current status of screening newborns for SCID in state-based newborn screening programs and surveillance updates from the NBSTRN. It also includes the impact, successes, lessons learned, and next steps developed by expanding SCID pilot studies.

On behalf of the Committee, I thank you for allowing us the opportunity to showcase the benefits gained from adding SCID to the RUSP. We have been extremely pleased with how rapidly these pilot studies have examined samples from over 900,000 newborn infants, covering 25 percent of the births in the United States. Preliminary analysis of the pilot study data has produced important information that will help facilitate wide-spread implementation of newborn screening for SCID. During these pilot studies over 60 infants with immunodeficiencies have been identified and are now receiving life-saving treatments. Please know that the Committee continues to stand ready to be of service to you to help strengthen the newborn screening programs that play such an important role in improving the health of the Nation's children.

Sincerely yours,

/S/

R. Rodney Howell, M.D.
Chairperson

Enclosure:

Tab A: Report - *Newborn Screening for Severe Combined Immunodeficiency*