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Playing in the fourth quarter of life as Huntington's disease looms

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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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TUESDAY, AUGUST 21, 2012

Playing in the fourth quarter of life as Huntington's disease looms

Seeing my mother succumb to Huntington's disease at the age of 68 and living in fear of the onset of my own symptoms, I have come to appreciate the preciousness of time.

One of my closest HD confidantes and I frequently measure time in terms of the four quarters of a football game. We see most people like us, in our early fifties, as playing somewhere in the third quarter, the prime of life.

However, I'm well into the fourth quarter. I've already reached my mother's age of HD onset, and I will be extremely lucky to reach 60 without a serious reduction in my brain power and the start of chorea, the shaking and trembling experienced by most HD patients. Indeed, I cannot imagine life beyond 60, a time when my only child will be in college. I'm deeply saddened that, in an era when more people than ever are working into their late seventies and even eighties, I may have to stop in just a few years.

Because HD is inevitable, I know the symptoms will start, even as I hold out hope for some scientific breakthroughs. Maybe I'll get a "mild" case – or maybe I'll suffer just as badly as my mom. Like hers, most cases of HD I know devastate people physically, behaviorally, and cognitively, leaving them mere shadows of themselves.

So, these days I'm throwing long passes, aiming for touchdowns.

I'm also starting to focus on putting my affairs in order to facilitate matters for myself, as well as my wife and daughter, if HD becomes so bad that I can no longer work or take care of myself.

It's time to prioritize. That includes stepping back a bit from this blog. Regular readers will notice that recently I've written much less. After a period of intense writing, I need to replenish my emotional energy.

And, in perhaps the most important process of all, I'm learning to accept my defeats, the disease, and, ultimately, my mortality.

Throwing long in the publishing world

As an activist for the Huntington's Disease Society of America (HDSA), I've strived to help build awareness, although my need to remain anonymous and avoid genetic discrimination has, until recently, stymied that goal in terms of reaching out personally to people.

In mid-2010 I started to exit the terrible and lonely "HD closet" by making speeches about my family's struggles with HD. Since then, I've made some ten presentations, most recently at the HDSA annual convention.

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

As a writer, I decided to attempt some long passes in the hope of generating greater media exposure about HD and the need to research and treat neurological disorders.

This is my moment.

Towards my goal, I'm working to publish a book about my family's experiences with Huntington's and scientists' and drug firms' quest for effective treatments. I hope to add to the excellent writings of other HD authors, including Jim Calhoun, Trish Dainton, Susan Lawrence, Carmen Leal-Pock, Sandy Sulaiman, and Alice Wexler.

How to 'sell disease'

In today's world, publishing a book on HD is an especially daunting challenge. With the rapid decline of traditional bookstores and the rise of the e-book, publishing is undergoing a revolution. It's also become a virtual monopoly of an elite of blockbuster authors.

One clear message is that "disease doesn't sell."

Furthermore, so-called orphan diseases such as HD – with an estimated 30,000 affected people and some 250,000 at-risk – are orphans not only for the drug industry, but for the media.

Despite the terrible drama of conditions such as HD, in this information-saturated age it's hard for people to grasp a disease that doesn't directly affect them or loved ones.

However, in June came the encouraging news that former *Palm Beach Post* reporter SusanSpencer-Wendel signed a book contract for $2.3 million to chronicle how she will fulfill her "bucket list" of desires as she struggles against Lou Gehrig's disease – a condition with approximately the same number as affected individuals as HD. She also received a seven-figure movie deal.

Indeed, disease *can* sell – if one has good media connections like Spencer-Wendel and discovers a way to link a story to trendy themes.

As a gene-positive HD person and HD activist, I believe disease *should* sell. The imminent tsunami of people affected by neurological disorders will add enormous stress on caregiving communities and the healthcare system.

Not in my wildest imagination have I thought a publisher would pay millions for a book about HD, but I *do* hope that, by earning at least a modest fraction of that, I could help insulate my family from financial crisis in the event of my illness and make a substantial donation to HDSA.

Focusing on the basics

As I've reflected on my goals, I've also come to recognize the danger of my ego taking my focus away from what matters most.

"Vanity of vanities!" the biblical Book of Ecclesiastes tells us. "All is vanity."

I will continue to write about HD and strive to publish a book. However, as I head deep into the fourth quarter, other goals take on increased importance.

"Forget about the glamor," I told myself. "Get to the basics."

Later I quipped to myself: "God doesn't read resumes!"

For 10 days in June, I got away from the worries of writing, career, and Huntington's disease by traveling with my family to restful spots in northern California.

After visiting the La Brea Tar Pits in Los Angeles, we spent several days hiking in Yosemite National Park. We traversed the expansive and hot Central Valley, drove down the Avenue of the Giants in one of the state's virgin redwood forests, strolled along the idyllic shoreline of Crescent City, took in the wild coast of Mendocino County, and celebrated our HD-free daughter's twelfth birthday in San Francisco.

Enjoying these natural and human treasures together gave us a deeper appreciation of our home state. It also strengthened our family bonds and deepened my commitment to my daughter as she prepares to embark on a new adventure at a private school just as she enters adolescence.

At Glacier Point in Yosemite National Park

On the dock at Crescent City

Confronting the hard reality

In the HD movement we all need to strive for the big successes – such as big fundraisers, media attention, advocacy for stem-cellresearch, improved Social Security legislation, and other pressing needs.

But, as our community knows so tragically, both individuals and families need to prepare for the hard, scary reality of HD.

Instead of writing, this summer I've focused on dealing with the inevitable onset of symptoms – and my eventual death.

Already in January, as I prepared for the potential fallout of going more public through my writing, I had participated in an HDSA webinar on

genetic discrimination. On July 11, I took part in another webinar titled "preparing for the unknown," which discussed the importance of establishing end-of-life directives for caregivers and loved ones. On August 8, after my annual appointment for cognitive testing at the HDSA Center of Excellence for Family Services and Research, I picked up a copy of a sample advanced directive.

This summer I also reviewed the slides from a March webinar on "workplace accommodations for HD" – an especially crucial topic for me because I plan to continue as long as possible in my position as a university professor.

Receiving this information has helped me start to prepare mentally, emotionally, and logistically for the onset of HD

Putting things in order

In recent months I've fantasized a lot about retirement – from both my career and the HD movement.

"Our culture thinks it's cool to be exhausted," I wrote recently in my notes about this fantasy. "We wear it as some kind of badge of honor. I myself have been like this. But it's absolutely nuts! I need to pace myself, keep getting down time. It's so true what I've heard in Brazil: Americans live to work, Brazilians work to live."

In particular, this summer I've also felt a powerful urge to put my life in order, especially those areas I've long neglected because of time spent on HD activism. In the fourth quarter, it's time to take stock of my life – and to enjoy doing so.

I began by transferring the songs from several hundred music CDs onto iTunes. Listening to many of these songs for the first time in decades brought a flow of good memories from my twenties and thirties.

Next, I reorganized my home office for the first time since we moved to this home in September 1999. I threw away garbage bags laden with hundreds of old 3.5-inch diskettes, checks and check registers going back to the early 1990s, and numerous other unneeded items.

I like the idea of traveling lighter on my journey with HD and through life.

I finally caught up on our home movie collection, started scanning old family photos that are beginning to fade, and filed work and HD-related CDs and DVDs in a storage case I had bought about four years ago.

I like caring for plants. I potted three new ones and placed them by the window. It felt great to get my hands dirty and to smell the soil. Sunday evening is watering time.

What causes this desire for order? The natural rhythm of life? A side effect of HD's subtle psychiatric symptoms, which can include obsessive-compulsive behavior? Just plain fear of onset?

Whatever the cause, the greater sense of order has brought me a sense of comfort, of preparedness for HD and whatever else life might bring, of living the moment.

Shifting passions, accepting fate

I'm in a fight for my life against HD. Ironically, that means that perhaps it's time to stop fighting so hard. Fighting *too* hard can worsen stress. A positive family life, exercise, tranquility – these are the real keys to personal survival.

I have a stable job, a loving family – and the tremendous gift of so far having avoided HD's classic symptoms.

Tranquility and stability will help me negotiate the dramatic shift in my professional career from an emphasis on Latin American history to the history of science and the chronicling of the HD movement.

In one of my recent dreams, I plunged down a Rio de Janeiro hillside on the back of a wheelchair driven by a disabled man – undoubtedly an HD man – who, like my mother, could not speak.

I used to value traveling to Brazil. Savoring those experiences brings a warm glow to my heart. As a professor and father, I pass on those experiences to the next generation.

Now I'm becoming excited about new kinds of travel: through the biotechnological revolution, through my own mind in search of its meaning.

Yet, despite the vast progress in brain research of recent decades, the drug industry still has not produced a single remedy for neurological disorders. Although I never abandon hope, I also understand that a treatment may not arrive in time to save me.

Ultimately, tranquility and stability will help me prepare spiritually for the onset of HD: the realization that, in the end, I must accept my fate.

Posted by Gene Veritas at 4:18 PM

Labels: activism , activist , advocacy , Alice Wexler , awareness , brain , caregiving , chorea , discrimination , genetic , HD closet , Huntington's , Lou Gehrig's , mother , neurological , onset , orphan , Social Security , stem-cell , symptoms

5 comments:

Anonymous said...

I just happened upon your blog and was touched by your journey. My father was diagnosed with HD at age 63 and died from complications of a stroke and heart attack during the middle stages of HD at age 69. We were spared the agonizing end. I am 49 and at-risk. I have not been tested so I do not know my genetic status, but I self-watch for emerging symptoms to comfirm my worst fear.

Thank you for putting a voice to the fears, concerns and hidden thoughts that I have. I admire your courage in sharing your journey with this most horrific of diseases and your advocacy with this daunting cause. Good luck and may God bless you in your fight.

8:26 PM, August 21, 2012

Blake Harrington said...

Thanks so much for your blog. I married a man that has HD (he was my highschool sweetheart) and we just found out about 2 years ago. I feel like we carried this secret, and finally was done feeling like I was in hiding. So on Monday I posted about HD and us in my blog, and had a great response from friends and family regarding this. Feel free to check it out

http://thatssewblake.blogspot.com

God Bless!

10:53 AM, August 22, 2012

Corrine Johnston said...

Thank You for your Blog. My husband is 35 and is in the very early stages of HD as well. We have also started a plan of simplifying our finances and and our goals.And also have stated raising money for HDSA For Team Hope in Alaska. He tries to take time to enjoy what makes him happy. His mother only has maybe a couple of months if that left and my husband has just earlier this year gone back to God and that is what gets him up each day and allows him to be at peace with this horrible disease. Thank You for all that you have done and I hope that you enjoy your wife like never before and that you and your daughter can get closer than you ever thought possible. Take care and God Bless you.

11:29 PM, August 23, 2012

Anonymous said...

I just found out this spring that i, too, have the hd gene. I dont even know where to start, but i know that i am also feeling a need for a plan of some sort...probably because i have no control over how the disease will progress. The thought of not knowing terrifies me. Thanks for sharing. And apologies for the typos, i'm mobile.

6:59 PM, August 24, 2012

Anonymous said...

I just read this and cried, I am third generation known HD gene postive person. My Nana is 84... mom is 59...me 39.... we are all in very different stages of our fight, its so hard but trying to be positive,

7:34 PM, October 21, 2012

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