A Father's Fight After Tragic Allergy Loss Transcript

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Introduction to Food Allergies in the Black Community

All right. Good health and welcome to today's edition of Black Doctor Speaks, which is a dedicated space where we explore complex health issues that impact the African-American community.

Today we're talking about the complexities of food allergies within the Black community, particularly among our children. In this episode, we lay the foundation for an enlightening series discussing why this topic is so important.

And what we aim to achieve is understanding of the food allergy, its impact on Black children, our special guest today is Mr. Thomas Silvera. He has a story to tell.

I turn that over to our co-host, Dr. Renee. Dr Renee, It's up to you. Hi. So I'm so excited. Thomas Salvera, I met him actually a few years ago. But I heard his story and did a blog post about it.

And his wife actually DMed me when I was promoting my post. That's how we got connected. His story is amazing. Please, please share with us your story of how food allergies affected you and your family.

Okay, thank you again, Dr. Mahmood, for having me here. Dr Renee, I appreciate you guys having on this platform, platforms to share my story. So I can say, well, been sharing this story so much, it's still always brand new to me for sharing it.

My son, Elijah, was such a vibrant, loving boy. Like many parents, we entrusted his child care center and believe in that they would provide a safe space for him in terms of having a nurturing environment.

So Elijah had severe allergies to dairy, which was well documented and communicated with the child cares.

Elijah's Story and the Foundation's Mission

Unfortunately, on November 3rd, 2017, despite all clear instructions, and precautions, he was given a grilled cheese sandwich by an educator that was watching over him.

And this seemingly simple oversight, as they call it, led to him having a severe allergic reaction. The child care staff there failed to recognize the signs and symptoms of the itaphylaxis and did not administer his epinephrine, did call his mother right away or 911. And by that time he was taken to Harlem Hospital, which was the local hospital close by, and it was already too late for that.

And we lost my son. So losing Elijah was one of the most devastating experience I think any parent will experience. But within that, it ignited a fierce determination like within me, within his mother to just prevent this from happening to any other family ever again.

And we created the Elijah Alavi Foundation, named in honor of him and in memory of them, to work on advocacy, education and awareness and policy change across the nation.

You know, we capture that by just working with so many people here today. So it's very impressive. Do you know how many states you guys have been able to get the policy changes in?

Yeah. So we started off with the advocacy efforts in New York state. And on September 12, 2019, we enacted our first law called Elijah's Law, which was named after my son Elijah.

It was a mandated law in new York State, and it just created a precedence of how things should be done within every child care center, not just in your but across the nation.

Then we had a bill that was passed in Illinois, Virginia. That was three bills that we have at the time. We got a city ordinance in Kansas City. we also have a component of Elijah's law attached to an epinephrine bill in Connecticut.

And we just passed a law in Maryland, I believe, about a week or two ago. So you could say about four or five around that time, It all sounds great. Yeah, we've got these laws passed, but there's so much work behind it that needs to be done in order for it to fulfill everything that is said within the legislation.

Yeah, so you got to get the education, the signs and the symptoms, which Dr. Lenore can talk about of anaphylaxis. And then also, of course, how to administer, because some people are like, well, what do you mean?

You know, epinephrine autoinjector, or how does it work? That and, you know just having that you guys had an. Before we go too far into the discussion of the laws, tell us a little bit more about your son.

about Elijah? Oh, man. And then how he was diagnosed, presented with his allergies and how was he diagnosed. So I have another son named Sebastian. He was, he's my first one.

he has multiple food allergies as well. He started being affected by his food allergies at a very young age, which he was rejecting his mother's breast milk.

Then soon on, every food introduction that was given to him, he had an emergency reaction to. On top of that, you can't diagnose asthma at an early age.

So it was undiagnosed respiratory disorder. Him having the unddiagnose respiratory disorders, the food allergy, and we know how food and the respiratory disorders just come hand in hand.

And it creates that ticking time bomb of we don't want to experience. So he had several anaphylactic reactions over time, which a scary thing is to administer epinephrine.

But to talk about my son, Elijah, we'll be talking about how beautiful the sky is, how bright the sun is how green the grass is. That's how he was. And I love everything about him, what he embodied, and what we tend to continue giving back to our community because of his vibrant energy is what want to give back.

And knowing that he had multiple food allergies and asthma at the time was we had to make sure everything was, he was like protected. Unfortunately, it happens to you.

It happens too many African American children. How did you finally make the diagnosis of what he was actually allergic to? So the diagnoses, I mean, also I have food allergies as well.

But again, when we talk about food allergy, we went to his primary care physician. And at that time, you go to the ER for the first experience, and then it was like, okay, we'll go talk to your primary care physician.

Nothing was really given to us to follow through on what he was experiencing, so we had to go through the primary position. We are living in Harlem, middle-class family, but an underserved community.

So a lot of the information is not privy to us, so we have to go outside of our insurance network in order to retrieve that information. So paying out of pocket to see an allergist to determine what type of food my son, Elijah, was allergic to.

Elijah was alerted to multiples, I think a little over 10 allergens. And one of them being dairy on the high note was one that was severe. It was dairy, eggs, peanuts.

And a couple of the garlic onion goes on. So when we we talk about, you know, when it comes to that community and black children are. with food allergies faced like, you know, dealing with that in the community is like they're faced with severe, unique challenges.

And first of all, most they are often lack of awareness and understanding about food, allergies in these communities, which means severe delay diagnosis.

and a lot of these kids go to the primary care positions or ER with these undiagnosed conditions from either it can be like their stomach or other respiratory issues being diagnosed differently.

Policy Wins and the Need for Better Allergy Education

So it's like And I talk about this all the time, it's like not having the access of food allergy management and healthcare access is a big part on, especially when you're talking about young Black children or specific communities.

Yeah, because not a lot of people know that you should take your child to an allergist to get them diagnosed for the allergies. They have no idea. And so I'm glad that were able to at least, you know, do that.

But unfortunately, there's just not enough allergies to go around. Not enough black allergies just to around and unfortunately primary care physicians, the pediatrician, They don't have allergy tests to administer.

So how would you get to this diagnosis? It's kind of paradoxical because we live in 125th and Lennox for 25 years. Oh, wow. And Harlem Hospital had one of the best black allergists in the country.

And he was in charge of both pediatric section. The problem is that the symptoms of food allergy and the sophisticated way in which you have to hone down on it is just not a sense of awareness within our community.

And I think that And that's one of the things, obviously, that you were up against. Yeah, correct. And I was like, I'm an educated man. At the time, it was very educated.

We both made sure, not just in terms of education academically, but we educated ourselves. we had to educate ourselves on food allergies and asthma. Weren't given the resources.

Here's the communities to reach out to, to give you the information and understanding. So we felt alone. You know, it was like we felt alone and we feel like who else has food allergies.

It was hard to find that that kind of like niche. Yeah, he wasn't into my son passed away where the floodgates open and everybody was coming in and I was They do exist, unfortunately, is using that term, but the food allergy community does exist.

But one thing that doesn't really exist is a very short community when it comes to Black families with food allergies or asthma. It's because of the prevalence of it.

Although we are at higher rate of having food analogies in Arizona, based off the communities we live in and so forth, and socioeconomic conditions, it's not talked about.

you know, the community is not talked about. So it's like, we were being open about it, but we couldn't find that connection. Dealing with our primary care physician and analogist is like a one and done.

You have to keep, keep coming back. And then it stresses out financial, you So naphram, allergies, medications, like it's, I don't know. I can call it a cluster.

Well, your frustration is shared by many, many parents. Like I said, as a black allergist, see children who are on the cusp of very serious problems like you have.

And the problem is that the primary care doc, for a number of different reasons, sees our symptoms somewhat differently. I'm not saying that they would selectively select symptoms for white children than for Black, but there's a certain thing called lunch-conscious bias.

And if you don't have the resources within the community, then the diagnosis is relatively uncomplicated to make, because it does require a number of things we'll talk about in just a minute.

But tell us a little bit about your focus on epinephrine, because that's really where the rubber reaches the road in trying to save Black children and other children with serious food allergies and anaphylaxis.

I think the focus of epinephrine when it comes to you talking about the Black community or any like underserved community, what comes down to the financial burden of it?

Because you have Black families, and I've done community work where A mom will come up to me and be like, hey, I have three children with food allergies, but only could afford a pack of them, a set of epinephrine.

So they have to give one to the school and keep one in their pocket. Now you gotta look at the ethical standard considerations in the event of, imagine two child's having an anaphylaxis, you only have one eponephrin.

Who are you gonna save first? So you look those ethical standards, that messes with a parent's psyche. That's pretty serious. With us, Dealing with that cost is like, I'm lucky there are laws being passed currently that are capping epinephrine, but it's still a financial burden if you can't afford it, whether it was $50 or $100. Right, or 600 or whatever.

Yeah. It's, it still financial burning for the specific communities. If you don't have the money to get to your doctor's appointment, you do have to have money get your eponephrin.

And that's why it is, like unless they make eponephrine free, For one, I know under certain insurance, you can get the epinephrine for free, but you're, can't get it multiple times.

You can only get at that moment and then possibly for that other refill to come in and so forth before you could get again. But then you leave the vulnerability open when it comes to your kids being in school or a kid being at home and someone, God forbid if anyone has an allergic reaction and go into an anaphylactic shock.

So how is an epinephrine administered? My focus is, like, hopefully there can be an understanding where they don't, you know, have any financial burdens where epinephrine can accessible for free, even possibly over the counter, where it's at cost, which is not, it is going to, spend so much money on that.

But it all comes into legislation. In order for us to make things happen, we have to change legislation, and it, a daunting type situation, but it daunting, cumbersome, I know in due time it can happen.

So there is an EpiPen Act that, last week when I was in DC, that's one of the bills that we were working on. And it's Epipen, I always have to tell people, Epepen is actually a brand.

It's an epinephrine autoinjector because I actually have Avacue. But EpiPen Act is actually an acronym, can't remember what it stands for, but that act is to get it so that it's capped at $60. And so hopefully that will pass.

But these things seem to take a very long time because last year we were talking about a bill that we we're talking again this year. These things take time, unfortunately.

There is an act that is trying to cap it at $60, which is still not cheap, but it's better than in the hundreds. It's interesting because when it comes to anything in terms of legislation, it all comes down to the financial implications.

Who's going to pay for it? When you talk about getting access to epinephrine, you're capping it. But I may be speaking out of the scope of my own practice, the big pharmaceutical is going have lobbyists to push against that.

That happens all the time. in any type of legislation when it comes to medication. So they can make the voluntary considerations, but it's not enacted.

Those are the things we have to look at. That's why some bills sit in legislation or in Congress, because it is like, I don't know, who is going to take on the burden of the cost?

When I look at that even with my own legislation, even though it's a simple bill, but the financial implications still will hinder within it. Yeah, we're going to educate these people.

Recently, two pharmaceutical companies did cap the cost of inhalers, so that is what gives me a ounce of hope. because when one did it, then a second one came.

And then, you know, so hopefully, and these are, mostly they're rescue inhalers, which is extremely important to an asthmatic. So that is a wonderful thing because those can cost hundreds of dollars for some people as well.

I am very hopeful that this EpiPen Act will go through. But I also, Dr. Lenore Thomas has a new thing that I wanted him to talk about as we talk, about inhaler.

Can you tell us about that? So, you know, our organization also focuses on not just food allergies, but also asthma education and awareness because of my son, Elijah, also having asthma.

So we started a new initiative called Happy Halers, which I can actually show you right here. This is one of the Happy Hales. What it does, it's a cover that goes over one of the inhalers here.

Diagnosis Challenges and Access to Allergy Care

And it kind of like gives children like a peace of mind and feel comfortable walking around or using their inhaler. So it actually has it where it can actually, you can fit a spacer on it.

You can use it or play with it for right now. For happy halers, we actually got so much information that we had to put everything coming soon because now we're like, everything kind got put out already so quickly.

Now we have to wait to rebuild on that. So it's one of our new initiative. We want to focus on asthma education and awareness. You know, it is one the key things that we want focus.

Well, you know unfortunately, time for this segment is up, but I think we've covered enough in the first segment of my program to make this a more complete situation.

I do promise you that the African American Wellness Project through all of the platforms that have will be a friend to you and will try to amplify not only your message, but the other things that you're doing, both for asthma and anaphylaxis.

So thank you very much for the time you've taken with us. And thank Dr. Renee for once again, having Mr. Silvera with this. For those of you who are listening to our podcast, remember what we talked about here.

If your children are having these kinds of symptoms, then find out a certified allergist who can help you with these problems or contact us at the African American Wellness Project at aawellnessproject.org.

And always remember health is your biggest asset, so protect it. Okay, now we'll go back and do the first part of the show. Okay, the first part of the show is a bit more didactic.

We're gonna ask you about your son's, what happened to your sun. When I ask about what he, and you can ask with me, Dr. Rene, when I asked about he finally was allergic to.

I'm gonna to ask him about the trouble that you had getting proper evaluations and management. And then we're going to talk a little bit about how food allergies are diagnosed today as opposed to they weren't even five or six years ago.

So let's start the second. You know, so the first program would be the 2nd. All right, let me go back to the introduction again. All right, welcome to today's edition of Black Doctor Speaks, the podcast where complexities of issues that impact the African-American community are discussed.

Our subject today is food allergy, something that African Americans and Black Americans really don't encounter much in terms of an accurate diagnosis.

We have too many of our children with clear symptoms of food allergies that are not managed properly, they're not evaluated even. And I'm getting too wordy.

Let me start again. Welcome to today's edition of Black Doctor Speaks. My host Dr. Renee and I are here to explore complexities of issues that impact the Black community.

Today we're talking about food allergy, something that the black community simply does not seem to be able to, let me try one more time. Welcome to today's edition of Black Doctors Speak.

We're one of your hosts, Dr. Michael Norton, with my co-host Dr Renee. Today we're talking about food allergies. As you know in Black Doctor Speak, we try to talk about our issues, in fact, all children and adults, but how they uniquely impact the Black community because our experience is always different.

I'm gonna turn it over to Dr. Renee who's going to talk to Mr. Thomas Silvera about the experience we had with his child. And then we'll talk about food allergy in general and what's being done in this day and age is different from when he had his experience.

Dr Renee, it's your turn. Yes, so Thomas Silveira, please share with us your story on how food allergies affected your family. Yeah, no, absolutely. So my name is Thomas Silver.

I am the co-founder of the Elijah Levy Foundation. To give you a little bit of my story, my son Elijah was such a vibrant, loving boy. Like many parents, myself and his mom, we entrusted in his childcare center, believing that they would provide a safe and inertial environment for him.

But unfortunately, my son had come to his demise on November 3rd, 2017. Elijah had a severe derealogy, which was well documented and communicated with the child care center.

And one day, despite all the clear instructions and the precautions, he was given a grilled cheese sandwich by an educator. This seemingly simple preventative led to him having a allergic reaction.

And what hurts and what is very deep is that the child care staff failed to recognize the signs or symptoms of his anaphylaxis and did not administer epinephrine or call the parent or his mother or called 911. And by that time, he was taken to a local hospital in Harlem where it was too late and we lost our precious son.

So what was the… Oh, go ahead. No, no, it's okay. Okay. How was he diagnosed and what were the hurdles you faced along the way with the diagnosis? So, He was diagnosed probably not until almost close to one years of age.

Over time we, upon discovery with him, not be able to ingest his mom's breast milk. He was being lethargic from that, and we understood there was something was wrong.

And over time, even introducing him to certain foods, he was having a simple allergic reaction. Then, knowing that we had to administer epinephrine using his brother's epinedephrine to minister him.

So taking him the emergency room, the room was like, oh, you may have an allergic reactions. Using a term, may having an allergy reaction, which is kind of odd for us.

But luckily we are parents who also, I also suffer with food allergies and also asthma. And so does his mom. So we took him, you know, we follow up with the primary care physician and it was like, okay, here's an epinephrine.

We'll see you later. There was the communication aspects weren't there. When we talk about food allergy management and access to healthcare, it wasn't really given to us the way we wanted it.

it took us to try to go o sure his carrier and pay a specialist. And that's wh all the skin testing um to determine what he wa And so there was, I just wasn't an allergist in yo The doctor didn't really inform us on where to go to get the allergens.

We had to do our due diligence and utilize search engines in order to find our own allergists. And we were able to found one not that far, but we had it come out of pocket from our insurance to pay for that.

Yeah, that to me is a little unusual to have.

Understanding Anaphylaxis and Epinephrine Use

an insurance policy that doesn't have access to an allergist, but we see all too often that primary care doctors don't really appreciate the danger that certain foods cause to children.

You know, I've been an allergies now for 40 years and there's never been analogies near me within a hundred 50 miles of me and a Black allergist. And so when you don't have a black position in the community, we're not the only ones that can do a good job.

But that community suffers because of lack of interaction between the allerogist and the primary care doctors and for patients themselves. what should have happened and what would happen in this day and age.

And I think it's important, and I know it is not a good trip down memory lane, but I do think that it was important for parents to understand if their children are in a similar situation, is that they should've done some evaluations, not only the skin test, probably some challenge tests as well, to really define what your son was reacting to.

There was a time when I first started in practice, I don't want to date myself, when we used to feed at three to four weeks of age. I mean, we didn't really have any trouble with that.

But then the American Academy of Pediatrics said, OK, let's just watch this and let us wait six months. Well, now we know that if you've got a child who has an allergy, food allergy in the history, it's better to see them early than late.

before the age of nine months because it can change the immune system at that particular point in time. Once that situ diagnosis is made with the exquisite sensitivity Yosun has, we would start a process of desensitization.

And what that means is coming to the office for quite a long time, taking little bits of food under controlled circumstances where the doctor can handle anaphylaxis and then gradually getting him to the point where he can tolerate small portions and sometimes larger portions of that food.

In addition, for older children, There are now a couple of drugs that we can give. The newest study in the New England Journal in last couple months suggested that using Zolair on a regular basis will reduce food allergies and certainly can reduce allergy sensitivities.

One of the bigger problems we're seeing as we move more quickly to biologics, then we are starting to find that African-Americans are not getting these biologists.

So I think that there's lots of things that could have been done that weren't done. And I make what we hope is with the message that we're getting now from you today, then other black families will understand the danger they face with undiagnosed symptoms.

Now, you want to say something about what your foundation does. We're going to deal a lot with that in our next segment, but tell us a little bit about your Foundation and how the successes that you've had.

Yeah, absolutely. So we started the Elijah Alavi Foundation in honor and memory of my son, Elijah, who, you know, tragically passed through the food allergies.

Um, so in 2018, we launched out the organization and we've been working diligently, grassroots rooting and tirelessly. Even in our grief, um, We were able to push through and work in advocacy and passive legislations in New York.

in Illinois, Virginia, Connecticut, Maryland, and we also have several legislations in the pipeline as well. But we don't just focus on legislation, we focus more on awareness, on food allergy training, community advocacy, our main goal is to make sure we can try to focus in underserved communities and give them the information that is not privy to them.

So, you know, it's one of the things that's our main focus, because we've lived in those communities, we were raised in these communities. And I understand the health disparities and the lack of health access is not given to us.

So it is unfortunate that we have to go outside of our own communities in order to receive the information when it should be given automatically, but it isn't.

So within the organization, it's our mission. It's how it driving force that ignited us. What happened with my son is to create change, not on a local level, but on the national level.

Not just an advocacy, Well, I think that's very much needed, as I said, any of the people who we talk to in situations like this. The African American Wellness Project lives to support projects like yours and to try to amplify exposure that your foundation gets and hopefully other children will not suffer the way that you do.

Well I, think your story is so compelling that it's bound to really help. as many people as we are able to reach. Dr. Rene, you got any final words for this segment?

No, I just wanted you to explain anaphylaxis, but… Okay, no, let's talk about it. Well, when you have an allergy problem, It's really not an immune deficiency, it's an excess immune response.

And what happens is the body makes a chemical to a particular food, usually it is of a class called IgE where they two connect the antibody and the food let's say for milk.

When that happens, there are cells in the blood called mast cells and those mast cell release chemicals, one of the major. chemical being histamine, there are probably others.

Histamine has several impacts on the body. It causes the vessels to swell, causes vessels leak fluid, and causes airways to close down. And if it happens all over the bodies, probably the first symptom is abdominal pain in many instances.

Because there's many more arteries and vessels in the abdomen. that close down first and constrict.

Asthma Awareness, Inhaler Access, and Closing Remarks

But then that goes on in a cascade to have a skin problem, gastrointestinal problems, respiratory problems and then central nervous system issues. What most people don't realize about anaphylaxis, is that the most dangerous thing is the third spacing of fluid.

Because once the fluid starts spacing, the blood pressure drops and it's very difficult to intercede at that point finding a vein or a vessel to use. Only drug, the only drug that should be considered in any evidence of anaphylaxis is epinephrine.

No benadryl, no steroids, none of that. I can't tell you how many children have gotten into trouble because

benedryal was the first drug of choice. We all focus on epimorphine is a very vital piece of anything we have to say about food allergy.

And so ananphylaxes doesn't occur that often. But if you have a child who has that kind of problem, then everybody has to be involved. in the discussion of what to do if something happens.

Because if you're challenged from a cheese sandwich, think of when it happens when a child gets a glass of milk or gets an egg or a drug. And so consequently, I've been in those situations where you try to establish the intravascular volume, and that's the most dangerous piece.

You deal with the respiratory pieces, you deal the little skin pieces. But once those vessels start to leak, that when you have a real problem. So the use of epinephrine and your foundation's focus on that, both nationally and legislatively, is so critical.

And we thank you for your efforts, and we're sorry for you loss. Definitely. You get that last one. One last thing is that unfortunately, many people do not know what dairy is.

I will tell you that a few years ago, I was one of those people because I know I couldn't have eggs. Don't laugh at me, but people don't realize what dairy is.

And so I've heard this many times. People are at a restaurant and they tell the waitress, I have a dairy allergy, and then she recommends something with cheese.

So that's the other thing is that education needs to be across the board. The lunch ladies, the weight staff, everyone needs understand exactly what categories of foods contain what.

Absolutely. I think it's one of the key things is like addressing these challenges requires a multifaceted approach in terms of education and awareness.

It's like if we need to educate parents, caregivers, and community members about the series of food allergies and the importance of early diagnosis and proper management, that's what we needs to do.

Well, thank you for taking the time, Dr. Silvera and Dr Renee. Thank you joining me. each week on the Black Doctors Speak podcast, and thank those of you who have taken the time to listen and spread the word to come back to the podcast and have them listen, especially if they have symptoms like we described.

Always remember that our website is www. AAWellnessProject.org. AAWellessProjec. Org, Mr. Silvering, you're not a very good promoter of your own foundation.

What is your website? So if you want to find out more about the Elijah Alavi Foundation, you can go to www.elijahalavi.org, where you get to know everything that we're doing in terms of legislation, education, and awareness.

And to those of you taking the time to listen, always remember, it sounds kind of corny, but health is your biggest asset, so protect it. We'll talk again next week.

Okay, so that gives us two programs.