

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:

Welcome everyone to the Eye on the Cure Podcast. I'm your host Ben Shaberman with the Foundation Fighting Blindness, and I am delighted today to have as my guest, Dr. Sanford Greenberg, who from here on out, I will call Sandy, if that's okay with you, Sandy.

Sandy:

Absolutely.

Ben:

Okay, well welcome to the podcast. It's really wonderful to have you.

Sandy:

Thank you so much, Ben.

Ben:

So a few years ago, Sandy came out with a very powerful memoir that chronicles his life, including going blind pretty quickly at the age of 19. And the memoir is titled Hello Darkness, My Old Friend. And for those of you who aren't perhaps that old, those lyrics are from the brilliant song Sound of Silence by Simon and Garfunkel. And there's a connection there to Art Garfunkel, and we'll talk more about that. But the book includes A Forward from Ruth Bader Ginsburg, an intro from Art Garfunkel, and a final word from author Margaret Atwood.

And I want to say I was really captivated by Sandy's story and a lot of my questions for Sandy are based on things that I read in the book. And before we get into a conversation, which I want to do quickly here, is to just review some of Sandy's really incredible and numerous accomplishments. You got a bachelor's and master's degree from Columbia, an MBA, Columbia, New York, an MA and PhD from Harvard. He was a Marshall Scholar at the University of Oxford in the UK. He was a White House fellow for Lyndon Baines Johnson when he was president back in the sixties. And then Sandy went on to launch a company for a device that compresses speech. So people who use audio recordings, people with vision loss often, they can listen to them more quickly. And I think those of us who are around people with low vision who use these technologies often hear the very fast speech. And Sandy, you were on the forefront of that several years ago.

Sandy also launched a company called EDP that helped develop the onboard computer system for Apollo 11's lunar excursion module. So this is the little spacecraft that landed on the moon on July 20th, 1969, a very iconic and memorable moment in US and world history. I'll continue here. Sandy is chairman with the Board of Governors at Wilmer Eye Institute at Johns Hopkins. He's a fellow of the American Academy of Arts and Sciences. He's on the Council of Foreign Relations. Sandy, I'm not sure if you're still on that council, but you were.

Sandy:

Yes, I am.

Ben:

And the list goes on. And the one thing I want to spend some time talking about at the end of our conversation is his campaign to end blindness, a very generous program to raise money to end blindness. So Sandy, you were born in Buffalo and you had a modest upbringing in a Jewish household. Your parents, it seemed were strongly influenced by the Depression in World War II. Your dad was a junk dealer. Can you just tell us a little bit about what it was like growing up in Buffalo as a kid?

Sandy:

Be happy to, Ben. I grew up in a benighted area of Buffalo, New York. We lived in a flimsy wooden house, but I had the strength of four people behind me that, to this day, made it possible for me to accomplish whatever it is that I have accomplished. My father, Albert, escaped Nazi Germany in 1939. He was a tailor and a very good one. Every night at six o'clock, my mother and I would walk to his little tailor shop and bring him dinner. And we had some sweet times together, but not nearly enough because when I was five, he died and his death devastated me. He left my mother, Sarah, with \$54 to raise three children under the age of five. And my mother was a resolute, quiet, deliberate, thoughtful human being who given what she had been through, as you pointed out, the Depression and World War II had this skin for grimness.

And unfortunately, in many ways, grimness followed her through the rest of her life. One of the most painful situations for her is when I lost my eyesight and she was by my bedside to see this happen. My grandmother lived with us. She was like a second mother. At eight years old, she was living in Poland and babysitting and a spring from a cradle burst into her eye, causing her to have a glass eye in the future. She came from a little nowhere place in Poland, somehow was able, this frail woman, to get to London, operated a candy store, came to Buffalo, New York and settled there where she raised my mother. And I think it's fair to say she raised us as well, my brother and two sisters.

My father, Carl, who you mentioned before, married to my mother several years after my first father passed away. He was, as you pointed out, a junk dealer, which wasn't particularly glamorous, but without him we would never have been able to move from the poor neighborhood we were in at the beginning of our lives to a very fine respectable area. It wasn't Fifth Avenue or Park Avenue, but it was certainly much nicer than the environments we grew up in. He, too, was slighted by an incident which took his right eye. A disgruntled employee hurled a brick at him, catching him in the eye. And so just like my grandmother, Pauline, he needed a prosthetic. He was stronger, more powerful than me in almost always he was made of iron because he had to be.

And with these four people that I grew up with, they afforded me an environment of richness and warmth that has stayed with me to this day. And I will be forever grateful for their not only physically raising me, but provided me with a set of values that I garnered by simply watching them live. There were no sermons, no advice, no counseling. I simply saw the way they worked, which was very hard, very long hours. They helped the community. My father, Carl, always signed for one of his neighbors who needed a mortgage. They gave charity when in many respects they didn't have anything to give. That's a long answer and I apologize for it, but that's where I grew up.

Ben:

Thanks for sharing that background. And I think reading the book, one learns that you are a very determined soul, but you can see in part where you get your determination, which we'll learn more about. So you go on to make it into Columbia University in New York, that's a pretty impressive achievement, especially given your modest roots. And one thing I loved reading in the book is just the

adventure and the camaraderie you had with your friends, your college life. You had really an insatiable passion for learning and intellectual adventures. I mean, you're in Manhattan at college age, what could be more exciting? And you really have this great group of friends, including Art Garfunkel, several years before he becomes part of the iconic Simon and Garfunkel. And can you talk about your relationship with Arthur, because that's an important thread throughout the book and your life, obviously.

Sandy:

Yes, I'd be happy to. I met Arthur in freshman orientation week 1958. And for some reason shortly thereafter he became a very good friend. We went to class together, we studied together, we had a group of similar friends, and one day we were completing a humanities class. As we walked onto Amsterdam Avenue after class, he asked me to come and look at a patch of grass and he said, "Sanford, look at this patch grass. Seriously, look at it." And he then delivered what I'd call a disposition on how the light influenced and illuminated the beauty and complexity of the colors of the grass. And I was stunned because my other friends, we could call them jocks or eggheads or whatever, who always talked about sports, women, occasionally homework, here's a guy who's showing me a measly patch of grass and telling me how beautiful it is.

But it was that small incident which changed my view of nature forever and indeed my way of experiencing life itself. And that bound us together for life. Shortly thereafter, he came over to me and said, "I think we should be roommates, and I'll give you five reasons." And I was stunned because I had no expectation of doing that. He said, among other things, "You and I will create a pact that if either of us is an extremist, the other would come to his rescue." Little did I know that a couple of years later, that would be one part of my salvation. And so we roomed together the remaining years, and as you say, we participated in the delights of Manhattan. He brought his guitar to school, I brought my drums, and at night after homework, we would play and sing rock and roll largely. I was the DJ and we recorded what we sang. And it turns out that for a very large birthday of his some years ago, I had taken the tape, which I kept from college and put it on a cassette and labeled it Sanford and Garfunkel, 1958.

Ben:

That's great. You got to jam with Art before Paul Simon, that's a great distinction.

Sandy:

Yes, yes.

Ben:

So it's your junior year of college. Things are going along really well for you in college and with the friendships you described and you're having this issue with your eyes. They're irritated, they're itchy, and the doctor prescribes some steroid drops and that's where things take a turn. Can you talk about what happens next and the ultimate diagnosis?

Sandy:

Sure. It started when I was pitching in the baseball game in the seventh inning where my eyes clouded up. Things became intensely steamy. I almost hit the batter and I stumbled to the sidelines and fell to the ground. Fortunately, my girlfriend, Sue, who is a major participant in the book, as you know, I believe she is the hero of this book, not me. I say that because she had a choice to stay with me or not. I had no choice. So hers was a degree of morality that has always amazed me and has been a blessing to

me my entire life. In any event, the topical steroids, which the ophthalmologist gave me caused me to lose my eyesight. From the time I got back to Columbia in September '60 until my final exam in January '61, it was as though there were brooding on the presence in the sky watching me and then the thunderclap of blindness on that final examination day.

And then I went to Detroit with my mother to try and resolve the situation. The doctor who saw me after examining me looked at me and said, "Well son, you are going to be blind tomorrow." And I had no response. I sat there frozen and my stomach in knots. I wanted very much to hit the doctor, but my mother was sitting right next to me when she heard this news. In short, he told me that he was going to have to operate on both of my eyes because of the severity was such that couldn't take the risk of just doing one at a time. And so the following day as he had predicted, I was blind.

Ben:

What you had was a case of glaucoma that went undiagnosed or misdiagnosed, and it was the steroid drops that worsened the glaucoma dramatically, basically destroying your optic nerves. Correct?

Sandy:

Absolutely correct.

Ben:

It's mind-blowing. Absolutely mind-blowing. So in the book, you talk about those four days in the Detroit Hospital where you just had the surgery you talked about, and you go from relatively good vision to no vision almost overnight. And tell us about what it was like sitting there in the hospital with your mom for those four days.

Sandy:

Needless to say, to call it the winter of my discontent is an understatement. It was February in Detroit, Michigan, icy cold. And inside this hospital room, my mother sat at the foot of my bed and she had just seen her eldest son go blind, his eyes cut open. To me, that pain, knowing what she was going through at that moment was the worst pain I've ever experienced. It had nothing to do with me or my feeling sorry for myself about my condition. It was all about this horrific thing that had happened to my mother and how she was going to survive raising four kids, taking care of my father. And this is why I said earlier, my mother had the skin for grimness. That's what it was like.

Ben:

Right. And I think for our listeners to understand, this all happened in 1961 and there was no social worker, rehab, counseling. You're just sitting there with your stoic mom trying to figure out a path forward. And you leave the hospital, you go back to New York and you're faced with the daunting question of what do you do next staying on at Columbia? Because you were a junior if I-

Sandy:

Yes, you're absolutely correct.

Ben:

And then ultimately, as I noted in the introduction, you got a couple degrees from Columbia. So you did move forward, but that was an agonizing decision about what to do next. Can you talk about who and what influenced you to move forward in that path?

Sandy:

Yes. I should also tell you, which we can come back to later, that I promised myself something in that hospital room that I'd like to discuss later. But what happened is that I returned to Buffalo with my mother and I was in a terrible state of disrepair or despair, and I didn't want to see anybody, my friends, my family, because I sat there in frigid isolation. I didn't want to be seen and I didn't want to talk about my circumstance and I refused to have anybody come and visit me. But Arthur, bless his soul, flew into Buffalo and he said, "Let's take a walk." So we walked down the avenue, I lived down and he said, "Sanford, you're coming back to school." I said, "Arthur, you're crazy. There is no way on earth that I'm going to be able to come back to school. Can't you see I'm blind? I have no resources. I'm going to go to Manhattan and get killed. No sir."

And he tried to lighten up the conversation as he always did whenever we spent time together. But to no avail, I just was convinced that there was no future for me. I had no eyes, I had no money, and I, therefore, had no future. But he persisted. And halfway through perhaps a little more of our walk, he said, "Sanford, let's talk about the Greeks, the classics that we studied in school. You remember Sophocles' Philoctetes. He was marooned on an island. His festering leg kept him from leaving the island, but the gods had given him armamentarium that could conquer anyone he wanted to conquer. And he, in fact, did together with Odysseus, they conquered Troy." Arthur said, "Sanford, why don't you come back to New York with me and conquer Columbia?" For some reason that struck me with such force that I couldn't really respond because anyone else in the world that told me that little story, but it would've been meaningless. But his credibility and his decency and caring, which was always there from the time we first met, took my breath away.

And when I went back home, I sat down with Sue and I said that I was considering a return to the university. And she said, "How are you going to do that?" I said, "I don't know. I just think I have to go back." Her parents and my parents suggested that we get married so Sue could go back to New York with me and help me out. And I said, "No, if I go back to New York, I have to do it on my own to prove that I can live an independent life." But she was as supportive as Arthur, quite to the contrary of my parents who were violently opposed to my returning. They told me that if I returned to Manhattan, I would be killed either by a bus or falling into a manhole or some other freak accident. And in any event, she said, "You don't have the resources and we don't have the resources to make that possible." That was one of the most difficult decisions I ever made, particularly because of the opposition of my parents.

Ben:

But thankfully, you moved forward because you went on, as I said in the introduction, to accomplish so much, degrees from Columbia, Harvard, you went to Oxford, the companies, the White House Fellowship, really amazing stuff. And I remember in the book you mentioned all those readers that you had in school because back then there wasn't books on tape. You had to have all those readers read to you or have things recorded. And I think they deserve some recognition as well.

Sandy:

Oh my God, just a special note, they surely do. Those people made it possible for me to go through academia the way I did. I'll tell you interesting story. Margaret Atwood, who was a very good friend of

mine and who wrote the final word as you know and she and I met at the World Economic Forum 10 or 15 years ago. And when we first met, she noticed that I had an eye problem. And she said, "When I was at Harvard, I used to read to blind students." It turned out that she was at Harvard at the same time I was. But she and I never connected.

But as soon as I heard that, I knew that she was a person of immense decency and probity, which is what I feel about all the readers who took time off to read to me. You're in a competitive school, taking off an hour or two a week means you can't study, means you can't date, you can't rest. It was quite a sacrifice. And fortunately, many of the readers I had have become lifelong friends. So I cannot speak too highly about the group of human readers that essentially help save my life.

Ben:

Yeah, they are pretty incredible selfless people.

Sandy:

Yes, sir. Good word.

Ben:

Yeah, it's a very compelling part of the book. Again, we've talked about your many accomplishments and in reading the book, there always seem to be a little bit of, if I can call it this, self doubt or questioning yourself like have you accomplished enough? Is there more you could do? And now that you've gone through this really glorious career, can you point to a moment where you feel like, hey, I finally made it. I've achieved what I set out to do, although you really didn't have a specific goal in mind.

Sandy:

There was a moment which I discuss in the book where Arthur and I did a reprise of a trip. He induced me to take on the subway alone while we were still in college. And the National Geographic was doing a story, the cover story was the End of Blindness and they wanted to feature my story. So they asked if I would walk through the subway system that I had gone through alone in 1961 and this time go with Arthur arm in arm, which we did. And we got back to campus and I could see standing on one of the steps there, the past 50 years float before me. And for the first time in my life, I felt proud of what I had accomplished. And it was a very good feeling.

Ben:

And that happened when you-

Sandy:

2016.

Ben:

Okay. So not too long ago, six years ago.

Sandy:

Right.

Ben:

Yet that chapter, if it's a whole chapter, where you decide, well, where Arthur lets you try to get back to campus across town on your own without a cane or a dog, that's a really moving story. And I'll encourage readers to get the book to read that passage because it's very powerful. So I want to move on to something else that's a common thread in the book, especially the second part of the book is your passion for imagining things and for ideas. Taking a quote from the book, you say, "After a half century of thought, I've come to the conclusion that the only worthwhile things are people and ideas." And there's another quote that supports that quote even further. You say, "To experience the beauty of an idea is to experience pure joy." And your mind is always looking forward and thinking of new things. It's really remarkable. Can you talk more about that passion for ideas that you have?

Sandy:

Yes. I think that I would broaden that a bit. My mentor, David Rockefeller, once asked me casually at lunch, "How did you do it, Sandy?" And I was stumped. I didn't know what to say. I sat there, must have been 10 seconds or so, which is a long period of time to be silent in response to a question. And I blurted out, "I chose life." And the passion, yes, for ideas for sure. But going back to that patch of grass that I talked about in our freshman year at Columbia that Arthur introduced me to is what would I find simply amazing about this life of ours.

I know this may sound like I'm not answering the question directly, but let me just give you one of my favorite quotes from Einstein. He said, "The most beautiful experience we can have is the mysterious. It is the fundamental emotion which stands at the cradle of true art and science. Whoever does not know it can no longer wonder, can no longer marvel, is as good as dead and his eyes are dim." And to me, unless you can experience the magic of daily living, the magnificent gargantuan essence of it, the beauty and the joy that can be uncovered by any of us on any day, walking with the person you love, being on vacation with your family, or in my case, I like to stand by the banks of the Potomac waiting for something extraordinary to happen. And it always does.

Ben:

That's great. I love the Einstein quote, a wonderful quote. He was quite a humble guy given all he knew.

Sandy:

You bet.

Ben:

So you mentioned this earlier, back in Detroit and the hospital when you first went blind, in the book you talk about the "deal with God" that you made and that leads forward to really your campaign to end blindness. Can you talk about that?

Sandy:

Yeah. It was really a promise I made to God when I was a total extremist. And I said that if I recover, then I will do everything I can to make sure no one else would go blind. Now, in 1961, that really was the height of absurdity, that I couldn't share that with a lot of people because they would think that I have, as I used the phrase, slipped my moorings. So I kept it to myself and just a few people, obviously my mother and family and Sue and Arthur and Jerry. But science wasn't helpful in the sixties or seventies or eighties or nineties. And it was only until this century that it appeared to me that we might have a shot

at trying to do something serious to end this scourge. Now look, this affliction has been with humanity for more than six million years.

Billions of people have been affected over these centuries. We've lost so many Churchills, so many Mother Teresas, so many Gandhis. And we stand to lose more in the centuries ahead. And while there has been significant progress technologically, Louis Braille did something significant to help blind people. Thomas Edison did something significant to help blind people. Hopefully, my compressed speech machine has helped some blind people. But there are products, technological products, that improve the quality of life of blind people, as well as cited obviously, but it doesn't get the blind employed. More than 70% of blind Americans are unemployed. It's unspeakable. And so my conclusion is that we, as a civilization, have no choice but to end this. As I said many times before, this is human kinds oldest cruelty. And to me it seems to be a subversion of the creator's intent. So we must, given all of our knowledge and resources garnered over the millennia, to address this.

And so Sue and I started the campaign in 2012 with the help of some of the most distinguished scientists in the world and some of the most important civic leaders in our country. And we decided to award prize to the person or persons contributed most to ending blindness. And in December 2020, we had a ceremony and our scientific advisory board and governing council agreed that there would be 13 prizes given to 13 extraordinary scientists from all continents. And subsequently, Sue and I were asked by Johns Hopkins if we would create the Sanford and Susan Greenberg Center to End Blindness. And to me, that's really the opportunity of a lifetime to try and fulfill my promise to God.

Ben:

That's awesome, Sandy. And can I ask how much you've raised to this point for the center and the campaign?

Sandy:

Our goal is a hundred million and we've raised two-thirds of that.

Ben:

Wow. Incredible.

Sandy:

Well, I think people recognize, you see, it goes beyond just blindness. As you may know, once you get into regenerating the optic nerve, you're opening up the entire central nervous system. And once you are dealing with the central nervous system, you have the possibilities of dealing with Parkinson's disease, multiple sclerosis, and ultimately Alzheimer's. So the implications of this are not just simply oh, we'll end blindness and it stops there. No, it's a much broader canvas that we're painting on.

Ben:

Right. The eye, specifically the optic nerve and the retina, their extensions of the brain and the central nervous system. So what we learn in addressing those conditions can potentially help people with myriad other neural issues. So that's really wonderful. Sandy, on behalf of our constituents, many of whom are losing their vision or have lost their vision, I want to say thank you for being so honest about your story. It has not been an easy journey. You've accomplished an incredible number of achievements, you've done so much. But in reading the book, it was never easy. And I know a lot of people listening to this podcast are dealing with a lot of those same issues now. But I also know that people listening are

grateful for your commitment to trying to end blindness and the generosity of you and your wife in striving to do that. So thank you, again, from me and all those constituents out there who stand to benefit from what you're trying to do.

Sandy:

Thank you, Ben. It was a pleasure being with you.

Ben:

It was a pleasure talking with you. Again, for our listeners, the book is called Hello Darkness, My Old Friend, those lyrics from Sound of Silence and you can get the book on the usual websites and outlets, Amazon, et cetera. And Sandy, thank you, again, for taking time out of your, I'm sure, busy schedule to share your story. It's been a lot of fun. It's been great to talk to you in person after reading your book. And I wish you the best moving forward with your family and Sue.

Sandy:

Thank you so very much, Ben. You are a very gracious person and I appreciate your sensitivity to all the items we discussed.

Ben:

It's my pleasure and privilege to talk with you, Sandy. And listeners, thank you, again, for tuning into another episode of Eye on the Cure, and please come back for the next episode. Thank

Speaker 1:

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