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Local News and Video for McHenry County, Illinois

Looking for a cure to health insurance codes

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CRYSTAL LAKE – There are about a dozen foods that don't make Grant Moen sick.

The 3-year-old can have eggs, wheat, pasta, bread, potatoes, broccoli, zucchini, orchard fruits, tropical fruits, carrots, beans, grapes, lettuce, and an amino acid-based formula called Neocate.

Grant, of Crystal Lake, has eosinophilic esophagitis, a condition characterized by unusually high numbers of white blood cells attacking and inflaming the esophagus. Forbidden foods, such as citrus fruits, melons and berries, trigger an attack and make him sick.

"We can't go out to dinner because of the cross-contamination issue," Jennifer Moen, Grant's mother, said.

Neocate, a nutritive formula that provides about 90 percent of Grant's daily intake and that can cost about \$30 for about 14 ounces of dry powder, currently is not covered by insurance in most states. Jennifer Moen estimated that her family would spend an average of \$500 a month on the formula if they weren't among the lucky families that have 80 percent of the formula cost covered.

A proposal making its way through the Legislature could make them the norm in Illinois, not the exceptions.

Legislative efforts

State Rep. Kathy Ryg, D-Vernon Hills, is the lead sponsor of legislation that would require that insurance companies help foot the bill for orally administered medicinal foods such as Neocate. House Bill 1560 amends the current insurance code to require companies or the state to provide coverage of amino acid-based formulas without regard to how the foods are administered.

State Rep. Mike Tryon, R-Crystal Lake, has signed on as one of about a dozen co-sponsors of the proposal, and state Sen. Pamela Althoff, R-Crystal Lake, voted in favor of the bill when it passed the Senate on March 30. Ryg said she hoped to have the bill passed in the House this spring.

"Currently insurance companies will cover them if they're administered via a feeding tube and not orally," Ryg said. "There's no one who disagrees that doesn't make sense."

The nutrition question

But Wendy Morphew, spokeswoman for Aetna Health Insurance, said her company had to draw a line between nutrition and food that was medically necessary. If the same formula is administered through a feeding tube, it is covered, she said.

Morphew added that her company, and those of other health-care insurers whose policies fall along the same lines, were aware that Neocate was an expensive means of survival for families.

"We are not unsympathetic to that, but on the other hand, we simply can't cover everything, and we have drawn the line at nutrition," Morphew said. "We're not so much covering the formula as the method of delivery."

"In those [feeding tube] situations it's a matter of the child is medically unable to either swallow this or if they can take it in, the body can't absorb it," she continued. "In those cases, we would view it as ... medically necessary."

Howard Lossing, director of marketing for Neocate maker Nutricia North America, said insurance did not

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cover the costs of the product in 44 of 50 states.

"What effectively the law is saying is go ahead and poke a hole in your child's stomach and then it will be OK," Lossing said.

Morphew said responsible doctors must to make the decision to put in a feeding tube only if it is medically required.

A medical malady

A feeding tube opens the door for complications such as infections and increased costs, said Ellyn Kodroff, the president of the Campaign Urging Research for Eosinophilic Disease Foundation. Her 14-year-old daughter shares Grant's condition and is subsisting solely on Neocate.

"As of now, there is no known cure and the treatment is either steroids, which is very unsafe for the body, or no food," Kodroff said. "Those are your two basic choices."

Grant Moen first was diagnosed at 14 months, after his parents said his stomach swelled up to the size of a small basketball. The little boy, however, has flourished on his Neocate diet, and looks and acts like any other playful preschool-aged child.

The Moen family is one of the fortunate few that does get reimbursement for the Neocate. After a year of arguing with insurance providers, the human resources director for Nordstrom in Schaumburg, where father Eric Moen is a manager, stepped in and got the formula covered.

But Eric Moen said for many families, the choice of how to care for their children comes down to either surgery or financial ruin.

He testified as such in a March 20 letter to the House Health Care Availability and Access Committee.

"It could be so much worse," Eric Moen said last week. "I just hope that these insurance companies will pay for all these families."

About the condition

Eosinophilic esophagitis is a condition characterized by unusually high amounts of white blood cells that attack and inflame the esophagus. Symptoms include reflux that does not respond to therapy, difficulty swallowing, nausea and vomiting, poor growth or weight loss, abdominal or chest pain, poor appetite, malnutrition and difficulty sleeping.

Source: The American Partnership for Eosinophilic Disorders

Support a CURE

What: The fourth annual Bet on a CURE fundraiser for the Campaign Urging Research for Eosinophilic Disease. Includes a luncheon, open bar, silent auction and live horse racing.

When: 12 to 5 p.m. Sunday, May 6

Where: Arlington Park Racetrack, 2200 W. Euclid, Arlington Heights

Why: To raise money for research of eosinophilic disorders such as eosinophilic esophagitis

How to get tickets or make a donation: Visit www.curedfoundation.org. Tickets cost \$100 for adults, \$50 for children and young adults ages 5 to 20 and are free for children 4 and younger.