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At Risk for Huntington's Disease

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## To strive or to chill? Seeking balance in the fight against Huntington's disease

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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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SUNDAY, JANUARY 29, 2012

## To strive or to chill? Seeking balance in the fight against Huntington's disease

In late 1995, after I received the shocking news that my mother had Huntington's disease, I decided to fight back for her by learning all that I could about this incurable disorder and also advocating for treatments and a cure.

Then, after testing positive for the HD gene in 1999, I sought to save myself by finding ways to stimulate my brain in order to stave off the inevitable neurological symptoms.

As I worked to maintain my health, my HD activism grew into a full, second career parallel to my professional work, and complicating my life as a husband and father.

### Two views, two necessities

"Keep striving," a close friend wrote recently after reading one of the articles in this blog, which, for seven years, has served as a chronicle of both my advocacy and strategies for avoiding HD and, in and of itself, has provided an escape valve for my frequent anxiety about the onset of symptoms ([click here](#) to read more).

I am living a very complex paradox. I *must* strive, but as I do, I also must avoid allowing my activism to exhaust me physically and emotionally.

As I wrote last year, I walk an [HD tightrope](#) that requires me to very judiciously balance all aspects of my life. One slip, and I could fall off the wire and plunge to disaster.

The past year has proved exhilarating but also psychologically trying, beginning with a major [coming-out speech](#) before world-renowned HD scientists last February and ending with wrenching articles about HD and [suicide](#), [abortion](#), and the [deaths of two girls](#) from juvenile HD.

"You need to chill more," another close friend of 32 years has counseled me repeatedly throughout my journey with HD.

He recommends that I "chill" as an antidote to the striving. He recommends spending less time on work, writing, and the HD movement and more on the simple, relaxing things that I could enjoy: good food and wine, books, movies, conversation with friends, walks with the dog – or just plain doing nothing.

To strive or to chill? That's the question I face each day.

### The rhythm of life

In a memorable sermon during my college years, the pastor of St. Thomas More Chapel at Yale, Father Richard Russell, spoke of the need to "get into

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 GENE VERITAS

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## HD Links

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[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](#)

the rhythm of life.”

As an HD activist, I especially feel that need. When I achieve that rhythm, my existence feels like the alternating phases of the heart's cycle – pumping and relaxing over and over again.

Over the past day, that's exactly how I've approached HD and the rest of my life.

This past Saturday afternoon, my wife, our 11-year-old daughter, and I took an hour-long walk in the San Diego beach community of Pacific Beach. Couples and families like us strolled, while more adventurous people on bikes or roller skates weaved in and out. The 70-degree sun bathed us all. We dined on Greek fare at our favorite restaurant, followed by frozen yogurt.

Late at night I worked on this article. This weekend, I had consciously chosen *not* to write on a difficult topic. I wanted to “chill.”

While I wrote, I couldn't forget how during the previous night I chatted on Facebook for an hour, trying to help a person recently shocked by the revelation of HD in her large, extended family.

Last night I turned off the computer without finishing the article. I read for a while before turning in.

This morning, I walked door-to-door with my daughter as she sold Girl Scout cookies in the neighborhood.

What a great feeling! Watching her take charge of the sales, I recognized how much more mature and confident she has become.

I forgot not only about HD, but all my other cares.

Now, after lunch, I sit again at the computer, contemplating how I must stay in the rhythm and find the right balance between striving and chilling.

### Enjoying the ride

It's nerve-racking to wait and wonder when and how the individual symptoms will start, especially because, at 52, I have reached the age at which my mother had already developed symptoms.

I sometimes become impatient about the rate of progress towards treatments and a potential cure.

Sometimes my fear provokes megalomaniacal thoughts about striving against HD, as if I'm a lone knight battling a fire-breathing dragon.

Then I remind myself that I cannot singlehandedly defeat this disease.

We all must get into the rhythm together: patients, asymptomatic gene-positive individuals like me, caregivers, physicians, and researchers.

And we all need to take a break from striving in order to chill.

As one of my California HD Facebook friends likes to say: when matters get rough, “go surfing!”

I don't surf, but the thought of the power, immensity, and majesty of the ocean brings home the point: I control only a very small part of my destiny, and I might as well enjoy my ride on earth.

Posted by [Gene Veritas](#) at 4:25 PM



Labels: [abortion](#) , [activism](#) , [advocacy](#) , [blog](#) , [caregiver](#) , [daughter](#) , [death](#) , [father](#) , [gene](#) , [gene-positive](#) , [Huntington's](#) , [juvenile HD](#) , [neurological](#) , [onset](#) , [other](#) , [researcher](#) , [suicide](#) , [sympmtoms](#) , [testing\\_positive](#) , [wife](#)

3 comments:



**Unknown said...**

How true! :) We must always take a break and just enjoy the little things--singing along to a song in the car at the top of your lungs, having a movie night with friends, doing nothing all day but read a good book...etc. Those moments matter, they keep us sane and happy. Great blog! :) Thanks for all you do!

5:46 AM, January 30, 2012



**lilleba said...**

Hello !

I found your blog, searching for HD, and must say you write good articles.

I am a speech therapist, and have added your blog to my blogroll

here: <http://logopedene.blogspot.com/>

I am from Norway, and write in norwegian, but I am quite sure my readers will enjoy your articles.

Thank you so much !

Best from Bjorg Meland

9:59 AM, January 31, 2012

**Roger Vaughan said...**

I whole heartedly agree with your friends. I'd love to see more posts on your efforts, both successful and not, to chillax.

We, forinstance, recent empty nesters, have a new puppy. It's way more work than I remembered leaving way less time for stuff like writing about Huntington's.

See "Bear's" gotta go... now! Bye!

1:20 PM, February 12, 2012

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