**Everybody Lives with Dan Doctoroff**

# **Transcript**

Narrator

Target ALS Foundation is a nonprofit whose mission is to accelerate ALS research into successful clinical trials. Since 2013, the foundation has built an innovative ecosystem for biomedical research that has catalyzed ALS Drug discovery through collaborations. Target ALS envisions a world where everyone with ALS lives.

Stan

Hello everyone, I'm Stan Crooke. I'm chairman and CEO of n-Lorem, and I'm also your host for the n-Lorem podcast series, which focuses exclusively on the needs of patients with nano-rare mutations, which of course, is what we do at n-Lorem. And today we are joined by a really interesting and remarkable person that I'm looking forward to chatting with, and it's Dan Doctoroff. Dan, welcome.

Dan

Thanks so much Stan. You've been a real inspiration to me, so I'm really thrilled to be here.

Stan

Well, it's great because it's a mutual admiration society then.

Dan

Okay, that'll make it easy.

Stan

So, Dan, I think we could spend a month or two on your remarkable career, and your life, but I won't. I promise we'll do it faster than that. But why don't you just introduce, you know, where you grew up and all that to our listeners before we turn to your career.

Dan

Well, I grew up in a suburb of Detroit called Birmingham, Michigan. In fact, this past weekend, I was with my two closest friends from junior high school, where we were celebrating the 50th anniversary of our friendship which was cemented with a Risk game, a three-day Risk game 50 years ago. And then after that I went to Harvard, worked back in Detroit as a political pollster, and then went to law school at University of Chicago. Coming out of law school, I decided I didn't want to be a lawyer. So, I went into investment banking at Lehman Brothers, spent three years there, and left to form a, we call it today, private equity firm called Oak Hill. So that was my early career.

Stan

I remember Risk. That was a really popular board game of world conquest, right? It could get, you know, like world conquest everywhere, fairly violent. Did you manage to avoid any fist fights while you were at it?

Dan

It got pretty intense. But you know what? Going through experiences like that is what forms deep friendships, and as I said, we've been best friends for 50 years and it was definitely a milestone worth celebrating.

Stan

Yeah, that's great. Is Birmingham near Grosse Pointe? That's the only one I know because of that great movie Gross Pointe Blank.

Dan

It's on the other side. It's northwest of Detroit, but I loved growing up there, and I still have lots of friends, some family there. So, I get back there from time to time.

Stan

Well, Detroit's an interesting example of some of the things that you've been interested in in your nonprofit life. So, you ended up at Lehman as a banker, and fortunately for you, you left long before Lehman had its difficulties, of course you know, I had a wonderful friend who I credit with starting the biotech industry really. And that was Fred Frank.

Dan

I worked with Fred. Not a lot, but his office was just across the hall from mine, and he was one of the greatest investment bankers that I certainly ever knew, and some people think of all time.

Stan

I agree with that. I think, you know, when capitalism is at its best, it's building, and I think Fred did as much as anyone to create the biotechnology industry, and the path for me and you in this conversation really. And I miss him very much. He passed away a couple of years ago.

Dan

I know that I know.

Stan

Yeah, he was a wonderful man.

Dan

I went into finance mostly because I wanted to earn enough money to be free to do what I wanted to do, which I didn't know. I got a strong sense of that, just sort of gradually. In fact, you know, I became very interested in New York City. I went to, it's ironic that it's this week, the World Cup is this week. But back in 1994, I went to the World Cup semifinal game. I was out at the Meadowlands in New Jersey, and somebody dragged me there. I didn't even want to go. It was in July. It was 100 degrees. We took the bus. It took forever. But you know, I walked into the stadium, and it was immediately apparent that it was the most amazing sporting event I'd ever been to, you know, it was Italy versus Bulgaria. The stands were filled with Italian Americans, Bulgarian Americans, Italians, Bulgarians, face painted, flags flying. And I stood there because you couldn't sit down the entire match. You know, the amazing thing about New York is you could play that game with any two countries in the world in New York and it would feel exactly the same. So, I started thinking, you know, why has New York, the most international city in the world, never hosted the Olympics. And I left the stadium that day with this vague notion. New York ought to host the Olympics. And for the next, you know, 11 years I pursued that dream. I started the effort to bring the Olympics to New York. But what I realized, as I was studying kind of the dynamics and the benefits of hosting the Olympics, is the Olympics, which have real deadlines, could be a catalyst to real change in a city. You'd seen that in Barcelona. You'd seen it in Atlanta, which was just about to have the Olympics. You'd seen it in Tokyo, where they built the subway around it. And there have been a lot of things in New York that people had been talking about doing for generations, but they never were able to generate the political will or the financial wherewithal to get them done. And so, I developed a plan with a lot of help that used the Olympics as a catalyst to dramatically change the city. I, at one point, was raising money, and I went to Mike Bloomberg, who was just at that point a billionaire. He wasn't mayor yet. He gave money, and went on our board. And then he ended up running for mayor. And when he ended up running for mayor, when he won, surprisingly, after 9/11, he asked me to be his deputy mayor for economic development and rebuilding, which I did for six years.

Stan

That's pretty neat. And then you were actually president of Bloomberg as well, right?

Dan

I was CEO of Bloomberg LP. One day, we sat in an open room in City Hall, and I pretty much sat behind him. And one day he just turned around and said, "You got a minute?" And I said, "Sure." So, we went sort of into a corner, and he said, "You know, how would you think about going over and running Bloomberg the company?" And I said, "What are you talking about? You know, I've never run a big company. I don't know anything about yours." I knew one person at the company, and he said, "No, I think you'd be really good." So, I said the next day, "Let me think about it." The next day I went to him and said, "Okay. I'm prepared to do it." I won't get paid the same thing that I got paid in government, which was $1.00 a year. And you know, I then started about six weeks later, just in time for the financial crisis. It also was a great experience. I, you know, led the company through the financial crisis. We almost doubled our revenues in seven years organically. So that was a great experience too.

Stan

So, in all that, if I force you to tell me the three things that you learned that were the most important.

Dan

Well, I think through all of those experiences, the first thing I learned was to get stuff done, and this is particularly true in government, you need to operate on two speeds at the same time. You need to be patient cause there's process for everything but at the same time you have to operate with a sense of urgency at all times and it's that combination of those two speeds that enable you to get really complicated things done, you know, in government getting anything done is really difficult. I initiated in my time in government something like 289 separate initiatives, and we did all but a handful of them, so it required a real skill set of operating on two speeds. A second thing, I think which is true for anything, is you gotta learn to listen. And you know, for example, when I started at Bloomberg, I knew nothing about the company, I really didn't know anything about the product, I didn't know any of the people. For the first three months, I just listened. I think I met with 500 people over those three months, and you began to see patterns and come up with, you know, solutions. And this is a big company. I think at the time it had 12,000 people in 90 different countries. We were at that point still, we were the dominant provider of financial news, and data, and systems to the securities industry, but we were starting to leak a little bit that had been masked by the boom before the crash. And so, I started there. I think a couple months later, you know, the financial crisis started to unfold. But I had pretty good sense by taking those three months to really listen. A third thing was you gotta get rid of the dead wood. And I met with somebody, cause I've never been a CEO of a big company before, and he gave me the advice, it's the guy actually who is the CEO of Uber today, and he said, "You really gotta show people that you're gonna be decisive, and one great way to do that is get rid of the dead wood." And through my listening tour, I understood where those weaknesses were and got rid of people while, at the same time, announcing a set of initiatives and strategies that we're going to drive the company forward. I think those three things are really interesting. It's very interesting to watch, for example, Elon Musk with Twitter today because I'm sure he feels that he has to change the culture of the company. I fortunately didn't have to do that. I had to adjust it, but you know, changing the culture of anything is incredibly hard, and you gotta be pretty dramatic in order to, if you believe that's needed, you gotta be pretty dramatic to do it.

Stan

Well, those are all really important lessons, and lessons I think that almost all of us can subscribe to and that can fold in patients. You know, being patient for the long term, but impatient in the short term is a big deal, right? Those are important and very well said.

Dan

You know, if you don't act with urgency, particularly in a complex situation, you know, everything just dies of its own weight, so you gotta drive things. Obviously, you have to inspire people to drive them on your behalf if you're the leader. And I think one of the other things that I am proud of is I, in all of those situations, I developed great teams. And you know, I may have been the leader, but at the end of the day, you know, the more you delegate, the more you can do. But you gotta delegate to great people as well.

Stan

Yeah, yeah, I think great leaders are sources of positive energy. When they leave, the void is there, and it's very apparent that it has that impact, and for sure, you've had a positive impact on all kinds of organizations of all sorts. But now you're facing something that you can't control, right? You are dealing with something that will destroy you, or could destroy you, and you're a controlling person.

Dan

Right.

Stan

I know a lot about controlling people, I'm one of them. How do you deal with that? Why don't you tell us about your problem and how someone like you tries to contend with a problem that can't be fully managed by yourself?

Dan

So, the problem you're talking about is that I was diagnosed about a year ago with ALS. And just a little bit of background, ALS is pretty common in my family. My father died of it, my uncle died of it, they had a first cousin who died of, had the same genetic mutation that they did. But he died of a related disease, frontotemporal degeneration. For me, you know, I was vaguely aware that there was a specter hanging over me. I never, because I'm an optimist, I never expected to be diagnosed with ALS, but I was always vaguely aware of it. And so, when I turned 60, I was really worried about time. I'm 64 now and for the first time in my life, actually, I went to see a therapist to deal with the issue of time remaining. I was gonna pack more in, and he was incredibly helpful in helping, this is before I was diagnosed, think about time, but ultimately, we started to focus on ambition and why it was so ambitious. And without getting into too many of the details, we had an insight and it related to the relationship between my mother and my father. And you know, I came to the realization that I was ambitious because I never wanted to disappoint my mother. And once I realized that, and realized that my mother had died 20 plus years ago, I thought to myself, do I need to be the same way? Well, I never really changed at that point. I was running a company I started with Google called Sidewalk Labs, which was a really pioneering company focused on urban innovation. You know, I thought that at some point I would probably slow down, but not for several years. So, to some extent, when the diagnosis occurred, I was semi-prepared for it. And obviously, I'd witnessed my father and uncle go through it. My college roommate actually died of ALS. I had an office mate at Lehman Brothers who died of ALS. And so, I think I was kind of prepared, but you're never actually prepared for this. But something interesting happened to me when I was diagnosed. I stopped thinking about the future. And it wasn't something I tried to do. It just happened. And I've always been someone who obsesses over the future. I never actually enjoyed an achievement because I was always on to the next thing. But I think my personality, as a result, actually changed somewhat. I became much more patient. I was not ever patient. I'm sure you sympathize with that. I became much more present. I stopped being competitive. I just lived in the moment, started to live in the moment. You know, a good example of that is while I was being diagnosed. My son and daughter-in-law were in the last month of her pregnancy. So, I think to myself, you know, if I'm diagnosed with ALS, there's probably an 80% chance I won't live to see her turn 5. And that would be just crushing to me, once I was diagnosed once she was born, because I just focused on the future, on the today. I never think that way anymore. I just revel in her presence and her development and I really live day-to-day. And that is with one exception, that we'll talk about, but that is just a gift, a complete gift. And I don't know why it happened. I think in part it's my optimistic nature stepping in to protect me. But since I've been diagnosed, and I find this surprising, and a little weird, I would say I have not been depressed more than a cumulative total of an hour over the last year. You know, I'll get a bad test result, or I won't be able to do something that I could do the day before or I'll, you know, occasionally recognize, usually like at a family celebration, that I won't be around for those in the future, but those have lasted like five minutes, and then I'm back. And I have been incredibly happy. I think in some ways I've actually become the best version of myself over that period of time. There's a lot of other reasons why I think I've been incredibly happy. I've been just surrounded with love and support from friends and family. I stepped away from the company that I founded, and a lot of other activities, so I have more time, so I feel less pressure. And you know, I also watched my parents and others go through their illnesses, fatal illnesses, with incredible grace. And I think I, you know, want people to recognize that I'm doing the same. But overall, I said I've been incredibly happy and the last part of it is I feel like I have a real sense of purpose with the organization that I founded when my uncle died, Target ALS, which has been a major catalyst to accelerating research in ALS into clinical trials. So, you know, I feel like, you know, I've been blessed. I feel like, you know, I look back on my life, and I don't have any regrets. I feel like I've just been lucky. I've got a wonderful family. I've been married to my wife for 41 years. We met freshman year in college, and we've gone out. We have three wonderful kids who, by the way, live in New York near us. We now have a grandchild. We have another one on the way. I've got tons of friends. I've done, career wise, what I wanted to do. I've engaged in outside activities that have fulfilled me. So, you know, I'm a lucky guy and you know that helps too.

Stan

And that's a wonderful story, Dan. And it is about optimism and grace. You know, when I saw patients, I saw cancer patients.

Dan

Right.

Stan

And very often I was struck by how facing, you know, perhaps the one of the scariest sorts of diagnosis that a person could have, how often they were at their best, how graceful they were. And you know, I think generally an optimist is an optimist always life.

Dan

Now, the way you respond to this, I think is just, it's consistent with your nature, your basic nature, and well, I do think I have changed, as I said, to not focus on the future, be more present within the moment. I think just being an optimist is a huge benefit.

Stan

I think it's associated with longer and better life, of course. So, what's the most frustrating ability you've lost so far? What drives you crazy?

Dan

Nothing has driven me crazy. I'll be completely honest. Yeah, I mean some of the physical things are frustrating. So, for example, my major symptom is respiratory. The disease seems to be honing in on my diaphragm, which is responsible for about 80% of breathing function. You know, when I sit down like this, I'm sitting down, I'm fine, I don't have any breathing issues. When I stand or when I walk, especially walk up hills, I guess the pressure on the diaphragm makes it hard to walk. So, you know, I walk with walking sticks. My right hand is very weak. So, you know, I'm learning to be left-handed. And I think one of the things that I've accepted as sort of a fun challenge is adaptation. So yeah, it's hard to cut with a knife and a fork. But I've learned to do things. Anyway, I can't tie my shoes. But you know what? That's not a big problem. I just got shoes without laces. They also make great shoes that have laces, but you don't have to tie. So, you know, look. If you take the attitude that adaptation is a good challenge rather than getting depressed by the things you can't do, it's much easier. And you know, said I don't think about the course of the disease, because that was my, you know, that was the not thinking about the future kicking in. And that said, I'm not worrying about what's gonna happen. Taking things day by day, and adapting successfully has been just, as I said, just a complete blessing. So, I am actually doing incredibly well emotionally. You know, physically I'm, you know, declining. But I'm dealing with it.

Stan

Well, I think that's great advice for everyone.

Narrator

Changes are coming very soon to nlorem.org. In March 2023, the new nlorem.org will launch with an updated design that features new pages for patients, physicians, and institutions. You can also learn how to access treatment, read heartfelt patient stories, check out our fresh patient empowerment program page, and more. Thank you for listening to the Patient Empowerment Program podcast. Now back to the episode.

Stan

Let's focus on Target ALS then for a minute. Target ALS is focused on making sense of ALS, understanding the mutations, and then providing, you know, advances in treatment. And if I understand it correctly, right now you're completing a fundraising that you hope to have done that will fund it in even greater level than what it is now. Is that right?

Dan

So just to give you a little bit of background on Target ALS, when my uncle died in 2010, and my dad had died in 2002, it was clear my family was hereditary. You know, when my dad died, I thought it was just some random freak thing. But when my uncle died, it was clear my family was hereditary and so, you know, it was very personal for me. I realized I'd do something, and I didn't know anything about the state of ALS research, but what I found was there had been almost no progress for the 140 years since the disease was discovered, it was discovered in 1870. And so, I hired a team of scientists to help me understand why there had been so little progress in the disease. And we came up with a set of hypotheses relating to the way ALS research was funded, the nature of research, it tended to be very siloed, other IP issues that slowed things down, there was almost no common resources that the researchers could draw on to lower the barriers to getting research done, or drawing new people into the field, and you know this, there was almost no involvement from biotech, pharma or venture capital. So we decided to create a nonprofit foundation that would address all of those different problems around sort of the solutions to the problems. So, what we do is four or five things. One we only fund consortiums of researchers around vexing problems in ALS, including understanding the genetics, the biology, pathways, and potential solutions to them all, with the goal of accelerating research into clinical trials. Second thing we do, we fund a set of core scientific resources that anyone in the world can draw on essentially for free, and those include things like animal models, viral vectors, stem cells, human tissue samples, both longitudinal biofluid samples, as well as postmortem tissue samples, antigens, couple others. And those, just over the last several years have been accessed I think on 500 separate projects. Third thing we focus on is getting the industry involved. At the end of the day, and you are the greatest expert of that, at the end of the day, you're not gonna save anybody's life if you don't have drugs and its biotech and pharma that produce the drugs. And for biotech, they need venture capital. So, we prioritize getting the industry involved, and we do that by engaging them in everything we do. So, they've led 50% of the consortia, very unusual to have industry leading academics, but they are working together. They're 50% of our board. They're 50% of we have an independent review committee, so people from the industry and people from academia decide every single grant we make. In fact, when we started in 2013, we were involved with, I think, eight on an ongoing basis, eight companies or firms. Today, that number is 123, where we are actively involved with, which says something about the progress of the science and the fact that they think ALS can be a profitable area to focus on. We also do other things, including we work with other diseases because we think we can learn from them and there are common pathways, biology, genetics. So, we have a partnership with the Association for Frontotemporal degeneration. We have a partnership with Gates Ventures and the Alzheimer's Drug Discovery Fund together, to look for biomarkers, for example. I think we also have become a hub of the research community, which also gives us the ability to bring all these different constituents together, industry, venture, nonprofits, academia to focus on industry wide issues. The biggest one probably is the search for a biomarker today for ALS, or a toolkit of biomarkers for ALS. You know, we built the credibility to actually bring people together as well, so I've been incredibly pleased. I'm not the one doing the work. We have a great team led by our CEO, who you know, Manish Raisinghani. And when I was diagnosed, I said, "You know, look, my last mission, if you will, is to dramatically scale up target ALS." So, I said, without knowing whether I could do this, that I wanted to raise 250 million for target ALS. I started in May. I've made great progress. And I think I'll get there. The people I know have been incredibly responsive. And so, I got a lot of work to do still. But you know we've developed a strategy; it's got seven pillars to it. One of them is to address every single patient, rare forms of ALS. And obviously we have a partnership with you and n-Lorem to do that. You know, there are genetic mutations for ALS. There's 31 genetic mutations that have been discovered. Some have less than 50 patients in the world, and we believe that every single patient should be able to live with this disease. And that's what our mission is, everybody lives, and partnerships with you will help us actually achieve that.

Stan

And I think we probably close in on our relationship, which really began just this year, and I really don't know for sure how it all got together, but with Neil Shneider at Columbia and Manish and you, and then we were chatting. And at n-Lorem, obviously we're committed to treating every patient irrespective of the mutation or the number of patients. And so, you know, right now I think we're treating together one patient but that one patient is really an important test.

Dan

And you know, hopefully we will expand that dramatically. We have so much respect for you, what you've done in your pharmaceutical career, but really what you're doing today, you didn't have to do that. But you believe too that everybody deserves hope. And you are providing that, and we want to be incredibly supportive of what n-Lorem and you are doing because you know we can't just focus on you know, familiar forms of disease. We need to span that dramatically to rather random or sporadic, but also the rare forms of the disease. And we're just really proud to be your partner in this effort.

Stan

Well, it's mutual. I mean, ALS is a terrible disease. And we think that there's some things that we can do to fix some of it. And you're helping us do that. And obviously you and the organization you build are an inspiration to us, as well as others. So, Dan, it's one of the great privileges that I've experienced in a life of many, many privileges, is that in the time I've been working on n-Lorem, I've met just an amazing array of wonderful people and an astonishing array of graceful, noble, caring patients. And you are the combination of a remarkable human being and a remarkable patient. And so, this interview has been, well, it's very important for me and I'd like to close by just asking you to sum it up. What would you say to people who are listening to this, who either have a loved one, or themselves, who have an illness or are thinking of getting involved in some way?

Dan

Yeah, what I would say is the progress that has been made over the last 10 years is really phenomenal. And I think the trajectory for greater progress, and even starting to save, over the next several years, people’s lives, or extend them, I believe that within 10 years we will be able to look out to a period of time, and I can't exactly predict when that'll be, when everybody lives. That is a possibility, but we need more resources, particularly focused on research. We need greater collaboration. But given the trends, I think that is entirely possible and that gives me hope. Particularly, you know, for my family and for the one in 400 people alive today who will die of this disease. We are going to get there, but we all have to work together, and I think that is beginning to really happen.

Stan

We've never lived in a moment of such great possibility.

Dan

I agree with that completely.

Stan

And we stand on the shoulders of the great people who preceded us.

Dan

Absolutely as well.

Stan

And we look forward to moving much more aggressively with Target ALS and really getting to a bunch of ALS patients, maybe even Dan Doctoroff.

Dan

Well, it's been a complete honor to get to know you and work with you, and I agree the partnership between Target ALS and n-Lorem offers incredible possibilities. So, it's really been a thrill to be with you today, but more importantly, build on the relationship that we got already.

Stan

Give your grandchild a kiss for me and we'll talk soon, okay?

Narrator

We hope you're enjoying the n-Lorem Patient Empowerment Program podcast. We at n-Lorem want to provide support to our podcast listeners the best way that we can. There's no better way for us to do that than to ask you directly. Do you have questions you want to ask Stan Crooke? Stan will be taking questions directly from you and other podcast listeners and dedicating an entire episode towards answering your questions, AMA style. If you're a nano-rare disease, patient, family member, friend, physician, rare disease advocate, or you just enjoy the podcast, we want to hear questions from you. Please don't be shy. All questions are important and may end up helping other listeners. So, don't miss a great opportunity to get your questions answered by the Patient Empowerment Program host, CEO of n-Lorem, and the father of antisense technology himself, Dr. Stan Crooke. To submit a question for the upcoming Q&A episode, e-mail podcast@nlorem.org that's podcast at nlorem.org with the subject line podcast question. If you wish to be identified, mention your name and e-mail. If not, we'll keep your submission anonymous. n-Lorem is a nonprofit committed to discovering and providing personalized, experimental treatments for free, for life to patients with genetic diseases that affect 1 to 30 patients worldwide referred to by n-Lorem as nano-rare. Many of these patients progress and die without ever achieving a diagnosis. This is where n-Lorem comes in. They do the impossible by providing hope, and for those that they can help, free lifetime treatment. For more information about n-Lorem or today's episode, visit nlorem.org. Any questions can be sent into podcast@nlorem.org. Search n-Lorem on Twitter, Instagram, YouTube, LinkedIn and Facebook to connect with us. This video is hosted by Dr. Stan Crook and produced with the help of the following professionals. Thank you for watching.