



Dear Washington DC Lawmakers,

These are the stories of some of your Washington DC constituents whose doctor-ordered treatment includes medical nutrition. These constituents, and thousands of others, rely on medically necessary nutrition to survive and are counting on you to co-sponsor the Medical Nutrition Equity Act.

Washington DC has a state law governing medical nutrition, but it has the following exceptions*:

- **Private Insurance:** No Coverage
- **Public Insurance:** Limited to certain diagnoses, and by age and nutritional delivery method

PATIENTS & PROVIDERS FOR MEDICAL NUTRITION EQUITY

<https://nutritionequity.org>

* State-by-state coverage based on data from the National Coordinating Center for Regional Genetics Networks' 2016 report in cooperation with the Catalyst Center, updated July 2017 and the National Organization for Rare Disorders (NORD) State Report Card 2018.

Sarah, Washington DC Nurse Practitioner

Inborn Errors of Metabolism and Conditions on the RUSP Provider Stories

Staff time alone is the most major barrier. We are fortunate to have a Metabolic Clinic Manager to keep on top of all the insurance issues that arise for our metabolic formula patients but she spends at least 5-10 hours per week dealing with barriers. The cost to families in terms of time, costs and even anxiety about the future is hard to understate.

A young couple in the DC region had a baby diagnosed with PKU via newborn screening. They lived in a state with no mandated coverage of medical formula (Virginia) and when they learned their insurance expected them to cover the costs of 20% of his Periflex they were devastated that they would barely be able to cover it and afford rent. They made the difficult decision to move to another state and region where they would be able to depend on full medical food and formula coverage and to afford the cost of just one child with PKU.
