DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary
Washington, D.C. 20201

JUN 0 3 2015

Joseph A. Bocchini Jr., MD
Chairperson
Advisory Committee on Heritable Disorders
in Newborns and Children
5600 Fishers Lane, Room 18W68
Rockville, MD 20857

Dear Dr. Bocchini:

Thank you for your letters to Secretary Burwell regarding the Advisory Committee on Heritable Disorders in Newborns and Children's (Committee) review of current practices related to timely newborn screening (NBS) and recommendation to add Mucopolysaccharidosis Type I (MPS I) to the Recommended Uniform Screening Panel (RUSP). The Secretary asked me to respond to you on her behalf.

We appreciate the significant effort that went into the review and development of the recommendations on the timely collection and receipt of NBS specimens as well as timely reporting of NBS results. To support state-level NBS programs, the Health Resources and Services Administration (HRSA) issued a funding opportunity announcement (FOA) called *Improving Timeliness of Newborn Screening Diagnosis* that recently closed. Under this FOA, HRSA will award a cooperative agreement to improve the time that it takes for infants undergoing newborn screening who receive a presumptive positive result to move from screening to diagnosis to treatment. The majority of funds for this agreement will be allocated to support states and coordinate collaborative learning so that states will be able to implement strategies to improve timeliness and share best practices. HRSA intends to award the cooperative agreement by September 1, 2015. In addition, HRSA supports an NBS technical assistance center that maintains a centralized data repository for NBS programs. The repository has been updated based on the Committee's timeliness recommendations and will better support states in their efforts to conduct quality improvement activities.

We are also grateful for the time and work of the Committee regarding the recommendation to add MPS I to the RUSP. Please be assured that this recommendation will receive careful review within the Department.

Again, thank you for forwarding the information and recommendations in your letters. Please accept my personal thanks to you and the members on the Committee for all of your valuable work to improve the health of our nation's infants and children. We look forward to continuing our work together.

Sincerely,

Mary K. Wakefield
Acting Deputy Secretary