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Engaging a 'scared population' of Huntington's disease families by respecting their journeys

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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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TUESDAY, APRIL 07, 2015

Engaging a 'scared population' of Huntington's disease families by respecting their journeys

The number of clinical trials for Huntington's disease treatments has increased exponentially, pushing up the demand for volunteers. Now advocates ask a pressing question: how to inspire more affected families and individuals to participate?

I have addressed this theme with increased frequency in recent years, as in my last two articles (click [here](#) and [here](#) to read more). As a carrier of the devastating HD mutation who saw his mother succumb to the disease, I feel in my gut the urgency to involve other members of the community.

"If no patients or gene-positive people show up for trial participation there will be no novel treatments, ever!" Daniel P. van Kammen, M.D., Ph.D., wrote in an e-mail in response to my articles.

For several years, I have maintained a dialogue on this topic with [Dr. van Kammen](#), from 2007-2011 the chief medical officer for [CHDI Foundation, Inc.](#), the nonprofit virtual biotech focused exclusively on developing HD treatments. A professor emeritus at the University of Pittsburgh, Dr. van Kammen currently serves as an independent consultant for central nervous system (CNS) clinical trial development.

"The notion that if you build it they will show up, just does not work!" Dr. van Kammen continued. "In general only 5% of people diagnostically eligible for drug development study participation, do so. This is fine for a large population with Alzheimer's. Not for the HD community either at risk or diagnosed. So people have to come forward."

As he indicated, there's a relatively small number of HD-affected individuals, estimated at 30,000 in the U.S. By contrast, as many as [5 million Americans over age 65 may have Alzheimer's](#).

Beyond that, a good number of HD-affected individuals cannot participate in clinical trials because of so-called exclusion/inclusion criteria. (I'll write about this issue more in a future article.) So that leaves an even smaller number of potential trial subjects.

The [Enroll-HD](#) program, the global platform, research project, and family registry aimed at facilitating clinical trials and the discovery of treatments, recently marked its 5,000th registrant but needs as many as 25,000 more volunteers.

People deciding at their own pace

Over my nearly two decades of advocacy – my mother was diagnosed in 1995 – I have learned that it's important to respect the unique journey of each individual touched by HD. Without that respect, we cannot begin to engage what Dr. van Kammen described as a "scared population."

[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](#)

From a pure research standpoint, the more at-risk people who test for the HD gene, the better. Despite the enormous psychological burden of *knowing* that I will develop HD, I don't regret undergoing genetic testing.

I often wish that more individuals from the untested at-risk pool – the vast majority of those people *don't* get tested – would also test and/or participate in programs such as Enroll-HD, which doesn't require that people learn their genetic status.

But then I remember how I wanted to get tested immediately after learning of my mother's diagnosis. I postponed the decision after receiving advice regarding the discriminatory consequences of testing, and, more than three years later, bit the genetic bullet because my wife and I wanted to know my status before starting a family. Six months later our daughter tested negative for HD in the womb.

What a journey!

When I meet people new to HD, I am aware that I can offer ample advice based on experience. However, I stick to the basics, allowing them to ask questions and share their stories and fears at their own pace. I remind myself that testing for HD is often an extremely trying process, with implications for the extended family. This personal decision requires time and reflection.

People new to HD are embarking on their own journeys based on their backgrounds and particular point in life.

The same respectful approach applies in encouraging people to attend a support group, visit the local HD clinic, participate in fundraising activities, and enrolling in studies and clinical trials.

The dynamics can be complex. In the face of HD, many families close ranks. However, many split, beset by fear, denial, and the stigma of HD.

Activists' self-respect

I have received enormous respect from my fellow HD advocates.

We activists must always remember to respect our own journeys.

At 55, I have passed the age of my mother's HD onset. Each day without symptoms is a gift.

To maintain self-respect, I must allay guilt about doing too little for the cause. I especially feel this way when missing a support group meeting or a local event of the [Huntington's Disease Society of America](#) (HDSA).

Lately I have also faced advocacy fatigue. However, seeing other, often less fortunate families suffer from HD – like the young man holding his HD-stricken grandmother or the family with members stricken by both adult-onset HD and juvenile HD – leads me to gird myself again for the fight. On April 11, at an HDSA educational event at the William W. Backus Hospital in Norwich, CT, I will share my story and the hope offered by the upcoming gene-silencing clinical trial planned by Isis Pharmaceuticals, Inc., and Roche.

In re-engaging, I remind myself that my journey is unique, too, with my own particular moments and needs.

Enjoying the present, planning the future

Twenty years into the cause and ever closer to disease onset, I need to focus on my health, enjoying life, and my family.

With a sabbatical from teaching duties, I am also writing a long-gestating book on Brazilian politics that I had partially put aside because of my work as departmental chair the past five and a half years and my developing interest in the history of science, technology, and medicine.

As our daughter approaches college age and my wife and I initiate conversations about retirement plans, we are also focusing on shoring up the family finances. As all HD families know, losing a working family member to the disease not only severely reduces family income but also creates a caregiving burden very costly in both time and money.

Luckily neither of lost our jobs in the Great Recession, but like many Americans in the eroding middle class we have received little or no increase in income during the recovery.

At 55, I also face the normal challenges of aging. Over the past eight months I have struggled with a nagging elbow pain that has prevented me from swimming, my preferred exercise and excellent for cardiovascular and brain health. Luckily, with my doctor's okay, I am back swimming, although the pain continues. Because of pain elsewhere in the body, I have spent many an hour at physical and occupational therapy sessions.

I want to remain as limber as possible to facilitate coping with HD symptoms (more on this in a future article).

I also continue to exercise my mind. As I wrote to an old friend regarding the recent [tenth anniversary of this blog](#) and its 200th article, "Writing for survival is my motto."

Affirming the good in our lives

Like many others in the HD community, my journey has deepened my search for spiritual meaning.

I have added another book to my morning meditation, *Gratitude Works!*, a book about gratitude journaling by Robert A. Emmons.






Writing regularly about the positive experiences in our lives promotes a shift in awareness from "what we are lacking to the abundance that surrounds us," Emmons writes.

"Gratitude leads us to affirm and acknowledge the good things in our lives," he adds.

Our community has immense suffering, but is also has immense good.


I am grateful for remaining asymptomatic today, for the many people bravely struggling to come to terms with HD, and for the great respect the members of the HD community have for each other as we live our unique moments together.

I'll be even more grateful when more people enroll in clinical trials. Yes, we may be a "scared population." But we may also be a "sacred population," one dedicated to a deeper purpose, helping to conquer this awful disease.

Posted by [Gene Veritas](#) at 10:03 PM     

Labels: [advocacy](#) , [at risk](#) , [clinical trials](#) , [Daniel van Kammen](#) , [denial](#) , [diagnosis](#) , [Enroll-HD](#) , [fear](#) , [genetic bullet](#) , [gratitude](#) , [Huntington's disease](#) , [journey](#) , [mutation](#) , [respect](#) , [spiritual](#) , [stigma](#) , [symptoms](#) , [untested](#) , [volunteers](#)

6 comments:

 **Anonymous said...**

Thank you for all you do to keep us up-to-date on Huntington's disease drugs in clinical development.

The link below is to a new article in Vancouver discussing the upcoming Isis Pharmaceuticals HTTRx clinical trials. It also highlights the assay for quantifying mutant Huntingtin manufactured by Promidis (which, as I recall, you highlighted in a previous blog entry).

<http://metronews.ca/news/vancouver/1333888/new-drug-for-huntingtons-disease-to-be-tested-in-vancouver/>


4:04 AM, April 08, 2015

 **Jimmy Pollard said...**

"Sacred," indeed.

Keep on keeping' on, my friend.

9:27 AM, April 08, 2015

 **Anonymous said...**

My husband has HD, and was all for joining trials, but as the disease progressed, involving mental illness, he has become unable to take part. Such a cruel disease, I urge anyone who is capable to help those that are not.

1:23 PM, April 08, 2015

 **Anonymous said...**

My 8 year old daughter is in rapid decline. I would love for her to participate. I understand the desire to protect children from the unknown but for terminal diseases I think that they should be allowed. All we have is hope. Another topic for another time perhaps.

3:53 PM, April 08, 2015




 **Unknown said...**

In a speech to an audience of researchers and HD families, my husband said, "Imagine a world without clinical trials. That would be a world without hope. A world with clinical trials gives us a reason to be hopeful." I share our community's desire that more at-risk individuals would be tested and volunteer for clinical trials. Knowledge will not change the future, but it can allow us to make realistic plans and offer us the opportunity to be pioneers in finding a cure for HD. HD may rob us of many things we value, but it offers us the chance to be generous and brave by helping to find a cure for HD.

7:35 AM, April 09, 2015



 **Unknown said...**

Great blog as usual. I personally find it quite to deal with the fact that hd sufferers who present with the mental manifestation of the disease are excluded from any trials at all.

Certainly in my experience this accounts for 50% of sufferers which reduces the 'pool' of volunteers even more. Bizarrely as well as then psychiatrists with no experience of hd often give them a cocktail of anti-psychotics, depressants, beta blockers and electric shock therapy, experimenting until they get the right combination of often powerful drugs which can make the hd symptoms worse. Sadly, have also found that the hd specialists often have little or no interest to in these patients (England)

2:00 PM, April 09, 2015

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