

## EPISODE 27: A PATIENT STORY ABOUT DIABETIC RETINOPATHY

**Dr. Rita Kalyani:** 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](http://hopkinsdiabetesinfo.org).

For today's podcast, it is my pleasure to introduce a person with diabetes, Derrell, who will be sharing his journey living with diabetes, particularly focused on the effect of diabetes-related eye disease on his life. Along with Derrell, we are thrilled to welcome Dr. Sharon Solomon, an expert on diabetic eye disease and one of Derrell's care providers. Dr. Solomon is the Katherine M. Graham Professor of Ophthalmology at the Wilmer Eye Institute, a retina specialist and board-certified ophthalmologist. Her clinical expertise includes medical and surgical treatment of age-related macular degeneration, diabetic retinopathy, epiretinal membranes, macular holes and retinal tears and detachment. She has a large national and international referral practice at Wilmer. Dr. Solomon is the first Wilmer faculty inducted into the prestigious Miller Coulson Academy of Clinical Excellence at Johns Hopkins. Welcome, Darryl and Dr. Solomon.

**Dr. Sharon Solomon:** Thank you, Rita, for having us.

**Derrell, a patient with diabetic retinopathy:** Good morning.

**RK:** Thanks so much, Darrell and Dr. Solomon for being here. Dr. Solomon, since you know Darrell the best, I wonder if you might want to start off the conversation for us today.

**SS:** Certainly. And I want to say I think it's so important that you have this platform, Rita, for patients. I think it's invaluable for patients to realize how important secondary complications are from diabetes mellitus and what role they can play in maintaining their general health. And Derrell, thank you for joining us. I wanted to start by asking you, Darrell. Do you recall how long ago you were diagnosed with diabetes?

**Derrell:** I think it started in 2002.

**SS:** And do you remember the circumstances around which you were diagnosed?

**Derrell:** Yes, what happened was, I was at work one day. I work for the post office, and I was at work, and I felt really bad that day. And I drove from the post office, which is downtown Baltimore, to the Northwest Hospital. Once I got there, I was admitted into the emergency room, and they kept me and they said my sugar levels was like, 600. And they couldn't believe it. You know, they was like looking at, you know, "How you get here?" "Did you drive?" And I drove. So from since then, it's been a struggle getting it under control.

**SS:** And do you recall the first time you began to realize that maybe your vision was affected by your diabetes?

**Derrell:** My vision was unaffected until maybe 2019, after I had trauma, I had amputation done to my foot where I had to have my toes removed. And it started right after that.

**SS:** And what were some of your first symptoms, Darrell, that you've experienced that let you know that maybe your eyes were being affected by your diabetes?

**Derrell:** It was the blurriness first, and then they would like go blurry, and then would come back. And then I started developing where you couldn't see the hemorrhaging that was going on in my eyes, but I could see it. If you were looking at me straight, you couldn't see it, but me focusing on looking at you, I can see it. It was like it was dripping down, [it] looked like cane syrup that was dripping down in my eyes. Then that's when I knew there was something going on.

**SS:** I recall that visit, too. And I recall that you came in with vitreous hemorrhage in your right eye and actually, the vision was down to hand motions so it's important to emphasize that diabetic patients can have a spectrum of degrees of vision loss because of diabetic retinopathy. When patients are first diagnosed with diabetes, as you were and it sounds like you might have even

come in with something called diabetic ketoacidosis, where your blood sugars are extremely high, that's often how patients will present for the first time not realizing that they were diabetic. At that time, of course, the primary thing to do as Dr. Kalyani knows is to get the blood sugars under good control and to get the patient on a strict regimen. But even when patients aren't having any eye symptoms, we recommend that they have a baseline eye exam at the time of diagnosis. And despite that recommendation, oftentimes the first presentation is just what you described, Darrell, where patients come in because they've noticed that their vision is being affected.

So, I recall that you came in with that right eye, having hand motions vision, meaning that literally you couldn't read anything in the eye chart [and] you couldn't count fingers, but you could tell that an object was moving back and forth or up and down in front of your eye. And it was because, just as you described, you had a cavity filled with blood in the back of the eye, and there are different stages of diabetic retinopathy and you had come in in the more severe of the two stages which we call proliferative diabetic retinopathy, where there's been enough if you want to describe it as oxygen deprivation to the retinal vasculature that your eye is compensating by growing secondary vessels, which are unhealthy. And we call these retinal neovascular vessels, but they tend to break and when they break, a patient can notice an acute and dramatic drop in vision, which is what you had. So you go from seeing 20/20 and driving yourself to the hospital, as you said, to coming in and being legally blind in the eye because the cavity is filled with blood. And I don't know [but] do you remember what we did after that encounter?

**Derrell:** I think you recommended that I was to have the surgery where we had to have the blood come out of the eye.

**SS:** Right. Yeah. So that's generally how we handle it. But oftentimes, we'll have a series of steps for that. It depends on how severe the hemorrhage is. In your case, it was very severe. But oftentimes, if we catch patients where they're having just the diabetic blood vessels growing, or else a little bit of hemorrhage, but they can still see and they're functional, we will recommend intravitreal anti-VEGF injections through the wall of the eye to introduce this anti-vascular endothelial growth factor medication to limit this aberrant blood vessel growth and it actually helps the hemorrhage to clear faster also. So I believe in your case, if I recall correctly, we did a series of those injections. And it was only after we still had hemorrhage that wasn't clearing that we did take that right eye to surgery. And you actually had limited retinal detachment in that right eye as well, which is another severe complication that can happen with diabetic retinopathy.

So I should emphasize for patients who are listening that again there are different stages of diabetic retinopathy. You have the early stages, which are called non-proliferative, where patients may just have a few little dots of blood in the eye, nothing that's affecting the vision and the patient would never know that he has this unless he came in for an eye examination. However, it's important for the patient to know when we do this that we see these changes, because it's a sign of perhaps the need for tighter blood glucose control, ideally, a HbA1C that's closer to 7%. And I cheated this morning, Darrell. I went back and looked at your chart and when you came to see me, I believe your HbA1C was 11%. And I know you have much tighter blood glucose control now from our most recent visit.

**Derrell:** Yes!

**SS:** But all of those things are important because diabetes mellitus while it's the leading cause of blindness in working-age adults, it is a systemic disease. So the first line of therapy, of course, is to try to control the underlying diabetes mellitus by keeping tight blood glucose control. And that is supported by data from something that Dr. Rita Kalyani used to lecture about, in a course we did at Wilmer years ago, the Diabetes Control and Complications Trial which showed that tight glucose control limited microvascular disease in Type 1 diabetic patients. So they had a lower incidence and prevalence of diabetic retinopathy. So number one is tight blood glucose control. The second thing is when you begin to see these very mild nonproliferative changes, you need to follow the patient more closely. So our standard as ophthalmologists and as retina specialist is if someone has no diabetic changes, when he comes in for his baseline exam, or minimal diabetic changes, a little dot of hemorrhage in one or two quadrants of the retina, we'll have that patient come in once a year for a dilated exam. If we see more hemorrhages, maybe hemorrhages in three quadrants and some signs of what we call exudate, or fatty material that leaks out of blood vessels, we'll have patients come in maybe every six to eight months or four to six months. But when patients come in, as you did, with full-blown proliferative disease, a aberrant diabetic vessels growing in the eye, bleeding. We didn't even realize it at the time but early detachment, those are patients that we often see them monthly and we intervene immediately with therapy. As you said, we did go ahead and do surgery to that right eye and I remember we cleaned out the blood. We had to peel away scar tissue to reattach the retina, put in lots of laser, which is another therapy that we'll use in diabetic retinopathy to tap down the peripheral retina to prevent detachment. And then we focused on your left eye as well. And I think you ended up having laser early in that left eye. Do you remember what happened to the left eye later though?

**Derrell:** Yeah, if I remember back, I had a little bit of hemorrhaging in the left eye.

**SS:** Yes.

**Derrell:** And I think you treated that one too. And you took care of all the outside vessels.

**SS:** Yeah. So despite getting laser, a pan retinal laser into that left eye and you're getting better HbA1c control maybe because of the length of time that you had diabetes or perhaps weren't yet diagnosed, the left eye still progressed and developed proliferative diabetic retinopathy and bleeding and ultimately that left eye went to surgery also to clean out the vitreous and to put in more peripheral laser to try to prevent those secondary complications. So you've had severe changes because of diabetes to both eyes. But fortunately, the last time I saw you, and I think you were just in to see me in the office maybe just two or three weeks ago, right? You have driving vision in each eye, right?

**Derrell:** Yes. Yup.

**SS:** You're not, as far as I'm aware, limited by the vision. Is there anything that you feel that you can't do because of your level of vision currently?

**Derrell:** No. My vision has changed. It's not changed dramatically, but I can really tell it has changed. But I think I need to change my prescription in my glasses too. I got the glasses before you did the EYLEA (Eye Injections for Retinal Diseases). So now, I think I'm going to go back and make another appointment to go back to eye doctor/specialist to see if I can get another prescription because I think it has changed. But really, I can see; it's not bad. I mean can still see; I can read signs and all that. It's not that bad, I really don't have to change (anything). Even my up-close reading has changed since the EYLEA.

**SS:** So I'm glad you brought that up because what we're treating now for you is diabetic macular edema. When you first came in, we were treating bleeding in the eye because you had progressed from non-proliferative to proliferative disease. There is another entity that can affect vision under the umbrella of diabetic retinopathy called diabetic macular edema, where patients simply have clear fluid that seeps out of their capillaries and tiny blood vessels in the retina. And that fluid and exudate, the fatty yellow material, settles right in the center of the retina. So I often tell patients to think of the retina like a bull's eye. And the very center of that bull's eye is the macula and the fovea. And that's what one uses for reading. So diabetic macular edema is the most common cause of vision loss, and it can occur at any stage of diabetic retinopathy. So even though you've had vitrectomy surgery, you don't tend to have bleeding as frequently and you have good vision. You've had times where you come in, and we pick up that there's swelling just in the very, very central few degrees of your retina. But that can have a profound impact as you're describing on your reading vision. And the standard of therapy for that is to give these intravitreal injections of anti-vascular endothelial growth factor agents. One is EYLEA, as you describe Aflibercept, and there's another one called Ranibizumab, or Lucentis, and another one called Bevacizumab, or Avastin. And these agents work tremendously well. Years ago when I was in training, we used to do thermal laser, and we had to laser the bleeding capillaries in the fovea to try to limit the amount of leakage. And sometimes we had to do it over and over again. And the therapy itself would cause patients to have blank spots in their central vision because you are burning the retina. So the advent of these intravitreal drugs that we can inject in the eye, and I'm sure you're not crazy about getting the injections, but as you described, you notice that it improves the vision, and it does cause this leakage to slow down and to become more limited in conjunction with tight blood glucose control, as we as we described,

**Derrell:** Yes. Well, you know, it's been a struggle. But I think what you have been treating me with has been working really well, because I have had injections in the last one or like two years, two and a half years, I believe.

**SS:** Right.

**Derrell:** Yes.

**SS:** I think one eye has been more active than the other. I think one eye seems to require these sort of maintenance injections, but at an interval of maybe every six months or eight months, which is actually very good. And like I said, I think it's because you've done the hard work of getting your HbA1c under better control. I do have some diabetic patients, unfortunately, where the

HbA1c is still extremely high. Dr. Rita Kalyani knows better than I, but I've had patients come in with an HbA1c of 14% or 17%. And they are in their late 20s or early 30s and bordering on legally blind in each eye because of the severity of the diabetes. Luckily, when you came in, you were still at a level where we could intervene and get a good outcome and you've maintained excellent vision. But some patients we do the same things that we've done for you. We do the injections, we do laser, we do surgery, and because of another complication that I haven't described yet, which is circulatory, the same way you described that you had amputations of your lower extremity because diabetes affects small blood vessels and distal blood vessels and it affects circulation, some diabetic patients end up having amputations. We don't amputate the retina, but the circulation to the retina can also be affected because of diabetes. So we have patients whose circulation to the retina becomes inadequate, and it becomes so severely compromised that the tissue just dies. No matter how much laser or how much surgery or how many injections you do, we can't get the vision back because the tissue is no longer viable. So unfortunately, we have those patients as well. Luckily, you presented at a time where we were still able to intervene and make a difference.

**RK:** It sounds like, if I may ask Derrell, even under excellent care with Dr. Solomon, it sounds like you've had multiple complications related to that eye, from your diabetes. You have done so well with all the treatments that Dr. Solomon has offered to you. And also with taking care of your blood sugars with good functional status right now with your vision, being able to do the things that you want to do. When you were first diagnosed with diabetes, did anyone talk to you about the complications that you could have in the eye? Was this something that you even knew about? Or was it a total surprise?

**Derrell:**

After I went to Northwest because I was in Northwest for like four days, and then when I came home, my primary care doctor hooked me up with this nutritionist just to get the HbA1c down and talk to me more about diabetes. But the thing was with me, my aunt, she was like, "Well, why don't you talk to an endocrinologist?" So I went to an endocrinologist. But the first thing is okay, you are already dealing with the diabetes. But another thing is to sit there and listen to what can happen means that it's not so much as you sit here and we talking to have a conversation, he was more so like, "You know, you're gonna get this amputated. This could happen to you. You know, you can go blind." And instead of forcing information in to me, how about you just sit down and have a decent conversation about what can we do to fix the problem. And I didn't go back to him because I really didn't feel comfortable. I'm already on edge about going through the process of having diabetes. I was talking to my aunt one day. And she's like, "Well, how about you go see my endocrinologist?" Really one of the greatest guys that you can sit down and talk to about diabetes, because like I said, when I started going to him in the beginning, it was at an HbA1c of 12% and I've got it down to the 7.2%. It's because of the way he talked to people and the way how he reacts to what's going on. He never [forced information on] what can happen. All he was concerned is how can we fix this problem. And that's how I look at Dr. Solomon. Dr. Solomon treated me as if I was her kid, her son. And she's like, "We're gonna treat this. We're gonna take care of this problem." That's why I really love going to her. I really love what she has done, because she's always given me the best advice on how to do things. And I think that's why I'm where I'm at today is because of her.

**RK:** It's truly wonderful to hear that Dr. Solomon has given you this excellent care over this long period of time. And Darrell the excellent care you've taking of yourself, really, you know, and getting your sugars under control. Congratulations.

**Derrell:** Thank you so much.

**SS:** Absolutely, you did the hard work, Darrell. I mean, I admire you, because it's not an easy condition to have. It's common but I don't ever underestimate or take diabetes lightly. And you've been a wonderful patient who's taken responsibility and really been compliant with your visits and with your health. You and your wife, I couldn't neglect to mention her.

**Derrell:** Yeah, and I say this a lot, because, you know, she dealt with a lot. And you know, I do it because it's something I want to do. I don't mind, if somebody tells me, "Hey, that's what you got to do for you to see and for you to stay on the face of this planet," I'm going to do it, I'm going to do my part. There is not a day that I don't really think about it. Listen, I can see, I'm here, and that's what I do. That's how I feel.

**SS:** But I can tell you that I think we're going to be able to maintain excellent vision for you. We just need to continue to monitor. And when things are quiet, we just look in and make sure that you're doing well. And if you ever notice a change, you've done an excellent job of knowing to seek attention right away. So I anticipate that you're going to maintain the excellent vision that you have, Darrell.

**Derrell:** Yes. Yes. And I really appreciate you, Dr. Solomon. It's not easy. You make it so that when I come and see you, it's just you, your personality, your attitude, your spirit that I'm comfortable [with]. Pretty much I could talk to you about anything. Pretty much in saying that, me and my wife really do appreciate you so much for what you have done for us. And for me, especially. I'm very grateful. Yes, my vision is good. I'm here. I can see. I'm happy.

**SS:** Well, that makes me happy, Darrell. Thank you so much.

**RK:** So, Darrell, if there's anything you could advise other people with diabetes, you know, having gone through these eye complications that you've had, what would you recommend to them to really ensure that they take good control not only of their diabetes, but their eye health?

**Derrell:** First of all, you have to listen to your specialist, the person who's taking care of you. Second of all, your HbA1c plays a big part. You really have to watch what you eat because what you eat, it's really going to affect you in the long run. I look at it as if you know "Hey, I know I want to eat it." But I don't eat it, I'm not with that no more. And I think lately, my weight loss has really been a big thing because I'm now down like 41 pounds off. I think now, as a person with this eye disease, you have to listen to your doctor; that's first and foremost. And you really have to watch what you eat. Because the what you eat can really affect your blood sugar and your blood sugar affect your eyes, the most. For me telling somebody else about it, it's a serious thing, and that's what I would tell them. I would just take really serious precautions about taking care of yourself, especially dealing with the eye disease, because it's very serious. For me, it's losing weight, maintaining HbA1c down to low numbers, and periodically going to see an eye specialist. I guess I guess go get an eye exam every year or every six months, however you think you need to go see an eye specialist. I just think everybody needs to get in that and just to see one because it's serious.

**RK:** And what was it like to go into the ophthalmologist's office to go into Dr. Solomon's office and get your eyes examined? Was it difficult? Was it pretty straightforward? Is it something that you would say to others that is easy for them to do and really not too strenuous? How would you describe it?

**Derrell:** You have to take into consideration that this is my body. If you want to live and be around, it's best to go in there with a clear head and just say to yourself, "I want to get this done. I want to see what's going on." That's like what I told my wife, I wasn't scared. It's something that I had to deal with. I would rather go in there and get it done. Get it checked out before it's too late. Because sometimes, Dr. Solomon says sometimes when you are going in and it's really high numbers and they try to work with you, sometimes the damage could be already done. I would just tell anybody, "Hey, if you need to go, go in there as soon as possible and get it checked out, with a clear head." Just knowing that, "Hey, I'm going to get this taken care of so I can see."

**RK:** Well, that's really great words to share. And I like the way you described it just go in with a clear head [and] be open to what needs to be done to preserve your vision. Dr. Solomon, I wonder if you might first be able to describe: when should someone with diabetes see an ophthalmologist or even a retina specialist such as you? And what kind of equipment do you usually use to examine the eyes? Is it pretty convenient and straightforward? Or does the person with diabetes really have to do a lot to prepare for it?

**SS:** I'm glad you brought up that point because I will often have patients who come in and they'll tell me "But, I've been having examinations" and I'll come to realize that perhaps they're seeing an optometrist, and maybe they're not having dilated examinations. So, while I think there certainly is a role for optometrists and helping patients to maintain good eye health, I can say that once someone has been diagnosed with diabetes, that patient should really be coming in to see an ophthalmologist or an MD eye specialist. And if there's retinopathy, of course my bias is, the person should be seeing a retina specialist to have a dilated eye examination.

Why a dilated eye examination? In *late-late-late* stages, diabetic retinopathy can also affect the front of the eye. So, anyone can see that on slit lamp examination, you don't have to be dilated, you'll see blood vessels growing on the blue part, or the hazel part, or the brown part of the eye which we would call the iris. But that's an extremely late complication. And it indicates that inside of the eye that these diabetic blood vessels are already running amok. So, it's essential to have a dilated examination by an eye MD or ophthalmologist or retina specialist. We put in medications that cause the pupil to dilate and we use something called indirect ophthalmoscopy, where we put an instrument on top of our head, and we use lenses. And that enables us to see globally the complete peripheral retina because often that's where neovascularization occurs, or that may be where a diabetic detachment is starting, or even if the patient has vitreous hemorrhage.

Darrell, you've described at the beginning of the interview that you were seeing things floating around that I couldn't see it. Oftentimes, patients will describe that because they're having small bleeds in the periphery, and only when you dilate the patient and tilt him back and sometimes you have to scleral depress to bring the peripheral retina into view. You can see where these tiny areas of bleeding are occurring, so that the earlier one can catch it, the better. And then we also do biomicroscopy, where we look with a less intense light at a very magnified view of the central retina or the macula. And that's important for picking up what's called diabetic macular edema or diabetic vessels on the surface of the optic nerve. So all of these clinical markers are important ways of monitoring the incidence and progression of diabetic retinopathy and I am biased again, but I feel that there is some expertise in being able to diagnose the onset and the stages and deciding the appropriate intervals at which patients need to be followed, and when you need to intervene and offer therapy.

**RK:** I fully agree. As an endocrinologist, I know we rely a lot on those specialist referrals to you, to Sharon, as an ophthalmologist and retina specialist to really give that expertise and to detect early any complications that may occur before they become problematic. And I think those early referrals are very important. And I'm sure, Darrell, you feel that when you got to see Dr. Solomon, when you did, that's really when your eye health really was able to be properly managed and preserved your vision as long as you can. So, it's so great to hear about the positive outcomes that you've had, Darrell, under Dr. Solomon's excellent care. Dr. Solomon, it was really great to hear about all the expertise that you had to offer here today, to our audience on all the great work you do as an ophthalmologist, a retina specialist. So, thank you to you both for being here today. Did you have any last words that you wanted to share?

**Derrell:** I just would just tell everybody; I would just take your eye care a lot better. If you are starting to have symptoms, problems, or issues, I think it's best to get in there and to see a specialist as soon as you can. Because the longer you wait, the worse it can be. And for me, I'm glad I did. I'm glad I did take the initiative to go and see what was going on. Because it helped me out a whole lot. And I can't thank Dr. Solomon enough. I'm just kind of glad I got it. And I just encourage everybody: if you're dealing with the same eye disease that I have, it's best to get in and see what's going on. It really is. And I go and educate guys who's going through amputations, and I go over there and sit and just chat to them and just tell them because, you know, a lot of guys pretty much [say], I walk as if there's nothing wrong with me, so according to them, they say, "Man, why are you here? What's wrong with you?" until I take my shoe off. And then I start telling them about my eye disease, and I try to educate them on what I know. Now I'm not the best person, but I educate them. So, they won't go through what I'm going through. And then, when I'm going through how to deal with it, I try to encourage a lot of people [to do] what I'm doing. It's not as bad as you think; you know, you can get over it, you can fix it; you just have to move forward. You know, it's not the end of the world, and that's how I look at it. I look at my daughter every day, and that's my inspiration and my wife. I just keep it moving.

**SS:** And Darrell, I would just thank you for letting me participate in your care. It's been a privilege to be your physician and to Rita, I think this is a wonderful platform that you have for patients. So, congratulations to you. And I hope that this continues for years in the future.

**RK:** Well, thanks so much to you both. This has been such an informative discussion. I know I've learned a lot and I know many of our listeners will come away with this informed and inspired as well to really get their eye health managed and make sure that they have good vision for as long as possible. So thanks so much, Darrell and Dr. Solomon, for being with us today.

**Derrell:** Thank you.

**SS:** Thank you.

**RK:** I'm Dr. Rita Kalyani, and you've been listening to *Diabetes Deconstructed*, we develop this podcast as a companion to our Patient Guide to Diabetes website. Our vision is to provide a trusted and reliable resource based on the latest evidence that people affected by diabetes can use to live healthier lives. For more information, visit [hopkinsdiabetesinfo.org](http://hopkinsdiabetesinfo.org).

We love to hear from our listeners. The email address is [hopkinsdiabetesinfo@jhmi.edu](mailto:hopkinsdiabetesinfo@jhmi.edu).

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