

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 am Ben Shaberman with the Foundation Fighting Blindness. I am your host, and we have a very special episode today. I am delighted and honored to have as our guest the co-founder, and chairman emeritus of the Foundation Fighting Blindness, yes, Gordon Gund. And what's really special ... It's always special to talk to Gordon, but as I think many of you know, the foundation is celebrating its 50th anniversary, so I will be talking with Gordon about some reflections over the past 50 years. There's a lot to talk about.

But before we start our conversation, I wanted to give you a little background on Gordon. I learned some things in doing my little research here. So, Gordon attended Harvard where he majored in Physical Sciences and Sociology. And he also played ice hockey. I didn't realize that, Gordon. That's pretty cool. He also served in the US Navy, and he was the department head on two destroyers. That's pretty cool. As I think a lot of people know, he's CEO of Gund Investment Corporation, and he's been on the boards of Kellogg, and Corning. And I know in our Columbia office there were beautiful sculptures of birds, and other natural sculptures done by Gordon. Gordon, you're a very accomplished sculptor. And then, finally, by no means least, Gordon has owned the Cleveland Cavalier. He's been the majority owner, I should say, of the Cavs, Cleveland Cavaliers, the San Jose Sharks hockey team, and the Minnesota North Stars hockey team. And excitingly, Gordon, you drafted LeBron in 2003, and I've seen videos of that. That was a cool moment.

Gordon Gund:

That was a great moment. Thank you, Ben.

Ben Shaberman:

And what's exciting, I joined the foundation in 2004, and as being a kid from Cleveland, it was really cool to join a foundation, and see LeBron on our webpage. So, thanks for doing that. So, again, delighted to have you, Gordon. And I have some specific things I'd like to talk to you about. But before we go into those specifics, this is a big question. But we've approached, reached our 50th anniversary. It's been an incredible journey. And I was just wondering if you have any thoughts, or reflections you wanted to share looking back over that long period of time in all that's been accomplished.

Gordon Gund:

Well, I think that the key thing, and it has always been the case with the Foundation Fighting Blindness, is that it's been the result of extraordinary teamwork of a lot of people, and a lot of leadership over the years, over 50 years, and a lot of researchers that have been part of the whole picture, and really hugely important to it, the Scientific Advisory Board that has been world class since it started back in 1972. We started the foundation in '71, but realized because all of us who were part of that founding group were lay people did not have PhDs, or MDs, or any real background in medicine to speak of either. And so, we needed people who were world class both as clinicians, and as PhDs in various disciplines. And so, it was really, I think teamwork that the lay people that have always been part of the board, and chapter systems, and part of our professional staff have always worked very well as team members with the researchers, and with our Scientific Advisory Board members.

And that's been a key to the foundation all the way through the 50 years. We've had a lot of great teamwork, a lot of passion about the goal and the mission of the foundation that comes from all the chapter heads, the board members, and all of the scientists really have this passion about the foundation's mission. And so, I would say that's been a key all the way through. And it's been a real joy having the ability to work closely with the number of people over years to try and advance the progress of the foundation, and achieve its mission. And it's great to be able to say we are now doing that, and have done it in many significant ways, at many advancements, and we're much more in the pipeline right now, which is very exciting.

Ben Shaberman:

Yeah, it really is an exciting time. As we often say, we have somewhere in the neighborhood of 40 to 45 clinical trials underway. And I know those early days were quite a difficult journey, but I want to ask, I know your journey with retinitis pigmentosa was particularly challenging. You lost your vision pretty quickly. As you've said before, the last stone that you turned over was that journey to Russia to try to find an answer. But then, when you realized that you weren't going to be successful in saving your vision, you decided to try to do something for everybody else. And can you reflect on the moment when you, and Llura, who was so important to the foundations beginning, and operations that moved forward ... Can you reflect on what that was like, or what happened in your mind to decide [inaudible 00:06:44] foundation?

Gordon Gund:

Sure. And when I was losing my sight back in the '60s, I started having ... You mentioned that I'd been an officer in the Navy, and was able to do that fortunately and maintain my sight through that time. But then, it started to go right after, or I started to really notice it after I'd gotten out of the Navy in 1965, early '65. And I started losing my night vision, and was having more and more difficulty seeing at night. So, my retinitis pigmentosa was of that kind where night vision went first, and down into a tunnel. And then, I'd lost my night vision by 1968, '69. And then, my day vision went in 1970. And it went in about six, or eight months, very atypical. And I wouldn't want to frighten anybody by the suggestion that that might happen to them. It was very unusual the way it happened very quickly for me, the day vision went. And by the end of 1970, I'd lost all of my central vision, and my day vision.

And it was very, during those years, Llura and I were married in '66. And when we first were married, I didn't know that I had a retinal degenerative disease, and I didn't know really for a few years after we were married, and there was no real sense that I was going to lose it very fast. But as that happened, as it was going, the night and then the day vision, I was looking all over. Llura and I were together to find ways to hopefully treat it, maybe slow the progress of the disease, or even stop it, or even possibly reverse it. So, it was very frustrating, because there was no research going on then to speak of, which really struck us ... I mean, really impressed us as the fact that even though we just sent a man to the moon, and all of that in '69, that we weren't able to ... There was no research really going on of any major nature, or comprehensive nature around the country, or around the world.

And I kept running into dead ends when I'd go see a doctor who I was told that was doing research on finding treatments and cures for these diseases. Each time I'd get to their office, they diagnose me, and then they tell me their research had run into a dead end, or wasn't at a point yet where it could benefit me. I mean, that was actually true, even with Eliot in 1970, Dr. Eliot Berson, who was so important to the original multidisciplinary lab. He told me that, too. He told me in the summer of '70. I said, "Well, how's your research going?" He said, "Well, I'm sorry to say I haven't gotten very far with it. I have plans. I'd like to start the first multidisciplinary laboratory for the study of retinal degenerations, and I have a

plan to propose to the Mass Eye and Ear Infirmary," where he was. And he was also on the Harvard faculty, and see if they would allow me to start the first ever lab for this purpose.

And he said, "And I'm going to be putting together a proposal to raise funds for it." So, I said, in the summer of '70, "But the only thing I had left to do was to try this research in Russia, which you mentioned, which was the last stone I could turn over to try it." Because by then, I'd talked to everybody who was supposedly involved with research, and there was none that was available to me. So, I planned to go to Russia. But after that, if that didn't end up providing any help for me, then I said, "I would like to get involved with him." And I would call him after I'd gotten back from Russia. And as it turned out, Russia was a tough go there.

It was clear within a few weeks. I was there for about six weeks. But it was an animal bio stimulant kind of program, and ultrasound stimulation, the combination of the two shots, injections of animal bio stimulants, and also using ultrasound to stimulate the retina. And those were the composition of the treatment. It didn't work. I could tell within two weeks that it wasn't. I stayed there for another almost four in Odessa. And so, during the time I was there, Llura wasn't able to go with me. She had just given birth to our second son, who fortunately, I saw before I left to go to Russia. My brother Graham took me over. He had had experience with that group, bearing in mind that it was the heights of the Cold War, too, towards the end of 1970. So, a very unusual time to go there. In any event, what happened was that it didn't work.

And Llura came to pick me up at that other end of this six week-period, or so. And on our way back to the States, we had lots of time to talk about what I did, and had had lots of time to think about which, "Well, where do we go from here? Where do I go from here? What do I really want to be able to do, and care about, and want to think about in terms of how I adjust, and deal with blindness, and how I hopefully can be a good husband, and a father of two?" We, then, had two sons, and also what we would turn our own frustrating experience ... try to turn it into, which was something positive for other people. So, that's kind of how I came to wanting to get ahold of Eliot when we got back, and after he'd put his proposal together, and then start considering how to find financing for it, or fund the funding for it.

Interestingly, what that consisted of was Mass Eye and Ear wanted to have the Foundation Fighting Blindness when it was finally put together later, the fall of 1970, November of '71, I should say, but wanted us to pay for the construction of the lab in their new building, Mass Eye and Ear Infirmary building, and also wanted a ... So, they wanted \$300,000 to be raised by the end of 1971, and then by July of 1972, another \$375,000 to be used for financing the equipment of the laboratory, and the staffing of it. So, the challenge that was given to, well, Eliot had, and gave to me, and to Ben Berman when he introduced the two of us together, was to raise a total of \$675,000 by July 1 of '72. We had to show the first \$300,000 by January 1, and we did. And if you ran those numbers, just out of curiosity, in today's dollars, that would be the equivalent of four and a half to \$5 million as a challenge in today's dollars, now 50 years later. To give you an idea of what that meant to us as we looked at it, in terms of what we had to produce to get this lab going.

So, that was the catalyst that got us starting the foundation. And Ben and I, Eliot introduced both of us together in the spring of '71. And we agreed by that summer that we wanted to take on this challenge. And so, that's how it originally got sent started. Llura and I agreed that we would commit ourselves, or dedicate ourselves to trying to make this work, realizing that I wasn't going to probably ... I didn't think my sight would be restored, or that I would have the benefit of it. But at least we could turn the very frustrating experience we'd had into something positive, and that's what got us involved.

Ben Shaberman:

Right. And I'm glad you mentioned how much you needed to raise for that first lab, because your first project was a pretty heavy lift. It wasn't like you-

Gordon Gund:

Oh, yeah.

Ben Shaberman:

... put it off small. That's a big project. And I think one other thing that's really remarkable is how many great pioneering investigators, clinicians, researchers, joined our Scientific Advisory Board at that early stage. And that was a time when so little was known about these conditions. It wasn't like they were jumping in to make a lot of money in developing, or selling treatments. Because they were just still figuring out how the retina worked. And I understand one of our Scientific Advisory Board members was a doctor named George Wald.

Gordon Gund:

That's right, yes.

Ben Shaberman:

And you had mentioned this to me previously. I did a little research on him. He won the Nobel Prize in 1967 for basically discovering, and outlining how light activated photoreceptors in the retina, and sent electrical signals to the brain. I mean, that's just basic retinal function. So, they didn't really understand how the retina worked until the late '60s, really.

Gordon Gund:

That's right. Yeah, that's remarkable. And I would, just going back to the Scientific Advisory Board, and the Dr. George Wall, but also the composition of our Scientific Advisory Board from the very beginning was really the genius of, well, Eliot, because he knew John Dowling, who was Professor of Biology at Harvard, and was on our board for many years, and Alan Ladys, who was the chairman for the first 32 years, and Dr. Mark Goldberg among others were on that original board. And many of them were ... They knew each other, and admired each other's abilities, and knowledge. And where they stood, they also recognized, as we did, that the big challenge was to better understand the retina, and the whole visual process, and to better understand these diseases. Because until you've had that level of knowledge, or understanding, how could you begin to look for possible therapies, or treatments, and cures? You had to understand the diseases to begin with, and the whole visual process. So, yes, he was hugely ... George Wald was hugely important, and John Dowling had worked at his laboratory. So, John knew him, and was able to convince he and his wife, also George Wald and in research, Ruth Hubbard, were both on the board early on. We were very lucky to have them.

Ben Shaberman:

Thanks for sharing that. So, I'd like to switch gears a little bit. We've been talking about the Scientific Advisory Board, and some of the researchers, but I think one of the really successful elements of the foundation's story is just the ability to raise awareness, and fundraise. And I remember when we had our office in Baltimore, in Owings Mills, we had photographs from events in those early days. I want to say they were the '70s, maybe the '80s. I remember seeing a photograph of Dolly Parton and Kenny Rogers at an event. We attracted quite the Hollywood group of stars. I don't know if you remember.

Gordon Gund:

Oh, very well, I do, sure. And I know that a lot of this happened because not only had we heard from Steve Wynn, who had been in touch with us when he had read about us, and actually read an ad placement in the New York Times, a full page ad. And we got this check from him, which was very nice, and followed up to see why, and so on. As you know, he was very generous to the foundation. Well, with the Golden Nugget, he had contracts with people like Frank Sinatra, and Dean Martin, and Dolly Parton, and Kenny Rogers, and Lionel Richie, and on, and on, Billy Joel, several very high profile entertainers. And they gave dinners for fundraising dinners in New York at the Waldorf Hotel. And the first of those was where Frank Sinatra and Dean Martin performed in the early '80s. It was quite extraordinary to have those two as performers. But then, on and on it went with a lot of other wonderful entertainers like that. And that helped us get some publicity.

We worked with a lot of different TV programs, the Today Show, and 20/20, and 60 Minutes, many, many others over the years where we've had the chance to tell the foundation's story, and describe why we existed, and what we were trying to do, and that we needed funding in order to accomplish our mission. So, anyway, it was hugely helpful. And what happened when we started doing that, once we had this challenge that I mentioned earlier from the Mass Eye and Ear, and from Harvard University to fund, to get started the first multidiscipline lab ever for the study of retinal degenerations. But once we started the publicity efforts, it started to really become clear that there were many more thousands of people interested in seeing successful research done on these diseases. And there were a lot of people who wanted to help raise money, and help do fundraising events, and so on.

And so, we knew by the middle of '72, after we'd achieved the goal, that had been set for us that we knew we could expand the scope of this effort a lot more than just by funding this initial, lab that we could do a lot more research of all kinds around this country, and around the world. And so, that's when we worked very hard to put together the Scientific Advisory Board to start with. So, we had an architect group of people, world class people, who could help us design the program for the research, and then raise additional money along the way. And that's how we got started. It was really as early as '72, and '73, when we had the Scientific Advisory Board. And the first lab was dedicated in November of 1974. That is what was called the Berman Gund Lab. But by then, by the time of that dedication, we were moving fast and furiously after additional research efforts.

Ben Shaberman:

Right, and as we've been discussing that early research was just very basic, and very challenging. It didn't move nearly as quickly as our constituents would've liked. But I know, when I started in 2004, we were still doing mostly basic research, a lot of lab research. But things, a few years later, really started to change when things started moving into clinical trials. And the gene therapy that ultimately became Luxturna really started showing some efficacy in early 2008. I remember that well.

Gordon Gund:

Oh, that was a very exciting time.

Ben Shaberman:

It was very exciting. And really, I think the trajectory of research began to ... That was sort of the beginning of the really surge in clinical trials, and human research, and over time just attracting more, and more companies into our space, and collaborating with companies. And as that progressed, I think it was now five or six years ago, you made the decision as having been the chairman for over 40 years to

step down, and pass the baton to David Brent. And that was a big moment. I don't mean to embarrass you, Gordon. You still are, but you were really the rockstar of the Foundation Fighting Blindness, and not only our leader, but just a wonderful personality that everybody so much enjoys, and you brought hope to so many people. So, that the decision to pass the baton was a big deal. Can you talk more about that decision, and why you decided to do that then?

Gordon Gund:

Yeah, but maybe, let me just fill in one area that you mentioned earlier, which was when we first started, what it was like. There weren't that many PhDs or clinicians doing research in the field. So, we had to populate the field early on. And that's where the Scientific Advisory Board, again, became so important. Because we had no credibility to speak of from a medical standpoint. We, the founders, we had a lot of passion about trying to achieve the mission, but we didn't know what we were doing. They gave us the credibility to attract very top-notch PhDs, and clinicians into the field to start with, which was really very important. And it didn't exist really before that. So, moving forward to 19 ... I mean 2015, when both Llura and I were, I guess you could say, getting a little long in the tooth. At least, we'd been at it for quite a while. And I didn't want ... Neither of us wanted the foundation caught without having a succession plan for the roles that we had been playing for some time with the foundation.

So, we both felt it was very important that we challenged the board to do something, to have a committee study, not ... we called it the board organizational and succession strategic planning, or became called the Boss Committee, and was headed up by some of our very able board members, including Haynes Lee, who was the chairman, but several others who did hugely important to the foundation. And they analyzed what was the best thing to do to be sure that the foundation wasn't left stranded without Llura and I as being active. We wanted to be sure it continued on successfully. And I feel very good about the way that has happened. And along with that, what Llura and I also felt is, we felt, if we want to give the next leadership, David Brent, and so many others who have been so important to the foundation, not only volunteer leadership but also professional leadership, we wanted to try and help provide some funding to move some of the potential therapies along into the clinic.

And so, in order to do that, what we felt was very important was to do that the Gordon and Llura Gund Family Match, which has been able to help significantly fund, thanks to the support of a lot of people who have matched our challenge. That's allowed the new leadership to have a head start on the funding needed to do translational research, and carry it forward, which was very much our objective, and our desire. So, to help with the succession, and to help make it work, that's why we went ahead with that challenge.

Ben Shaberman:

And so many people generously heeded your call. Do you recall exactly how much was raised in total through your family challenge?

Gordon Gund:

About \$108 million.

Ben Shaberman:

That's incredible. That's incredible. And that was, if I remember correctly, I think over an 18-month period?

Gordon Gund:

Well, no, the challenge was issued that over that period, but people had five years to pay off major gifts.

Ben Shaberman:

That's right, okay. And shortly after that concluded, not too much later, then the RD fund was established, which has been just a whole new funding source, and avenue for moving treatments into clinical trials. And the RD fund has been so exciting, because we're collaborating from a funding standpoint with venture capital firms to get these companies off the ground, and move promising treatments into the clinic. And ...

Gordon Gund:

Well, the original capital, the fund first fund, came from the challenge match from both the donations from others, and our matching challenge. And the idea of that really started around the year 2000, when we started the National Vision Research Institute, which the idea for which was that if we're going to be able to help develop the funding needed for clinical trials for translational research, which is far more significant than the cost of laboratory research, we really needed the fundraising capabilities, in this case dealing with venture capital companies, and early states, biotechs, and so on, and using the market to help fund those things, and commercial enterprises, so that we could do more than just raising money through fundraising events. We could help provide the funds needed other ways as well.

So, that's something I think it's important, that is another key strength, and has been over the years of the foundation. We keep looking for new ways to apply technology in a research sense, but also new ways to raise funds that are unique, and have their own special aspects to them that are attractive to raising money for eye research. And I think the key is we're constantly looking out ahead, where are the gaps? What are the problems that we're going to confront? And now, if we're going to start having clinical trials that need funding, how are we going to raise that money? What steps can we take to help move that along?

Same thing with if you need to go through animal models, that was what went through our thinking when we built the animal facility back in 1989, the first dog facility in New Bolton, Pennsylvania, was because we knew there were some potential therapies coming along that needed to be proven to be safe, and efficacious in the lab, but eventually in animals in order to get the FDA approval, which is what happened with Spark Therapeutics. And fortunately with animals that we had already identified that had the same genotype that exists in humans allowed us to be able to do those trials early< well in 2000, 2001. And then, which led eventually to advancement into humans in 2007 and 2008. So, we were constantly looking out ahead to try and identify what hurdles we're going to have to get over, and then how we're going to get over them. And that's been the way it's worked for 50 years.

Ben Shaberman:

And I think what's interesting about that model, and always being the forefront of science, and looking ahead with foresight is that the foundation now, and we see this with the RD fund, is really looked at as the experts. We provide almost a seal of approval, or the housekeeping seal of approval [inaudible 00:32:36].

Gordon Gund:

That's right.

Ben Shaberman:

When companies, and venture capitalists see us investing, they feel confident that it's a good investment, because that scientific prowess that we've demonstrated for so many years throughout our history. So, it's paying off not only in what we're funding, but the investments that we're attracting.

Gordon Gund:

Oh, I think very much so. We get a tremendous amount of leverage out of the expertise that we've developed through our Scientific Advisory Board, and how well we are working on these problems from different directions. The expertise that we've demonstrated have really gotten us a leadership position with commercial enterprises, with the venture capital companies, or biotechs, or pharmaceutical companies who see us as the expert in the field, which is, you're right, I think a very important aspect of why the RD fund is showing so much potential for success.

Ben Shaberman:

Exactly. And Gordon, if we can close out with just one other question and thought, and this is something that's near and dear to my heart. Because I talk to a lot of patients, and families. And they come to us looking for guidance, and hope, and understanding of the research. What would you say, or what do you say when you meet somebody who's newly diagnosed, or maybe has a child that's newly diagnosed? The message, I think, is a little different than what it was 50 years ago.

Gordon Gund:

Oh, for sure. Well, first of all, I'm happy to say that I believe they can really have hope now in ways that wasn't possible 50 years ago. We were just starting out. But now, I think to start with, I would urge them to get genotyped, or to have their child, or their friend, or relative genotyped, and have them registered in my retina tracker with our patient registry, so their information is part of solving the puzzle for that particular genotype that they have, and how to make sure that those who might have potential therapies for that will know about them, and be able to contact them, and involve them in clinical trials. Another thing, I think it's a way for them to help themselves. The foundation offers them an opportunity to not only get involved, and be active in fundraising, which is going to be critical to solving these problems along the way, and to getting the clinical trials underway, and accomplished, getting the approvals that are needed. So, I would say, look at it as a source of great hope for their relatives, and their children, and whoever it is that's close to them that has these problems, and see it as a way to help yourself. And that's what the foundation has always been, and hopefully will continue to be, and be very important to people.

Ben Shaberman:

Definitely. And I think that's such an important message, is that there's a lot people can do, even if you can't get a treatment today between the genetic testing, the register trials, and of course fundraising. There's so many ways people can drive the mission. And I congratulate you and Llura, and our other volunteer leaders for doing such a great job, inspiring people to drive our mission. It's been an incredible journey. We've raised now over \$850 million toward our mission. And that number, the momentum just keeps growing, and growing every year. And that is in large part from your leadership, Gordon. So, we thank you for being such an inspirational figure, and giving so much of your time, and your generosity toward the mission.

Gordon Gund:

Well, Ben, thank you first of all, so very much for the long, very strong effort you've given to the foundation over the years, and tremendous help. And the way you make the story about it, as understandable as you do, and you really have made a terrific difference. So, thank you for that. I think the other thing people, I would hope, would understand is that the way one of the great things about the foundation as it's moved along is how it's been rejuvenated over, and over again with new blood, new people who want to make a difference to it, and bring that passion, and new professional staff, like yourself who makes a great difference to the progress of the effort, and to making it understandable, and motivating. So, I thank you for that, and I hope we will all continue to do that. It will only work successfully if everybody pitches in, and does what they can.

Ben Shaberman:

Definitely. And it's been thousands, and thousands of dedicated donors, volunteers, scientists, and other constituents who have got us to this wonderful juncture.

Gordon Gund:

Yes, it is. And that's been a key. And I just urge everybody who can find a way in many different ways to make a contribution, not just financially. Certainly that's important, but I think they can also learn a lot from each other at our Visions conferences, and other gatherings, and working with our chapter efforts. That's all going to make a huge difference, and it's all critical to it.

Ben Shaberman:

And speaking of chapters, I'd be remiss if I didn't mention our new chapter initiative, Llura's next chapter, and all the new people that we brought onboard to build that chapter network. And thank you Gordon, for being a big part of getting that off the ground, and strengthening our presence in communities around the country. We have more than 40 chapters, lots of inspired volunteers, and staff, and that's just helping us drive our mission even further.

Gordon Gund:

Well, thank you. It is critical for all of us who care about having these diseases treated, and dealt with. It's going to take all of us to do it.

Ben Shaberman:

Definitely.

Gordon Gund:

Thanks, Ben.

Ben Shaberman:

Thank you, Gordon. Thanks again for taking the time to just reflect. We could go on for hours, because there's a lot of ground to cover in 50 years, but I think we hit some salient points, and I appreciate, again, you taking the time to talk about those. And I want to remind our listeners that if you have questions, or comments, you can send them to podcast@fightingblindness.org. Again, that's podcast@fightingblindness.org. And for people who just want to learn more about the research, just visit fightingblindness.org where we're reporting on all the latest developments, and we have tons of educational information. And Gordon, congratulations on a wonderful run with the foundation, and

you're still doing a lot, very active. We appreciate that. And I hope you, and your family have an enjoyable holiday season.

Gordon Gund:

Thank you, Ben. Well thanks for all your help, and I hope the same for you, and for all your listeners.

Ben Shaberman:

Okay.

Gordon Gund:

Appreciate it. Thank you.

Ben Shaberman:

Thank you. And happy holidays to everybody listening across the world, the cyber space, and we appreciate you tuning in, and for supporting the foundation's mission. Take care, everyone.

Speaker 1:

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