An Interview with Katie Jackson

Patient Advocate, Vice President of Help 4 HD International

Katie Jackson is a patient advocate for the Huntington's disease community. She is also the Vice President of Help 4 HD International, a nonprofit organization using new age technology to educate the world about Huntington's disease. Ms. Jackson has been involved in creating new programs and platforms to help with clinical trials and science educational tools within the Huntington's disease community.

Katie Jackson

You are a passionate advocate for patients with Huntington's disease. How did you first become involved with this community?

My husband was diagnosed with Huntington's disease eight years ago. I don't know what was more terrifying—knowing my husband was just diagnosed positive with this horrific terminal neurodegenerative disease, or that seeing as how Huntington's disease is a dominant genetic disease now each one of my children has a 50% chance of inheriting their father's same fate. I am a mother and I am supposed to protect my children. The one thing that I learned very quickly was I could not protect my children from Huntington's disease. The one thing I could do though was fight. I could stand up and do anything I possibly could to help advocate for new treatments, therapies, and hopefully the cure for Huntington's disease. I could fight to help start change. So why am I a passionate patient advocate? It is because my children, my children's children, and all the future generations of my family will come to depend on the change we start today. I fight to be the last generation to have to live with Huntington's disease the way my generation and past generations have had to.

What is your role in this advocacy organization?

As a Huntington's disease advocate, I knew that I wanted to get involved with an ethical and credible organization who was truly trying to help our Huntington's disease community. That's when I found Help 4 HD International. When the CEO invited me to be a guest on their radio show, I realized that this organization would be the perfect platform for me to use my gifts in advocacy and my humanitarian spirit. I am now the vice president of Help 4 HD International, a next-generation nonprofit organization serving the Huntington's disease community.

The mission of Help 4 HD International is to utilize new-age technology and multimedia communications to educate the world about Huntington's disease. Some of Help 4 HD programs I'm most proud of are Help 4 HD Radio show with over 87,000 listeners; the Clinical Trial Support Platform; *The Huntington's Post* newspaper; *Help 4 HD Magazine*; H4HDiRegister, a patient registry; Circle of Support; Research 4 HD; and many more.

Part of my responsibility at Help 4 HD International is to go out and speak about Huntington's disease to anyone and everyone who will listen. I have also spoken at government events and many symposia, conventions, and summits about Huntington's disease. I have also spoken on funding grants for Huntington's disease research and will continue to educate and advocate wherever I can for our cause.

Could you tell us about your family's personal journey?

My husband was diagnosed with Huntington's disease when he was 28 years old. After learning that my husband's biological father had died of Huntington's disease at age 49, my husband decided he was going to be tested. Who would have known one simple blood draw would change my life so much? After many nights of crying and living in complete fear, my husband and I decided something needed to change. We decided we were not going to bow down to this disease. We were going to get involved. We were going to educate ourselves about everything that was going on in the Huntington's disease world. The one thing we really got involved in was clinical trials, because we know that the future of our family relies on science and clinical trials. We knew that if the clinical trials were not enrolled and retained, we would never see any new therapies or treatments come to market for those who suffer with Huntington's disease. My husband is now enrolled in five clinical trials and studies.

Does your grassroots organization interact with other organizations? Which are the main benefits of such interactions?

We work with other Huntington's grassroots organizations internationally. We also work with other organizations in different disease communities. We are able to share ideas and talk about different programs that each organization has started, which benefits the community they serve. We have been able to help different organizations start their own radio shows. We ask for advice from other organizations about programs such as our patient registry. These are beneficial relationships for all parties involved. We are all looking to build and start new programs to serve our

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community better. Programs are typically really hard to form. If we can take advice from someone who has already done it and share ideas, it makes the development process for that platform or program faster and more efficient. In return, we can pass on our knowledge to upcoming organizations to help give them a boost in their own development. We all have the same passion and desire to address unmet needs within our Huntington's disease community. We always say when we work with other organizations, "together we stand united and strong."

How has your grassroots organization engaged with the California Institute for Regenerative Medicine (CIRM)? What has been accomplished through this partnership?

The first time I was introduced to the remarkable people at CIRM was in July 2012. I attended an Independent Citizens Oversight Committee (ICOC) board meeting in Burlingame, California. Together with 30 other Huntington's patient advocates, I showed up to speak in support of a 19-million-dollar grant that was being voted to fund Dr. Vicki Wheelock's phase I clinical trial for the first potential therapy in the world for Huntington's disease. That day, CIRM's ICOC board voted YES to fund the project. It was a historical day for Huntington's disease. Thanks to CIRM, a clinical trial using mesenchymal stem cells (MSCs) as a potential therapy for Huntington's disease is funded. My husband is enrolled in this ground-breaking trial. The world is watching, and we are all so thankful to Dr. Nolta and the lab at UC Davis, Dr. Vicki Wheelock and the Huntington's disease clinic at UC Davis, and CIRM. Because of this "perfect storm," we have hope.

We at Help 4 HD International support CIRM and are thankful for the 26.2 million in CIRM research grants that have been funded to advance Huntington's disease science. CIRM has funded amazing researchers like Jan Nolta, Leslie Thompson, John Griffin, Vicki Wheelock, and others who have dedicated their careers to Huntington's disease research. CIRM has brought hope to the Huntington's disease community like there has never been before. We recently had Kevin McCormack and Dr. Ellen Feigal from CIRM speak at the Help 4 HD Symposium 2014. We have also had CIRM on Help 4 HD Radio a couple of times. CIRM has helped educate our HD community through radio and events about regenerative medicine and all that CIRM is doing.

I am proud that proposition 71 passed and CIRM was formed. What CIRM has started is a movement that has the potential to ease so much pain and suffering for individuals living with chronic illness and injury. Being a Californian, I am proud to have voted YES on proposition 71. If we ever have a stem cell initiative come up for a vote in California again, I will support it and be waiting in line when the polls open!

What do you see as the greatest challenges for patient advocacy organizations like yours?

Help 4 HD International's biggest challenge is how to become sustainable. We are not taking fundraising dollars from our community at this time, but we rely solely on educational grants and private donations. The mission of Help 4 HD International is to educate the world about Huntington's disease, but we know it's so much more. We are developing programs not only to educate the world, but also to produce platforms that can help other organizations like ours. Only in our first year as a fully exempt public charity, for now we are focused on educational symposia. We have so many great ideas for much needed programs for our Huntington's community; the biggest challenge is finding ways to get these programs funded. We are a next-generation nonprofit organization pioneering needed change and adopting elements of successful programs from other organizations as we go. Pioneering clinical trial outreach is one program we feel is very important and our clinical trial platform has never been done in the way we have through our multimedia and communications platform. Through this communications platform, we can reach a greater population of our community to educate and impart hope.

What do you think needs to be done to advance the stem cell field toward clinical applications?

We believe the answer to this is education and funding. We all know that getting this science from the bench to clinical application takes millions of dollars. I think it is a travesty to lose promising science due to lack of funding.

What role do we play as patient advocates to help stimulate funding? We use our voices to tell our stories. We have to educate the public about how important regenerative medicine is to care and cure. There are so many stigmas and barriers when it comes to regenerative medicine. We as patient advocates have to break down those barriers to dispel the stigmas through advocacy and education.

As an informed California voter, we started an advocacy movement the day that proposition 71 passed and the California Stem Cell Agency was formed. We continue our mission to educate the voters about the prospect of regenerative medicine and seek philanthropy and private funding, but ultimately we need the government and industry to back our scientific endeavors. We have to empower the people to stand behind regenerative medicine, and how we do that is through education. People who are living with chronic illness already know and feel the desperation for new therapies and treatments. We must also educate the people who have not been afflicted. Everyone who is walking this earth is at risk for chronic illness and injury. Time is of the essence for many, and delays due to funding can be devastating. We have to show up at public forums and use all forms of media to tell our stories and teach layman's science. We are fighting against time to educate the world about regenerative medicine so

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What was the best advice you were given? What advice would you give to other people entering the advocacy movement?

The best advice I have received in my advocacy journey was from a fellow Huntington's disease patient advocate who has been doing this for over 20 years. Judy Roberson is one of our pioneers and has been a part of many movements in the Huntington's disease community that has brought about change. Her advice was "show up and speak up." She said show up to whatever you can. If there is a convention, summit, or symposium, "show up." If there is a government meeting or anything to help bring support or awareness to our Huntington's community, "show up and speak up."

I am always thinking of her "show up and speak up" concept. When there is a funding meeting and there is a Huntington's disease grant on the table, I always show up if I can. When it comes to clinical trials and studies, my husband and I show up. Mike is now enrolled in his fifth clinical trial. We know if we ever want to see any new treatments, therapies, or the cure come to be, we have to show up, enroll, and retain clinical trials. Here in the United States we have the FDA, who is there to protect us and make sure that all new treatments and therapies pass safety, tolerability, and efficacy during the clinical trial phases. We have to show up for clinical trials and be brave to prove to the FDA that a treatment or therapy is going to work. Without the patients and patient advocates, no new therapies will ever come to market. Our scientists are doing their jobs working countless hours in their labs finding these new amazing scientific breakthroughs. We also have a job as patients and advocates and that is to enroll and retain clinical trials. We must all work together to complete the circle of science to clinical application.

My advice to individuals getting involved in the advocacy movement would be, never give up. Sometimes this whole advocacy journey is frustrating. Time is our worst enemy when living with a chronic and fatal disease. We want and need things to happen right away because delays are devastating. I would tell people to keep going and don't give up no matter how frustrating it may get. If you think that something you are advocating for is a long shot, if you feel like the chance of a project's success is small, don't give up and still show up. We never know what is going to happen. We also need to understand how powerful our stories and voices are. We need to use them and fight and show up and never give up. The future generations are depending on the change we begin today.

What does this award means to you and the grassroots movement you represent?

It is a great honor to be appreciated and acknowledged for what we are doing. We often just keep going, not knowing if anyone truly sees what we are doing. We at Help 4 HD International are driven to make change happen for our families, our entire Huntington's community, and the next generations to come. We are focused to turn the ship of despair around, pointed to the true north that we call regenerative medicine.

We thank Genetics Policy Institute for recognizing us this year at World Stem Cell Summit. We have always been an organization who supports regenerative medicine and focus much of our attention on programs to bring about education, information, and resources to help our community understand this science. We do believe in its potential to ease so much suffering in our community and others. Being recognized at this great institution, World Stem Cell Summit, is a great honor to all of us at Help 4 HD International. This kind of recognition just inspires us even more to push forward and keep doing what we do best, educating the world about Huntington's disease.

I would like to finish with this thought. I have been asked a lot lately if I am too hopeful when it comes to this science. If the trial my husband is in doesn't work with all the hope I have put into it, would I be disappointed? This is my answer to that question: We live with Huntington's disease, we live with disappointment every day. We are educated people who understand that these potential new therapies and treatments are just that—POTENTIAL. We can handle the disappointment if the science doesn't work. The one disappointment we cannot handle though is if no one tries. If no one tries to save our loved ones, that would be the biggest disappointment. I am thankful to all the brilliant scientists in the regenerative medicine field for trying.