EPISODE 19: A REAL PATIENT STORY – LIVING WITH PERIPHERAL ARTERY DISEASE

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 developed 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.

For today's podcast, it is my pleasure to introduce a patient with diabetes, Antonio, who will be sharing his journey living with type 2 diabetes (T2D), particularly focused on the effect of diabetes-related peripheral artery disease (PAD) and its effect on his life. Along with Antonio, we are pleased to welcome Dr. Elizabeth Ratchford, an expert of peripheral artery disease and one of Antonio's care providers. Dr. Ratchford is an Associate Professor of Medicine and the Director of the Johns Hopkins Center for Vascular Medicine. Her research and clinical interests include peripheral artery disease, cardiovascular disease prevention, and fibromuscular dysplasia. Welcome, Antonio and Dr. Ratchford.

Elizabeth Ratchford, MD: Thank you so much. It's a pleasure to be here. I have had the pleasure of knowing Antonio for several years now — I guess about three or so. And I guess to get started, first we can talk about the diabetes, and then maybe that'll lead us to the PAD. They're closely connected.

Antonio, a patient with T2D: Sure, and pleasure for me as well to be part of this program, and hopefully be a little bit of help to those listening to us in understanding the diseases. So talking about diabetes, I was diagnosed probably 10-15 years ago, and it really was totally unexpected. I have no one in my family directly family that has had diabetes. Then there was my annual physical exams. Our family doctor said, "Well, let's do all your panel analysis," do the glucose testing and my A1C came in at about like 7.8 or so, and that was a surprise. I got a call saying, "You know that you're a diabetes person." I didn't. And so I came in and we had a conversation about what to do and what kind of medication I need it. And also started looking at my diet and exercise, seeing how to address the situation. Fortunately, I don't have to take insulin, so that was good. But I've been primarily taking Metformin as the as treatment, and that those have to be kind of calibrated with it, I'm now able to maintain my A1C. It's still not perfect, but I'm hovering around 6.9-7. So it's a much more… much better value.

I started paying a lot more attention to my diet and so no more ice cream and things like those. Also to exercising. The exercise — in which I wasn't doing at all, frankly, — but the exercising became a bit more part of my routine. I just wasn't truly doing it in a very consistent basis. So I do it one day, then go a week without doing it. I just wasn't aware of the disease before and so that really was the situation. So I've been able to keep it controlled in that sense. But I certainly have to start paying a lot more attention to my health, my physical activity, and into my diet. Not that I was doing too many wrong things but certainly I love ice cream, and I like chocolate and all those kinds of things. So I started thinking more about it, you know, "Shall I have another spoon or not? Maybe the answer is no. You need to stop." So it was a learning day when I realized that I had diabetes. The first question I asked is "Can this go

away? Can I take care of it?" And the answer was "No, you are going to have to be careful and take your medication and it's okay, you are going to be fine." But you do have to pay attention to it and be serious about it and follow what your doctor is telling you. So that's how it happened.

ER: So you're somewhat unique in that in some cases, if somebody has a problem with their weight, then that can get rid of or really significantly decrease the diabetes. But in your case, your weight is in the normal range.

A: Yeah, I did lose weight. I was not thin but I was not overweight. And I don't smoke. So I thought that was doing fine until I heard the news.

ER: I think it was several years later… back in maybe 2019 when you first noticed some symptoms in your legs?

A: Yes. So for a number of years — 10 years or so — I dealt with diabetes. Again it was under control. You start coming down the A1c and again I like to see it lower than what it is now which is as I said about seven or so. My doctor keeps saying I need to get to 6.5, but much better. And so I felt fine and was at least taking care the best I could. But as you said about three or so years ago in 2019, I noticed when walking that I started developing pain in my right leg and after walking for a little while I started developing pain. Initially, I thought, "Oh, this must be… maybe I pulled a muscle or something" because I had no other symptoms, whatsoever. So I didn't really pay attention, I just said, "Ah this will go away." But it didn't. And with time, and what I mean [by] time is over several months that I kept it, having that symptom, and nothing else on the other leg, the left leg was fine. But it didn't go away. I noticed that it actually was getting worse. In a period of a few months, three months, four months, I realized that after walking, like for three minutes, two or three minutes, I was now developing that pain, and I had to stop, actually. Take a rest and then I could walk again but then I have to stop and my job does require that I walk. And on campus there are some hills and so on. And so I just felt something is wrong here. So I said this muscle is not being pulled. It's just taking too long to recover.

ER: This brings up a really important point that a lot of people who develop leg symptoms with walking or… it is usually with walking in fact, when it has to do with the circulation… a lot of people will attribute it just to normal aging or arthritis or their back or pulled muscle like you said. I think it's really important for everybody to be aware that if there is discomfort in the legs that comes on with exercise and is relieved with rest, then that really suggests that there's a problem with the circulation. So the symptoms that you're describing are a classic textbook symptoms of what we call claudication. Claudication comes from the Latin word 'claudicare', which means to limp, which is actually named for the Emperor Claudius, who didn't have peripheral artery disease, which is the topic of today, but he actually had cerebral palsy, so he walked with a limp. People will sort of limp as they go along and that's because the muscles are not getting enough oxygen. So when you walk uphill which is what you described, that requires more oxygen delivery to the muscles. And while when you're sitting still, your muscles are getting enough oxygen. If you start to walk, then they need more and if you go up hill, then they need even more.

And that's the perfect description of what we call vascular claudication. And that is due to that peripheral artery disease, which is blockages in the leg arteries, put simply. A lot of people ask, "what is peripheral vascular disease?" or it has a bunch of different names. But years and years ago, when I was in medical school, it was called peripheral vascular disease. But then over time that got changed to… first it was peripheral arterial disease, and then it got changed to peripheral artery disease. So the current proper term is peripheral artery disease. That's because vascular refers to both arteries and veins. Peripheral vascular disease is just not specific enough so the symptoms that you're describing really fit with peripheral artery disease, which is the blockages in the leg arteries. Now that you've described the symptoms, then the next best thing would be to have an ankle brachial index, which is the best test for diagnosing PAD. That's not always the test that gets done, but that's what should be done. It's where you measure the pressures and the ankles and the pressures in the arms and the pressure should get higher as you go down the leg. But in PAD, the pressure actually drops because of the blockage in the arteries. So the blood pressures in the arm should also be equal but you can get blockages in the arteries as well, which is really common in people with PAD. So we measure the ankle pressures and divide that by the arm pressure, which gives us a number for each leg. And that would generally be how the doctors would figure out what the diagnosis is. I'm assuming that that's what happened to you?

A: Yeah, so again, I need to do something about this. So again, I went back to my personal physician and asked her about the symptoms. "You almost have some problems with your cardiovascular circulation in your legs. So I want you to go…" what I think would be a sonogram study. And so she sent me to a clinic somewhere in town where they do these kinds of tests, and then depending on the results, they can do something about it. So I went for that test. And sure enough, the technician who did them for me came out with the results that I have, I believe 60% obstruction or something of that range. And so she said, "Yeah, you need to you need a procedure. This has to be taken care of." I recall that she was telling me that they were already setting up a meeting or a time for me to go in at this procedure. And the tools involved, basically, I call it to go to insert a catheter through my leg and go there and drill away whatever obstacles were there, and maybe there could be a need for a stent and all kinds of things. And I asked the insurance, "Is that a complicated process?" And they said, "No, it's… there are some dangers. But don't worry, we have a hospital nearby. If there are complications, we'll take you to the hospital and they are prepared to take care of any emergencies. " And so I said, "Let me think about this." Because again, I just all suddenly my life was changing in front of me and I was hearing all of these concerns and procedures that I had to go through very quickly. And so I came home, I told my wife what was happening, and we agree that we go for a second opinion on this. And so I called Dr. Sadi, who was our specialist and asked him, "Can you please recommend someone that can go and have the situation analyzed?" And that's where he recommended Dr. Ratchford to me. I was so delighted to have that recommendation, because I really when I went to see you for the first time, I was very scared. I don't get scared easily, but I was. And so that's when we explained what was going on. And of course, you have to redo the tests and do everything that was necessary to really diagnose it. But you told me that "No, you don't have to do that. That's not… that's not the best process. And so we're going to do something different." And that's when we started on the routine that you can talk about that really made the difference in terms of what I am now versus situation I was in about three years ago.

ER: So you've been a perfect follower of directions as far as your exercise and the routine that we usually advise is called Start Stop Exercise and walk until you get moderate discomfort and stop and rest until it goes away. And then start walking again. We usually ask that you bring on the symptoms within the first five to seven minutes of walking. And there are supervised exercise programs and unsupervised exercise programs. But with the pandemic, that we've had less and less of the supervised exercise, but sometimes people are able to do it at home, if they're really dedicated, and some people need more motivation so they want to come to the to a center to do it. But the mechanism and the method is the same depending on whether you're at home or in the program in a supervised center, walk, stop, walk, stop. You bring on the pain to a moderate degree. So on a scale of one to five, it's supposed to get to a four. So you don't want to be falling over in terrible pain, but you don't want to just stop immediately when the pain comes on. Because what you're doing is training the muscles to extract the oxygen better. So people like to think of it as other blood vessels forming but that's not actually really what happens based on the science behind it. But you're really training the muscles. So what one of the other things that happens is if people stop exercising, then they often get back to square one. So if somebody injures their knee and they take a month off from the treadmill, then they might notice that their leg pain is all of a sudden much worse and then we end up worrying and bringing them in and checking their pressures again, and it turns out that the pressures haven't changed, it's just that the muscles forgot. And some people will actually say that if they even miss one day of walking that they'll notice a difference. So I personally think it's really important to do that walking every single day, because that's what makes it a habit so that if you're not doing it, then you feel like something's wrong if you're not exercising. So you've just been a beautiful example of how you can really improve your walking ability by doing that exercise regimen. I don't know if you remember, but the first time we met, you said you could only walk 10 minutes at the most without having to stop. So how has that changed over the years?

A: Well, it was even worse than that as I was mentioning earlier. I think about four or five minutes I have, which was very dramatic for me; [I] like to get things done and get going. You told me a number of things that I tried to follow very closely. It was the workout routines as you mentioned. You also again reinforced the need to watch my diet and gave me some examples of diet: not have much meat; vegetables; fish; all of that. So I passed all that along to my wife who takes care of all of our meals. In addition to walking, you also told me that it would be nice to lose a few pounds. Again, as we discussed earlier it was not a situation where I was overweight. But you did suggest, you know, 'You can lose five pounds or so in the next two or three months, that would be great." So what we did is I went home, the first thing is we… and again, I gave a lot of credit to my wife, very frankly, she told me you shall do everything that Dr. Ratchford told you. And so she saw to it. So not only she totally changed the diet, and really making sure that we were the right components there but also she said, "I'm going to work every day. And I'm going to work with you." And every day, either in the morning or in the afternoon we're scheduled to go and walk around the neighborhood for about 25-30 minutes. And sure enough, I was every three or four minutes I had to stop because of pain. She hadn't really realized that because we just haven't really discussed it that much. And so she says, "Well, you're really in pain." And I said "Yeah, I have to stop, I can't continue." So we did that for two or three weeks and then I think we got into the colder months of the year. And so I decided that I was going to get a treadmill, which we didn't have one. And so we got the treadmill, put it in our basement, and then I switched primarily to the treadmill as the exercise, and I didn't even know

how these things work. You can increase the speed and you can increase the angle and all of that. So it's really wonderful variations that you can have. We got Netflix, which I didn't have. And so now I can do my exercise and watch TV and all of that. I really went into routine every day I was either up at six in the morning or then coming back home from work, I go down there for again, for half an hour, and did exactly what you told me to do. So I go for four or five minutes, and then I have to stop because the pain and then I will rest for maybe a couple of minutes and then restart in that for a period of time, that said half an hour or so. And I started noticing that I was feeling better in better time. Essentially, right now, no dialing forward about three years, I continue to do it. I'll be honest… I don't do it every day. But I do five times a week or so. I always wait on weekends, Saturday and Sunday and then during the week depends on really my schedule. I travel quite a bit, and now I travel with my running shoes and my gym-wear. So I look for hotels that have a fitness center. So even when travel, we go on cruises, and I make sure that I exercise during the cruise, as well. By doing that, right now I am able to go easily 20 minutes without stopping. And towards the end of the 20 minutes, I increased speed. I also start increasing the slope, and when I walk now in the normal activities, I have no pain. [I] really can now walk across campus and back and forth, and I'm fine. I can climb stairs and not feel any pain. And it's really, really totally changed my life in terms of being able to do what I need to do and do it in a way that I feel again, comfortable and happy. In addition to that, I did lose weight. You have given me the target of five pounds. I actually lost 15 pounds, and I've maintained it. So when I come to see you or any other they asked me, "What's your weight? Let's weigh in." I said I know what the weight because that's what it is in the I'm usually within a pound or so of the previous weight. So I've been able to maintain the weight. I'm walking I'd say normal and in the cruises that we take, we go into these excursions and you walk all day, and I'm fine. I can do that and totally not impact my lifestyle anymore.

ER: That's great. I think that the weight loss issue is something that is not talked about a lot with regard to PAD treatment in our vascular world, but I think it really deserves mentioned, because if you think of… well, as I mentioned, walking uphill… it requires more oxygen. But if… you were never that overweight, but if you could imagine if you had 25, 30, 40 pounds of extra weight, then it would be like if you put on a 40-pound backpack and you try to walk up the stairs, that is a lot of extra work for those muscles in your leg. I think it's important to note that weight loss can be a really good part of the treatment for the claudication symptoms because you're just decreasing the amount of work that your legs have to do with walking so that's great. You and your wife also sounds like she deserves credit for. It's really amazing that you had had such good support and a partner to walk with because…

A: And she does not let me get away with it, you know. She will ask you every day, "Have you exercised today?" <chuckles>.

ER: Wow, that's terrific.

A: Yeah, she does. That again, support system is always very important as you as you all know. So again, I recommend everyone to talk with your spouse, with your mom, dad, whatever… get someone to watching you in making sure that you are not taking it easy or feeling that, "Oh, I'm better now. So I don't need to do it." It's half an hour a day… at least five days a week as I do it. It's fun, I actually look forward to spending time in front of the TV. And

I know the thing many shows now I didn't know before. It's fun. You can do it. And it goes by very quick. Before you know it, you're done. You go on.

ER: Yeah, that's great. The more distractions you can have, the better when you're walking because then you're not so focused on the leg. So walking with other people or listening to audio — I like to listen to audiobooks. Or in sometimes if watching a show, you can even put subtitles on the show and then listen to music. Because the music makes you walk faster and then you're so distracted between the music and the reading the subtitles that then you don't think at all about the leg pain. There's lots of tips for how to, how to start that and stick with it. But the more distractions, the better. And then and I like to think of it as a special sort of quiet time that you get to yourself where it's prescribed, so it's kind of a requirement from a medical perspective. And it's also like a blood pressure medication because it… exercise has such beneficial effects on cholesterol, diabetes for the glucose and the blood pressure and from a mental health standpoint, especially now with all the stress that people have been under over the past few years, I think having that time to yourself where you're not being bombarded by you know, news or emails or work or laundry or dishes depending on how you spend your time. It's nice to have that half hour that's protected where you can just kind of do something that you want to do because it should be a treat.

A big component of the treatment of peripheral artery disease is the medication. I like to think of it like everything that we do is either aimed at making you feel better or live longer and a lot of the medicines are aimed at… some of them are aimed at both of those things but for example, the blood thinners we use is usually aspirin. But there's actually a new medication that I think you and I haven't even talked about yet. But rivaroxaban has become kind of a standard treatment to add to aspirin now for some patients with peripheral artery disease at a very low dose to thin the blood to prevent heart attack and stroke. And then I know that in some of the other discussions that you guys have had with the podcast, you've covered the cardiovascular disease in general, but statins are really, really important and probably the most important medication for treatment of peripheral artery disease. There's even some studies that show that statins can improve the walking ability, but those are some really old studies which will never be replicated because it's really not ethical at this point to deprive somebody with PAD of a statin because the reduction in rates of heart attack, stroke, and death actually are huge. So the statin is just really, really critical. Even though on a day-to-day basis, of course, the walking and weight loss and diet and everything are really important but the medications are really key to keep the arteries open. There's also some blood pressure medications that are particularly helpful in reducing that cardiovascular risk because there is an overlap. Obviously, if you have blockages and leg arteries, then you can have blockages in the arm arteries, or in the neck arteries, or in the heart arteries; and the whole purpose of these medications is really to prevent heart attack and stroke because usually the legs are fine.

But it is also worth mentioning… luckily you didn't need to undergo an invasive procedure but there are sometimes when an invasive procedure like a balloon and stent or even bypass surgery is necessary. But there's only very rare circumstances in which that occurs and that would be if you had pain at rest, like every time you [inaudible], I always say, “Have you had any sores on your feet? Do you have any pain in your feet at night when you sleep?” And those are… if you have gangrene or a sore on the foot that's not getting better or pain at rest at night, for example,

those are kind of alarm symptoms that we worry, “Okay, is the circulation getting worse? And do we need to restore the blood flow to the leg because we certainly want to avoid things like amputations?” And the amputation rates are actually much higher in patients with diabetes. In fact, 50% of amputations that occur in the United States are in patients with diabetes, so taking good care of the feet is really important. And then checking that circulation is key. And if there is some kind of a wound that needs to be addressed right away. And then also if your symptoms hadn't gotten better with the exercise regimen, then if the symptoms are what we call lifestyle limiting, then we would recommend if you wanted it, you know, the balloon and stent procedure. But that's really just to make you feel better not so much the live longer part of it. I used to work in New York City and we measured everything in terms of city blocks so if you were a mailman in New York and you couldn't deliver the mail and you weren't able to do your job, then that would be it. After three months of doing this exercise regimen if you if you couldn't deliver the mail anymore, then we would consider doing the invasive procedures. We talk a lot about city blocks. And if you can increase you're walking ability from two blocks to five blocks, then usually that can get you to a Starbucks in Manhattan so that would be enough so you wouldn't have to have an invasive procedure.

RK: Dr. Ratchford, you mentioned how PAD often goes along with cardiovascular disease and stroke. And I'm just curious, Antonio, did you have any other history of cardiovascular disease at all?

A: No, not at all. Not at all. I mean, I do have a tendency for high blood pressure. And again, as Dr. Ratchford was saying, keeping the medications and regimen that [has] eventually optimized my blood pressure now. I had days where I know it was like 160, over whatever 80 or so. Now, my blood pressure is typically about 120 to 130 over 70. And so that's good. But no, I did not have any alert that this was a problem. Again, the key issue was that as I was walking, I started having the development. It kind of happened overnight. I was fine one day, and then next day, I'm walking and I start feeling this pain. And I said. “Hmm, what’s going…?” And that's what led me to say maybe I just sprained a muscle or something.

RK: Can you describe the pain for listeners that you had: where it was located and what it felt like?

A: It was located in my leg in the back, lower part of the leg in the calf area. You almost felt like something getting very tense and then hard and you just see this acute pain coming onto your leg and you just have to stop. You just could not continue. And then you stop and then two or three minutes, then it would go away. It's interesting now that when I'm exercising on the treadmill, I might start feeling the pain, let's say after 10 minutes, 12 minutes, but what I'm finding is that it may come but then it goes away without me needing to stop. You see it kind of coming but then it just vanishes away and I can typically go as I said 20 minutes or longer without having to stop at all because even if it develops, it's very manageable and doesn't force me to stop the exercise.

RK: Sounds like it could be tremendously disabling if it's, you know, occurring quite often. And so glad to hear that with the exercises Dr. Ratchford gave to you that your pain is improved. Dr. Ratchford, I'm curious… what are the risk factors for PAD and, you know, why might someone

with diabetes develop PAD and not the other cardiovascular diseases, for instance? I'm just curious if we have any insight based on Antonio, what you shared with us.

ER: Age is the most important risk factor for PAD and we can't control that so we don't focus too much on it. But the other two most important risk factors are diabetes and smoking. Smoking is really, really a critical risk factor. And you're twice as likely to develop blockages in the leg arteries as you are to develop blockages in the heart arteries if you smoke. But interestingly, smoking tends to cause blockages that are higher up like in the pelvic arteries and with diabetes, they're often lower down like below the knee, which makes them actually harder to fix in patients with diabetes. I think now you have a cardiologist as well, right? So I'm a vascular medicine specialist, I should mention. So I'm not a cardiologist, but I work in cardiology at Hopkins and I'm also not a surgeon. So I do vascular medicine, which is the non-invasive diagnosis and treatment of blood vessel problems. And PAD is literally my favorite topic. You do have a cardiologist now. Do you want to talk a little bit about how that came about?

A: Well, it was one of our appointments that you were doing an EKG on me and you notice that there was some extra beep or something which was happening with a certain frequency that was abnormal. And also you thought that at some point, I might have had some sort of similar to a heart attack or something like that, because signals were indicating that. Again, I couldn't remember anything certainly that happening in that vein. Suddenly, it was a good idea to go and see the cardiologist which confirmed what you were suspecting. But again, I think three years later with the kind of activity that we have been talking about, now my EKG is and there is even an echocardiogram and so on that are starting to show much better functioning in the heart and I think last one we did a few months ago, I believe you use even the some sort of better functionality in the heart in terms of the pumping capacity and things like that. So again, to me these things are all related in some way. I'm just still amazed how change in my exercise habit and socially just walking has totally changed my life. Yeah, my lifestyle and clearly, physiologically has also improved in my functions because it certainly looks like the heart is healthier. It seems to have almost like regenerated itself and you know, not sure if I'm talking about regenerative medicine here but it certainly feels like my heart is gotten better and stronger. And I think it's just keeping at it, maintaining your medications and the exercise and paying attention to your diet; all of that has totally made a major impact on my life.

RK: What about your blood glucose management? You know, I'm just curious what your A1C's had been like. And Dr. Ratchford, do you usually think of glucose management as impacting the risk of developing PAD?

ER: They say, I guess, the glycemic control affects the micro vascular disease more than macro vascular, meaning that it has more effect on the little blood vessels — certainly having the higher the hemoglobin A1C, the higher the risk of PAD and there is a direct correlation there. Fortunately for you, your glucose was never completely out of control. But actually, I saw somebody earlier today where their hemoglobin A1C is like 14 and there's a sore on her foot and she's, you know, heading towards having that balloon and stem procedure. So there's certainly a close connection between the glycemic control of the glucose with the sores and

wound healing and it's all very, very connected. But you've done a really good job of controlling that I think over the years.

A: Again, as I said, I've been paying a lot of attention to the diet, courtesy of my wife, but it doesn't mean that I have truly not skipped or eliminated what I like. You know, I'll be honest, I'll have a scoop of ice cream here or a little piece of chocolate or if there's a birthday in the family, I'll have a little bit of birthday cake. So I have not eliminated it. What I have certainly paid attention is not abuse in the kinds of foods that are really not good for you. We have fish every week, maybe twice a week. I might have steak maybe once a week… lots of vegetables and fruit, as well, and paying attention to the type of food because some food have a lot of sugar, also.

RK: Dr. Ratchford and Antonio, thank you so much for being here today. And Antonio, especially for sharing your experiences living with PAD and your successes and your challenges along the way. It's so great to hear about how your work with Dr. Rochford has really allowed you to live with PAD and continue to have a good function. We really appreciate all your input and candid stories today. So thank you so much, Antonio, for being here. And Dr. Ratchford for your expertise as well.

A: My pleasure.

ER: Thank you for the invitation.

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 love to hear from our listeners. The email address is hopkinsdiabetesinfo@jhmi.edu. Thanks for listening. Be well and see you next time.