Interviewee: Cheryl Stavley
Interviewer: Alison White
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Abstract:
Perseverance is the word that Cheryl Stavley used to describe the Huntington's Disease community in this interview—something which, as a caretaker, she is extremely familiar with. Through this telling of her story, Cheryl weaves through her first run-ins with HD, what it is like going through the diagnosis of a significant other and children, insight into the life of a caretaker, and offers her outlook on the HD community and why she now works to further awareness of the disease.

AW: This is Alison White on April 15, 2014, and we are here with Cheryl Stavley . . . so, Cheryl we're going to jump right in.

CS: Ok.

AW: How did you first hear about Huntington's Disease?

CS: I actually, it was back in April of 1978 and I was a junior in nursing school, and I was doing my pediatric rotation. And I had to, umm, follow a school nurse for one week. And, um . . . so, I was at the, the school, and that summer, July of '78, my husband and I were getting married. And so, during the conversation at one time or another during the week with this nurse, you know, I said how I was engaged, who I was engaged to. And all of a sudden she said to me, "Oh my goodness." She said, "I took care of his mother. Did you know that she had Huntington's Chorea?" I was like, "No, you know, neither John nor his father—nobody said anything." Now, John's mom was an only child, no siblings or anything to be able to compare anything to . . . but I just kept thinking, oh, you know, it's such a common name, she has to be, she must be thinking of somebody else. I remember going back to my dorm that day, looking up Huntington's Disease, and you know, there was two sentences, which didn't say very much. That night, I went to John's house, and told he and my future father-in-law what this woman had said . . . they were like, especially my soon-to-be-father-in-law, he said he'd never heard of it, that his wife had had heard disease, that she had always been sickly. But, again, so I just kind of chalked it up to, you know, there's the 80 zillion Sullivan's. But, something about, and she seemed – John's mom had died when she was, he was 14, so I never met her. But it just seemed to be a few, the little bit that I knew about her . . . she seemed like this nurse, she knew what she was talking about, so it just kind of always kept it in the back of my head. That's really how I first had heard of HD.

AW: OK, so . . . you mentioned John was your first husband, he was, he . . . he was gene positive . . .

CS: How did he get diagnosed?

AW: Yeah . . . how did . . .

CS: Essentially . . . so one other interesting fact before . . . after we got married, but before we decided to have children, we did write to his family doctor who had taken care of his mother, and you know, he and his brother their whole lives, and of course this was way before HIPPA. So . . . but just wanting to know, and this family doctor was very emphatic and said, "No, John, your mother did not have HD." So, but again, umm, like I said, after that initial time, from time to time, whatever I could find out about HD, and again, pre-computers and internet—it was kind of difficult, but it was still always in the back of my head. But, in the summer of 1989 – so John and I had been married for 11 years, and my older daughter was eight, my younger daughter was 2, umm, and we were taking a family vacation. And I noticed for the very first time that day as John was driving, you know, finger flicking, some shoulder shrugging, and I noticed facial grimacing. And I had never noticed any of that before. And, umm, so from July to December of 1989, I kept seeing these very subtle things. And even though I was a nurse, I had only ever seen one person with HD, so I really didn't know what I was looking for, but I knew something about this didn't seem right. And the week before Christmas in 1989, one of John's colleagues at the police station, John was a police lieutenant, called and said several of the police officers were concerned about John. They couldn't put their finger on it, but they knew something wasn't right. And immediately, then, I knew what I had been seeing, and you know, we discussed this, and . . . I called . . . John's godmother, who was his mother's cousin, but on the opposite side. She wasn't at risk or anything. And I told her of this conversation I had had with, you know, 11 years prior with the school nurse and then what I was seeing. And she told me, John's godmother was a nurse, but I had only recently come to meet, to have met her. Um, and she told me, in no uncertain terms, that she definitely felt that John's mother had had HD. And that, you know, she felt that this was probably early symptoms of . . . I immediately called a neurologist at a prominent facility nearby, and within 10 days John was diagnosed. And again, this was before the gene was even discovered. But I kind of think he was only diagnosed because I said something to the doctor, "Gee, I don't really know, but there could be a family history of HD." Because, until I said that, the neurologist said, "I can't find anything wrong with him."

AW: That's interesting, to be able to talk about diagnosing a genetic disorder prior to anyone really understanding how it really interacted with our DNA.

CS: Exactly.

AW: It's fascinating. Do you remember what you were feeling when John started showing symptoms?

CS: Again, I was a little concerned. But it would be, from at least that period of July 1989 to December of 1989, like, I might see it, and then for two or three weeks I

didn't really see anything. Then again, I would see the same finger flicking, shoulder shrugging, . . . and I just kept thinking, he was, he was all, he was 37, and I just kept thinking, "Oh, but I guess that the little bit of information I had had in the previous time, that I thought oh, he would have been symptomatic for sure by the age of 30, so somehow I thought—he must have escaped it if that was really what his mother had ever had had. Um, but again, I was a little disconcerted. And obviously, when I mentioned that to the doctor, and suddenly he was like . . . I mean it was kind of weird that he went from, you know, at one hour the doctor saying, "Well, overall his neurological exam is fine, and I really don't know what to tell you." To when I said, "OK, What about HD?" And then it's like everything started clicking. And so then, of course, everything was very scary. And then it just suddenly felt like, you know, we had been handed a death sentence. But the thing that was even scarier of course, was realizing that our daughters were at risk.

AW: I imagine that's something very baffling, that it's something very hard to deal with. And that's probably you're more immediate reaction after the testing and after you found out that John was HD positive. Have you . . .

CS: And to me, he was more than gene positive; he was certainly already then, symptomatic.

AW: . . . already symptomatic.

CS: The neurologist at this first prominent facility had very little understanding about HD, and he told us three things on that day: that indeed, if John had HD, and again, he couldn't prove with anything, that he felt John should retire, immediately, I should start looking for a nursing home, and I should not let John live at home alone, or be alone at home with my children. So that was even, you know, we walked in there at 9 o'clock that morning, and you know, at 1 o'clock he says, "Gee, I don't know." At 1:05 I say, "What about HD?" At 1:30, "Oh, you do have HD." And by 2 o'clock he's telling us . . .

AW: It makes it sound like your life is over.

CS: Right.

AW: Like everything has totally turned up side down.

CS: Right, and in five hours how does it go from, in one hour, "I don't know, you seem fine," to, "Quit your job and find a nursing home."

AW: I think that's actually part of the reason I think it's important that we do the oral histories. Some people only see the face and the symptoms, but there's a lot more to us doing this. There are stories about this; it's not like our lives end when we're diagnosed.

CS: Exactly.

AW: I think I a lot of ways a diagnosis isn't to one person in particular, it's very much so a family disease. And it affects everybody in a lot of ways.

CS: And also I just remembered, when that the doctor said, you know, of course I started crying, and he was like, "Oh, what are you crying for?" He said, "You're a nurse, you'll be able to support your family." Never mind that he just handed this diagnosis to my husband and that we ultimately realized what it means for our daughters. But that was ok, I'm a nurse, so I can support my family.

AW: That's terrible. That's obviously before there were protocols in place for how to actually go through testing, therapy, um, genetic counseling and things like that prior to being tested.

CS: Right. And also, since the gene hadn't even been discovered, but more importantly it was genetic. Some kind of genetic counseling that this neurologist didn't allude to any . . .

AW: How did your views . . . how did your life change as John's disease progressed?

CS: Well I guess, first and foremost, I mean, almost that very same day that he was diagnosed, we knew that there were two paths we could take. That we could either just lie down and die and let this totally overtake us, or we could try to face it head on; learn as much about it as we could. And you know, be good advocates, and educate people. A, starting with, age appropriately, letting our daughters know what this disease was, what it meant. And you know, we never wanted what just happened to us, to happen to them. So, we were always as pro-active as we could be and John was very, you know, immediately he signed up for, you now, any clinical trials. He wanted to be a part of, help the medical research community, you know, as much as possible. And he also had the philosophy that, I'm going to do everything that I can, you know, for as long as I can. And he certainly embraced that and fulfilled that. So, we all just kind of, you know, went with that. Not that it was always easy, but in the long run, it helped our daughters have as normal of a life as possible, but to learn. And for them to be educated . . . and it made them better people . . . so . . . sorry . . .

AW: No, you're fine!

CS: Did I answer the question?

AW: Yeah! You're just fine! With, you mentioned that your daughter, one of your daughters has juvenile HD. What was different when your daughter was diagnosed? Or how did that come up?

CS: With my younger daughter, actually, probably at about the age of 14, I feel that she started showing very subtle symptoms. But it's kind of like once you've lived with someone with HD, I mean the symptoms. . .

AW: You pick it up a lot quicker.

CS: Right. You know, it just feels obvious, just the red light flashing. One thing about my younger daughter, she used to . . . she . . . she was a ballet, she did tap-jazz-ballet. She was always very graceful. She did gymnastics, as well, and twirled the baton. And it seemed like A, when she entered high school, she was becoming less graceful. She was a straight-A student, but she spent copious amounts of time on her homework. More than the average, even scholarly student would. When she probably was about a junior in high school, she actually had just started to wear contact lenses, but I had noticed a little bit of facial grimacing, but also the eye movements, where her eyes would be popping. And, but, it would always be, is she doing that because she's trying to get adjusted to the contact lenses. For everything that she did, it was always like, well, it could be HD, but maybe it's something else. Also, when she was a junior in high school, I had her tested for learning disabilities, because she, again, because she spent so much time, study and what not. And one of the first things I asked the nurse, after all the results were in, you know, could this be possible juvenile HD. Her answer was, well that my daughter had many of the similar learning disabilities as many of her other clients who were not at risk for HD. So, I chose to just, OK, well, hopefully she's just in that other 50% that this could be anybody. And also, because I knew the fact that they wouldn't routinely, you know, test somebody under the age of 18, I felt at age 16, yeah—as that nurse oncologist had said, if you want to know for sure, go into Boston and have her genetically tested. But I thought at age 16, would she be able to handle knowing this and I felt at that time, emotionally, no she could not. If there were treatment or a cure, I would have had her in there right away, but, and I was just kind of . . . lets just wait and see what happens. So, by the time Megan, between the summer of her freshman and sophomore year of college, it was very apparent that she did, the subtle symptoms were turning not so subtle. Her balance was off. And her first semester of her sophomore year of college she dropped one of her classes, and then, for having, four classes, she was calling me every day telling me she was spending ten hours a day studying, but she couldn't remember. And for the first time in her life, girl that barely ever got a B, was getting Ds and Fs. And deep down, she also knew because kids at school would be coming up to her and saying, "Oh my god, it's 10 o'clock on a Monday morning. I can't believe you're already drunk." She knew she wasn't drunk.

AW: It was called the drunk's disease at one point, because the symptoms appear to someone who does know, very very similar to someone who is.

CS: Exactly.

AW: Wow. It's interesting to hear that it's still the way that it's perceived from the outside. When was your daughter actually diagnosed?

CS: She was diagnosed at the age of 19, in March 2007.

AW: OK.

CS: Initially it was just by the physical diagnosis.

AW: OK.

CS: And the day that we walked in there, I mean, she even, the month prior, "I know that I have this disease." It was very important to her though, she did also want to have the genetic test done, and her CAG repeat was 61.

AW: Ok, that's pretty high. Did you react differently when your daughter was diagnosed as to when your husband was diagnosed? Emotionally, was it different?

CS: I guess in some respects, because John, we didn't, even though I had that prior knowledge from the nurse, since everybody else was denying it, it was still—it still really did come as a shock because, to know, wow, this is really HD. With . . . my younger daughter, having seen the subtle symptoms for several years, just every time I would see a symptom, or that would seem to be more prominent, it just felt like a dagger in my heart—because I knew this was it. And I had already, obviously I realized that both my daughters were 50% at risk, but, and I knew the juvenile form was so rare, that I just kept thinking, that if god forbid either one has to have it, you know, at least we have another 20 years. Knowing that she got, even the rare juvenile, that was a tough pill to swallow because I just wasn't, on that sense, I wasn't prepared. I guess I had prepared myself during the course of their lifetime growing up, knowing that it was a 50% reality, but again, thinking that we had more time. Also, just as a parent, as a mother, you want to protect your child. I felt very helpless. I wasn't able to protect her from this.

AW: You did say though, that you engrained in them, both of your daughters, a lot of fight—might be a word—or a lot of strength. How do you think that helped you and your daughter, or daughter's with your youngest daughter's diagnosis?

CS: . . . again, I guess, just always having known that this was a possibility—I had always kind of planned two routes for my life: one that had HD, and one that didn't. But I knew that if one or both have HD, then this is the course we're going to take. And again, we're going to fight the best we can, and remain as positive, accomplish as much as we can. First, I was heartsick, as was my daughter. But again, to lie down and die, especially at that point, was not an option.

AW: In your path, you know, in the one where we do have HD, the one where we don't, you've definitely taken Huntington's as head on as you can, and you've done a

lot as far as advocacy goes, as has your daughter from what I understand. How, what types of things do you do to help put the message out there, or to advocate on behalf of the disease or patients, or research, or caretaking, or things like that?

CS: We've spoken to many many different kinds of groups. We've spoken to all kinds of, just, college and high school students, to medical, nursing, social work, genetic, physical therapy and occupational therapy students. We've spoken to current medical researchers worldwide. To neurologists. We've spoken to political, and you know, civic organizations. Really, anybody that will listen, or that has any interest. It has run the gamut. But just being able to tell our story, to talk about what HD is. We both looked at it that, ok, there's a few more people that didn't know about it, that do… when I would speak to medical students or to researchers, I would always like to think, "Maybe there's somebody in that audience. They're going to find an effective treatment, or they'll be the one to find the cure, because they heard about it and became interested." And an audience full of philanthropists, maybe there's going to be the millionaire, who's going to say, "Here." And especially me, knowing I am the only one in my immediate family that won't ever get HD, it's the best way I know to honor my family and to feel like I'm doing something positive, that it's helping.

AW: To carry the torch.

CS: Even if it won't help my family now, hopefully it will help other families down the road.

AW: It definitely seems like you've been inspired by everyone in your family who is effected by the gene. Are there other ways that you've been inspired by Huntington's disease, or by the people who are affected by it?

CS: . . . I guess just, again, just to honor them the best way that I can. And just, the amount of pride and respect and love—obviously—that I have for them.

AW: OK.

CS: And that hopefully, in turn, what they have done has made me a better person, and made me more courageous.

AW: What have you learned from your experiences with Huntington's Disease?

CS: Perseverance.

AW: Ok.

CS: First and foremost, that yeah, really to fight. To arm yourself with as much education. A, not only about the disease, but also, how can you . . . like, and embrace, ok, what do I need to do financially, legally, socially, emotionally, just to, you know,

every channel or every path of life that this disease is going to effect, How do you manage all of that? To have as a productive as a productive life, but, in so that you can manage your assets, or the best medical care available. Does that make any sense?

AW: It certainly does! How do you define success in your life?

CS: I guess for me, success has been . . .

AW: It might be just making it . . . it might . . .

CS: Right, just seeing my daughters, and the people that they have become. It makes me feel that I have helped in some way make them successful, productive . . . people. So I guess, in a way, my children are a large part of what I would consider my personal . . . success.

AW: Do you think your view, this is kind of awkwardly worded, do you think your view of what success is in your life has changed since John was first diagnosed with Huntington's Disease?

CS: Yes. Because maybe prior to that I would think, I'm a registered nurse. I didn't have a huge career, I always worked part time. I was interested in raising my daughters, and providing a home, and sometimes I would think, oh, all that education is that really being successful—and to me, being a mother and molding children's lives was important. Now, I see that success, you don't have to be rich or famous, or you know, win a Nobel Peace Prize, success can just be, you made it through each day. And you know, you're in tact, and you love everybody, and you know you have provided the best possible day you could for others as well as for yourself. So success could be something as simple as that.

AW: Ok. Based on your life experiences, what advice would you give to other people going through your, the same situation? Or a similar one?

CS: Again, if it's HD or if it's something else but, gain as much knowledge and information as you can about whatever this possible barrier or problem or concern is. Again, find out each avenue. What is it going to most affect, and how do you need to prepare as best that you can. And again, I guess, just mostly, just try and remain as positive as you can. Face it head on, and surround yourself with as many helpful and loving people as you can. Because you will need a lot of support, from others.

AW: You touched on a support system. How big is your support system? Who do you consider your support system?

CS: Always my own family. My parents and my siblings. I've had, I have a lot of friends and as do my daughters have a lot of friends—and they have been of tremendous help. My current husband—he has been a tremendous help. See how

we take care of John, he actually was very instrumental in John actually getting diagnosed and he has helped me with the girls and everything. And because of him, I am able to travel and educate and advocate. Obviously, he is a big support as well.

AW: That's awesome. When you meet people who are unfamiliar with Huntington's Disease, how do you explain it? I think we all have our funny one snippet kind of phrase. What do you use?

CS: I guess I'll just say that think of Alzheimer's, Parkinson's, and Alzheimer's. All rolled into one, but that it could affect up to three generations of the same family at one time, and that . . . imagine that it's hard enough taking care of one person with a terminal illness, that you could be doing more that one at the very same time. I know that's really patent, a lot of people will probably say it's Alzheimer's, Parkinson's and ALS all rolled into one. And . . . even though I see there are certain aspects of each of them, but really—we know that doesn't really define HD—but if you don't know anything, at least most people have heard of those three.

AW: Definitely. How has your life and worldview changed –we've kind of covered this already a little bit—since involving yourself in your support system and the Huntington's Disease support community? How has participating in advocacy changed how you kind of view . . .

CS: I guess in a way it has expanded my horizons, because before HD, not that I didn't know what was going on nationally, or politically, but I wasn't maybe as invested as now. Travelling, and meeting other people and even if I'm politically trying to help Medicaid or Social Security or the Parity Act, that in some sense it has broadened my horizons.

AW: Has it, in broadening it, has it also narrowed what you focus on? Is a lot of your traveling, does it revolve around Huntington's Disease?

CS: Correct.

AW: It's taken one path, but in many places that you probably didn't think about before.

CS: Correct.

AW: Do you think your story is important to tell?

CS: Oh definitely. Any family's pers- . . . any family with HD's story is important. Mine to me is important, again, because of the perseverance, and the courage, and the strength. And ultimately, having my granddaughter, whom we know does not have HD—and that the chain—that link of HD—is forever broken. So… and again, other people learning, that you don't just have to give up. Have courage, you can

still live and enjoy life and do things, as, even as the disease progresses. There's always something good in every stage.

AW: Is there anything in particular that you want someone to take away from the story you've been telling today? You've said perseverance . . . that might be gain in . . .

CS: Right, and to have hope. Never give up on hope. Because if you don't have hope, you don't want to get out of bed the next day and that. And I feel that . . . in the HD community, especially in regards to the researchers and the medical doctors that they are all trying so hard, and we want a cure as much as the families do. And send them positive thoughts.

AW: I've pretty much gone through a lot of the questions that I had, is there anything else that you wanted to talk about? Or anything else you think is important to have on record?

CS: Maybe just for the HD caregivers that I'd like to add to don't forget to take care of yourself. If you're burnt out, how are you going to help your loved ones with HD or whatever the disease might be? And that I know sometimes, feasibly, it is really hard to say, "OK, I'm going to take an hour for myself." I have gone through periods when I felt like I was on the verge of caregiver burnout. And you just need that little escape. Even if it's just going for a walk. You don't have to go for a trip to Europe, even though that might be nice, but there's a lot of little simple things that you can do. And ask for help. That was something that I would never do before, but again, that's why the bigger support system that you can have, maybe the more easily eventually, you'll be able to ask people. It could be, "Could you sit with my loved one for a half hour so I can take a walk, or do an errand." And I have found that your support people, your people that love you, your friends, many times—they want to do something but they don't know and they're not mind readers and neither are we. So go ahead and ask. It's ok to ask for help, and you don't have to be a superpower to do that.

AW: What do you do to take care of yourself?

CS: I do go to the gym. Twice a week and that is actually a very new thing. After being a caregiver for 25 years, I've only been doing this for about 9 months, although I've had a gym membership for a very long time. But, just being physically a little fitter, it really does mentally; give me more piece of mind, or more stamina. I also like to read, spending time with my granddaughter—those are three things that definitely give me a break and kind of revitalize me.

AW: Awesome. Is there anything else that you want to add, or anything that you think we didn't discuss?

CS: I can't really think of anything.

AW: You're ok?

CS: Yeah, we did . . .

AW: Ok. Then, thank you very much Cheryl.

CS: You're so welcome Alison, I hope this was ok!