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At Risk for Huntington's Disease

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## An experiment and a death

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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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## HD Links

[Huntington's Disease Society of America](#)  
[International Huntington Association](#)

SATURDAY, OCTOBER 03, 2009

## An experiment and a death

On September 25, as I went through two different MRI machines and a battery of psychological tests aimed at detecting changes in my brain caused by Huntington's disease, an e-mail arrived in my inbox informing me that my father had died.

[This Huntington's disease warrior](#), who lovingly cared for my mother for fifteen years before she died of the disease in 2006, gave up his last breath less than a week before his 82nd birthday and just two days before what would have been his and my mother's 51st wedding anniversary.

That day and the hours since have been marked with all of the agony and irony flowing from my mother's illness, my own gene-positive status for HD, and my extended family's difficulties in facing up to HD's hard reality.

The day of tests and experiments had exhausted me emotionally and, when I turned on my computer at home, the news of my father's passing made me downright depressed and anxious.

## Painful memories

My father started giving up on life about a year after my mother's death, and after going into an assisted living facility a year ago, his mind and body steadily declined to where he had an apparent stroke in April. Several weeks ago he broke his leg. At the nursing home where he spent his final days he refused to eat and drank very little liquid. The aides had to use a lift to move him back and forth between his bed and a chair. He hardly spoke.

So his death was not surprising. In fact, I welcomed it as an end to his physical and emotional suffering.

But his demise reminded me poignantly of my mother's own decline, and the circumstances of his death and its aftermath are like a knife in my heart.

The long string of events that led to my receiving the communication of my father's death not from a concerned family member but objectively and coldly in a lawyer's e-mail leads back primarily to Huntington's disease.

## HD and family disputes

A year ago I wrote about how my sister and her family and also my mother's brother and his family remain in deep denial about Huntington's ([click here to read more](#)). My mother's condition, my insistence on optimal care for her, my activism in the Huntington's Disease Society of America, and my gene-positive status all made them deeply uncomfortable and angry.

Over the years my sister has gone back on a promise of lodging at her

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[Huntington's Disease Lighthouse](#)  
[Hereditary Disease Foundation](#)  
[Huntington's Disease Advocacy Center](#)  
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[Heather's Huntington's Disease Page](#)

home when I went to visit her and my parents back in the Midwest, angrily hung up the phone on several occasions, and refused to see me or simply ignored me when I was in town.

Last year she ignored several phone messages about my father, then strangely called to holler at me. "I can't talk to you!" she said in an exasperated and definitive tone and then hung up yet again.

Her strange behavior reminded me of my mother's outbursts during the early stages of Huntington's. She is untested, as are her three grown sons. To my knowledge she and her family have never had a conversation about HD.

### Growing anger

Whether she has HD or not, I had to find a way to help my father get placed in a proper facility. At one point, if I had not intervened in the absence of initiative from my sister, the local adult protective services agency would have simply taken my dad away without any input from the family.

So now I asked my father's lawyer to assist her in finding a facility. Because of her inability to communicate with me and her husband's and oldest son's use of vulgar language when I tried to reason with them, I also asked the lawyer to serve as an intermediary.

My anger over the past year has grown. When I visited my father in March, I did not see my sister.

After my sister did not instruct the lawyer to call me about my father's death, I became deeply upset.

### An inexcusable lack of compassion

A couple hours after I opened the e-mail, my father's sister called to talk about my dad. Then she dropped a bombshell: the wake would be in less than 48 hours and the funeral in less than 72. The obituary, the destination of donations, the Mass, the burial – my sister decided everything without any concern about my wishes, without any message to the lawyer or any relative.

This was the polar opposite of the situation after my mother's death, when the funeral home held the body several days so that my family and I could buy tickets and make other arrangements in preparation for the cross-country flight. Back then my sister and I were talking, because, during a previous visit back home, I had called her to insist that we work together to find a nursing home for my mother.

After my father's death I wanted to call the funeral home and the church to postpone things, but my wife pointed out that my sister would never agree. The situation would become only worse. We agreed that it was a bad idea to attend the funeral.

I asked the lawyer to transmit a brief message to my sister, in which I stated, "Your attitude and actions are insulting and inexcusable. You lack compassion."

### A California dreamer

At the time of the wake, I took my dog for a long walk and reflected on my father's life and his meaning to me.

His heart was always in California. He had actually moved the family here for a couple of weeks in July 1966, but then rushed us back to the Midwest because he was homesick. He loved visiting us here and always spoke

longingly of California as a kind of paradise, especially during the long and harsh Midwestern winters.

My sister had his body, but I had his spirit, I told a friend. It's as if he's hovering above me as I enjoy the hot weather of the first days of the Southern California fall.

The past few days I have been going through slides that he took over the years. The California trips figure prominently in the collection. I recalled with my wife how we had tried to convince him to move out here with my mom in the late 1990s, before the housing bubble, in part so that we could arrange for better care for her. He became very excited but ultimately got scared of too much change in his life, even if that change was for the better.

### **A senseless, painful rift**

Going through those slides and also pictures from my own collection, I also reflected a lot on my relationship with my sister. I found several images where I am having a rollickingly great time with her sons, with her and her husband looking on. One photo was from New Year's Eve in 1989, when I babysat the three of them so that she and her husband could attend a party.

I remembered long and meaningful conversations we had in her home. In fact, my parents used to get angry and jealous because I would spend more time at her house than at theirs.

Then, about five or six years ago, in the midst of our family's increasing difficulties with my mother's condition, my sister told me on the phone, "You're not really a brother."

How, I asked myself, could this senseless, painful rift occur?

How could I be denied a part in my own father's funeral?

### **Touching raw nerves**

Undoubtedly part of the cause lays in differences in personality and life experience, but these are things that all families experience. Exploring them all would require a book.

Although my sister clearly lacks sensitivity, it only really became noticeable after Huntington's disease appeared in our family.

Fear of HD brought out the most boorish, most ignorant kinds of behavior that I could imagine.

It also touched some very raw nerves.

My sister, who had wanted a daughter, became resentful and angry when my wife and I had ours. Most important, our child was free of HD, because we had her tested in the womb.

I became the family expert on HD and urged my father and my sister to take measures to help my mother, but my sister and her family always saw my efforts to help my parents as an intrusion that upset their comfortable cocoon of denial.

### **The impetus for a cure**

While the final social consequence of HD for my sister is to sever all familial ties, I forged ahead in helping the effort to find a cure.

As I wrote in two previous entries ([click here](#) to read more, and also [here](#)), finding the cure means affected and gene-positive individuals need to

participate in experiments.

CHDI Foundation, Inc., the world's biggest organization aimed at finding treatments and a cure for HD, is studying the progression of the disease in the brains of non-symptomatic gene-positive individuals like me. We are crucial in this experiment, because symptomatic individuals, who have chorea (uncontrollable movements), would move during the scans and therefore compromise the images. In fact, in the first scan the researcher, psychology Ph.D. student Ian Greenhouse, placed my head in a head clamp to prevent even the slightest movement.

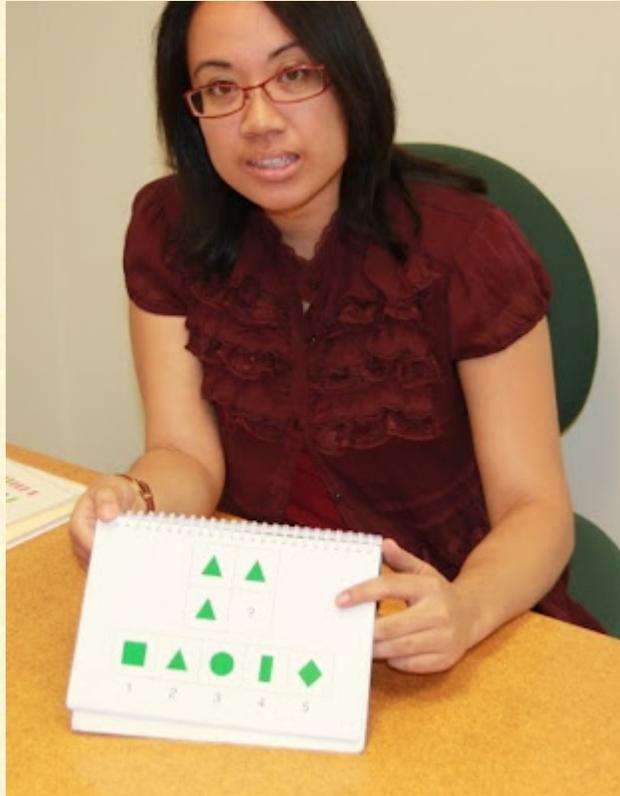


*Ian Greenhouse explains the use of the structural MRI machine in the experiment (photo by Gene Veritas).*

The researchers hope to discover if it's possible to use MRI scans to observe what happens in the earliest stages of the disease, said Ian, who previously worked at Harvard University and helped to establish an MRI center at the University of California, San Francisco. He now works in a cognitive neuroscience laboratory at the University of California, San Diego (UCSD). These early signals, he explained, could help predict when and how a patient would develop more serious symptoms. This data could help in the development and administration of drugs.

Last year I volunteered to take part in the experiment at its UCSD site, one of several CHDI is using. On September 25 I returned for the one-year follow-up, which was necessary to trace the changes in the brain that may have occurred. In addition to the scans, I performed a battery of cognitive tests, answered a questionnaire about my health and Huntington's disease in my family, took a mood test, and gave blood. Some of this data will go to

COHORT, the Cooperative Huntington's Observational Research Trial sponsored by the international Huntington Study Group.



*UCSD researcher Melissa Generoso displays one of the cognitive tests I performed (photo by Gene Veritas).*

### **Predicting the weather**

The first scan, done in a structural MRI machine, included two parts: an anatomical scan and diffusion tensor imaging (DTI). The anatomical scan measured the amount of gray and white matter across my brain as well as cerebral spinal fluid. The DTI measured the strength of connectivity between different areas of the brain.

Afterwards Ian showed me my brain on computer – the brain I inherited from my HD-stricken mother and my father, the tireless, dedicated Huntington's warrior. Ian and the other researchers aren't allowed to comment to test subjects on what they see in the scans, and I wasn't really interested in hearing if my brain had been damaged.

In the second, functional MRI machine I performed two experiments, both while holding a control box with two buttons. In the first experiment, the weather prediction paradigm, I had to determine whether it would be rainy or sunny based on symbols flashed on a screen. After I pressed one of the buttons, the program revealed the correct response. The symbols themselves – for example, a rectangle – did not signify anything about the weather, so I had to make my predictions based on trial and error.

The research team adopted the weather game because of the success scientists achieved with it in Parkinson's disease patients, explained Sarah Sheldon, the coordinator of the CHDI-UCSD project and a research associate who performed the second set of scans on my brain. In the Parkinson's experiment, researchers compared their ability to predict the weather to that of amnesia patients. The amnesia patients learned well, because the part of the brain used for this procedural learning was independent of conscious memory, Sarah said. But, even though they had their full memories, the Parkinson's patients had difficulties predicting.

For this task, the area of the brain affected in Parkinson's, the frontal striatal basal neural circuitry, is the same as in HD, Sarah explained.



*Sarah Sheldon, coordinator of the MRI research project, stands at the entrance to the UCSD center where she ran one of my brain scans (photo by Gene Veritas).*

### **Threats to white and gray matter**

In the second functional MRI experiment I had to press the left or right button according to the indication flashed on the screen. Sarah instructed me to respond as quickly as possible. If, however, I heard a beep, I was supposed to do nothing. The beeps came almost immediately after the visual signal. I had to comply with two imperatives: quickness of hand but also in the ability to hold back. Sarah called the latter "stop signal reaction time."

With this experiment, which is also used to assess people with brain lesions and attention deficit hyperactivity disorder, researchers hope to gain a better understanding of chorea. Chorea, of course, prevents people from inhibiting their movements, so people who are losing that ability would do poorly in the experiment.

According to Sarah, to date the researchers have observed that the HD test subjects' white matter (the filaments of the brain's network) is deteriorating more quickly than the gray matter (the cells). Thus they are hypothesizing that the network starts to go down first, later leading to the destruction of the structure, the cells.

Sarah noted, however, that the conclusions are only preliminary, as they

still need to evaluate the rest of the data, including the information from the cognitive and mood tests and questionnaires.

### A very long day

The stress of being reminded so extensively about my gene-positive status – as well as the exhilaration of assisting with critical research and meeting the young scientists who carry it out – caused me to want to tune out at the end of the day, especially because it was a Friday.

Little did I expect that my routine check of e-mail at the end of the afternoon would bring the devastating news of my father's death.

With all the anxiety in my life, my wife and I agreed that trying to confront my sister about his funeral or even simply attending it in such horrible circumstances was not worth the risk of greater emotional trauma. We both recalled how my father had suffered a heart attack at the age of 53 and how heart problems afflicted many other members of my family.

### My father's son

Then my wife had a brilliant idea: we would hold our own memorial service on Sunday, October 4, at our home. This would afford me the opportunity to grieve with our closest friends and my cousin and her family, who live in Los Angeles.

Planning the memorial, including the preparation of a photo presentation spanning my father's adult years, took practically all of my energies this past week. I have privately mourned, and I have quietly processed the meaning of his life for me and the monumental impact of Huntington's disease on our family.

The sadness is profound, a heartache that will never disappear. However, we will not focus on our loss, but celebrate what he gave to me and the world.

I am my father's son, and my dedication to the HD movement is ultimately a result of the life path he prepared for me. And the strength and courage I need to persevere will also well up in me because of the example he set in caring for my mother.

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Posted by [Gene Veritas](#) at [4:41 PM](#)



### 6 comments:

#### 🌀 Anonymous said...

Gene your father would be proud and I am sure he was with you on that warm day and he will be with you always. My sympathy to you and yours. Stay strong

[7:48 PM, October 03, 2009](#)

#### 🌀 Anonymous said...

Gene -- You are a warrior in your own right and the price you pay to go after this disease is an inspiration to us all. I grieve with you at this, another loss and continue to pray for you and your family. In many ways, perhaps your sister has become a casualty of war...unable to fight -- whether because of denial or disease...only time will tell.

[9:31 PM, October 03, 2009](#)

**☼ Anonymous said...**

Such a beautiful post! Thank you. My heart goes out to you and know that you and your family are in my prayers. You and your wife came up with a brilliant way to mourn your father under very difficult circumstances. May it be an example to other families of how to deal with denial and fractured family relationship.

And thank you also for the description of your day of testing. Hopefully it will encourage other gene positive individuals to take part in the testing.

You are a very brave soul and God has blessed you.

[6:03 AM, October 04, 2009](#)

**☼ Anonymous said...**

Gene, I am so sorry about your father's passing. I am also very saddened that your sister and her family would be so insensitive and selfish.

It is so heartbreaking to lose a parent but in your situation it is even more heartbreaking...not having your own sister to share the pain with and to even talk to about it. I feel so bad for you.

Thank God you have a wonderful wife and good friends.

Thank you so much for sharing about your MRI and other testing experiments. It is good to know what you are experiencing so that I can be prepared when I start participating in the experiments also.

By the way...it is awesome that you know your daughter is negative for HD. What a blessing that is.

Sincerely,

LP

[10:14 AM, October 04, 2009](#)

**☼ Anonymous said...**

Please accept my condolences to you and your family on the loss of your father. You are doing a great thing having your own private memorial service. It's too bad that your sister is so afraid of her potential future that she lashes out this way.

There's nothing you can do about her, stay strong for your battle. God bless you and yours.

[6:03 PM, October 05, 2009](#)

**☼ Anonymous said...**

I was just doing some research on HD when I came across your site. I was deeply moved by your latest post. I wanted to send my heartfelt condolences to you. I'm at risk and lost my father to HD this past summer. One of my brothers was just diagnosed earlier this week. I've known for some time that he

was symptomatic but he refused to seek help. So I'm actually very relieved that he has finally been diagnosed and is receiving care. It's always a relief when I come across someone else who is dealing with this devastating disease. There is so much denial, fear and anger surrounding it. Thank you for sharing your experiences.

10:31 PM, October 08, 2009

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