

## Testimony in Support of SB 200

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

#### Insurance and Real Estate Committee

March 6, 2014

Thank you for the opportunity to testify in support of Senate Bill 200 to expand coverage of medical food. My name is Lisa Aschen, I live with my husband Sean, and son Stefan in Torrington.

Stefan, was born in 2009 at the top the growth charts. We had a very rough first year, filled with many colicky nights, weeping rashes, and reflux. We discovered he had a few "typical" allergies, but treating them didn't help. By the time he was diagnosed with EoE at 15 months old, he had fallen off the growth charts and was labeled "failure to thrive". We made drastic food eliminations without success. Through these first 2 years, he consistently missed typical developmental milestones, being late to crawl, walk, and talk. He wasn't a happy child, often cranky and clingy from discomfort that we didn't understand. He couldn't stomach food, frequently gagged when he tried, often refusing to eat or drink. He didn't sleep well for the first two years, crying for hours every night.

His health and development continued to decline, having less language at 22 months then he did at a year old. Things were getting worse despite being in feeding therapy. We were about to start speech therapy, when his GI eliminated all his foods and put him on an elemental diet consisting solely of Neocate formula, the only FDA approved treatment for EoE. Within a month, my son transformed from a quiet, practically non-verbal child who cried every time I left his side, to a babbling, active toddler. He started speaking, a lot, and creating small sentences. He enjoyed playing and being a child much more then he ever had. Although the formula is rather unpalatable, eating finally didn't hurt, and he drank enough to start growing.

The next couple of years, we started with tedious food trials, testing out one food at a time, followed by an endoscopy, every three months, without much success. His sole source of nutrition has been his Neocate formula. When food has made him sick, he couldn't tell us, he'd just stop eating and become more irritable and withdrawn, but always continued making up the nutrition and calories with Neocate.

Now, with medications, he tolerates 3 foods, though his tolerance has been changing over time, and he may not continue with these foods. We are working with the doctors taking these aggressive measures to find him a safe diet, but it's a slow process. This preventative treatment is far cheaper then emergency care that would be needed if he continued eating eating food.

We're not guaranteed to ever arrive at a complete diet, and he may rely on Neocate formula indefinitely. Like the other families in CT effected by this rare condition, only about 50, we are fortunate to have coverage for his Neocate formula. However, my husband, who carries our only insurance, will point out he's very lucky to have survived 8 layoffs since Stefan was born. There may be a time when we aren't so lucky, and our little boy could lose the one thing keeping him alive and thriving.