

Interviewee: Chris Scarcella

Interviewer: Alison White

Date: 26 April 2015

Location: Quincy, MA

Transcriber: Alison White

Abstract: Chris Scarcella spends his time advocating for research as he navigates the hurdles of living with Huntington's Disease. In this interview, Chris walks us through his day-to-day life with HD, while reflecting on a childhood spent with a gene-positive parent. Despite all of the challenges Chris continues to overcome, he radiates with a positivity that infects those around him and carries through his efforts to educate others and advocate on behalf of HD.

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AW: This is Alison White. Is April 26, 2015, and I am here with Chris Scarcella to interview him about his relationship to Huntington's Disease. Chris, how do you identify yourself as a member of the HD community? Do you consider yourself an advocate, gene-positive, gene-negative, caretaker?

CS: I am a positive gene advocate.

AW: OK.

CS: And I try to educate people as much as possible about the gene and about how people can work through difficulties using things like the iPad, and that's what I was talking about a little bit earlier with you – that's my, kind of doing Education Days with the HD, MGH, right? And Circle of Excellence.<sup>1</sup> Connecticut asked me to do theirs back in April 11<sup>th</sup>. So, me and my speech therapist, who helped me with this, came up with my strategies for life with HD. So, that's how I kind of go through and

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<sup>1</sup> Correction: Center of Excellence (A. White)

kind of map out what I'm going to do for the week, for the month, using my iPad, and I just do different things with it – such as journal, journal bad thoughts, good thoughts, when I have insomnia, it really sucks. Because sometimes I'm up at three o'clock in the morning and you know, just kind of bitching at it. But, sometimes it's those moments that the real truth comes out – you know what I'm saying?

AW: Yeah, definitely. So, as an advocate, do you, who do you try to educate, who do you try to reach?

CS: Well, I've been doing information days for HDSA and HDSA affiliates, such as Massachusetts chapter, the Connecticut chapters. I've worked with Virginia Goolkasian. I did the HD awareness at the statehouse.

AW: Oh, OK!

CS: I spoke in front of about 20, 25 of the reps that were there. And, so, anything to just get the name out about what it is, and how it affects people, because a lot of the people don't know what it is. Because it's easily . . . it's very easily misdiagnosed. And that's why you don't have a lot of Circle of Excellence's.<sup>2</sup> You know, sending, you know, you have people from Vermont sending, they're sending their people down here because they can't diagnose it correctly. So, my thought is: as long as I can be a helpful mentor and, I've actually spoken with Dr. Rosas and she had me speak, I think between two and three different classes of, one was MGH at the Simches Center, I spoke with PhD students, doctors, people who were graduating coming in the next couple of years. I did that at the Simches Center, I did that at MIT as well as the BU group down there. So, I've spoken to three groups of doctors and drug companies and. So, and, a lot of it has to do with just my story. And then the information days was like that.

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<sup>2</sup> Correction: Center of Excellence (A. White)

AW: How did you first hear about Huntington's Disease?

CS: My mom had it . . . back in 1975 she was diagnosed as a I was a young boy and she had terrible bouts of pneumonia, sorry, insomnia, and terrible mood swings. Kind of, no one back then, Dr. Bird was the top doctor in the area, so . . . and so she sent to him, she was diagnosed with it, and her mom is the one that had it because her dad was, lived to an old age and didn't have it. He remarried. She had, her mother had seven kids. Only three, supposedly, are gene positive, and . . . but I think Alzheimer's, there was an aunt out in Ohio that was diagnosed with Alzheimer's but at that point . . . I'm pretty sure she was probably, because they say it was dementia, but you know, it's very close between the two.

AW; Certainly is. Aside from your, I guess, considering your mother had it, how has Huntington's Disease affected your life? How did it affect you growing up? How does it affect you today?

CS: Well, you have to kind of consider things like, there are things in my childhood that you want to remember. Sometimes I had a great childhood, but there are other points in my childhood where I put a box on my head and I don't want to take it out. One of them might have been, you know, my mom keeping me up all night long to learn how to fold and properly fold, you know, shirts and underwear, and I was six years old.

AW: So your mom was symptomatic very young.

CS: She got it in her mid-30s.

AW: How does HD affect your everyday? You mentioned a little bit about some of the advocacy that you do, what . . . how has it affected your routines?

CS: Well that's the whole thing about being an advocate and Dr. Rosas and the Circle of Excellence<sup>3</sup> at MGH, really kind of helped me understand that I need to do things a certain way every single day, you know, do I get up at 7:30 like they want me to? Maybe not. Maybe 8:30 . . . but I do do the things that they ask me to: take, you know, take, put my pills on the iPad, put everything, eat food, when I first . . . back in 2013, I was going through a tough time because I had lost 30 pounds, and I was 145 pounds at that point. And she was like, "Ok, this is not working, so let's do some reset, and kind of look at what you're taking in, what you're not taking. It was a medication Zyprexa that helps me with depression, and also has a side effect of you know, gives me weight gain. And, but, back in 2013, I was on a 6000 calorie a day diet. I had to take Ensure's plus, five, six of them, you know, every day. And that really kind of sucked. So, but the Zyprexa I take one pill at night and I haven't looked back. I'm 20 pounds heavier. So, you know, they're very happy where I am right now.

AW: That's awesome, congratulations on gaining your weight back!

CS: Thanks.

AW: Chorea can definitely have that affect and that's something that not everybody is sym . . . not everybody presents with chorea. Do you mind if I ask how chorea affects you everyday?

CS: It does. It makes me tired. I take a pill in the morning that helps me focus and I used to be able to . . . for 25 years I worked at a mutual fund company, which had become my second family, they're awesome. For 25 years I sold mutual funds, 65 products, and my main, you know, my main customer was the advisors. So, I had to remember, I wrote scripts out so I would remember, and make myself better. Now, they gave me some help in regards to what I used to cover and what I covered when

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<sup>3</sup> Correction: Center of Excellence (A. White)

I finished. I had two territories, and when I finished in 2012 I had just one territory. But the company that I had was awesome, just fantastic, but that's . . . the chorea is part of it, because I can't . . . my fine motor skills, you know, touching a computer screen, touching a . . . something at home, let's say, fixing a light – I can't do that anymore. I used to be Mr. Fix-It. And now I can't even climb a ladder, so it's terrible,

AW: Yeah, how has that, how has that affected your mood over the years?

CS: Sometimes I'm moodier than others. I'm mostly I see, I see the glass as half-full most of the time. But there are times, I'm not kidding, sometimes I do delve into some crappy moods because I'm just not happy with where my, I might not be happy that particular week because I hadn't reached out to my friends or been apathetic towards doing that. You know . . . this . . . this is kind of what happens to people with HD. You know . . . and you kind of wall yourself in with how you treat people. I never, ever, treat people negatively, I don't expect them to treat me bad, but it doesn't mean that I don't have those thoughts.

AW: How has Huntington's Disease affected your more personal relationships with friends, your spouse?

CS: Marguerite has been awesome. She tells me straight out that I am the love of her life, and she was so lucky that I said I like kids when I asked her, to buy her a drink on July 23<sup>rd</sup>, 1993. So, it was fantastic. And you know, at that point, later on in the night, I told her all about my mom and you know, so she knew at that point . . . that my mom was sick because she was already in a nursing home, so . . . cause my mom passed away in 1996 at 63.

AW: Oh, wow. We're going to switch gears just a little bit, what advice do you have for the HD community?

CS: Don't give up, keep fighting. Even though you may have a terrible day, sometimes, you know, it's . . . sometimes what you don't say makes something much more better than what you do say. And I learned that rule from my rehab person, Rachel Licker at Spalding, she said let it lie. She gave me a rule to take home with me, and it was, it was good. So that's what I use. And so, whether or not it's something with my boys or something with Marg, or something with a friend.

AW: What do you admire most about the HD community?

CS: . . . I admire how much compassion there is from the doctors, nurse – social workers, and the people that actually do the work, you know the volunteer work. So, because I get it. I understand. You know, I volunteered for Make-a-Wish for a long time. So I understand the volunteer side of it, and there's much more work that goes into it than people realize. I'm much, much more appreciative of what they've given me.

AW: What are you most proud of within the HD community?

CS: I can say that . . . anything Dr. Rosas and her team at MGH need I'm proud to say that I would do anything for them. I'm proud of my three sons. Proud of my wife and how she is handling this and, you know, I just hit the lottery when I met her, because I was not expecting at 28 to restart my life. I had already, I had a college sweetheart that I married and it didn't work out, so a year and a half after that, it's . . . it's, you're busy making your own career at 28. So, that's what happened. But, you know, when a door shuts, something else opens and it did.

AW: What are you proud, what accomplishments of your own are you proud of?

CS: . . . Accomplishments . . . I'm proud of the fact that I have three grown boys. I'm happy that my middle son has a brand new wife. I am . . . can't wait to have a first grandchild. I'm proud of all of my sons, by the way. I'm proud of my family too, on

my side. I'm proud of my sister Lindsay, who's now on the treasury, she's the treasurer of the Massachusetts chapter of HDSA. She told me that a couple of weeks ago, so I'm pumped to, you know. And, I'm really proud to also be able to inform and make aware of the needs of the HD community because of the cuts that have taken place. The MGH needs money, and that's my advocacy. Sorry.

AW: Oh, no!

CS: I was a salesman, so I always go back to what I was best doing.

AW: Don't apologize, it's awesome! When people don't know about Huntington's Disease, how do you try and explain it to them?

CS: When they say, "What is it? You know, I can't see you having anything." Picture yourself losing reason, losing muscle control, high function, multi-task and your balance. Put that all together, and there's no cure. You can treat the symptom, like, for chorea. But there's not cure, so, that's what it is, and that's what I tell people.

AW: It's a really good answer. A lot of people tend to describe it using other disease, and that's the first time, I think you're the seventh interview I've done, and you're the first person to describe it independently, which is awesome.

CS: I'm just glad I know so much about it. Because I'm constantly trying to educate myself on what's going on. So . . . yeah.

AW: Yeah. Why did you choose to participate in the interview today? Or did Lindsay just talk you into it?

CS: She didn't talk me into it. She said, I have this awesome person coming that I know, they are putting together this awareness month in May for HDSA in Massachusetts Chapter, and I'm not afraid to be an advocate for it, I'm not afraid to

tell my story to anybody. So, I can say, you know what, I have this disease, it needs more awareness, and the budget cuts need to be given to this area of excellence, where a ton of people go to. But, you know, those numbers aren't really seen because those are people from Iowa, people from upper Vermont, people from all around the U.S. They look online, they see where, they say, "Oh, I know this in Boston." And they go. And I just, wish it was easier.

AW: I think we all do.

CS: Yeah.

AW: Who do you hope hears your interview? How far do you hope it goes?

CS: . . . I wish someone from, say, a NIH listens to the interviews because they're a part of the group that gets a lot of money and research. But they're also the, they give the money. Whoever is giving the money in California: share. I know it's terrible to share, but it's the same body, same minds. Everyone should, sorry, everyone should, with NIH . . . who else. I just want to be proud of whatever I said. I know I go on for a bit, but that's part of the . . . the HD, me just going on.

AW: Is there anything, I'm done with the questions I had, the formal ones, is there anything we didn't talk about that you'd like to bring up or cover?

CS: No.

AW: That's it?

CS: I think when you asked me about who you want to hear. I really do want people to realize people with HD may have it, it's just like cancer, just because you have cancer doesn't necessarily mean everyone needs to know . . . and . . . but it doesn't necessarily mean something can't be solved. You know, nobody knew about

Parkinson's Disease until Michael J. Fox got it, then it's all over the news. So, I hope someone gets it, or sees it – not gets it.

AW: I think there are—a lot of people have the same sentiment. It's a disease a lot of people don't know about; we don't have a public face, it makes it very hard to raise awareness.

CS: Right. So if I have to be that public face, you know.

AW: You'll deal with it.

CS: Yeah.

AW: Awesome, well Chris, thank you very much, I appreciate you participating today.

CS: Thank you, Alley.