October 2, 2009

R. Rodney Howell, M.D
Committee Chairperson
Secretary’s Advisory Committee on
    Heritable Disorders in Newborns and Children
Professor, Department of Pediatrics (D820)
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Dear Dr. Howell:

Thank you for your letter providing the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children’s (Committee) recommendations on the issue of insurance coverage of medical foods and other foods modified to be low protein for the treatment of a number of childhood disorders identified through newborn screening.

It is understood that the Committee feels that policies are needed to address gaps in coverage for items that are a vital component of medical management but are not typically included as “medical” services for the disorders identified through newborn screening. I recognize that medical foods and other foods modified to be low protein are important treatments for inborn errors of metabolism, and the Department will be further exploring these proposals. However, the Committee’s recommendations to enact legislation are beyond the Department’s authority. Therefore, I am neither adopting nor rejecting the Committee’s recommendations.

I value the advice that the Committee has rendered to the Department and appreciate the hard work that your members continually provide in guiding us in our health care deliberations.

Sincerely,

Kathleen Sebelius