



Vincent

Florida | Tyrosinemia | Annual costs: \$3600

The average child eats what everyone else eats and thrives based upon a combination of nutrition, exercise and genetics. While we can not control our genetic make-up, most of us can "eat right, exercise and enjoy good health" - but for metabolic patients, in particular children...it's not that easy. My little boy just wants to be able to eat a pizza with his friends at school, or spaghetti, or enjoy a bowl of mac and cheese with a side of veggies- however, there is nothing in place in my school district which forces or mandates medical food be made available. The school board currently ACTIVELY refuses to purchase low protein options via a leading medical food company who already works with schools and has a program already in place. Why should they? The child is obviously being fed.... But at what cost to his health? No child wants to stand out as "different" - adults don't fancy it much either. I recently spent \$125 on 4 loaves of bread and 2 bags of pasta, it took 8 weeks to arrive from Italy. How is this equal? As a direct result of not always eating foods that are not medically formulated, and a combination of the medical formula which is full of HFCS, my son is very heavy. This is not ok. It's crushing his self-esteem and causing behavioral concerns which hinder learning and do nothing to help him achieve personal success. I work for an amazing company with great medical coverage, however they do not extend the coverage to any medical nutrition in the form of food. They only agreed, via arbitration, to cover under RX TierIII the formula and drug. It would mean everything to me to give my son the gift of better health by having medical foods covered under the insurance I pay for under my employers group plan.

Vincent depends on medical nutrition to stay healthy. Vincent and thousands of others across the country are depending on you to co-sponsor the Medical Nutrition Equity Act. Please contact the offices of Sen. Casey, Rep. McGovern or Rep. Herrera Beutler.