

EPISODE 22: A REAL DIABETES PARENT'S STORY

Rita Kalyani, MD : Welcome to *Diabetes Deconstructed*, a podcast for people interested in learning more about diabetes. I'm your host Dr. Rita Kalyani at Johns Hopkins. We develop this podcast as a companion to our Patient Guide to Diabetes website. If you want a trusted and easy to understand resource for diabetes or to listen to previous podcasts, please visit hopkinsdiabetesinfo.org. Today, we are thrilled to welcome Kim Vaughn, a certified registered nurse practitioner in the Division of Endocrinology, Diabetes and Metabolism at Johns Hopkins. Kim's daughter was diagnosed at an early age with Type 1 diabetes and Kim had to learn firsthand some of the challenges and rewards of parenting a child with diabetes. Today, she'll be sharing her experiences being a caregiver for a child with diabetes. Welcome to the podcast, Kim.

Kim Vaughn, CNRP : Thank you. I'm glad to be here.

RK: We're so fortunate to have you here on the podcast today and to have you share your experiences of what it's been like to parent a child with diabetes. I wonder if we could start off by perhaps talking about when your daughter was diagnosed and how you knew that she had diabetes.

KV: There were a couple of warning signs for us. She was three and a half years old and started to lose weight. She had multiple mosquito bites on her legs. And I had just brought home our third child who was a preemie and I had to feed her quite regularly. I would sit down to feed the baby, have given her a drink of water, milk, or juice, and within five minutes, she's screeching that she was thirsty. And she had been completely potty trained at the time and started bedwetting again.

RK: So the symptoms of frequent urination. It sounds like she was urinating overnight when she'd already been trained not to do that and then feeling thirsty a lot sounds like things that were out of the ordinary. What did you do after you noticed those symptoms?

KV: I actually called my pediatrician and said that I didn't want to say what I thought it was, but that I wanted to bring her in and have her checked for a urinary tract infection. And unfortunately, that morning when we went in, I had given her cereal and chocolate milk for breakfast and her blood sugar was 814 on diagnosis with small ketones. So we got very lucky there.

RK: Did you suspect that she might have diabetes up until that point at all?

KV: Oh, yeah, it was in the back of my mind. I was worried that that's what it was going to be. You know, like anything, any parent, you hope for the best outcome. And you know, we just wanted to put that out of our minds, that this is what it was.

RK: And with your healthcare background, you probably were familiar with some of the symptoms, is that right?

KV: Yes.

RK: And then having seen the pediatrician very soon after noticing the symptoms, and as you mentioned, only having a small amount of ketones even though sugar was quite high. I'm sure was helpful for the early diagnosis. Just for our listeners, the ketones are acids that are produced as a by-product when the body can't metabolize carbohydrates and breaks down fat. As a result, you can have what we call diabetic ketoacidosis, which is not uncommon when patients are diagnosed with Type 1 diabetes. It sounds like your daughter was pretty fortunate that the ketones were not that high. Did she have to be hospitalized?

KV: Yes, we spent about five days on a pediatric unit. And we met with the diabetes educator, and of course, our pediatrician was managing her diabetes at that point in time. And upon discharge, we were set up with follow up at Hopkins Pediatric Endocrine Clinic.

RK: Even though you had background in healthcare and were familiar with the disease, I'm sure it was quite a shock when she was diagnosed. What was your reaction? And what was your family's reaction when you found out the diagnosis?

KV: I had both [of] my other children with me and we left the pediatrician's office with the orders to be at the hospital within two hours. I went immediately to my husband's place of work and said, "Look, this is what's going on. She has type one diabetes." I think we were both a little bit in shock. But I just said to him, "You know what, this is better than some other things. She can live with this. We're just going to have to learn how to take care of her."

RK: I like how you mentioned learning how to adapt really to this new diagnosis and adjusting to the demands that it might require, particularly from an early age, in her being so young. Did you have a family history at all of diabetes?

KV: Not of Type 1. My father and my sister and my husband's father had type two diabetes. But no, there was no history of Type 1 diabetes going back a couple of generations, that we were aware of.

RK: And just to give our listeners a sense of how long ago this was, would you mind sharing how old your daughter is now?

KV: She is 32 [years old]. Both of her children right now do not have diabetes at this point.

RK: That's wonderful. And it's wonderful that she's done so well for the past three decades. But I imagine when she was diagnosed, there wasn't the same availability of technology that we have today. What was it like managing her diabetes in the early days?

KV: It was variable. You know, we could be playing and having fun [then] all of a sudden, she would become lethargic and not feel well, and we kind of knew that her blood sugar was low at that point in time. So we would check and she would drink juice, and we'd bring it back up. We did initially NPH (neutral protamine hagedorn) and regular insulin, which was what was available at that time. And then at some point, we switched from NPH to ultralente [insulin]. With that, we had a couple of episodes where I ended up having to take her back to the hospital because I just couldn't get the hypoglycemia to resolve with oral treatment.

RK: So the NPH and regular are human insulins are still available today. The ultralente is no longer available. It was a longer-acting insulin available at that time. Now we have insulin glargine and also degludec, which are the long-acting insulins. But hypoglycemia, as you mentioned, is often one of the limiting steps to increasing insulin doses, you know, the onset of low blood glucose that can sometimes really limit how we push the dose up. How did you learn how to deal with situations like that? When the sugars were low? Did you know, with your daughter being so young, did you as a parent have too much of that treatment? Or how did your daughter adapt to the diabetes management plan?

KV: You know, as a three-year-old, she's basically coming out of being a toddler. Like most toddlers, we invested in every pretty girly Band-Aid out there, because every time we did a finger stick, we had to put a Band-Aid on. So you know, that was one of her ways of dealing with things. The other thing is that whenever we would have company over, she wanted to be the "hostess with the mostest." So she would carry around the food and try and feed everybody and always said she wanted to be a doctor who cooked for her patients when she was that age. She's actually a preschool teacher now. [laughter]

RK: That's so great. Well, it sounds like she adjusted, although I'm sure it took some time. What about the insulin injections? Did you do most of those until a certain age or?

KV: Yes, we did. We did most of the injections until she was about eight [years old]. When she was eight, she switched over to an insulin pump. She was one of the youngest patients that Dr. Plotnick had put on a pump. She and my girlfriend's son, who was also diagnosed at a young age, went into the unit and had their insulin pumps placed when they were eight and seven [years old]. And she wore that pump until she was about 16 [years old]. That helped. The original pump she didn't mind. The second pump that we got after that one, went out of warranty, and she didn't like [it] so she wanted to switch back to insulin injections. And at that point, we had Lantus and aspart, so that worked.

RK: Well, that's great that she was able to try the pump at such an early age. How did she do with the injections? Did she have a fear of needles at all? Was she pretty comfortable with taking the injections? How did she respond?

KV: Because she was so young. She doesn't remember a time [of] not having to take needles. At that point in time, she was amazing because she was that kid that she'd hold out her finger and we do the finger stick and she'd roll over and we'd give her the shot in her bottom. She never, ever, you know, ran away, screamed, or cried. She's just as tough as nails when it comes to things like that, [her] pain tolerance is very high.

RK: That's great. Well, it sounds like she adjusted really well from an early age. And I'm sure that having other children, as you mentioned you had two other children, also made it challenging. You had other children to take care of. How did they respond to having a sibling with diabetes?

KV: I think for a while my son, [who] is three years older than her, for a while, I think that he went through some adjustment period. And he started acting out a bit. You know, he was six and she was three and there were things that, I had to make sure that once I got her to bed and my infant to bed that I would go in and we would read together in the evening. That sort of helped with that, but it was a journey. It wasn't like everything was perfect all at once. It's funny, because in the beginning, it was very cathartic to be able to talk about things and share with other people. Incidentally, since that time, I have met so many people. I have two close friends who have children with Type 1 diabetes. Harley was the first, but then my girlfriend Kathy, her son was diagnosed and then my friend Mark, his son was diagnosed at 16. It was like why is this cluster happening? [laughter]

RK: So we were talking about how your children responded. Did your other children have a role in helping your daughter manage her diabetes? How did they support her?

KV: Well, Kelly was an infant. She grew up only knowing Carly having diabetes. Kelly was born on May 28th and Carly was diagnosed like July 10th. So she knew nothing about Carly having diabetes. Lee, I'm thinking back, I really don't think we put a lot of responsibility on him for helping with taking care of her. We all adjusted how we were eating at home. I no longer made big pancake breakfast with bacon and sausage on Sundays anymore. We did that on Christmas day, instead of once a week. That was a treat. We adjusted as far as [for example] they would go trick or treating, because we did let her do things like that. We had her pick out like 10 candies that she wanted and then my husband would take the rest to work and [we] did that with all of them in the beginning. That's what they knew, and I tried to treat everybody evenly.

RK: Well, I think as you say, it takes an adjustment from the family too. And everybody, you know, working together, but allowing those instances where she could still have those Halloween candies or the pancake breakfast. We often don't say restrict those carbohydrates but moderate them. Where did your family learn about the dietary recommendations for diabetes? How did you learn how to adjust the diet?

KV: At that time, when she was first diagnosed, the diabetes educator came into the hospital and provided a good bit of education[al] information verbally. But then, they also gave me a book on diabetes and they gave me a book from American Diabetes Association (ADA) on the diet that was [recommended] at the time. Everything was very structured at that point in time. I knew that every morning she had to have a milk and a protein and another carbohydrate for breakfast. For lunch she had to have a half a fruit and two carb servings and some sort of protein. And this is a kid who never ate sandwiches. So, she went to school every day with half an apple and six Ritz crackers with peanut butter on them. She ate that every day for lunch, for years. Even though the daycare provided lunch and snacks for us, we chose to still take her lunch in for her. If

they were having something she wanted, they would check with me and I would let her have that. But we had to make sure it was the right serving size.

RK: Well you mentioned the school setting, I imagine once she was old enough to attend school that brought upon different challenges. How did the schools accommodate some of these changes or adjustments that were needed for her and the medication doses too?

KV: We were very lucky. We had a two building Elementary School. And we had an RN at one school one and LPN at the other. We worked with them in the summer, you know, before school started. I had what we call her diabetes kit: I had a glucometer in there, with test strips; I had extra insulin that they kept in the refrigerator in case it was needed; I sent in four-ounce juice boxes and peanut butter crackers were in there. Just extra supplies. When she finally went on the pump, we had extra pump supplies, we kind of worked things out ahead of time to try and prevent anything. I tried to address any potential complications that could happen. I also was able to meet with the teachers. They would say whether or not they were comfortable with this, and most of her teachers were comfortable with taking care of her. And it's funny because all three of my children had the same second grade teachers. That worked out very well. Field trips - I would go on field trips because my friend Kathy, we always had the kids in the same class together, and Kathy was a stay-at-home mom at the time. So, she would do the class parties, so that she could regulate what was going onto their plates for that and I would do the field trips. That worked out well.

RK: So your friend Kathy also had a child with diabetes as well?

KV: Yes.

RK: Well, that's great that it worked out that you can both support each other and that you were so proactive. Also in ensuring that the accommodations whatever was needed for your children was made. Are there any unexpected challenges that occurred during the school days, or were things pretty smooth, for the most part?

KV: For the most part, they were pretty smooth. But with diabetes, you can't always predict every little minute. And of course, you know, we'd get a call once in a while that her pump battery died or they had to give her a couple of extra units at lunchtime, because her number was so high. So as far as the school goes, they were very efficient and we felt very comfortable with the children being there. There were always unseen episodes; she would wake up in the morning and have ketones because her pump got kicked off in the middle of the night. And so, we would have to take her to school a couple of hours late, instead of on time. So those things happened.

RK: Well, I imagine those kind of kinks, literally and figuratively got worked out, you know, during the early elementary school years. As she got older and perhaps took a more active role in her diabetes management, how did that transition occur and how did you facilitate that?

KV: Well, that's where we had the biggest challenges because she would not want us to know what her numbers were. She would sneak food. In a lot of ways, I equated it to being a typical teenager and her acting out was using her diabetes, or, you know, addressing her diabetes in not so healthy ways.

RK: So she knew how to push all the buttons, it sounds like. [laughter]

KV: Yes. [laughter]

RK: And then at what point did she really take ownership of her diabetes management? And really, do you feel kind of matured in the ability to manage her diabetes or you felt comfortable having her do it on her own?

KV:

I guess she was. . . when she was in high school, I was back at work full time. My husband was the full-time caregiver at that point in time. He had his own private business but was able to be there for the kids. And we'd take her to her endocrine appointments at that point in time. And I would say when she left for college, we thought she was ready to go and able to manage her diabetes at that point in time.

RK: That's great. Well, it sounds like it was good timing too because I imagine you're going off to college is a time of greater independence. And so having that facility and feeling comfortable at that time, I'm sure was a great thing. At what point did she transition to adult care/adult endocrinology care?

KV: So at 18, she transitioned to an endocrinologist who worked at Hopkins and saw young adults that were transitioning out of the pediatric program and she saw him for about three years. And then he moved away. Since then, at that point in time, she transitioned to an endocrinologist in Harford County and saw her for several years until she moved to New Jersey. And she has an endocrinologist at that university in New Jersey now.

RK: Did you notice any contrasts and the way that the diabetes was managed by the pediatric team versus the adult team?

KV: You know, I think that there was a lot more responsibility placed on Carly when she started seeing an adult endocrinologist. We weren't allowed to know what was going on, but she was accepting care for herself at that point in time.

RK: Got it. That makes sense that more of the onus would be put on her, as an individual with diabetes, as she grew older, as an adult. How did you see your role as a caregiver change from the time she was a toddler to the time that she was independent enough to go away to college and manage diabetes on her own?

KV: So it was evolving, you know, like I said, when she was very little, we did most of the hands on care ourselves. Having a very young child, it is totally different than taking care of an adult. I mean, the quantity of insulin that she would receive, we would go up by quarter unit, not by whole units, but quarter unit. By the time she was in high school, we were allowing her to buy lunch at school, taking more ownership. She would have to go to the nurse in the middle of the day and because at that point, she was on Lantus and Novalog and had to actually take insulin for her meals, at that point, when she stopped wearing the pump. And then when she went away to college, she had to let us know when we needed to reorder her medications, and sometimes that fell by the wayside. So you know, there were episodes where "Mom, I'm out of insulin. What can you do this? Can you do that?" And so I transitioned to be like her co-pilot instead of the pilot at that point in time.

RK: It sounds like it was a learning curve for everyone.

KV: Absolutely.

RK: Do you think that the diabetes held her back in any way from doing what she wanted to do? Whether when she was younger or even now that she's older?

KV: I don't. You know, she played sports all the way through. She did recreational sports in elementary school and then she rode horses in high school and in college she played lacrosse. So I think that it did not hold her back, as far as doing things that she wanted to do and that she was interested in.

RK: That's great to hear. Do you think that the attention to diet and healthy behaviors had an impact on her too, in terms of a positive impact?

KV: Till this day she tries very hard to eat healthy. It seems like she'll have lows and then she's got her head stuck in the refrigerator until that low goes away. And as a diabetes provider myself, I try not to be overbearing, but I'm like "Carly, just 15 grams right now. Wait, wait, wait" when I'm around and this happens. But she feels so shaky and terrible that she'll drink an entire, 12-ounce ginger ale before she feels better. And then she's [at] 200.

RK: Well, you know, I can understand the kind of the immediate urgency, feeling like you have to get your sugars up. And then we see this all the time clinically, as you mentioned too, the kind of swings that can occur after the hypoglycemia. And they continue to be something I think that we work through. But it's great to hear that she has you as a parent and also as a diabetes educator to give us some insights into that. I was wondering if you might talk a little bit about the role of your support system. When she was younger, did you have neighbors, friends, family that helped support you in managing a child with diabetes? Did you know others? You mentioned one friend who had a child with diabetes. Did you find support in that way too? It'd be great to hear some of your experiences.

KV: Yeah, ironically, you know, after Carly was diagnosed, all my friends were like bringing dinners over to me and trying to, take some burden off of me. My one friend Kathy, who the irony is, her son was diagnosed a year after Carly, was the one who came to me and said, "teach me how to do her finger stick. Show me what I need. How to feed her. Teach me how to give her an insulin injection. So if you need somebody to take care of her on a day here and there, I'm here for you." I had Cathy and then we both joined a diabetes support group for Type 1 diabetics. It was a group of parents and we would meet once a month and have different talks or different lectures or just have a get-together. We went to the Orioles game one time as a group. And Carly got lucky and was able to present one of the Orioles with an award of appreciation for all of his work with the JDRF. And we would go and do the annual walk at the zoo together. Not long after, Carly and Andrew were diagnosed, our friend Mark's son was diagnosed but he was an adolescent. And then, you just hear about all these people whose children, you know, on the periphery that they're being diagnosed with Type 1 diabetes. And while Carly was growing up, I probably met at least 10 other parents who had similar situations.

RK: Well, it's so great to hear the support that you received from your friends and family. That's so critical and so great to have someone who can do your role in case of an emergency. [Someone] who knows how to inject the insulin and knows what to do. Then finding that support group as well, I'm sure it was really great. Did your daughter do any of the diabetes camps? I'm not sure if they were available back then? Or did she find support herself in talking to other children with diabetes?

KV: She did not want to go to sleepover camp. We did go up to Glyndon for a couple of parties up there like for the day but she was not comfortable going to camp. She just didn't want to do that.

RK: It's different for everyone. Could you clarify what Glyndon is?

KV: Camp Glyndon was a diabetes summer camp. That's a sleepover camp that children with Type 1 diabetes could attend usually for a week at a time. So it was nice to be around other children who were experiencing similar issues.

RK: And I'm sure it was great to know that was there for the times when she wanted to go even for the summer parties. And there continue to be camps for children with diabetes offered today. We have one even in Baltimore and there are many around the country. So I'm glad to hear that going to some of those day programs, if you will, were helpful for her. I'm wondering if you can tell us how she's doing now. She's in her 30s . . .

KV: She has two children. Charlotte is almost nine [years old] and then James is a year old. She did have a pretty traumatic birth process with James. Out of that, she has really done very well. She lost close to 50 pounds carrying James and she went into full blown eclampsia with him at the end. He is a thriving nine- month-old. As cute as he can be, he can be very much a nine-month-old. Charlotte is in second grade. Her husband Jake is very supportive. After the birth, she was put on a

continuous glucose monitor and is getting ready to go back on a pump. She's supposed to see her endocrinologist sometime this month and transition to, I believe, it's the Omnipod that they want her to do because of the closed-loop system.

RK: Well, that's great. It sounds like she's doing really well. Does she have any complications from diabetes?

KV: She does not, thankfully. You know when she went in to deliver James, she was in renal failure at that point in time because she was sick for several days beforehand. Then she cardiac arrested during the delivery. But she has no residual heart issues or kidney issues or any cognitive issues. The one thing that she has struggled with [is] she's had hyperlipidemia since she was about 14 [years old] so she has been on Lipitor since then.

RK: So she said high cholesterol since her teenage years. And do they think that was a complication of diabetes or related to her diabetes?

KV: They do. Plus, there's a strong family history. My father had very high cholesterol. All of my siblings, except for I believe one had high cholesterol. I have high cholesterol.

RK: Well, it sounds like she's otherwise been thriving. It's so great to hear that she doesn't have any of those kinds of long-term complications that we usually worry about with diabetes: heart disease or kidney disease or eye disease or nerve damage. And I'm sure how well she's doing now is a testament to how much you did as a parent when she was younger, [during] the transition to independence and how well she's taking care of her diabetes as well. So that's really, really great to hear. I wonder if you have any takeaways that other caregivers or parents might benefit from in terms of advice that you might give them as they face challenges and hopefully successes of helping a loved one manage their diabetes.

KV: Well, I think, first of all, it takes a village, you know. It's not something you can do by yourself. And what I didn't mention before is that my family was very supportive. I have four younger sisters, and they all learned how to help take care of Carly, and they would step in when we needed a babysitter to get away for a little bit. That's one concept - it needs to be family-centered. It can't be that this child is stuck out there by themselves. I think keeping the family as a whole unit and trying to have everybody adapt is important. Some of the things that I think my husband and I did that we've talked about to this day is [that] we were too lenient on some things. We would say, "You can't do this, if you don't clean your room." [Then] it's time to go to the party, she went to the party and her room wasn't clean. And we were like, "Oh well, we don't want her to miss out because you know, she has diabetes." That's not always the best way to be. I would say if you have a rule for one, you have a rule for all.

RK: It goes both ways, right? Well, it sounds like those challenges as a parent with or without diabetes are always there. But it's really great to hear your experiences and advice to other caregivers who might have to encounter some of these challenges as well. If there's one last message that you might want to relay to other parents, what would that be?

KV: I would just say, you know, diabetes is a challenging disease, especially for young children. But it's very livable, and the advances that we've made in the past 15 years have been amazing. And so this is not by any means the worst thing that could ever happen to your child. It does take a lot of dedication and it takes a family to have support around you.

RK: Thanks so much, Kim, for sharing your story of being a parent of a child with diabetes so candidly, and sharing both the challenges and successes, and the reassurance of how well your daughter is doing. I'm sure that would be a great benefit to hear [for] our listeners. And we really thank you for being here on our podcast today. Thank you so much.

KV: Thank you.

RK: I'm Dr. Rita Kalyani, and you've been listening to *Diabetes Deconstructed*, a companion podcast to the Johns Hopkins Patient Guide to Diabetes website. For more information, visit hopkinsdiabetesinfo.org.

We'd love to hear from our listeners. The email address is hopkinsdiabetesinfo@jhmi.org.

Thanks for listening. Be well and see you next time.