

Interviewee: John Mirabito  
Interviewer: Alison White  
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Transcriber: Alison White

**Abstract:**

In hopes of inspiring others to participate and become involved in the caring HD community, John shares a bit about his life living with HD. Despite John's challenges, his positive outlook radiates throughout this interview as he shares stories about his diagnosis, and how HD has changed his life.

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**AW:** This is Alison White and I am here with John Mirabito and it is May 15<sup>th</sup>, 2014. John, how did you first hear about Huntington's Disease?

**JM:** My mother had the disease. So I heard about it when she became symptomatic, in, when I was in college. I didn't know too much about it at that point. But I kind of saw her get worse, and I was already in college by the time that she started having symptoms, so really—I didn't really see it much before that—only really when I would come back at the end of the year—end of the year or whatever. Other than that, I didn't really see, like her day-to-day while she was progressing. It was probably the first time I heard of it—I didn't' really know too much about it.

**AW:** Okay. What is your, aside from your mother being ill, what is your personal relationship to Huntington's Disease?

**JM:** I have it. I was diagnosed in 2011. At that point, I'd been - my Mom has it, and her father had it, and so I know I was at risk, but I never got tested because there wasn't really any cure or slowing the disease down at that point. And, you know, I just didn't really think I needed to be tested. Then it got to the point where I had a couple of things that were going on. I had a couple of falls, and I thought something might be wrong but I wasn't really sure what. So I went to see the doctor and they did a bunch of tests to rule out everything else. They also did the genetic test to see what the CAG repeat would be.

**AW:** Okay. What was it like going through testing? Or why did you—you said it was a few falls that—a few different things going on.

**JM:** I knew something was wrong, but I wasn't sure. So I figured at least I would, you know if it was HD, I could at least get help for that and if it was something else then I could get that addressed—instead of not doing anything. But it only just, there were a couple of times, I didn't have as good of control of my body as I should have, a

couple times. I wasn't really sure what it was, but, I knew there was something wrong. So, I went to get checked out.

**AW:** How has getting tested affected your life?

**JM:** I don't know, getting, I guess -- it kind of goes back and forth. You realize that you have this thing and that it is kind of like, you know, if you're still at risk you don't know that you have it. There's always the possibility that you don't have the disease. But, when I got tested, I was positive. I kind of just, had to do something to deal with it, and so, since then I've started participating in clinical trials and I went to see the neurologist and the psychologist and all that good stuff. And, there's not really any cure yet, but they're treating the symptoms or whatever and just all these various things. It kind of comes and goes.

**AW:** Yeah, what do you mean?

**JM:** There are days that I don't even think about it. And there are other days that sometimes I do a lot.

**AW:** Okay. Alright. How has your diagnosis changed your outlook? How has it changed how you think of things going forward?

**JM:** Well, I don't know because I always just kind of put off the whole dealing with it for a long time. I just didn't want to even think about it. You know, if I didn't have it there was no point. And, if I could treat it that was one thing, but if I couldn't then there's nothing I could really do, then I was just going to try to keep going, of course, and I was kind of young then too. So, since then, you know, I kind of got up and refocused. I really didn't do much at all as far as getting involved, you know, with the studies or that kind of thing. I didn't want to deal with it I guess. So, now I've been involved with it and now that I've left work I've got more time for being able to help with this outreach stuff. I've been doing one of these clinical trials.

**AW:** Awesome! So you're definitely fighting in some ways.

**JM:** That's kind of the good thing—because at least if you're doing something, it makes you feel like you're doing something positive. You're trying to find out what the, get the answer—I wish there was one, or soon may be one. I don't know.

**AW:** Yeah, nice. It's definitely an optimistic outlook. I know it's easy to fall to a very negative outlook, or you know days are very very different as well. What—how do you handle the tougher days, what makes those easier and still pushes you towards putting a positive spin on, on your diagnosis?

**JM:** There are some days where it's just hard to cope with this whole thing, and I don't know what I do with it. I just . . . I don't know, I just try to get through it—take one thing at a time. But there are days when its not very, you just get depressed

about the whole situation—really bad. But there's just times when you read or think something, sometimes they have information that's kind of like, in medical terms, and you see all these things. And it's difficult to deal with it sometimes. Or you start thinking about it. It's different if you can think about it in academic terms or if it's about somebody else. And you start thinking, "It's me too." You know, what happens in like five years, or ten years or whatever? But, I don't know. It's kind of taking it a day at a time I guess.

**AW:** That kind of all we can do sometimes, right? Let me see . . . You said that you're involving yourself in advocacy, what kinds of things are you doing?

**JM:** One of the things I got involved with is the national, HDSA wanted everyone to contact their senators and congressmen, on behalf of the Parity Act. So I wrote letters to them and we were able to set up meetings with the senators while their aides were in town, and that was rewarding. And I was able to contact my local state rep here and when we had the HD information session at the state house here in Massachusetts I got them to go, or the representatives to go or whatever. So that's been good. It's also—I've been trying to raise money for the walk, for the walk up there in Lowell—I've don't that a few times. I'll continue to do that.

**AW:** Cool. Do you, do you enjoy participating with the community—seeing other people—do you, I guess, let me try and phrase this a slightly different way: do you find involving yourself with the Huntington's community to help with the isolation that a lot of people feel with Huntington's disease. Or is isolation not something you feel?

**JM:** No, it's kind of, yeah. The good part of getting more involved with the community—and I've also joined support groups since I was diagnosed—there's information out there but you know, I was trying to figure out what you need to do to take care of yourself. Or, there's all kinds of things you can do to make your life a little easier, but without knowing where to go, you know I was spinning my wheels, the thing I think is, I got involved and introduced to the right people, or whatever, doctors and therapists. Just talking to people—it's good to talk to people who are in a similar situation. It seem that the one thing is that it can affect everybody differently. I don't know why, but it just seems to—you know, whether it's emotionally or physically or how people act and that's the one thing. It's just difficult for other people to really understand how there's something wrong –but if people in the HD community kind of already have experienced these kinds of things.

**AW:** Alright. What do you find inspiring being around Huntington's Disease and the community? How do they help you, aside from having the understanding that a lot of the general public might lack?

**JM:** I guess it just seems like, the biggest think I can see right now—even though I'm having some issues and problems right now, I just think that there area always people who are more in need or worse off or different situations that are stressful. I

mean, I think everybody probably has something going on—but it's the biggest, I don't know, I guess that might be the biggest thing for me is knowing there are people who just have a lot of history and they just keep on showing up and taking care of their loved ones, and doing whatever they need to do. But I guess that's the biggest thing.

**AW:** Okay. We talk a lot about the Huntington's Disease community being a big support system. What does your support system look like—whether it be small, large?

**JM:** I guess right now I've been going down to Mass. General for their clinic. I'm seeing Dr. Rosas, not Dr. Rosas, Dr. Hearsh. You know, they help out a lot. And like a lot of people, I've been seeing a psychiatrist who's outside of that practice—and that's helped with support. I've joined the, and the support group helps out quite a bit. And it's just—it seems I just keep running into people that just, are willing to help and they're not, and they're kind of like just are willing to jump in and help you no matter what the extra that they have to take, if they have to take extra time if they're doing that. Just more than you would necessarily expect, but that's helped quite a bit. You know, there's stuff that's always frustrating, but I think that's the biggest thing right now.

**AW:** Okay, if you don't mind—I'd like to ask a few questions about your day-to-day life. How has being, how have your symptoms, as they've progressed, how has that changed your day-to-day life?

**JM:** Well, I'm trying to think, I quit working last summer. That was the biggest change. I think at that point it was kind of hard because I was managing [unclear word] projects for a company up in Manchester, New Hampshire—a lot of driving up there. Every day traveling around—it just got to be too difficult. It kind of got to the point where I just need to concentrate on taking care of myself here. And I find even just when I get up in the morning and I try and do my stretching and balance exercises I kind of, and then I've got to make sure I eat right and stuff like that. And right now it's not too bad. I've had a lot of sleep deprivation. For, that was one when thing I really, got . . . right after I left work, for whatever reason, was just, I guess I was talking to the doctors and it's just a lot of change, a lot of things going on and I was really unable to sleep for three or four weeks—it just piled up. And you know, you just can't even think straight—I felt so bad. It was unreal. Because I didn't realize how bad I was doing until I started to feel better again, and it was just kind of unbelievable, it was just not good, not being able to eat or sleep.

**AW:** That seems really rough. You seem to be doing significantly better now though.

**JM:** Yeah, I think really since the fall, I kind of, started to sleep normally and kind of got back. Yeah, so I've been doing a lot better. There are still things here and there—I don't, there's some stuff I used to do and take for granted that you know, I've got to think about.

**AW:** Do you mind if I ask what, like what types of things you took for granted doing, and now you're unable to?

**JM:** Well, I guess the biggest thing is I'm trying to do stuff around the house, and I've just got to make sure I maintain my balance or whatever. Other times, you try to do two or three things at once or whatever, and that's not really a good thing if you have HD because you don't want to fall, you don't want to fall or whatever—that's one of the biggest things. My neighbor helped me clear the snow this winter, which is something I had always done myself. But it was just difficult for me to just go shovel the driveway like that. It was you know, fortunately, you know there was [unclear word] there to help me out. That was one thing that I didn't even think about—I was like, "Great, no problem, I'll just shovel it." But when you're dealing with snow and ice and stuff it's not the best time to be out and jumping around.

**AW:** No, not when your balance might be a little off already—probably not.

**JM:** One of the things I usually do that I really haven't been able to do in a while: I used to like to ride my bike a lot, and I really haven't been able to do that. That was kind of frustrating—I feel like I've given up. But I don't know, I can just tell that I was kind of wobbling around a little bit, and it's difficult not being able to do that.

**AW:** Yeah, that's unfortunate. What have you kind of replaced some of those things with? Like riding your bike, what do you do instead, now?

**JM:** I'm trying to figure that out. I do like to run still. So I was trying to, I'm still doing that. But it just doesn't, it's easier, even though it takes coordination. It doesn't seem as complicated as balancing the bike or whatever. But I don't know, just trying to think of different things to do. I just, I don't know.

**AW:** Just trying them out? Trying new things, seeing what fits?

**JM:** Yeah. Right.

**AW:** Okay. Awesome. Let me see . . . how have you noticed, or have you noticed changes in your mood? If you think of yourself prior to being—maybe even prior to being symptomatic—is there a difference between you at that point in time and now? It's kind of an awkward question.

**JM:** Yeah, I'm trying to . . . well, I think it's close to the same. When I was first diagnosed or when, like last summer I had some issues—I was losing a lot of sleep and I was stressed out about a lot of things. You know, that wasn't a good deal. Since then I've gotten a lot better—so I'm a lot closer to where I was before.

**AW:** Okay. Awesome. Do you think it's important that we tell stories of people with Huntington's Disease?

**JM:** Yeah, because it can help inspire other people. It can help give them guidance or something to lean back on so they know there are other people out there and they're not alone.

**AW:** If you could use one word to describe the Huntington's community—you included—what would it be?

**JM:** Caring?

**AW:** Okay. You kind of went into a lot of that before, but is there anything to expand on why you would label the community as caring?

**JM:** I guess the people I've met are all, really have a great empathy for people who have the disease, is affected by the disease. They're always more than willing to help somebody.

**AW:** Awesome. Who do you hope to reach by telling your story? You said you hope it inspires somebody, but who do you hope hears it? Who do you hope is changed by it?

**JM:** I don't know. I guess I really don't have an answer for that.

**AW:** Okay. I really don't have too many more questions—like I said it was going to be kind of short. What else would you like to cover, or is there anything else you would like to cover?

**JM:** I don't think so—there's nothing I can think of in particular.

**AW:** So we're good to wrap it up then I guess.

**JM:** Yeah, it's good.

**AW:** Thank you very much, John, I appreciate your time!

**JM:** Thank you for coming out here, it's great.