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Care versus cure: we can progress in both

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.

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HD Links

[Huntington's Disease Society of America](#)

WEDNESDAY, MAY 05, 2010

Care versus cure: we can progress in both

If you faced a deadly, untreatable disease that would leave you completely dependent on others, where would you want more resources to be invested – in *care* for you or in research for a *cure*?

In a nutshell, that's one of the biggest dilemmas facing the Huntington's disease community. Because HD attacks the brain and leaves people unable to walk, talk, eat, or perform most of the other basics of a normal life, they frequently require the kind of *care* that a toddler gets.

But if HD people and their families are to have any kind of hope, the search for *effective treatments* and a *cure* remains equally essential. Now, with a robust new research entity and a longstanding advocacy group ready for renewal, there is more opportunity than ever for both care and cure.

A personal stake in the debate

I have personally lived the tensions of care-versus-cure: my mother died of Huntington's in 2006 after nearly 20 years fighting the disease, and I tested positive for it in 1999.

I wanted my mother to have the best care available. Sadly, however, no specialized resources for HD existed in her county, and my father, although he cared for Mom at home almost until her death, never fully understood the disease.

I also wanted the cure to come as quickly as possible. For years I urged my father to help keep my mother as healthy as possible through exercise, proper diet, and supplements so that she might still benefit from a major breakthrough in the research. And, of course, I myself wanted to avoid the symptoms of HD.

In my own situation I have emphasized cure over care. In 1993, just two years before my mother's diagnosis, researchers discovered the HD gene. Euphoria about the possibility of a cure followed; the [Huntington's Disease Society of America](#) (HDSA), under the able leadership of Barbara Boyle, stressed research more than ever before.

While many people like me jumped on the research bandwagon, others complained about HDSA's apparent lack of attention to care. As a result, the organization established a national network of so-called Centers of Excellence for Family Services and Research. Today HDSA has 21 centers in 17 states, including three in both New York and California.

These centers brought care solidly back into the HD equation. They serve as a major resource for HD-affected families.

HDSA at the crossroads

[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](#)

Today HDSA and the HD community stand at a crossroads.

In the mid-2000s a generous anonymous donor who had supported HDSA and also the HD-oriented Hereditary Disease Foundation (HDF) of Los Angeles decided to intensify the search for a cure. Thus began a new initiative, known as [CHDI Management, Inc.](#) Unofficially, CHDI stands for "Cure Huntington's Disease Initiative." In 2008 alone, CHDI pumped \$80 million into drug-discovery efforts.

Although HDSA continues to sponsor important research, CHDI's leadership in that area has raises questions about HDSA's ongoing focus. Should HDSA now emphasize care over cure?

The renewed debate comes at a key moment; Louise Vetter, who took the helm of HDSA in March 2009, is taking a fresh look at the organization and the movement it represents.



Louise Vetter at the CHDI conference in Palm Springs, CA, in February (photo by Gene Veritas)

This month of May – Huntington's Disease Awareness Month – provides an opportunity for our community not only to tell the world about the deadly ravages of HD, but for everybody touched by HD to reflect on his or her personal situation and involvement in the movement.

Crying out for support

At my local support group meeting on April 26, I could see all of these issues crystallizing before my very eyes.

Surprisingly, many people in the HD community know little about CHDI's efforts. I gave a quick description of its program. People in the support group seemed pleased and impressed to learn that a very substantial private initiative had come to their aid.

I also suggested that CHDI's concentration on research gave HDSA a big opportunity to emphasize care and family services. I used to be all "cure," I said, but now I was shifting back towards "care."

The support group participants appreciated the need for a national entity such as HDSA to guide and organize the HD movement's activities.

From the passionate debate that ensued at the meeting, it became painfully apparent that many families desperately need help. Some attendees pointed out the woeful lack of Spanish-language materials, websites, and support groups. (In fact, information is needed in many other languages, too.) Speaking through a translator, one woman came to tears as she explained her struggle to obtain assistance for her HD-stricken relatives.

Local needs

Another long-simmering issue came to the forefront: financial support for the local chapters and Centers of Excellence. People understood the need to support the national organization – a common practice in the world of non-profits – but they also want greater assistance for local activities.

I have noticed over the years that our local Center of Excellence at the University of California, San Diego, needs more people and resources in order to reach out more effectively to our local HD community and to perform a myriad of other services. The people there are overworked! They do an excellent job of recruiting people for clinical trials and other research studies. But we also need to remember that nationally a shortage of subjects exists.

For their part, local chapters need advocacy training and additional staff or volunteers to assist with their many activities, including fundraising, website development, and community relations.

Grassroots action

I stressed to the group that we *all* make up HDSA, and we at the grassroots – the affected, families, caregivers, health workers, chapter board members – must speak out if the organization is to fully grasp our needs.

We also need to get families hidden in the woodwork to participate in clinical trials, support groups, and other vital activities such as fundraising events.



Alleviating suffering

"Care 2Cure" is the phrase indented on the official blue HDSA bracelet (pictured above in the photograph taken by Mike Nowak). This phrase echoes the ongoing debate over care-versus-cure, but also their shared importance in the campaign to alleviate the suffering caused by Huntington's disease.

As our community plans for the future, it's time to imagine a renewed HDSA that recaptures the spirit of its original purpose to support HD families and advocate for them in the public arena. We must also recognize the long road of progress traveled in search of the cure.

But none of this will matter if we as individuals and families don't join the fight and make our voices heard.

Posted by [Gene Veritas](#) at [12:27 PM](#)      

3 comments:

Susan Elaine said...

Great Article. I'm glad to see that the efforts of the researchers and doctors are becoming more recognized in direct relation to the progress. For so long, I had no idea who these "Ghost Researchers" were, and how the funding was being appropriated. Today, there is more of a direct connection between the HD Community and the HD researchers. Seeing the collaboration has given me the greatest sense of "HOPE" I've had in a long time. Thanks for your blogs and your recognition to all of the areas that not only have a role, but have a stake in it as well.

Susan

[1:51 PM, May 05, 2010](#)

Ryan McKenzie said...

You make some really great points. My sister was diagnosed with Huntington's disease in 2006 at the age of 11 and I've watched as her symptoms progressed. I've watched as my

mother was forced to work less and less to care for her.

However, even though things have gotten worse for her and the levels of care for her could always be improved, I am still VERY pro research. I, probably nearly as much as you, would like to see some sort of resolution to this devastating genetic disorder sooner than later.

I am a founder of a relatively large crowd sourced content web site, and we've recently launched a means for regular people who might not have the money to donate, a venue to help raise money. People can help fund raise for Huntington's by simply signing up, writing an article and clicking the button that states they want this article's revenue to go to charity. We launched this earlier today, and of our 13,000 members, we've already had over 300 articles contributed to help raise money for Huntington's disease.

It looks like you are busy with this blog, but if you have a moment to swing by InfoBarrel and either create some content for charity, or encourage your readers to do so, it would really help the cause. We will be donating the money to the Huntington Society.

Feel free to email me as well at ryan.mckenzie [at] gmail [dot] com

8:31 PM, May 05, 2010



Unknown said...

This is Hannah Bevills, I am an editor with Hospital.com. We are a medical publication whose focus is geared towards promoting awareness on hospitals, including information, news, and reviews on them. Given the relevance of what you are offering from your site and what our mission is, I feel we may be able to collaborate in some way or another, I look forward to your response regarding the matter. Thanks!

Hannah Bevills
hannah.bevills@gmail.com
Hospital.com

9:25 AM, May 20, 2010

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