

# CHICAGO SUN-TIMES

## Boy allergic to food lives on formula

March 11, 2007

**BY SUSAN FRICK CARLMAN Naperville Sun**

To the untrained eye, nothing looks amiss with Nate LaDeur. The energetic and precocious Naperville 4-year-old is a whirl of motion on a recent weekday morning, practicing free throws from all angles in the home he shares with his mom, dad and two big brothers. But for Nate, breakfast never brings a bowl of cereal or a plate of eggs. The morning meal, like all of his snacks, and lunch and dinner, takes the form of a not-very-tasty, predigested prescription formula called EO28: Splash. Disguised with orange-pineapple flavoring and packaged in an orange, kid-friendly juice box, it's the only food Nate's body can tolerate.

### Allergic to food

His disorder, the relatively rare autoimmune disease eosinophilic esophagitis, causes his body to reject virtually all food. When a foreign substance comes down the pipe, Nate's immune system kicks into overdrive and his esophagus seizes up.

"This is the only thing, basically, keeping him alive," said Debbie LaDeur, 47, of her son's extremely restricted diet. Diagnosis doesn't come easy, and the ailment often is confused with other gastrointestinal diseases. Nate's came about a year ago.

### Nearly \$1,000 a month

It wasn't easy getting her toddler to acquire a taste for the liquid. However, he was a huge fan of Spider-Man at the time, and the family managed to convince him that the stuff in the box was what enabled the famed webslinger to swing from building to building.

Debbie LaDeur, a stay-at-home mom, said the family's health insurance provider has not proven so accepting of Nate's lot in life. The EO28 isn't covered by their policy, and the almost \$1,000 monthly expense is a strain on the family. Her husband, Jeff, 45, is a general manager with Info USA in Lombard. The couple are keenly aware that as their active son grows, the cost will only follow.

What's particularly baffling, she said, is their health insurance company would pay for the formula if Nate consumed it through a feeding tube -- and it would cover the procedure that would surgically install the delivery device in his abdomen.

"I don't want to put my son through a \$20,000 surgery, with many, many possible complications, and the risk of infection, when he can live a completely normal life the way he is now," LaDeur said.

But the LaDeurs' health insurance provider says that when nourishment such as Nate's EO28 is consumed orally, it does not meet the FDA's definition of medicine.

"The way we see this through our policy is that the plan benefit is only when it's administered internally, through a feeding tube, or by the parent, intravenously," said Deborah Hoyt, a spokeswoman for Aetna Inc.

The LaDeurs plan to focus on a law to change that.

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Debbie LaDeur is poised to testify in Springfield, sometime in the next few weeks, supporting proposed legislation that would force private insurers to pay for the orally administered prescription nourishment.

## **Drastic measures**

Jason Eberstein, staff director of the medical lobbying group Children's Magic, said six states -- Arizona, Connecticut, New Hampshire, New Jersey, New York and Massachusetts -- already require insurance companies to pay for medical food, orally administered and otherwise. And prescriptions of families on Public Aid in Illinois will be filled by the state, too.

Bills similar to the Illinois measure have been proposed in Maine, Minnesota and Washington state, and they all boil down to the same objective.

Some families go to fairly drastic lengths to keep the liquid flowing. Eberstein said in some cases, couples arrange "paper divorces" so the household appears to have an income level low enough to qualify them for public assistance. And sometimes, he said, the kids have surgery simply because their families can't afford the formula anymore.

Sun-Times News Group