

## Emily's Story and Our Message

When Emily was about two years old, Paul gave her a peanut butter cracker, almost immediately she started to fuss and rub at her eyes and start to develop hives. He gave her Benadryl and the allergic reaction calmed down. It was only after Emily's death and subsequent research that Paul realized that this was when Emily's immune system started building antibodies to fight off nuts.

After this initial exposure to nuts, Emily's body developed its own protective warning system. If she came in contact with a food that had been exposed to nuts, she would have a tingling sensation on the back of her tongue, she would immediately spit the food out and then to protect itself, her body would vomit trying to expel whatever the offending allergen was. It was that reaction that made us comfortable with this allergy. She knew what she could and couldn't eat. If kids brought snacks into school and they couldn't tell her if it had nuts in it or not, she wouldn't eat it. If they said it was free of nuts, she would still test it by putting it to her lips and touching it with her tongue. If she didn't have a reaction, she knew it was safe.



I think you really want to know more of what happened that day, but I needed to let you know why I was so unprepared for what happened on April 13<sup>th</sup>. Elena (10), Emily and I had gone shopping that day for a graduation dress at a mall here in Cincinnati. After buying her dress (which she wore out of the store) we stopped to have lunch at about 2:50 at the mall's food court. We decided to have a sandwich at a place that we had eaten before (we considered it a "safe food" restaurant) because Emily, in fact, had eaten this very same sandwich many times before with no problems. Their website even shows that it is peanut-free except for two of their cookies. After having lunch, we walked through a new t-shirt shop where Emily fell, tripping over her shoes, and landing on her bottom. She laughed and got right back up. We continued shopping, going to a store where we were going to get Emily's ears pierced. While we were in this shop, Emily mentioned that she was afraid she might have messed her underwear when she fell and wanted to check it out. She came back about 5 minutes later, did two puffs of her inhaler, telling me that she felt hot and did her face look red. I told her no, but maybe we should leave. She said that her new dress felt tight and that she wanted to change her clothes. I said fine. She took her clothes and went to the bathroom. Elena and I stayed at the shop looking at "girly" stuff.

A few minutes later, I got a phone call from a girl in the bathroom asking if I have a daughter Emily and that she was having trouble breathing. Elena and I rushed to the bathroom where we found Emily gasping for air. She tried to do her inhaler again, but I could tell from looking at her that this was not good. The whites of her eyes were completely red and her normally pink cheeks were white. I immediately called 911. Emily had enough air to ask two questions. Emily became disoriented and wandered into the hallway. I had her lay down and she passed out. A woman passing by and I started performing CPR while Elena was on the phone with 911. The woman that was helping me said that Emily was O.K., and another woman said she felt air coming out of her nose. To me, Emily was not O.K., she was blue. Then I heard the strangest sound come out her mouth. People later tell me it was her death-breath. 911 had not shown up yet. Emily was taken to the hospital where they continued CPR. I arrived maybe 10 minutes later where the doctors told me they could not get her heart to start. They had finally got the breathing tube in the right spot, but they had given her all the medicine they are

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allowed to jumpstart her heart plus more, with no success. They were telling me my daughter was dead. It was 4:20. I believe Emily passed away in the bathroom hallway at the mall, which would have been around 3:45.

To answer your questions:

Did she have an Epi Pen with her? If so... Was it administered immediately?

NO, I did not have an Epi-pen with me. Unfortunately, if I did have an Epi-pen with me, I don't know if I would have known to use it. I thought Emily was having an asthma attack because of her fall. I didn't know that what was happening to her was associated with food. She didn't have the tingling on her tongue, she didn't vomit, it was a safe food (so we thought).

What did she have to eat at the Deli?

Emily had the Sweet Onion Chicken-Teriyaki Wrap. We knew it contained soy sauce. This particular deli did not make peanut butter and jelly sandwiches. We still don't know where the trace amount of peanut came from. Unfortunately, the coroner and the investigator can't prove anything at this moment, but because her reaction was so rapid and violent, the coroner has no other option but to point to the last meal Emily ate. Somehow a trace amount of peanut cross contaminated the sandwich she had eaten. We are still waiting for lab results – until then the findings are inconclusive.

How quick was her reaction?

We ordered around 2:50 and were done eating about 3:10. My best guess is that around 3:20 is when she started feeling hot and went to change her clothes. I called 911 at 3:26 and I believe she was gone around 3:40. The doctor's pronounced her dead at 4:20.

Did she have any close calls before her death from reactions to something she had eaten?

NO, she did not have any close calls before this incident. Paul and I were in a comfort zone counting on Emily's internal alarm system and the fact that she knew what she could and couldn't eat, while we were blind to the fact that she was still very much in danger. Please understand, Emily was terrified of the Epi-pen and was diligent about asking questions about food preparation and ingredients. She did not want to be stuck with the Epi-pen. That's what makes this all the harder to understand, Emily was her own advocate.

Your child is at a wonderful age, you can still control what they eat, you are watchful to make sure they don't put the wrong thing in their mouth, you are their advocate. During this age, you can learn what the symptoms of anaphylactic shock are, you can develop a plan in case of an emergency, and go over and over what the plan is with friends and family so, God forbid, that emergency comes, you don't think, you react.

As your child gets older, and they become more independent and responsible, don't relax! According to FAAN, children between the ages of 10 and 19 are at a much higher risk of fatality. It defies logic, because you think now your child is at an age where they know and understand the dangers of their allergies and they will not take a chance. But what you don't know or think you know is what can take their life so quickly. It is almost as if every time you eat prepared food, your child has a gun pointed at their heart. We don't want to scare parents, but we want you to be scared, so that you stay vigilant in protecting your child.

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I know this may sound irresponsible but please read it for what it is, learning lessons. As a learning lesson, my family would eat shelled peanuts on the couch. When they were done, Emily and I would go into the living room and vacuum the couch and the carpets. I wanted her to understand that she has to protect herself and that she can't count on others to be as diligent as she had to be. Another time, we were taking a flight to San Diego. At the time, they still served peanuts on the plane. I had Emily wipe down the fold-down tray and arm rests in case the person who sat there before her ate peanuts and the residue remained on the surface.

The most bizarre part of this past 14 years is that I don't think I understood that Emily could die. I thought she would get hives, swelling, asthma attacks, or really sick, but never in all of my thoughts did I ever think of death. Why didn't that ever cross my mind? Did I not want to think that was a possibility? I now look at a lifetime of guilt, wondering how I could have done more. Please don't ever feel you are being too protective when it comes to the health of your child and if someone tells you to relax, tell them Emily's Story.

