

Watching what they eat

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More than 12 million Americans -one in 25- have food allergies and about 3 million are children. The highest incidence of food allergies is among children under 3--

For one Woodbridge mom, reading food labels is a matter of life and death. Colleen Inclima's 6-year-old son, Ben, has a severe peanut allergy, one that could cause an anaphylactic reaction not only to eating peanuts, but even from eating cross-contaminated food.

Knowing how his food was made and teaching him what foods are safe to eat are a big part of the family's life. Most of their meals are made from scratch, she said. (Ben is also allergic to shellfish and has environmental allergies while his sister, Kate, 4, also has tree nut, penicillin and environmental allergies.) Diagnosed when he was about 2, Ben's allergies put the family into a spin, said his mom.

"We were overwhelmed," said Inclima. "I went through all the cabinets and everything I was feeding him, I had to throw out.

"Most of it said 'Made in a facility that makes peanuts,' " she explained.

According to the Food Allergy & Anaphylaxis Network's Web site, www.foodallergy.org, more than 12 million Americans — one in 25 — have food allergies and about 3 million are children. The highest incidence of food allergies is among children under 3. Eight foods — milk, eggs, wheat, soy, peanuts, tree nuts, shellfish and fish — are responsible for 90 percent of all food-allergic reactions, according to the site and, in a five-year study (from 1997-2002), FAAN discovered that peanut allergies among children had doubled. Why food allergies are on the rise is unknown, say the experts, although there is the "hygiene hypothesis," said Dr. Mark Davis-Lorton, director of clinical immunology at Winthrop-University Hospital in Mineola, N.Y. In a German study comparing 1,000 children living in the country and 1,000 youngsters living in the cities, researchers found the country kids were exposed to much more bacteria and were less likely to develop asthma and food allergies than the city kids.

"By living in cleaner societies our body's immune system isn't doing what it should," Davis-Lorton explained. A food allergy is the immune system's response to a food that the body mistakenly believes is harmful and creates specific antibodies against it to

protect the body, states FAAN. Allergic symptoms can present in different ways, said Dr. Anita Kohli-Pamnani, an allergist and immunologist in Orange. There can be hives, trouble breathing, facial swelling, a rash, itching, nausea and abdominal pain.

"The most serious is anaphylaxis," she said.

Anaphylaxis is a life-threatening allergic reaction to particular allergy-causing substances such as food or latex as well as medications and insect-venom such as bee stings, according to FAAN. It can be fatal within minutes due to blockage of airways and dramatic drop in blood pressure. Epinephrine has to be given to the patient at once.

After Ben's diagnosis, Inclima said a pediatric allergist gave her a prescription for an EpiPen (self-injectable epinephrine) and told her to avoid all peanuts. Beyond the medical information, she found little support on handling her now more complex day-to-day life. "You have no idea what it's like until you live it," said Inclima. "The biggest obstacles are other parents' and relatives' take on what you're going through.

"Older generations say he's going to outgrow it; they look at [a food allergy] like a seasonal allergy," she continued. "They think you're overblowing it, but don't realize this is something that can take your child's life.

"You lose play dates and friends [who say] 'We eat peanut butter; sorry you can't come over any more,' " she said. "You lose any support network you thought you had."

But she did remember one friend she could call on — Heidi Gianquinto, who lived in nearby Bethany. Gianquinto's son, Peter, also had food allergies.

Five years ago, Gianquinto started FLAAG (Food and Latex Allergy Awareness Group) with bi-monthly meetings at Milford Hospital. While Peter, 6, has outgrown several of his allergies — wheat, oat, barley, bananas and eggs — others, including peanuts, raw dairy and latex, he has not.

"The slightest amount will cause anaphylactic reactions," said Gianquinto.

At the first meeting of FLAAG, about 25 people came, she said. Today the group has more than 100 members. Most of the participants are dealing with major allergen problems, she said. "People who attend the meetings are people with newly diagnosed [children] who want to manage the process," said Gianquinto. The most difficult part is trying to figure out what their youngsters can eat.

Learning how to read food labels is the first step, but that can be difficult and was even more confusing before the Food Allergen Labeling and Consumer Protection Act, which went into effect in January 2006. It mandated that "food manufacturers declare food allergens in plain language on their ingredient lists." These new guidelines have been very helpful for parents, who may not have necessarily known that albumin can be egg

protein or that whey was a dairy product, said Gianquinto. But, even with diligent label reading, parents cannot take anything for granted.

The women say they continue to call manufacturers to double-check ingredients and even if they've bought a safe food once, they call again in case there was some change in manufacturing, making it unsafe.

Davis-Lorton is on FLAAG's medical advisory board. He said safety is a huge concern for moms and dads.

"We educate parents on how to read labels, not sharing foods, not sharing utensils," he said. "It's easy when a child is home [but] when you're not accompanying them, you need to teach them not to share food with other people even if they tell you there's nothing [wrong with a food]."

"You can't trust anyone except for your parents who can tell you what to eat," said Davis-Lorton. Inclima said her son, even at this young age, understands that he has serious allergies. "He has to be the first to say 'I can't eat that' if he sees someone eating a peanut butter sandwich," she said.

At this evening's FLAAG meeting, Loretta Jay, founder of Parasol, a Fairfield-based organization that specializes in the management of food restrictions (www.parasolservices.com), will discuss strategies to empower children on restricted diets.

"One of the philosophies I have when supporting children with food allergies, is 50 percent is keeping them physically safe and 50 percent is keeping them emotionally healthy. That's challenging," she said.

It's important for children to feel included, not isolated from other kids, she said. It starts with the parents being prepared for different situations. For example, if your child's class is having a birthday party with foods your child can't eat, have emergency cupcakes already in the freezer that you can bring along.

It's true, as Inclima has found, that party invitations do decrease, Jay said, because some parents don't want the responsibility if a child has an allergic reaction.

At the meeting, Jay will have handouts of sample letters parents can give to other parents explaining their child's allergy.

"Most other parents, when given the information, want to help and be supportive," she said.

Grandparents instinctively want to feed children, she said, and some have a hard time believing a small amount of a certain food could hurt their grandchild.

"Partnership and knowledge are the keys to success, both with our children and [their] caretakers," Jay said.

FLAAG meets today from 7 to 9 p.m. at Milford Hospital, 300 Seaside Ave.

On Sunday, the group is coordinating a Teddy Bear clinic for children of all ages at the hospital from 1 to 3 p.m. Youngsters can bring their own teddy bears for a check up with a "beary special" doctor who'll explain different procedures. Stations will include a bandage table, immunization table and allergy testing table. For more information on FLAAG and special events, visit www.flaag.org.