

United States Senate

WASHINGTON, DC 20510-2102

Remove Barriers to Treatment for Individuals with Rare Metabolic Disorders Support the Medical Foods Equity Act

February 8, 2011

Dear Colleague:

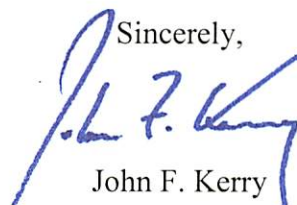
Each year an estimated 2,550 children in the United States are diagnosed with metabolism disorders. For the rest of their lives, they will require modified foods that do not have the nutrient or nutrients which the child's body is incapable of processing. They may also require supplementation with pharmacological doses of vitamins and amino acids. Without these foods and supplements, patients can become severely brain-damaged and hospitalized. With treatment they can lead normal, productive lives.

We have made great strides in improving how quickly babies with these disorders are diagnosed. Newborn screening has made a tremendous difference in the early diagnosis of a metabolic disorder. However, affordable and accessible treatment options remain out of reach for too many Americans. Medically necessary foods and supplements which are necessary for treatment may not be covered by insurance policies and can be prohibitively expensive for many families. For those with a metabolic disorder, medical foods are the course of medical treatment, just as other conditions are treated with pills or injections. In response, more than 35 states have enacted laws to enforce coverage of medical foods. Unfortunately, too many loopholes remain. I believe this legislation is needed to ensure that these individuals receive what they need to stay well.

The Medical Foods Equity Act follows the April 2009 recommendations of the U.S. Health and Human Services, Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. This legislation would require medically necessary foods and supplements to be included in the definition of essential health benefits for qualified health plans, covered by federal health programs (Medicare, Medicaid, CHIP, and TRICARE) and by the private health insurance market (fully insured group health plans, self-insured group health plans, and non-group health plans). The legislation requires the Secretary of Health and Human Services to make a determination of minimum coverage levels for medically necessary foods and supplements for certain rare metabolic conditions.

I urge you to consider cosponsoring this important legislation. For more information, or to cosponsor, please contact Megan Thompson at megan_thompson@kerry.senate.gov or 224-2742.

Sincerely,



John F. Kerry