



Food Allergy Bullying

How to protect your child from harassment

For little Thomas, second grade should have been the year of learning about dinosaurs, outer space and multiplication.

Instead, second grade quickly turned into a year of horrors. Two boys bullied the happy, blonde boy who loves baseball, swimming and football—repeatedly kicking him, punching him and calling him names. The teacher was on medical leave for the entire year, so a series of long-term subs came in and out of his Virginia classroom.

A few months into the year, any sense of classroom control was long gone, as was any adherence to Thomas' Individualized Healthcare Plan (IHP) set up because of his multiple food allergies to peanuts, tree nuts, sesame, wheat and milk. His mother, Eleanor Garrow, vice president of education and outreach at the Food Allergy & Anaphylaxis Network (FAAN), asked for her son to be transferred to another class but she was consistently denied. The bullying got worse.

"They would hit him and call him names," Garrow says. "They also bullied him because of his food allergies, where they chased him on the playground with pebble rocks and said they were peanuts and were going to smear them all over his face. They took his medicine bag from him, because he carries his own

epinephrine auto-injector and has since kindergarten. They took his lunch bag from him, even though that's the only food he can eat."

In March, an intolerable situation turned even more dangerous. One of the bullies took peanut butter and smeared it on Thomas' neck in the lunchroom, thinking it was funny. Knowing that one bite of peanut butter could kill him, Thomas sprang into action.

Garrow recalls: "He said, 'Mommy, Mommy, I'm so proud of myself. I ran to the bathroom and washed my neck off with soap and water with a paper towel, so I didn't actually touch it. Then I washed my hands with soap and water, so I didn't have anything on my hands.'"

"I said, 'Honey, I'm so proud of you, but you should never have had to do that,'" Garrow says. "Why did my son go to the bathroom alone? Why wasn't he monitored? What if something had happened to him, where he accidentally swiped his lips, ingested some peanut butter and then developed anaphylaxis?"

Risks of Bullying

About 35 percent of children over age 5 with food allergies have been bullied, teased or harassed, according to a 2010 study

published in the *Annals of Allergy, Asthma & Immunology*, the first study to assess food allergy bullying.

Compare that percentage to the National Institute of Child Health and Human Development's 2001 study that found that 17 percent of kids in grades 6 through 10 were bullied. In the 2010 study, the rate of food-allergy bullying was an astonishing 50 percent for that same age group, says study co-author Scott H. Sicherer, MD, professor of pediatrics and a researcher at the Jaffe Food Allergy Institute at Mount Sinai in New York. Sicherer is author of *Understanding and Managing Your Child's Food Allergies* (Johns Hopkins Press).

Most of the bullying in the 2010 study was verbal but kids also reported physical acts, such as having the allergen thrown or waved at them or having their food intentionally contaminated with the allergen. The bullying took place mainly at school and by classmates. But 21 percent of the time, teachers or school staff were perpetrators. For example, Sicherer says, a child might be singled out when the teacher says, "We're going to have a birthday party today but we're not going to have any cake because Johnny has food allergies."

Sicherer was inspired to conduct the study after seeing many of his patients express sadness about being teased and harassed because of their food allergies. Children who are different from their peers are often targeted. A food allergy can be a stigmatizing factor that marks a child as different and exposes him or her to bullying.

"Not being able to do exactly the same things as the other children when it comes to mealtime makes the child with food allergies different. They are also at a disadvantage because they can't do something the other children can do, so there's an imbalance of power," Sicherer says. "These are all set-ups for bullying."

Know Your Rights

In Thomas' situation, the bullying was fed by an unstable school environment. Then to make matters worse for Thomas, Garrow says, the school bungled the emergency. The principal, assistant principal and school nurse were not on campus at the time of the incident; the clinic aide was at lunch; the office staff couldn't find Thomas' emergency action plan because they had misfiled it; they didn't immediately administer epinephrine and instead waited for Garrow, who happened to be working from home that day, to arrive at the school clinic.

After some more missteps, the school told Garrow that they would comply with Thomas' IHP and that they would move

him to another classroom. But it was too little too late for Garrow, who didn't feel her son would be safe in the school. So she placed Thomas in a private school for the remainder of the year. But as a single mother with two kids, Garrow knew she couldn't continue to afford the private school tuition. For third grade, she asked that her son to be transferred to another public school in the same district.

According to the U.S. Department of Education, schools must offer students with disabilities, including those with life-threatening food allergies, a "free appropriate public education." If the school district can't provide such a program and the student is placed in a private school, the district has financial responsibility.

As a FAAN vice president, Garrow understood her rights. She told the superintendent: "I know I can still press charges against the boy who did this to my son and I know I can make the district responsible for paying my son's tuition at a private school, because his rights were violated in one of your schools. I want my son transferred to another school and I want to know what you're going to do to make this happen."

The transfer was signed, sealed and delivered the next day. "It's sad that you

have to go that route, when you feel you have to threaten people in order to make a change," says Garrow, who kept meticulous documentation with names and dates of every bullying incident and of the school's noncompliance with Thomas' IHP. She recorded every time she was called by the school and every time she had to go into the school office.

Garrow now has a 504 Plan for Thomas, as well as FAAN's Food Allergy Action Plan. "To stay educated and on top of it and to keep advocating for your child's rights is the way to go. You have to keep doing it until it's right," she says.

As Thomas started third grade, the emotional effects of the bullying in second grade continued to afflict him. His grades declined. He was combative and inattentive. He acted out in school toward his teacher and at home toward his mother and sister. Then in October, he broke down while driving in the car with his mother.

"He had a meltdown and said, 'I just want to kill myself. I just want to die because of my food allergies.' I stopped immediately in the middle of the road and said, 'What did you just say?' He was crying and saying, 'You don't have to worry about taking one wrong bite and it killing you. Someone tried to hurt me last year and they knew it could kill me. And I'm only in third grade, Mommy. I'm only 8 years old,'" Garrow says.

Over the next three months, Thomas twice more repeated that he wanted to hurt himself, that he wanted to die.

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Evaluations with a psychologist and psychiatrist determined Thomas had attention deficit hyperactivity disorder (ADHD), along with depression and anxiety that stemmed from the bullying he endured in second grade.

“No child should ever have to go through bullying. No matter what, it’s unacceptable. And to be bullied with something that can kill you, it’s even worse,” Garrow says. “When you see your child going through this, you wish you could take all their pain away and make everything better. Then to think that they’re having thoughts of hurting themselves and not wanting to be here—it’s a total heartbreak I can’t even explain.”

Warning Signs

Children don’t always tell their parents about bullying but the signs are usually there. A child can appear sad, upset, withdrawn or anxious, have trouble sleeping or say that he or she doesn’t want to go to school. Other indications may be changes in the child’s behavior, stomachaches, nightmares, lower grades, outbursts and social isolation. Kids who are bullied because of food allergies might also have changes in their eating habits, come home with an untouched lunch box, exhibit unexplained weight loss or display other dramatic changes in eating behaviors.

In March, Sicherer presented preliminary findings of an unpublished study in which parents and children were interviewed separately about food allergy bullying. Results showed that nearly one-third (32 percent) of parents were unaware of the allergy-related bullying. For children who reported being bullied more than once a month, nearly two-thirds (64 percent) of parents were unaware of the problem.

“Many children with food allergies have reported bullying but the parents often don’t know about it,” says Sicherer, who adds that parents, teachers, camp administrators and allergists should all have a “high index of suspicion” about food allergy bullying. Since children with food

Know Your Rights

Don’t allow food allergy bullying to intimidate your child—or you.

- Protect your student by filing a 504 Plan with your school. Food allergies are considered a disability under Section 504 of the Americans with Disabilities Act, because food allergies affect the major life activities of eating, breathing and digestion.
- Find out the school’s bullying prevention policy and how it’s being implemented.
- Discuss the bullying with appropriate school administrators (the principal, guidance counselor, psychologist, case manager).
- Keep documentation of every bullying incident, including dates and details. In addition, keep notes every time you talk to the school about the bullying, the school’s response and the school’s compliance (or non-compliance) with the procedures spelled out in your child’s 504 Plan.
- Discuss bullying with your child’s allergist. If needed, ask the allergist to write a letter to the school, stating the child’s health is in jeopardy and asking that the child be transferred to another school.
- Write to the school board superintendent or the school board attorney. Include documentation of bullying, the school’s response and, if appropriate, the school’s non-compliance with your child’s 504 Plan.
- Check out the Food Allergy & Anaphylaxis Network (foodallergy.org) and its booklet, *Students With Food Allergies: The Laws*.
- Ensure your child has access to an epinephrine auto-injector at all times, in case of emergencies. All states except New York protect students’ rights to carry and self-administer anaphylaxis medications.

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allergy are vulnerable to bullying, adults should be aware of the potential danger and bring up the topic with the kids.

Food allergy bullying can present emotional danger, just like any other form of bullying. But if it involves ingestion of the food to which the child is allergic, it can be life-threatening, says Ralph E. (Gene) Cash, Ph.D., nationally certified school psychologist and professor of psychology at Nova Southeastern University in Fort Lauderdale, Florida.

Cash often speaks about the risks of

food allergy bullying alongside his wife, Dana Wallace, MD, associate clinical professor at Nova Southeastern University and past president of the American College of Allergy, Asthma and Immunology (ACAAI).

“When people are threatened with something that they fear—whether it’s a fist in their face or peanut butter smeared on their head or a fish thrown into their locker—they’re going to be frightened. And justifiably so. Bullying is intimidating and it causes tremendous psychological problems for the kids,” Cash says.

Take Action

It’s important for adults to be responsive to a child who reports bullying and to reassure them that you will get them help, Cash says. Find out the school’s bullying prevention policy and how it’s being implemented. But parents should not confront the bully, tell the child to confront the bully or encourage retaliation, because it can make matters worse.

“The parents should say to their child,

'I'm glad you told me. You did the right thing. Now let's talk about what's the right thing to do together. Let's formulate a plan together so we can deal with this.' And by doing so, you teach your child problem-solving skills," Cash says.

"Some of the strategies that one might think would work— like, tell your teacher— might not be effective, particularly if the teacher is the one who's doing or supporting the bullying. So the child and the parent need to talk about what's likely to be successful. Can we go to the school principal? Can we go to the school guidance counselor? Can we go to the school psychologist? If that isn't likely to work, can we involve our allergist in going to the school or at least communicating with the school in some way?"

If the situation worsens, Cash says, parents can ask the child's allergist to write a letter to the school saying the child's health is in jeopardy and asking for the child to be transferred to another school. Or parents can write to the school board attorney, as there are legal precedents of parents suing schools that don't take an active and positive role in preventing bullying.

Allergists are so busy with managing the child's food allergy, they usually don't inquire about bullying, Wallace says. "We may not be asking enough at the right time. In a short office visit, there's so much to talk about, it may get pushed to the end of the list."

At the root of bullying behavior is domestic violence, Cash says. "If we could eliminate domestic violence, I'm convinced that it would eliminate most of the bullying," he says. "When kids are victimized, particularly if they're victimized at home by people they trust or are supposed to be able to trust, they tend to bifurcate. Some become chronic victims and develop a victim mentality. Others identify with the aggressor and become bullies themselves. The ones who are bullied then bully those who are lower on the hierarchy, so to speak. It's the kick-the-dog syndrome."

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Providing Comfort

Kids who are bullied need to feel support from their families, says Kenton Duty, who stars in the Disney Channel series, "Shake It Up!" and who has been active in anti-bullying campaigns.

"What they need is some comfort. They need someone they can talk to, who can at least tell them, 'You're doing a good job putting up with it and we're going to stop this.' Knowing someone cares about you is huge."

But not all kids have supportive adults in their lives.

"There are a lot of problems with how bullying is dealt with in general. A lot of people are like, 'Kids will be kids. It happens,'" Duty says. "Well, it doesn't have to happen. Adults can monitor it and make it safe for these kids."

Duty, 17, is allergic to chocolate and wheat. As a celebrity ambassador to FAAN, he's talked to students at FAAN summits, giving advice on how to speak up about bullying, especially if you have food allergies.

Kids with food allergies can feel vulnerable because they have to carry or wear bulky allergy medications like epinephrine auto-injectors.

"If you carry your EpiPen on you, it's this

big, clunky thing and everybody knows you have food allergies. A lot of kids don't want to carry it, so they'll throw it in their locker or they just won't take it to school because they don't want people seeing that visual reminder of their food allergies. But if it's in their locker or they don't bring it because they don't want to get bullied or teased about it—if they're in anaphylactic shock, it's big trouble."

Duty is tall now but for many years, he was one of the shortest kids in his class and he'd get bullied because of it.

"What helped me was I had family and friends who backed me up. My friends always stood by me," he says.

He's also been teased because of his food allergies, with kids waving chocolate treats in his face.

"Yeah, I've been through that. Everybody with food allergies goes through it," he says. "There are people who'll take advantage of you to try to make themselves feel better."

Many people just don't understand the severity of food allergies, says Duty's father, Jeff Duty.

"If there are chocolate cupcakes, they'll put one under his nose and say, 'You can't have it.' It happens more times than I would've guessed—even at his age,"



Kenton Duty (left), star of Disney Channel's "Shake It Up!", with actors Tharon Trujillo (middle) and Nick Dean (right) at a recent "My Life My Power" anti-bullying campaign event in Los Angeles.



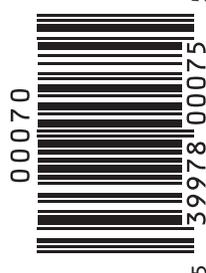
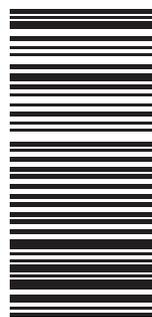
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Jeff Duty says about his son's experiences. "The parents don't get it and the kids don't get it. They think they're being funny. I've tried talking to the parents, even the kids, and some don't think anything is wrong. If we can't educate them, we just have to remove ourselves from that particular situation and know that it's nothing personal. It's just the way some people are. Don't stick around to let them continue doing it."

Positive Signs

Eleanor Garrow didn't stick around Virginia. After Thomas' bullying in second grade and depression aftermath in the beginning of third grade, Garrow and her two children moved back to Illinois, where she grew up and where her family lives. Divorced, she realized that Thomas needed his father during this unsettling time. She asked to be able to work for FAAN remotely from Illinois.

Bullying Stats

A Sad Reality

In a 2010 survey of 353 parents and caregivers of food-allergic children conducted at regional FAAN conferences, 24 percent of all respondents reported that the food-allergic individual had been bullied, teased or harassed because of food allergies. For those age 5 and older, 35 percent had been affected.

Of those who reported being bullied, teased or harassed:

- 86 percent reported multiple episodes.
- 82 percent of the episodes occurred at school.

- 80 percent of the episodes were perpetrated by classmates.
- 21 percent of the episodes were perpetrated by teachers or other school staff.
- 65 percent described verbal abuse, such as teasing or taunting.
- 57 percent described physical events, such as having the allergen thrown or waved at them.

Source: "Bullying Among Pediatric Patients with Food Allergy," *Annals of Allergy, Asthma & Immunology*, September 2010.

Now in fourth grade at his new school, Thomas is doing well, his mother reports. The new school has gone above and beyond in accommodating him, she says. Everyone who comes into contact with Thomas throughout the school day,

including his bus driver, has been trained to administer epinephrine. His grades have come back up. He'd been getting Cs and Ds but now is back to As and Bs.

Thomas is no longer ashamed to say he has food allergies. He always carries his life-saving medications—epinephrine auto injectors, antihistamines and his asthma inhaler—in his backpack. At his new school, kids kept asking him why he carries his backpack everywhere. So he asked his mom to do a presentation about food allergies, not just to his class but to the whole school. Garrow is thrilled that he's no longer embarrassed and anxious about his food allergies.

"I'm hopeful and optimistic," she says. "We still have a long way to go but I've definitely seen improvement. There's still some anger but it's nowhere near as bad as it was when we were in Virginia."

"For almost a year and a half, he was not the son I knew, the boy who was so full of life, laughing, giggling, eyes sparkling all the time, compassionate and caring about everyone around him. We really lost him. And it was hard, so hard," Garrow says. "Now we're finally getting him back—and I'm so grateful." **LW**

Chicago-based health writer Eve Becker is author of *glutenfreenosh.com*. Her youngest daughter has celiac disease.

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