



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

January 27, 2014

Joseph A. Bocchini, Jr., M.D.
Committee Chairperson
Discretionary Advisory Committee on Heritable
Disorders in Newborns and Children
Professor and Chairperson
Department of Pediatrics
Louisiana State University
1501 Kings Highway
Shreveport, LA 71130

Dear Dr. Bocchini:

I am providing you with an update to my July 15, 2013, response on the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children's (Committee) recommendation specific to the addition of Pompe disease to the Recommended Uniform Screening Panel.

After consultation with relevant agencies within the Department, I have referred the Committee's recommendation to the Interagency Coordinating Committee on Newborn and Child Screening (ICC) for additional review and input. I plan to instruct the ICC to submit a report with its analysis, advice, and recommendations by July 31, 2014.

Thank you again for the Committee's efforts in conducting an objective and evidence-based review of newborn screening for Pompe disease. I appreciate the Committee's valuable and highly respected work to improve the health of our nation's infants and children, and I look forward to our continued work together.

Sincerely,



Kathleen Sebelius