

To: Tina Liebling, Chair, Health Finance and Policy  
c/o Josh Sande, Committee Administrator  
cc Rep. Kim Hicks  
re: HF 3889 Amino acids feeding tube formula health insurance coverage required

This written testimony is in support for HF 3889, a bill to require insurance companies to cover amino acids based feeding tube formula for patients for whom it is medically necessary.

I have a feeding tube. I had to go through a "trial" period on "standard" formula which made me vomit constantly and really made me sick in general. This went on for a least a week after I had the feeding tube surgery on January 12, 2024. I had no idea that it was the formula itself that was making me sick. It took quite some time for the nutrition team at the hospital to explain to me that there were different formulas for different needs.

Believe me, not all formulas are interchangeable.

When you are reliant on insurance companies decisions as to what formula they will pay for and how much you "need" to stay alive, it is not a comforting experience. Doctors who are experts in nutrition and gastrointestinal disorders should be the only people authorized to determine what formula you need and how much of it you need to not become malnourished, miserable, and die.

Digestion and nutrient absorption by the GI system is complicated. Formulas are created by only a few manufacturers and are very specialized to function as your body requires when it is not functioning normally. This means if your stomach is paralyzed (gastroparesis) like mine, the stomach does not process oral intake of food and break it down into nutrients that can be absorbed by the small intestine.

Without a feeding tube and the right formula with the food broken down to the right elements, you starve to death after becoming malnourished and suffering.

No insurance company should be entitled to dictate what kind of formula you need, or how much of it you need. Their motivation is not "do no harm" their motivation is "profit over people."

Insurance companies who claim that feeding tube formula is simply "groceries" are being deceptive. You cannot buy feeding tube formula at the local grocery store. You can't grow it in a garden. It is very expensive to make at an industrial level in the many varieties needed by people with various malabsorption or digestive disorders.

The cost of the boxes and boxes of feeding tube formula needed to stay alive can easily exceed \$1,400 a month (not counting the pump rental and DME supplies for the feeding tube process). This is not equivalent to someone spending \$100 or \$200 for food in a grocery store. This is a catastrophic financial medical burden. When you are already disabled like I am and have to lived on a fixed low income, you simply do not have \$1,400 to spend on scientifically created nutrition that your body can process.

Starving to death because of medical conditions is not an acceptable alternative if an insurance company doesn't want to pay for the feeding tube formula you need to stay alive. They are not bound by the oath to "do no harm."

HF 3889

Amino acid-based elemental formula health insurance coverage required.

Chair Liebling and Committee Members,

My name is Bethany Porter and I live in Rochester.

Due to chronic GI issues, I have dealt with impaired nutrient utilization resulting in protein-calorie malnutrition. Because of this, I have a J tube, which is a feeding tube that delivers formula straight into my small intestine via a pump. I use a specialized enzymatically pre-digested formula that requires very little effort for my intestines to absorb, maximizing my body's ability to utilize the nutrition I need to stay alive. The good news is that, after about five years of tube feeding, I no longer have any significant vitamin deficiencies, and I've gained lean muscle mass. I am no longer slowly starving to death. However, this formula is expensive. It would cost about \$1400 per month to purchase it myself.

Doctors don't place feeding tubes unless they are medically necessary. People who rely on feeding tube formula do so because we have no other choice. My medical team has no financial incentive to prescribe a more expensive formula or a larger quantity of formula than I need.

This fall, my healthcare team became concerned about how much weight I was losing and recommended that I increase my caloric intake. The amount of formula I receive determines how many calories I get, so this meant they were prescribing more formula. My insurance didn't approve that and hasn't paid for any of my formula since December. Fortunately, my DME company has continued to provide formula to me, as they believe the appeals will go through and they will eventually get paid. I pay my insurance premiums & formula is a covered benefit, yet I'm still in financial limbo.

That the decision about how many calories I get should be in the hands of an insurance company is absurd. Insurance companies should not be allowed to keep patients in a state of malnutrition to save money.

I am very grateful to Representative Hicks for bringing this much needed bill and I ask you to support HF 3889.

Thank you,

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