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Rare disease doesn’t slow Webster boy down

By Dan Glickman, staff writer
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Webster, N.Y. — At first glance, Donovan Cullen appears to be a ordinary, healthy 7-year-old boy. On one recent day, he could be seen playing basketball with his father, Dean.

“I don’t know how he gets as much energy as he does,” said Dean.

However, the kitchen in the Cullens’ Webster home tells a different story, as stacked pyramid-style on a table are jars of Neocate formula, and alongside them, a EpiPen.

This is because, for all of his youthful energy, Donovan has a rare condition known as **Eosinophilic Esophagitis**, or EE. It is a condition where the esophagus has a large number of eosinophils — a type of white blood cell — that cause the esophagus to be damaged and inflamed. As a result, people with EE have a hard time swallowing, are prone to vomiting and are highly allergic to most types of food.

Although doctors have told the Cullens that EE is hereditary, neither Sara, who is from Webster; or Dean, who is from Wayne County, can think of anybody in their families who has it beside Donovan.
For Donovan’s mother, Sara, it became clear that something wasn’t normal about her son shortly after she introduced him to solid foods, leading to his diagnosis at 15 months.

“He was choking and throwing up on a daily basis,” she said, “I couldn’t figure out what food he was allergic too.”

“The doctors wondered maybe [he had] acid reflux — and he does have that — but I thought there was more to it,” she continued, “We did allergy testing, we tried taking some food away ... he was only diagnosed when they did a endoscopy.”

It would be the first of 12 endoscopies that Donovan has had throughout his life. It’s the only option in order to see whether he has reactions to some foods. The Cullens make the eight-hour drive to a children’s hospital in Cincinnati that has a eosinophilic center. Donovan often will try certain foods for about three months, at which point they will travel to Cincinnati and be scoped to see if his esophagus is being affected by the food. If it is, he has that food removed from his diet entirely.

Sara, who also has three other children — Sean, 10, Gavin, 8, and daughter Samantha, 4 — summed up Donovan’s current diet in rather plain terms: he is anaphylactically allergic to eggs, chicken and lentils. He can have soy and wheat, but he is allergic to some degree to almost everything else.

Most of his nutrition comes from the formulas on the Cullens’ kitchen table. However, it is not something that Donovan will usually take alone, as Sara opened up her refrigerator and pulled out a bottle of a thick juice.

“As of right now, he’s on this V8 juice, I mix the formula with it,” she said, “But now I’m in trouble, because V8 has stopped carrying this flavor.”

When V8 discontinued the juice eight months ago, Sara “went to every Wegmans and Tops and bought out everything they had.”

Now, however, only three remain. Sara remarked that it had happened before, with a certain brand of carrot juice that was also discontinued.

“I have called up companies and told them, ‘This is the main source of nutrition for my child, if I can’t find a juice that he likes and he can tolerate because of his food allergies,” she said. “But, they won’t bring it back, they just weren’t selling.”

“We’re always doing research to find what he can eat, but sometimes then he doesn’t like it,” Dean said. “It’s frustrating.”

Despite all of these challenges Donovan remains active. He plays baseball, soccer and basketball, and also goes fishing. He also likes hockey, enough that his father builds a rink in their backyard during the winter. Still, he realizes that he isn’t like the other kids in school, and said that sometimes he feels sad that “I can’t eat stuff.”

The Cullens also wish that EE could become more widely known.

“We’ve met some people through allergy support groups,” said Sara, “There are adults that have it, kids that have it, some college kids that have it, but it is so rare that the doctors are only just becoming aware of it, and it’s misdiagnosed a lot.”

But despite the rarity of the condition, Donovan is not the only one who has it, even locally.

“Kids with this condition are all over Rochester,” said Sara, who estimates that there are about 17 in the Rochester area with EE or a similar condition.

Although there is no cure, though, the Cullens remain optimistic. In fact, Donovan, who says he wants to be a fireman when he grows up, has also said in the past that maybe he'll be something else:

A doctor. To try and find a way to help people like him.

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Thank you for sharing your story Donovan and to your parents for their effort to spread awareness about Eosinophilic Esophagitis. You did a great job and sound like a remarkable boy that has a wonderful family to support you. May you also have a cure within your lifetime. In the meantime, I hope that you are able to find some juice that is safe for you to drink.- Tobie M., Wisconsin

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