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Bin Laden and HD

Kenneth P. Serbin
University of San Diego

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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.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▼ 2011 (33)
 - ▶ December (2)
 - ▶ November (4)
 - ▶ October (4)
 - ▶ September (2)
 - ▶ August (1)
 - ▶ July (2)
 - ▶ June (2)
 - ▼ May (4)
 - [S.O.S. for Huntington's disease families, and an i...](#)
 - [Holding the potential cure in my hand](#)
 - [The Huntington's community rising and converging](#)
 - [Bin Laden and HD](#)
 - ▶ April (4)
 - ▶ March (3)
 - ▶ February (3)
 - ▶ January (2)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me

 [GENE VERITAS](#)

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MONDAY, MAY 02, 2011

Bin Laden and HD

Most Americans will always remember exactly where they were during the 9/11 terrorist attacks.

And most of us will probably remember exactly what we were doing when word came of 9/11 mastermind Osama Bin Laden's killing on May 1, 2011.

I was checking HD-related e-mail. "No bearing on HD... Thank God Osama Bin Laden is DEAD," read a message from a member of the Facebook discussion group called "HD Family."

I immediately jumped to CNN.com to confirm the report. I shouted the news to my wife in another room, where she was getting our 10-year-old daughter ready for bed.

"What a relief!" my wife and I told each other as I rushed to put the TV on CNN.

Riveted to the screen, we watched President Barack Obama's announcement.

I could feel the two of us being transported back nearly a decade, when we spent so many evenings in that same room anxiously watching the television and worrying what other atrocities Bin Laden might perpetrate upon the nation.

A cause hampered

In fact, Bin Laden *did* have an enormous – if not always direct – bearing on many facets of American life – including the cause to eliminate Huntington's disease.

In the economic boom of the 1990s, as scientists got their first inklings of possible treatments for HD in the wake of the discovery of the HD gene (1993), the cause started to build substantial momentum under the leadership of the Huntington's Disease Society of America (HDSA) and the Hereditary Disease Foundation.

Even the tech stock crash of 2000 didn't seem to threaten the promise of new research.

But Bin Laden's attacks on the World Trade Center and the Pentagon struck at the heart of our financial and military might. And, as I feared, they diverted the national focus towards security issues and away from philanthropic activities and medical research, both crucial in the fight against HD.

Thus, like many Americans, I took the attacks *personally*. For the first time that I could remember, I cried for our country.

HD Links

[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](#)

My worst fears

In June 1999, fewer than two years before 9/11, I had tested positive for HD. In January 2000 our daughter tested negative in the womb. So I was acutely aware of the threat posed by the defective huntingtin gene.

The 9/11 attacks seemed to dash all hope of a quick solution to HD.

I was angry at the Bin Laden terrorists for disrupting our lives and the promise of progress.

I felt especially forlorn about my own gene-positive status, because my mother, who had already been suffering from HD for at least a decade, was rapidly declining and could no longer talk.

As I told a friend at the time, my worst fears had come true: a cataclysmic event threatened to break the back of the nation, perhaps postponing the discovery of a treatment or cure to a date well beyond the start of my inevitable HD symptoms.

But, like the rest of the country, our local HDSA chapter somehow moved ahead, and we proceeded with our plans to raise awareness and funds.

On September 20, 2001, I volunteered at a fundraiser at a small amusement park that brought in \$5,000 for HDSA-San Diego. I remember the strange mixture of emotions as I hustled around the park and worried about terrorism.

Exactly one month after 9/11, I attended our chapter's very first Celebration of Hope Dinner. We raised almost \$63,000 – about \$10,000 more than our goal.

Generosity and terror

In December 2001, still caught up in the whirlwind of 9/11, I wrote an editorial for our chapter newsletter titled "Generosity and Terror":

The most immediate concern is about funding. The attacks quickly focused Americans' sympathies on the plight of the thousands of victims and their families. We mourn these horrible losses and support the efforts to bring the killers to justice.

The attacks also harmed our economy, and the outpouring of sympathy has diverted attention from many other charitable activities.

Government at all levels shifted its focus to dealing with the aftermath of the attacks and protecting the nation against future threats. We are at war. This all means that the government is spending – and will likely continue to spend for years to come – tens of billions of dollars for military defense and national security.

This combination of difficulties could undermine long-term philanthropic giving and reduce the level of activities of many charities and programs that fight disease.

But HDSA-SD supporters have suggested that the reality can and should be otherwise. Within weeks of the attacks they helped us raise tens of thousands of dollars. Other HDSA events went on as planned elsewhere. This is a resounding message that generosity and compassion will overcome the hateful politics of terror. The American spirit is to move ahead, no matter what the odds.

We thank those who have supported us during these difficult moments.

And we urge our leaders to remember that a great nation survives not

only with a strong defense, but through the continuation of its programs for the betterment of human life. That includes funding for the National Institutes of Health and other initiatives against disease. In the campaign against terror we must not lose our public soul of domestic concern and generosity by overspending on weapons.

Strong health is our most basic prerequisite for survival as a nation. In the fight to stop disease, the test tube will topple terror, MDs will outlast murderers, and veneration of life will overcome the cynicism of violence.

Ups and downs of philanthropy

American charitable giving slumped from 2001 to 2003, but grew to record levels by 2007.

During the early 2000s downturn, HDSA also took a hit. Previous, ambitious plans for a \$20 million annual budget fell by the wayside. Public advocacy languished. And, for a number of reasons, HDSA fell into financial disarray. Only now is financial stability in sight.

Under new leadership, HDSA is seeking to reconfigure itself as a community service organization for HD families. (May is [Huntington's Disease Awareness Month](#), and I'll be writing soon on HDSA's outlook.)

CHDI: a godsend

Meanwhile, in the past six years the [CHDI Foundation, Inc.](#) has invested heavily in potential treatments and a cure. Its budget will reach an estimated \$100 million this year.

Informally known as the "cure Huntington's disease initiative," CHDI has been a godsend for the HD community. It is partnering with biotech companies, the government, and academic labs to speed up the hunt for effective drugs.

Thanks to a wealthy, anonymous donor, CHDI has kept spending at high levels despite the deep recession of 2007-2009, occasioned by a record drop in charitable giving that dwarfed the post-9/11 slump.

Thus, while in the short run Bin Laden's attacks impacted the HD cause, in the long run the emergence of CHDI trumped terrorism.

In 2001 the 9/11 attacks had caused me to lose much of my hope for an effective treatment or cure. In 2011 I now have a level of hope previously unimaginable – in terms of the organizational and financial commitment to the cure *and* the research progress.

Unity and ingenuity

In his speech about Bin Laden's killing, President Obama appealed for a renewal of national unity and reminded Americans that we "can do whatever we set our mind to."

Listening to the president, I felt proud to be an American and rejoiced in his optimism about our future.

American ingenuity can bring about better care for our HD patients and their families and the treatments that I and tens of thousands of other gene-positive and HD-affected people so desperately need to stave off the devastation of our brains and eventual premature death.

On May 6, I will travel to Sacramento, CA, to interview a team of scientists working on a potential Huntington's disease stem-cell treatment under the leadership of [Dr. Jan Nolte](#). The next day I will deliver a speech on my experiences as a gene-positive HD activist at the annual convention of

HDSA's Northern California Chapter.

On May 17, I will give a similar speech at [Alnylam Pharmaceuticals](#), which aims in the next year or so to begin Phase I clinical trials for a potentially revolutionary HD treatment.

HDSA, CHDI, Dr. Nolta, Alnylam, and so many other scientists could together change the history of Huntington's disease and of science and medicine.

It took America ten years to get Bin Laden. With similar determination we can defeat Huntington's disease in the next ten years.

Posted by [Gene Veritas](#) at 3:36 PM     

Labels: [9/11](#) , [activist](#) , [Alnylam](#) , [awareness](#) , [CHDI](#) , [CHDI Foundation](#) , [cure](#) , [daughter](#) , [drug](#) , [gene](#) , [gene-positive](#) , [Huntington's](#) , [Jan Nolta](#) , [mother](#) , [National Institutes of Health](#) , [symptoms](#) , [tested positive](#) , [treatment](#) , [wife](#)

6 comments:



 **[Rob Millum](#) said...**

Gene only you would be organized enough to have your newsletter article from 10 yers ago. It was relevant and is another demonstration of your relentless pursuitof a cure!

[6:56 PM, May 02, 2011](#)



 **[Mike Anthony](#) said...**

Lets have a Cure Like Yesterday Gene :O}

[4:18 PM, May 03, 2011](#)



 **[Sharon](#) said...**

I remember when the marker was first discovered. My husband (who is now deceased) had been diagnosed with HD; we felt certain that a cure would be found within 10 years. Now our son is 25, HD+, already showing symptoms, and I just hope and pray that treatments and a cure are a whole lot closer than another decade away!

[6:10 PM, May 03, 2011](#)



 **[Unknown](#) said...**

I am so curious to know who the wealthy, anonymous donor to CHDI is. Thank God for them!

I do believe we can defeat or at least treat Huntington's disease within the next decade. It is truly possible.

Thanks for the great article, Gene.

Linda Ingle

[10:59 AM, May 04, 2011](#)



 **[Mike Anthony](#) said...**

We Thank God for that silent donor.:O}

[5:11 PM, May 04, 2011](#)

 **[Mike Anthony](#) said...**

We Thank God for that Anonymous Donor :O}

5:12 PM, May 04, 2011

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