

Little girl's fate spins in a formula of money and politics

March 13, 2000

From staff reports

WEST ALEXANDER, Ohio (CNN) -- Kaitlynn Bogen, a cute little girl with blue eyes and pale red hair, has one big problem, a digestion disease, and to survive she needs a special, expensive food supplement imported from England.

The disease will only allow her body to properly absorb amino acids. These are the building blocks of proteins, essential to life. Her reaction to regular food, baby formula or even human-breast milk can be violent and painful.

"She developed skin rashes, screamed, threw up," said her mother, Lydia Bogan. "She had diarrhea, was bleeding."

Kaitlynn's mom also has a big problem -- paying about \$18,250 year for the food supplement called Neocate her daughter needs for survival.

The money is a burden because United Healthcare of Ohio, the insurance company the Bogen family paid premiums to, says food supplements are not covered.

Executives of the company have some problems, too. They are feeling public heat because they appear to value profits over a little girl.

Entering the food-money-political fight is Gene Krebs, a state senator. He's introduced legislation that would require health-insurance companies in Ohio to cover the type of food supplement children like Kaitlynn need to survive. Twenty-four other states already have similar legislation.

One issue is whether a product such as Neocate can be a "food supplement" to one person and not paid by insurance but can be reclassified as a necessity for another person and be covered.

At least 3,000 families are in the same situation as the Bogens in Ohio. They have established a group called "Mothers Aligned for Medical Advocacy" -- MAMA. Members push politically, even communicating with presidential candidates, to make the insurance companies pay.

If so, says Dr. Lee Newcomer of United Healthcare, the cost will be passed on to other families. Premiums would rise dramatically.

"Everytime you add one more mandate to insurance, the price has to go up," said Newcomer.

Not a real problem, replies Sen. Krebs. "This would raise premiums 1.6 pennies a year for the average family."

At the center of Kaitlynn's life is Neocate, a 100 percent synthetic amino-acid based powder, which is mixed with water. The manufacturer in Liverpool says the product is a "complete nutritional support for infants with cow-milk allergy and multiple-food protein intolerance. Neocate is hypoallergenic and is proven safe for use in severely allergic infants who cannot tolerate soy formulas" or other foods with protein.

Sen. Krebs' bill is stalled in committee. But Lydia Bogen and her MAMA colleagues are not stalled. They vow to continue the fight.

CNN Correspondent Ed Garsten contributed to this report.