

Speaker 1:

Welcome to the Eye on the Cure podcast, the podcast about winning the fight against retinal disease from the Foundation Fighting Blindness.

Ben Shaberman:

Welcome everyone to the Eye on the Cure podcast. I'm your host Ben Shaberman with the Foundation Fighting Blindness, and I'm very much looking forward to my conversation for this episode with Alex Cohen, who is a professor, but he doesn't hold the typical PhD that most of our podcast guests hold.

We're going to discuss his unique educational and professional journey, which was strongly influenced by a diagnosis of retinitis pigmentosa while he was pursuing a bachelor's of science in hotel administration at the University of Nevada, Las Vegas. Part of our conversation will cover what happened as Alex moved forward in his career.

But what initially inspired me to reach out to Alex and do this interview was his founding of a company called Accessible Pharmacy, so we're going to spend a good amount of time talking about that as well. I think many of our listeners will be interested to learn about Accessible Pharmacy. Alex, welcome to Eye on The Cure. It's great to have you.

Alex Cohen:

It's awesome to be here, Ben. Thank you for having me.

Ben Shaberman:

Thank you for joining us. To begin, tell us a little bit about your diagnosis with retinitis pigmentosa and how that influenced your life's journey and even your career.

Alex Cohen:

Well, from a very early age, I was always nearsighted and always had a great deal of difficulty seeing at night. My night vision was terrible. And as you progress, as you get older, more and more of your social life takes place in the evening. And I was finding that I was having a great deal of difficulty navigating, playing sports, being able to, for example, find my friends in a movie theater once the movie had already started or something like that, or being able to play football at dusk in the street.

And in my late teens, I received LASIK surgery and the problem with the night vision still persisted, even though my nearsightedness was all but gone. I am lucky to live and grow up in Philadelphia, Pennsylvania, a pretty established hotbed of ophthalmology and research. We went to Wills Eye Hospital to figure out what was going on, and they said, "It looks like you have retinitis pigmentosa."

I said, "Well, what do we do about that? How do we fix that?" And they were like, "There's not really a cure or anything like that right now, but there's a doctor in Massachusetts doing a lot of work in this area." And that's when I first became a patient of the late great Dr. Burstein at the Massachusetts Eye and Ear Infirmary, and became one of his patients involved in some of the earliest studies to see how different supplements and nutrition could help possibly halt the progression of my retinitis pigmentosa.

Of course, the diagnosis comes as a shock and a bit of a bummer, but I could still see at that time reasonably well except for my night vision and was really living my life and making the most of it ... With the knowledge that eventually the retinitis pigmentosa is going to kick in and rob me of my vision, but not yet. So I might as well not let anything at all hold me back, not fall into any kind of depression, finish my degree, pursue my career, et cetera.

And so, I've never really let it hold me back. There are certain challenges faced by having RP, but if anything, it gives me more strength and resolve. Being involved with the FFD allows me to have the power of positive thinking that hopefully RP is just going to be a temporary inconvenience, and we'll eventually find some remedy through different gene therapies or different things that the foundation is helping to work with.

Ben Shaberman:

Well, we appreciate your support of the foundation. You're one of the thousands out there who's driving the research through your support. I know you're active in VisionWalk and that means a lot to us. You were in college when you were diagnosed and early on in your educational journey you knew you wanted to be in the hospitality business. What was it that drew you to hospitality?

Alex Cohen:

As simple as this, I always loved traveling and always loved going on vacation and staying in hotels and especially resorts. I had an uncle who had run different hotels and resorts in St. Thomas and the Virgin Islands. I heard about what he did and saw him in action. What a great career opportunity. So I went to talk to my dad about it and said, "I think that this is something that I want to do."

So at the earliest opportunity, I believe I was around 15 years old, we knew somebody who owned the Warwick Hotel in Philadelphia, and I was able to get a summer job there as a front office agent taking reservations and answering phones and doing check-ins and checkouts. I thought it was fantastic and I loved it. That was really my first stop in my hospitality career progression. I really never looked back until eventually having to make a career change in my thirties.

Ben Shaberman:

And so, you got your bachelor's degree in hotel administration from UNLV?

Alex Cohen:

Yes. The University of Nevada, Las Vegas, if you can imagine, really does have a phenomenal program. For anybody who's been to Las Vegas and you get off the airport, you go down Paradise, and to the right is the UNLV campus and to the left is Las Vegas Boulevard and Tropicana.

My goodness, there are more hotel rooms on those four corners than the entire city of Philadelphia. It really is an incredible place to receive that kind of education and I loved it.

Ben Shaberman:

After you got your bachelor's degree, didn't you spend a good part of your time in Las Vegas professionally?

Alex Cohen:

After I graduated, I immediately got a position with Mirage Incorporated, working specifically in the Golden Nugget Casino and Resort, a lovely property downtown. And it was great experience and I really learned a lot there. The problem that I was facing is my night vision was getting a bit worse and I was feeling less and less comfortable driving.

Anybody in one of these western cities can tell you, you have to drive everywhere. Public transportation isn't terribly reliable or consistent. Even if you just wanted to go out and get a gallon of milk or something, you need to get in your car. It was getting pretty apparent that this was not a great place for

me, and that's why I made the decision to move back to a more pedestrian-friendly northeastern city. I moved back to Philadelphia.

Ben Shaberman:

You stayed in hospitality. In fact, you even moved deeper into that profession, because you ended up going back for a PhD in hospitality. I didn't even realize one could get a PhD in hospitality.

Alex Cohen:

No. So my PhD is in marketing.

Ben Shaberman:

Okay. Got it.

Alex Cohen:

What had occurred is I had reached a point in my career where it was going to be difficult to continue being a general manager of a hotel. I decided that I wanted to make a career change and I wanted to become a professor in a hospitality program.

I went back to school with the help of the Pennsylvania Department of Occupational Vocational Rehabilitation and Blindness and Visual Services, and went back to school at Drexel University and received my master's degree in hospitality management, with the intent of continuing on to a PhD in the business school at the LeBow College of Business going into the marketing program.

Because I wasn't going to leave Philadelphia. Although there are more than 200 different universities around southeastern Pennsylvania, there aren't really that many hospitality programs. Getting a PhD in hospitality, I don't think most people really do that. Those are available, but I think a lot of people go through business school and then return to hospitality that way.

That was initially my intention, and I got accepted and began in the doctoral program at Drexel, getting my PhD in marketing. And the opportunities, including the salaries, were a bit more expansive than they would be if I had stayed in hospitality. Now, I teach marketing and I teach courses in consumer behavior, sales and sales management, entrepreneurship. And I'm actually developing a course in hospitality marketing for my university.

When I'm using examples in my real life experience, it's still quite relevant. My students actually really understand my hospitality examples a bit more than maybe talking about retailing or pharmaceutical selling or something like that, because everybody has gone to a restaurant or gone on vacation, and has at their core a sense of what the hospitality business is all about.

Making the career change to becoming a professor was not an easy decision. Getting a master's degree takes a while and there is an expense to that, and getting a doctorate in marketing, it was a five-year program. Discussing it with my wife, "This is going to be a seven-year commitment to make this happen."

Ben Shaberman:

Are you primarily a professor now? Are you still in the hospitality business?

Alex Cohen:

I am not in the hospitality business anymore. I still love the hospitality business and still hold onto that enthusiasm for travel and going out to eat and special events and event coordination.

But primarily, I teach my marketing courses and I research. And the research I do is primarily focused on how to create a more inclusive marketplace for customers with disabilities. And that's actually what I had done my dissertation on, which actually eventually led to the creation of Accessible Pharmacy Services.

Ben Shaberman:

And that's what I'm very excited for you to talk more about. So tell us how you got Accessible Pharmacy off the ground. You came up with the concept. Maybe we should even start with that. Why did you think there was a need for such a business?

Alex Cohen:

While I was doing my research, I made a contact who is now one of my best friends, Andy Burstein, who is actually our CEO of Accessible Pharmacy Services. At the time, he was doing some work with his partners on creating an accessibility plugin that would work to make most websites accessible or more accessible. And so, I was doing some consulting work with him and he asked me a bit more about research that I was doing.

At the time, I had just completed a five-year study looking at analyzing and evaluating the accessibility of the online retail environment of the top 100 retailers in the US. Most businesses are woefully inaccessible for their online content. While we were looking through this and analyzing the data, you notice that pharmacies were particularly inaccessible, whether that was a standalone pharmacy or a pharmacy within a grocery store or a big box retailer.

What's going on here? Why are these so inaccessible? Whenever you get a good research question, you dig in. And so, we did more research and we started doing field research and going to pharmacies and asking at the pharmacy counter, "I'm blind. What type of accommodations do you have at the pharmacy for people who are blind?" You would get one of three possible answers, which is, "Well, we don't really have anything ..." It's a lousy answer, but it's an answer.

The second would be, "Well, I think that we can print out the labels larger for you," and maybe in some cases that could help. Or the best case scenario was, "I think we have something somewhere that might be able to read labels. I don't know what it's called. I'm going to have to look it up and see what that's all about." Or we would call the 1-800 numbers and ask them and they wouldn't have any clue and we would end up stuck in the voicemail hell trying to get a live person.

We conducted focus groups and all sorts of things to ask people what they thought about the pharmacy environment and its accessibility. And it's through that research together with me and Andy that the initial idea was created. And then, we found our third business partner, our chief medical officer, Dr. Jason Barrett, who has 25 years of experiences as a PharmD and was really the pharmacy healthcare arm of what Accessible Pharmacy Services has to be, which is first and foremost a premium healthcare company.

Ben Shaberman:

Right. I'm sure in talking about Accessible Pharmacy as you just have, you've peaked the curiosity of a lot of our listeners who have low vision or maybe no vision eyesight and are interested in the service.

How does somebody get access to Accessible Pharmacy? What's the process like for ordering prescriptions and what are some of the value adds that Accessible provides?

Alex Cohen:

Well, that's a multi-layered question, but I'm certainly happy to jump in. Anybody who is curious to learn more about Accessible Pharmacy Services is strongly encouraged to visit our website, which is accessiblepharmacy.com. We also have a 1-800 number. It's 888-633-7007. Again, that's 888-633-7007. I guess we should first talk about what Accessible Pharmacy Services is and what it provides.

We are a full service healthcare company that specializes in the needs of medication management and diabetes management for the blind, low vision, and deaf-blind community. The process is that each one of our patients, we look at as a unique patient, as a complete individual. Everybody has so many different characteristics and variables that from accessibility and blindness and medication management, no two people are really the same.

People have different levels of vision. They came to their malady at a different time in their life, different reasons. People have different support systems, different levels of education, income, where they live. Are people urban or suburban or rural? How many maladies or comorbidities could they be dealing with at one time? So not everybody is the same. Certainly, people are more complex.

For example, I have retinitis pigmentosa. I also have a little bit of high blood pressure and bad genes, so I take a statin for my cholesterol. But what I do is I receive my medication, I'm also a patient of Accessible Pharmacy Services. In the morning, I have a packet that is full of my vitamin A, my lutein, my NAC, amino acids and fish oil, as well as my blood pressure medication. And then, I have an evening packet that has my NAC and my cholesterol medication. So I'm a pretty easy patient.

There could be people who are taking pills in the AM as soon as they wake up, at their breakfast, at lunchtime, after dinner and before bed and have a pretty complex medication profile. But where it really all begins then is a phone call. You call Accessible Pharmacy Services, and it's a brief interview. We ask you about your level of vision and start asking about your medication history and what difficulties and challenges you may have experienced with your medication management in the past.

And then, we help identify the best ways to overcome those barriers, whatever they may be. For example, we have over 30 different types of packaging that we offer based on how many medications people need and how they need to be organized, as well as dozens of different labeling options from braille to large print, different contrasts.

We can print labels, I believe, in 200 different languages. We also have talking label options in, I believe, 50 different languages. All different levels of support in order to find what is going to help the patient be most compliant with managing their medications. So it really is a mix and match, but it all starts with a conversation.

You couldn't go to your primary care physician and say you want to start using Accessible Pharmacy Services, because we need to have that interview with you so we can explore what your needs are. We also have ... It is free home delivery and we have a continuous refill, where there's no break in the continuity of medication. It gets shipped out the same day each month, and will arrive at your home as expected the same time each month.

There's no break in the continuity of care. We go through and we refill. It's automatic refill, and we reorder the prescriptions for you on your behalf. We do everything. We take all of this on ourselves as a company and reach out to the prescribing physicians in the event that the refills are done, and in the event that the prescribing physician says, "Well, the patient needs to come in before we would do a reorder." Then, we'd go back and we'd communicate with the patient about what their doctor had said about their prescriptions.

But we try and take this off their plate. We try and alleviate the challenges and burdens of communicating with the primary care physicians or whoever the prescribers are. We want to run point.

We're the point guards for medication management. We want to make sure that the primary care physician, the oncologist, the endocrinologist, the cardiologist, the psychiatrist, everybody knows what everybody else is prescribing, because it's going through us to make sure that there aren't any negative interactions.

Also, something that we strongly promote for all of our patients is genomic testing, which of course, I know quite a bit about from FFB and My Retina Tracker. Getting those types of tests is really important, but the genomic testing makes sure to help us ensure that the patient is on the right medications that will be the most effective for them in terms of how they absorb it into their system or interactions it could be having with things in their diet or other medications or vitamins or supplements.

And then, in terms of vitamins and supplements, I did mention myself ... We can also, whatever packaging we find works best for the patient or what they find works best for them, can include any types of vitamins, supplements, over the counter medications. Anything at all can be included for convenience in those packets.

I remember what a pain in the neck it was just in the morning to open up the six or seven different things that I take just to do what I can to keep my RP at bay. That was a lot to throw out there, but I hope that would have answered the question.

Ben Shaberman:

Well, you answered the question very well, very thoroughly, and it's really remarkable how much your business does to help the customer. And it's customizable. When I think of a lot of services in today's world, the fact that you're tailoring the service to the needs of the customer, it's a remarkable thing. As I think about it, I'm not someone with significant vision loss. I want to sign up for your pharmacy just because of the great services you have.

Alex Cohen:

Well, what we find though is with any good universal design approach, if it works well for the blind, low vision, deaf-blind community, it works well for everybody who might have some difficulties. Or particularly seniors or people with a bit more of a complex medication profile as it were. So it really can benefit whomever wishes to take part or become part of our community. But really, what we strive for is the pursuit of accessibility.

For us, accessibility is not an afterthought. We don't do things in case the blind guy from the neighborhood comes in with his cane and we want to be prepared. This is a primary focus for us. A lot of that comes initially from my personal experience. But then, as we did more and more research and learned, we were continually learning from our patients of how to make things more accessible and new things that are coming on the market.

We test them out and we let our patients know that, "Hey, this is something that could work for you that's new in the marketplace." We offer a lot of educational webinars. We just actually had one last week on glaucoma, where we're looking at doing some on different mental health concerns within our population and many others throughout the year.

Again, people are encouraged to visit our website to learn more about the different webinars that we have usually every other month or so, but they have gained a lot of popularity. We want to be at the forefront of our community as it relates to healthcare and medication management and making sure things are accessible as possible from A to Z. From having an accessible website that works very well with screen-reading technology, all the way through the consumption packet, the consumption of the deliverables.

We've thought about accessibility all along the way. It's not just having an app that reads labels. That's not all there is to making healthcare accessible. There's so much more to it than that. And so, that's something that we've strived for and I believe that's a great differentiator between ourselves and the standard pharmacies that exist in the marketplace.

Ben Shaberman:

That's really awesome that you're making accessibility core to the business. My understanding is there's no additional cost for all that great extra service that you're providing. Is that correct?

Alex Cohen:

That is true. We accept all insurances. Now, insurance dictates your prices and your copays. What we find in the vast majority of circumstances, nobody's rates or prices or copays or anything like that would go up as a result of joining our community, becoming a patient of Accessible Pharmacy Services.

Now, there are those rare instances based on somebody's insurance where the insurance companies might make it more difficult to work with Accessible Pharmacy, because they have contracted with a specific provider. We do have some ways at times to help patients get around that, but that necessity is more of a rarity.

Ben Shaberman:

For somebody who's listening, who wants to get started, do you recommend they call first? And if you'd give us that number again. Or can they go to accessiblepharmacy.com and sign up there? What's the best first step?

Alex Cohen:

Two different things. Right? You could go to accessiblepharmacy.com and you could arrange to have one of our customer care representatives contact you at a time that's most convenient for you to answer any questions you have and help you sign up. It's not an online process to sign up to be a patient. We want to have a conversation.

Of course, again, people can always call our 1-800 line, which is 888-633-7007. Again, it's 888-633-7007. That's 888-MEDS-007. We would rather have a conversation, because there's nuance to these conversations. Also, our customer care representatives are specifically trained to work and be sensitive to the needs of people with varying degrees of sight loss and disability on the other end of the phone.

Also, our sales team is primarily made up of people from the blind and low vision community as well. This summer, we just had a new crop of interns from the community as well who want to learn about sales and the pharmacy business and marketing. We really are out there in the community, and so for those community-minded businesses, we are looking for your support and would greatly appreciate it.

Ben Shaberman:

Well, Alex, it's been really fun learning about your career and your launch of Accessible Pharmacy. I'm really heartened that you took your passion and chops for hospitality and marketing and accessibility and are really providing a valuable service for so many people with low vision out there. So thank you. Thank you for taking time today to talk about your background and what Accessible Pharmacy is all about. It's been a great discussion.

Alex Cohen:

Well, it's been a pleasure to be with you, and I'm so grateful for what you do, and of course, for what the foundation does. Certainly, keep plugging along. We're making a dent in the overall accessibility of the marketplace. Progress is slow, but we're getting there. We're making it happen.

Ben Shaberman:

Well, it sounds like you're off to a great start. Again, thank you for all you're doing, and listeners, thank you as always for joining Eye On The Cure. It's great to have you. Stay tuned for the next episode.

Speaker 1:

This has been Eye On the Cure. To help us win the fight, please donate at foundationfightingblindness.org.