

EPISODE 1: INAUGURAL PODCAST WITH AMY ROHRBAUGH Transcript

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 *Hopkins diabetesinfo[dot]org*. That's all one word.

On today's inaugural podcast we are honored to welcome Amy Rohrbaugh, the founder and director of the Frannie Foundation.

The Frannie Foundation was established in 2010 to enhance the lives of individuals who suffer from diabetes and other cardiovascular-related diseases. As part of its mission, the Frannie Foundation provides funding for the Johns Hopkins Patient Guide to Diabetes website, of which this podcast is now a part.

Welcome Amy. We're so thrilled to have you here today.

Amy Rohrbaugh: Thank you. I'm happy to be here.

RK: Amy, could you start off by telling us a little bit about why you started the Frannie Foundation?

AR: Yes. The Frannie Foundation was established in memory of my mother, Frances Josephine Scebor (Frannie), who passed away on December 28, 2000, from complications of type 2 diabetes and cardiovascular related diseases. She was only 52 years old. The Foundation was developed exclusively for charitable and educational purposes. Providing better access to crucial information is the core mission of the Foundation.

RK: Well, it is really so important, isn't it, to educate patients and make sure that they're aware of the complications of diabetes. Why do you think this website for patients is so important and, why patient education in general is important?

AR: I think, due to the complexity of the disease and its comorbidities, multiple providers are necessary to manage the patient's care. And I think this, in turn, can be all consuming because there's so many pieces to the puzzle... because there's so many people involved. So, through my mother's medical journey and her story, this energy inspired the Frannie Foundation to make a gift to support the development of the Johns Hopkins Patient Guide to Diabetes website, which launched in 2016.

This web-based patient guide is a comprehensive, evidence based, expert reviewed resource for patients and their caregivers.

A resource with information on broad topics, ranging from living a healthy lifestyle with diabetes to treatments, complications, nutritional blogs, videos in both English and Spanish on how to administer insulin, and now the addition of podcast to an already rich content site.

Patient education for diabetes, or any other disease state for that matter, is a necessity and through this partnership and website, we are providing all relative resources in one place.

RK: It's so true, isn't, it that navigating the healthcare system can be especially difficult for a patient with chronic disease and their family members and finding a reliable resource for education in particular is what we hoped to accomplish together in our partnership with the Frannie Foundation is providing a trusted source of information that was based on the latest evidence. Do you have a favorite part of the website that you'd like to particularly point out?

AR: I actually have two areas. Even though I feel that all the topics are relevant, the two areas that I really like are the glossary and the patient stories. I think an integral part of the Patient Guide website is the glossary. The team has included key terms in diabetes care with the goal of making the definitions accurate and clear, and by translating all the medical jargon, which is often confusing, into easy-to-understand language. The glossary has proven useful in initiating and navigating learning to better comprehend this disease and its complications for both the patient and the caregivers. I also really do love the addition of the patient stories, I feel that their strength in numbers, so to speak. And I would think by people sharing their medical journey and experiences that others, including patients, caregivers, and even providers, will learn and grow from these. All of these stories prove that you are not alone in this journey which, at times, can feel overwhelming, frustrating, and burdensome.

RK: I agree with you. I think the patient stories are really a very humanistic aspect of the website. They really give the patients the voice to share with others who have diabetes and we're really quite grateful for the patients who have chosen to share their stories in that forum.

Moving now to talking a bit more about your mom and her story... would you be able to tell us a little bit about what her journey with diabetes was like and how that pans out?

AR: Sure, her presence was huge. She was a firecracker. She could command the attention of an entire room and she could win a debate on any issue and make anyone laugh. Needless to say, those fortunate enough to know her could tell you what an impression she made on them.

You know, her ambitions and desires were really for the simple things in life... spending time with those she loved, holidays with family and friends, a comfortable home, her family to be taken care of, and enjoying her pets. Most importantly, she really looked forward to seeing me get married one day, and hopefully, have children of my own. She desperately wanted to become a grandmother; I heard that a lot.

So, her journey with diabetes. Frannie was diagnosed with late onset type 2 diabetes and peripheral vascular disease or, more recently termed, peripheral arterial disease, around the age of 42. For years, she struggled with these diseases and in her late 40s, over a period of just a few years, those close to her watched the horrible toll this disease took on her and how it restricted it and changed her life. She spent much of her time in and out of hospitals, coping with debilitating surgeries, and gradually losing her independence.

Although the challenges she faced were huge, she remained in contact with family and friends, attended functions and gatherings when she was able, and, more importantly, she kept her sense of humor.

RK: Well, she sounds like a wonderful person, and I wish that we had the chance to know her. And she was diagnosed at a relatively young age and I'm sure that came as a shock and to develop the complications that she did. What were some of the challenges that she had in dealing with her diagnosis.

AR: um. I can think of two challenges off the top of my head. Type 2 diabetes at the time was also referred to as a lifestyle disease; that one can hope to alter its course by managing a healthy diet, exercise and physical activity. However, because of the severity of the peripheral arterial disease, exercise in most forms were extremely difficult for my mother to manage. So as you can imagine, this became the start of a vicious circle which led to multiple hospitalizations and surgeries.

Insulin shots were also a challenge. It's extremely important for those around the patient to know the proper way to administer these shots. I recall an episode when my mother... she just kind of froze you know, like had a mental block or whatever you want to call it. And at the time I was away in college and had come home for a weekend visit. I hadn't been shown how to administer the insulin at that point. I believe at the time the providers were teaching this process using an orange. Does that does sound right? Something like that?

However, you know my mother who did have a medical background talked me through the process and I was able to give her the injection. At that point, she requested to take oral meds only, which probably was a bad idea, as far as the management of her diabetes at that time.

RK: And it can be a lot, especially for patients and family members, to deal with a new diagnosis of a chronic disease. Did she have any background medical background, or this must have all been new for her. Is that right?

AR: Yes, it was definitely new for her. She did have a medical background. You know, it's interesting for us... as the two of us, we had an understanding of what the diagnosis meant, but you know at the time, I feel like patient education, the providers, everyone talks more today. It's really a group team effort, and I feel 20-something years ago all of that was maybe just starting. So you know, we had the podiatrist, she had the general practitioner, you now have the vascular surgeon, and then you were diagnosed with diabetes, and you had an endocrinologist, and you had whoever else came to the table. And I think that's the part that was really difficult to manage, because if those providers didn't have the proper staff to help manage that patient, the information wasn't going to who it was supposed to go to from provider to provider. So that was definitely a challenge for both of us and that's where the caretaker steps in and really has to advocate for the patient if they're not able. You know my mother was able, she was young, understood it, and was able, but between the two of us, you know, we were able to do what needed to be done.

So, I feel this website and the Frannie Foundation, you know they're really helping you to understand you have to be a voice for yourself as the caretaker, as the patient, and that there are resources to help to help everyone. And especially the older generation who maybe aren't tech savvy and maybe they don't have a caregiver who can help them, so you know you just have to get this information out, however you can, to help to help people who can't do it on their own.

RK: Was it a challenge getting the various specialists to coordinate together?

AR: At that time, very much so. The office staff, unfortunately, maybe weren't educated in what they really should have done and how you have to help the patients. It's not about maybe answering the phone or typing up the reports at the time, and you know they just went were filed in a folder. Now everything is shared between providers, because it is a multi-disease. Many providers to help care for diabetes, because as you're aware, there's comorbidities that come with it, so you will need other providers to help you manage.

RK: Yes, and it's so important to have the family support, as well as a patient. What was it like being a caregiver for her and supporting her through this journey?

AR: At times it was very difficult. It's hard to go through something like this when the person you're assisting is independent and has a strong personality. So, having to ask for and or need help was very difficult for my mother. So there was a slow progression of her losing her independence, and this was really difficult to witness.

RK: Were there times where it was scary, or uncertain what would happen?

AR: Because she had the medical background and I worked in the vascular department at Johns Hopkins, you kind of knew how some of this was going to play out based on her diagnosis, because it wasn't just the diabetes. It was the peripheral arterial disease, it was the hypertension. There were so many factors, and I think, unfortunately for my mom, I think it's a rare case she just unfortunately had everything go against her. It's you know where you thought you had one part under control, something would happen in the next part and it just kind of unraveled for her. And you know because she was stubborn and she couldn't exercise the way she was supposed to, it just never got to where it should have been managed.

RK: Well, as we talk about patient education and in the importance and the story that you shared of your mom's experience, do you think that if a resource, such as the patient website were available at that time, if there were other patient education resources available, do you think that might have helped her as she is going through her diabetes and the complications.

AR: I do. I think all of these resources are extremely beneficial and I think as a caretaker I would have benefited from all of this as well, because if there was something maybe she didn't understand or we had questions about, you

could take this information and go to your provider and sit down and ask for clarification. Yes, so I do. I just think at the time, this was 20-something years ago... longer, so 30 years ago when the process started.

Technologically, none of this was... we weren't there yet, so this has been a progression for medicine, I think, as a whole. I mean look at telemedicine now. Like I don't think that was around 30 years ago.

RK: That's true.

AR: There wasn't the capability to do that, so I think, yes, any of these resources, I think, would have definitely benefited myself and my mother for sure.

RK: Amy we're so excited to have the opportunity to partner with you and the Frannie Foundation over the past five years on the development of this website and to provide an electronic resource that really is accessible all over the world. We have users from many countries around the world and we're really excited to launch this new diabetes podcast series and are so grateful that you are our inaugural podcast speaker.

What are you most excited about for our new diabetes podcast series?

AR: I think I'm most excited about the potential expansion of outreach to a group of people where this information is absolutely necessary. I'm constantly reminded of the many people this website has helped and will continue to reach worldwide.

We established the Frannie Foundation in my mother's memory to provide assistance to others who are affected with these diseases, but more importantly, it's to assist with prevention, which is what will allow many to see their desires come true by living a long and healthy life. And Dr. Kalyani, to you and your team, through the shared vision, we continue to contribute to my mother's legacy by breaking barriers and providing the best up-to-date information, tools, and resources through the Johns Hopkins Patient Guide to Diabetes website, glossary, and now this podcast series. I'm forever grateful.

RK: Well, Amy, thank you so much for your continued support, your shared vision, and we are really thrilled to move forward with this podcast series and we're grateful to you as well, so thank you.

AR: Thank you very much.

RK: Well, thank you listeners for tuning in today. Join us next time, as we explore the "Whats, Hows and Whys" of diabetes.

I'm Dr. Rita Kalyani and you've been listening to *Diabetes Deconstructed*. We developed 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 *Hopkins diabetes info dot org*.

We love to hear from our listeners. The email address is *Hopkins Diabetes Info at JHMI dot edu*. Again, all one word. Thanks for listening. Be well, and see you next time.