

Going Public to Help Others with Huntington's Disease

Webcast

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Katie Moser

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Introduction

Andrew Schorr:

Andrew Schorr reporting from the American Academy of Neurology meeting in Seattle this year in 2009. This is where there's a discussion of neurologic conditions. People come from around the world; thousands of researchers, neurologists, neuropathologists; and all sorts of people trying to help folks who are affected by serious conditions.

Katie's Story

Andrew Schorr:

One of the conditions that's been so elusive has been Huntington's disease as people have a genetic abnormality that may run in their family, and one person affected that way who is actually here at the conference is 27-year-old Katie Moser from New York City. Katie, Huntington's does run in your family. How many people do you know are affected?

Katie:

In my family? There are approximately five people affected.

Andrew Schorr:

Okay, and that includes your grandfather and your mother and then when there was the test you decided to eventually be tested about four years ago, a genetic test. That took a lot of courage to want to know. You had no symptoms, but you knew your mother was affected, your grandfather, other older relatives, and the test showed you were positive.

Katie:

Yes.

Andrew Schorr:

Okay, and in Huntington's we talk about these sort of CAG, or C-A-G, repeats and that's some indication maybe of the development of the illness, and the repeats for you for people who are knowledgeable was how many repeats?

Katie:

I had 44 repeats.

Andrew Schorr:

Okay, and was that seen to be a lot?

Katie:

It's...

Andrew Schorr:

Sort of a moderate number?

Katie:

It is. There are a lot of mutations that can happen.

Andrew Schorr:

Right, and you have no symptoms at this point?

Katie:

No.

Andrew Schorr:

Now you took this step to be tested with no symptoms and also no federal protection at that point for genetic information. Why did you do it?

Katie:

I wanted know. I wanted to be able to live my life differently. In my family growing up Huntington's disease was a secret. I wanted to know. I wanted to be able to prepare for it both physically and mentally, financially, prepare my friends, potentially my children that someday if I had the gene I could have the disease.

Andrew Schorr:

We did an interview also from this conference with Dr. Rajeev Kumar who's a noted expert in the field, and he really felt it could help people in planning their lives. It seems like you would agree.

Katie:

Yes, I mean I kind of, you know, I know more of what I want to do with my future. I don't spend as much time making decision. I kind of just act on what I want.

Andrew Schorr:

Now you went public in a "New York Times" article in 2007, and that took a lot of courage I would say. I'm sure people have told you that.

Katie:

It was a long process. She interviewed me for a year, and then when the article finally came out it was a little shocking at first, but after I understood why I did it because other people read it and then they felt connected to somebody and felt part of a community.

Andrew Schorr:

Right, and there have been other programs you've been on; BBC and "The View," and much wider publicity as sort of, if you will, really an example of a patient advocate where we don't have a cure for the illness, and we don't have a way to at this point understand if we can slow the progression. We have one now approved medication for some of the symptoms that can develop in people, and actually you decided to go to work as far as an advocacy manager for that company. Why did you do that? Did you just feel that this was yet another platform to help speak out for patients and families?

Katie:

Yes, I wanted to create awareness, educate the public about Huntington's disease, and I feel the company is committed to the HD population.

Andrew Schorr:

Yes and this has been sort of an underserved population. As you said in your family it was a secret. Up until the fall there were no approved medicines at all right?

Katie:

Yes.

Andrew Schorr:

And so now we have one. We've heard from Dr. Kumar in another interview on Patient Power that there are a lot of trials going on. So what would you say to families where this has been a secret? Do you feel they should confront it, and what's your view of testing? Testing is now available; what's your view of people testing and also participating in trials?

Katie:

Testing is a very individual decision.

Andrew Schorr:

It's very personal.

Katie:

Yes, I mean, I'm not a doctor, I'm not a genetic counselor, but if someone were thinking about testing it would be a good idea for the first step to get in touch with maybe the Huntington's Disease Society of America, one of their Centers of Excellence, and talk to the genetic counselor or the doctor there or a social worker. You can talk about testing and find someone that they feel comfortable with.

Andrew Schorr:

Yes you sort of have to get your mind around the idea of testing and then the idea is what would you do with the information?

Katie:

Yes, what would you do with the information if you found out that you have the genetic mutation, but also it's a life changing event even if you test and you find out that you do not have the genetic mutation? Once you find out this information there's no turning back, so really thinking through what would you do, what are your plans?

Andrew Schorr:

As you said, it's life changing even finding out that you do not because there may be another family member where it is positive.

Katie:

Yes.

Andrew Schorr:

Your sibling for example or someone in the family they might be positive, you might be negative, or the reverse.

Katie:

Right, and you question why me or why not me.

Getting Connected in the HD Community

Andrew Schorr:

Or why not me, right. Lots of questions. So now you're involved a company that has one product, and you're here at the neurology meeting where there's discussion. Dr. Kumar was saying he's encouraged. He feels there's a tempo picking up in Huntington's. Do you have a sense of that?

Katie:

I think there's a lot of hope. There seems to be a lot more going on now. You know getting a drug approved by the FDA after 30 years of trying to work on that it finally puts Huntington's disease on the radar, and it gives a lot of people hope and the motivation to move forward and see what could we do next.

Andrew Schorr:

You know, I'm a fan of "House, M.D." I don't know if you watch it, but Dr. Thirteen, one of the characters on it, has Huntington's, and one of the earlier episodes they had her in a clinical trial. What's your thought? Have you thought of being in a clinical trial or having your ear to the ground related to research to see could this help improve your own situation?

Katie:

I'm active in clinical trials as long as I can qualify for them. I'm always looking out for what's coming down the pipeline that I might be able to get involved in because it doesn't just affect me. It affects my family, it affects my friends, it affects my whole HD community.

Andrew Schorr:

I was going to talk about the HD community. People need to know now that they're not alone, not only that they're not alone probably in their family if the secret comes out and is discussed honestly, but also that there are other families throughout the world really trying to deal with it and that you can work together with the research community, the clinical community, and the Centers of Excellence to try to move things forward.

Katie:

There's a great sense of community once you're connected into the Huntington's disease. There's the Huntington's Disease Society of America every year has an annual convention, and it's less like a convention and more like a family reunion. We get together once a year and we see people, we find out what's going on in different areas of the country, and even what's going on in different areas of the world because all of these researchers are all working together.

Andrew Schorr:

Fortunately they're working together, and that's a good thing. So how do you approach every day? You had the test, you know it's within you as far as the repeats, and you don't know when or if even another shoe will drop or how it will affect you. How do you approach every day?

Katie:

I just, I wake up, I figure out what I have to do, I mean, there are days where I mean everything will just pile on, you know like the straw that broke the camel's back, and I'll just break down and feel like why am I doing this; what really do I do next? But then I think of my friends that are also affected. I have friends that have juvenile onset who are already far progressed into the disease and are teenagers. You know I think of them, and that's who I do it for.

Andrew Schorr:

That propels you.

Katie:

Yes.

Andrew Schorr:

And family members of course you know and you've been in that situation. We should also mention that prior to working with a pharmaceutical company you were an occupational therapist working with people who were in a center being treated for Huntington's right? So you've seen it a lot first hand.

Katie:

Yes.

Andrew Schorr:

And you know you want to make a difference. Well, you're certainly to be congratulated Katie Moser really in what you do. It's taken a lot of courage to talk about it, but every day you're fueled with this mission, and I want to thank you. As a patient advocate really my experience is in cancer, but I can imagine families touched by it and you personally that I know you can make a difference. You're a young woman, so I wish you a lot of success in what you do. Thank you for being with us on Patient Power.

Katie:

Thank you for having me.

Andrew Schorr:

All the best Katie Moser. Andrew Schorr reporting from the American Academy of Neurology talking about Huntington's and really hope for a brighter future. As always, knowledge can be the best medicine of all. Thanks for joining us.

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