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A restless soul at the HD research meeting

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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, FEBRUARY 14, 2010

A restless soul at the HD research meeting

Curing a devastating and complex illness like Huntington's disease requires a team built of some of the world's top scientists.

To that end, CHDI Management, Inc. – the multi-million-dollar "cure Huntington's disease initiative" – brought more than 200 people from around the globe to its Fifth Annual HD Therapeutics Conference from February 8-11 at the Parker Palm Springs hotel in Palm Springs, California. A tandem event, the CHDI Clinical Workshop, took place on February 8.

In addition to HD specialists, the conference included representatives of biotech and pharmaceutical firms, the Huntington's Disease Society of America (HDSA), the Huntington Society of Canada, and a number of advocates from families affected by HD.

The latter included conference keynote speaker and writer Steven Seagle, the author of the acclaimed graphic novel *It's a Bird*, which addresses his family's way of confronting Huntington's and juxtaposes the reality of disabling HD with the fantasy of Superman.

A front-row seat on science

The HD specialists form a virtual community where they share information and challenge one another through publications in academic journals, in teleconferences, and via the Internet.

Only occasionally, however, do they get an opportunity to meet as a group, challenge one another in person, and get the "big picture" of the rapidly growing and increasingly specialized field of HD research.

As an official invitee to the conference, I watched the scientists present their work to their colleagues, answer pointed questions from the audience, and discuss their findings over meals and in informal conversation. I literally had a front-row seat to witness the process of intellectual discovery and debate.

Worrying (again) about symptoms

Everything said and done at the conference impacted *me* personally: I tested positive for Huntington's in 1999, and my mother died of the disease in 2006. Listening to the scientists discuss research advances and possible treatments was like watching a television series about my future.

At first I felt deep sadness. I wondered whether a treatment would be found before I experience symptoms. Once again I had to "look into the genetic mirror" and see myself ending up like my mother – unable to speak, walk, or swallow. A part of me did not want to be at this conference.

I was especially concerned about the data on premanifest (gene-positive, asymptomatic) people like me. Andrew Leuchter, M.D., of the University

Huntington's Disease Drug Works
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Hereditary Disease Foundation
Huntington's Disease Advocacy Center
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HDSA Orange County (CA) Affiliate
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of California, Los Angeles, presented his findings on EEG (electroencephalogram) readings taken on affected and premanifest HD people. By placing electrodes on the scalps of his subjects, Dr. Leuchter and his collaborators were able to measure shifts in both the level and location of power in the brain. They found that brain dysfunction clearly occurred in the premanifest subjects.

Dr. Andrew Leuchter of UCLA reports on EEG readings (photo by Gene Veritas).

I was shocked to learn that EEG readings could detect changes in the brains of Alzheimer's patients 20 years before the onset of the disease. What, I wondered, if the same thing happened in HD? Because I have already passed the age when my mother's symptoms began, was my brain already deeply compromised? I worried about this as I looked at Dr. Leuchter's PowerPoint images of premanifest HD brain readings.

Dr. Leuchter pointed out that HD EEG studies have been lacking. He proposed that more studies be done, and that subjects be tracked over a longer period of time.

MRIs and affected brains

I had an even more eerie sensation in watching the presentation by Nellie Georgiou-Karistianis, Ph.D., of Monash University in Victoria, Australia. She had studied HD people's brains using functional magnetic resonance imaging (fMRI). I took part in this study by undergoing MRI scans at the University of California, San Diego, in 2008 and 2009 (click here to read more).

Dr. Georgiou-Karistianis found reduced activation in the brains of both affected and premanifest individuals.

Dr. Nellie Georgiou-Karistianis (photo by Gene Veritas)

However, because the study lasted only two years and did not illustrate whether actual changes were occurring in the brain, she proposed the tracking of individuals over a longer period.

Another aspect of her study, which employed diffusion tensor imaging (DTI), demonstrated that affected HD people suffered from significant degeneration of the white matter in their brains. I was relieved to hear that no such effects were evident in the premanifest group.

Immense progress made

But witnessing the scientists' intelligence, dedication, and passion for their work heartened me. As I took extensive notes on staccato-like presentations that compressed years of work and reams of data into a half hour, I came to understand the immensity of the progress made in understanding Huntington's disease.

I was also impressed by the many angles from which science now views HD. The conference included 31 presentations (I heard 20) and 59 posters on the latest work done in Huntington's research labs.

It's now 17 years since scientists discovered the HD gene. Many people in the HD community had thought that an effective treatment would have been found by now. Others thought it might take decades. CHDI has sped up the process considerably with its huge investments in research and encouragement of scientists through events such as the conference.

Advances in such areas as antisense oligonucleotides and RNA intereference – both discussed at the conference – have brought the idea of treatments and a cure close to the realm of human testing. CHDI itself has identified some 700 potential drug targets.

Thus the problem today is not *lack* of possibilities, but a *plethora* of fronts on which the disease could potentially be fought. The scientific community now faces the challenge of choosing the correct targets and finding a way to administer them safely and effectively in humans.

Non-stop emotion

The challenge of assimilating this huge charge of information caused me to sleep fitfully.

I also felt the strange new sensation of being open about my real identity. I fully planned to tell people at the conference that I was "Gene Veritas" and gene-positive for Huntington's. But my official CHDI name tag had only my real name and my affiliation with HDSA-San Diego.

When I arrived, CHDI President Robi Blumenstein asked me, "How are you going to present yourself?" I told him that I would tell people about my HDSA activism and let one thing lead to another. "Why not write 'Gene Veritas' on the bottom of your name tag?" Robi suggested. I thought, "What the hell," and got a Sharpie to add my pseudonym.

I have been a living example of the many ambiguities and multiple identities that author Seagle observed in people. One of those identities was invisibility. Although I've stood on the barricades of the HD movement, I've preferred to remain pseudonymous for fear of discrimination. At the conference I took another big step towards visibility. I wanted, in Seagle's words, to "soar" – to dominate the terrain of my life and the disease that threatens it.

A number of people who knew my blog said they were glad to meet me. Many more learned about the blog for the first time as I handed out a business card with the blog address written on the bottom.

I was especially moved when Michael Hayden, a world-renowned HD researcher at the University of British Columbia and reader of the blog, told me that I was providing an important service to the HD community.

Dr. Michael Hayden, HD expert and proponent of "civic science" (photo by Gene Veritas)

He added that he expects all of the scientists in his lab to practice "civic science" by meeting HD-affected individuals. That approach reflected what I felt from many people at the conference: seeking treatments and a cure for HD is a mission to assist people.

The CHDI conference kindled non-stop emotion. My adrenalin was pumping. I felt fully energized to continue the fight for a cure.

But the many new ideas and sensations stirred the core of my being. Near the end, as I was walking alone through the grounds of the hotel and trying to collect my thoughts, I suddenly heard my inner voice say: "My soul is restless."

(Next time: a detailed summary of the scientific data presented at the conference.)

Posted by Gene Veritas at 3:21 PM

3 comments:

Susan Elaine said...

What an incredible experience Gene. I was right there with you feeling the very same hesitations, worries, and looking for the pros to arrive, but it's a difficult thing to find positives in such a huge realm of possibilities, but at the same time...it's easy to find possibilities because there is a factor called "HOPE". We all have it, we want to know more, and I'm ever so delighted to continue reading on through your blog for my soul is restless too. As a Gene positive woman (one of 10 children and over 44 direct "At Risk family members) I have my heart and soul "Invested".

Susan

5:12 PM, February 14, 2010

Anonymous said...

Your blog has been a true Godsend for me to find. I thank you for writing this and helping so many people during the past 5 years.

I am ashamed to say I had never heard of Huntington's Disease. Not until I got into a relationship with the kindest, most caring man I could ever wish to meet. He told me he is at risk for HD, the 50% chance, and he is too afraid to test. He is 33 and I find myself looking for symptoms, which I know is bad of me. I feel I care too much to ever leave him.

I pray every day for a cure.

I am so happy to hear that you have not seen any symptoms at 50. My boyfriend's mom developed it at 60. I believe you will go this next decade and not see a symptom. And our next decade, there will be much better treatment and we will see a cure.

It is people like you who make this world a good place. If only there were more others like yourself.

My prayers are with you and your family. I'm glad you have an amazingly wonderful wife like you so deserve. Take care and thanks for keeping us all posted here on the latest research.

-Thankful in NYCity

9:05 AM, February 24, 2010

Anonymous said...

Gene,

I love your blog...I am 28 years old, and am at risk. I have been searching for someone else's "thoughts" on being at risk/positive for HD... Thank you for sharing your life and what has been on your mind!

I didn't realize that this month was HD Awareness month! If I hadn't stumbled upon your blog, I'd have never known!!

3:31 PM, May 25, 2010

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