

# Fighting

By Erin Graham

It's not unusual for parents to feel the pangs of separation anxiety on the first day of school. But when Robyn Nasuti gave her 5-year-old son, Brett, a goodbye kiss as she left him at pre-school, she wasn't worried about whether he'd make friends or get homesick. Brett has life-threatening food allergies, and in the past, Robyn had entrusted his care only to family members, having decided that the chance of him getting exposed to a potentially deadly food at daycare or with babysitters was too high. In fact, he was so sensitive that when people kissed him after eating certain foods, a hive would balloon up on his cheek in the shape of their lips. "Most people give their kids to the school system for them to be educated, but we handed over Brett and said, 'Please keep him alive,'" says Robyn.

That first day of school, Robyn sat in her car in the parking lot for hours, waiting for disaster to strike. Sure enough, when a little boy sitting near Brett opened a snack containing peanut butter, Brett was consumed by wheezing fits so severe that he had to be hospitalized for two days. "I ran in to see him struggling to breathe," Robyn remembers. It wasn't the first time she'd seen Brett gasping for air. Once, the mere smell of a quiche baking in the oven prompted an asthma attack that landed him at his doctor's office. Another time, a bite of his dad's birthday cake caused him to balloon up, turn

# food allergies

**THE KARATE KID** Brett started practicing the sport when he was 5 to give him the confidence and self-discipline to manage both his allergies and bullies at school.



purple and break out in a rash from head to toe, and they whisked him to the ER.

Robyn and her husband, Alan, had lived with a steady feeling of alarm since Brett was 1, when a phone call from an allergist explained Brett's near-constant bouts of hives, eczema and rashes. She sobbed as she heard, 'Brett tested positive for wheat, soy, spelt, dairy, egg, nuts...oh God ... you'd better get him in here, he needs an EpiPen...barley, oat, corn, lamb, beef, penicillin, tree pollen, ragweed, mildew, mold, cat and dog....' Brett had 21 allergies all together, 15 of which were food. "We were completely overwhelmed," says Robyn. "I thought, 'How will I ever feed him?'"

## The allergic generation

By the time Brett was 2, the Nasutis had seen five allergists but were still desperate for advice. Eventually, they came to Children's Hospital Boston's Allergy Program, where nutritionists, psychologists and doctors helped them manage Brett's allergies, eczema and asthma. In addition to "How can we feed him?" the big question on the Nasutis' minds was, "How did this happen?"

The Allergy Program's Director, Lynda Schneider, MD, provided some insight. According to her, about 7 percent of children are allergic to foods—a number that's thought to have doubled over the last 10 years. The number of new patients with food allergies at Children's increased dramatically, from 14 percent in 1998 to 46 percent in 2005. But what's behind the jump is another matter. "We know that genes are involved and we know that the amount of exposure a person has to an allergen, and the age of that exposure, are likely important factors," Schneider says.

Researchers at Children's are considering a wide range of other possibilities. One theory suggests that improved vaccines and a generally cleaner culture (with potent cleaning agents, ubiquitous hand sanitizer and purer water supplies) have caused Westerners' immune systems to overreact. The rates of diseases like salmonella, Hepatitis A and measles are much lower than in the past, and we're exposed to fewer bacteria and infections. We're also treated with more antibiotics for infectious diseases. These health improvements could mean that our immune systems are essentially lazier than they used to be. Without having to put in overtime doing their traditional jobs of infection-fighting, their skills have become less sharp and they may

misidentify harmless foods as threats. Another factor under investigation is diet. For example, the bacterial content of the gut, which is affected by food, could have strong effects on the immune system. Other studies show that maternal diets with lots of antioxidants and vegetables are associated with reduced asthma in children, while vitamin D deficiency is associated with higher rates of asthma.

### The dairy dose

While researchers search for clear answers, Schneider and her colleague, Dale Umetsu, MD, PhD, are tackling food allergies head-on. In March, Brett, who's now 11 and has outgrown all of his allergies except to dairy, nuts and eggs, became Children's first patient to go through a groundbreaking study to train severely allergic patients' immune systems to tolerate milk. Much like environmental allergy shots, patients get exposed to tiny amounts of the allergen over many months—in this case, by drinking cow's milk—so their immune systems become desensitized and don't react to it. Until recently, the only treatment for allergies was avoiding the food and managing any reactions. Children's desensitization trial—the first of its kind in the country—represents a bold new way of thinking about

after a pause decides, "It was good. I liked it."

Brett soars through the first "milk challenge" unscathed, and every week returns for more. He gets regular Xolair injections and knocks back bigger and bigger shots of milk. Slowly, his resistance increases, and after a few months, he's drinking milk in gulps every single day. "It's absolutely amazing," says Robyn. "Before, he couldn't be near anyone drinking milk, and now, this." After a few more months, Brett will stop getting injections and, if all goes well, he'll still be reaction-free.

### A family affair

If the desensitization is successful, it would ease the burden on the whole Nasuti family. "Our stress level goes up and down," says Robyn. "At first, when Brett was diagnosed, we read everything we could get our hands on, which made us more overwhelmed. We never went out. But we started to realize that we needed to teach Brett how to live in this world, so we started calming down and figuring out ways to keep him safe." They devised strategies, like cooking his food in separate pots and pans and carrying "allergy cards" to give to chefs at trusted restaurants so the kitchen staff had a list of forbidden foods while preparing Brett's meal.

But their stress level jumped back into the red when Brett's little brother, Nicholas, was born with 16 food allergies that, as luck would have it, didn't completely overlap with Brett's. Nicholas, now 5, sums it up best: "I'm allergic to bananas, dairy, wheat, eggs, milk and everything else." Amazingly, Brett's sister doesn't have any allergies, but helping her deal with her brothers' conditions comes with its own challenges. She obeys strict rules: She can't drink out of certain glasses, has to meticulously wipe up her crumbs, eat her crackers at the counter, wash her hands and mouth before touching her brothers and keep her food in designated "off-limits" drawers.

There's nothing routine about meal times at the Nasuti house. "It's a bit of a challenge because we have to make three different meals every time we eat," says Robyn. "Cooking takes a long time." So does food shopping. Robyn drives to three different grocery stores in order to find allergy-friendly foods for each boy, like dairy- and egg-free pizza crusts and gluten-free cereal. And these specialty foods don't come cheap; dairy-free milk alone costs her \$10 a gallon. "I spend about \$850 a month on groceries," Robyn says.

The most important thing Robyn has learned about food shopping is to reread food labels, no matter how many times she's bought something. "I've had too many accidental ingestions because a product changed its ingredients," she says. Two years ago while food shopping, she opened a brand of chips she'd bought for years, without glancing at the label, and gave one to Nicholas. Within minutes, he complained that his was mouth on fire. "These chips are no good, Mommy," he said, as hives erupted down his neck and he started coughing. "He ended up going into anaphylaxis and was taken out in an ambulance," Robyn says. "The company had added a sour cream flavored line and I didn't realize it."

Certain stores know the family well: Robyn has made

friends with workers at deli counters, who know they need to change their gloves after touching each food item, wipe down the scale in case of cheese residue and make sure they clean the slicer in between cuttings, to make absolutely sure that Brett's chicken won't contaminate Nicholas' pork.

### The power of pizza

While crossing one of the boys' milk allergies off the family's lengthy list may sound insignificant, it would make a big difference to Brett. He's had to be hyper-vigilant in avoiding products that contain even the smallest trace of eggs, peanuts and dairy, which can lurk in everything from bread to hand soaps, lotions to shampoos. He's had to bring his own food to parties, carry EpiPens with him everywhere in case of life-threatening anaphylactic shock, and ask his friends to wash their hands and faces when they come to his house. In elementary school, he had to sit at the peanut-free table and couldn't sit near anyone drinking milk.

He's also had to deal with a fair amount of pre-teen persecutors—classmates who see his allergies as a weakness and, in typical middle school fashion, prey on it. "There are a couple of bullies in my life and I'm always afraid they'll punch me out one day because of my allergies," Brett says. "They call me things like Peanut Boy and tease me." Once, a classmate thrust a peanut butter sandwich in Brett's face when their teacher left the room—an assault that Robyn felt was the equivalent of "a kid taking out a knife."

Despite the bullies and constantly being on high alert, Brett is incredibly well-adjusted. "I tell my friends that mostly it doesn't affect me, and it's something normal kids have," he says. "Some kids are born with allergies and some kids catch it along the way. I don't worry a lot about it." A dedicated Boy Scout, Brett's also about to try for his black belt in karate, which he started when he was 5 to give him the confidence and self-discipline to manage both his allergies and the bullies.

Not all of the patients in the Allergy Program have adapted so well. Some struggle with the stigma and others become overly anxious about the possibility of having food allergy reactions. Sometimes, children can be so worried that they develop obsessive-compulsive disorder and repeatedly wash their hands or wipe the table in case there are allergens, or refuse to eat anything they didn't see being prepared or use utensils that aren't theirs.

Brett, on the other hand, could be the poster child for living well with food allergies. He's taken it upon himself to educate his peers by organizing an annual Food Allergy

WHEN HE WAS LITTLE, Brett couldn't sit near anyone drinking milk. Now, as he and his mom, Robyn, bake cookies, the nearby milk doesn't affect him at all. Soon, he may be able to even drink a full cup of it.



Awareness week at school, during which he raises money for research. He's even traveled to Washington, D.C., to lobby for food allergy legislation. "He's quite the advocate, and now wants to be President to keep other people safe," says Robyn.

### An allergy-free future?

As Brett nears the end of the study, his doctors are hopeful that he'll be its first success story. "If this works, it would be a totally new way to approach food allergies," says Umetsu. "We're starting with milk, but we believe this process could be applied to any food. Hopefully, in the near future, we can tell patients, 'We can cure your food allergies.' It's a totally new era."

If Brett passes the final milk challenge without having a reaction, he'll need to keep drinking milk on a regular basis for many years, to make sure his tolerance doesn't slip. He'll still have to be careful and carry an EpiPen for his egg and peanut allergies, but for now, he's focused on one thing. "I've thought about drinking milk my whole life," he says. "But mostly I want to eat real pizza with real cheese, not soy cheese. I think that would be really awesome."

**"I've been waiting 10 years for this," says Brett. "I'd do anything to get rid of my milk allergies. After the study, I might be able to have milk with all my friends."**

—Brett Nasuti

food allergies. "I've been waiting 10 years for this," says Brett. "I'd do anything to get rid of my milk allergies. After the study, I might be able to have milk with all my friends."

At the start of the study, Brett got regular injections of anti-IgE (Xolair), a medicine that helps block the protein responsible for setting off allergic reactions. Schneider and Umetsu had found that this medicine helped children with allergy-related asthma, and theorized that it could prevent reactions that would likely occur as patients drank the milk. Now, after getting the injections in his thighs for eight weeks, Brett is ready to taste his very first sip of milk—something he's avoided like poison his whole life, and that he knows could still hurt him.

A team of doctors stands by with six intravenous medications, ready to shoot them into Brett's IV to stop any allergic reactions. Nurses carefully monitor his vital signs and fill a tiny syringe with less than a milliliter of the creamy liquid. Lying on the hospital bed wearing a new "Got Milk?" shirt that Robyn gave him to mark the occasion, Brett steels himself. "I'm a little nervous because there's a big chance I'm going to have a reaction," he says. He squeezes it into his mouth, making a terrible face. "It's like nothing like I've ever tasted before," he says. And then

### MORE AT CHILDRENSHOSPITAL.ORG/DREAM/FALL09

 Watch a series of videos that follow Brett as he goes through the study. Hear him and his mother, Robyn, talk about what it's like to live with his life-threatening food allergies, and much more.

 Lynda Schneider, MD, director of Children's Allergy Program, dispels food allergy misconceptions.