

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

2-21-2012

It's time for the Huntington's community to speak out - and HDSA is listening

Kenneth P. Serbin
University of San Diego

Follow this and additional works at: <https://digital.sandiego.edu/huntingtons>



Part of the [Nervous System Diseases Commons](#)

Digital USD Citation

Serbin, Kenneth P., "It's time for the Huntington's community to speak out - and HDSA is listening" (2012).
At Risk for Huntington's Disease. 123.
<https://digital.sandiego.edu/huntingtons/123>

This Blog Post is brought to you for free and open access by the Department of History at Digital USD. It has been accepted for inclusion in At Risk for Huntington's Disease by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.

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)
 - ▶ December (2)
 - ▶ November (3)
 - ▶ October (1)
 - ▶ September (2)
 - ▶ August (2)
 - ▶ June (2)
 - ▶ May (1)
 - ▶ April (2)
 - ▶ March (3)
 - ▼ February (3)
 - [It's time for the Huntington's community to speak ...](#)
 - [The quandary of denial in the Huntington's disease...](#)
 - [The quandary of denial in the Huntington's disease...](#)
- ▶ January (5)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me

 [GENE VERITAS](#)

[View my complete profile](#)

TUESDAY, FEBRUARY 21, 2012

It's time for the Huntington's community to speak out – and HDSA is listening

The HD community has a golden opportunity to both strengthen and shape the future of the [Huntington's Disease Society of America](#) (HDSA) and its mission of care and cure – a mission that some grassroots advocates have seen as not fully encompassing their concerns and struggles.

With a deadline of February 24, a task force of the HDSA Board of Trustees seeks feedback on a proposed strategic plan for the years 2012-2016.

“Before the Plan is finalized and implemented, we want to receive input from *all* interested members of the community,” HDSA CEO Louise Vetter wrote in a letter posted on the HDSA website. The letter contains a link to the plan. A feedback form is located at the end of the letter. [Click here](#) to read the letter.

“The Strategic Planning Task Force spent hundreds of hours over 18 months conducting data review, community surveys, and holding discussions with individuals from every constituency of the HD community,” Vetter stated in the letter. “They used this information to assess the business of HDSA and develop this Plan for the growth of the Society, so that we can provide more services to families affected by HD and fund more research that can improve our knowledge base on HD and therefore lead us closer to effective therapeutic interventions.”

The task force included Vetter, HDSA Board of Trustees Chairman Donald Barr, and four other board members.



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](#)

HDSA CEO Louise Vetter and Board of Trustees Chairman Donald Barr (photo by Gene Veritas)

As the [2011 HDSA Person of the Year](#) and a former board member of the San Diego chapter, I urge everybody in the HD community to become familiar with the plan and provide comments. While the Board of Trustees and the HDSA professional staff in New York City perform key leadership functions, the chapters and volunteers are the lifeblood of the organization.

We are HDSA, and it's up to us make our voices heard.

Below I present an outline of the plan as well as my own suggestions for improving it.

Plan introduction: balancing care and cure

The first eight pages of the 39-page document provide an overview of HDSA's values, mission, and community.

As the document states, the organization's last strategic review took place in 1998 – well before dramatic advances in both communications and science. Since then, scientists have come much closer to understanding HD. We now stand on the verge of revolutionary clinical trials.

It's important to point out that the [CHDI Foundation, Inc.](#), the so-called "cure HD initiative," which spent approximately \$100 million in 2011 and has a far more narrow focus than HDSA, has emerged as the non-governmental sector leader in developing potential treatments ([click here to read more](#)).

HDSA's current budget is approximately \$8.5 million. According to the [2009-2010 annual report](#), 26 percent of the budget went to family services, 20 percent to fundraising, 20 percent to chapter development, 17 percent to education, ten percent to management and general expenses, and just seven percent for research.

Those amounts are a far cry from the early 2000s, when HDSA annually spent millions on research.

Vetter told me in an interview in May 2011 that HDSA will strive to increase its budget to as much as \$20 million. For now, however, the proposed strategic plan aims for more modest annual increases of five percent, with a goal of raising \$10.2 million in 2016.

Despite CHDI's massive investment in research, the HDSA plan proposes a continued commitment to both "care" (services, education, and advocacy) and "cure" (research). As I discuss below, HDSA aims to launch a new research program, which would complement research done by CHDI and also the [Hereditary Disease Foundation \(HDF\)](#).

I agree that HDSA should continue to sponsor research, but I believe it should also invest more in other areas.

In the past, HDSA has primarily supported *basic* research, that is, research that leads to a deeper understanding of the disease but not necessarily to immediate application as a treatment or cure. CHDI now focuses on what is called the "treatment pipeline," the search for ways to delay or halt the progression of HD using the knowledge of basic research created by others but also through its own projects.

Of course, in this fast-paced era of biotechnology, the line between basic and applied research has becoming increasingly blurred. Frequently, scientists can quickly turn new basic knowledge into a strategy for a treatment or cure. In this respect, the HDSA plan for continued research

makes sense. CHDI and the HDF will continue to perform the bulk of the research, but HDSA-sponsored research will likely turn up new clues and perhaps even potential treatments.

The more brains we have working on treatments and a cure, the better our chances of success.

A community service organization

Crucially, the strategic plan recognizes the key part played by HDSA's 21 Centers of Excellence in providing assistance to HD patients and their families and serving as a focus for patient research and clinical trials. The creation of the Centers has given greater visibility and some additional funding to local HD clinics around the country, practically all of them associated with universities. Annually the Centers each receive about \$50,000 in support from HDSA.

"The Society will seek to enhance the Centers' role in clinical research by creating linkages with the new research program," the document states. "Imagine if a basic scientist who was used to testing hypotheses in mice could finally test a theory on human blood samples made possible by a Center of Excellence?"

The plan involves expanding "care" from "family" services to "community" services.

"HDSA is committed to offering programs that can have the broadest impact and affect the most lives," the document states.

The meaning of expanded care

In my opinion, the shift in emphasis from "family" to "community" stands out as the most important aspect of the plan. In light of CHDI's emergence, I believe that HDSA can best support the cause by focusing on services to HD families, raising awareness, and recruiting individuals for research studies and clinical trials.

Indeed, the second part of the plan (pages 9-13), which outlines the seven major goals of the strategy, begins with "Goal I: Build an *HD Community-service organization*."

To achieve this goal, the document sets forth four "core strategies": 1) expanding access to clinical care; 2) enhancing social services and support resources; 3) improving access to long-term care facilities skilled in HD; and 4) increasing access to counseling.

To implement these goals, the plan proposes a series of actions. I'd emphasize two: the strengthening of the Centers of Excellence and the "development of a regional network of social workers to augment the existing National and Field-based social workers."

The staffs of the Centers and social workers regularly come into close contact with the patients and their families. They provide the vital services and first-hand information that families so desperately need in the fight against HD. And, as HDSA recognizes, the Centers stand in the best position to help implement clinical trials.

The next six goals support the idea of community service: support of HD research, removing barriers to quality care (legislative advocacy), communication, expansion of the volunteer base ([click here](#) to read my previous analysis of this question), operating in a fiscally sound manner, and fundraising.

Trying too hard to catch up on research?

Despite the emphasis on community service and the clear movement away from pitting care against cure, the document left me with the strong impression that the task force has thought more about questions of research and less about other organizational needs such as advocacy and volunteer recruitment.

While the task force established yearly goals for all seven of the major strategic goals, it included an appendix only for research – a three-page synopsis of an HDSA research planning meeting held in April 2011. In this section (pages 37-39), I could sense the renewed commitment of HDSA to make a difference in HD research.

There and elsewhere in the plan, the task force mentioned the need to hire a “medical-scientific director to oversee and coordinate research programs.” The director would help lead HDSA’s efforts to educate the community about the importance of clinical trials and “deepen our partnerships” with other organizations seeking treatments and a cure.

The plan seems solid, in part because it gives the medical-scientific director the task of education on clinical trials.

Furthermore, the document reveals that the national board aims to end a difficult situation of delinquent payments to researchers – a situation that practically brought the Coalition for the Cure research program to a halt. According to the 2009-2010 annual report, the seven percent of the budget that backed research amounted to just \$370,000. In informal conversations, I have heard that HDSA spent practically nothing on research in 2011.

Fortunately, CHDI’s large investment in research has counterbalanced HDSA’s diminished role.

However, precisely because of CHDI’s huge role in research, grassroots volunteers might wonder why other areas of the strategic plan did not receive a more detailed plan of action, not to mention the possibility of hiring, when possible, additional specialized personnel in areas such as advocacy and volunteer recruitment.

Local needs

As [I wrote previously](#), “I believe it’s implicit that the chapters and volunteers, as usual, will need to take the initiative locally” with respect to volunteer recruitment and other activities.

To cite just two examples of local need: HDSA should increase funding to Centers of Excellence for programming and staffing, and the all-volunteer chapters could also benefit greatly from increased clerical and other paid staff support.

As someone who came to HDSA through a support group, I would have liked to see a more detailed discussion of these groups’ importance.

I agree with the plan’s assertion that “personalized support, like financial aid or case management, for every family facing HD is not realistic for the Society given our budget.” Nevertheless, I definitely believe that, along with our families, HDSA should brainstorm on how to help relieve the tremendous and often financially crippling care burden of HD. One possibility frequently mentioned in HD Facebook discussions involves support for local, private assistance initiatives. HDSA could partner with these initiatives and help raise their profile.

As a disease community, we need to become more creative in these areas – including better information for families seeking specialized nursing home care for their loved ones.

Communications and advocacy

I believe that the plan overreaches by aiming to make HDSA the “premier communicator of HD information.”

The community obtains information from a wide variety of sources. Hundreds (if not thousands) of families rely on HD Facebook communities and other sources of HD news. So far, HDSA's presence on Facebook is limited, although the strategic plan briefly mentions the need to expand the use of the social media for advocacy and fundraising. HDSA might also promote a communications network in which it can play a key coordinating role.

In conjunction, it could form a kind of “HD news service” in which volunteers could report on HD issues in their local communities and share news items and articles with the national organization.

While HDSA has made important strides in advocacy, I believe the organization should invest even more in this area and assure long-term continuity of specific programs and initiatives. In recent decades, the organization has too often started from scratch, leaving the volunteer base confused and making advocacy inefficient. The organization also should promote greater awareness of the history of HDSA as an entity founded by a great HD advocate – Marjorie Guthrie – and partly dedicated to the memory of another great advocate of humanity – her husband Woody Guthrie.

Optimism – if we participate

I am optimistic that HDSA can reach these many goals and inspire people to become active.

We need to keep in mind that HDSA has limited resources – but also that, ultimately, we grassroots activists, volunteers, support group members, chapter board members, relatives, friends, and supporters are the organization's most important resource.

To its credit, the HDSA Strategic Planning Task Force has defined its plan as an “active, living document” to be “reviewed regularly to revisit timelines, push progress and help the Society evaluate opportunities.”

Let's not pass up *this* unique opportunity to express our opinions and make a real difference in the future of HDSA.

In my previous article, I mentioned that the *A Physician's Guide to the Management of Huntington's Disease* was not available online. HDSA will put the guide online following the [2012 national convention](#), June 8-10, in Las Vegas.

Posted by [Gene Veritas](#) at [10:09 PM](#)      

Labels: [advocacy](#) , [advocate](#) , [awareness](#) , [biotechnology](#) , [brain](#) , [care](#) , [Center of Excellence](#) , [CHDI](#) , [clinic](#) , [clinical trial](#) , [counseling](#) , [cure](#) , [grassroots](#) , [Hereditary Disease Foundation](#) , [treatment](#)

2 comments:

Anonymous said...

You wrote it gene- I believe that the plan overreaches by aiming to make HDSA the “premier communicator of HD information.”

The big reason why my family wont support them anymore they push everybody away and only want to be in charge. My

family read the plan and shame on them and God bless all of our community family.

6:10 AM, February 22, 2012

🌸 Ruth Stanton said...

Thank you so much for helping me digest this 39 page document. Stay tune for an upcoming USA Today article on Kristen Powers on her choice to document her genetic testing journey -- Twitch: The Documentary (google on Kristen Powers and Twitch: The Documentary for more info).

1:37 PM, February 22, 2012

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

Subscribe to: [Post Comments \(Atom\)](#)
