

Children's Food Allergies: How prevalent are they and what can we do to help?

OLIVIA RICHTER (PRODUCER): Hello, and welcome to Big and Little, the podcast of Boston Children's Museum.

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OLIVIA (PRODUCER):

When a retail store moved into the museum building last year and began serving peanut butter sandwiches from the store's cafe, the response from our surrounding community came quickly. Parents and health professionals expressed their concerns that the new cafe presented too much risk for kids with food allergies. The outpouring of concern over the cafe led the museum to work directly with physicians, allergy experts, and the cafe owners on a solution to minimize the risk to kids and raise the awareness of food allergies.

Joining us today are doctors Michael Pistiner and Ali Yurkovic, who also happen to be the parents of kids with food allergies. Michael and Ali speak to the prevalence of allergies in kids, their own experience as parents of kids with allergies, and how people can get involved in advocacy efforts to protect those with food allergies in public spaces.

This episode of Big and Little intends to start a dialogue around food allergies, with the greater goal of ensuring that all kids and adults can feel welcome and safe in public spaces like the museum. So without further ado, let's get into Carole's conversation with Michael and Ali.

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CAROLE CHARNOW: Hello. This is the Big and Little podcast from Boston Children's Museum. I'm Carole Charnow, President and CEO. I have with me today two very distinguished guests, Dr. Michael Pistiner, the Director of Food Allergy Advocacy, Education, and Prevention at the Massachusetts General Hospital for Children Food Allergy Center, and Dr. Ali Yurkovic, the Senior Director for Population Health at Grand Rounds Health and a general internal medicine physician. Both of our guests are parents of children with food allergies. Ali and Mike, welcome.

ALI YURKOVIC: Hi, Carole.

MIKE PISTINER: Hello. Thanks for having us.

CAROLE: Thank you. Before we start, I wanted to make a quick mention of how we all met last year. A retail shop moved into a space immediately adjacent to the museum and opened a small lunch counter that featured peanut butter sandwiches. So as you can imagine, this caused great concern on behalf of parents whose children have nut allergies.

And as we were working through this difficult situation, we received a letter from two physicians at the Food Allergy Center at Mass General Hospital inviting us to meet with them to learn more about food allergies. And this led to a number of meetings between the museum and physicians from both Mass General and also Children's Hospital and other places, during which we learned a lot about food allergies

and subsequently created our comprehensive Allergy Awareness Program, which we believe is the first for a museum, certainly in our region, and perhaps across the country.

So we are here today to talk about the subject of food allergies. And I'm really thrilled to have our two guests with us today. So to kick things off, Mike, why don't you start by telling us, what is a food allergy, and how do people manage having a food allergy?

MIKE: So a food allergy is an abnormal immune response to food. We use our immune system to fight things like viruses or bacteria, to fight germs. And, sometimes, the immune system can fight something that would be harmless to most people, like food.

And that way, if somebody eats the food that they're allergic to, then they can have a reaction that can cause coughing, wheezing, hives, sneezing, vomiting, diarrhea, multiple symptoms that can affect respiratory, GI, gastrointestinal-- the different organ systems of our body-- making us feel pretty terrible pretty quickly.

Now, when someone has a food allergy, they have to avoid eating their allergen. And you'll need to implement food allergy management strategies when you have somebody who has a food allergy. For example, if we have a kid who has a food allergy, then you'll need to prevent allergic reactions and be prepared to deal with emergency accidental ingestions and allergic emergency.

So those are the two pillars of food allergy management-- prevention and emergency preparedness. So a family who has a child who has a food allergy has to keep those pillars going, no matter where they are and no matter who they're with. So whether the kid is with their grandparents, whether the kid is at school, and whether the kid is visiting the museum, they will need to implement those pillars of prevention and emergency preparedness.

With prevention, you need to learn how to read labels to avoid accidentally eating your allergen. You need to prevent cross-contact, which is when food can get into something else and ultimately get into the person with allergy by eating it or putting it in their nose or eyes. And you need to communicate really well.

And those are the pillars of prevention. And you also need to be able to recognize an allergic reaction, recognize an allergic emergency, have the treatment for an allergic emergency present, which is epinephrine, and then know how to use it, when to use it, and then to call 911.

CAROLE: Wow. That is a lot. It's a lot to manage for a parent with a child because there are so many other things to be thinking about. So, Ali, I want to turn to you. Having this as a part of your life, what do you do to keep your child safe from a serious allergy reaction, both at home, and in school, and in public places?

ALI: Yeah. As Mike was describing, managing food allergies is something we do every day, every waking hour, essentially. There's really no days off. When someone in a family is diagnosed with a food allergy, you suddenly become aware of the fact that food is everywhere. It's a part of holidays, and celebrations, and events, and school, and camp.

And for food to be risky means that families and individuals managing food allergies really need to fundamentally change how they think about and approach mealtimes, socializing, and many things that the rest of the community considers just normal. And at first-- I'll be very honest-- it was easy to feel overwhelmed and really anxious. Over time-- and this is still a learning process. And each year, and as our son grows, there's new challenges and things to think about.

But we've learned some strategies that help us feel confident navigating society. First and foremost, as Mike was talking about, we are sure that we are always carrying EpiPens with us, as well as some wipes. And we make sure that any adult who is caring for our son is comfortable identifying the signs of anaphylaxis or of an allergic reaction and knows how to administer that life-saving medication. So we do a lot of training and education around that.

And we spend a lot of time planning for meals and snacks. The best meal for us is a safe meal. And sometimes that's really easy. Sometimes restaurants are very allergy-aware. Sometimes there are great, safe options on the shelf.

And sometimes it's really hard. Sometimes we have to say no to something, like at a birthday party, or we were just out at an amusement park. We have to say no if we can't be sure that it is safe, and that's really hard to navigate with young children.

And so we spend a lot of time trying to ensure we always have a backup option. We always have options in place. And I think also, especially with younger children, thinking about the ages that you're seeing at the Children's Museum, Carole, there's just a lot of vigilance on the parts of parents and caretakers. Not only are you watching what your child is picking up and putting in his or her mouth, but you're also watching all of the children around yours.

What's going on in the environment? Is anyone eating? Because as soon as food gets introduced, you need to be cautious and making sure that your child is not inadvertently putting something in his or her mouth that another child just did the same to.

There's a limit, though. As parents, we can ask and inquire about safety. We can be vigilant. We can encourage our child to increasingly take that role, as well.

But, on some level, we have to trust that the community is going to help us protect our children. And so my husband and I spend a lot of time educating informally to our friends and family members, schools, and camps to make sure that they feel comfortable being an advocate, being an ally, and being an early responder to keep our son safe and keep him included, which is really, really important as he grows and develops.

CAROLE: That is so important-- so many important points that you just made. So having heard from you both, we can now understand that dealing with the food allergy is not a choice. And I would like to ask you both, what would you like families without food allergies to know about how to support families like yours?

MIKE: Yeah. The simplest thing that people can do is have an awareness and an understanding that these prevention strategies and these emergency preparedness strategies are not an option, not a choice, and that the families who are managing a kid with a food allergy need to do this. And that awareness and that understanding that the other families can have to just let them do what they need to do to take good care of their kid-- that, in itself, is so helpful.

So this way, if I don't need to worry that someone else is annoyed because we can't go into a restaurant with the rest of the families because they can't safely serve my kid, and we need to go to another place, then it's going to help me do my job of taking care of my kid. So that first step is just having an awareness and an understanding that allows the families with a child with a food allergy to do what they need to do to take care of their kid.

The next step would be, if a family of a child without food allergy or relatives-- if they were interested in learning more about how they can help manage my kid's food allergy, then that is even more helpful.

Then this can sometimes take some of those times that a child may not have been quite as included and include them.

So this would be a great example is sleeping over at another kid's house, going to a drop-off birthday party, going to a drop-off play date. This is where the parents of the kid without food allergy will need to take on some extra responsibilities, as Ali was mentioning before.

CAROLE: Ali, do you have anything to add to that?

ALI: I think your point, Mike, around understanding as being core-- every family who's managing food allergies is really, by and large, trying to make the decisions and take the steps that they believe are needed to keep their child safe. And I think building that understanding within the community is so, so critical.

And it's complicated. It's hard to manage food allergies. I still feel like I'm learning on a daily basis. And so I have no expectation that other families are going to know all the rules or know all of the steps.

But it really comes down to a willingness and an openness to ask the questions and make space for us to make it possible for our children to be just as included and be a part of all the non-food fun that is going on, whether it's at a museum, at a birthday party, at school, et cetera.

CAROLE: That seems hard-- really challenging. And to think of something even more challenging and more complex, I wanted to talk a bit about how schools manage food allergies and perhaps what we can learn from schools about how they do manage this complicated situation. Mike, you probably have a lot of experience with that from the Food Allergy Center.

MIKE: Yeah. So Massachusetts has actually led the way in managing food allergies in schools. And Massachusetts was the first state to implement their own guidelines and also to have data collection built into their guidelines. And now, throughout the rest of the country, now there's voluntary CDC guidelines towards schools, and other states have started their own guidelines.

And there's been a lot of forward momentum in dealing with and managing food allergies in schools. Especially in Massachusetts, there's a lot of really sound school policy that goes towards managing food allergies in schools. And we're also blessed, in Massachusetts, to have very solid school nursing to help with training and to help with coordination.

And so things that Massachusetts has been doing really well that we can take from the school experience and implement it in other community settings is this idea of community education and this idea of knowing the policy and knowing steps that it takes to prevent accidental exposure and to deal with an allergic emergency, if need be. And so I think that implementation of solid policy that supports both prevention and emergency preparedness is what schools have been doing well and something that we can take with us into other settings, for example, the museum.

CAROLE: So, Mike, that sounds like Massachusetts is really responding correctly to this situation and could serve as a model for other states and school districts, which brings me to the moment where I thought I would say a bit about our own program. So I mentioned to you how we came about needing this Allergy Awareness Program. And it took us about six months to put together.

And, throughout, we were so grateful to Mike and Ali and other physicians for supporting us and giving us so much great information. This program now could be easily implemented in other public spaces that we've been talking about. It's basically based on the concept that all children and adults should feel safe and welcome in the Children's Museum.

We have about half a million visitors each year, and we certainly can't promise to be allergy-free or completely nut-free because there are so many people coming in and out of the museum. But we have put in place many practices to create an allergy-aware environment. These practices include, for example, encouraging families to leave nut butter products at home, not offering nut products in museum vending machines or at events or museum programs.

And, in fact, we do have signage for if there are other potential allergens in programs to alert parents that that is present in the program, for example, milk or some other food allergens. But we do not offer any nut products because they create such a severe allergic reaction.

We have learned a lot from the physicians we've been speaking to and encouraging hand-washing before eating, as we always have, but now after eating, as well, and only in designated spaces which are cleaned very, very often, have wipes available, and have very attractive and educational signage. And I think you both have been talking about educating families without food allergy, which is something that we are really committed to now because all of us have so much to learn from you.

We offer training for staff about how to manage food allergies in the museum and also how to prevent food allergic reactions. We have much more information on our website, and we're hoping in the future, to have a food exhibit that will have some information also about food allergies. Basically, this program is aimed at helping all families become more aware of how they can support individuals-- children and adults-- with food allergies.

I would also mention very briefly we do have a program called Morningstar Access, in which families with very severe allergic children can come to that. There is a very small number of people who come to the museum at that time. There's no food anywhere. So if people are extremely worried about severe allergic reactions, they have that option, too.

But we have found that this Allergy Awareness Program has been welcomed by all our visitors. Our staff loves it. It's easy to implement. And it's something that I hope we will, with our guests here today and others, be able to share with other museums and other public spaces. So, Ali, I would love to hear you say a word about how this program, you think, is going and also how it could work for your family in, say, a mall food court, or a zoo, or any other public space where all these foods are being served.

ALI: First of all, a huge thank you, Carole, for all of that work. You described it very briefly, but I know there was a lot of time and energy that you and other leaders across the museum put into making that a reality. That being said, as you described, the policies themselves and the trainings required aren't that complex.

And so to your question around, how could this be done in other public spaces, other institutions, other museums, I would really love to see kind of the steps that have been taken at the Children's Museum explored by other science museums, children's museums, public spaces in post-COVID times.

But I think what's really exciting about the work that has been done at the Children's Museum is that education piece because, for families who are not managing food allergies, probably the most common way they've encountered food allergies are from school saying you can't do this, or you can't do-- setting very specific rules. And that has to happen. But I'm so excited at the opportunity to start a dialogue and help families understand the why for the hand-washing, the why we need to be aware and inclusive, especially around food.

And so really just want to celebrate the steps that have been taken. And I think that the food allergy community would be really excited to support other institutions in taking these simple steps to keep all of our children safe, and welcome, and included.

CAROLE: That's just great. And I'm excited to get started on spreading the word, too. Mike, one of the areas that we really do need to address in this conversation are restaurants. I know that you spend time out in the community, working with restaurants who are allergy-aware. Can you tell us a bit about how restaurants respond to food allergies?

MIKE: Cool. Similar to the school situation, Massachusetts has been leading the charge. And for over a decade now, there's been a law that increases awareness in eating establishments in Massachusetts. And it requires that a food protection manager, a food safety manager be aware of food allergies and be trained and also be able to identify major eight allergens and also have education poster and notification on menus to tell the establishment of someone in the party's food allergy.

Now, what this awareness law has done is increase that dialogue and increase that awareness that then gives people the opportunity to disclose their allergy and have someone they can talk to about it. And, ultimately, it may turn into the fact that an eating establishment can't safely serve someone.

But at least, this way, there is that important awareness and dialogue. And that's also something that we can learn from and implement, really, in all circumstances, including in the community settings like in a museum.

CAROLE: So I wanted to talk for a minute about advocacy. I know both of you are involved in advocacy at a number of levels, and I'd like to give you the opportunity to talk about the kind of work you're doing, and also how we can help support your advocacy efforts to protect children, as there is a lot at stake here because some of these severe allergic reactions can be very, very dangerous.

So I'm going to turn first to you, Ali. I know that you are involved with a number of parent groups and others. How would you suggest we support advocacy efforts?

ALI: Yeah. There are-- as you can imagine, parents of children who have food allergies are very, very activated around this issue and very passionate about creating an environment that's going to allow their children to be safe, included, and thrive.

So there are a number of local, regional, and national organizations, including AAFA, as well as FARE, which are supporting both local, regional, and national legislation to support the establishment of broader policy that is going to create the environment that's necessary to protect and support families managing food allergies. And I think Mike can talk a little bit about some of the work that's ongoing in Massachusetts right now.

MIKE: Yeah. So in the Food Allergy Center, we have an advocacy program where our purpose is to support the food allergy community and to be able to identify holes and to be able to help activate and fill them and to also help support potential legislation that is going to support the food allergy community. And right now, schools and restaurants are both-- there's opportunities for this.

Currently, there is a bill that is in the Education Committee that will require that all Massachusetts schools have a policy directed towards food allergy and have staff training to support that policy. There is also a bill that's also sitting in the Education Committee that will make nondesignated-- so it's called stock epinephrine-- epinephrine that would be available for use for people who don't have a known food allergy already and allow school staff to be able to treat somebody who has a first-time severe allergic reaction.

Then, in addition, there is a bill that will augment the law that I mentioned before in Massachusetts, the food allergy awareness law in eating establishments. And what this proposed bill will ask for is that someone who has the specific training towards food allergy awareness is on the premises at all times in the restaurants. So not only is there a food protection, a food safety manager who has the training, but there's always someone on the premises who has that training.

So that's what the restaurant bill will ask for. So those three are very worthwhile to get behind. And what we're asking people to do is ask your local legislators to support these bills and to possibly champion them and cosponsor each of them. That would be fantastic. And then, also, if you also have the bandwidth, please reach out to the Education Committee, specifically the chair and vice chair, asking for their support. And I think Carole will provide links for those.

CAROLE: So yes, we will provide information about this legislation on our website with the podcast and also through social media. Ali, I know that you're involved with a number of local and national organizations. You mentioned some of your advocacy work earlier. Can you talk a little bit about more how people could connect with these organizations and support them?

ALI: Absolutely. Yes, Carole, there are a lot of both local, regional, and national organizations out there that are both really focused on building and supporting the food allergy community. Two that are very well-known within the food allergy community-- the Asthma and Allergy Foundation of America, AAFA, which I had mentioned earlier.

Their New England chapter is located just outside of Boston, Massachusetts. And they are doing an enormous amount of work in the New England community in terms of creating speaker series, fostering education, supporting research, and really trying to bring together the voices of the food allergy community.

Another organization that has a national footprint is the Food Allergy Research and Education organization, or FARE. And, very similarly, they are focused on research and advocacy that are impacting food allergic individuals, not just in New England but nationally. And Carole, I believe you'll share both organizations' websites on social media after this.

CAROLE: Yes, we will, and we can also put them on our education page about food allergies on our website. So this has been an incredibly interesting conversation, and I think all of us have learned so much. Would you both have any last messages for parents-- not only parents with food allergies, but also parents who do not have children with food allergies? Mike, what would you say to our listeners before we go?

MIKE: When families of kids without food allergies are open to learning and understanding why it is that the families of kids with food allergies have to do the things we need to do to keep our kids safe, it just makes the job of the parents so much easier. So being understanding and aware and giving other families permission to take good care of their kids-- that goes a very long way, and thank you very much.

ALI: Yeah, I would just like to echo that thank you. Thank you for listening to the conversation. And I really hope that we were able to provide a little bit of insight into the experience of raising amazing kids who just happen to have life-threatening food allergies.

And I think inclusivity is something that our culture is really thinking a lot about right now. And understanding and willingness and openness to be an ally and advocate for our children is something that I'm really thankful for. So this has been a wonderful opportunity, Carole, and we're very appreciative for it.

CAROLE: Well, I want to thank you both on behalf of the Children's Museum, not only for working so hard to protect your own families, but to work so hard for all families, other families with food allergies and those that aren't, to help us all become more inclusive. And I'm really grateful to you both for spending this time with us this morning. Thank you so much, and good luck to you with all of your advocacy efforts.

ALI: Thank you, Carole.

MIKE: Thank you, Carole.

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OLIVIA (PRODUCER): That's it for Big and Little. Thanks for tuning in. If you like the show, make sure to subscribe to us wherever you get your podcasts. And stay tuned for more episodes coming soon.

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