10-25-2009

Creating hope

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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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GENE VERITAS

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HD Links

Huntington's Disease Society of America
International Huntington Association

SUNDAY, OCTOBER 25, 2009

Creating hope

Living at risk for Huntington's disease frequently leaves me emotionally drained. Sometimes I fantasize that it's all just a nightmare from which I'm about to wake up. Other times I wish I were a different person with just normal worries, free from thoughts of suffering and death.

I discovered that my mother had Huntington's in 1995. I tested positive for the disease in 1999. I attended her funeral in 2006. This year, on October 4, I held a memorial service for my father, the Huntington's disease caregiver-warrior who gave up on life not long after her death.

It would be a vast understatement to say that the last few years have been difficult. Life in the Huntington's disease trenches brings a steady barrage of troubling thoughts resulting from the death of loved ones, abandoned dreams, and the underlying worry about when my own symptoms will start and how my wife, daughter, and I will cope.

But at the core of the human spirit lies hope. Each day I must summon that hope. As an activist for the Huntington's Disease Society of America (HDSA) and at-risk blogger, I have met this challenge for more than eleven years.

Acting and living hope

I have learned that hope is not just a feeling, nor fantasies about a better life, nor a fervent prayer for the cure of HD – it's action.

I can't just *feel* hope. I must *live* hope.

As I wrote in my previous entry (click here to read more), my HD activism has become the center of my life and transformed me as person.

Understanding the research

When I research and write about the efforts to find treatments and a cure, I am building hope. The potentially most significant effort at controlling HD happens to be occurring just a few miles from my home, at Isis Pharmaceuticals, Inc., in Carlsbad, California (click here to read my report). In 2011, Isis scientists hope to begin the first human tests of a drug that would halt HD at its genetic roots.

I visited Isis last year and again this past July to interview the scientists involved in the research and shoot photographs of their work. Incredibly, the Isis project, which is funded by the Los Angeles-based CHDI Foundation, Inc., is still relatively unknown in the HD community.

I believe deeply in the need to understand and monitor this project. The privilege of meeting and understanding the work of these individuals gives me at least some sense of control over my own destiny. I want to know exactly how this disease works – and exactly how the potential Isis drug

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
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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

might work like a soldier within my brain cells to defend them against the ravages wrought by my mutated huntingtin gene as it generates handicapped proteins.

Electrifying news

Several years ago I described how watching my mother struggle with her symptoms was like looking into a "genetic mirror" (click here to read more). I had inherited my defective huntingin gene from her and would likely develop the disease around the same time she had – in her late forties and early fifties.

I turn 50 this year. As Isis and many other projects explore the intricacies of HD-affected cells and seek solutions for the disease, I gaze into another kind of genetic mirror: a model of my own compromised cells.

Not long ago people thought that the Isis approach might be feasible around the year 2025. Back then every other possibility of a treatment seemed at best partial, both limited in its potential effectiveness and quite distant in the future. (Click here to read about my "ups and downs" in waiting for a cure.)

The first news about Isis two years ago came to me like a lightning bolt, and I want to keep passing on that electrifying feeling to everybody else in the HD community and beyond. Although nobody can guarantee that a potential Isis solution will actually work, I want my articles on Isis to generate excitement and hope.

Excitement and confidence

Now I am preparing a series of articles on CHDI, which has become the prime mover in HD drug discovery with a budget last year of $80 million. In a nutshell, CHDI is like a miniature Manhattan Project to stop HD. The researchers' excitement and confidence are palpable.

I had a similar feeling on September 28, when Dr. Jody Corey-Bloom, the director of the HDSA Center of Excellence for Family Services and Research at the University of California, San Diego, revealed a plethora of approaches for HD treatments during her annual research update to the local HD support group.

One of the most inspiring HD presentations that I have seen, Dr. Corey-Bloom's report is a "must see" for everybody. I posted it online the next day.

At the ninth annual HDSA Celebration of Hope Gala in San Diego on October 17, the master of ceremonies, ESPN Monday Night Football anchor Mike Tirico, briefly described the Isis project to the 500-strong audience and congratulated the company on its efforts. Events like HDSA-San Diego's "In the Huddle" mainly focus on fun and fundraising, but the mention of Isis allowed the science to shine through for a moment (click here to watch the video I shot).

That moment became possible thanks to CHDI's generous backer and the many scores of HDSA fundraisers of all sorts and sizes held across the country in recent years. They have kept the money flowing into the labs, where scientists are hard at work on treatments and a cure.

We in the HD community surely need a big shot of confidence after so many decades of discrimination, ignorance, and lack of progress in the search for treatments.

Hugging HD-affected friends

I always come away from the gala emotionally wired. To see an important

part of the local community – including the president, coaches, and many players of the very generous San Diego Chargers NFL football team – rally to our cause is a great confidence-builder for our local HDSA chapter.

At the gala I also encounter families affected by HD. I hugged two of my oldest friends from the at-risk section of our support group. Both of them are now symptomatic and have left their jobs. But they have fought every step of the way to minimize the impact of their symptoms and to galvanize others into supporting our cause.

Sharon just contributed an article to the HDSA-San Diego website about the 2010 Race Across America, in which her husband and three other men will for the third time cross the country by bike in just eight days or less! (Click here to read more.)

Julie simply inspires me. We forged a friendship outside of support group, and every year my family and I look forward to the holiday cards she designs with one of her beautiful paintings on the cover. A few years ago, before her symptoms started, Julie fought and beat breast cancer. Although she has lost some of her stability and had to lean on her husband during the dinner, we conversed normally. I was glad to hear that she is at work on yet another painting.

The mystery of solidarity

Hugging these sisters in Huntington's disease is a deeply moving and mysterious experience. It inevitably reminds me of my mother, but it is much more than that.

We know one another so profoundly because of the genetic defect we share and all of the sadness, loss, and discrimination that have resulted from that fact. I feel sorrow for them as their symptoms progress. (I've heard Sharon say that she's not worried about herself, but about the future of her two teenage daughters.) And I know that they fear for me and my family as we worry about my health.

But I also gain strength in watching them persevere. By sharing our experiences and building solidarity, we once again create hope for ourselves and for the HD community.

Spiking adrenalin

Less than 72 hours after the dinner I was scheduled to undergo my annual checkup at the Center of Excellence. I started getting informal checkups around eight years ago. I could do this because the people at the center knew me from my work for HDSA. I wanted to keep HD out of my official medical record, because of my very real concerns about potential discrimination.

Four years ago, however, I decided to become an official patient so that I could go through the full, formal workup all HD patients get on a periodic basis. I wanted to make sure I'd get the best possible monitoring of my health and the best advice on how to care for myself. Luckily, the Center of Excellence is separate from my health plan, so my confidentiality is protected.

I awoke at 4 a.m. on October 20, an hour and a half before my usual time and with my adrenalin already spiking. It was going to be a long day at work before the 3:30 p.m. appointment at the clinic. I wrote in my blog notes: "HD clinic today – yet one more reminder that I could get very sick! How many times do I need to be reminded?!"

When no change is good

Because I had recently gone through numerous batteries of

neuropsychological tests for HD research experiments and done well, I entered the consultation room confident that I could repeat my good performance. I successfully carried out the tests administered by an assistant.

The doctor gently shook one of my hands up and down in his hand while asking me to draw a circle in the air with my other hand. He had me look up, down, left, and right without moving my head. He checked my reflexes, and he had me stand still while he pushed me hard from the back to see if I could maintain my balance. Finally, he had me walk down the hallway and then return on a straight line in the same way that a cop checks a suspected drunk driver.

The doctor supplemented these observations with questions about other aspects of my health and a general conversation about my life, my work, and my HDSA activism. He also reviewed the notes from past visits.

The doctor had personally examined me on past visits. (Last year I had been assigned a relatively inexperienced resident who mechanically performed the examination and did not appear to have the more holistic approach that this doctor had acquired, so I firmly insisted that I get to see him too.) “I see no change over the past four years,” he concluded.

In an era when Barack Obama made the word “change” a great national slogan, the phrase “no change” provided great relief. I had survived another year without any apparent overt symptoms of HD. Those symptoms could start at any moment and carry me down quickly, as I saw in the case of my mother and many other HD patients. But for now, at least, I can continue to function normally, enjoy my family, and carry on with my advocacy.

I had worked diligently over the past year to get to this point in stable health. Once again, with the assistance of the Center of Excellence, I had created hope.

Another side to HD

Shortly after I, in deep pain, wrote about my father's death, Dr. Martha Nance, the director of the Minneapolis Center of Excellence, sent me an article that she had just written and titled “The other side of a dark disease." Two days ago, I finally had a chance to read it.

“There is another side to HD ... which needs to be told – a story of beauty, courage, engagement and inspiration,” she wrote.

Dr. Nance recounts the valiant actions of children coming to the aid of their HD-affected parents, communities creating fundraisers and rallying around families touched by the disease, and old high school buddies and rivals joining to help care for a former classmate who has HD.

“As it passes from generation to generation, HD insinuates itself into the fabric and history of a family and community,” Dr. Nance concluded. “I have heard many stories of sadness, scorn, and hopelessness among my patients. But I hope that these tales of humanity and generosity will serve as a reminder that families, friends, and communities have the potential to do great good – and that the goodness, in turn, will rub off on others in ways that we may never know.”

Because a few people fearlessly stepped forward to assist people with HD and raise awareness, thousands learned about the disease and became an extended community of caregivers.

That, too, is how we can live hope and create it anew each day.

Posted by Gene Veritas at 5:24 PM

3 comments:

Marie Clay said...

Hi Gene,As always, an inspiring article. Even though my daughter had a rough weekend,hope is all we have.If I give up on that,where will that leave us? You give me hope Gene with your words.You say how we all feel.Keep fighting.
Marie Clay
Va. Beach,Va

8:30 PM, October 25, 2009

lisa_marie434 said...

hi gene, i have been at risk for 17 years and just now got lucky enough to be meeting some very influential people on the forefront of change in hd. anyway, i have a technical question? how do i make my blog known to others that need it? i just created one and if i can't even find it there's no way anyone else will either! so frustrated. hopefully you can help. was also wondering if you could post my page to yours (after you look at it ofcourse). thankyou so much for atleast reading this...
desperatley&sincerely,
lisa
lisa_marie434@yahoo.com
860-908-8990

6:36 AM, November 02, 2009

shashank said...

Here is a link to more information about the genetics of Huntington Disease-Like Syndrome that was prepared by our genetic counselor and which has links to some useful resource for those dealing with this condition: http://www.accessdna.com/condition/Huntington_Disease-Like_Syndrome/688. There is also a number listed for anyone who wants to speak to a genetic counselor by phone. I hope it helps. Thanks, AccessDNA

4:44 AM, February 05, 2010

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