

Interviewee: Ryan Lallier  
Interviewer: Alison White  
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Transcriber: Alison White

**Abstract:**

In this interview [and dialogue] Ryan Lallier covers many aspects of living with and working with Huntington's Disease: as a family member, Ryan discusses how HD has been interwoven into many aspects of his life. As someone who has been through genetic testing, Ryan opens up about the process and the emotions behind testing. As a volunteer and an advocate with a background in marketing, sales, and technology—Ryan enters a dialogue about his hopes for HDSA and for advocacy on behalf of Huntington's Disease. Ryan's honesty is refreshing and inspiring in it's own right.

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**AW:** This is Alison White and we're here with Ryan Lallier, remotely interviewing him about his relationship to Huntington's Disease. Ryan, how did you first hear about HD?

**RL:** I first heard about HD in 2005 when my mother was diagnosed with Huntington's Disease.

**AW:** Aside from that what is, aside from being a child of a parent with HD, what else is your relationship to the disease?

**RL:** Currently I'm involved in the New England Chapter of HDSA as a volunteer board member. In addition to that, my relationship is, I've done some additional research on top of just my mother being diagnosed when we needed that. We found out that's actually how my grandfather, her father, passed away as well. He was actually misdiagnosed with Alzheimer's. So, that's basically what my current relationship and you know, past relationship and experience with HD is.

**AW:** Okay. From speaking to you in the past, and from knowing a bit about your history, I am privy to the fact that you've gone through genetic testing. Is it alright if I ask a few questions about that?

**RL:** Yeah, absolutely.

**AW:** Okay. When did you choose to get tested?

**RL:** Yes. I chose to get tested about two and a half years ago . . . maybe two years ago. The main driver for that decision was my wife and I wanted to have children.

So I looked at it from two perspectives: I mean, first, I wanted to know, I wanted to know for my own health and wellbeing, but more importantly, if we had a child I didn't want to pass the gene to that kid. So, we wanted to take every precautionary measure we could. And I also wanted to get an idea, too, what my future would be like; if I was going to be diagnosed with the disease, if I was going to have it, and then allow us as a family to actually prepare for it better. You know, give myself an advantage that my mother just didn't have. But yeah, that's about it.

**AW:** Do you remember what you were feeling when you were going through testing?

**RL:** Yeah, absolutely. You know, guilt and anxiety, tons of stress—am I making the right decision, am I making the wrong decision. How do I tell people that I'm gene negative? How do I tell people that I'm gene positive? Who is the first person I'm going to tell besides my wife? You know, all of those things kind of go into what goes through your mind at that point. For me, I have two older brothers. Neither of them have decided, or have gotten tested, and I don't think they're going to. That, for me, getting tested, and then getting my-my results, and passing it on to them—you know, again, gave me anxiety. It definitely brought on a sense of guilt as well—and of course, celebration too.

**AW:** So, you mention a lot of guilt. Are you able to expand on that?

**RL:** Yeah, of course I can expand on that. I mean, guilt basically coming from the side that I had two older brothers. My oldest brother actually has two children. So, imagine him having the advantage I had—finding out whether or not I was gene negative or gene positive, and being in a position to not pass that on to my children. And of course, financially plan for anything if I did have the gene and I was going to potentially become onset. So, that's kind of where the guilt factor came in, you know, having nephews and thinking, "Wow, this could be passed on to them." And we still don't know if it has. But, you know, that's pretty much where the guilt came from—and then you know, of course you feel guilty celebrating as well, you know, that sense of freedom—I don't have the gene or I do have the gene and that sense of stress and fear and all that good stuff. But that's really where all the guilt came from, telling a family member who could potentially be at risk that I'm quote-unquote, free and clear. Which, still, bothers me to say it to this day.

**AW:** Okay. When you say free-and-clear, you're talking about yourself. In a lot of ways, it's something that you'll continue to be involved with, regardless of your personal gene status—do you think that, what do you think about that?

**RL:** Yeah, I mean, absolutely. I'm going to stay involved, for sure. I like being involved with the board on a volunteering basis. I like helping out with some of the events that we do. I like bringing awareness to those who may not know about it. You know, my mother passed away on Thanksgiving of 2012, so that has opened up the doors for more conversation. People ask, "How did your mother pass away?"

And I would explain to them that Huntington's Disease, and of course, the next logical question is, "Well, what is Huntington's Disease?" So, you know, it gives me the opportunity to really spread the message. And then I'd say one out of every ten conversations are like, "Yeah, I know someone with HD, or someone who's been affected by HD," and then the rest of them just have no clue. So there's a lot of just, education, that I get to kind of pass along, in hopes that they sort of spread the word too that I know someone who's affected by HD in some way, shape, or form.

**AW:** Awesome. I'm going to jump back a little bit—do you remember what you were feeling after you got your negative test results?

**RL:** Yeah, I do. I'll never forget it. It's kind of, it's kind of like being a deer in the headlights. I was with my wife at the time, and she was just a big ball of emotion. She did the crying, you know crying for the both of us. I just remember getting on the elevator and kind of, you know, wanting to go back to the car, and, for a moment if felt like the world had come off my shoulders, like I had been given a second chance. And took a deep breath, and again, like a deer in the headlights. The first phone call that was made was to my wife's mother-in-law [wife's mother/my mother-in-law], and then the second call was to my father. So, I do remember that. And I remember just kind of sitting in the car . . . in the parking lot for about 20 or 30 minutes—just, I don't even know, reflecting, thinking back. I think I did shed a tear at one point. But yeah, those were sort of the emotions and the events. I don't know, it was pretty simple in a way, but obviously meant a lot.

**AW:** I imagine. You kind of touch on the things you go through now, guilt, feeling like the world has been lifted off your shoulders in some respects, feelings that you've been given a second chance. How has getting tested impacted your life and changed your outlook?

**RL:** Yeah, absolutely. I mean, I take things for granted. I definitely make more of an effort to stay in communication with friends—even if it's a simple text message, just letting someone know you're thinking about them. I think a lot of people will think about a friend, and think about a loved one, someone they care about, but they don't actually take action to let that person know that they're thinking about them. So I've definitely done a lot more of that. If I happen to think about my brother for whatever reason, I'll send him a quick text message, best friend from high school, you know, my dad. Just those things, "Hey, you know, was thinking about you today." A simple text and click send, and that's about it. It's probably about as far as it goes. But, I think you think to yourself: if I got hit by a bus after clicking that, that sending that text message, at least they know the last thing I said to them was, "Hey, I was thinking about you today." I think we take those things for granted a lot. I say, "I love you," a lot more to friends and family. I hug a lot more people. And this is all true, but, you know, after that, that's pretty much—I'm kind of back to being myself I guess—but you know, showing a little bit more emotion that maybe I didn't show in the past. Just making sure, again, you know, that people around me know that I care

about them. Being more verbal about it, not keeping it inside or assuming people know.

**AW:** Okay. How has your gene status impacted how you involve yourself with the Huntington's Disease community?

**RL:** You know . . . I, I think I've actually lost momentum—to be frank. I think when you're at risk and your parent has it, and you're really involved. And you know, you've got a lot at stake. I think once you . . . are diagnosed with it—or sorry—gene-negative or gene-positive—you can go one of two routes. You can say, you know, again, I'm free and clear—I'm going to take off and separate myself from this. I chose to stay involved, even as my mother progressed in the wrong direction. And I think, now, when she died I kind of went through a phase of, "I want nothing to do with Huntington's Disease, I don't want to talk to people about it, I don't want to deal with it," and I've sort of made like a comeback in the last three or four months. It look me like a solid year of not really wanting anything to do with Huntington's Disease. It sounds selfish, but, you watch your parent go through it for six, seven years or so, to eventually lose their life—you kind of need a break. And I did that. I took a break. And you know, now I'm definitely in a happier place—and emotionally I'm in control again. I'm trying to help out again, and just be active.

**AW:** Awesome. Yeah, it umm . . . I'm trying to think of how to kind of phrase this. I think definitely giving ourselves breaks as advocates and activists is definitely important, especially when it's something where we're so unbelievably involved, and it really, really does take up a huge portion of our lives aside from just the activist part—it's very much so our family lives and personal lives. That being said, what have you learned from your experiences? And that's a very broad way of asking this question.

**RL:** Yeah. I learned that, well, experience with my involvement in HD or my experiences with what I've dealt with—with my mother's situation?

**AW:** You can go into both.

**RL:** Okay. I mean with my mother's situation I think I grew closer to her. And I was already super close to her. So, you know, watching her lose her-her independence, you know, slowly going from the kind of woman that liked to dress nice and wear make-up and go out and do all those great-great things, you know, lose the ability to do that . . . you just develop a huge appreciate for life and it can happen to anyone. I've also been much more sensitive to other diseases and other charities. Not so much turning a blind eye, but you know, I say yes a lot more to charitable-type things, whether it's donating a small amount of money or my time or whatever it may be, making other people get involved passing along a message, selling tickets to an event. You tend to get more involved because, you know, a person that has a father or mother who has cancer, for example, and loses that parent, I think they feel the same pain as you or I would feel losing a parent from HD. It doesn't mean that

we don't have anything in common—in fact we do. I think I went through a time where it was like, “I don't really have anything in common with someone who has cancer because they don't understand what I'm going through with HD. The end result is death for everyone, and losing a loved one is still the end result for everyone. So it definitely opened my eyes to other diseases. I mean, learning about other disease, and helping out in any way that I can. So, as far as donating my time, and being active with the board and everything—it's hard. Because I'm a career professional and I work 60 hours a week, now that I'm managing, I'm probably going to work even more hours. So, I feel guilty in a sense that I signed up for this—I can't give as much as I originally anticipated or in my mind I thought I'd be able to. I've realized that time is a very precious thing—it actually has a lot of value, especially monetarily when you're taking yourself away from work or other things that you want to do. So, I'm starting to realize that when people say they want to volunteer for something and they want to join a board—I have a deep, deep, deep appreciation for those who really, really dedicate a substantial amount of their time freely to HD, the board, or other volunteer boards for that matter. I just, I just do. I can't give as much as they're able to give. I don't know if it's because I choose career over doing that sometimes or what it is. I'm not sure if I'm answering your question, I'm kind of going off here, but . . .

**AW:** You're doing fine.

**RL:** Okay, cool. So, I mean, those are pretty much the two things I've taken away from my experience.

**AW:** You talk about the balance between work and volunteering or every other aspect of life, and pouring a ton of time into doing a lot of heavy advocacy and volunteer work. Why do you think that it's important to participate in that and why is it something you choose to do—even if you're not able to give as much as you would like, you do still choose to do it?

**RL:** Yeah, I think that being a team member is important. Showing up to the essential board meetings is important. Being another set of ears and eyes on the group is important. I'm always an email away. The worst thing I could do is say, “No, I can't help.” So, you know, strength in numbers. If it's just me giving five percent and Gina giving forty percent, it's still strength in numbers. And I think we need to have a large group—it doesn't necessarily mean that everyone in the family can participate, right? I mean, that's the way that I look at it. I'd rather be a part of it and be available through email and phone and showing up to meetings—and being able to spread the word—leverage my non-profit, board-member affiliation to get a donation or get someone to pay attention to what we're doing. You know, being in business, and being in sales, I don't think it's a bad thing to have that board-member affiliation associated to my name because a lot of people will request a LinkedIn request or you know, reach out to me, and in some way, shape or form, if they look at my social footprint or my profile they'll see that I'm involved in a non-profit. And

if that gets one person to click on that logo, and drives them to our website, then it's worth it for me.

**AW:** Awesome. That being said, why, you touched on why you choose to involve yourself with the Huntington's Disease community, you've touched on how, and why you think it's important. Where do you see yourself fitting in the HD community—if we think of the different silos that are often discussed, where do you fit?

**RL:** You know, I see myself as someone who would be more of like, family support. Talking to someone one-on-one that is thinking about getting a test, is weighing a genetic test for HD. Not so much to just tell them what to do—but to offer them both sides of the coin, maybe share my story with them—kind of what I was thinking. You know, I'd wake up one morning and say, "I'm not going to do it;" I'd wake up the next morning and say, "I'm going to do it." And then eventually how I arrived at that decision to do it. If anything, just to give them a sense of relief, someone to listen to, or someone to listen to them. I wouldn't mind being involved in that capacity—but I want to talk to people who are considering a test and want to talk to someone besides a doctor, or a therapist, or, you know, a genetic counselor. You know, someone that's there to guide them through the process, who may never have gone through what someone like you or me have gone through. So, I'd like to participate in that capacity—if it was possible, and I think that this is definitely one way to go about doing it.

**AW:** Okay, we're going to steer away from some of the questions I have—on that note. What do you want to tell people?

**RL:** I want to tell people that, you know, it's a tough decision to get tested. It's not just a decision you have to make; it's a decision that I think the village has to make. Don't be afraid of consulting others, asking what their opinion is, even if they don't know what Huntington's Disease is, or if it hasn't affected their family. If they're your friends and family, and they're your family members, and they understand both outcomes of the test, then you should solicit their opinion. It doesn't mean you have to go with what they say, but it's nice to kind of get an idea of what they're thinking about what you're going through, what you're thinking about doing. And on that note, you know, I would advise them to read-up, find information online, read the stories about people who have gone through it—who are open to sharing their stories. And just arrive at a place where that decision needs to be made on what you want your future outcome to look like. You have to picture yourself where you're going to be in 30 years. And that's the reason why I was able to arrive at my decision—I tried to look so far ahead as much as possible. Okay, when I'm 60, what do I want for me? What do I want for my family—good, bad or ugly? What do I want at that stage? And I think that's the message I would pass along. I don't know if it's the right message, but I would talk to as many people as possible—I wouldn't keep it bottled up—and I'd find the right decision not only for myself, but for the people that I love and care about.

**AW:** Okay. How did your family react when you were tested? Whether you start at when you told them you were getting tested, if you told them you were getting tested, and when you got your results?

**RL:** Yeah, I mean, my father was kind of—he just said, “Thank God.” Monotone. Nothing really, no emotion, that’s kind of how he is. My brothers were you know, high-five—sounds great!—so happy for you! But it was really tough to tell them, again, because I felt guilty. And then my in-laws were super pumped. My two sister-in-laws were very emotional—you know, because we had grown to love each other as a family—I’m not their brother-in-law, I’m their brother. And for them, it was a very emotional time too. So, it’s funny, it’s like my in-laws, and my wife’s family, were more [inaudible] than my family. Maybe it’s because I talked to three males who are blue collar guys, and were like, “Cool, great, that’s wonderful,” and I called my wife’s side of the family who’s, I don’t know, all women, and happen to love me, and happen to show their emotion a little easier than my three rough, rough family members.

**AW:** Awesome. How has getting tested and going through testing changed your relationships with your family? Or has it?

**RL:** I mean, first and foremost—my father was an alcoholic for, I’d say 80% of his life, when my mother died—the day that she was buried—he stopped drinking. So, I have a different relationship with him now, because I talk to somebody who has a very clear head. Now when I talk to someone, I can actually understand when the talk because they’re not drunk. I have certainly operated with a clear head too, in terms of how I talk to my brothers. And, if anything, it’s definitely brought us closer together. You know, I think with, shit, our mom died so young, and we’re still young guys, you know, and all, but we live in three separate places—we should do a better job of communicating with each other and just really staying in touch. So that had definitely improved as well.

**AW:** Okay. We’re going to switch a little into talking about the HD community again, if that’s okay. If you had to pick one word to define the community, what would it be and why?

**RL:** One word?

**AW:** One word. You can think on it for a moment.

**RL:** Small.

**AW:** Okay.

**RL:** And you want to know why, I forgot!

**AW:** Yes! Tell me why it is “small.”

**RL:** Yeah, I think it's small because the statistics of how many Americans have been diagnosed with Huntington's Disease is so low. I think it's small because we don't have the quote-unquote "poster-child" or the "front-man" or the "spokesperson" to speak about our disease. I think it's small because frankly because I think a lot of people are misdiagnosed, and I think more people have Huntington's Disease in our family that they actually know about. And I think we're small because we're sort of dwarfed in terms of our overall footprint and our ability to raise money and awareness, versus something like heart disease, or cancer, or breast cancer—and all those things are very important and their equally important to find cures for, but it's like—there's our little family genetic disease and only affects a very small portion of the population. And I feel like because it's small, it gets a small amount of attention.

**AW:** Okay. So, you touched on one of my other questions, was what are the challenges you see working with the community? You touched on a lot of that, aside from it being small, how do you think we breach those challenges?

**RL:** Beside it being small how do, I'm sorry, how do we what?

**AW:** How to we breach those challenges?

**RL:** Oh, breach. Okay, sorry, I didn't . . . Breach the challenges. You know, I think that as a non-profit, and you know, I think you might agree with me in what I'm about to say—I think the way we go about our messaging and the way we go about reaching an audience is 1995, and you know, I look at the other non-profits and charities—and I know this is going to sound terrible—I look at them as competitors. We're trying to go for disposable income. We're trying to go for money from people who are willing to give it, but families can only donate to so many charities. And if we keep mailing letters in the mail, and sending flyers, and taking this archaic approach to advertising ourselves no one's going to find out about us. And I think if the community put forth more of an effort to creating more content and being more digital—just taking more of a social media type approach to driving attendance—I'm sorry, attention—and traffic to what we do, we'd raise more awareness. And I think we have to start to advertise and act like a business and do that as modern marketers, not people who are you know, mailing out letters and postcards and selling raffle tickets. And that probably sounds really, really terrible—but we're losing ground to the other non-profits who are doing a better job at marketing themselves.

**AW:** I don't think you're too far off there.

**RL:** Okay, cool. I don't want to upset anybody it's just my opinion. I'm still kind of a young guy and I [inaudible] technology, and I see these amazing social campaigns and crazy email campaigns, and all these ways to donate online. Just buying a ticket to the gala is the most archaic process I've ever seen—and it shouldn't be that way.



**AW:** I gotcha. So, you just mentioned that we need more contemporary marketing campaigns to raise awareness, to help us raise funds for the disease—that being said, what are the messages that you find most inspiring that you think we should tell?

**RL:** Yeah. I mean. It should be video, it should be family based. I think that children with Huntington's Disease are a very powerful asset for our cause. You know, people are very sensitive toward children. Even those who have children—and they don't want to see any kid suffer. And, it's evel to roll out a child and say, "Look what this child is going through," but if we really want to raise money and find a cure, we need to put everyone out there—adults, children, with everyone's consent of course, that are affected. We need the parents to talk about their kids, we need to talk about how it's affecting our lives. So I think video is a great way to do it. I see a lot of non-profit . . . I go to a lot of events where, video is definitely showcased. Families don't do that this often—the whole situation: what it really means to have Huntington's Disease, not only for the person who has it, but what it means for the family. Economically. Socially—like how much stress it puts on a family, because people don't realize how long it takes for someone to pass away from Huntington's Disease. They don't realize how long you have to take care of somebody with Huntington's Disease. You know, they think it's, you're diagnosed and 8-weeks later the doctor says, you've got the summer—and it's over. They don't realize that it's a long, drawn-out, caretaking process. And I think if people really understood what families are going through, and the impact it has on them—we'd get the message across really faster, really, quicker—and we'd raise more money. It really just goes back to—we need to do a better job of articulating and marketing what this disease really is.

**AW:** Yeah, I think that's very, very accurate.

**RL:** Thanks.

**AW:** Yeah. Anyway, let's skip around—I'll talk to you after we finish this. Do you think it's important that we tell your story, as someone who has tested gene negative—you've touched on thinking this is a story that needs to be told, it affects people, you know, who are thinking of getting tested—why do you think it's so important?

**RL:** To share the story or get tested?

**AW:** To share the story.

**RL:** Because it's going to affect every child of a parent with Huntington's Disease. Whether you're young, and don't care, and are like, I don't want to know. Or you're going to get to a point where you're going to marry that significant other and you want to spend the rest of your life with that person. Those are life decisions that you're going to have to make, whether you decide to get tested or not—if someone

is at risk, if someone has it in your family, you're at risk, and you need to plan for it. And I think people deserve the opportunity to at least plan for something. Not everyone gets that opportunity. I think it's actually one of our only advantages. A genetic disease gives people an advantage to at least financially plan. I mean, imagine waking up one day and finding out you have cancer? And going, "Oh, shit! I didn't see this coming!" Because you don't. But, you at least kind of have an idea—if your mom had Huntington's Disease, you have a freaking shot of having Huntington's disease. Start saving, or go get some kind of extra care plan. Or do something, even if it's putting \$10 a week away. I mean, we didn't have that opportunity with my mother—and it financially stressed us out, I mean, put a lot of a burden in everyone. You know, at first—she didn't get to go to the best care facility. So, that's the reason why I would do it. I would say, think about the family, think about the future, think about the people you care about, and how you want to live if you have Huntington's Disease.

**AW:** So, who do you want to reach by telling your story? How far do you hope it goes?

**RL:** I hope it goes as far as the story will take it. Anyone who is just out there, wondering what it's like to get tested, or what it's like to go through, or have someone. Optimal reach? I mean, obviously I want it to reach everyone. I'm not going to hide. Anyone can call me at any time. I'm more than happy to talk to people about it. I don't treat it as a private matter. It's not like, you know, it a global issue right now. So, there's no reason to be private about it. Everyone needs to know about it.

**AW:** So you're going to share your interview everywhere, right?

**RL:** I would love to, sure!

**AW:** I've kind of covered most of the questions that I have. What else would you like to talk about? What else haven't we covered?

**RL:** I think we pretty much covered everything. I just, again, I want to stress that I don't want to give a negative vibe off about how I feel about the marketing and the positioning of HDSA.org. I think we can do a much better, better job of marketing ourselves and raising more money. So, if we can, if we can somehow come together. Imagine if we all focused our energy on that, instead of like, a walk—or this event, or that event—these monstrous events. I'd rather get \$20 from 100 people in 45 minutes, than have to spent three months trying to sell tickets to 100 people, and then all the logistics and everything else that goes into it to escape within that profit of 30% or 40% or whatever it works out to be. I mean, what's the profit of an online donation, 99%, or whatever fee you have to pay to have that money processed online? I'm just yapping right now, but I want to be sure that I'm not being negative about how I feel about the advertising. I just feel that it needs to be kind of improved and modernized.

**AW:** That being said—I keep saying “That being said,”—what, who, what type of people, what backgrounds do we need to recruit for our advocacy efforts—to help improve how we do things?

**RL:** Yeah, I think we need to focus more on, I think it’s really like an age-group, if you will. I think it’s an age group of 26 to 40-year-olds. You know, people who are moving up in their careers, maybe have a little bit of disposable income. Have energy—to do interviews at eight o’clock at night—or to call people, to show up to a meeting, to go to an event on a Wednesday night after work. Whatever it may be. I think we definitely need that. We need more corporate penetrations. We need that, someone like me, who’s at a new company, someone who might say, “Hey, there’s a walk coming up in September, we’d like to have all of you guys there.” Just, I think we could cater to more of a younger audience. We don’t see a ton of young people at our events, and I wish we saw more.

**AW:** Yeah. We are very limited to the families that are affected, or friends of families that are affected. There are, there doesn’t seem to be much more outreach than that. You’ve talked about social media and things like that—how do we get beyond that?

**RL:** You know, I would love to see HDSA make an investment into someone who is a digital marketer with a non-profit background. There are tons of those people that will take a modest salary to go to HDSA and be that person who is going to drive social awareness; drive inbound traffic, and help increase online fundraising. And, I’d rather see, you know, Louise Vetter or someone from the top, give 3-5% of what they’re receiving as a salary to funding another role. That could get someone in a true marketing capacity who knows what the hell they’re doing. There are ton’s of people in non-profits, or even work in marketing for companies that sell to non-profits, that would be a great fit. You know, I’d like to see us make a push to get someone like that.

**AW:** Nice. So, what else, is there anything else that you want to cover? I’m sorry—I’ve kind of poked at your brain in different ways.

**RL:** No, it’s ok. That’s all I got. I’m running out of gas over here.

**AW:** Oh, alright, I’m sorry!

**RL:** No, it’s all good!

**AW:** Well, you know, it is eight o’clock at night, and we only have so much energy.

**RL:** Exactly, you’ve got it.

**AW:** Alright, awesome. Ryan, I’m going to wrap this up over here, and I will talk to you in a moment. Thanks guys.

