

# **Anonymous Speech delivered at HD 2008 Symposium, Cambridge, MA**

Hi everybody. I am very excited to be here. I would like to thank everyone for your time today. Also, I would like to thank Nancy Wexler for her invitation to come to the conference. 4 years ago, I attended my first HDF conference in Boston as a new graduate student. Today, I am here as an HD patient. When Nancy first asked me to speak here, I felt honored, but my thoughts quickly raced to this question: What if the information that I'm sharing today, somehow comes back to haunt me at my current job. Unlikely, right? As I pondered this question, I realized that I could give a full lecture just citing 'coincidences' from my life that have shown me how very small the world really is. And let's say my work does find out, would they fire me right away? Or would they wait until I made a mistake, which lots of people always do, and then correctly assume there are many more mistakes to come? People at my job already, like to make well-intended jokes about how I seem drunk, even though I don't drink, or how I'm always hitting into things and dropping others. Or how it's a miracle if I can make it to my desk without spilling a half filled mug of water. Often people cannot understand me when I speak, and I'm always being asked to repeat myself. And all this without my coworkers even being tuned into the HD symptom display. Other symptoms that I am currently experiencing, is that I have difficulty sitting comfortably without fighting. Often, when I'm doing anything from a work related task to a casual conversation with friends, I can physically feel my brain short circuiting as it is trying to process the information. Every movement and step that I take every day is earned and requires focus. And on the bad

days, it seems like all the focus in the world can't get my feet and legs to do what I want them to. These are some of the things that someone with HD has to face and think about every day. And this is why I decided that I would speak anonymously. My sister also has HD and she is more affected than I am. A year or so ago, she worked as a teachers aid. One day, she was having a hard time, or more accurately, a harder than usual time with her symptoms. She felt that this had caused her to have difficulties dealing with one of the kids, so she started to cry. One of her co-workers tried to help and talk with her. During this conversation my sister confessed to having HD. A few short weeks later, and she was let go. Of course, all that they had to say was that she was not performing well. More recently, she lost her job. This time it was because her HD symptoms truly made her job impossible to do. About the same time, she got a DWI, without even having a drink. She had to face the bitter reality that she could not drive anymore, something she refused to accept. As horrible as this sounds, I am relieved that she finished driving without hurting or killing someone else or herself. This is what HD does, as it whittles away a person, it forces impossible choices under the most difficult of conditions.

Make no mistake about it, my sister and I are in the most difficult of conditions. The only hope we have is that science will produce a cure. For people like me, the hope for a cure is my reason for being. It is the reason that I can get out of bed in the morning. It is the reason that I can keep fighting HD in spite of the tremendous losses that I have already suffered. I cannot stress enough the importance of this to my survival. It is because of this, that I feel the need to express my deep, genuine and heartfelt gratitude to all of you. This is my main motivation for speaking today. From my family to

everyone, “WE THANK YOU.” What I hope to accomplish with this speech is to provide more clarity to the big picture of why we are all here today.

[With that said, I hope to give you further insight into what HD does to people, and their families.]

I was born to a loving family. My parents, loved each other, and both me and my sister very much. My father was a good and kindhearted man. Even though, I have very limited memories before his HD began, there are some things I remember clearly. My father had an endless patience and would stand outside pitching me waffle balls, until I would declare that I was tired. As a kid, I always knew to go ask my father for whatever it was that I wanted. Somehow, I sensed that he felt guilty saying no to me. Overtime, as the HDs first began to take hold of him, his movements when throwing a ball became increasingly erratic. Slowly, but surely, playing catch occurred less often, then not at all. His ability to think things through also deteriorated. He stopped driving and closed his optician shop business around the same time. He had been making bad business decisions and as a result, racked up some serious debt. The patient man that was my father, turned into an easily angered, irritable person. The man who loved talking with me and telling me that he loved me, morphed into someone who rarely communicated verbally at all. The man, who seemed to be able to do everything and then some, could no longer cut the lawn, cook, or even walk the dog. He couldn't teach me how to shave, or talk to me about girls. When you add all of these changes up, it's a very ugly picture. HD had cut down a man in his prime, and replaced him with a shell of my father. Piece by piece, HD relentlessly carved him away, until he more resembled a child, than he did a grown man. It was very painful for me to be stuck watching helplessly, as bit by bit he

was taken from me. In effect, I had to mourn my father because that man was gone. And yet I still had to see his shell every day. I still had to face the inhuman condition that HD left him in. Of course, when he finally passed 13 long years later, and 3 short months before today, I was deeply saddened. And so, I am mourning my father for the second time in my life. I know he is in a better place, but it's hard for me to think that I can't see even the shell of him anymore.

I don't remember when exactly I became aware that the same thing that happened to my father could happen to me. The time when I discovered both that I could inherit HD, and that there was a genetic test available, was the point that I knew that I wanted to know. For me it wasn't a long drawn out decision making process. Rather it was a relatively clear-cut choice with enormous stakes. More accurately, I needed to know. The way I saw it, even though there was a 50% chance of me inheriting the gene, there was also a 50% chance that I didn't. That was enough odds for me to step up and bet it all on black. The power of seeing my future was too alluring; I could not stop myself from looking into the crystal ball. I saw two very different paths in front of me, and I needed to know which one was my fate, so that I could plan accordingly. I had to wait a number of years before I turned 18. On my 18<sup>th</sup> birthday, I went into the clinic to start the long testing process. After I found out that I was gene positive, the psychologist at the clinic asked me what I was going to do now that I had the result. I said to her that the one thing I was completely sure of was that I would never get married or have kids. I would never let HD do to my own family, what it had done to my father's. I then got up, went to bathroom and splashed some water repeatedly into my face. As I looked up into my eyes in the mirror, I realized that I no longer recognized myself. The realization

that I was gene positive set off an atom bomb inside me that I didn't even know existed. This atomic explosion destroyed all the weak, the normal and the child-like parts of me that growing up with HD had not killed already. All that remained were the strongest, most battle tested remnants of my former self from which I would begin to build a person who could live in the shadow of the HD monster.

I floundered around psychologically in the few years directly following my test. And during this time, I thought constantly about what I wanted to do with myself and what life I still had left that was mine. When I started college, I didn't have any ideas about a career in medicine or science. The more that I thought about it, the more unhappy I was with the classes and directions that I did take. I decided I would try to be a doctor and treat patients like my father. I tried out some science classes and did well. One day around this time, I was in a bookstore and happened to come across a book called Genome. The book has 23 chapters, each one dedicated to a different human chromosome and a gene on it. The author uses that gene to show how it controls a specific human trait or life characteristic that we think of as uniquely our own. Chapter 4, was entitled 'Fate.' It discusses how a simple genetic mutation in one of our genes can determine the fate of our lives. It talks about the huntingtin gene, HD and of course it told the story of HDF. I learned of their astonishing success in finding the HD marker and then the gene and mutation. Further, I learned of how they were still searching tirelessly for a cure by funding critical scientific research. I was so blown away and inspired by the story; I must have reread the chapter 50 times. The knowledge that people were working on a solution to the very problem that plagued me and my family, filled me with hope. I learned there might be a way out of my fate, and I wanted to be a

part of it. [The more that I learned about the state of knowledge and treatment in the HD field, the more I continued to be drawn to research.] Ultimately, I decided to go to grad school, where I could focus on HD research.

With such a crazy life, in such a crazy world, pursuing science made a lot of sense. I realized that even if I was unsuccessful with scientific findings, I would be better off knowing that I had tried, than always wondering 'what if?' This let me add a few lines of color to the pitch black canvas that was my future. It would eventually bring in the eye of the HD storm, a period of time when I was the most at peace with the presence of HD in my life.

On an interesting side-note, when I was a grad student, I took a Human Genetics course. Halfway through, we were all given a copy of the (83) paper that first describes the HD gene marker. Our assignment was to explain the significance of the findings. I felt it was a tremendous stroke of luck and that I was more than enough prepared to answer that question. I quickly hammered out a paper, discussing all the key points that I could think of, from the genetic test to the research that has been done and the possibility of a cure. I handed it in, content that I had just nailed an A paper. When I got the paper back, there was a big 'C' on it. That was the lowest grade I got as a Grad Student. When I questioned my professor, he thought he was being generous. He promptly explained to me that nowhere in my paper did I even attempt to discuss how this critical, initial discovery opened the door for the era of modern human genetics, and the myriad of significant findings that followed. As is usually true, I learn the most from my mistakes. I was awestruck by how much more important this paper was then I

originally thought. I was excited thinking about the possible ripple effect that one of my findings as a scientist might have, beyond even my dream of a cure.

There is an interesting paradox that exists living with HD. HD has revealed to me the true value of things in life, in a way I would have never believed, had I never lived through it. This truth was so important to me, that a number of years ago, I was so happy and proud of the person I had become, that I wouldn't have traded my gene positive status back in, if it meant that I would also have to trade in the person that I had become. Speaking now I can tell you [that I would trade everything that I have learned and all that I am, just to know that there are a lot of interesting questions that you are all trying to answer. To be able to live a life free of HD] that if God came to me one night in a dream and said 'You can choose your life. The door on the left is your life as it is now. The door on your right is your life with the thread of HD completely removed, so that all that you have learned since then is gone.' I would run so fast to the door on the right, I'd light the ground on fire. The reason being to avoid the incredible pain and torture that HD is inflicting on me and my family. Even though HD has vividly illuminated all the incredible beauty that exists in the world, it subsequently has thrown up an impenetrable barrier that separates me from it all.

The symptoms started when I was in my third year of grad school. For years, I had been extremely vigilant, always looking for the signs of HD. The mild physical and mental symptoms began to occur frequently enough that I could no longer write them off as my own paranoia. I began to grow concerned over how many variables I might be introducing into my experiments. And if not now, how much longer before I wouldn't be able to do science experiments anymore? I wondered how much time before I would no

longer be able to work? Then, what would I do for money after I couldn't work anymore? The answer to these questions, told me that it was time to leave grad school.

After leaving grad school, HD continued beating me down a steady spiral, far into a deep hole. I had been depressed a number of times in my life, but I found myself in a place that was so much darker and deeper than I had ever experienced before. I lost the ability to laugh. I could only recognize that situations were supposed to be funny, and then give my best impersonation of a laugh. I was unemployed and there wasn't any job that I could do; not any physical labor, a janitor or even a cashier. Hope was non-existent in my life. I became disconnected from life, stuck watching the bad movie that was my life from far inside my shell. I also became disconnect from the people that I care about. I knew they were there for me, just a simple phone call away. But even thinking about calling anyone, made my mind numb before I even had to engage in a conversation. Every single thing that I did, would drain my brain and make my symptoms worse, at which point, I could do nothing besides sleep or watch TV. This reminded me of my father. When I was down in the hole, I also became filled with regret and negative emotions or thoughts. As an example, I started to believe how I shouldn't have went to grad school, because in the end, I only found negative data, and the money that supported me as a grad student, could have been used to support someone who would finish and ultimately make positive findings. I remember, one of these dark days, I looked at my reflection. And I realized that for the second time in my life, I didn't recognize the person in the mirror.

I didn't think that things would ever get better. I was barely surviving. I just hung on and did the best that I could. Thankfully, I have found both God and anti-depressants, and I haven't let go of either one since. This one-two punch combo has pulled me out of the hole and got me back into the fight with HD.

Now, I can stand here today and say that I am 100% confident that a cure will come. This isn't even a question I ask myself. The real question is WHEN will it happen. I am very hopeful that this will be sooner, rather than later. If I didn't have this very crucial hope, I wouldn't be able to be up here speaking today. I am very excited to learn about your latest results and ideas. I thank you all for the work you have already done, and the work you continue to do. From the grad student who contributes various pieces of negative data (like myself), all the way up to the PI compiling numerous publications, we are all part of the process that will ultimately produce the cure for HD. Each of us has already contributed our own grains of sand to a pile. When this pile of knowledge gets high enough, it will give us a cure. When that cure comes, as I have no doubt that it will, in the end, we will find that we were all part of one of the most powerful and incredible stories in the history of science.