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The quandary of denial in the Huntington's disease community (Part I)

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Serbin, Kenneth P., "The quandary of denial in the Huntington's disease community (Part I)" (2012). *At Risk for Huntington's Disease*. 121.

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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.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▼ 2012 (26)
 - ▶ December (2)
 - ▶ November (3)
 - ▶ October (1)
 - ▶ September (2)
 - ▶ August (2)
 - ▶ June (2)
 - ▶ May (1)
 - ▶ April (2)
 - ▶ March (3)
 - ▼ February (3)
 - ▶ [It's time for the Huntington's community to speak ...](#)
 - ▶ [The quandary of denial in the Huntington's disease...](#)
 - ▶ [The quandary of denial in the Huntington's disease...](#)
 - ▶ January (5)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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THURSDAY, FEBRUARY 09, 2012

The quandary of denial in the Huntington's disease community (Part I)

The natural human tendency toward denial presents one of the biggest obstacles to strengthening the Huntington's disease movement, including the recruitment of individuals for the observational studies and clinical trials crucial for developing effective treatments and a cure.

How do we more proactive members of the HD community influence those living in denial? How do we convince them that they need to inform themselves about HD and join the effort to defeat it?

I have wrestled with these important questions, as well as my own multiple forms of denial, ever since learning in late 1995 that my mother had HD and that I had a 50-50 chance of inheriting the condition. My denial, and feelings about others' denial, became dreadfully more complex after I tested positive for HD in 1999.

I remained deeply in the "HD closet" for many years because of the fear of genetic discrimination, but became vocal via this pseudonymous blog. In mid-2010, I began to speak publicly about my condition.

A year ago, I "[unmasked Gene Veritas](#)" and revealed my story to some 250 prominent scientists and other observers at the Sixth Annual HD Therapeutics Conference, sponsored by the CHDI Foundation, Inc., informally known as the "cure Huntington's disease initiative." I made other presentations at my local support group, an HDSA chapter convention, a pharmaceutical company aiming for a revolutionary clinical trial, and a symposium on clinical trials.

Now I want to tackle the problem of denial head-on.

Yes, we rely on denial to face the daily fear of HD symptoms, as well as the stigma accompanying the condition, but we ultimately must overcome it if we are to win the battle against HD.

And, yes, each family situation differs. In some cases, it may be easier than others. But by looking at my own family as an example, I aim to analyze some of the causes of denial, how it plays out in HD families, and how it maintains its insidious grip.

A powerful firewall

Denial often shadows my family life.

Despite my dramatic exit from the HD closet, I continue to maintain a firewall between, on the one hand, my HD activism and, on the other, the workplace and my neighborhood.

I would like to break down the neighborhood barrier, but my wife, who has [lovingly stood by me](#) through the entire trauma of the HD experience, has

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!](#)
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HD Blogs and Individuals

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

resisted the idea of expanding my advocacy beyond the HD community

After being named the 2011 Person of the Year of the [Huntington's Disease Society of America](#) (HDSA) last June ([click here](#) to read more), I wanted to solicit an article in the community newspaper as a way to build awareness and support for HDSA locally. I hoped the prestige could help take my advocacy to a new level.

My wife said no. "I don't want this in our house," she stated adamantly, referring to HD and all of its implications, including the impact such a newspaper article might have on our daughter, now in her first year of middle school.

My daughter knows that I am gene-positive and that she tested negative in the womb, and she even has read some of my blog articles. However, my wife does not want to see her constantly exposed to HD, and she wants her to enjoy her final moments of childhood without having to worry about my health and the future impact on the family of HD when my inevitable symptoms begin.

I respected my wife's wishes – I know she will shoulder the burdens of HD in the long run – but I was deeply frustrated. "This is such a HUGE accomplishment in my life," I wrote in my blog notes at the time. "The greatest recognition I have received to this point – one that is about changing the world. And I can't celebrate it!! Because of the stigma. I need to talk more, get HD out there more."

My wife initially didn't want to display my HDSA award plaque in our hallway of family photos, but she later changed her mind.

A bittersweet award

I wrote in my notes:

I will show plaque to [my daughter]. Families that deal with [HD] naturally and up front are the ones that have the best outcome in the long run. Denial necessary in life, but when carried to extremes, or used as the main way of dealing with life.... It becomes harmful/pernicious.

Nothing is ever simple with HD! This just can't be a great award. [Instead] it's got to be a reminder of my situation – and of our entire community's situation.

Ends up being bittersweet.

If it were any other award, we'd be celebrating. No celebration. No mention. No discussion.

I hate denial!

'Mental problems'

The HD community is filled with sad stories about denial among family members. People from HD families viscerally bond regarding the feelings of frustration, hurt, and anger over relatives' denial.

My mother's brother and his wife hid Huntington's from their two children and their spouses. They explained away my mother's behavior as "mental problems" ([click here](#) to read more). Only in the days before my mother died – six years ago this month – did my aunt tell my cousins the real cause. My cousins weren't close to my family, but at the wake they were still so shocked by the news of HD that they cried much more than my sister, my father, and I.

Over the years I nudged my uncle, a successful small businessman and

active in his community, to join the cause against HD. Many years ago, before my mother's death, I wrote him a long and heartfelt letter outlining ways to help.

I never got a response.

To this day, I don't know if he ever tested for HD. In his mid-70s, he has apparently showed no symptoms. Out of sight, out of mind, perhaps.

Jealousy over testing

For more than a decade, I have clashed with my sister and her family over their own denial, lack of involvement with my parents, and refusal to join the cause ([click here](#) to read more).

My sister, who to my knowledge remains untested, had her three sons before we learned of HD. Although we have never discussed it, she has undoubtedly agonized about whether she inherited the gene and, worst of all, passed it on.

She became extremely jealous of my wife and me for two big reasons: we had a daughter, and our child had tested negative.

Around that time, in 2001, my sister started to cut herself and her family off from me and my family.

Isolation

I tried to keep in contact, but she showed little interest in learning more about HD. While I have long taken doctor-approved supplements and lived with the hope that treatments could save me from developing symptoms, from what I can tell, she has chosen not to learn about such potential solutions.

As my mother declined, although I lived thousands of miles away in California, I strived to find a good care regimen for her and to assist my father with suggestions and gentle exhortations. My sister, who lived only a couple miles away in Ohio, would visit my parents but took very little initiative to improve their situation.

She became angry and resentful about my offers of assistance and suggestions. I grew increasingly frustrated with the lack of communication with the family member geographically and personally closest to my parents.

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."

I was stunned, perplexed, and offended. I had traveled regularly to my hometown to visit not just my parents, but my sister, her husband, and my three nephews. My wife and I had also offered to fly out my oldest nephew to San Diego and take him to Disneyland, Sea World, the San Diego Zoo, and other California attractions, but my sister never responded.

Failed communication

In 2005, after several years without speaking, I insisted that we reestablish communication to help my father admit my mother to a nursing home. We became close again during the final months of our mother's life and, when she died, my sister planned the wake and funeral so that my wife, daughter, and I could fly out in time.

However, as my father rapidly declined in the wake of my mother's death, my sister and I again disagreed about a plan of care for him. When dialogue became impossible, I asked my father's attorney to serve as an

intermediary and to assist her with his affairs, including the transition to a memory care unit in an assisted living facility.

My father died in September 2009. I learned of his death in an e-mail from the lawyer after I participated in an intense, day-long HD observational study. However, my sister did not delay the funeral, making it practically impossible to get to Ohio on time. ([Click here](#) to read more.)

I was so distraught about the situation that I also concluded I might suffer a heart attack if I attempted to attend the funeral. I organized a private memorial service for my father at our San Diego home.

I have not spoken to my sister since August 2008. In 2010 we both attended a memorial luncheon for a deceased aunt, but we did not speak or even acknowledge each other's presence. I was still livid about her lack of compassion in failing to delay my father's funeral so that I might participate.

Keeping a distance

At this point, the anger and resentment are so deep that I believe my sister and I may never speak again.

While I have fought to combat HD, my sister has preferred to ignore it. That has compounded the kind of intense family disagreements that sometimes accompany inevitable life-and-death issues.

After so many failed attempts at establishing a relationship with my sister, I have concluded that, because of denial and other reasons, she and her family simply have no interest in me and my family. I concluded that it would be foolish to insist.

I am a firm believer in love as a solution to many of the world's problems, including personal hatred and misunderstanding.

In my interpretation, love means keeping one's distance from people who don't want a relationship.

Advocacy in my home state

On May 14, I'm tentatively scheduled to speak on my experience with HD at an HDSA event in Northeast Ohio, where I grew up and where my parents are buried side by side.

Returning to my home state to speak out as an HDSA advocate will surely stir powerful and difficult emotions.

Many questions are running through my head. Should I invite my uncle and my sister – and their families – to attend? Would they even show up after so many years of conflict and denial? Would we talk and, if so, what would we say? Part of me doesn't want them to attend, because I fear my anger at them might diminish the effectiveness of my activism.

Frankly, I don't think they want to hear what I have to say, especially because I advocate activism. Years ago, my sister used to read at least some of my blog, but now I have no idea whether she follows it. I doubt my uncle even knows I have a blog. Should I continue to chalk them up as a lost cause? Or, in the name of the movement, should I make the extra effort to bring them into the cause?

As an advocate, I feel obliged to reach out. However, as a member of an HD family, I feel forlorn about the prospects for action by people such as my uncle and sister.

How to untie this knot?

I am reaping the fruits of my family's long denial of HD.

The great irony is that my sister, my uncle, and their families probably don't even know that I was named the HDSA Person of the Year.

The easy solution is to do nothing about the May event. Despite my award and my long years in the HD trenches, I feel powerless to change them.

My fellow HD activists, family members, and friends, what would *you* do?

How do we untie this terribly complex knot of denial?

I am in quandary about how to act – and to overcome this problem that threatens our march to treatments and a cure.

Continuing to speak out

Denial is like an added curse on HD families already so overwhelmed with the disease's medical burdens.

My family's story pales in comparison to other examples of denial and insensitivity.

As I reflect on these stories, I'm struck by the immensity of the stigma surrounding HD.

Perhaps I can take comfort in the fact that, no matter what my uncle or sister or anybody else thinks, I *will* speak out again about HD on May 14. In the final analysis, that is all I can do.

Someone will be listening, and that is good.

(Next: further reflections and concrete suggestions for overcoming denial.)

Posted by [Gene Veritas](#) at 8:26 PM     

Labels: [activism](#) , [advocacy](#) , [CHDI](#) , [clinical trial](#) , [ctivist](#) , [cure](#) , [denial](#) , [discrimination](#) , [gene-positive](#) , [genetic](#) , [HD closet](#) , [HDSA Person of the Year](#) , [Huntington's](#) , [stigma](#) , [tested positive](#) , [testing](#) , [treatments](#)

10 comments:



Unknown said...

My father has HD and I always appreciate your informative and heartfelt blogs. I know you have done a ton of research on ways to hold off the onset of HD and I was wondering if you had ever researched anything from Dr coriander. He claims that if you don't eat wheat you will never develop symptoms. Can you let me know if you have heard anything further on this? Here is the link where he briefly discusses this.

<http://thepaleodiet.blogspot.com/2009/12/paleo-diet-q-8-december-2009.html>

10:38 PM, February 09, 2012



Kate's Kronies said...

My hats off to you and your blog! We have had to deal with the issues of personally accepting it and than not talking about it..Kate and I both.. It has been Landon that has helped us come to terms with speaking out; and with fighting against it...

We find very little people judge Kate instead we have found more support and best of all we have found we need to educated people..the more people know the more like we are to have treatment found good job and God Bless!

5:15 AM, February 10, 2012

❁ **Susan said...**

We all have areas in life where it takes a little more time to process information or events than it does for others. We are individuals with our own personal opinions and emotions. Human beings are not programmed to respond in identical ways to things that happen, and we all need space to let things sink in while catching our breath for the next life changing event.

It is only possible to move forward from an issue after we allow ourselves time to process the event, accept it, and catch our breath long enough to be able to ask questions and seek resolution. No one should ever be rushed or forced to move at the pace of others before considering their own feelings first. There is nothing that truly prepares a person for hearing that they have a terminal illness; a genetic illness that has no cure. The only word I personally was able to hear was "Terminal" and to me, that meant "The end of my life".

There is a time and a "Pace" for all things! Please do not make the mistake of pressuring anyone to talk about HD before they are ready. Believe me, there will come a time when they are ready to speak, but it won't be at the command of another person who won't take "later" for an answer. There are many stages to acceptance that must naturally occur before a person can "Want to" move forward and learn to accept what they cannot change. For example, when you lose a loved one, the first response is always "Shock".

I'll never forget how many times my ex-husband tried to get me to listen to him as he'd shove HD facts down my throat before I was ready to hear about it. He would send me articles, post them on my computer, write me long winded letters that were not personally relevant to me, but instead, about how my HD is causing my inability to listen to him without flying off the handle (according to someone else's experience). My "ex-husband" did not come from a family with HD but they did have bipolar and mental illness. I thought he was using my illness to try to "Relate" to me. Maybe your family feels the same way. For me...at first, it appeared like he was trying to help me to understand HD and he looked to
SNAP ME OUT OF DENIAL

But, the fact still remained that I was not ready to talk about it, and I resented having to wake up every day and hear about it again. My illness became his focus in life, and he became my reason for wanting to run from everything before it could "Get Me". I just wanted him to shut up!

My final thoughts are: There is a time, and a "PACE" for all things. Processing HD is no exception, and we need to take as long as we need to accept it. We need to be comfortable with our ability to make our own plans to address the symptoms, so that we can move on with our lives having faith in our abilities to interact with others and not feel alone. We will survive, and our lives will make sense in time! Be a Champion, not an imposter.

My Brother has given me the best advice...for you and your family...For ANYONE.

"Begin from where you are, not from where anyone else thinks you ought to have been by now."

~ SDL

Thanks for bringing up this difficult subject, but my thoughts are to live by example. THEY ARE LISTENING...but I think they also wish you would not forget what it's like to see things from their prospective to. ~ Susan

5:22 AM, February 10, 2012

⊗ **Anonymous said...**

HD has split my husbands family too. When his phd mom was alive no one would deal or talk about it. She was neglected, but somehow that was ok... When we tried to intervene we were shut out.

My husband is the first of his siblings to be diagnosed (2005). His family never asks how he's doing, how they can help, how we are. They still won't discuss it. We have a right to talk about what is going on even if they choose to remain in denial. Their denial does not help us nor does it make the situation go away. Denial=fear. Fear paralyses. I can't see any of his family helping with research, fundraising, or educating. Now, since my husbands diagnosis, we are cut off from his family. I can't see how this "denial" helps anyone. And, I don't know how to overcome it either.

10:02 AM, February 10, 2012



⊗ **MawT26 said...**

usually i enjoy reading your blog but not so much today.....i think your HD is showing today.

because one doesnt become a spokesperson or an advocate or speak to their family the intimate details of their HD life does it

mean they are in denial. it simply means they choose to be defined by something other than HD.

my sweet family is riddled with HD....my hubby, one son, sister in law, father in law, grand father in law, an aunt, cousin.....and 5 other children who have yet to be tested.

there is no denying HD at Christmas dinner...we just choose to dwell on the holiday, the memories, the good times.

today my heart goes out to your sister.....if she read this blog i would imagine she would be hurt, offended and violated.

you sound angry today....could be the HD talking.....

i want my husbands legacy to be what a wonderful father he was, what a beautiful person he was, what a fantastic husband he was--how hard he worked to support his family-----NOT how HD left him a shell of a man.

10:10 AM, February 10, 2012

❁ **Vida Hermosa said...**

Thank you for this blog article Gene , as much as some people might not agree , this complex denial, HD closet , Is a major part of being in a HD family. I am really hurt that the above post states that your personal opinions and feelings is your "hd showing". It is so obvious that the person who wrote it is not at risk or gene + ,has no idea what it would be like to have that said to them.Sad how people can act sometimes...

keep up the good work Gene!

4:33 PM, February 10, 2012

❁ **Anonymous said...**

I need you to know that I thank you every day for your blog and your thoughts. You always write clearly, honestly, and hopefully, and I cannot express how much it means to me. Recently, my husband's mother was diagnosed with HD and it has become obvious that this is something that many of her family members have suffered from and died from. The only thing that has given me hope and helped me maintain a sense of sanity is your blog. I appreciate the honesty of this post(and all of your posts for that matter). The emotions you are struggling with are true and common for all of us, gene-positive, at risk, or not. I have found that there are times when you need to let things go and that includes relationships. My humble opinion, for what it is worth, is that you are right at this moment in time. Loving your family and yourself means keeping distance right now.

5:03 PM, February 11, 2012

❁ **Missypk said...**

Gene, thank you so much for this post on a subject I have been thinking about. I am convinced that denial has propagated the spread of HD. Denial to me equals silence and suppression of reality. I think a little denial can help us cope but more can be

so detrimental. Also it occurs to me how ironic it is that silence has hurt HD families and now we are praying for silencing the gene! I feel like a combination of shouting out awareness while silencing the gene can change the world of HD! Thank you so much for being so willing to be such a big part of the shouting out part! BTW, I can totally understand your wife's point of view. Her maternal instincts are at work here. God bless all three of you Gene, as well as your extended family!

1:01 PM, February 15, 2012



☼ **Tracy Brady said...**

Thank you for your post. My boyfriend has HD. His 4 adult sons are in various stages of denial, and I feel very isolated sometimes dealing with him alone. It helps to know that this is a common problem. Best of luck and blessings to you and your family in this journey.

12:03 PM, February 18, 2012

☼ **Anonymous said...**

Gene,

This is a very interesting perspective and I thank you for articulating it so eloquently. I am also saddened to hear of your family's situation and how it affects you.

I too live in a world of denial. I am open about having HD as part of my life, I married into the disease and my children are at risk. I deal with it everyday trying to manage their lives and that of my affected wife from outside the home as an advocate and responsible party. The hardest part is trying to get my ex to admit that she suffers from HD and that she could get improved treatment as well as have me as an advocate for her. I do not expect that to change and simply move forward with compassion.

I am also glad that you encourage your readers to elicit comments to the HDSA on the strategic plan. Communities are shaped by their members and we can all help to shape the HDSA with our suggestions and commentary.

Lastly, one thing we rarely discuss, and which I think is so interesting, is how HD families address "learned behavior". By this I mean children raised in HD families may not know that HD is active in their daily environment and that it is accepted behavior to be reclusive, have dramatic flares of anger, or even to accept and promote denial as if nothing is awry. I would love to hear your commentary or that of others on this specific subject.

Thank you again for your courage and openness.

12:17 AM, February 22, 2012

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