December 14, 2010

R. Rodney Howell, M.D.
Chairperson
Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children
5600 Fishers Lane, Room 18A19
Rockville, MD 20857

Dear Dr. Howell:

Thank you for your letter on behalf of the Advisory Committee on Heritable Disorders in Newborns and Children in which you urge the Department to consider the inclusion of medical foods and other foods modified to be low in protein as essential health benefits for treating children and adults with inborn errors of metabolism for the purposes of defining a health insurance plan’s coverage. While I appreciate your thoughtful recommendations, I cannot adopt the Committee’s recommendations at this time.

As you are aware, the Department must follow the relevant language of the Affordable Care Act in determining essential health benefits. The statute states that essential health benefits shall include at least ten general categories specified in the law and the items and services covered within these categories. Additionally, the scope of benefits must be equal to that provided under a typical employer-sponsored plan and the determination of the scope of benefits should be informed by a survey conducted by the Department of Labor. The statute also states that benefit packages must be balanced appropriately across service categories and must be constructed in ways that do not discriminate against individuals because of their age or condition.

The Administration and this Department have moved quickly to develop a process for determining essential health benefits. A survey is being conducted by the Department of Labor to inform our determination of a typical employer-sponsored plan. The results are expected in March of next year. We are also seeking advice from the Institute of Medicine on considerations to be taken into account with regard to essential health benefits both initially and over time. The Institute of Medicine will be holding a public workshop on essential health benefits early in 2011 and its report is due at the end of September.

The information you have provided will help inform our ultimate decision about essential health benefits. However, until I have the results of the Department of Labor survey and the Institute of Medicine recommendations, I am not in a position to make determinations about particular benefits. Please be assured that when I am able to make these decisions, I will give serious consideration to the issues you raise.
Thank you again for your letter. I value the work of the Committee and the dedicated service of its membership.

Sincerely,

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Kathleen Sebelius