

Interviewee: Gina Delucia
Interviewer: Alison White
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Abstract:

Gina Delucia is an advocate for the Huntington's disease family—as she says. In this interview, Gina discusses her goals as an advocate as well as the changing landscape within the HD community. By telling her story—Gina hopes to reach people far and wide to help push for advancements not only in research, but also in law and care for people living with Huntington's everyday.

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AW: It is May 6, 2014. This is Alison White. I am here with Gina Delucia to discuss her relationship to Huntington's Disease. Gina, how did you first hear about HD?

GD: In 1983, I had started to date a man, who—his mom died the following year of Huntington's Disease. At the time there wasn't a whole lot written about HD. It kind of was, I had to take what he said was the disease rather than finding it out on my own.

AW: How did you end up more intertwined—or was it just dating somebody?

GD: It was really just dating somebody that's mom died of it. I really didn't – nobody in my area had it except for his mom. No one that I knew had had it in their family. He came from a family of six siblings. They really didn't talk about it. He rarely ever talked about it.

AW: What is your current relationship to Huntington's Disease?

GD: Well, that man I ended up marrying. He developed HD at the age of 33, after our second son was born. We also had a son that was diagnosed later with HD.

AW: Did you notice a difference before your husband was diagnosed?

GD: I really didn't—and a lot of people ask me that. But, I guess hindsight is 20/20. I didn't realize how much weight he had lost in a short amount of time—I think that was the first symptom that we ever saw. The second saw was very very angry. Awful mood swings. And I guess I just thought he was under a lot of stress because we had our second child, we weren't financially stable, we'd bought a house that needed a ton of work. I just thought his aggression and his anger was due to his having all of that stress—in it.

AW: So, looking back you look at those as symptoms, but at the time you didn't?

GD: Absolutely.

AW: At what point did you guys decide that you needed to go forth with testing?

GD: He actually never got tested. The day that my second son was born, my obstetrician said to me—I believe he has Huntington’s Disease and you need to get him tested. He attempted to have an MRI done, he just could not do it. We just went by his symptoms. He never officially got tested.

AW: Was this prior to genetic testing?

GD: Nope. The genetic test was available. He declined to have genetic testing. As did all of his family members.

AW: How did that make you feel?

GD: Well, we were pretty sure that he had it. So, I didn’t . . . I guess at the time—and I still feel the same way, that there was nothing we could do to change the diagnosis he—we knew that’s what the diagnosis, what it was—I just feel that his family should have gotten tested because they’ve all have had children. And I think that those kids had a right to know what their fate would have been.

AW: You said that you had a son who tested as well?

GD: He was also diagnosed through MRI. He had a lot of different symptoms. He walked on his toes, he had awful speech, he didn’t really grow between the ages of 9 and 10—that’s what started us going to numerous doctors. Again, hindsight is 20/20; I think the doctors thought Huntington’s was never an issue. They thought it was developmental delay—it was this, it was that. They tested him for pretty much everything but Huntington’s, and then they gave him an MRI and said it is Huntington’s.

AW: Do—how do you . . . Let me think of a way to phrase this. Of the many different “identities” that we have in the Huntington’s community, where do you fit in? Where do you think you fit in?

GD: I’m an advocate—because I believe that more can be done, in the way of the law. I’m an advocate for my son, who’s at risk. I think he has a right to know, now, when he wants to know—because he’s 16, and he knows what he wants and he should have the right to decide his fate now—rather than waiting until he’s 18 or symptomatic. I also am an educator. I go out there and talk to the community, educate the community about this disease. I also think that I am a person that is searching for research. I’m out there hitting the streets trying to raise money for research.

AW: Awesome. You mentioned that law is one of your primary advocacy points—is there anything in particular that you're working on right now?

GD: Not right now. I did go to the state house in November [2013], and talk to some state reps. My son actually did come with us, and he spoke also. And we both spoke about how testing was a big thing—and also about how the law is—was—unfair. I mean, there have been some gains in how people with Huntington's can get their disability faster—which, instead of the two year waiting. We've also gone on our local TV with our state rep., talking about Huntington's and trying to make people aware of, you know, how difficult it is going through life not knowing. Especially being a teenager now knowing—and have seen your father and brother die of it.

AW: I imagine that's ridiculously rough. How . . . how has Huntington's affected you as a mother? Aside from it clearly determining the type of motherhood you've had. How has it . . .

GD: I don't think it's changed me as a mother, I think it's changed me more as a person. I think I've always been an advocate for my kids. I think that I've pushed them, and it's something that's—that a lot of people said to me when my son died; that I'm such a strong person that I pushed him to do what he could. I believe that as a mother I expect their independence until they can no longer do it. So, I've tried to instill that in my kids—that they should strive for the best that they can possibly be; not say I can't. I can't do it today, but I can do it tomorrow.

AW: Ok. I'm going to switch gears just at little bit. I've asked this question of everyone. What is one word you would use to describe the Huntington's Disease community? And why?

GD: Family.

AW: Why?

GD: Because that's what we all are—is a big family. I talk to people from all over the world, all the time—and we're just one big family.

AW: Is there a reason you use that term?

GD: I think I've met a lot of people and I've talked to a lot of people through convention, and through the internet, through chat-groups, through support groups—when we see each other it's like seeing a family member. We talk to each other like we're family members. When we get together, it's family. Huntington's made us stronger and built a bond that will never ever break.

AW: How have you noticed with—interacting with people—globally, locally, nationally—how are the stories different and how are they the same?

GD: They're the same with the same testing, and not knowing, and they've very similar in how the families interacted. A lot of us talk about how the families never talked about HD—like it was a taboo! Like you don't talk about it. You don't do anything about it! If you pretend it doesn't exist, it doesn't exist. A lot of us talk about that.

AW: Do you see that changing now?

GD: I do see it changing now. I think that the younger group that's been affected by HD—they're more willing to speak up. Where the people of yesteryear, like my father in law at the time, didn't want to talk about it. If we don't talk about it, we don't have to think about it. Where, the younger generation now is out there. They're like, let's find a cure! Let's push for a cure! Let's get researchers! Let's get, let's get a treatment! They're out there—and I see that as being a big change.

AW: How do you think that's going to affect things in the future?

GD: I think it's going . . . I think the more people that get out there and push for things, the faster it's going to get done. It's like the expression: the squeaky wheel gets the oil. We're the squeaky wheel—we're getting noticed, and we're getting the oil.

AW: Nice. It's a very positive way to look at that. How do you encourage interaction with the Huntington's Disease community with your family? Aside from speaking—is there anything else that you . . .

GD: All of my kids—I have two children from my now marriage—we are all very involved. Whether it's speaking, fundraising. I have my nine year old daughter that has done projects on it, and they're out there working on it. It's funny, my son's—who passed away—my son Patrick, who's friends are now in college—they're all doing reports on HD. They're still connected to HD through him. So . . . my kids feel comfortable because they have older people that they consider siblings that they can talk to about it. We don't hide about it. If they have a question or a concern, or read a book about HD, it's open. It's an open discussion—and it's never ending. It's an open discussion that never ends.

AW: Do you see the same being true in how advocacy is currently headed?

GD: Yes, I do. I think advocacy has come a long way. I started getting involved in HDSA in 2009, after Patrick Anthony had died in 2008. It's so incredibly how advocacy has started to take over—and the momentum is really there—and it's out there. And people are out there going to state houses, and talking to Congress, and it's wonderful because we didn't have that before.

AW: In speaking to everybody—what story do you tell?

GD: I tell two stories. I talk about Patrick Anthony's life and how he lived a positive role model, and that he never ever ever let the disease get to him. I often tell the story about the first day he walked into Mass General after getting—we knew the diagnosis but he didn't—and we stepped into the clinic at Mass General and Dr. Chara was going through all the MRIs, and telling us and look at this, and this and this and this, and this is what I think it is. And Patrick Anthony just sat there with his blonde hair and blue eyes and said, "What do you want me to do about it?" Like it was, like he knew it was nothing he could do, and that he would go through everything there was to live his life to the fullest.

So I talk about that. I also talk about **[REDACTED]** life of the unknown. He has a life of unknown right now. He's at risk, and he doesn't know if he has it or he doesn't. And he talks often himself about, if he would change things in his life, if he would change his career—what he wants to do. Would—so we talk about that a lot when we go out there and talk to people.

AW: How—having a son who's at risk—how do you, how do you help navigate, help him navigate those decisions as a parent, aside from advocating? Right now, I know it's: at 18 you—where does it put you at odds? Or does it?

GD: I don't really, I just stress to him that it's his choice. I'll stand behind him whatever he wants to do. I won't let him ever curl up in a ball and give up—so that's not an option for him. But if he chooses something—chooses never to get married, never to have kids—than that's his choice—and I will stand by him 110%. If he decides on his 18th birthday, "Hey, I don't want to get tested." I'll stand by him. I am not him, and he is his own person, and he has to live with his decisions. Yes, I'm his mom and it kills me to say it, but if he chooses not to get tested—that's his choice. It's not my choice, and I can't make that choice for him. Right now—he has said, for five years, every birthday, "One more year until I can get tested. One more year, I'm that much closer." He's two years away—I don't know if he's going to change his mind in two years. I've told his that, you know, if you test positive—then what do you do? We've talked about it, and talked about it. And he knows that if he tests positive, he may have to change his career choice. He might not. I mean, his brother got it when he was 6 we're assuming—his dad got it at 33. There's a big age span in-between there.

AW: Looping back a little bit, you mentioning your son was likely symptomatic around the age of 6—do you view yourself as a caretaker?

GD: Oh yeah. I was definitely are caretaker for, he was pretty independent up until probably the last year of his life. Not that I had to feed him or do anything with him, but he, towards the end it was difficult for him to walk. He became incontinent within the last month of his life. I mean, that was a caregiver thing. But I'm a nurse so I'm a caregiver . . .

AW: . . . you do it anyway . . .

GD: . . . it's my job. To me it was nothing out of the ordinary. A lot of parents have said to me, "Oh I don't know how you could have done it." It's my kid.

AW: It's what you do.

GD: It's what you do. I didn't view it as I was caring for him—I viewed it as I was being his mom, and that's what mom's do. With my ex-husband it was kind of the same way. I was his wife. I didn't think of anything else. He's just a person—and that's what you do. Even though we were divorced towards the end, it's still my husband. And you just love them as a person—you don't really see the disease.

AW: You say that you are, you still are a nurse—did you view it differently taking care of one of your children than you would one of your patients? What was the difference in that?

GD: The difference is my patients have no bond to me—so to speak. Where the child is, you're their mom. It's a different kind of caring, because you're with them 24/7. You're not with a patient 24/7, you're there for eight hours and then you go home. They're not with you. I didn't view it—I viewed it as: he wasn't a patient, he was my child.

AW: You said that, I'm going to go back again—jump around a little bit more, you said that you tell two different stories when using your advocacy voice. You tell the stories of your two children. What story do you tell about you and caregiving, or do you?

GD: I don't. Because it's not about me, it's about them.

AW: Is there a reason? There's, I just think there's been more of a push for caregivers recently . . .

GD: There has been a big push for caregiving recently. However, I just don't want to center on myself, because I don't have the disease. I don't carry the disease. I don't—my future is pretty certain, how I'm going to live. It's not about me. It's not about what I had to do, it's about what they had to do, and what my son has to do in his life. It's not about me.

AW: Awesome. How has your, how . . . prior to dating your ex-husband, and finding out about Huntington's there, and then eventually him having the disease—how did your worldview or goals change in your life? Or how has your personality changed the direction you've gone?

GD: Oh, my personality hasn't changed in all the years. I think how I viewed life was a little different. You know, when you're young you think that you have to have everything in the world. I have to have this, I have to have the best TV, best

computer, I have to have the best of everything. When your loved one is sick, you realize that those things aren't important anymore. They're really not. Family is important. Time spent alone is important. Not what you got.

AW: That's actually something a few other people have touched on as well—that it sort of redirects your focus.

GD: Yeah. It really really does. I often talk to friends and family about this. I just, you live with, in yourself—you find a solitude and peace within yourself and you just, you don't need all the materialist things. You value the time with your kids, your spouse, at a whole different level?

AW: Can you expand on that?

GD: For instance, I am a mom that does everything with the kids. Everything. Go to ever ballet class, every football game. I think before, I went and I was, "Oh, got to go to a soccer game," – "Oh, got to go here." Now it's, "Oh my gosh, I've got to go! I've got to hurry up and get there!" It's a different perspective. I think, when I was married to my first husband—it was, "Ok, let sit here and watch TV." Now it's, "Let's sit here and watch TV and maybe we'll have a conversation." You enjoy that just a little bit differently; it's at a whole different level.

AW: How . . . I kind of want to pair these two questions a little big: how would you describe that to someone who doesn't understand?

GD: How would I describe it?

AW: How would you describe it to someone who hasn't been through the situation, or having?

GD: I have family members that have gone through it with me, and they still don't get it. There are two types of people: people that are going to get it, and there are people that are never, in their entire world, never going to get it. They have to have the best of everything, they have to do everything their way, they never ever see the other side. They can't imagine what it's like, even if their spouse gets sick, they would never understand it.

AW: This is a different question entirely. When you meet people who are unfamiliar with Huntington's Disease how do you describe it to them?

GD: The most horrific disease you've ever seen in your entire life—that will rob someone of everything that they've ever been and ever will be.

AW: Alright.

GD: However, I also say, because they're like, "Oh, that's awful." But I'm like, "But, you have to die of something, and no disease is pretty."

AW: That is very true, very true! Having gone through Huntington's with your ex-husband, as an adult, and one of your children, as juvenile HD, what were the differences?

GD: It's funny, because I always think of this. My husband was very aggressive, angry, mood changes, and his physical symptoms was, he had the dance-like movements. And his voice changed. And when you, his persona changed. My son, however, never had the mood swings. Was always even keel . . . he became very stiff rather than very movement like. Never complained of pain; were my husband would always complain of pain. And then it flipped. At the end, my husband never complained of pain, and my son always complained of pain.

AW: Interesting. Why do you think it's important that we tell stories of Huntington's Disease?

GD: I think the more we tell our stories, the more people will hear it. The more people will hear it, the more people will get interested. The more people that get interested, the more money will be raised. The more money that gets raised, the more research we can fund. The more research we can fund, the faster the cure.

AW: Nice. So, that being said—I've run through a lot of the questions I have actually. Is there anything else—what's important for you to tell that you haven't said already?

GD: I think it's important for people to know that every Huntington's story is different. Not any two are the same. Not any two patients are the same, not any two families are the same. There are a lot of similarities—but there are none that are the same. Mine, my story may replicate somebody else's, but a lot of the stories are different. People need to understand that just because you have Huntington's in your family you go, "Oh, Jane Smith has Huntington's and she does this, this and this. It's totally different from person to person. And I think by telling our stories, people will actually see that there is a difference, and there is not a stigma anymore. It's not bury your head in the sand and it won't happen. Because it's going to happen.

AW: Awesome, do you have anything else that you want to add?

GD: Nope.

AW: Well, thank you very much, Gina. I appreciate your time.

GD: You're welcome.

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