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Fathoming Huntington's disease, genetic testing and the biotechnological era in an academic setting

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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FRIDAY, MAY 02, 2014

Fathoming Huntington's disease, genetic testing and the biotechnological era in an academic setting

The decision to undergo genetic testing for an inherited, untreatable disease carries the risk of a devastating, life-transforming result. We in the Huntington's disease community know all too well the medical and social consequences of carrying the genetic mutation for this neurological condition, which produces uncontrollable movements, dementia, and mood and psychiatric disorders.

At the same time, testing positive for a genetic disorder can potentially provide an individual with sufficient advance warning to enable informed decisions regarding planning a family, finances, insurance coverage, career, and other key matters.

I've reflected frequently on the perils, benefits, and ethical challenges of genetic testing. In fewer than five years, my family faced three tests: my mother's positive test (and diagnosis) for HD in 1995, my positive test in 1999, and our daughter's negative test in the womb in 2000. I have discussed genetic testing in many articles in this blog as well as in the nearly dozen speeches I have made on HD in the past four years.

I prepared practically all of these written and oral accounts for audiences mainly familiar with HD and the issues surrounding genetic testing. Testing was always just one topic among many covered.

As poignant as ever

Recently I was prompted to ponder genetic testing again, but in a different format and setting. At the invitation of Nazin Sedehi, a senior at the [University of San Diego](#) (USD), I participated in a video on HD and my family's experiences with genetic testing.

After exiting the "HD closet" in late 2012 with the publication of an article in *The Chronicle of Higher Education*, USD placed a [feature story](#) and photos of me and my family on its website.

Now, at Sedehi's behest, I did an interview for two websites aimed at helping a general audience explore the dilemmas of genetic testing and other bioethical challenges.

Sedehi conducted the interview with the benefit of her studies as a pre-med interdisciplinary humanities major. I was distinctly the *subject* of Sedehi's research. The interview had a decidedly *academic* purpose in the broadest, most positive sense of the word: gathering, reflecting upon, and disseminating critical knowledge.

For the first time in an oral presentation, I focused almost exclusively on genetic testing.

HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
[HDSA Orange County \(CA\) Affiliate](#)
[HD Free with PGD!](#)
[Stanford HOPES](#)
[Earth Source CoQ10, Inc.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

Despite having touched often on this topic, it felt as poignant as ever to reflect on it again.

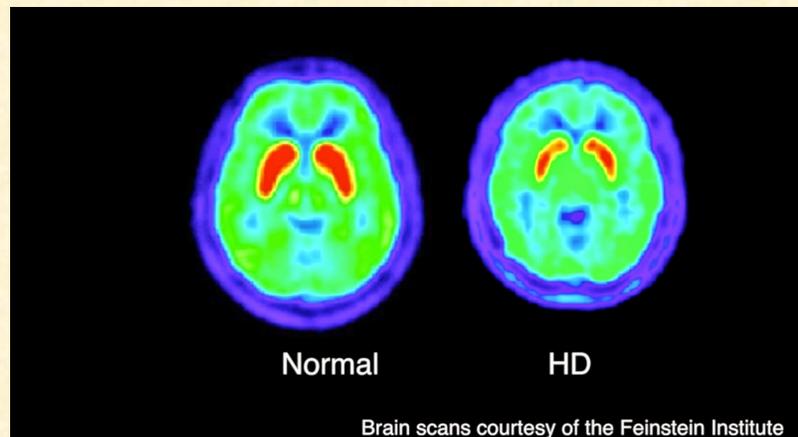
'You can't kill the gene'

I met Sedehi after reaching out to her and others at USD who last year set up a new student-designed website called Genetics Generation. The site aims to provide impartial information about genetics-based technologies and engage the general public regarding genetics and ethics.

The interview took place in my office at USD, where I have taught since 1993 and chaired the Department of History since 2009. Sedehi produced the video for an independent study supervised by Laura Rivard, Ph.D., an adjunct professor in the USD Department of Biology, with the purpose of generating content for the student-run site and Dr. Rivard's Genetics Generation blog at Nature Education's Scitable online teaching/learning portal.

"You know, you can't just extirpate this thing from your body," I state at the start of the video, underscoring the genetic nature of HD. "It's not like a virus that you can hope goes away with time if you take some orange juice, and the cold virus goes away. It's not like a bacteria, which you can treat with an antibiotic."

I speak as the juxtaposed images of a normal brain and a shrunken HD brain fill the screen.



A scene from the video comparing a normal with an HD-affected brain

"It's not even like cancer," I continue. "In cancer there's chemotherapy, there's radiation. You can kill the cancer cells. But you can't kill the huntingtin gene."

Sedehi cuts to my response to the question about my reason for getting tested. I explain that I wanted to get tested "immediately" after learning of my mother's diagnosis. However, on the advice of people familiar with the social risks of genetic testing, I postponed my decision.

Ultimately, I decided to get tested.

"It would be a way for me to fight back," I declare. "Knowledge is power, and having that knowledge would enable me to care for myself in the best way possible, as a way to avoid the symptoms of the disease."

Our most difficult experience

Then the interview tackles the most difficult issue my wife and I faced: the testing of our daughter.

“We knew that because I had tested positive for the disease, the potential child had a 50-50 chance of inheriting the mutation,” I say. “We also knew that when a father passes on the disease, he in some instances can pass it on in a far worse form. She was tested in the womb.”

I note that this was before the arrival of preimplantation genetic diagnosis, which couples today use to screen embryos for the HD mutation.

“The happiest day of our lives was learning that she had tested negative for the Huntington’s disease mutation,” I state, adding, however, that the “entire experience was certainly one of the most difficult, if not *the* most difficult, experience my wife and I went through together.”

No regrets, but a changed life

When Sedehi asks if I ever wish I hadn’t been tested, I respond that I have no regrets. I fantasize about a treatment that would free me and the rest of the community from the scourge of HD.

At the same time, I recognize that HD has profoundly changed my family’s life.

“Life’s not just about Huntington’s disease, but it really did change the way we looked at life,” I recall. “It changed the way we think about money, about career, about whether we should move, about the number of children we should have, whether we can buy a retirement home in South America. ... It really made us much more cautious in planning for the future.”

Sedehi wants to know what comes to mind when I hear the words “Huntington’s disease.” I respond instantly: my mother and her utter dependence on my father and other caregivers.

Families of HD people witness two deaths, I add.

“The first death is when the person loses a large part of his or her personality, and cannot talk any more, cannot communicate,” I explain. “It’s as if you’ve lost that person already. The second death is when they die the physical, final death.”

Germinating beneficial ideas

You can read Sedehi and Dr. Rivard’s introduction, watch the video, and participate in an online discussion by [clicking here](#). You can also watch the video below.



Huntington's Disease Interview with Dr. Kenneth Serbin

from **Know Genetics**

11:14

[Huntington's Disease Interview with Dr. Kenneth Serbin from Know Genetics on Vimeo.](#)

The connections to Sedehi and Dr. Rivard mesh with my HD advocacy and the concomitant expansion of my scholarly research into the history of science, technology, and medicine ([click here](#) to read more).

Through our joint efforts, we can help raise awareness about the difficult challenges, as well as the great potential for medical breakthroughs, of the biotechnological era.

Our collaboration reflects the trend towards what academics refer to as “interdisciplinary” research and teaching, where professors from seemingly disparate fields pool knowledge and differing perspectives to understand problems.



Dr. Laura Rivard (photo from Genetics Generation website)

(In a similar vein, on April 3 USD sponsored a well-attended interdisciplinary panel discussion on ethics and genetic testing, with a focus on the [highly controversial](#) direct-to-consumer genetic testing service [23andMe](#). Dr. Rivard organized the event. I plan to write more about it in a future article.)

Ultimately, the interdisciplinary approach can and should seek to *solve* problems – in this case, the dilemmas of genetic testing and the dire need for treatments for neurological disorders that strain millions of families and the nation's caregiving system.

Dr. Rivard's efforts embody the capacity of academic institutions to teach and reflect. Though some criticize higher education and especially the liberal arts for their purported ineffectiveness in preparing young people for the workplace and life, we should recall that the germination of ideas in universities produces numerous benefits for society.

Posted by [Gene Veritas](#) at [12:12 AM](#)      

Labels: [academic](#) , [biotechnology](#) , [genetic testing](#) , [Genetics Generation](#) , [history](#) , [Huntington's disease](#) , [interdisciplinary](#) , [Laura Rivard](#) , [Nazin Sedehi](#) , [negative test](#) , [positive test](#) , [Scitable](#) , [University of San Diego](#)

2 comments:



Unknown said...

Once again we thank you for so eloquently sharing you Huntington's story.

[4:01 AM, May 02, 2014](#)

Anonymous said...

Exactly what I feel but in a (much!) more eloquent & elegant way.

Albert Counet, Waterloo Belgium

[4:27 AM, May 08, 2014](#)

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