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The diary of a Huntington's disease activist

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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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About Me

 **GENE VERITAS**

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MONDAY, APRIL 25, 2011

The diary of a Huntington's disease activist

In my [previous blog post](#), I described my secret, second career as a Huntington's disease activist.

Today I was off from work because of the Easter holiday, so I decided to catch up on a few of the most pressing tasks on my HD "to do" list.

Recently I've received questions from other members of the HD community about how to engage in or improve upon work in the cause. I hope that this blog article – which I am fashioning as a kind of diary entry – will provide some suggestions.

Also, next month is HD Awareness Month – an opportunity for everybody in our community to reflect on our roles in the cause. On May 7, I'll be speaking on the topic of effective activism at the annual convention of the Northern California Chapter of the Huntington's Disease Society of America (HDSA).

6-7 a.m.

After having gone to bed early (9:30 p.m.), I arose to prepare scrambled eggs for our "miracle baby," who tested negative in the womb in January of 2000. She's taking state achievement tests this week, and my wife and I want her to eat an extra good breakfast to help boost her performance. As my wife got her ready, I checked the first e-mails of the day from the HD Facebook discussion groups to which I belong, and did my morning stretch.

8 a.m.

I returned home after dropping my daughter off at school. With both my wife and daughter off to their activities and the house quiet, I performed my morning deep breathing exercises and mini-meditation.

This morning ritual helps me face yet another day of living at risk for HD while juggling job, family, and other responsibilities.

8:10-9:15 a.m.

I started thinking about tonight's monthly HD support group meeting. I always come back from support group distraught at seeing people with HD and hearing others tell their sad and difficult stories of living at risk or experiencing the initial symptoms such as problems with driving.

I don't want to go – but I must. I decided to go back to bed for some extra sleep – and to help my mind work through the fear so that I can function normally the rest of the day.

9:20-10:30 a.m.

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](#)

I awoke after about an hour of sleep feeling less depressed.

I responded to some work and personal e-mails, and then turned to HD e-mail again. I exchanged several messages with the local special events coordinator for HDSA-San Diego about corporate sponsorship logos for our chapter website, which I oversee. These logos need updating to reflect new 2011 supporters of the cause here in San Diego.

I also made a few phone calls about Senate Bill 648, the Huntington's Disease Parity Act of 2011. If passed, the law would make it easier for HD-affected individuals to obtain federal benefits.

I found out over the weekend that the sister of a very good friend is a staffer to Rep. Xavier Becerra (D-Los Angeles), a member of the powerful Committee on Ways and Means and the ranking member of the Ways and Means Subcommittee on Social Security. Rep. Becerra did not back the bill last year, when advocates obtained 153 co-sponsors in the House of Representatives. His support is crucial, and we need to get him on board. ([Click here](#) for a previous blog article on the bill.)

I recalled HD advocate Allan Rappoport's sage advice: if you don't know a representative or senator, ask five friends for help. At least one of them is bound to know an elected official or how to contact one.

10:30-10:45 a.m.

I phoned Jeri, a middle-aged woman who cares for her nephew Tony, who was stricken with HD in his early 20s. I want to write a blog article about care, using Jeri's selfless dedication to Tony as an example. Completely disabled, Tony now lives at Edgemoor Hospital, a public facility where Jeri visits him each evening to help him eat dinner.

Jeri told me that Edgemoor was in the news because a 50-year-old non-HD patient, who was recovering from a car accident, allegedly bled to death because of hospital neglect ([click here](#) to read news coverage).

Later I sent the link about the article to the HDSA-San Diego board and support group facilitators.

Edgemoor personnel have cared for dozens of HD patients over the years, and I fear that I, too, may end up there if my family cannot care for me or afford to find proper assistance. I have visited Edgemoor on several occasions. The facility seems to have improved, but the news of neglect – and a \$2 million legal payment from the County of San Diego to the dead man's family – left me deeply worried about the fate of HD people there.

11 a.m.-noon

I drafted the letter below to Sen. Barbara Boxer (D-CA) about the HD Parity Act.

Dear Senator Boxer:

I urge you to join Senator Kirsten Gillibrand as a co-sponsor of S. 648, the Huntington's Disease Parity Act of 2011.

One of the cruelest of conditions, Huntington's disease destroyed my mother's brain, leaving her unable to walk, talk, or swallow. HD is like a combination of Alzheimer's and Parkinson's, with psychiatric problems added to the mix. After more than 15 years battling the disease, my mother died in 2006 at the age of only 68.

I tested positive for HD in 1999. There is no treatment or cure, and I will very likely develop symptoms within a few years. I am 51.

This genetic killer strikes people like me in their prime, saddling our families with a huge caregiving burden and ruining their finances.

Individuals affected by HD qualify for Social Security Disability benefits and Medicare. However, bureaucracy and inaccurate information about the disease make it difficult for HD people to actually secure their benefits. Some are even denied those benefits.

S. 648 would enact two very important changes in the law.

First, it would require the Social Security Administration to update its decades-old, inaccurate disability criteria for HD.

Second, it would waive the two-year waiting period for patients to receive Medicare benefits, thus bringing assistance quicker to families in dire straits.

Passage of the HD Parity Act will bring immediate relief to HD-affected families. I have paid Social Security taxes all of my working life, and my wife and daughter will urgently need federal benefits when I can no longer help support them. Passage of the Act will provide at least some peace of mind for us as we fight as a family to deal with the devastating symptoms of Huntington's disease.

12:20-1 p.m.

I started writing this entry.

1-1:30 p.m.

I ate lunch (tilapia, brown rice, roasted vegetables, olives, and yogurt) and took my midday dosage of my [Huntington's Disease Drug Works](#) supplements (trehalose, Omega-3 fish oil pills, and Coenzyme Q-10).

1:30-1:55 p.m.

I normally take a "power nap" this time of day, but because I slept extra in the morning and need to work on this post, I skipped it in order to write.

1:55 p.m.

I got ready to pick up my daughter from school. I normally spend part of Monday afternoon at home with her as she reads or does homework, and at around 4 p.m. I drive her to her weekly piano lesson. Today we moved her lesson up to 3:15 so that I can prepare for tonight's support group meeting. I usually leave around 5:30.

3:45

I read an e-mail noting the "lukewarm response" of California Senators Boxer and Dianne Feinstein to the HD Parity Act. We will have to redouble our efforts to get them behind the bill.

6-7:30 p.m.

I attended the support group meeting. Tonight the HDSA-San Diego board made its annual visit to the group to discuss chapter activities and the goal of national HDSA to strengthen ties to the grass roots, providing greater service for HD families. I was happy about the renewed commitment to care.

I also conversed with several HD people. Once again, I looked into the "genetic mirror" – my own probable future as a gene-positive individual.

Big goals – but little ones, too

As you can see, there's no secret ingredient or spectacular formula for being a Huntington's disease activist. Such work requires time, focus, and clear objectives.

It also requires a strong belief in the cause. Without commitment, it's easy to be discouraged and give up.

I constantly keep in mind our overall goals of raising awareness, providing better care for HD-affected individuals and their families, and finding treatments and a cure.

However, along the way we must tackle the many small, intermediary tasks. When each one of us completes these tasks, together we build a movement – and make a difference.

That's what today was all about for me.

Posted by [Gene Veritas](#) at [8:54 PM](#)      

Labels: [activist](#) , [advocacy](#) , [Alzheimer's](#) , [brain](#) , [care](#) , [caregiving](#) , [cure](#) , [disability](#) , [gene-positive](#) , [genetic](#) , [genetic mirror](#) , [Huntington's](#) , [mother](#) , [Parity Act](#) , [Parkinson's](#) , [psychiatric](#) , [support group](#) , [symptoms](#) , [tested positive](#)

2 comments:

 **Anonymous said...**

Gene,

Activism as you write does not stop with the big tasks. I remember urging my European friends to take the issue of HD up with their local governments. The answer they came back with was that Alzheimer's was a much bigger problem than HD. However, because HD groups are so well organized in the EU (HD Registry, longitudinal observation studies, and represented in so many states), HD became the model for rare diseases. France initiated an HD care guidelines project funded by the EU and France. So advocacy is not in the absolute numbers of affected patients, it is in raising awareness, persistence and knowing that your cause is just. If enough noise can be created about the HD parity act, people will jump on the band wagon. Being well organized and working well together is the first step towards accomplishing your goals. We can complain about people 's lack of knowledge, inertia, or even prejudices, but those can be overcome if we all do our part. I am sure there are HD family members out there who take comfort from your courage and openness. You and they are not alone. We re only as helpless as we think we are. We all have apart to play, whether as a family member, a scientist, a drug developer or just a concerned bystander.

Take care!

Dan

[7:28 AM, April 26, 2011](#)

❁ Marissa said...

I have been receiving your blog post notifications for some time now. When I say some time I mean I have no clue, years maybe? It feels like that. I've never opened an email or selected the links which would direct me to your blog. I filed them away in a 'Huntingtons' folder. I wasn't ready. I wasn't ready to accept the reality that HD is my reality. It is real and it doesn't only affect me, my brother, my sister, & my niece – but a number of other real people, people just like me.

I am recently married {6 mths} and just returned from visiting my parents. There is nothing that could have prepared me for said visit. In saying that, the visit, like your blog, has helped me accept this reality, my families' reality. It has helped me hold it by its horns and ride the sh-- out of it.

I admire you for being able to log your HD journey. Some days when I read your posts I am angry. Really angry. They make me think hard. Think more. Long story short. I am glad I began to read your posts. I am ready now. Thank you.

3:26 PM, April 26, 2011

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