

Tucson Citizen

Moms seek bill to save kids with rare disorder

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There's been plenty in the news lately about the wrong way to get a law written. (For a primer, type the phrase "lobbyist Jack Abramoff" into Google.) But before there were lobbyists, there were people - people who had a problem or a situation that needed to be addressed. And they would talk to other people in the same situation, reach a consensus, then go to a lawmaker and persuade him or her that something needed to be done.

It sounds quaint and old-fashioned, but once in a while, it still works that way. And three Tucson mothers are hoping it will happen this year in the Arizona Legislature. Michelle Racioppo, Denise Bianchi and Christina Dean are undertaking a fight not for themselves, but for their children - and for untold numbers of other children with a rare, life-threatening and little-understood malady.

Their fight is this clear-cut: If they don't persuade the Legislature to change the law, other parents who find themselves in a similar situation may not be able to keep their children alive. Each of the three mothers has a child with eosinophilic gastrointestinal disorder, a disease first diagnosed a decade ago. The disease makes the children allergic to virtually all types of food. Some children with the disease can eat a few specific foods that don't bother them; others can eat nothing. The only thing that keeps them alive is a medical liquid poured through a feeding tube directly into their stomachs.

The liquid costs up to \$1,200 a month. And because of the way a state law is written, insurance companies have refused to pay that cost, maintaining that the liquid is food, not medicine. State Rep. Steve Huffman, a Republican who has met with the three mothers and heard their plea, has introduced a bill that would require insurance companies to pay for the liquid. But the bill faces a tough road in the Legislature.

Racioppo's son, Sam, is 8 1/2 and, until three years ago, was a perfectly healthy, normal child. Then, for no discernable reason, whatever he ate caused him intense abdominal pain. Eosinophilic gastrointestinal disorder was diagnosed. The disease occurs when excessive white blood cells infiltrate the digestive tract, tearing up the esophagus, stomach and colon and leaving children in excruciating pain.

"There is no cure for this disease," Racioppo said. Some people manage by finding a few foods that do not trigger the reaction. But for the child whose body viciously attacks itself, survival requires him to live only on the costly medical liquid administered through a stomach tube. Bianchi is another mother in this situation. Her 4-year-old son, Anthony, had a terrible time with food from infancy.

When he was 18 months old, Anthony was diagnosed with Guillain-Barre Syndrome, in which the immune system attacks the nervous system, leaving patients temporarily paralyzed. He had a stomach tube inserted, was given the medical liquid, and his parents have noticed a significant improvement.

Five-year-old Paige Dean has been unable to handle food since she was a baby. Her mother, Christina, said Paige had a tube inserted into her stomach almost a year ago and was started on the medical liquid. She now is pain-free for the first time in her life.

The vagaries of health insurance policies are incomprehensible to the average person. Insurance pays for the liquid when it is administered in the hospital, pays for the feeding tube to be inserted so parents can administer the liquid, but will not pay for the liquid once the child leaves the hospital.

So Huffman introduced a bill that modifies insurance contracts and policies sold in Arizona, requiring them to pay at least 75 percent of the cost of the liquid, up to \$20,000 a year.

"I think this is inexcusable we don't have these types of protections for families in Arizona," Huffman said. "Insurance companies are right when they say state law excludes this, but I don't think that's right."

Arizona's insurance system is "murky and cloudy," he said. "We don't need to change the law so that insurance companies cover this, but it's pretty clear they won't unless we do.

"I find it amazing that insurance companies will take your money every month and not cover this," Huffman added. "To me, this is the same as insurance companies denying treatment for cancer." Racioppo estimated 40 children in Tucson have the disease. But that may not reflect the total problem because some children don't develop the allergy until they are teenagers. Huffman said he has talked with insurance company representatives and expects them to oppose his bill. It also is sponsored by Republican state Rep. Pete Hershberger and by Democratic Reps. Linda Lopez and Phil Lopes, all of Tucson.

The three mothers are passing out fliers and urging people to contact their legislators to support the bill, HB2364.

"Imagine if you could not feed your child one carrot, one piece of food," Bianchi said.

Racioppo is particularly incensed that insurance companies are refusing to pay for the liquid because they consider it food. "If we could feed our kids, we would," she said.

The bill has been assigned to three House committees, but so far none has scheduled a hearing on it. Unless the chair of one of those committees allows a hearing, the bill will die.

Huffman is hoping that won't happen. "I wouldn't bet against any of these moms," he said.