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Disease, denial, and support: the many kinds of family

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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.

MONDAY, SEPTEMBER 15, 2008

Disease, denial, and support: the many kinds of family

Huntington's disease, a cruel and fatal illness with no treatment or cure, triggers the best and worst in people's ways of facing adversity.

In my own extended family the different reactions to HD have brought me both the deepest emotional pain and the warmest feelings of human solidarity.

Something's wrong with Mom

In the late 1980s my mother started having strange emotional outbursts. When I visited home during the holidays in 1989, I heard my mother crying as she told a friend on the phone that she couldn't handle having me home, even though I hadn't seen her in more than a year. My father complained that they would dress for church or an evening out, only to have my mother insist at the last minute that they stay home. By 1992 her legs sometimes starting shaking uncontrollably at night. My father would hold them down in the bed for a while, but the shaking would not stop. At the time I did not know about these incidents, and my parents, probably thinking the shaking was not a serious problem, did not seek medical assistance.

I was living in another time zone, so I could not observe my mother's daily behavior. My sister, who lived around the corner from my parents, did not take any action, and, for a combination of reasons that included lack of knowledge about medical matters, she never commented to me about the changes in my mother.

Then, in early 1995, my parents came to spend two months with my wife and me. We immediately saw that something was wrong with Mom. She was depressed and would pout like an angry child. I took her to a bedroom and, with my father watching, gave her a neck and back massage to calm her down. I suspected (wrongly) that my mother's anti-depressant was causing a negative reaction or was at the wrong dosage.

I urged my father to take my mother to a specialist, and he finally did. They made the rounds to different doctors and heard diagnoses such as dystonia and chorea (but not specifically Huntington's chorea, as HD used to be called). Then a neurologist suspected Huntington's disease. In mid-1995, without my knowledge, my mother tested positive.

Ignoring the problem

Although my parents had learned that HD was a genetic disease and that my sister and I each had a 50-50 chance of inheriting it, they did not call or write with the diagnosis. (They never explained why. I can only speculate that at the time my parents didn't fully understand the disease, and, like lots of other members of my extended family, believed that ignoring the problem would make it disappear.) The day after Christmas I opened a

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GENE VERITAS

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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

holiday letter from my sister stating that she was relieved to finally learn the cause of my mother's problems.

I immediately called her and for the first time heard the phrase "Huntington's disease." In the space of a few minutes, the seemingly distant and certainly resolvable problems of my mother had become something very different. Not only did she face a monstrous future; so too, possibly, did my sister, her husband and three sons, my wife, and I.

Reacting to the trauma

I quickly became involved in the local support group of the Huntington's Disease Society of America (HDSA). But I did not react calmly. In a few months I went into a period of denial and irresponsible decision-making. I did not right myself until the spring of 1998, when I became an activist with the local chapter.

With each year my activism has grown exponentially, as I have recounted in so many entries in this blog. As my wife puts it, not a day passes that we don't think about Huntington's disease.

As I learned about the disease, I passed information along to my father and sister in the hopes that they would do everything possible to keep my mother as healthy as possible as we waited for a treatment or cure. My father cared for my mother until she went into a nursing home in August 2005. I deeply admired his love and devotion, but I became increasingly frustrated at his and my sister's inability and unwillingness to obtain therapies that might slow my mother's decline.

Unbearable possibilities

I was the family problem-solver and, whenever I went home, I mobilized the family to take necessary steps. However, living so far away, I was limited. And I could not force my father and sister to take my advice.

Aside from concerns about specific aspects of my mother's health, I had few conversations about HD with my father and practically none with my sister. I sent them publications and told them about dietary supplements and experimental drugs. Once, at the beginning of my HDSA advocacy, I convinced them to donate $300 each to a fundraiser. My father followed my suggestion to serve my mother blueberries and have her take a fish oil supplement. But we had no serious, sustained engagement about Huntington's.

Whereas I took the HD test in mid-1999 and have rigorously taken the supplements recommended by Huntington's Disease Drug Works (HDDW), my sister decided against testing. Because there is no effective treatment or cure, she would rather live without the devastation caused by a positive test and the long-term worry of wondering when symptoms would start. Many, many at-risk individuals take this path. For her, I believe, it's unbearable to consider the possibility of having inherited HD from my mother and perhaps having passed it on to her three sons.

My father and especially my sister have preferred total denial. Before a visit back home in 2001 my sister had agreed to allow me stay at her house so that I could save hotel money and would not have to see our deteriorating mother every minute of my time there. At the last minute she went back on her word. Distraught, I cancelled the trip.

During another trip home I called my sister to discuss the need for communication and family solidarity. She hung up on me. We did not see each other that visit.

Around that time my wife and I offered to buy her eldest son, a high-school student, a round-trip plane ticket to come visit us. My sister never responded.

My gene-positive status is a constant reminder to my sister and her family of the threat of HD. Our daughter, who tested negative in the womb, is a symbol of the peace of mind my sister must wish she could have for her own children.

No sympathy

After I revealed my positive test result to my sister and father, they did not respond: no sympathy card, no phone calls, no offers of help or solidarity. Not once did I hear the phrase: “I’m sorry that you tested positive.”

Only when my mother’s death became imminent did my sister express any sympathy. After I visited my mother in the nursing home in January 2006 and contemplated my possible future by looking into the genetic mirror, my sister said: “That must have been hard for you.”

Only about a year after my mother’s death did my father, watching me take HDDW supplements, recognize for the first time that I could be struck with HD.

Now that my mother is gone, my sister and I have had to focus on finding an assisted living facility for my father, who is going downhill rapidly. During July 4 week I took my eight-year-old daughter back home to visit her grandfather for what could be the last time. I hoped the trip would create a sense of family for my daughter and build family solidarity.

But the attempt at solidarity backfired. My brother-in-law refused to shake my hand and to greet my daughter, and my sister was visibly nervous throughout the visit.

In recent weeks I left my sister messages to call me about our father. She called me back once and, with her family egging her on in the background, she began an angry tirade, then hung up. When I tried to call back to calm her down and reason with her, my brother-in-law and oldest nephew angrily answered the phone and swore at me. When I started to raise the issue of HD, my brother-in-law laughed and hung up.

With no hope of effectively communicating with my sister and her family, I have turned over my part in the matter of my father’s care to a lawyer and asked him to serve as an intermediary between me and my sister.

HD all over again?

My sister’s strong reaction eerily reminded me of our mother’s outbursts at the start of her disease. My sister is 46, and it was in her late 40s that my mother perhaps began to show the first psychiatric symptoms. My wife and I wondered: could my sister be showing the first signs of HD?

In a farewell e-mail to one of my nephews, I asked whether my sister had ever sat down with him and his brothers, now adults, to discuss the possibility that they and their potential children could inherit HD. They know that their grandmother died of Huntington’s, but, following in the footsteps of their mother’s denial, they seem oblivious to its implications.

“Mental problems”

For all their denial and aggressive behavior, at least my sister and her family know what HD is. An uncle and aunt have displayed an even stranger, more perverse form of denial.

Ever since they learned about my mother’s illness, my mother’s older brother and his wife have completely hidden the fact of HD from their two children, their son-in-law and daughter-in-law, and, by extension, their five grandchildren. According to my aunt and uncle, my mother had “mental problems.” My aunt has always alleged that she needed to protect her family from having to worry about HD.

I have heard rumors over the years that my uncle would get tested, but I don’t know if he ever went through with it. He’s now in his mid-70s and probably does not have the disease.

My uncle is a successful small businessman. He lives in a fine home and always drives the latest cars. Whenever I tried to call him to ask for a donation to fight HD, he complained about all of the solicitations he was getting from HDSA and other causes. One time he gave $100. I later wrote a long letter explaining how the family had to rally together around my mother. I hinted that, as a successful businessman with many contacts, he could make a substantial donation and also play a leadership role in fundraising. I never heard back.

Over the years I became weary of hearing my aunt talk of the need to shield her children. She and my uncle rarely visited my mother throughout her illness. Only when she came close to death in the nursing home did they come to visit more frequently. Even then, my aunt could not get much beyond her concerns about protecting her immediate family.

However, when my mother died, my aunt and uncle had no choice but to reveal the truth. But they told only my cousins – not their spouses – about HD. Somehow they arranged for only my cousins, and not their families, to attend my mother’s funeral. I can only imagine what strange logic was used.

I never pressured my aunt and uncle to change their views or to reveal anything to their children. The fear and stigma of HD in this branch of the family seem like a page out of Alice Wexler’s new book on Huntington’s disease, which I recently reviewed (click ***here*** to read the review). HD had become such a huge taboo that I decided simply to live and let live.

A polar opposite

Another branch of the family has acted in a completely different way. From the start, my father’s brother and his family have demonstrated complete solidarity.

I hadn’t seen my cousin—my uncle and aunt’s eldest son—in some fifteen years. When I called him out of the blue in 1999 to seek a donation for my first HDSA fundraising event, he demonstrated that he had been completely informed of my mother’s illness. When I sheepishly asked if he could donate $300, he shot back: “How about $1,000?”

I opened up immediately to my cousin about my gene-positive status and got advice from him on insurance questions. Later, when HDSA sought to improve its advocacy program, my cousin used his connections in the legal profession to help out. When *The Washington Post* published an article about HD and my story in 2005, my cousin immediately ran out to buy extra copies of the newspaper for me (click ***here*** to read the article).

During my July 4 trip back home I visited my cousin’s home along with my daughter and my father. We talked about HD, my sister, and my father’s decline, but we also enjoyed many stories from the past. I don’t drink hard liquor, but my cousin showed me his collection of Scotch whiskeys and got me to try a few. It’s been decades since I’ve felt such family togetherness. I was thrilled that my daughter could experience such a warm reception from relatives. My cousin is a true leader in the family. I know I can count on him.

Building a new family

After my sister and her family yelled and swore at me on the phone, a feeling of deep gloom about humanity came over me. I wanted to write this entry immediately, but for several days I became emotionally paralyzed.

Sadly, it is the inability to overcome denial and the lack of solidarity that sometimes make HD families their own worst enemies. Rather than reaching out, these families hide.

How wonderful it would be if my sister and maternal uncle and their families could join our cause. But they operate with the belief that information is harmful. I operate with the hope that it can ultimately be liberating.

I cannot change their way of thinking. And although it confounds me, I do not judge them. Because they have never opened up about HD, it's impossible to fully understand their motives. I have to accept that each person deals with adversity uniquely. And as adversity goes, HD is extremely difficult. The bigger life's challenges, the greater the potential for rising to the occasion – or hiding in the sand. I truly hope that they do not have to face the scourge of a positive test result for Huntington's disease and all that it implies.

The good news is that I *can* focus on the positive side of the family in the person of my cousin and those around him. And *I* can be a force for greater openness by writing in this blog and continuing my work with HDSA.

And the gloom begins to dissipate even further when I think of all of the HDSA support group members, fellow activists, scientists, physicians, generous attendees at our fundraisers, and the virtual community of HD people and at-risk individuals with whom I communicate from around the world. They do care. Together we have built our own family.

Posted by Gene Veritas at 6:07 PM

6 comments:

Anonymous said...

Remember always that family is more than blood. You can choose the people you allow into your life and your daughter's. I am also at risk and choose not to be tested at this time. I am 40. I will probably test eventually for my children's knowledge. At this point, I feel that I am better prepared for a possibility, with all the research and information we have today, than my parents were prepared for a diagnosis in 1982.

6:15 AM, September 16, 2008

Anonymous said...

Thanks for your touching comments, Gene. I am a neurologist and a neuroscientist working on HD, and it is voices like your that keep up motivated in the fight. My goal is to put myself out of business. I am constantly amazed by the grace of individuals who come from HD families. I have people who work in my lab read your blog. There simply is no better way to motivate them

7:28 PM, October 08, 2008

Anonymous said...

This comment has been removed by a blog administrator.

1:19 AM, October 09, 2008

Anonymous said...

this is a tough story to read, i hope you can find some peace. it sounds like much of your family is lost to you, what a shame

6:16 AM, September 18, 2009

Anonymous said...

Thank you so much for your blog. I recently found out someone I really care about is at risk for HD. I hope and pray the wonderful people working for a cure find one within our next decade.
You are in my thoughts and prayers.

5:56 PM, December 01, 2009

Anonymous said...

This is very hard for me to read. My partners mother has HD. All four of her children have yet to be tested, my boyfriend is the eldest. His father is no longer with us as he committed suicide. We went to celebrate her birthday and I was just appalled at the way her family ignored her and acted so inconvenienced. My partners step father even leaned over to his half brother in the car and said "just ignore her" as if she wasn't there. I couldn't believe it. I think my boyfriends denial allows him to disconnect and having his younger half brother (by 10 years) around during visits allows him to disconnect from the reality that his mom is sick,and he may be too. I couldn't sleep last night and my stomach has been in knots all day. I want to shake him and scream at him! Pay attention to your mother while she is here! You could be in her shoes one day! Imagine if I spoke about you as if you aren't here!

Im at a lose. I don't run the risk of inheriting HD, however I am in my early 30s and think about a family from time to time. My boyfriend is not a coward, his ability to deny this has a profound affect on me and our future together.

Im lost and don't know what to do. I know it pains him deep down yet can't address it with him until he comes to tern with everything...

2:21 PM, September 02, 2016

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