

Announcer ([00:00](#)):

The HD Insights Podcast is brought to you by the Huntington study group. The Huntington Study Group is a nonprofit research organization dedicated to conducting clinical research in HD and providing critical training on HD to healthcare professionals. Funding for this podcast is made possible through the generous support of listeners like you and sponsorship grants from organizations like Teva Pharmaceuticals.

Kevin Gregory ([00:43](#)):

Hello, and welcome to the HD Insights Podcast. I'm Kevin Gregory, Senior Director of Education and Communications for the Huntington Study Group. And today I'll be joined by someone who has been a very prominent, recognizable advocate voice in the HD community, especially for young adults. And that's Seth Rotberg.

Kevin Gregory ([01:01](#)):

Seth is a patient advocate, community connector and motivational speaker who is passionate about bringing his personal experience to support the health community. On this episode of the pod, we dive right into that drive and urgency that Seth is putting into his current work with young adults in the HD community. And now with young adults across a wide spectrum of rare and chronic conditions.

Kevin Gregory ([01:26](#)):

In 2019, Seth cofounded the nonprofit, Our Odyssey, to provide year round social and emotional support to young adults impacted by a rare or chronic condition. He has a master's in nonprofit management from DePaul, and currently resides in Cambridge, Massachusetts. Professionally, he works as the patient leader recruitment manager at WEGO Health. So without further delay, here's my conversation with Seth Rotberg.

Kevin Gregory ([01:56](#)):

All right, well, Seth, I really appreciate you joining the HD Insights Podcast today. And it's a pleasure to speak with you. I know a lot of people in the HD community are familiar with your story. But I'm sure there's still a healthy population of people out there that aren't as familiar with it. And you tell the story the best, so I certainly don't want to take any of the wind out of your sails. But again first of all, welcome to the podcast.

Seth Rotberg ([02:26](#)):

Yeah, thanks, Kevin, I appreciate you inviting me on to share a little bit about my story and some of the work I'm doing in the space to really help make a difference in the community.

Kevin Gregory ([02:37](#)):

Let's start with your history, your personal history and experience with your family and Huntington's disease. Starting there I know you've been an open book with your diagnosis. But take us back, what is your earliest kind of memory of where Huntington's disease started to impact you in your life?

Seth Rotberg ([03:02](#)):

So I think it started probably in 2005, when I was 15 years old. I did that math right? Yeah, I did the math right. And that's when my mom was first diagnosed with Huntington's disease. But I think the prior few

years leading up to that, we knew something was off with her, we just didn't know what it was. And not just with Huntington's disease, but with a lot of rare diseases, there tends to be a misdiagnosis. It can be five to seven years, even longer.

Seth Rotberg ([03:38](#)):

And we were noticing that my mom had those drunk-like movements, the slurred speech. And she had the mood swings, where one minute her and I are talking the next we're in an argument or she's upset about something, and then snap of the finger, and everything's fine again. And at the time, the doctors said, "Oh, maybe she just has mood swings, or bipolar disorder, or major depression." But that didn't explain those wobbly movements.

Seth Rotberg ([04:12](#)):

And so, it actually took like a small family intervention, I remember again, being 15 at the time or around that age, and my older sister was off to college. So it's my dad and I, my mom's getting worse, we're running out of options. So my dad myself, my two aunts, my uncle, one night sat her down and said, we have two options right here. One is that we have to check my mom into a mental facility to get more tests done and figure out what's going on or two my dad and I were going to leave, because when you live with a parent with Huntington's disease, it can take a toll not just on the person with it, but the family too.

Seth Rotberg ([04:56](#)):

And that's why I always believe it's a family diagnosis because it does impact Everyone, she wasn't happy with those choices, of course. But she was willing to go to the mental facility. And that's when they ran a bunch of tests, and determined, oh, she has Huntington's disease, and was the first in our family. So of course, that's new to us because we know that there's usually family history. So my mom's one of four, her three other brothers and sisters got tested, all tested negative.

Seth Rotberg ([05:29](#)):

We figured out it was her dad who had it. But we think he might have been in that gray area, which I know it gets a little confusing, but essentially, he may have not had it, but that he could still pass it down. So kind of the CAG repeat that doesn't show that you have HD but your kids could still be at risk. That's just our guess, because according to my family he wasn't showing symptoms, and he was perfectly fine.

Seth Rotberg ([05:59](#)):

And so that's where it kind of all started was 15 year old me trying to learn about it, going Google, which we know never really helps. It does help in some sense, because you learn about it. But it's also quite scary when I saw the symptoms and saw that everything my mom was dealing with lined up with this disease, and that the average lifespan's 10 to 20 years, and there's no cure.

Seth Rotberg ([06:25](#)):

I think the challenge was not only trying to come to accept this as a part of my life for the rest of my life, but at the same time trying to fit in with my peers in high school. Which it's always a tough time to try to fit in. And then I have a mom who is sick, and I'm like, people aren't going to understand this. So I was embarrassed being out in public with her or having friends over. And so it was just very challenging for

me. And it wasn't until a few years later, where that's when I decided to learn more about it. And then five years after learning about it went through genetic testing at the age of 20. And found out that I also tested positive for it.

Kevin Gregory ([07:01](#)):

Would you say... When you first learned about your mom's diagnosis of HD, would you say that was a relief that you finally found an answer to the issues? Or in your mind did that make it worse knowing what you had learned about the disease leading up to that? The fact that it is going to get progressively worse. There is no cure. Do you remember what was going through your mind and kind of that range of emotions?

Seth Rotberg ([07:34](#)):

Yeah, I was definitely an angry child growing up, to be honest, which surprises some people today, because they're like, "Seth you angry person or you lashing out? That just doesn't seem like you." But I think it was kind of saying, "Okay, why did this happen to my family? Like, what did we do to deserve it?" And then kind of like how do you deal with it. I was in so much denial about it. And I just didn't want it to impact my life.

Seth Rotberg ([08:03](#)):

So I was trying to still be a typical high school kid playing sports, hanging out with friends. And I ended up picking up a few jobs, staying after school just to kind of stay away from the house. And it wasn't because of my mom, I think was just because of trying to accept this disease that's going to take over her and her life, and it's going to change my family's life. I think that was the challenging part, it was a relief to know what was going on.

Seth Rotberg ([08:33](#)):

Because again, the other option was that my dad and I were going to leave. And I feel like I would have a lot more guilt if we ended up leaving and finding out later that she had it. Saying, "Wow, we could have done something." And so yeah, I was definitely just quite upset about it and angry about it just because I just didn't want to accept it. And I guess you could say I was going through that grief and loss stage. I was in the angry part of it and being in denial.

Seth Rotberg ([09:02](#)):

And then I don't know really what hit me in college that made me be like, "Oh, wow, actually, I'm at risk." I think one part of it had to do with my biology class, junior in high school and doing those Punnett squares and talking my teacher about it. And what I was taught it was not the right thing, which was the father usually has the dominant genes. And so because of that I'm in the clear. And that's, of course, not how it works.

Seth Rotberg ([09:30](#)):

And so when I realized that, I was like, "Oh, wow, I'm at risk. And I could end up like my mom one day. So what do I do now?" And that's when I decided I want to get more involved. I wanted to host a fundraiser. I also kind of wanted to make up for lost time because to be honest, like I was so upset that I ended up taking it out on my mom because I just didn't understand it, and I didn't know how to cope

with it. And so it was a challenge. I think the guilty side of me is saying how do I, not fix the past but how do I kind of help improve it for today and for tomorrow.

Kevin Gregory ([10:13](#)):

Once you learned that your mother had Huntington's disease how did that change your role as a caregiver? Obviously, you now had access to maybe different professionals, or different tactics or approach. Whereas before, you were kind of managing the issues, like you said, and it was getting to the point where you and your dad were thinking about leaving. What was the shift, then like, and how does that relate to some of the work that you're doing now with youth that are going through some of those similar transitions.

Seth Rotberg ([10:51](#)):

So I think a couple things, my dad being the main caregiver, and he was there, through the whole... Through the good parts, and not so good parts. And my hat goes off to him, because seeing that, and him when I was growing up, him being like a role model to me, made me realize how important life is and how you need to just appreciate the little things.

Seth Rotberg ([11:17](#)):

And I think my sister would of course, help out when she came back from Arizona. But when I was in high school, and that was kind of the meat of things, like when it was starting to get really tough, I would have to take her out for errands, I would have to take on more responsibility at home. And so it felt like I was growing up a lot faster than my peers. And so even though I'm 30 now, I feel like I'm such an old soul because I had to grow up a lot faster.

Seth Rotberg ([11:47](#)):

And I've talked to a lot of people in the HD community who deal with any rare or chronic condition, or even just any adversity. You grow up a lot faster, and you just appreciate life, and you understand what you need to do for yourself, but also the people you care about and you love. So my caregiving role, it was just kind of helping out my dad, or my sister, with my mom and whatnot.

Seth Rotberg ([12:14](#)):

But I think what changed is when I tested myself it got a lot tougher for me mentally. Because when you see your loved one go through, and you say, "Wow, that could be me." It gets quite scary. And what I mean by that is, so my mom, she passed away six years ago, she was 60 years old, she end up in a nursing facility. And I remember like my sister would come home, usually during the summer, because she was a teacher, and she was like, "Why aren't you going to visit mom more? Like, why aren't you going?" And I just was like, "I don't want to."

Seth Rotberg ([12:54](#)):

But deep down inside, it was because I feared seeing her and seeing myself in her, being like, "This is tough." Especially towards the end of it. It kind of made me realize, wow, this could be me one day, unless I do something about it, unless I take action. And that's kind of what stemmed me to get more involved in the HD community. At first getting involved with HDSA, eventually getting on the board for HDYO.

Seth Rotberg ([13:20](#)):

And now to stay really working with early stage biotech companies that have a focus in HD, or just trying to figure out how do we advance research through my own story and the story of many others who are either A, at risk and are deciding to test. B, like me are pre-symptomatic, but have tested positive. Or maybe are even early symptoms? And what I mean by that is, maybe they have the cognitive and psychiatric piece of it, but not the motor symptoms yet. And how do we get their voices heard? When it comes to research?

Kevin Gregory ([14:00](#)):

Yeah I'm curious too, So you went through all this and then you ultimately came to the decision for yourself to get the genetic testing. At what I would think or consider a fairly early age at the age of 20. Which is a period in most people's lives where they feel invincible. You're at that college age, nothing's going to bother me.

Kevin Gregory ([14:27](#)):

And you talked about it a little bit where it's kind of maybe the less I know, the better I am. Ignorance is bliss kind of approach. Talk about what really finally prompted you to make that decision for yourself and how you kind of carry that message forward. Obviously the choice to get tested is an individual one and there are people that should be involved in that. But for you specifically, the process you went through to get to that decision point, and then how you communicate that to youth today.

Seth Rotberg ([15:07](#)):

You're obviously writing that genetic testing is such a personal decision, and it shouldn't be based off of anyone else except for your own decision. But what I would say is making sure you have the right resources and support when figuring out if you have Huntington's disease or any other kind of genetic condition.

Seth Rotberg ([15:25](#)):

I know with kind of just some stats that I think it's about only 10% to 15% of people who are at risk for Huntington's disease actually decide to go through testing. And I understand that part, because they're like, "There's no treatment, there's no cure, why do it?" For me, it was kind of like, I wanted to know, my future. I wanted to know, what the future and entailed and how can I use that to my, I guess, advantage of preparing for life with or without HD?

Seth Rotberg ([15:58](#)):

I think what was going through my head was, really, as I dive deeper into understanding HD when I was in college, seeing kind of the list of symptoms, and then resembling, I guess, my mom, in some ways, whether it was dropping a phone, forgetting an earlier conversation. It was very easy for me to just say, "Oh, is this HD or not? Is this HD or not?"

Seth Rotberg ([16:23](#)):

And I kept thinking about that, where it's just mentally draining. And I wanted to know, so I didn't have to worry about it anymore. I mean, at the end of the day it most likely wasn't HD, but in my mind, it was like it could be. It was probably just me being a typical college student and not realizing that.

Seth Rotberg ([16:43](#)):

But what I decided to do, and I share this in a TEDx talk that I did in 2018, is that I went in pretty much by myself. I got a referral from my primary care physician to a neurologist. Went in, talked to him about the family history. Two weeks later went back. And that's when he told me I tested positive. I didn't go through genetic counseling, which I always recommend people today to do, because it's such a valuable resource.

Seth Rotberg ([17:16](#)):

I had a friend who was in the waiting room, but not in like the doctor's room. And I recommend having a friend, even family. Because the other part was, I didn't tell my family for a few years. And that was my own personal decision, because I didn't want them to worry about me. And I also didn't want my mom to never find out, because I didn't want her to feel guilty. Luckily, she didn't.

Seth Rotberg ([17:41](#)):

But then I realized the importance of telling them. Told them a few years later, they understood, they support me, they love me. Same with my friends. And I realized that with all of this, that you'll realize who your true friends are, which are those that aren't going to treat you differently. And aren't going to define you by your condition, they're going to be the ones who see you for more than just HD. And that they're going to appreciate you based off of your values, interests and personality.

Kevin Gregory ([18:11](#)):

Yeah. You in that TEDx talk that you mentioned, you told a really cool story about your dad's reaction and how nervous you were going into it. I was wondering if you... You do it much more justice. If you wouldn't mind sharing that with folks. I thought it was a really cool reaction.

Seth Rotberg ([18:30](#)):

Yeah, so... I think that was a such a nerve wracking situation. Telling my dad as well as telling my sister about this big news. And one thing I didn't mention in my TEDx talk, I will admit, I needed a little liquid courage. Because I was like, I don't know what he's going to say, how he's going to react.

Seth Rotberg ([18:59](#)):

And at the time I walked into my living room, my dad's watching TV, probably watching the Red Sox, he's a big fan of that. And I told him, I had something important to tell him. He kind of looked at me and said, "All right, what is it? What do you need to say?" And I said, "I tested positive for Huntington's disease." And he just kind of looked back and was like, "All right, sounds good." Like, he was so nonchalant about it, that it kind of caught me off guard to be like, "All right, you don't have any questions. What's the deal?"

Seth Rotberg ([19:33](#)):

But I think it was just kind of his positive outlook on life. And I think also what he learned just as a caregiver to my mom was just kind of like, hey, researchers are making great progress and that there's going to be something sooner rather than later. Now, that was... I was going to say that was about seven, eight years ago.

Seth Rotberg ([19:58](#)):

And yes, research has been amazing. I've learned so much about all these different companies working in HD. But I think now is the time to also take that next step of reframing that mindset of, "Hey, we can be hopeful but hopeful..." Feeling hope is not going to necessarily move the needle acting with urgency. Well, and that's kind of my new message today is how do we act with more urgency for treatment options and making sure that we can slow this down, halt it in its tracks or even reverse the course.

Kevin Gregory ([20:36](#)):

Yeah, so that's a great point for follow up. So 20 year old South Rotberg, he's been tested, he knows his outcome. And a couple years later told friends and family. So now you've gone from having been involved in activities, kind of in support of your mother's diagnosis to now knowing that you have to, you want to do something for you. And you talked about the urgency. And in terms of timing, with everything with the community currently with recent trial outcomes, yeah, there is a sense of urgency. So, talk about how after, after the diagnosis, after you told everybody. What was the motivation then? And how are you communicating that level of urgency into a plan of action now, and steps going forward, to help people that are going to start entering that same phase, that same transition that you did several years ago?

Seth Rotberg ([21:44](#)):

So, I think the first thing is understanding you can't do everything for everyone. And what I mean by that is I wanted to do everything, I didn't know how to say no to things. And so I was like, "Oh, you want me to share my story? Sure. Oh, you want me to do this fundraiser? Oh, you want me to volunteer for this?" I was saying yes to everything, because I just wanted to help everyone. And I realized at the end of the day, if I can't help myself first, it's going to be tough to help others.

Seth Rotberg ([22:11](#)):

And so that was like one of the biggest kind of lessons I've learned even more recently is one it's okay to say no, and to like, focus on a few things, versus trying to do 100 things that are kind of at a lower level. And so once I was more open with it, I think I really focused on trying to support more yet young people. That's why I joined the board for the Huntington's Disease Youth Organization, was because I didn't want anyone to go through the similar experiences myself. I knew that they a lot of great resources and educational content, and I wanted to make sure people were aware of that.

Seth Rotberg ([22:50](#)):

And also, just the idea of connecting with another young adult is very different than connecting with an older caregiver or an older person living with HD. And I remember the first person I met was right before I went through testing, when I was in college. Someone who lived down the hall said her friend was coming, that her mom has aged 30. And as soon as I met her, I just felt like I could let my guard down, just be myself again.

Seth Rotberg ([23:16](#)):

And there was no feeling of being judged. And I just was so open with her. She was actually the person that came with me for my genetic test results. And I think that's something that I'm still passionate about is making sure young people are aware of... They're not alone in this. There's a lot of other people going through, whether they're at risk, they've tested positive, or even tested negative. Some good friends who have tested negative and I tell them, "Hey, I appreciate you that you're still involved in this

community." Because I get with some people, they test negative, they're like, "All right, I'm out of this I don't need to worry about anymore."

Seth Rotberg ([23:56](#)):

But then I'm kind of like, "Well, what about me? And what about everyone else that you build a relationship with, that are still dealing with this." And so I do have a good amount of friends who have tested negative and are still fighting by my side, or for me, and for their loved ones and for their friends, and I appreciate that a lot because we need as many people to continue to advocate.

Seth Rotberg ([24:20](#)):

But to kind of shift over to the research side of things. I think one thing I've been continuing to learn about is someone like myself doesn't qualify for any of these trials. And I'm talking more interventional trials where it's taking a treatment or not. Of course, I do participate in Enroll HD and any other trials that are more observational. But part of me thinks if I'm considered pre-symptomatic, but the goal is to stop the condition in his tracks or slow it down, then I need to be in some capacity involved in these trials.

Seth Rotberg ([25:02](#)):

And the reason I say that is because we know right now to be diagnosed with HD, it's mainly due to motor symptoms. But we've also learned more recently that you can see changes in the brain and the cognitive symptoms 15 to 20 years ahead of time. So it's someone like me, who is 30 now and so okay, I might start developing motor symptoms in my early 40s, similar to my mom. So has the cognitive parts already happened? It's possible, but I think that's why I want to start acting with more urgency is how do we look at the diagnostic criteria? How do we make sure that people like myself and others can participate in these trials, as well as help develop these potential treatments by getting their voices heard in these companies early and throughout drug development?

Seth Rotberg ([25:59](#)):

That's something that I'm still passionate about is understanding that with advocates like myself. If you're coming to us after you're trying to recruit, to me, you're not going to be as successful as coming and say, "Okay, what is the most burdensome parts of the symptom... Of the condition. What are the most burdensome symptoms of the condition? What about the trial design? Any other protocols? Oh, you're part of a patient advocacy organization? Oh, could you help pass this along about these upcoming trials?" Things like that.

Seth Rotberg ([26:38](#)):

I know, it's a lot easier said than done. I know, companies have to go through legal, compliance, regulatory. But part of me is kind of like, Okay, do we need to educate them on the importance of talking with the community early and throughout drug development, because if we take a study that saying, you have to come in once a month, or even once every other month. Let's say once a month. That's 12 days a year, may not sound bad.

Seth Rotberg ([27:10](#)):

But if it's someone like me who's working full time, that means I got to take 12 days off of work, possibly more for follow-up visits. And then I don't have any time for me, for self care. And so it's how do we kind

of make sure that we're aware of some of these challenges that might be faced? Or how do we make things more decentralized, and more virtual so that it could be a simple checkup via an app on my phone, or a Zoom call or anything that's virtual. So that someone like myself doesn't have to come in for a follow up visit? Or we can make it a little more manageable.

Seth Rotberg ([27:48](#)):

So these are just things that kind of come to my mind of saying, how do I... Not how do I, how do we rally up the community so that we bring more of this urgency of saying HD impacts someone for 10 to 20 years, but I don't have 10 to 20 years to wait. I don't even have five years to wait, I want to act now. By not just sharing my story of a story of many others who are living with HD.

Announcer ([28:16](#)):

We'll return to the interview on the HD Insights Podcast in a moment. We hope that you're enjoying this episode. As a nonprofit organization the Huntington Study Group relies on the generous support from the community and listeners like you to continue bringing you in depth content on HD, like this podcast series. If you like what you're hearing and are interested in supporting HD insights through a grant or donation, please contact us through our email address [info@HSGlimited.org](mailto:info@HSGlimited.org). Or by calling toll free at 1-800-487-7671. We greatly appreciate your support. And now back to our episode.

Kevin Gregory ([29:10](#)):

And these are really fantastic points. I absolutely agree with that. In your role in advocacy, the work that you have done or are currently doing. Have you had conversations with industry and what types of obstacles have you encountered or potential successes have you found so far in getting them to understand the potential for getting pre-symptomatic patients involved in these studies? Or understanding the time commitment. Like you said, if it's a monthly visit, it doesn't sound like a whole lot maybe to somebody managing the books. But depending on your location or your job situation, like you said that's an additional 12 days off a year that you may only get 18 days a year to take off. And if 12 of those are for study visits, you essentially only have another week to enjoy your own personal vacation.

Seth Rotberg ([30:17](#)):

Exactly. I think with industry some of them get it, some of them don't. And that's not to knock off any of them. That's just kind of what I've seen over, even just the last few years. And what I mean by that is those who are bringing in the community perspective and the right people, they understand it, whether they're doing focus groups, advisory boards. Some of them are doing market research, but then it's like, are you getting the right audience to answer your questions?

Seth Rotberg ([30:53](#)):

I've seen a lot of even the surveys that go out, and I'm like, "Oh, maybe I'll help out." But then it says, "Are you diagnosed?" And technically, I'm not. So I'm like, do I fit the criteria or not? And then if I do say I'm diagnosed they say, "What are your symptoms?" I don't have symptoms. But that doesn't mean my voice isn't important. Because one day, I might be taking that treatment. So you need to understand my perspectives or people like myself.

Seth Rotberg ([31:21](#)):

So I think, when it comes to that, that's the whole goal for these patient advocacy professionals within an industry to build these relationships, not just with the nonprofits, but I think there is a whole new market of like, patient advocates or patient influencers. If someone goes to HDYO, or HDSA, or help for HD to hear any of the others that's one thing. But I'm not involved necessarily with any of them. So how do I get my story out there, and there's a lot of other people like myself who aren't directly involved with patient advocacy organizations who have a really good insight into the community.

Seth Rotberg ([32:01](#)):

So when I think of like, getting that feedback, it's not just patient advocacy organizations, it's also the advocates, who are out there who have been involved in some capacity or who are knowledgeable in the community, who can provide that sense of feedback as well. But it takes a village, it takes all of us to kind of work on this together, and to really bridge that gap between the community and industry.

Seth Rotberg ([32:31](#)):

When it comes to for me to get involved in these trials that's something I'm trying to learn about. I'm saying, well, what are the barriers of having someone who is presymptomatic involved? Part of it could just be the risk. I'm not technically showing symptoms, but part of me is like, well, maybe there needs to be different biomarkers to look at, different endpoints to look at. Maybe there's an experimental endpoint to look at, where then you can extend the trial to people like myself, who may not fit the first time around, but can fit the second time around.

Seth Rotberg ([33:10](#)):

Because again, I say if they're not working with people who are this pre-symptomatic stage, and they're trying to slow it down? Well, by the time I'm showing motor symptoms, to me, that's too late. And so that's where I think we need to try to revisit how to diagnose. And I'm not the expert, I'm relying on the researchers, neurologists who are in the field of how do we look at the diagnostic criteria.

Seth Rotberg ([33:40](#)):

I know, there's another organization who has gathered data from the community saying we need to figure out how to also look at cognitive and psychiatric symptoms. Because they're so important. So it's cool to see that the community is coming together for something like this. I think some of industry understands it, and they support it. I think we can continue to get the buy in of other companies and say, "Hey, we need to look further into this." But I'm just one voice. I think just getting more people. And there are plenty of people out there who are in a similar boat who say, I want to do something now and I want to help make a change.

Kevin Gregory ([34:24](#)):

What do you say to those people like that? So somebody out there who wants to get involved, but isn't exactly sure how to or what their best role is. Is it something that's based on the person's personality? Or is there a standard skill set that you think somebody who can be a successful advocate should possess? Or just is it purely a numbers game, the more people the more voices you have, the better off you think it'll be?

Seth Rotberg ([34:57](#)):

I think it's about making noise. I mean, I think it can be through podcasts like this. People blogging, people sharing their story in a variety of different outlets. Even on social media. I'm bringing this up because I posted a blog post about kind of this hope and urgency piece. And several people said, "How can I join? How can I get involved?" And to me, it's saying, "Okay, well, you also share your thoughts on this." Or maybe some people are like, "Hey, I just want to be behind the scenes, or I want to just volunteer."

Seth Rotberg ([35:37](#)):

And I also recommend volunteering for a nonprofit organization and getting involved that way. It could also be reaching out to these industry companies, their patient advocacy team and saying, "Hey, I'm interested in learning more, can you spare me 20, 30 minutes?" Or, "Hey, I want to share my story." And in that case again, my personal belief is that if someone is sharing insight, which is their story to industry, that they should be compensated.

Seth Rotberg ([36:09](#)):

But that's probably a whole nother podcast. But I think there's plenty of ways to kind of get that message out there. I think going through the patient advocacy organizations, sharing your own personal story. And I've seen it, but kind of just continuing to make noise. And I think that's by making also these nonprofits be aware of the challenges so that they can also help fight with us. Kind of be on the battlefield, I guess, next to us. And then I think it's also making industry, not that they're not aware of it, but more aware of it, of the urgency piece.

Seth Rotberg ([36:48](#)):

And I think also even the FDA. And that's just more for the US based, the Food and Drug Administration, making them aware of some of these maybe cognitive psychiatric symptoms that come before the motor symptoms, how do we diagnose earlier? How could we maybe bring them into trials in some capacity? Depending on what we're aiming for, when it comes to treatment options.

Kevin Gregory ([37:14](#)):

Yeah, absolutely. I was actually going to ask you, if you felt that there was a regulatory aspect that is potentially a barrier. Because as somebody who's pre-symptomatic it's in the eyes of what the FDA is looking at, it's kind of hard to prove, if there's been improvement if nothing has changed. But what you're saying is exactly that, I want to stay pre symptomatic I don't want to get into the symptoms. And that sounds like that is potentially the challenge too.

Seth Rotberg ([37:48](#)):

Yeah, there's definitely a challenge there. And I think it goes back to like the biomarkers. And again, I'm not... I started looking more into cognitive biomarkers. I know, two that kind of come to mind is the neurofilament light chain, which there was a study on, I believe, last year. And then there's the striatum. And I think both of those, we need to keep stable, but they can show changes in kind of that cognitive piece.

Seth Rotberg ([38:16](#)):

I know with psychiatric symptoms, it can be a little bit more challenging because of how do you evaluate it? How do you differentiate it? Just having a bad day versus is this a symptom? And so I think if we can

at least start with cognitive that can help, with just feeling independent. My mom lost her independency, she had to give up her license. And that can be very challenging on someone to feel like, "Hey, I don't... I can't be as independent, I have to rely on others."

Seth Rotberg ([38:50](#)):

Especially when you're not perhaps elderly, or you're not in like a nursing facility. So there is probably a regulatory challenge. I think that's also where part of me just thinks, when looking at companies and the regulatory or their legal and compliance is maybe they need to be in these conversations too. The people I talked to, is not necessarily them, but maybe they need to be more aware and bought into the community to know hey, we're not trying to break the rules, we're just trying to help. And if we are too strict on it, then we're going to be too slow and trying to advance research. And so how do we get our message to them as well, as well as just to any stakeholder who has some type of hand in the cookie jar when it comes to the HD community?

Kevin Gregory ([39:47](#)):

Absolutely. Seth I did want to ask you to a little bit about you talked about working with nonprofits and the impact that they can have. You actually went back to school to get a degree in nonprofit management and have kind of taken that to the next step currently. Can you tell us a little bit about what you're currently focused on with the Our Odyssey?

Seth Rotberg ([40:16](#)):

Yeah, sure. And it's interesting, because I decided I wanted to go back to get a master's in nonprofit management. And actually, one of the first classes is they explain why it's not a good idea to start your own nonprofit and here I am doing that. And I can understand why. I mean, nonprofits need to be run by like a business. I mean, you're raising money. You're pushing out programs. I mean, you could say programs are like a business's product. You're providing a service. And so I think you got to look at a nonprofit like a business. And I'll be perfectly honest never thought I was going to start one.

Seth Rotberg ([41:03](#)):

I think the reason behind it was because there's this unmet need with young adults who were impacted by a rare or chronic condition that we're between the ages of 18 to 35. I looked at kind of the cancer model of young adult cancer patients and survivors. And I noticed that there's data out there, there's support out there, there's organizations out there. But then when I looked in kind of more specifically the rare disease space, there's a lot of these great patient advocacy organizations, including HDYO. But there wasn't like an umbrella organization that supported young adults living with any condition.

Seth Rotberg ([41:45](#)):

Because with some of these rare diseases, the closest person could be across the country or even across the world. But what we've learned is that you don't need to have the same condition to have the same experience or similar experience of how do you navigate college or figure out your career plans or family planning or dating or talking with friends about it, being financially stable. And I think of course, all those things are challenging, but then add a health condition, and it makes it a lot more complex.

Seth Rotberg ([42:17](#)):

And so I just decided to ask young adults themselves. Say, would you be interested in connecting with other young adults? Would you be interested in person events, virtual events. And after young adults from, at the time, from 65, different health conditions, saying "Yeah, I would love to do this."

Seth Rotberg ([42:38](#)):

I was like, "Well, you got to do it then. Got to make it happen." Because if I don't do it, then who's going to do it? And so Our Odyssey was founded two years ago, to really provide that year round support versus the one off approach. Because that was the other challenge that I noticed was that organizations would have a one off event or a big conference convention. And it was awesome. I mean I'd go to the HDSA convention, and I'd reconnect with my friends and catch up with them.

Seth Rotberg ([43:07](#)):

But then after a few days convention's over, back home. And I'm like all right, I'll see you next year. I think that was the challenge to me is because I just felt like, oh, wow, I got to wait a whole year for me to see them again. And I felt like how can we make this more year round? How do we provide more events, whether it's in person or virtually, so young adults can stay connected throughout the year, get that peer to peer support, and really help improve their quality of life?

Seth Rotberg ([43:37](#)):

And so that's kind of what we're trying to do now with Our Odyssey is provide that sense of belonging, make sure young adults feel connected to each other, and then try to also provide some resources to them. And it's not necessarily our own resources. It's not reinventing the wheel. So if there's an organization out there, that's a great resource. We're going to say, "Hey, check out this resource from so and so organization." I know, there's like global genes and the National Organization for Rare Disorders, also known as NORD. A lot of great resources, we're not going to create our own we're going to say, "Hey, check out their resources that they've provided that might be useful or helpful for you along here kind of health Odyssey per se."

Kevin Gregory ([44:21](#)):

Right. Taking it back to something you covered earlier in our conversation, you talked about someone you had met that you felt you could just easily talk to and she ultimately accompanied you to your genetic testing. Have you found that that's been the case, bringing together youth even across different rare diseases that they instantly make those connections. And it doesn't have to be disease specific or symptom specific or issue specific.

Seth Rotberg ([44:59](#)):

Absolutely. I mean I, at one point thought, "Oh, is it just me that enjoys this." Because I started going to these health conferences, meeting other young adults. And being like, "Wow, we can connect on a whole nother level, like they get it." And I just again felt like I could be myself again. And it's not that my friends or family judged me just like, I think there's a difference between living with a health condition and kind of being on the outside of it.

Seth Rotberg ([45:28](#)):

And so, when I met all these other young adults, I was like, "Oh, this is awesome." They're all really cool, easy to talk with and connect with. And when I saw that they were connecting with each other. I was

like, okay, there's something here that is bigger than just me, it's not just me who enjoys these social connections. It's a lot of other young adults.

Seth Rotberg ([45:54](#)):

And I think the big thing that I learned is never assume what's best for them. Your community, or whoever your target audience is that you're trying to support. Simply just ask them. Say, "Hey, are you interested in this." Or, "Hey, we're going to put out a quick survey, and see if what we're thinking is good for the community, is similar to what the community thinks too." Now, again, it goes back to you can't please everyone especially with some of these larger organizations who can only do so much.

Seth Rotberg ([46:26](#)):

And I've already learned that. I mean, some people have individual needs that we just can't support. And we explain that to them. We say like we're a small organization, I do this full time, as a volunteer, we have one part time staff member, we have a lot of great volunteers and board members. But again, we can only do so much as a small organization. And so we try to remind not just our community about that, but ourselves too, managing those expectations and understanding let's start small and grow from there. But let's do it strategically, as well.

Kevin Gregory ([47:03](#)):

You have a motto that you live by, and as I understand, and I've seen the picture, you have a tattoo of it on your back. Can you share the origin of that and how it drives what you're doing now and how it kind of permeates what you're doing in the community.

Seth Rotberg ([47:27](#)):

I never thought I would actually get a tattoo to be honest with you. I think it just kind of came to me, I guess one day. And I'll give the backstory. So I was a senior in college. It was the day before my last semester, when a good friend of mine, Jake, unexpectedly passed away. And it was very challenging, because I think that was the first time where I lost a friend that was around my age, especially when it was again, the unknown.

Seth Rotberg ([48:09](#)):

And no one likes the unknown. That's honestly one of the reasons why I went through genetic testing. I mean, you think about with COVID. There's so many unknowns, it gives people anxiety, it gives people mixed feelings. There was just unknowns of this unfortunate circumstance. And I didn't know Jake too, too long to be perfectly honest, I only met him the year before. But I felt like our friendship seemed a lot longer because we just understood each other. And he was always kind of living in the moment, and enjoying just life and living life to the fullest.

Seth Rotberg ([48:45](#)):

And there's the quote that you reference, that's a tattoo on my back. It's live as if you were to die tomorrow, learn as if you were to live forever. And it was in his high school yearbook. And it was on his headstone. And I think I saw that quote. And not only did I think of him, but also thinking kind of living just in the moment and understand my own circumstances, understanding my mom was kind of living in the moment and even though she was suffering from HD.

Seth Rotberg ([49:21](#)):

And so, that's kind of what I tried to live by each day. Of course, some days are tougher than others. I'm not that invincible kid that we all wish we were. But I try to accept it and understand it, reach out to my support system, my resources, and then remind myself that tomorrow is a new day. And I have to remind myself of that, especially these days, with everything going on in the world as well as just with HD and how it is slowly creeping up year after year, where I might end up with symptoms.

Kevin Gregory ([50:02](#)):

Yeah, I mean, that's got to be the... Does that weigh on your mind more than anything? Or is it something that's kind of a passing thought from time to time? I'm curious, like you said early on you said you might drop a book or something and think was that HD. Do you still dwell on that or does it just depend?

Seth Rotberg ([50:29](#)):

I definitely do. I mean, it not as much because I got to remind myself that I'm only in control of so much. But from time to time, even like, not that my friends meant to do it, but out and about, and they jokingly, "Oh what are you drunk?" And for me, it's a trigger of, "Wow, okay. No, I'm not." And that's something that people would say to my mom. Or it's like, "Oh, how did you forget that earlier conversation?" I was like, "I don't know, I got brain fog or I can't multitask."

Seth Rotberg ([51:08](#)):

And so it does get to me at times for sure of like, just thinking about it and thinking is it a symptom or not. But I've been able to manage it more to just kind of accept it and understand that it may or will happen. But if I keep trying to plan for the future, I'm not going to enjoy what I have today. Because yes, I am a planner. And yes, I want to plan ahead. But what I've learned is that the more I try to plan and the less I'm able to just enjoy what I have today.

Seth Rotberg ([51:42](#)):

And I think my friend Jake taught me that and several other people to make me just appreciate life. And that's why I went to Costa Rica one year, and I went bungee jumping, and went to Nepal and did a 10 day trek with a friend and really just trying to enjoy what I have today. So I can look back at life.

Seth Rotberg ([52:05](#)):

But at the same time I want to be able to have a family one day, and make those memories because a lot of my memories of my mom are when she was sick, unfortunately. And so I want to make sure that I do have enough time for that, to have these good memories. But I just think as much as I do stay hopeful I need to stay realistic with life of what may happen. I think that's where I won't say I feel the pressure, but feeling more of that urgency mindset of saying, "Okay what can I do now to help bring change or help make noise in the community? To say, hey we need to do something now, we can't just wait around for these companies and be on their timeline. They need to be on our timeline as patients."

Kevin Gregory ([52:53](#)):

Absolutely. Well, I mean, your story is a absolutely fascinating one, it's very inspirational. It really is a story in resilience, I do want to give you the opportunity, if there's anything else you want to add. But I

want to make sure that is there somewhere that a website or somewhere that people can go if they want to get more information about the work that you're doing?

Seth Rotberg ([53:18](#)):

Yeah, so I think there's not to add too many websites but they can go to my own personal website which is just SethRotberg.com, there's no H in my last name. So think of it as Rot and then Berg or they can go to ourodyssey.org. Either of those, I'm more than happy to connect with people, whether it's around nonprofit work, community involvement, just wanting to collaborate. Whether it's, again, with a nonprofit or with HD related work.

Seth Rotberg ([53:49](#)):

That's something I definitely am trying to do more of. And it's not just with the community, I want to collaborate with any stakeholder involved in HD. Neurologists, social workers, physicians, industry. Researchers, whoever wants to really help take this initiative with me, as well as many others. Let's do it now. Let's not wait for another five years. Because, again, I think we need to start acting now.

Seth Rotberg ([54:21](#)):

And honestly, I look at two different communities who have made noise or are starting to make more noise. One is the AIDs community with the AIDS epidemic back in the 80s. They pushed the agenda, and they said, "Hey, we need to do something now." And they were able to make it happen. And now the ALS community I feel like is doing very similar work, where they're saying, "Hey, we can't wait around, like we need to make things happen." And so again, for me, it's always about not reinventing the wheel. It's how do we learn from these other communities and apply it to the HD community to say, "Hey, let's work together and let's make something happen now."

Kevin Gregory ([55:02](#)):

Seth, I appreciate you joining us. And we will put those website addresses in the podcast description so people can click on those and make sure they have the right spelling and all that. But I appreciate you joining us today. And we look forward to chatting with you many times over the years to come in the future and help push for that urgency that you mentioned.

Seth Rotberg ([55:27](#)):

Yeah, thanks again, Kevin. I do appreciate you having me on podcast and looking forward to collaborating again in the near future.

Kevin Gregory ([55:39](#)):

Wow, what a great and interesting time I had listening to Seth on this episode, talk about his personal experience with his mother's Huntington's disease, his decision to undergo genetic testing, and how both have shaped him over the years and the urgency that he's pushing for on behalf of the HD community because of that. As I mentioned, the full websites that Seth referred to Ourodyssey.org and SethRotberg.com are included in the podcast episode description for you to click on to learn more, or to get involved with Seth and his work. Until next time, thank you for listening to the HD Insights Podcast. Stay safe, be well and take care of one another.

Announcer ([56:26](#)):

This transcript was exported on Jul 19, 2021 - view latest version [here](#).

We hope you enjoyed this edition of the HD Insights Podcast. Remember to subscribe to this podcast to make sure you automatically get the latest episodes to your device. Please rate and review this podcast with your feedback so we can continue providing the best possible content. If you are interested in providing financial support for the work needed to produce this content, you can do so by becoming an ongoing sponsor or through a tax deductible donation. To do so please email us at [info@HSGlimited.org](mailto:info@HSGlimited.org). That's I-N-F-O@HSGlimited.org. Or by calling our toll free number at 1-800-487-7671. Thank you for joining us on the HD Insights Podcast from the Huntington Study Group.