

Treating Food Allergies One Bite at a Time

Stephanie Sorkin*

Perspective

My 10-year-old daughter had just returned home from sleepaway camp. Yes, a child with multiple food allergies (eggs, sesame, tree nuts, flax seed, shellfish, mustard, and canola oil) spent 7 weeks away from home. With the guidance and encouragement of one of the leading allergists in the United States, I took his advice.

“Teach her to self-advocate.” He recommended.

“She’ll learn life skills.” He suggested.

“Don’t isolate her.” He maintained.

After going over detailed instructions with the camp, reading and re-reading every label in the camp kitchen, supplementing foods and desserts where needed, I left no stone unturned. A camp allergy specialist to oversee my daughter at mealtime was also part of the equation.

It was the first night home from camp and my daughter was excited to meet a bunch of friends at a local ice cream shop. We had gone there for years without incident and got the same thing every time, out of a new container with a clean spoon. According to the store, the ice cream is not prepared on shared equipment. Their allergy binder is thorough and lists every ingredient in each flavor. It was our go-to place where we felt safe, yet somehow, something went horribly wrong.

Within seconds of taking one lick of ice cream, my daughter's skin grew pale, and she began to throw up. Her head hurt, she was dizzy, and she asked to lay down, all signs of an allergic reaction. My daughter had spent several weeks at camp, reaction free and within a few hours back at home...with ME... her mom, her protector, her biggest advocate, a reaction to what we think may have been eggs. How dumb I felt. The guilt. Why didn’t we just eat at home?

Food Allergy Advocate and Educator,
Spokin Food Allergy Ambassador, NY,
USA

*Corresponding Author: Stephanie
Sorkin, Food Allergy Advocate and
Educator, Spokin Food Allergy
Ambassador, NY, USA.

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I have been at this long enough to know that there is not yet a cure for food allergies, a condition that according to F.A.R.E., affects over 32 million Americans. I had been hearing a lot about treatments and was now at the point where I was willing to try anything. I had done a ton of research about Oral Immunotherapy, or “OIT”, a process of slowly introducing foods until tolerance is reached. The process does not enable to patient to “outgrow” the allergy, but rather tricks the body into no longer seeing the food as an enemy.

I had learned of a doctor, within an hour drive, who was just one of two doctors offering such a treatment in NYS at the time (2017). The treatment was only once per week and truthfully, I would have walked there barefoot with my daughter on my back if it meant that she would be safe.

I took their next available appointment. Before the visit, extensive blood work was needed to determine not just IGE levels, but overall health such as kidney function and vitamin levels, particularly Vitamin D. While my daughter is allergic to many foods, we decided to treat eggs, as that seemed to be her biggest challenge.

At the first appointment, the doctor needed to determine my daughter's actual “dose”, or amount that she'd need to take twice daily. To do this, the doctor's office prepared 20 small doses all containing micrograms of the allergen, in our case, egg. I was told that each dose got incrementally higher meaning the first dose contained less of the allergy protein than the next and that patients typically reached dose #20. With each dose given approximately every 15-20 minutes, it is typically an 8-hour day. Giving my daughter her allergen, voluntarily, was no easy task for me. If they had offered me any type of sedative, I would have gladly taken it. With that being said, as most allergy moms do, I swallowed my fears and hid my anxiety, as I knew that it could be contagious, and I did not want my daughter to sense that I was uneasy.

As it turned out, day one did not go as smoothly as we had hoped. Doses 1-12 were fine, however, by dose 13, I noticed a hive on my daughter's lower lip. They had us continue. Dose 14 and 15, the hive remained. It was not until dose 16 that my daughter began to feel sick. She was nauseous and asked to lie down. It seemed like the start of a reaction and the doctor suggested stopping there. Although he had only treated a handful of egg OIT patients so far, he seemed surprised that she was having a reaction, as the amount of egg protein in the doses was practically immeasurable. This further validated my feelings that she needed such a treatment, as her allergy was extremely severe. They gave her Benadryl but no epinephrine as her vitals were being monitored and were all normal, she did not throw up, and did not have any swelling, hives or trouble swallowing. My heart broke into a thousand pieces when my daughter, still not feeling well, whispered, “Does this mean that I can't do OIT?” The doctor calmly explained that she can still do the treatment, it will just take about 4 weeks longer than a patient who made it to dose 20. We decided to come back the following day to take the first real dose in the office, rather than take it at home which is usually the protocol.

We began with a liquid solution two times per day then “updosed” or increased the concentration, once a week for 8 weeks. Next my daughter graduated to another liquid with an even higher

concentration, taken for 3 weeks. She then graduated to an egg powder, which she took for 7 weeks. Next was monumental...a quarter of a hardboiled egg, still twice per day. Soon, it was a half, then $\frac{3}{4}$, then finally a whole hardboiled egg! It was surreal, like I was watching someone else's life. I remember the pride I felt in the hard work that my daughter put into this process. She earned this.

As it takes a village to raise a child with food allergies, that same village must be in place to treat them. The friends who understand that my daughter couldn't play tag or ping pong for at least 2 hours after dosing, as you must not raise the heart rate. The teachers and administrators who supported us when my daughter had to be late every Tuesday and would need to catch up on the work. The school nurse who knew the signs and symptoms of an allergic reaction. The family members, namely siblings, understood that a new schedule was in place, and everyone had to cooperate.

If I did not personally witness this treatment with my own eyes, I would've found it very hard to believe. A child with an anaphylactic egg allergy, a child who would react to the equivalent of a grain of sand, was able to eat an entire egg, reaction free, after just 6 months. Imagine, something that is so normal for most people, was a call for celebration for our family. My excitement had little to do with nutrition. The landmine that we had been living in for 10 years had just gotten a little bit safer. One less bomb was waiting to go off.

We have been in the "maintenance phase" for four years now, with my daughter eating one egg per day, as well as eating eggs freely - cooked in foods or alone.

What's interesting is upon reaching the one egg graduation milestone, I was presented with comments such as, "Maybe your daughter wasn't that allergic to begin with!" or "You could have probably done this at home if you gave her eggs little by little." To answer simply, we tried this alternative therapy because she was THAT allergic. We were willing to try anything and figured if the treatment didn't work, then it didn't work and we'd be back where we started. We just knew that we needed to do SOMETHING. Allergy families must not try this at home. This treatment needs to be doctor supervised and although most doses are given at home, they need to be medically prepared.

This treatment is not without potential side effects, although we did not experience any. 1-2% of patients develop EOE. 50% of patients experience mild to moderate stomach upset and many develop acid reflux. Some may even experience anaphylaxis.

A positive side effect may occur as well. As many as 33% of patients with multiple food allergies see a dramatic reduction in their untreated food allergies after a successful treatment of just one food. We are lucky enough to be a part of that group, not only resolving eggs with treatment, but having now outgrown sesame and almond. We were told that if egg was "the ringleader" that this would happen, so although we are unsure if that's the reason, it is quite possible.

While our brilliant doctor has now successfully treated hundreds of patients with OIT, there is a lot that I don't know.

-Is the BAT (Basophil Activation Test) accurate in predicting when you can stop dosing, or will my daughter be eating one egg forever?

-Will OIT ever be approved by the FDA and be readily available for the entire food allergy community?

-Will insurance companies ever recognize OIT as a potentially lifesaving treatment and cover the expenses?

-Will doses be available in pill form?

I'm aware of how far we have come in a short period of time. I have witnessed what seem like modern medical miracles, with not just my child but others we had met in the waiting room, once anaphylactic to various foods, now eating their former offenders!

With the multiple food allergies that remain, we have a long road ahead. It feels incredible to be on such a road, rather than what often felt like looking over the side of a cliff. We hope to continue to move forward and eventually begin OIT or another treatment in the near future. Little by little, microgram by microgram - each day one bite closer to food freedom.