Lessons From a Teen Food Allergy Tragedy

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For a young teen with a peanut allergy, it was a fleeting lapse of vigilance on the last evening at summer camp. Thirteen-year-old Natalie Giorgi was camping with a group of families in Sacramento, California when she ate a single bite of a Rice Krispies square. She recognized the taste of peanut and spat it out. At first she didn’t show any symptoms and her mother gave her a dose of antihistamine; but in 20 minutes the systemic reaction began. Her father, a physician, gave her three doses of epinephrine, but it wasn’t enough to stop the rapid-fire chain of events. She began vomiting, her throat swelled to the point where she could no longer breathe and she went into cardiac arrest. She died in his arms.

“It’s beyond words what they’re feeling,” said the Rev. Michael Kiernan of Our Lady of Assumption, the family’s church.

Natalie’s story has spiked fears among Allergic Living’s readers, in particular parents of children and teens with food allergies. It has also raised questions about just what to do in case of an accidental allergen ingestion, so we turned to two experts for answers. First to be interviewed is Dr. Robert Wood, the director of Pediatric Allergy and Immunology at the Johns Hopkins Children’s Center in Baltimore. Next is Dr. Susan Waserman, an allergist and professor of medicine at McMaster University in Canada.

Allergic Living’s Jennifer Van Evra: There seems to be a lot of confusion about whether to administer epinephrine in the case of allergen exposure and how soon. What do you tell patients?

Dr. Robert Wood: There is no single set of recommendations, because it depends on many factors. But the general rules are that you need to have epinephrine readily available; that it needs to be given promptly in the event of a reaction; that the longer it’s delayed before being given, the greater chances that it won’t work; and that every patient needs to have an individualized action plan that they’ve worked out with their caretaker.

AL: What determines that type of action plan?

RW: There are certainly people who are at higher risk than others. The four main risk factors are the individual’s prior reaction history — although you can have no history of severe reaction and still react very severely in the future. But if someone has a history of severe
reaction, you never wait and see what happens. The second is that any food has the potential for dangerous reactions, but most fatal reactions are related to peanut and tree nut allergy, so they automatically indicate a higher possibility of a severe reaction. The third risk factor is having asthma because it’s very rare to find a fatality in someone who doesn’t have asthma. Then the last risk factor is that the vast majority of fatalities have occurred in teenagers and young adults.

**AL:** Is that a function of physiology or lifestyle?

**RW:** Likely some of both. There is some increase in allergy severity to peanuts and tree nuts through childhood, so by the time you’re a teenager or young adult, most people are at their peak level of sensitivity. But the far more important factors have to do with lifestyle: a greater availability of food items, less supervision, more risk-taking behavior, and less chance that your epinephrine will be on hand.

Next: *Length of time for systemic reactions*

**AL:** What if a child or adult ingests a bit of an offending food, then spits it out and shows no symptoms?

**RW:** It depends on the individual, but I have large numbers of patients where their action plan does recommend automatic injection of epinephrine for any known exposure or even an expected exposure. In most instances, the more quickly it’s given, the better.

**AL:** When someone doesn’t have symptoms for 20 minutes, then suddenly goes into anaphylactic shock, what’s going on?

**RW:** Even when food is spit out, there is still absorption of the allergen in the mouth and throat, and the absorption typically happens over a period of 10 to 40 minutes. As that food is absorbed systemically, the chain of events that make up an allergic reaction are all put into effect. It can be delayed by up to two hours, but nearly all allergic reactions will begin in the first 30 minutes.

**AL:** A lot of people think they will feel the effects instantaneously.

**RW:** That’s often a localized reaction in their mouth and throat where they’ll feel itching very quickly. But systemic symptoms won’t happen instantly, because you have to absorb the food. You can see them within minutes, but 20 minutes would be a typical timeframe.

**AL:** What are the signs that tell you, “OK, time to inject”?

**RW:** For my patients, we talk about reactions that are very localized versus anything more than localized. Localized would be itching in the mouth, a few hives around their mouths, and nothing beyond that. Anything beyond localized, even just hives that are spreading, indicates a need for epinephrine.

Then certainly involvement of other systems in the body: if you’re having repetitive vomiting, any respiratory symptoms, then you would automatically get epinephrine. High-risk patients aren’t given any discretion: they’re advised to give the epinephrine automatically and immediately.

**AL:** Many people take antihistamines such as Benadryl as a first, and sometimes only, line of defense. What is your take? And can it mask symptoms?

**RW:** Antihistamine is a useful medication for some relief of symptoms such as a few hives, but has no capacity whatsoever to prevent or control more serious allergic reactions. If a reaction is going to progress, the administration of Benadryl will not help to prevent any real progression.
We don’t worry that it’s masking things; it’s not potent enough. So we don’t think there is any risk in giving it – except for the false sense of security that it might give, that it will help relieve or prevent a more dangerous reaction. It won’t do that at all.

Next: **How safe is epinephrine?**

**[2]** AL: But people are nervous about administering epinephrine. What do you say to them?

RW: We reassure them that it’s incredibly safe, and even if you get a dose you didn’t really need, it is not a problem. So it’s better to give it if there’s any doubt rather than not give it. Every study has shown that it’s dramatically underused, even in highly educated populations, and there are a lot of reasons for it. In some it’s fear of the needle, in some it’s fear of the drug.

There’s a misconception about danger with the drug, which is actually still held very strongly by a lot of emergency-room physicians, so even in the setting of the emergency room, epinephrine is dramatically underused. But 80 percent of the time, one dose of epinephrine will completely reverse an allergic reaction, and it is very safe.

**AL: Do people need to go to the hospital every time they take epinephrine?**

RW: You do, and one of the big misconceptions is that most people think you’re going to the hospital because you’ve just given your child a dangerous drug. But the reason you’re going to the hospital is because you’re having an allergic reaction that required epinephrine, and you need to have your allergic reaction further evaluated and monitored. We want them to stay at the hospital, typically for a four-hour observation period, because the reaction can look like it’s resolved and then come back two hours later. It’s not because of the epinephrine.

If 100 people took their EpiPens right now accidentally, and they didn’t really need it, we would say, "Stay at home, you’re fine." The medication is not a worry at all.

**AL: One parent e-mailed to say: “Besides food allergies, my child has highly sensitive skin. If I gave her the auto-injector every time she had a hive, it would be once or twice a week.” How do you differentiate between a localized reaction and a systemic reaction?**

RW: Every symptom needs to be interpreted and treated in the context of the situation. So if those hives showed up in a situation where the parent is quite confident there was no ingestion of a problem food, we would treat them as a very benign condition. If hives showed up with a child at a birthday party or at a family picnic where there’s lots of food around, and the child’s been out of the parent’s sight, then you have to assume that there’s been a food exposure, and treat that possible reaction more aggressively.

**AL: Parents are also struggling with how to talk with their kids about the potential dangers of their conditions, and cases like Natalie’s. What do you advise?**

RW: My feeling is there’s no benefit to talking about death in the preschool- or school-age years. When the child is literally a year old, the message is that foods can make you sick and you need to be careful. And then it becomes a little more specific: you can’t eat anything that
I don’t approve or provide for you, because it can make you sick.

As the child becomes late school-age, early adolescence, then talking about fatality is completely appropriate. So depending on the maturity of the child, that’s when they’re 10, 11, 12. All it will do to a 6-year-old is upset them. They can’t conceptualize that to a point that there’s any value to it.

**AL:** When speaking to adolescents, do you do it in a way that doesn’t scare them?

**RW:** An element of fear is actually part of the message and is appropriate – and the message is typically given to that 11- or 12-year-old in the context of them taking more responsibility for carrying their epinephrine. So there’s a gradual transfer of responsibility from the parent to the child.

The message is, “If you don’t have it with you, you could die.” And that is an important part of the reason why they need to be convinced to have the medicine with them all the time.

Next: **Interview with Dr. Susan Waserman**

*Allergic Living*'s Jennifer Van Evra interviews Dr. Susan Waserman, allergist and professor of medicine at McMaster University in Hamilton, Ontario.

**AL:** With the death of Natalie Giorgi of anaphylaxis, a lot of *Allergic Living* readers are expressing confusion about exactly when to administer epinephrine. What do you tell patients?

**Dr. Susan Waserman:** We [Canadian allergists] propose that epinephrine be given, at the first sign of any reaction. Or if you know that you’ve eaten something accidentally and have a history of anaphylaxis, most allergists would still say give epinephrine right away. I think that young Natalie’s issue speaks to how quickly these reactions can come on, how no two reactions can be the same. She’s described as never having had a severe reaction. By the time it was recognized as such, it’s described as 20 minutes that had elapsed, by then it was too late to reverse.

People can ask, ‘Do we know for sure the reaction could have been reversed?’ We don’t know anything. But to maximize your chances, when we look at fatality data, the ones who succumb either didn’t inject epinephrine in a timely fashion or didn’t even have the epinephrine with them.

**AL:** But how do you define when a reaction may become severe?

**SW:** That’s just it. We don’t know where the line is. Once the reaction has passed and you’re feeling well, it’s fine to say, “OK, that didn’t go anywhere.” But in the throes of the moment, you don’t know how quickly these reactions can progress. Because of that, if you have a history of allergy to tree nuts or peanuts or one of the primary food allergens, it’s always safer to inject yourself with an epinephrine auto-injector if you know you’ve had an accidental ingestion.

If you’re somebody who’s had a severe reaction in the past, even more so: don’t wait for a fire to break out, inject! But the trend is that many patients or parents feel uncomfortable injecting, almost an admission of a severe reaction, which they don’t want. So they will try to ward off injection as long as possible, and it doesn’t always work in your favour. Thank goodness we don’t have many fatalities, but when one happens, it is tragic.

**AL:** Where do Benadryl or other antihistamines fit into the treatment picture?

**SW:** In most guidelines, antihistamines and asthmas inhalers are not a replacement for epinephrine auto-injectors. They will not reverse anaphylaxis. Where people have gotten
confused is that in guidelines like the Australian ones for school and some anaphylaxis action plans, they are making allowances for what they call "milder reactions" where Benadryl can be given.

Our guidelines in Canada do not support that, but we’re also hearing opinions to the contrary. People want the ability to treat mild reactions just with Benadryl. The issue remains what’s mild, and how do you know that a reaction won’t progress? The California teenager’s case is instructive: here’s somebody who had no symptoms and then escalated quickly after 20 minutes, and then even epinephrine was not enough.

In Canada’s guidelines, we don’t support the use of Benadryl if symptoms are developing in response to the accidental ingestion of food. However, some allergists will disagree with me. They think that mild reactions should be treated with antihistamines and that we’re “over-calling” a lot of mild reactions. Maybe we are, but we don’t know that they are mild until it’s retrospective, and then by the time things do advance, you can’t always reverse.

Certainly when it comes to somebody with a history of severe reactions and needing hospitalization, there is no debate in my mind whatsoever that they get epinephrine right away. This is especially if the patient has asthma, where they’re at risk for more severe reactions.

Next: Signs that it’s time for epinephrine?

**AL:** There’s some perception that there’s danger to epinephrine. You may be uncomfortable, you’re shaking, or your heart’s flying ....

**SW:** Those are generally non-dangerous side effects of epinephrine: increased heart rate, the tremulousness, the anxiety. Used within reasonable amount, like one or two injections, there is no downside. It is not a dangerous drug used as a treatment for anaphylaxis, and that’s what we teach people: no downside.

**AL:** What are the signs that it’s time to inject?

**SW:** There are signs where it’s undeniable: dizziness, shortness of breath, difficulty swallowing, loss of consciousness, drop in blood pressure, tongue swelling, severe abdominal pain, profuse vomiting. But it’s hard to use those signs of fairly advanced symptoms to say at the start of a reaction that it won’t progress. The idea is to prevent those symptoms from happening.

**AL:** But there is a tendency to wait for significant symptoms before using the auto-injector.

**SW:** I know. Yet, everything that you read in the medical literature points to too little epinephrine being given – by patients, by the community, by the emergency room. Still, there’s no question that there’s a trend that people do want this mild-severe type of spectrum where antihistamine is enough.

But there’s a downside to that. And young Natalie represents is just one of them. Somebody can always say, “The signs must have been there, somebody missed them” – well, people don’t judge severity very well; it’s not that straightforward. Most of us [allergists] are fairly convinced that we don’t know that every mild reaction stays a mild reaction, and that’s the danger.

**AL:** Is there anything else you would add to this discussion?

**SW:** As sad and tragic as Natalie’s death is, I think it reinforces really basic principles about treatment, about how reactions can advance very quickly and you’re not aware of it. Now that there is much discussion around this issue of antihistamine use for mild reactions, which
many of us are uncomfortable with, I think this reinforces why it’s not a good idea.

[In Natalie’s case], even if they’d used epinephrine early, you have no idea what the outcome would have been. One cannot go back in time and address those issues – you can only try to stack the deck in your favor in future situations.

*If you’d like to comment on this discussion, please write to editor@allergicliving.com. Thanks to Dr. Wood and Dr. Waserman for generously giving of their time to take part.*