Transcript

His Passion For ALS Research Starts at Home feat. Daniel Barvin ‘18

Publishing Date: Jul 5, 2023

[00:00] **Intro:** Welcome to Owl Have You Know, a podcast from Rice Business. This episode is part of our Pivot Series, where guests share stories of transformation in their lives and careers.

[00:12] **Maya:** Thank you so much for being with us today on this Owl Have You Know. It's a special Owl Have You Know because it is Reunion Weekend, and we have some phenomenal guests with us today that we, kind of, snagged out of partio to talk to us. Hopefully, you've been able to have a drink or two before you've, like, walked in here to the Rice Alliance.

[00:31] **Daniel:** We've been having a good time. And hopefully, I'll keep my wits about me.

[00:35] **Maya:** Okay. All right, promise?

[00:36] **Daniel:** Promise.

[00:37] **Maya:** All right. Well, so our guest today is Daniel Barvin. You are a professional MBA from the class of 2018. Welcome back.

[00:43] **Daniel:** Thank you. It's great to be here.

[00:45] **Maya:** It's been five years.

[00:46] **Daniel:** You know, I parked in the parking garage and I said, "Oh, my God, it feels like an eternity since I've been back."

[00:52] **Maya:** Really, the parking garage told you this?

[00:53] **Daniel:** Well, you know, the, the ambiance of the entire, you know, Rice University and Rice Business did. But it feels great to be back amongst this community and sharing in this innovative discussion of thought. Just I missed being a part of this school.

[01:08] **Maya:** Well, you're always welcome to come back. I mean, you do live in Houston, right?

[01:11] **Daniel:** I do.

[01:12] **Maya:** So, you can always just, you know, pop back in whenever you want to.

[01:15] **Daniel:** I'm starting to do that.

[01:16] **Maya:** And whenever, you know, whenever the, the, you can always walk on campus and, you know, come and see some familiar faces. You were just telling me that you, you and Al Danto are, are very close. He was probably one of your favorite professors, like he was for me as well.

[01:29] **Daniel:** Definitely was.

[01:30] **Maya:** Also, he's, he's got a phenomenal story of, of what's happened to him in the last couple of years. And you have a phenomenal story as well. So, so, you started out in wealth management. That was... so did you study that as an undergrad?

[01:42] **Daniel:** No, my background in undergrad was focused in mechanical engineering. I had a lovely grandfather who said, "Daniel, I need you to go to school. And commit to doing something that, that can make things happen. Don't get a career in X, Y, and Z." It was basically what he said. And I spent the first 10 years of my career in oil and gas, designing deep sea drilling equipment, and never had a passion for it, and was searching for this passion. And my wife, I think she's my wife at the time, but we bed-dated for the, pretty much the majority of our adult lives. Was a violinist or is a violinist and now is a violin teacher. And I saw the incredible passion that she derived from her studies, from her practice, from performing, from teaching children. And I said, why don't I have something like that? And it was actually, I was thinking about getting my MBA. And I saw, I went to her master's graduation at Rice.

[02:44] **Maya:** From the Shepherd School?

[02:45] **Daniel:** From the Shepherd School. And I saw the Rice MBA's going to graduate. I just said, wow, I want to be one of them. And that was the moment that it clicked. You know, I'd think I'd been studying for the GMA already, but that was when I said, "Rice is the only place

I'll go, and this is exactly what I want to do." And so, that started this next stage of my life and the transition from oil and gas to wealth management. But that's an entire story in itself as well.

[03:12] **Maya:** Well, let's go and talk about that story. So, so, so you came to Rice in 2018. And you did want to find that passion and that drive for something other than oil and gas. But I bet about a bunch of folks in your cohort were oil and gas people, weren't they?

[03:30] **Daniel:** 100%.

[03:31] **Maya:** And so, how many people were in your class?

[03:33] **Daniel:** So, I think we had about 90. We were split up into cohorts, you know. Obviously, I was the evening class, not the weekend class. I mean, just so many phenomenal companions, friends, colleagues from those days. You know, we're now at alumni reunion party. We were definitely more of the PCF crowd, post-class festivities for the evening crew.

[03:56] **Maya:** I like that, PCF. We're, we're, we're making new acronyms.

[04:00] **Daniel:** Well, it's definitely not new.

[04:02] **Maya:** For me, it is.

[04:04] **Daniel:** But we had, you know, the most incredible time. And I just loved that environment of being thrust, you know, with others to, to learn, to collaborate, to be a part of something. And I think that I took a, a very precarious turn. I was doing the MBA, and I wasn't sure where to, to end up. And I had someone put a, a bird in my ear that wealth management might be a good place for me. And I was attracted by a few successful wealth managers to join their team. And I appreciate everything they did to, to bring me on to their team.

But I think that when I joined, I said, I love... in the end, I love making real relationships. And I felt so burdened by the fact that I had to then ask them about their finances and how can I, you know, bring in their, their, their money, their assets.

[04:57] **Maya:** It's an awkward conversation.

[04:59] **Daniel:** It, it doesn't always have to be, but it definitely can be. And I, I just felt the pressure to hit quotas was so awful. And it ruined every interaction I had, I felt, because you had to be on 100% of the time. Every event you went to, you had to think about, is that person going to be the right person? Anyways. And throughout that time, I was there for about three and a half years, and I had a realization about my health. I'll start diving into that story.

Early in my life, my first interaction with neurogenerative disease was when my uncle was diagnosed with ALS when I was about 10. And as a young child, I didn't really know what any of that meant. He also lived in New York City, so I just saw brief snapshots of severe degradation of ability. And, you know, still haunted by that loss of capacity that he went through. And we would never... we, we thought we would never endure that again. However, about 10 years later, my father started experiencing early onset dementia, which went undiagnosed. My mother took him to various doctors, but no one knew what was going on.

[06:15] **Maya:** What year was this?

[06:16] **Daniel:** So, my... 2000, my uncle had ALS, probably when I was beginning high school. So, 2002 was probably around the time my father started exhibiting symptoms. And then, a few years later, his sister, right...

[06:32] **Maya:** Your aunt.

[06:33] **Daniel:** My aunt was also diagnosed with lower limb onset ALS. So, we were just, you know, like a punching bag over and over again, beaten by this disease and beaten by the trauma that, that comes with it.

[06:45] **Maya:** Is that what, what, what, sort of, made you think, "Maybe I should go and get tested for this gene?" Is that, was that [crosstalk 06:54]?

[06:54] **Daniel:** So, that was a little bit later, you know. So, from 2000 until my father passed away in 2016, we lost three out of four siblings in my father's generation. It had zero answers as to whether that would be any connection to my generation. And it was only after my father sadly passed away that we received an autopsy that showed that... I don't think we requested this, but it showed that he carried the C9orf72 gene mutation. And that suddenly gave us answers, but also incredible, you know...

[07:27] **Maya:** Anxiety.

[07:28] **Daniel:** Yes, anxiety about what that might mean for my future. And so, it was that point I'd actually just gotten married. My father passed away when I was just starting the MBA. It was very difficult. But I think the MBA kept me busy, kept me connected to, to friends and, and brought me through that experience. I got married in the middle of it. And towards the, the end of the MBA or a little after year after I got married, I went and got tested to find out if I had the, the gene mutation. And that was really driven by the fact that we wanted to have... start a family, ensure that that gene mutation that caused so much trauma in my parents' generation did not affect my children. And that was the impetus to go find out, even though that's an incredibly difficult journey to go down. We found out in 2018 that I carried the C9orf72 gene mutation.

[08:22] **Maya:** Is that a blood test? How do you... or what, what do you have to go through in order... Because I know there are things like 23andMe, right? Because I've done that for, for, you know, just to know who I'm related to and, and all. And then, they have this, you know, potential to tell you if you have these gene mutations, and then you can decide whether or not you want to know or you don't want to know. So, so how did... what, what is the process of discovering whether or not you have this gene?

[08:47] **Daniel:** So, the process is, and I love that you brought that point of 23andMe, and the, the proliferate proliferation of how commonplace it soon will be for everyone to know a bit of their genetic future. And so, I think that my story is so indicative of, not only my future, but what the world is about to experience. So, for my case, you know, it's very rare to have the gene that I have. You know, in the, in the world population, it's incredibly rare.

[09:19] **Maya:** Statistical probability back to MBA classes, low.

[09:23] **Daniel:** Yes, very low. But if you have this in your family, you are aware of it because you've had generations of trauma. You've had ALS and FTD in your family and you've seen people pass from those diseases in such a way that there's a likelihood that you're trying to figure out why. And so, there are what are called longitudinal research studies that focus on the pre-symptomatic community, because we are the best test subjects, let's say Guinea pig, test subject's better. Test subjects-

[09:53] **Maya:** Both fine.

[09:54] **Daniel:** ... to track, to understand the earliest biomarkers and causes and signs of the onset of ALS. And they also provide genetic counseling and genetic testing. So, there was a series of three visits to my... the study I go to is called DIALS, dominant inherited ALS. That's the name of the study out of MGH in Boston. And I absolutely love that entire team there. They are the care community that I have. You know, in, in my world, we cannot go be seen in, in the actual clinic, because all that we'll do is put that we have this genetic mutation on our medical records.

[10:34] **Maya:** Right, then you have insurance issues.

[10:37] **Daniel:** Exactly.

[10:37] **Maya:** And liability.

[10:39] **Daniel:** And those doctors have never, they don't understand what it's like to treat someone with pre-symptomatic disposition for a gene.

[10:46] **Maya:** Right, that's not something that they're taught about in medical school, right?

[10:48] **Daniel:** And there's no, what do you do for me, right?

[10:52] **Maya:** Right.

[10:53] **Daniel:** And so, really, it's, you know, these frequent checkups, this, this understanding and care of the situation that's so vital because we can't get anywhere else. And so, it was, it was that process. And I remember going with my wife. We were going on vacation right after we went to Boston to find out.

[11:12] **Maya:** Gosh.

[11:13] **Daniel:** And, you know, we were praying for a no, and we got a yes. And, you know, my wife, I remember her saying, you know, "We're so young. Like, how is something so difficult being thrust upon us?" And, you know, we were... it was tough, very tough, but I think what was so... the, the silver lining was after we came back from vacation, I was asked to do a talk for a high school helping explain my story after an ALS documentary was shown. And I went and spoke at Carnegie Vanguard High School, in front of the entire student body, 800 students, and told them the story of my life. And it was just so... the connection was palpable. And I said, "This is it. This is, this is what I need to be doing."

[12:09] **Maya:** Not wealth management.

[12:10] **Daniel:** No, like that, oh, my goodness. So, that's where I, I felt, you know, shivers down my spine. And, you know, this is the story I need to tell. I can make change here. Let's do that.

[12:23] **Maya:** You found your own violin.

[12:24] **Daniel:** Exactly. And so, at that point in time, there was absolutely no resources for patients like myself, the patients in that community. Nothing. No stories online. If you were to go Google, "I have ALS in my family like the chicken pox," you know, nothing comes back. And so, I made it my mission to, one, put my story out there and be vocal, so that anyone else who was young looking for, you know, some glitter of hope of how they might deal with the situation could find my story and be empowered to take action, to move forward in their lives and not be depressed by this incredibly, this incredible burden.

[13:11] **Maya:** So, that's why you decided to start something that was really a disruptive technology, a disruptive innovation, so to speak, right?

[13:21] **Daniel:** I guess you could say so. I definitely saw a gap in resources. There was a complete gap in this, in this space. And I said, "I can fill that." And after doing a few podcasts and other blog type things, I, I realized that there was a community that was somewhat silent on Facebook. And I said, "Hey, guys, I want to step up and I want to create resources for all of us, mostly focused on education. How do we ensure that others don't fall into the pitfalls that I fell into along the way of finding other genetic status. How do they have support in terms of family planning? How do they have support in terms of the generational trauma they've endured, X, Y, and Z?" And so, I've posted a post on the familial ALS page, and I think five people responded saying, "Hey, let's do this." And...

[14:13] **Maya:** Five people that you didn't know.

[14:14] **Daniel:** Did not, I've never heard of them, never met, you know, internet strangers.

[14:18] **Maya:** Internet strangers.

[14:19] **Daniel:** But all tied, you know, by this connection to ALS and FTD and the fact that they also carried the, the gene mutation. And we started a, an organization. I, I will say, before that, I had an idea because I didn't, I didn't have a job, you know. I left wealth management, state that. I thought I was going to go around the country raising money for my cause. And I said, "I'm going to go raise $10 million, speaking around the country, fundraising, and, and this is going to be the next ice bucket challenge," right? How if ALS in one, in one instance is so compelling, the fact that my entire father's generation almost was, was killed by this disease and now I'm at risk. How is that not?

[15:04] **Maya:** Well, not only are you at risk, but now any of your future children and future generations as well.

[15:10] **Daniel:** Sure, sure. But luckily, we took care of that.

[15:12] **Maya:** Yeah. So, tell me about that.

[15:14] **Daniel:** So, you know, a big part of why we got tested was that we found out we could do family planning. There are options, obviously, for adoption, for not having children. But also, you can do IVF and PGD, pre-genetic diagnostics. And unfortunately, that is very burdensome on the, the woman in the, the relationship, as she's the one doing the hormones and the everything, X, Y, and Z for IVF. But I think that we carried this torch, knowing that our children would not be at risk of this, this genetic mutation. And that brought us closer through these incredibly difficult times, my wife and I. And now, we have two beautiful children who are not at risk. And I will be the last person to ever experience this disease in my family line.

[15:59] **Maya:** That's, that's remarkable. So, how did, how do you do it?

[16:03] **Daniel:** So, it's no major science in this one. They... in IVF, you create embryos. And all they do is they put the embryos through a test to see which ones carry the, the gene mutation.

[16:16] **Maya:** Like down syndrome as well?

[16:17] **Daniel:** Exactly. And so, they say, "We're not going to implant those."

[16:21] **Maya:** Implant.

[16:23] **Daniel:** And, and, and that's it.

[16:25] **Maya:** That's amazing.

[16:26] **Daniel:** But it, it means it's so simple, but just phenomenal, you know. Change the future of this disease, you know. What I said when I was doing the advocacy part, I said, "I'm going to make less ALS patients and I'm going to make better ALS patients," because I think that if, if I eventually get this disease, the fact that I'm able to plan, prepare, connect, comprehend, you know, this entire life of advocacy, and then I eventually get it, my mindset will most likely be far different than someone who just-

[17:01] **Maya:** Has to live with it.

[17:01] **Daniel:** ... just got it, right?

[17:03] **Maya:** Yeah.

[17:04] **Daniel:** And so, I said, "If I can transmit that to others, that's, that's such a gift." So, going back, we, we collaborated with this group of, you know, young passionate patient advocates, and we started an organization at under I AM ALS, which is one of the major ALS [crosstalk 17:25].

[17:24] **Maya:** I AM ALS. So, if people would like to know...

[17:27] **Daniel:** I AM ALS is run, started by Brian Wallach, a fierce advocate and just a phenomenal man. And I also had gone to every major ALS organization prior to this and said, "Look, here's my story. I want to work with you to promote familial ALS education resources. How can I take part?" And they all turned me away and said, "Look, that's not our focus. That's not." You know, I can't reach X, Y, and Z reasons it did not work. I AM ALS has the beauty of being patient-led, letting anyone who comes say, "We'll let you start a team. We'll provide resources in terms of team management." And that was just the perfect place for us to start this ferocious, you know...

[18:20] **Maya:** Movement.

[18:20] **Daniel:** Yeah. And so, we started out. And about a year and a half into that, we had created an amazing amount of resources, helped people connect with longitudinal research studies, breaking down the barriers for access to those. Because, in the end, the more people who were involved in, in research, the more insight, the quicker we'll find developments, the...

[18:46] **Maya:** Cures.

[18:47] **Daniel:** Yeah. So, about a year and a half in, I still was not having a paid job. My... we, we had had our son in May of 2020.

[19:02] **Maya:** Right after COVID.

[19:03] **Daniel:** Yeah, in the middle of COVID.

[19:04] **Maya:** So, were you able to be there when he was born?

[19:06] **Daniel:** I was able to be there, and I was able to be at home with him for nine months because I wasn't working for a while.

[19:12] **Maya:** Well, nobody was really working for a while, right?

[19:14] **Daniel:** But most people were employed in remote.

[19:17] **Maya:** Yeah. Got it.

[19:20] **Daniel:** And, you know, I was working. I was creating this, this organization that did not exist. So, I was working but not getting paid for it. And my wife said, "Daniel, I've had enough. I really need you to go make money. You've got an MBA. This is... what are you going to do with your life?" And I've stumbled around in terms of which... where I would land. I said, I think that this advocacy focuses where I need to be, but should I go into an industry that just makes money? You know, should I go into real estate? Should I go into finance? What should I do? And in the end, I started focusing on, "No, I, I want to be in this world and I want to find a biotech that I can join that is focused on ALS, so we can provide therapies for patients." And I made that my mission — networking, doing everything I possibly could to make that happen. And none of it worked for a while. But, you know, so many closed doors and, you know, that just, kind of, plays into the fact that the, the role I was able to finally find at Coya was so serendipitous, so special, so incredible. My CEO, Howard Berman, found me on LinkedIn and texted me one day.

[20:34] **Maya:** Because you didn't have any environmental science background, which is why you were having a difficult time trying to find a job specifically in this field, right?

[20:42] **Daniel:** PhD, I guess, in, in biotech.

[20:46] **Maya:** Right.

[20:47] **Daniel:** But or in, in science, in biosciences.

[20:49] **Maya:** Biosciences, right.

[20:51] **Daniel:** But, you know, he, you know, texted me out of the blue and said, "Daniel, I'm the CEO of a biotech focused on therapeutics for ALS. Can we talk?" And this is, you know, a year and a half of not having a job, doing all this advocacy. And I just... you know, that blew my mind. And I said, "Oh, my God, I'd love to talk to you."

And it turns out that he had licensed to therapy from Dr. Stanley Appel, the leading neurologist in Houston, potentially in the world, focused on ALS and Neurogenerative disease and was bringing forth that therapy to commercialize it. And he had just raised a Series A of $10 million in November of 2020. And this was January, 2021. And he said, "Look, I found you because you've had a lot of experience in, in the ALS world. I need an expert in that. I saw you into Rice Business. I spent a year there before I went and pursued my PhD. And I know they create great people."

[21:53] **Maya:** So, it was Rice Business that got you that opportunity?

[21:55] **Daniel:** 100%. I don't think you would've found me on LinkedIn otherwise. And he said, "I need someone who's going to be passionate, die-hard for this company." And I said, "I'll do everything I possibly can to... I'll bleed for this company," right? This, this means the absolute world to me to be able to make change for patients like myself, like my family members, etc.

And so, that started this unbelievable journey at Coya. And I'd love to share all of that. We... I started just after our Series A in January, and it was me and the two co-founders, so three people. And we really built this company from nothing over the next year and a half, slowly hiring C-suite members, slowly adding on, you know, to R&D, progressing R&D, figuring out our strategy. And we were incredibly focused on cell therapy at the, the outset, as that is the therapy we licensed from Dr. Stanley Appel.

And I'll take you a step back. The reason we licensed Dr. Stanley Appel's therapy is that he discovered that all neurodegenerative disease drives inflammation. And what that overblown inflammation does damages regulatory T-cells, which are basically the control system of the inflammatory system. Without a control system, if you have overblown inflammation, that is just a, an onslaught of inflammation on the body. And that, despite whatever the initial insult is, drive degeneration, and eventually death.

And Dr. Appel created a method to, through cell therapy, to modulate and make more efficacious regulatory T-cells showing in the initial Phase I study incredible efficacy in stopping the progression of disease. My CEO brought his father, who was, who was suffering from dementia to meet Dr. Appel. And he showed him the data, and he was so compelled by that data from Phase I that he quit his job in big pharma and said, "I'm going to commercialize your therapy and bring it to the patients. I'm that compelled."

And so, going back, beginning stages of me joining the company, we're focused on cell therapy and we are gunning to raise money. We raised 10 million initially, but that's only going to get us through, you know, a year or so. So, we are, you know, bootstrapping everything, spending as little as possible, trying to hire consultants, but use them as little as possible for just what we need. And we eventually raised a convertible note for another 10 million at the end of 2021.

[24:49] **Maya:** Wow.

[24:50] **Daniel:** Thank you to all of our initial investors who reinvested in that, in that convertible note, to continue this progress. And as soon as we raised, finished raising the convertible note, we said, "How do we raise the next round of funding immediately?" And that led us down the path of where we are now of becoming a public company on Nasdaq. And that experience being the, you know, second-in-charge behind the CFO in charge of getting that IPO through was unbelievable. And the, the lessons learned, the education from just going through that process, the, the immense drive that we all guarded from it, the long nights, the hectic...

[25:37] **Maya:** It's all worth it. It's all worth it.

[25:39] **Daniel:** So worth it. Just brought us all together right through this incredibly difficult experience. And so, now, we are a public company. And that brings new excitement and challenges with regulatory issues and financial reporting issues. But I think the most exciting thing, besides giving you the, the insight on the background of how Coya is run, is what we're doing and what we've shown that we can do for patients. And we just released proof of concept data from Houston Methodist in four patients with ALS and showed that we can stop the progression of ALS to negative one and a half points on the ALSFRS scale over 48 weeks.

Now, if you look at, you know, controls, people are progressing at negative 10 to 20 points per year, severe degradation in ability. If we can continue to produce the same results as we move through clinical trials, we will bring a new age of ALS. It will be something that you can live with, right? Instead of being this incredibly difficult, terrible death sentence. And so, that brings just such joy to me and such enthusiasm that we can continue this work and we can, you know, continue that development forward.

And the natural most exciting thing is we are about to release data in Alzheimer's utilizing the same therapy or biologic. That's coming out May 16th. So, everyone, pay attention to Coya Therapeutics.

[27:19] **Maya:** Okay.

[27:19] **Daniel:** But I think that we are in this age where we all know someone who's dealt with a neurogenerative disease. We've all had an incredibly horrible experience with that.

[27:29] **Maya:** Yes, I have, as was... as you have as well.

[27:33] **Daniel:** And Coya is looking to change what that experience is, change what it means to be diagnosed with these diseases, and show that through Houston's effort, through Rice's effort, through all of our efforts, that we can change the future of what it, you know, what it means to have this disease and have it not be a death sentence.

[27:52] **Maya:** Wow. Daniel, this has been one of the most inspirational interviews that I've ever been a part of. And I am just so inspired by, by you and your story and how it all relates back to this amazing university. And we will definitely keep up with May 16th, right? And then, if anybody is interested in learning more specifically about the, the work and the research or if anybody would like to invest, what's the best way to do that?

[28:19] **Daniel:** So, one, we're public on Nasdaq. Our ticker is COYA, COYA. Our website is coyatherapeutics.com. You can reach out to me to ask questions, etc. And I'm going to do a shameless plug-

[28:34] **Maya:** Okay.

[28:35] **Daniel:** ... for my... I, I, I think I may have gotten sidetracked in talking about how the organization I created at I AM ALS is now a nonprofit, called End the Legacy: ALS & FTD. And I'll finish with the fact that that is the only organization focused on the pre-symptomatic community, the only organization that is focused on saving my life and preventing ALS, a new way of thinking about this entire abstract.

[29:08] **Maya:** What's the future of genetics?

[29:09] **Daniel:** Future of genetics. And I am going to be riding in this incredible Gravel race called Unbound.

[29:17] **Maya:** In Kansas.

[29:18] **Daniel:** In Emporia, Kansas, on June 3rd. And I'm hoping to raise $100,000 for this nonprofit. And I'm counting on all of you to help donate. So, I'm sure we'll be able to throw in a link at the bottom. But this organization is doing things for a community that have never been done before, that is really going to change what it means to be a pre-symptomatic gene carrier, not only in my disease space, but, you know, we will write the rule book for what it means for anyone who stumbles upon a 23andMe genetic result. You can learn from us. So, help be a part of that way.

[29:57] **Maya:** Absolutely.

[29:58] **Daniel:** Thank you.

[29:59] **Maya:** It's been a pleasure. Thank you so much for being with us today.

[30:02] **Daniel:** Of course.

[30:02] **Maya:** We're going to keep up with you.

[30:04] **Daniel:** I'm looking forward to it.

[30:05] **Maya:** Thanks for listening. This has been Owl Have You Know, a production of Rice Business. You can find more information about our guests, hosts, and announcements on our website, business.rice.edu. Please subscribe and leave a rating wherever you find your favorite podcasts. We'd love to hear what you think. The hosts of Owl Have You Know are myself, Maya Pomroy, and Scott Gale.