

September 2, 2024

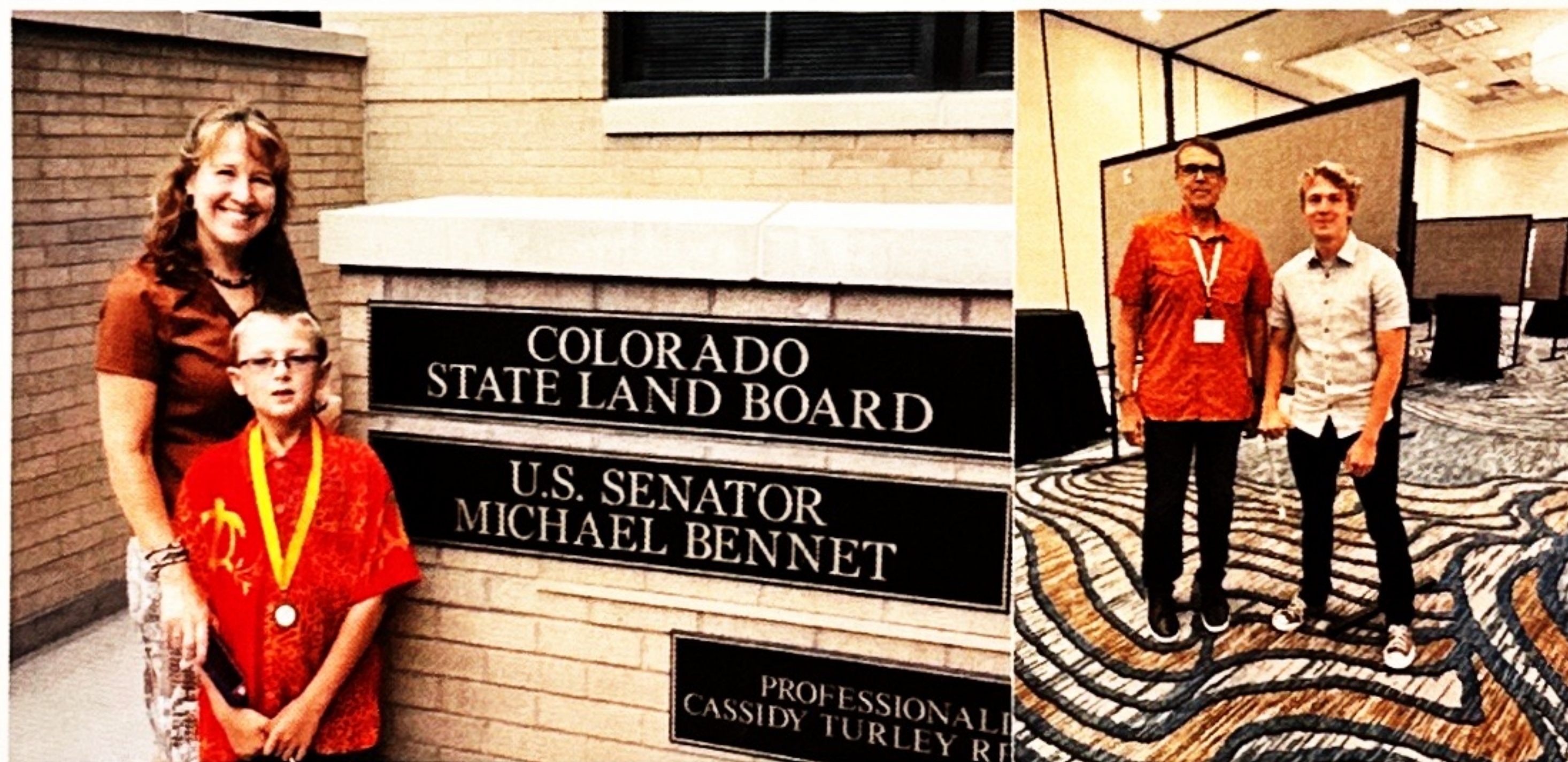
Senator Michael Bennet
Cesar E. Chavez Memorial Building
1244 Speer Boulevard
Denver, CO 80204
Office 303-455-7600

Dear Senator Bennet,

There is important legislation related to the health care of Colorado children and adults that I want to bring to your attention. I am requesting your advocacy, leadership and your VOTE on both topics.

The **Medical Nutrition Equity Act, H.R. 6892** would **require** private health insurance to cover the costs of medically necessary food, vitamins and individual amino acids for digestive and inherited metabolic disorders.

The reason I am reaching out to you, is because our family: Karen Casey, Chris & Bill Sullivan first advocated for this legislation, in person at your office in August of 2015 and it is still not enacted.



Our Family Advocating for Medical Nutrition Therapy.

Left picture Karen and Chris in 2015, Right picture Chris with Bill in 2024.

Nearly ten years without a national requirement to support amino acid therapy and formula.

This legislation is important to our son, Chris, and hundreds of other children in Colorado who are born with metabolic conditions that require a liquid formula in order to sustain life. Conditions like PKU, Phenylketonuria, are treated exclusively through diet, and are like diabetes. In the case of diabetes, sugar is restricted and in the case of PKU, protein is restricted.

This legislation is important because the costs of formula are very high, due to the complexity of manufacturing a product that consists of very specific amino acids. On average a can of formula costs \$70-\$140. Most children require 3-5 cans per week, so total annual costs range from \$10,920 - \$36,400. Children rely on this formula for life, and while there are treatments, there is no cure for PKU.

Medical nutrition therapy (MNT) is complex and is provided through a registered dietitian, integral to overall health and well-being of patients with PKU. Without medical formula treatment, a person with PKU permanently loses 4 IQ points per month starting at birth.

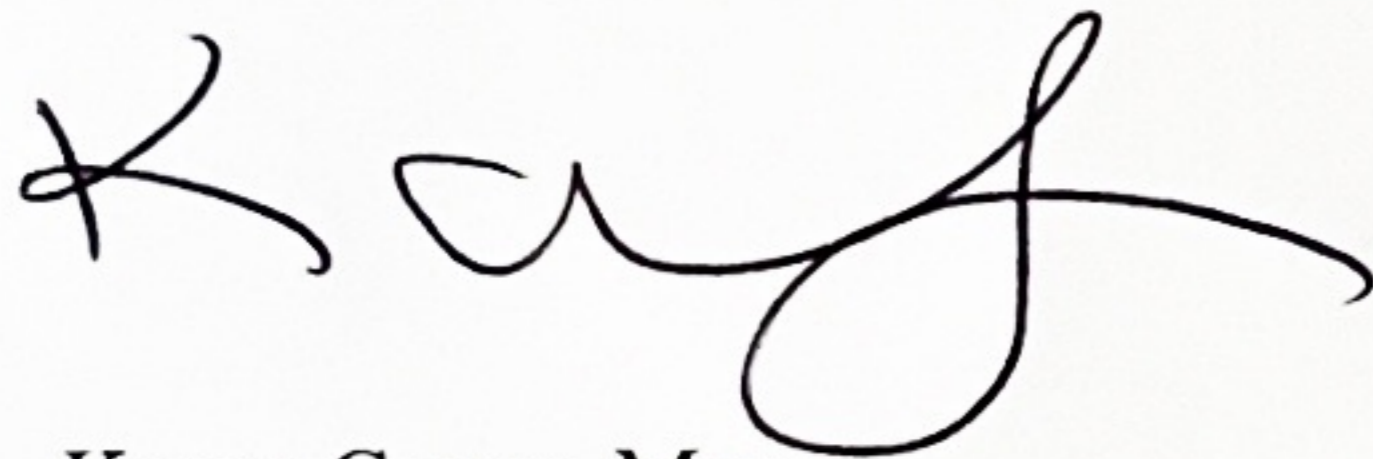
There is a related act, the **Medical Nutrition Therapy Act of 2023 (H.R. 6407, S. 3297)**. This bill would provide access to essential nutrition care services under Medicare Part B. This legislation is equally important, requiring Medicare Part B coverage of MNT care for prediabetes, obesity, hypertension, dyslipidemia, malnutrition, eating disorders, cancer, gastrointestinal diseases including celiac disease, HIV/AIDS, cardiovascular disease, medical conditions that require complex nutritional treatment.

Medical nutrition therapy is a cost-effective part of care for many of these conditions, including rare diseases like PKU. When our son turns 21, he will be further restricted to the type of formula insurance will cover, increasing our costs, and more importantly limiting his choice in treatment options.

We cannot wait another 9 years, please act now by advocating, sponsoring legislation, collaborating with other leaders to advance the legislation and voting yes as these bills advance.

I will be following up with a phone call to your office and look forward to the opportunity to explain the importance of this legislation and the dramatic impact it can make to improve the lives of Colorado citizens.

Sincerely,



Karen Casey, Mom
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Aurora, CO 80016
303-246-4150

Cc: Sherri Isaak, Program Director Andrews University
Lillian Isabella, NPKUA Advocacy Lead
Lauren Pickens, Colorado Academy of Nutrition and Dietetics Advocacy Lead

Resources: <https://www.npkua.org/about-pku/>