

## **Testimony in Support of HB 5432**

### **An Act Expanding Health Insurance Coverage of Specialized Formula for Children with Eosinophilic Disorders**

#### **Insurance and Real Estate Committee**

**February 19, 2013**

Thank you for the opportunity to testify in support of House Bill 5432 to expand coverage of medical food.

In February of 2008, my son, Zane, was diagnosed with an EGID, a genetic disorder prohibiting him from eating. When he does eat, white blood cells, called eosinophils, attack his digestive system. Prior to his diagnosis, Zane had three surgeries and multiple hospital stays for malnourishment and dehydration. He went from the 90% at birth to the 30%. He was vomiting up to twenty or thirty times a day and suffering from starvation.

At present, medical food is Zane's main source of nutrition and most of his calories are from enteral formula. Steroids allow him to consume a small amount of food a day. Prior to Zane's surgery to have a feeding tube in place, he lost approximately 15 pounds at the age of 4. He was lethargic, unable to walk, focus, or perform basic tasks like dressing himself. He also missed three months of school. He suffered from extreme hunger and developed behavioral problems as a result. Medical food is the only FDA approved treatment for kids with EGIDs and according to APFED 15% of kids with an EGID rely on it in some part with 34% of that 15% relying on it as their sole means of nutrition.

Our group, Thrive!, represents thirty families in CT. All of us are on self-funded insurance plans. Almost all of us had to appeal for coverage. The other approximate 20 families affected are on commercial plans covering medical food for people with EGIDs according to an APFED member survey. Therefore, the likelihood of expanding coverage affecting CT's state budget under the new ACA rules is slim to none.

It costs approximately \$26,000 / year for medical food and supplies to treat Zane. We pay 30% of that cost. \$26,000 is about 40% of the average CT family's median income. At one point, our insurance company agreed with APRIA to supply us medical food at \$120/ can. Zane goes through a can a day. By appealing United to go through a different medical supplier we are now paying around \$53 / can when we could get it directly from the pharmaceutical company for \$40/can. Insurance companies are profiting from medical food.

Covering medical food for kids with EGIDs is cost effective preventative care. In 2008, Zane was admitted to the ER at NYC's Mt. Sinai Hospital for one hour of hydration and nutrition at a cost of \$950. According to APFED, a 24 hour hospital stay for IV fluid treatment cost an average of \$5500. That would pay for 3 ½ months of medical food for

Zane. Families unable to afford medical food may be compelled to feed their children regular foods that could cause permanent damage to their gastro-intestinal system. According to APFED, one year of Total Parenteral Nutrition (TPN) would cost \$1.8 million dollars.

Medical food saved my son's life. It allows him to thrive in good health. The current law needs to be amended so it no longer presents an obstacle in treatment of care to children with EGIDs and FPIES.

Thanks you. I can take questions if there are any.

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