

Interviewee: Kathleen McCarthy

Interviewer: Alison White

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Transcriber: Alison White

Abstract:

With an amazingly up-beat attitude, Kathleen McCarthy discusses the challenges she faces as an advocate for the HD community. As someone formerly at-risk, and now gene-negative, Kathleen's story weaves through an adolescence and young-adulthood spent in an anxious purgatory of not-knowing her status, through to the other side as an advocate and caretaker in the HD community. Aside from struggles in advocacy, Kathleen describes the unique place in the community she now holds as someone who is gene-negative.

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Alison White (AW): This is Alison White and I'm here with Kathleen McCarthy. It is the 20th of April, 2015 and I'm going to be interviewing Kathleen about Huntington's Disease and how it has affected her life. Kathleen, why did you choose to participate in this interview?

Kathleen McCarthy (KM): I think that Huntington's Disease is still a fairly unknown disease so any way that we can spread awareness so that people will start learning about it is something that I want to try and do. Again, I feel like there are a lot of diseases that are more publicized and so there's more sort of volunteerism around it, more fundraising around it, so in order for us to catch up . . . I don't know, just get it out there more then people need to step-up and sort of talk about it more and put it in front of a bigger audience.

AW: What is your background with Huntington's Disease?

KM: So, my dad has Huntington's and my grandfather, his father, had Huntington's and we're not sure farther than that, where it came from. So, my dad and two aunts have it. ¹

AW: Is it something that affected your childhood or more so your adulthood?

KM: More so my adulthood. I am the oldest cousin on my dad's side, or the oldest grandchild I guess I could say. So, I knew something was going on with my grandfather but we weren't really sure what; and actually the gene was found in 1993 which is when I graduated eighth grade. So, I can remember looking at pictures of my graduation and seeing visibly that there was something wrong, but yet when I asked, I was told there was nothing wrong. There was something wrong, and I'm not really sure they knew at that time what it was. But as I started getting older I was the one that went with my aunts and uncles and my dad to meetings at Mass. General and educational seminars in order to figure out more about the disease. And then, a few years after I graduated college is when my dad was diagnosed. So it was, I knew something was going on when I was younger, but we didn't really know why, I didn't know what, but definitely throughout my adult years.

AW: Which role do you believe you play in the HD community, and by that I mean at risk, or if you know your gene status or not, do you think of yourself as a caretaker an advocate, an activist, many of the above?

KM: I guess up until last summer I was at risk. I decided last year to be tested. I was tired of worrying all the time whether I had it – every time I tripped, every time I couldn't think of a word to say. I would think it was the beginning of Huntington's

¹ Correction: Kathleen has one aunt who is gene positive (per K. McCarthy, 6 May 2015).

and it was just really starting to take a toll on me. So, I went through the process and was tested, and four weeks later I got my results and I'm gene negative. So that was a relief for myself, for my dad, you know, for my family and friends. I was happy to be able to provide some sense of relief with this disease. However, it doesn't mean that the fight is over. So now I think I'm more of an advocate for my dad; a caretaker; just trying to get the word out there and do a lot of volunteering and fundraising, because I don't think the fight ends when one member of the family is negative. There's still a lot going on within the family since it affects everyone. So I guess my part would be to help with my dad and sort of do as much as I can to create awareness and research.

AW: So you identified as, yourself as, formerly at risk, gene negative, an advocate, and a caretaker. How do you think those different roles have changed your worldview? You've touched on it a little bit, but can you expand on that?

KM: What do you mean, it changed my worldview?

AW: If you, I guess, going from someone who was at risk to being gene negative, how has it changed your outlook on life?

KM: Well, I think when I was at risk I definitely was more hesitant to get tested for a while. I didn't want to have to tell my dad that I was positive. As I had said, every little thing that happened in my life—if I tripped up the stairs, or couldn't think, I'm a teacher, so if I couldn't get the words out fast enough, I felt something wrong, anything like that, I immediately associated it with Huntington's and I thought that it was starting. I would ask people around me, and everyone thought I was crazy, that, you know, it was normal, sometimes you forget a word, sometimes you trip, but to me personally it was, "Oh my God, here it comes." So, in order to sort of put my mind at ease, then hopefully be able to give my family a sense of relief I decided to get tested. So, I just decided that I was ready to know it was one way or the other. I'd seen my dad, I'd seen my grandfather go through it, so I knew what was coming

and I was prepared for it. I'm old enough now, I felt like if I want to move forward and have a family and get married and all of that, that I wanted to know and be able to tell my boyfriend the same thing. I thought everybody should have all of the information before anything else happened. As I said, thankfully, going through the process everyone was with me and I'm able to now say that I'm negative. It's not like . . . I guess my outlook has changed because, you know, I'm not at risk, but I still worry about what other family members that haven't been tested.

AW: You mentioned saying that you decided you were ready to know, do you remember what that turning point was like or what flipped that switch?

KM: I think for me it was knowing a few people who were close to our family that had passed away from Huntington's that were younger than myself. So I just, I don't know, I sort of stepped back and, as I said, I was older now and I wanted to move forward with things, and knowing that I would either . . . if I had it personally I wouldn't want to pass it on to a child, so I would have to know in order to . . . I would have to know if I was gene positive in order to use one of the, the ways of having a healthy child, I guess I'm saying that right. So that was also another reason, and I guess I was just tired of worrying about it, it was sort of a combination of the three: looking at someone that had passed away, and then thinking if I want to have a family I'm going to need to know because I don't want to take the chance, and then realizing that it probably needs to get started now because I don't want to worry about it in case something happens.

AW: Now that you've pretty much crossed the bridge from being at risk to knowing your gene status, do you have advice for anybody who is at risk?

KM: I think it's a really tough place to be in. It's funny because I had a co-worker who was wondering if she should get tested for the breast cancer gene and after I got tested I thought, "Oh yeah, you should do it." And then I sort of, that's not really my place to tell anybody because for so long people had said to me like, "I can't

believe you haven't been tested, you're such a planner, you need to know everything." But it's different, in order to be . . . it's different to be a planner in things like you want to take a vacation, or my lesson plans, or . . . this is sort of a life-altering decision here. You're either going to know that you have it, or that you don't. And for people that know what the disease entail it means a whole lot more than people that don't really have any idea. People think, "My dad had a heart attack so I might have a heart attack," like it's the same thing. Well, in my opinion it's not really the same thing. I think it's hard. Like I said, I don't want to tell anybody what to do, but one thing I would say is to make sure you're ready, don't do it because somebody else got tested or because somebody is telling you to get tested. You have to really make sure that you yourself are prepared, sort of have your ducks in a row, if you will. [Make sure] somebody's going to be there for you, if you're taken care of medically in the future. And then prepare yourself mentally and emotionally, because it won't just affect you, it's also going to affect other people that are in your life and around you – family, friends, significant other . . . I think that's something a lot of people don't think of. I think they think, "Oh, I'll just go get it, then I'll know." It's really thinking about, well, you'll know, but how are other people going to feel when you find out.

AW: Yeah, sometimes it's kind of hard to follow things up with a question. So I'm going to do something kind of odd and un-enjoyable to listen to, but I'm going to completely switch gears.

KM: OK.

AW: What do you find admirable about the HD community? And, is there anyone in particular that you look up to or respect?

KM: Oh God. So, let me see, admirable about the HD community . . . I think they're resilient. That's something that I admire hugely. I've met a lot of people with a lot of crummy situations in their lives, I guess, to use a nice word. And just to see the

strength that they have – you know, they’re out there ever day, they’re trying to spread the word while taking care of their family members or children or spouses, you know, whoever in their lives is afflicted with HD . . . and yet, they’re still smiling at you and they’re [inaudible], and I don’t know how they’re not angry at the world. It’s just that to me has been amazing, there’s so many people like that that I’ve met. Let me see . . . to choose one person, do you want me to use their name or no?

AW: Probably not.

KM: OK. Aside from my dad, which I think is . . . he has dealt with this in a way that I don’t know I would be able to. He has four sisters, and like I said, he watched his dad and one of his sisters have it, but his outlook on life – he worked as long as he could, he’s volunteering still, he’s never once said, “Why me?” His focus shifted to sort of making sure the rest of us are ok. But outside my family, there was a woman I met who has two children and her husband had Huntington’s Disease, and both of her children have Huntington’s, and one of those children has passed away. And she, I just think, is probably one of the strongest women that I’ve ever known. I don’t know how anybody can go through that and not be a stronger better person for it. But I also don’t know how she went through it, didn’t just lay down and say enough if enough. She is someone I’ve definitely, that I’ve learned from, and have admired in the HD community.

AW: How do you think interacting with people, as you describe as resilient and very, very strong, how have they made you stronger?

KM: I think just by looking at how they handle themselves. As somebody who’s negative, it’s a weird feeling being around people, or having to tell people who are positive, gene positive I mean. I know my doctor has talked about the feeling of guilt. I don’t know if I would say that it’s guilt, but I do know that sometimes I feel uncomfortable. But I guess . . . just . . . knowing that we’re all in it together, and the fact that I’m negative doesn’t mean that I’m not going to get out there and do

everything I can. I'm running the New York Marathon in the fall, I've run two half marathons to raise money, we have other family fundraisers that we do every year. Just because I found out that I'm ok, doesn't mean that I'm not going to get out there. So I guess I would want people to know that. And then, meeting new people is sort of what we do it for . . . and how everyone handles themselves, and they continue to fight. Their battle to me is day-to-day, like my dad. My battle might be training for the marathon, but that's nothing compared to, you know, what someone with HD goes through ever day. I look at how people look at my dad, and how they talk about him and people that probably don't know what he has. Once they find out it's different. I think, sort of, just looking at how he keeps going no matter what people are saying or people think about him . . . and looking at it that way and realizing I have to keep going as well because something needs to change. We need to either find an effective treatment or a cure so that this doesn't happen to the next generation.

AW: So, you brought up doctors talking about feeling guilty as someone who's gene negative, and it's a recurring theme even though a lot of people talk about it. What you just described, ways you don't necessarily feel guilty, it just puts you in a slightly odd place in the community, or it can be slightly uncomfortable. Do you . . . do you find other people who are gene negative approaching it in a similar way, and guilt might just be a mislabeled way of describing that?

KM: I think it's hard because, I think like I said before, I'm not sure if it is guilt. I don't know what the feeling might be. I do know when one of my aunts was tested and she came back and told, I didn't know that she had gotten tested, but she told her other sisters and my dad and everyone was sort of like, "OK, good." And she had thought that they would make a big deal out of it I guess, and they just [inaudible]. And I think it's just because nobody knew that it was happening, but, so, I could remember her telling me, "I thought everybody would have been really excited," and I think everybody was – I don't think anybody wanted her to be gene-positive, but . . . I just think sometimes people don't know how to react when you tell them that

you're negative if there are people in the family that are positive. And for me, I think it was a little bit different for me, as I said I'm the oldest grandchild and the first to be tested out of the ones that are at risk, and so, it was sort of, "Oh, ok, so it hasn't passed to the next generation." But as far as meeting people in the HD community and telling them that I'm negative, I don't know. I mean it's, I guess it's a hard feeling to describe, and I wasn't sure that I would feel it, and it wasn't until I went to my first HD event after getting my results that I did feel it. Because I had to tell a few people who had children that were positive and some people that were positive themselves I had been tested and was negative, and you know, they were happy – I don't think they were mad. But I guess it's a weird feeling that for some reason you now, I don't have it and you do. Or that, It's just, I don't know. That's why I'm not sure if it's guilt. I mean, I know that I didn't have anything to do with it, those were just my odds. It happened while I was being made. I wasn't there. It's sort of a weird feeling to think that I for some reason don't, and someone else does. I guess I don't want them to think that I'm gloating or bragging or you know, I know it's going to be a tough road ahead – but that's sort of why I feel like I do so much for the community as well. Because, I know it's going to be a tough road whether I have it or I don't. So, I want to do as much as I can.

AW: Alright, I'm going to switch gears a little bit, again.

KM: OK. Am I answering the questions right?

AW: You are, you are! I'm sorry, I forgot to let you know that I'll let you talk, and talk, and let you . . . you know, go until you stop.

KM: OK.

AW: And there isn't a right or wrong answer, this is your story. So, what do you wish the HD community did better, and what do you think we need help with?

KM: Hmmm . . . that is a good question. I'm not sure. I definitely think, I'm not sure how this is . . . to say that we need help with it. I would love to see sort of a celebrity spokesperson, or something of that caliber where, I guess I don't feel like it's so well known yet. I feel like a lot of other diseases have a lot of publicity, and there are a lot of celebrities behind them, sports figures who talk about it. I've seen more recently, that have come out and talked about it. I know there's a hockey player, I think there was an advertisement or a video with a football player, but I don't really feel like we have a huge face-to-the-name type of thing. So I think that would be amazing. I'm not really sure how to get it, but I think that would be something that would be very helpful. And then, what was the other part? Something that they do well?

AW: So, actually something that we need help with – you were actually talking about something we don't have, a face, a very public face, that goes along with Huntington's disease, how do you think we overcome that aside from just the fact that there isn't anybody?

KM: Yeah. I don't know. I feel like there, like I said, there's starting to be more involvement – I'm reading the book right now *Inside the O'Brien's* by Lisa Genova, and people have asked me, "Is there going to be a movie?" And immediately I was like, "Oh my God, that would be amazing." Because I know she did, *Still Alice*. There hasn't to my knowledge been a major movie about Huntington's. I know it's been mentioned in some TV shows, but I think something like that would really open more people's eyes. Because I feel like, in the community the only people that know about it are the only people that, or the only people that have been affected by it in some way. So at least, my family, when we fundraise, we're always asking the same people to come – we try and branch out through Facebook, Twitter and all those things – but it's sort of hard to get new faces when they don't really understand because there are so many disease out there asking for fundraising efforts and support. So for people that don't really know what this is about, it's hard to make them understand, I guess, and want to get involved unless they know someone or.

So that's why I think having a major face to the name, or if they make this into a movie or, something like that would be huge for creating awareness. Even something like the [Boston] Marathon, we had tried to get numbers for the Boston Marathon, but weren't successful, but you know, wearing the shirts around, people will ask us, "Oh, what's that?" And I end up going into a long drawn out story and they're maybe like, "Oh, I shouldn't have asked her." But it's one more person who might know about it or something like that. So, I think with, I don't know, let's start asking celebrities. Anybody know celebrities that we can talk to? I just read an article that Lisa Genova said if she was going to make a movie, she wanted Matt Damon to play the father that's a cop. She said if he's listening to call her, so maybe he'll hear this as well and give her a call.

AW: Alright – you were talking about having to explain Huntington's to people who don't know about it – and this is actually a question I ask in almost every interview that I've done, how do you explain HD to someone who's unfamiliar with it?

KM: So, I usually start off by saying something that I've been told or heard, but it is similar to having Alzheimer's, Parkinson's, and ALS combined. I tell them that it affects people's movements, will eventually affect their speech, their swallowing, muscle control, cognitive impairments. I just say that the symptoms can be different for every person, but say that maybe they start differently, maybe some people have cognitive symptoms first, some have mobility issues first, but that eventually people will need full time care and won't be able to take care of themselves, and that each child of a parent who has Huntington's has a 50/50 change of inheriting the Huntington's Gene.

AW: Alright, thanks. I think we all have an interesting pocket-answer to that, and I think it says a lot about the disease that we use other diseases to describe it—which is kind of why I ask. I have one last question, we're almost done, do you have any words of advice to pass on to others in or outside of the HD community?

KM: Words of advice for people in the community I guess would say, keep fighting. You know it seems as though there's a lot of promising research out there. Whether it's just for Huntington's or another type of disease, Parkinson's, ALS. I feel like once there's a great cure for one of them, then the other's won't be far away, since some of them have similar symptoms. And another good thing is that they do know where it comes from, because if they didn't it would be even harder to find a treatment or a cure. There are many trials that people can get involved in – I'm in a trial. So, unless we have involvement in those we're not going to know if things are working. And for people outside of the community, I guess I would say, "Try to learn as much as you can." You know, if you don't know what you're dealing with and you jump to a conclusion, then chances are you're going to think that the person is drunk, or the person is on drugs, or who is this weird person over here. But, that's not the case, there's something medically wrong with them. Patience . . . and education I would say is the number one thing for people outside of the community that don't know about it. It's kind of hard because I feel like, probably everybody at some point has jumped to a conclusion about someone they see for the first time. But this is something that has taught me not to do that, because you don't know what people are dealing with in their life. Most of us are dealing with things, we just don't walk around with it broadcast on our foreheads or on our shirt. So, I guess, yeah, tolerance and patience and education would be what I would wish for the outside public, or general public I guess I would say.

AW: I guess I have a few more questions, I guess.

KM: OK.

AW: Throughout the interview you've addressed people inside the community, outside the community, people who are at risk, caretakers, a number of different groups – who do you hope listens to this interview?

KM: I would hope that someone, let me see . . .

AW: How far do you hope it goes?

KM: Oh I hope it goes as far as it can! I just said Matt Damon should call Lisa Genova! I mean, I guess that would be my ultimate goal, that someone would be willing to step up and sort of be the face of this disease. If I'm really reaching for the stars that would be amazing. But otherwise, maybe on a more realistic level, I don't know. I hope that people who are listening are looking for more information whether it's because they might have heard of it in the passing, or they might have, someone down the street has been acting weird and it got, Huntington's came up but they have no idea what it is, or . . . and even someone who might be at risk, or they themselves have just found out a parent has it, and is looking for more information, because I think the best way for us to help each other is to listen, and to listen to different stories. Because everybody's stories will be different, even though we're dealing with the same disease. And until, you know, there's a cure, we're going to have to go through this, so . . . I don't know. Matt Damon definitely though. No, Matt Damon – I don't want to leave out all the other celebrities, anybody that wants to step up is more than welcome!

AW: So, I'm just about done with anything that I had, is there anything that we didn't touch on that you would like to bring up?

KM: I don't think so, I mean, I guess I would just like to see people get more involved, even if it's once a year, if it's volunteering at a Hope Walk, fundraising, helping them out with that, or even taking time to talk to someone else. Like, "Hey, I just heard this interview, have you heard of this disease? I never knew what it was." The more people are talking about it, and it's out there, the more good stuff will come from it, I think. So that would be something I hope would come out of this.

AW: Definitely. I definitely think that's part of what we're trying to do with this project too. So, awesome . . . Kathleen, thank you very, very much. I'm going to wrap up the interview really quickly, just stop recording.