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The end of fear and exclusion: informing my health insurance plan about the risk of Huntington's disease

Kenneth P. Serbin
University of San Diego

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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WEDNESDAY, OCTOBER 16, 2013

The end of fear and exclusion: informing my health insurance plan about the risk of Huntington's disease

In my nearly two-decade journey with Huntington's disease, I hid my at-risk status not just from nearly all but my closest confidantes, but also from my health plan.

My warily guarded secret exemplifies the deep-seated fears many in the HD community have about denial or loss of insurance coverage. I regularly read or hear about untested at-risk individuals or gene carriers who worry about this issue.

To protect myself from losing coverage in the event of a job change or another of life's unforeseen challenges, I instead have relied all these years on the Huntington's disease clinic at the University of California, San Diego (UCSD) hospital. There I have paid out of my own pocket for consultations and established a medical record completely separate from all my other health records.

As a university professor, I have enjoyed the benefits of group coverage, from which it is at least theoretically more difficult to exclude people who have genetic and/or pre-existing conditions. Nevertheless, I have always erred on the side of absolute security, never knowing what life might bring, especially in the period before I obtained tenure and therefore had some but not total job security.

Over the past two months, however, I have initiated the process of informing my health maintenance organization (HMO) that I carry the mutation for HD.

"This is all so ironic!" I said the other day to my wife Regina, the very first person I had told about HD after learning the day after Christmas 1995 of my mother's diagnosis and my own risk for inheriting the mutation. "I'm now doing what I've avoided all these years."

Fearing exclusion, I had not resorted to the very system supposedly designed to help me.

Feeling liberated – again

Once again – as I did in definitively exiting the terrible and lonely "HD closet" on November 4 of last year – I feel liberated.

I began to apprise my HMO of HD on August 9 with a visit to my primary care doctor, who has treated me for about six years and with whom I have developed a comfortable and cordial relationship.

I had made the appointment to address a benign skin problem and other minor issues. Finally, at the end of my list of concerns, I came to the most important item. I had rehearsed the scenario in my mind many times. I decided to go right to the point.

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

Almost matter-of-factly, yet with the feeling of a huge wall coming down from around me, I told him that my mother had died of Huntington's disease and that I had tested positive.

The doctor maintained his usual professional calm. At first, I couldn't tell whether HD represented for him just another item on my list or something really significant.

From the ensuing conversation, I was reassured to learn that he clearly knew about Huntington's disease. He also knew the work of the UCSD HD clinic. In fact, he had previously worked several years in another sector at UCSD.

I handed the doctor a printout of my article "Racing Against the Genetic Clock," published last November in *The Chronicle of Higher Education*. He promised to read it soon.

My article, written "to combat the stigma and fear surrounding Huntington's and other neurological disorders" and "to help galvanize support for increased brain research," revealed my HD status to the many readers of the *Chronicle* print edition and website and, significantly, to my professional colleagues in the fields of history and Latin American studies.

It also set the stage for informing my doctors about HD.

"I truly enjoyed reading (your) article during my lunch today and plan to keep it around when I have visitors in the office for them to review," my doctor wrote in an e-mail later that day.

On a subsequent visit, he showed me the file where he kept my article and others about patients' responses to challenging health conditions.

Visiting the neurologist

With a referral from my primary care physician, I then scheduled an appointment with one of the HMO's neurologists in order to establish a relationship with a specialist in disorders such as HD and obtain a baseline reading of my neurological health.

A few days before the appointment, I faxed her a copy of "Racing Against the Genetic Clock" to provide her a detailed picture of my family's history of HD.

At my October 7 consultation, the doctor thoroughly examined me for signs of classic HD symptoms such as difficulties with memory and the inability to walk along a straight line.

As in previous consultations at the UCSD clinic, the doctor saw no evidence of symptoms.

We discussed the various psychiatric medications that I take to help remain psychologically stable and at least one of which might protect brain cells, according to one of the physicians at the HD clinic.

I added that I would schedule an appointment with my HMO psychiatrist to help in my struggle to deal with both the psychological stress of living at risk and to do all that is medically possible to protect my brain from a disorder for which there is no proven effective treatment.

The neurologist and I also discussed the supplements I take, such as creatine and coenzyme Q-10. She immediately arranged for blood tests to check for any deleterious effects the supplements might have on my kidney and liver. To obtain this same information in the past, I had always gotten

these routine tests by requesting a check on the effects of the psychiatric mediations, but without mentioning that I took supplements.

Unfortunately, my HMO will not pay for these supplements, which cost close to $2,000 per year. The health establishment does not recognize them as valid for attacking HD, as they're in the experimental stage: several such substances have undergone study in mice and even humans.

(Similarly, for more than a decade I have consulted with a private psychotherapist who knows about my HD status but whose services are not covered by any health plan or insurance.)

At the end of the consultation, I welled up with emotion as I thanked the doctor and explained to her how meaningful it was for me to have spoken about HD to a neurologist within my health plan.

Like my primary care doctor, she maintained a professional demeanor. However, I was very happy that she agreed to receive e-mail updates of this blog.

Moving beyond the political and social drama

As I have so far felt vindicated in my decision to go fully public about HD and meld my professional and personal lives with my advocacy, so do I now feel extremely relieved and hopeful about integrating HD care into my overall health care.

By bringing these and other professionals into the HD loop, I am strengthening the team that I will need to manage the inevitable symptoms of the disease.

At the same time, I know that I stand on the edge of history with many other Americans who for the first time are testing the political and social waters in the wake of the passage of the Genetic Information Nondiscrimination Act, signed into law in 2009, as well as Obamacare.

In speaking to people from countries such as Canada and England, where public health systems allow (at least in theory) greater openness about genetic conditions, I recognize how long and difficult the path to medical transparency has been for me individually and for the nation as a whole.

It all seems like such a needless drama, which we have relived again with a U.S. government shutdown resulting from the political impasse over the implementation of Obamacare.

We in the HD community have truly suffered the brunt of exclusion, not only from proper health care, but also long-term nursing.

As I stated in my *Chronicle* article, "As knowledge increases about numerous other health risks, medical ethics must undergo profound revision, and a genetic-rights movement must arise. To borrow one scholar's phrase, disease-gene carriers like me are 'moral pioneers' on the genetic frontier."

During these past few weeks, I have felt very strongly that pioneering aspect of my life. I'm thrilled now to have my HMO joining me on this journey.

(Next time: Huntington's disease and bioethics.)

Posted by Gene Veritas at 1:43 PM

Labels: clinic , discrimination , exclusion , fear , gene carrier , gene-positive , genetic , HD closet , health plan , Huntington's disease , insurance , mother , neurologist , Obamacare , stigma , UCSD

1 comment:

Anonymous said...

Well done forcoming out of the closet. HD will never be dealt with effectively until those affected by it,the organisations and professionals dealing with it stop supporting the secrecy strrounding it and increase the responsability of those at risk from passing it on. Wider community understanding needs to exist of the impact of this disease, both for appropriate support and informed decision making of potential spouses.The fact that there are any juvenile huntingdon's disease victims in current times indicates how fearful, avoidant and even selfish emotions can prevail and keep harming. That's despite existing solutions of revention from diagnistic testing from 1993 and pre-implantation options since 2000. If those still doomed to face HD want cures, or at least better symptom control and better social support, they need to get out of the closet while they are healthy, their families still in good shape to contribute most effectively wether to research results or HD causes.

1:08 AM, January 25, 2014

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