

The Herald Star – Steubenville Ohio

LOOKING FOR THE ANSWER Natasha Feher is currently seeking legislation with the state of Ohio that will require insurance companies to pay for a special formula needed by those individuals who suffer from eosinophilic esophagitis, as does her 2-year-old son Nicholas. The insurance companies currently cover the formula costs for those who intake the supplement through a stomach tube, but do not cover expenses for those who are able to drink the formula.

Seeking justice for Nicholas

By JULIE STENGER
Staff writer

WINTERSVILLE - One disease, two scenerios.

There are two children who require the same type of special formula in order to live. One does not prefer the taste, so they receive that nourishment through a stomach tube in order to survive.

The formula is then paid for through the family's health insurance.

The second child, who will actually drink the formula, despite the taste, in order to survive, is not permitted to have this same exact product paid for through his family's health insurance.

Therein lies the difficulty for one local woman, who is currently seeking legislation within the state of Ohio to require health insurance companies to pay for this supplement.

And it's all for the sake of her 2-year-old son, Nicholas Feher.

Natasha Feher is the mother of a child who has a rare disease known as eosinophilic esophagitis, an inflammation of white blood cells within the espophogus.

Nicholas was not born with this disease he acquired the various symptoms in February of last year when he was 18-months-old. Natasha and her husband Steve had noticed their son was pale in color and had dark circles underneath his eyes. He had also fallen off the growth chart, because he had simply stopped gaining weight.

He was always a good eater, Natasha stated of her son. His appetite suddenly dropped off and he had this food aversion.

He then became affected with chronic diarrhea.

The Fehers immediately took their child to Children's Hospital in Pittsburgh, thinking he had celiac disease. However, the results came back differently.

After being diagnosed with eosinophilic esophagitis following an endoscopy, Nicholas's parents were told he is not capable of eating most foods. He is, however, able to tolerate very small portions of rice, white and sweet potatoes, chicken, bananas and squash.

The hardest part emotionally is not being able to nourish him as a mom, Natasha said, and there's not a cure.

Natasha explained this disease is often mis-diagnosed as being acid reflux, and either results in individuals getting food get caught in their throat, or the feeling of having food be caught in the throat.

To supplement his nourishment, the 2-year-old must rely primarily on a special formula called Neocate Junior. This formula must either be specially ordered through the manufacturer or the Durable Medical Equipment Co., and costs between \$35-\$60, according to his mother.

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Approximately 16 cans are currently drunk by Nicholas each month, which is double the grocery bill of the Feher household.

This special supplement was given to Nicholas following his weight loss, and after 12 weeks on the formula, he had gained two additional pounds and had gotten his color back, according to Natasha.

While the formula would be covered through Medicaid, the family does not qualify due to their income.

We looked into getting aid and help but didn't qualify, Natasha said. We are just an ordinary family with one income. My husband works and I stay home with Nicholas so I can take care of his needs. I don't think that I would be able to trust anyone else to take care of him the way he needs to properly be cared for.

The law Natasha is currently seeking in Ohio, has been passed in six other states through an organization known as Children's Magic. Those states include Arizona, Connecticut, Massachusetts, New Hampshire, New Jersey and New York.

The Fehers have been through two appeals with the insurance provider over the matter, of which Natasha said, The insurance is doing a disservice to the families they represent.

I think its absurd that they're denying this, she noted.

She also compared the legislation experience to that of a roller coaster, with its highs and lows. Natasha said a bill has already been written for her to look over to ensure the information is correct, and anyone wishing to help in the matter or support her sons cause can contact her through e-mail.

The Fehers have also sought the help of Jason Wilson from the Ohio Senate and Jon Peterson from the Ohio House of Representatives, and are now working with the Ohio Department of Insurance.

Feher explained the issue needs to be passed in both the Senate and the House in order to have the governor sign it.

In addition, there are approximately 50 people within Ohio who are also working on the passage, according to Natasha.

The American Partnership for Eosinophilic Disorders states there are 70 registered cases of the disease within Ohio, and 1,000 registered cases nationwide.

Natasha stated where there was approximately one person diagnosed with EE each month, there are now one to two individuals that are diagnosed every week.

This is definitely on the rise, she said of the medical condition.

In addition to Nicholas, the Fehers have two other children, Casey, who is 9, and Alexander, 6. Natasha noted Alexander has recently been complaining of stomach pains, another symptom of the rare disease. He is expected to get tested in the near future, because eosinophilic esophagitis is hereditary.

Yearly meetings are held through the APFED, of which Nicholas's parents have begun taking part. The couple attended an August conference in New Jersey, where they heard from Cincinnati and Philadelphia doctors who specialize in assessing the disease, and provide information on

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medications and research updates. They hope to attend this years July conference in Utah as well.

Natasha also wants to help others who are going through similar experiences. She said she understands that the financial implications can be emotionally draining for most. As a result, she has started a support group for parents because as she stated, So many people just don't understand it.

We just want to raise awareness about this horrific disease, Natasha added. This has affected our family with this insurance battle, and Feher does not want others to have to endure such problems as well.

Those wishing to obtain information, can e-mail either Natasha at tasha@pghkidswitheos.com or Cathy Pascarella, a Pittsburgh woman Natasha met during the New Jersey conference, at

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Their Web site is www.pghkidswitheos.com