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The Critical Importance of Flu Vaccination: A Patient Advocate's Story

Announcer:

You're listening to *VacciNation* on ReachMD, and this episode is sponsored by CSL Seqirus. Here's your host, Dr. Mary Katherine Cheeley.

Dr. Cheeley:

This is *VacciNation* on ReachMD. I'm Dr. Mary Katherine Cheeley, and here with me today is Mrs. Alissa Kanowitz, a patient advocate who experienced the absolute worst-case scenario: losing a child to the flu. She'll be sharing her experience and perspectives with us so we can all work to stem the tide on this tragic disease. So with that being said, I'd like to welcome you Alissa. We're so thankful that you're here today.

Mrs. Kanowitz:

Thank you for having me.

Dr. Cheeley:

So now that we've touched on why you became an advocate for Families Fighting Flu, Alissa, can you share with us Amanda's story?

Mrs. Kanowitz:

Of course. Our daughter Amanda was a happy, healthy, beautiful 4-year-old little girl until one weekend she caught what we thought was an ordinary virus. She never had a high fever. She never seemed that sick. She was coughing one day, vomiting the next. But then that night, she really did not look good. She was very weak and her lips looked gray, so I called the pediatrician and she told me the rotavirus was going around and that there had been over 80 calls about it that weekend, and that we just needed to keep Amanda hydrated. But she also said make sure she just takes sips of water because if she drinks a whole cup, she'll vomit. So Amanda, being my good girl, called me in at 3:00 in the morning to say, "Mommy, I'm sorry, I drank the whole cup of water." So I reassured her that was okay, and I put her back to bed. And then 4 hours later I found her lifeless in her bed. You know we did not know at the time, but it was influenza.

Dr. Cheeley:

I can't imagine going in to my 3-year-old daughter's room and experiencing that. Thank you so much for talking about Amanda's story and what you guys went through. How did her providers give you guidance during that time, and how do you feel about their advice now?

Mrs. Kanowitz:

How do I feel... Sad, frustrated, angry. You know, just wishing that it was any other way. Our providers followed the CDC recommendations. Amanda was not vaccinated because back in 2004, the influenza vaccine was not recommended for her age group. It was only recommended for kids 6-24 months of age, and she was outside of that range. She was four and a half, but because she wasn't vaccinated, her body didn't know how to respond. And unfortunately, there's no way to predict which other children are at risk for reactions like this. Shortly after Amanda died, I spoke with a bunch of top experts across the country, and so many of them told me that unfortunately, kids' immune systems are not fully developed before age 5. So they weren't really surprised. And once I heard that, I knew that was our first mission. We needed to get those CDC recommendations changed to cover children up to 5 years old, and fortunately, within just a couple of years of this happening, we were able to help convince the CDC to do just that.

Dr. Cheeley:

Alissa, it seems like it happened really quickly. You talked about the fact that she was feeling poorly one day. You talked to her doctors.

She woke you up in the middle of the night, and then all of a sudden... What do you wish you had known at the time that you guys were experiencing this?

Mrs. Kanowitz:

I wish I knew all of the symptoms of the flu because back then, I didn't know that it was the flu. And I didn't realize how serious the flu could be. Anytime anybody has a fever virus or stomach bug, they call it the flu. But in reality, influenza is such a serious virus, and it can be very dangerous. I mean, as you know, in most years, over 300,000 people are hospitalized and up to 52,000 people die. I also wish that I knew the warning signs of sepsis back then. You know in retrospect, Amanda was most likely going into septic shock when her lips were gray. And I had no clue, and I have to live with the guilt about that. I wish that there was a class required for new parents that taught you what to look for. I mean, I knew you look for a high fever and you look for difficulty breathing. Well, Amanda didn't have either of those. And unfortunately, I was unaware of the other symptoms.

Dr. Cheeley:

For those just tuning in, you're listening to *VacciNation* on ReachMD. I'm Dr. Mary Katherine Cheeley, and I'm speaking with Mrs. Alissa Kanowitz about her personal story as a patient advocate after the absolute tragic loss of her daughter to the flu.

So now that you're a patient advocate, Alissa, how is it meeting with other patients or meeting with parents or healthcare providers?

Mrs. Kanowitz:

Well, we sort of live in our own little bubble because most of the people that we speak with, in terms of the conferences and things like that, are pretty much on board and they're flu supporters. But it's when we're out in the community, in the day-to-day when you're meeting with people and they're saying, "Oh, I never get the flu shot. I don't need to. It's not important." Or "Oh it made me sick, or "I got the shot and then I got the flu that year. And those are the people that you really need to explain, well, you know what? Even if you feel like it's not critical for you personally, you don't know who's standing next to you in the grocery line. They could be immunocompromised, and you could actually be responsible for somebody's death if somebody goes home and gives it to their grandparent and they're sick. So it's not just about you. It's about what's for the better good.

That number 1 message is that you need to protect your family against influenza because it can have serious complications and the most effective way to do that is to get your family vaccinated. Now I know everybody has you know vaccine fatigue and they don't want to hear it at this point. But it's so important.

Dr. Cheeley:

Absolutely. And it's easy. it's not that hard to do. It's available at pharmacies or your provider's office or the health department. We've made it really, really easy so I think that's such a huge point. Now you have an organization that you work with called "Families Fighting Flu." Tell me a little bit more about that.

Mrs. Kanowitz:

Yes. So after Amanda died, we got together with several other families and we formed what has now become a national nonprofit organization called "Families Fighting Flu." We have a website, familiesfightingflu.org, where you can see the stories of over 80 families who've lost children or they've had serious hospitalizations. So this is not just a one child issue. This happens from various complications. In Amanda's case, it was her immune reaction. Some are myocarditis. There's so many different things that can go wrong. But our organization works very strongly to get our message out there and put a face on the flu because when you hear numbers, they may or may not resonate. But when you actually see the faces of these children and of the families, we're in a unique position and all of us feel the same way, that's it's really our responsibility to get out there and to educate and make people aware just how dangerous it can be and that one simple trip to your healthcare provider for a vaccine that can take 2 minutes can really save your family's lives.

Dr. Cheeley:

So before we close, I understand that you have been diagnosed with mast cell activation syndrome, or MCAS for short, and your family suspects that Amanda likely had it as well, given her course. How has this new information kind of shaped your understanding of her health and what's transpired?

Mrs. Kanowitz:

Well, we always thought of her as the happy, healthy little girl, and I always thought of myself as a happy, healthy older girl. But about 10 years ago, I was diagnosed with Ehler-Danlos, which is hypermobility syndrome, the type that I have. And there is a high comorbidity with MCAS. And when Amanda died, I recognized that there have been several instances where her body had reacted to viruses. First to the MMR vaccine, which was a live virus vaccine. She had a full body rash and 104 fever, which it's not a 1-in-10-million thing, but it's not a common reaction. And then two years later, my son had the exact same reaction. So that kind of told me that there's something

genetic going on here. So the very first thing that went through my mind is can somebody be allergic to viruses? And the answer I got was no, no, no, and I'm like, okay, let me rephrase. Can somebody be hypersensitive to viruses? And again, I went to top experts, both infectious disease and immunology, and back then MCAS had not yet been discovered. So the reaction was, well there's no way to test for that, and there's no way to know because I was desperate to protect my 2-year-old son. Well, fast forward and within the past 10-12 years or so, MCAS has been identified. Unfortunately, most doctors are not even aware of it, especially those who have been practicing for a long time, and they're not aware of how prevalent it is. I mean, they think that up to 17 percent of the population has it, which by the way, coincides with long COVID. So I think that you have certain children and adults who are at risk for—or at greater risk, I should say—complications to viruses and diseases, and I think that healthcare professionals really need to look at that and say, wait we shouldn't just be looking to the children of asthma or diabetes or those conditions, but do they have a history of hives? Do they have a history of weird reactions? Do they have a history of overreacting to things? Do they have a history of blowing up from mosquito bites? You know, things like that. And to keep an extra eye on these kids.

Dr. Cheeley:

Yeah. I think that's really interesting to not just take the virus itself but also think about how our bodies react to the virus, and the more that you've learned – I applaud you for taking the time and the effort to learn about these things, to make sure that other people are educated about them, and to go back and educate providers too because as you mentioned, there's so many providers that have been out for a while that either may not keep up to date or don't have the opportunity to kind of hear these personal type of stories. So I am so grateful for you, for that.

Mrs. Kanowitz:

Well, thank you for giving me the opportunity.

Dr. Cheeley:

I cannot thank you enough, Alissa, for being here and for sharing your story and Amanda's story. She lives on every time you tell that story, and I know that this is going to help us better understand the seriousness of influenza, help describe it to our patients better, and help treat our patients better. Thanks for being here.

Mrs. Kanowitz:

Thank you.

Announcer:

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