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Peanut Allergies from a Caregiver's Perspective: Challenges & Insights

Announcer:

This is ReachMD. The following episode in the series, Cracking the Code on Peanut Allergies, is brought to you through an independent educational grant from Aimmune Therapeutics. Here is your host, Dr. Jennifer Caudle.

Dr. Caudle:

When treating an adolescent patient with peanut allergies, it can be easy to forget that their caregiver takes on much of the burden too. But what exactly does a day in the life of a caregiver look like, and how can these insights help shape the way you manage your allergy patients?

Welcome to Cracking the Code on Peanut Allergies. I'm your host, Dr. Jennifer Caudle, and joining me today to share her perspectives as a caregiver of a peanut-allergic child is Erica Spector from Livingston, New Jersey. Her daughter Avery is 13 years old and has been managing a peanut allergy, among other food allergies, since she was just a toddler.

Mrs. Spector, welcome to the program.

Ms. Spector:

Thank you, pleasure to be here.

Dr. Caudle:

As a caregiver of a child with a peanut allergy, I'm sure you've been through a lot, from adjusting to her diagnosis to managing treatment and prevention challenges, but how did you first discover that she had an allergy, and what was her path towards an official diagnosis?

Ms. Spector:

Sure. Well, I first had a suspicion when she was about 1 year old and I was giving her a bottle before bed—and I had just eaten peanut butter—and she had a few hives around her body. I thought, "Could it be a sweater I was wearing, which was wool?" I really wasn't sure. And in the back of my head, I thought, "Oh God, I hope it's not from the peanut butter I just ate." I gave her some Benadryl, she seemed fine, and I didn't really think too much of it at the time, but I didn't actually give her peanut butter until I was sort of mentally prepared to do so. I mentioned it to my husband. He was like, "No, that's crazy," and then we kept peanut butter in the house all the time. And then when she was about 2, he actually gave her a bite of a peanut butter sandwich and then she suddenly broke out with hives around her mouth. She came to me crying. I immediately gave her Benadryl, put her in the car and drove straight to the doctor's office. At that time the hives by then had subsided, she was okay, she didn't show other signs of distress or breathing issues, but the doctor did send me off with a script for epinephrine and suggested I go see an allergist.

Dr. Caudle:

Well, it's very helpful to understand your path and also your emotions and feelings as you were going through that, how you felt initially when she was very young and then later on when she had that bite of the sandwich. You know, I imagine at the time of diagnosis you were faced with several problems at once, probably having to learn how to prevent and treat the peanut allergy, but also how to prepare your daughter with coping with it as well. And what was that experience like for you both?

Ms. Spector:

When they are diagnosed really young—she was about 2 when she was diagnosed—they don't quite understand, and every activity and every bite of food is within the parents' control, or any type of caregiver at that time, so she didn't really understand other than we told her she is not to take food from anyone other than her parents or grandparents. At the time of diagnosis, I was very overwhelmed,

but you don't realize that it actually gets harder and harder as they grow up, especially the teenage years. So I took her to an allergist. We did a bunch of skin testing, blood work, to find out that she was allergic to all nuts as well as some other legumes, which peanuts are technically a legume.

And so we got an action plan, which then went with her to school. So, when she started school at about 2 ½, preschool, fortunately for me the preschool was nut-free and they had... You know, they kept her EpiPens in the office, and they knew that she was only to eat food that I gave her, that I packed for her. She was not to share because of the risk of cross-contamination. Any food or any treats that were given out in the school, even if they didn't have nuts, if they're not made in a bakery or facility that is nut-free, you still run into tremendous risk.

So, when she was little, I was able to control the situation, like I said. It's gotten progressively harder as she grows up and wants to go out in the world and is not with me all the time and is not in a private school. She's in public school now, so that continues to present challenges every single day.

Dr. Caudle:

Right. And kind of continuing along what you've been discussing, we were talking about, not only counseling, but education, all of the strategies that you're doing at home. We know an important management strategy is avoidance counseling, and is this something that you've been practicing with your daughter? I mean, clearly, you actually just described a number of scenarios which you have been, but how is that going on now? You mentioned she's in public school. How is avoidance counseling working out so far?

Ms. Spector:

I'm fortunate that my daughter—she's smart, she was reading at a young age, was reading labels. She takes it very seriously, and she understands the risks, having had one bad reaction when we were out of the country on a vacation, so she knows that she is not to take food from anybody other than a trusted source. She is to ask questions all the time. She reads labels. She knows that she cannot go to someone's house, and even if the food itself is safe, one of her safe treats like Goldfish crackers, if the bag is opened, we don't know that somebody in that family could have just eaten nuts and then stuck their hand in the Goldfish. So we've talked about everything from you are only to eat sealed, packaged goods that you can read the label. When you go to a restaurant, we avoid certain restaurants, and the ones that you go to, you are to reiterate your allergies, and you are to say it again when the server puts the plate down in front of you. So we've drilled this into her head pretty good.

That's not to say that on occasion I get the call if she's out. We gave her a cell phone, also, very young because I want her to be able to call me or take a picture of an ingredient or something, so we have constant communication when I'm not with her, so I have to say that it has been helpful, modern technology and her having a cell phone at a young age. But I do get that call once in a while like, "I think this is safe. Please, can I have it?" And we kind of say, "When in doubt, go without," and that's our motto. She also, whenever she goes to parties or events without me, she has a little bag that she takes with her that has her EpiPen, her Zyrtec, her Benadryl, as well as safe snacks, so she knows if she's going to a party, we bring her own cookies; we bring her own things to keep her safe.

Dr. Caudle:

Sure. Well, moving on a little bit from that—and that's so helpful to understand these sort of real-life strategies that you all are using as a family and the avoidance counseling that you provided with your daughter and how you managed it on a day-to-day basis—we know that a common strategy allergists like to take is to educate patients and parents on how to read labels. So let's talk about reading labels, and can you talk to us about your experience with this?

Ms. Spector:

Sure. So, reading labels, as you may or may not be aware, is very tricky in the United States. The labeling laws need improvement because just because something says contains, let's say, soy, dairy, wheat, doesn't mean that it's not made in a facility that is safe or on shared lines, because the "may contain" or "made in a facility" is all voluntary. So we know certain companies are very good and certain are not, so if we're not sure, we actually... There are plenty of times where I'll call a manufacturer and say, "Is this specific treat safe?" There's also this Snack Safely Guide, which you can find online, and they try to update the snacks for kids with allergies.

So, I know, for example, some labels like Goldfish might just list the actual ingredients, so we've had to call, and they say these particular items are safe. Like Oreo cookies, for example, the original are safe for her, but some of the other Oreos are not, so it's very tricky. And Avery knows. We kind of... If it says "may contain" and it doesn't say her allergens, then we feel comfortable that they're following the voluntary protocol, and if they are saying "may contain traces" or "made in a facility" and it doesn't say "nuts," they'd like to say it's safe. There are certain dessert brands or snacks that say "made in a peanut-free facility." Then we know we're in good shape, and we try to find those companies. And I am constantly, you know, sharing their brands on Facebook and trying to promote them so that the companies that do cater to the allergy community can survive.

Dr. Caudle:

Well, I think that's very helpful to our listeners and to those who are watching, right? You're talking about your practical experiences, what you do, even calling companies, and I think that's very valuable for those who are listening and who are watching.

So, earlier we talked about essential food allergy management strategies, but now let's talk about how caregivers, such as yourself, can prevent a life-threatening emergency from occurring. Erica, it's clear that your child has gained a lot of expertise in knowing how to avoid food allergens herself, but others around her may not be so well-educated or informed. Now, you've talked a lot about your strategies at her school, parties, birthday parties and things like that, so you've done a great job of kind of laying that groundwork for us. How do you both communicate with food handlers at places like schools and restaurants?

Ms. Spector:

The schools are not so great, and I pack her a lunch every day. I do not let her buy from the school cafeteria. Certain schools... She's now in her third public school. She started elementary; then she was in one middle school for 6th grade; now she's in another for 7th and 8th. She's in 8th grade. Certain schools were better than others, so we kind of just pack her own lunch. We know when you have a nut allergy, peanut allergy, I think most people tend to avoid certain restaurants, like Asian food tends to have more nuts, Thai food, of course, so we kind of stick to your basic bar and grills, diners, Italian restaurants. And some of those do contain her allergen, but I come to call ahead to a bunch of restaurants that I know my daughter may want to frequent with her friends, and then she knows when she's there she says her allergies when she orders. She says it cannot come in cross-contact. Please use fresh gloves or a separate area. And then she says it again when they put the plate down in front of her just to make sure there's no confusion. She is 13, going to a lot of parties, bar and bat mitzvahs in my area, so every weekend I call the caterer of where she's going to find out what she can and cannot have, and then she knows in advance what's safe for her to eat. You have to always make sure when your kids tend to like French fries, chicken fingers, what's in the fryer. Most places, at least in our area of the country, are not frying in peanut oil. It's more of a challenge when we go down south. But most places are using vegetable, canola oil, soybean oil. But what else goes in the fryer? Is it something else that contains nuts, almond-encrusted this or that, so we have to always check fryers, and we call ahead everywhere she goes. Every time she goes on a trip or a day trip without me, she checks.

Dr. Caudle:

Yes, and I really applaud you for really all that you're doing. I mean, I'm sure that you see it as what's simply needed to make sure that your daughter is kept safe, but I think that it will be really eye-opening and really telling to those who are watching and listening to this program really what goes into making sure that your daughter stays safe and the calls that you're making and the thought that goes into pretty much every day. I'd like to spend a minute on epinephrine auto injectors, which we know are essential backups when food allergy emergencies take place. What care challenges have you faced in trying to ensure that your child always has immediate access to an EpiPen?

Ms. Spector:

My daughter knows she is not to leave the house without her epinephrine, so we have a small bag which contains her epinephrine as well as her other medication, and we keep it by her shoes and by the garage door where we go out of the house, so she knows that she is not to leave the house without it. On occasion she has, and she's been told she cannot eat if she doesn't have her medications with her. So I'm fortunate that for a girl it's a little easier because she has a cute little pocketbook that she carries with her that has her medications in it. I've heard from boy parents it's a little harder because sometimes they don't have a bag and they don't want to have something bulky in their pocket or whatever, but most of them find ways to manage.

Dr. Caudle:

I'm also sure that there has been a fair share of highs and lows throughout this whole experience of managing food allergies. You've really talked about a lot of these. In that time, what progress have you seen your daughter make, and what setbacks has she really overcome as you have both journeyed through her food allergies?

Ms. Spector:

Well, initially, every play date was at my house; every sleepover was at my house. And she's an otherwise healthy, thriving, social, 13-year-old girl, so we've had our highs and lows. I'm happy to host as much as I can, but there are some times when she wants to go to someone else's house, a group of girls are going, or there's a birthday party and someone wants to take them to the latest dessert place or the Sugar Factory or Black Tap Burgers in New York City, and there are certain times where I'm just not comfortable with her going. There are other times where I go and I hang out at the place next door just because I want to be there when she's there. Initially, when she was little and going to birthday parties, I drove to every birthday party and I would sit in my car in the parking lot just in case she had a reaction, and it's emotional, and it's hard, because I want her to be like everybody else, and there are times when that's just not possible.

We're getting better and better with it. She goes to sleep-away camp, actually, and a bunch of sleep-away camps have now become nut-free. So she was at one that wasn't. I switched her camp, and that worked out. But one of her good friends from camp wanted to take her away in August when she got home for 3 nights, and I was a nervous wreck, but I wasn't going to not let her go, so I spoke to the mom and I sent her with a lot of her own food. Sometimes she has to eat something that's not really so healthy, but it just gets her through.

Dr. Caudle:

You want her to be independent and, as you mentioned, be like other children, but you also want to make sure that she's safe, and so it sounds like every day is really sort of a checks and balance system, and, yeah, I really applaud you for that.

Before we wrap up, I really want to ask you: What takeaways would you most want other people who are involved in the treatment and prevention of food allergies to know, given everything you've learned as a parent and as a caretaker?

Ms. Spector:

Sure. I think that medical professionals need to just continue to stress to their patients to always carry their epinephrine with them and not be afraid to use it, and certainly, if more than one system is involved, to make sure they use it, it won't hurt them, and that they go then seek emergency care. The other thing is just for scientists and doctors in this field to please continue to keep up the research, because it affects so many children and it seems to be rising the number of children that are affected by food allergies and the fatalities that I continue to hear about, so I just would implore them to keep up the research, and hopefully, someday we can find a cure. Avoidance is very difficult. It's very easy just to not eat straight up peanut butter or a nut, but the risk of cross-contamination with all sorts of things, it affects people going to restaurants, to traveling, leaving their homes. You're always at risk, so I just hope that someday there is a cure or a better treatment other than avoidance for children living with life-threatening food allergies.

Dr. Caudle:

These have been amazing insights, Erica, that you've given us into the challenges and also the things that you all have overcome as you've been taking care of your daughter who has a peanut allergy. Mrs. Spector, it was so wonderful having you on the program today. Thank you again for joining us.

Ms. Spector:

Thank you so much. My pleasure.

Announcer:

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