

Originally Published: 6/21/2011

For Berks boy, allergy turns food into an enemy

Eric Mock, 7, of Amity Township suffers from eosinophilic esophagitis, a condition that severely limits his diet by mouth.

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<http://readingeagle.com/article.aspx?id=315624>

Eric Mock played on the floor with a toy train while he talked about his favorite foods.

Because of a condition that causes the 7-year-old's esophagus to become inflamed, his diet by mouth is limited, and he gets additional nutrition via a feeding tube in his stomach.

The ordeal has also drained the family's finances, which limits vacations and other perks that are often part of childhood.

But there's a certain kind of ice cream sandwich he can eat, Eric said proudly.

Then his mom, Nicole, 43, shook her head sadly.

"I'm sorry, Eric, but I didn't tell you they changed the ingredients," she said.

"They did?" he asked and sat down dejectedly next to her on a couch in their Amity Township home.

Without needing further explanation, he understood he could no longer eat those ice cream sandwiches, or he'd risk a violent reaction to them.

Eric stared at the floor in silence.

"I'm sorry," his mom said.

Eric shrugged and then quietly said, "That's OK."

He looked glum, but he didn't look like he was about to cry.

His mom, however, looked like she was ready to weep.

Sudden problem

When Eric was 4 months old, he one day without warning refused to nurse.

Nicole and her husband, Thom, 46, tried several different kinds of baby formula to no avail, and Eric started losing weight.

His weight was so low that he didn't even register in the first percentile of standard size and growth indicators for infants, Nicole said.

"That's when it became really serious, and his pediatrician said we needed to find out quickly what was going on," Nicole said.



They were referred to The Children's Hospital of Philadelphia where a doctor ordered biopsies, or tissue samples that doctors could examine, and an endoscopy, or the use of a device to look inside Eric at his esophagus, stomach and duodenum, the upper section of the small intestine.

While they waited for the results, Eric constantly vomited at home for a few days and barely took formula.

"He would eat just enough to take the edge off his hunger but not enough to sustain growth," Nicole said.

When the family returned to CHOP, they received the diagnosis of eosinophilic esophagitis, an inflammatory food allergy that includes painful symptoms of heartburn, vomiting, nausea and difficulty swallowing.

"In kids like Eric, it also attacks their esophagus," Nicole said.

Doctors ordered Eric to be fed via a nasogastric intubation, a plastic tube that's inserted through the nose to the stomach.

Nicole and Thom had a one-day learning session at CHOP on how to install the tubes to avoid Eric's lungs, how to test his stomach acid and how to use syringes to get the acid out through the tube.

The parents often had to restrain Eric in a car seat because he squirmed and cried so much during the procedures.

"We were completely out of our comfort zone," Nicole recalled as her eyes filled with tears at the memory.

Nicole, who is now a hospital registrar, was a travel agent at the time. Thom is a truck driver.

"What we had to do to him, no parents should ever have to do to their children," she said. "Our kid's nursery, which was adorable, looked like a hospital room."

Before he turned 2, Eric was slowly introduced to new foods one at a time and, after each attempt, a biopsy was performed to test Eric's sensitivity to it.

Eric had to have a biopsy every six to eight weeks.

"It was a struggle finding foods he could eat," Nicole said.

Even now, his diet is extremely limited.

"They were saying he might grow out of it, but they're not saying that anymore," Nicole said.

Ordeal binds family

Because Eric kept pulling at them, the nasogastric tubes were replaced at age 2 with a gastric tube, which is inserted into the stomach through a small incision.

He has started to be self-conscious about the tube protruding from his stomach.

Fortunately, wearing swimming shirts is in style for children now so he can cover up, Nicole said.

But he can't eat cake at friends' birthday parties, and he usually has to bring his own food.

"We just have to be five steps ahead of everything he does, or he could get violently ill with a reaction that could last three days," Nicole said.

The family can't afford Disney World or more expensive trips after years of fighting for insurance coverage that at one point cost \$1,200 per month in medical co-pays and other expenses, Nicole said.

"We went through our 401(k)s, our emergency fund, all our savings," Nicole said. "The damage has been done. We have nothing now. I still have times when I start getting bills and have to fight the fight all over again."

But the ordeal has in many ways made the family a close one.

"We're a team," Nicole said. "We have faith that God's in control. We don't understand it, but it does give us comfort."

Besides a few brief trips to the beach, the family has taken only one extensive vacation.

The trip was all about Eric.

He loves trains, so his parents took him to the Steamtown National Historic Site in Scranton. Eric badly wants to go back.

He will talk at length about the full-size trains and the toys in the gift shop.

Eric often plays with a train he got there and is saving his money to buy two more.

"If I got all three of these trains, I guarantee you, that would be great," he said.

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