Parents of children with certain metabolic or gastrointestinal conditions face brutal realities. They find their newborn baby has a life-threatening condition and can’t consume breast milk or standard formulas. They worry about how their child will consume enough nutrients to achieve sufficient growth before life-saving surgery is possible. Or they may have to tell their four-year-old child that he has a condition that will require him to give up solid food – forever.

Thousands of children and adults in our country have a diagnosis of a digestive or inherited metabolic disorders that prevent their bodies from digesting or metabolizing the food they need to survive. For them, medical nutrition is their treatment.

Families and adults facing these complicated realities quickly find out the cost for medically necessary nutrition is 4 to 5 times the cost of “normal” food. And, perhaps most devastatingly, that it is generally not covered by health insurance.

Without medically necessary nutrition, these children and adults risk malnutrition, surgery, and repeated hospitalizations; they may suffer intellectual disability or even death. Risks in pediatric populations are particularly profound and often severe: inadequate growth, abnormal development, cognitive impairment, and behavioral disorders, in addition to those mentioned above. Specialized medically necessary nutrition is standard-of-care therapy for these patients and is essential to preventing such outcomes.

**Insurance Companies Do Not Generally Cover Medically Necessary Nutrition**

- Medically necessary nutrition is sometimes the best or only treatment for a digestive or metabolic condition.

- Insurance companies will typically cover pharmaceuticals or biologics for treatment of some of these conditions; however, these types of treatments may not be the first-line therapy a physician would recommend and do not work for all patients.

- Further, pharmaceuticals and biologics are often costly and can have undesirable risks such as cancer or suppression of the immune system, which can increase a patient’s risk of infection.

- Even when an insurance company does cover medically necessary nutrition, it often comes with the stipulation that the formula be administered through a feeding tube (for example, a nasogastric tube, placed through the nose into the stomach or a gastrostomy tube, surgically placed directly into the stomach). Surgery to place a feeding tube is expensive and these tubes carry additional risks. For example, a gastrostomy tube can leak, cause ulcerations, or cause infection at the insertion site. In severe cases, a patient may experience a perforation in the intestinal tract.
• Medically necessary nutrition, when administered under a physician’s order, constitutes life-saving treatment with lower costs and fewer risks.

Thirty-five States Have Passed Laws, but too Many Patients Fall Through the Cracks
• The fact that many states have passed legislation on this issue demonstrates its importance. Unfortunately, that coverage is highly variable from state to state and excludes all of those covered under a federal or ERISA plan.

• In addition, while all states have mandated testing for select inborn errors of metabolism, and more than 7,000 babies per year are diagnosed with an inherited metabolic disorder as a result, state medical nutrition coverage policies for these conditions vary widely.

There is a Precedent for This Legislation: Congress Improved Coverage for Military Families in TRICARE
• In December 2016, Congress passed legislation that improved coverage for medical nutrition for military families enrolled in TRICARE.

• Prior to the passage of the new statute, TRICARE medical nutrition coverage policies were inconsistently applied and fell short of meeting the needs of TRICARE beneficiaries.

But TRICARE Coverage Was Just the First Step:
• The Medical Nutrition Equity Act would expand coverage to include patients covered under Medicaid, the Children’s Health Insurance Program (CHIP), Medicare, the Federal Employee Health Benefit Program, and private insurance.

• It would ensure that both public and private insurance cover medically necessary foods, which are required to prevent severe disabilities and death.

• The legislation is narrowly drafted to ensure that it only covers patients for whom the physician-ordered medical nutrition constitutes the treatment.

YOU Have the Power to Provide a Lifeline to Your Constituents with Digestive and Metabolic Conditions.

Please contact the offices of Senator Casey, Representative McGovern, or Representative Herrera Beutler to co-sponsor H.R. 2501 or to become an original sponsor of the Senate bill TODAY.

#MedicalNutritionEquityNow