

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 Eye on the Cure. I'm your host Ben Shaberman with the Foundation Fighting Blindness. And for this episode, I am delighted to have as our special guest, author, and journalist, Frank Bruni. Welcome Frank. It really is wonderful to have you on the podcast.

Frank Bruni:

Well, thank you for having me.

Ben Shaberman:

So before we get started, a little bit about Frank. He's been a staff writer for The New York Times for more than 25 years, and at the times he has been an op-ed columnist, a restaurant critic, Rome bureau chief, and a White House correspondent. And Frank's authored several books including three New York Times bestsellers, one of which is titled, which I chuckle every time I say this. It's titled Born Round: The Secret History of a Full-Time Eater. And someday I want to hear more about that book, but we're going to hear about his latest book shortly. Lastly, in 2021, Frank became an endowed journalism professor at Duke.

So we're going to spend much of our time talking about Frank's latest book, The Beauty of Dusk, which is about vision loss. But Frank, my first question to you is what did you want to be when you were growing up? What did you think you were going to be? Because what you do now is such... You do such a variety of things and you seem like a restless soul, or perhaps you just need variety and new challenges all the time. Can you talk about that?

Frank Bruni:

Yeah, I didn't really ever have a plan. I'm not someone who is, as a kid thought, "Oh, I'm going to be a rocket scientist, or I'm going to be a doctor, or I'm going to be an actor, or anything like that." I just... I was a good student. I figured I would come upon something at some point. And both at the end of high school and in college, I was doing a lot of writing for school, literary magazines, school newspapers.

And a certain point in time I realized, "Oh, well there are people who make their living as journalists, as writers." And I stumbled into it that way. But I am a restless person. The kind phrase for me is I'm a jack of all trades, the less kind one, but equally accurate as I'm a dilettante.

And I think what I'm good at, if I'm good at anything, is getting up to speed quickly and learning things quickly. And so I've taken advantage of the many different genres and by ways of journalism to constantly be learning new things, and tackling new beats, and building a lot of variety into a writing career.

Ben Shaberman:

Well, you're clearly prolific as well because you've had so many different writing gigs, you've written so many books. And in the Beauty of Dusk, which I thoroughly enjoyed, you really cover a lot of grounds. So what you were just saying about learning new things and asking questions was pretty evident in the book. So let's talk a little more about the book and what inspired it. And basically your life took a turn in

late 2017 when you woke up with some blurred vision in one eye. And can you just tell us what happened next?

Frank Bruni:

Yeah, well, as you said, I woke up one morning, it was a Saturday morning. I remember that well. And there was clearly something wrong with my vision. It took me a bit to realize that what was wrong was that I was not seeing properly or well at all out of my right eye. And it was as if somebody had deposited like a smear or a blob of jelly in my right eye.

And I had no idea why that was the case, what was happening? I assumed initially that it would probably just resolve itself because so many things do, you have a neck crimp, and then it's gone. Your ankle hurts, and then it's a little better. But when 48 hours later nothing had changed, I found myself in the office of my normal eye doctor who examined me and said, "This is I think, I'm not sure what this is, he said, but I'm pretty sure it has to do with your optic nerve."

And so you should probably see a neuro-ophthalmologist. I didn't even know there was such a subspecialty. And over the course of basically the week and a half following, waking up that morning with strange, blurred, compromised vision, I learned that I'd had a stroke of the right optic nerve. The specific condition that applies to what happened to me is non-arteritic anterior ischemic optic neuropathy, which is so many syllables that people just usually say N-A-I-O-N.

And the optic nerve behind my right eye had been ravaged. There is no cure treatment for healing ravaged optic nerves. But I found myself in relatively short order in two successive clinical trials, successive but not successful. Both of them were suspended even before they reached full enrollment because people were not getting great results.

But before they were suspended, I was first in a trial where I was receiving injections in my right eye, and then I was in a trial where I was giving myself twice weekly injections for six months of an agent that they hoped would regenerate growth and damaged or dead into nerves, but it didn't work. And all of this was a medical odyssey that prompted many psychological challenges, many emotional questions, and those challenges and those questions felt to me both universal and fitting for a book.

Ben Shaberman:

Most definitely. And you definitely went through an emotional journey of... As you said at the beginning, not being too worried about this to trying to figure out what it was, and then realizing that there really wasn't a whole lot you could do after those trials. But one thing that emerged in the book, a theme that I thought was really powerful was, well actually there were multiple themes, just the idea of dealing with fear, the unknown vulnerability, entropy, and just general aging, which connects to all these other things.

We just fall apart as we get older. But obviously this eye issue is a little dramatic, but all these themes that are woven into the book are pretty universal, whether a person has a significant disability or not. And at one point you write, "Why should any of us be spared struggle when struggle is a condition more universal than comfort, than satiation, than peace maybe, than love?" And I found that to be a really powerful and important revelation. And I was just wondering if you can say a little more about that.

Frank Bruni:

Sure. First I should say something I forgot to say before, and you rightly said, I was dealing with the unknown. And I neglected to say that in that crazy week and a half of tests and doctors and interesting and unexpected news, right after I woke up with compromised vision, I was told that although doctors

aren't totally sure because the population of N-A-I-O-N patients is not huge, I was told there was a 15% to 20% chance that this would happen to my left eye at some point.

And I've since met many people who've had N-A-I-O-N happen to both of their eyes. So it's basically told there's a 20% chance that I'd go blind. And at first I thought, "Wow, what do you do with that? How does one process that, how does one be prepared for that but not be consumed by worry about that?"

And then I realized, and this goes to your question just now, that it was essentially, I was no different than anybody else. I was essentially dealing what we all do, but it was writ large and it was writ immediate. None of us knows what is going to happen to our health or what's going to happen to us medically down the line. All of us can pretty much assume something challenging, disruptive, maybe cataclysmic will happen.

And so we all live in a state of limbo in a certain sense, and all of us in small ways and large ways has all of us have to figure out to what extent we gird and plot for future difficulties and to what extent in the service of happiness today and in the service of an unencumbered life, to what extent do we just seize the moment and not sweat the disasters that may be coming.

And I think figuring out that balance, striking that ratio, that's one of the real challenges of life, and I realized in that sense I was going through, again, a version of that writ large writ immediate, but one that the experience of it and the lessons that would come from it were quite universal. And that's what convinced me it was worth thinking more about and writing about and maybe even putting a book into the world about.

Ben Shaberman:

And I think that's why the book is so powerful, your own personal journey of vision loss and trying to figure out what was going on and resolve it. That's all pretty traumatic and it's a good story, but you really pull out these universal themes of the fact that as we go on in life, we're subjected to things that we can't control. And as we get older, things are going to happen. But your book also has some really good insights into the science.

I was very impressed at how deep you could go into some different science topics and you don't get overly technical, which I think is really important. But one thing you talk about, which I thought was very interesting and especially important for a lot of our listeners who have vision loss, and that's brain plasticity. And I love the following excerpt from the book that you wrote on brain plasticity.

It's elegant writing, but I think it's an important concept. And you say, "Our emotional and spiritual circuitry is also at work drawing forth the extra care and extra cunning that an absence of basic function demands." The tiny victories that I experienced in my own daily life and the titanic ones that I read about in profiles and biographies of more remarkable people usually lay at some confluence of wiring and wilds synapses and soul.

It's just beautiful writing. That's one reason I wanted to read that, but I think it's an interesting insight into, again, brain plasticity. Can you say more about this insight and maybe give an example or two of how you've adjusted to this new way of navigating the world?

Frank Bruni:

Yeah, sure. Well, I mean brain plasticity is a very particular thing as you know, but I'll just say a word about that first since maybe some of our listeners don't. But brain plasticity or more formally neuroplasticity is basically the science and people are learning a lot of how the brain grows, rewires itself, changes in response to circumstance, in response to challenges, often in responses to deprivation.

There's anecdotal evidence and more than anecdotal evidence of people who lose the acuity of one sense and gain acuity with another sense because the brain is in a sense remapping and rewiring itself to take advantage of the stimuli that it can still respond to. And that's a scientific thing, but it's supplemented by, I think, matters. As I said in that passage, you read by kind of matters of will and matters of cunning.

And I'll give you an example. After I lost most of my vision in my right eye and was sometimes experiencing vision challenges because my brain wasn't editing out my right eye correctly, or sometimes just the phenomenon of my monocular vision means my depth perception is out of whack and stuff like that, I became better and better at using the more limited visual information available to me with only one eye.

I was sometimes seeing things I'd never seen with two because I was just being more alert and observant and being hungrier for the information that I could give me. And I remember in the years right after this happened, I was sometimes at night running in Central Park with my dog, and I would sometimes run at night around the bridal path or along the bridal path, around the other path around the reservoir in Central Park.

And the bridal path can be something of a moonscape, there're craters, bumps whatever. And so it's not the most intelligent or cautious thing to run it at night. It's also not consistently, it's very inconsistently illuminated. I was better than I'd ever been in my entire life at looking at that surface ahead of me at noticing the craters, noticing the bumps.

And it was not because my vision had improved quite the opposite, but my brain and then my will with my brain, were doing something about taking the available information, being much, much more alert to it, being much more concerned with it. And in that way, actually navigating it better than I had before. It's very difficult to describe, but that's my best stab at it.

Ben Shaberman:

So that's interesting. Despite having less vision, you were more perceptive of your surroundings and-

Frank Bruni:

Yeah, now, you have exactly. Now there are limits to that. That can sound fairly pollyannish, I still have from my left eye, I have significant vision and useful vision, but I was just making, I routinely make much better use of the vision I have, or I bring other supplemental things into play.

I tell a story that's too elaborate to go into here, but I tell a story in the book about dropping, essentially dropping my black iPhone in the middle of a forest at night and having it run out of battery at the same time so that I couldn't just say, "Siri, do this and wait to see where it power or if it was lighting up beneath the leaves.

And I found the iPhone and I found it by hatching various strategies to retrace my steps, remembering other visual landmarks that I thought might be near where I'd lost it. And I was just much more determined and much more creative than I think I would've been in less desperate straights.

And that's another example of the way we as people are just so nimble and adaptable and ingenious. And I tell these stories and I wrote the book in large part cause there's nothing unusual or extraordinary about me to the extent that I hatched some very good adaptations or showed some nimbleness. I'm an example of what anyone can expect or do not of someone who transcended in some extraordinary way.

Ben Shaberman:

Right. And I appreciate your humility, but what surprised me about the book is the story starts off with you and your vision loss experience and things leading up to that. You had some other events in your life that were also a bit challenging, but I don't know about a third of the way through the book, you start telling the stories of so many other courageous and inspiring people that either had disabilities or some significant health challenges.

The book really became less about you. And what I'm curious about, did you set off to write the book knowing that you were going to write about all these other people and personalities? Or did you just naturally migrate to that?

Frank Bruni:

A little bit of both. That's really hard to answer because they happened synergistically, simultaneously, and symbiotically to be ridiculously alliterative. I logically when this happened to me, I logically began as a kind of function of my own desire to handle this as best possible. I began talking with people around me whom I knew had been through significant medical challenges or significant analogous struggles of other kinds, and asking them, how do you deal with uncertainty?

How do you deal with the fact that you suddenly have limits that you didn't have before? How do you escape a sense of self pity? How do you turn, why me into a more productive question? And as I was doing that in a very organic sensible, natural way for myself, I realized that I was engaged in a fundamentally journalistic endeavor of the kind that I'd spent my whole life doing.

I was interviewing people, I was gathering their stories, I was thinking about their stories and looking at their stories for clues as to what other people could learn. And that naturally made me think, wait a second, this is a logical approach to and structure for a book. And so as you correctly pointed out, my book starts with me and what's happening to me. But as I gather information for my own use, I realize I'm gathering information for much wider use.

And I realized that I'm the person in a narrative that a long time ago in literature would've been called a picaresque, I guess, where I'm going from one situation to another situation, one person to another, and I'm picking up stories and wisdom that are worth relaying. And that becomes the arc and the structure of the book. And it was both an organic thing and something that as I realized its applicability became an intentional book oriented thing.

Ben Shaberman:

Right. And I think that's very powerful because first of all, I don't think well as the reader didn't expect that, but by doing so, you just added to the universality of it. And you just had so many intriguing personalities, people that were dealing with some pretty tough situations, but were making the best of it in pretty remarkable ways. And there were many stories I enjoyed.

One of the stories was of Judge David Tatel, who I did a podcast on earlier this year. And he's basically had no vision for decades and he's been a very prominent, successful federal judge. There's another story of the former lieutenant governor of Washington State, Cyrus Habib. And his journey has been pretty remarkable. Can you give us just a quick overview of his journey?

Frank Bruni:

Yeah. Cyrus Habib, so as you said, Judge David Tatel, he lost sight in his early 30s from retinitis pigmentosa. Cyrus Habib lost his sight at the age of eight in connection with a childhood cancer or cancer that afflicts children. And that takes away their sight, that affects their eyes. And not despite that

blindness, but he would say because of it, became a determined overachiever. He wanted to show the world all he was capable of.

And of course, he was capable of so very much because people are, people who have vision impairment, people who have hearing impairment, they don't cease to be incredibly capable, brilliant people who do great things. And Cyrus went to Columbia as an undergrad, got a Rhodes Scholarship, went to Yale Law where I think his roommate, or at least his best friend there was Ronan Farrow, interesting small world.

He then went into politics and in his late 30s, he was lieutenant governor of Washington State, which was a very high position for someone of that age, put him on a track on trajectory to be the governor of Washington. And if that had played out, he would've been the governor of a significant state at a very young age. And so we're talking about somebody at the pinnacle of American politics as a blind man.

And he decided to turn his back on all of that because he felt like he was letting too much of his life be driven by this need to achieve that it was in part, a defiant like I need to achieve and show people there's nothing I can't do. And he wanted to do something that in his estimate was more soulful. He wanted to stop looking at how to impress people and focus more on how he might serve people in a more immediate way.

And he decided to take vows to become a Jesuit priest. And he left politics, he left his lofty political station, he renounced most of his material possessions, and he is in training to become not just a Catholic priest, but to become a Jesuit, which is a more arduous course and a much deeper commitment.

Ben Shaberman:

Yeah. That's an incredible story whether somebody has vision loss or significant health challenge or disability, that really made an impression on me. So thank you for taking time to talk about your book and your journey. And just my last question to close things out, how are things now? Are you doing okay and what's next for you? I mean, you've done so many things over the years and you've had this more recent challenge. Is there anything on the horizon that you want to tell us about?

Frank Bruni:

I'm teaching now full-time at Duke University. I had another book in the works, but not one that I'm ready to talk about. Not one that has anything to do with vision loss. Things are good. I relocated from New York to Chapel Hill, North Carolina, which has a sweet homecoming aspect to it because I went to college here, I slowed down a little bit, but not as much as I thought I was going to slow down. I'm still pretty busy.

Things are good because I really approach life in an altered way. I realized when this happened to me, that one of the fundamental decisions I had to make, one of the fundamental emotional settings I had to decide on a master was whether to be someone who was focused on and tallied his losses, or whether I was someone who focused on, and celebrated, and savored, and felt gratitude about his blessings.

And I've learned in a way that I hadn't learned earlier in my life to be that person who is grateful, who celebrates all he has. I will never read as fleetly as I once did. I will never write with this few typos. I will never pound on the keyboard with this few typos as in the old days. And there were moments early on when that made me very angry and very sad.

But I'm someone who still gets to write for a living, who has publications, editors who want his words, even if they take a little bit longer to produce. I'm someone who's invited on your podcast and given the compliment of your attention, if I don't find all of that more compelling than whatever slight difficulty I have in my life, then I'm a jerk and I don't want to be a jerk.

Ben Shaberman:

Well, that's an extraordinarily self-aware perspective and quite a humble perspective, but I think there's a lot that people can learn from your journey, from the book, *The Beauty of Dusk*, and just the stories that you share about so many people that have dealt with some pretty challenging things. So Frank, thank you for taking time out of your busy day, your busy schedule to talk with us about your book and your journey. It's been a lot of fun, it's been inspiring, and we wish you well moving forward.

Frank Bruni:

Thank you very much, and my best to everyone is listening and to you.

Ben Shaberman:

Thanks, Frank, and thanks to everyone for listening to this episode and we look forward to having you back for the next episode of *Eye on the Cure*. Bye-bye.

Speaker 1:

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