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Making sense of Huntington's organizations, and a call for unity

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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)
 - [Huntington's disease in the news and entertainment..](#)
 - [Huntington's disease and the financial jitters](#)
 - [BDNF and 'Neurobics': building a 'beautiful mind' ...](#)
 - [Making sense of Huntington's organizations, and a ...](#)
 - ▶ September (2)
 - ▶ August (1)
 - ▶ July (2)
 - ▶ June (2)
 - ▶ May (4)
 - ▶ April (4)
 - ▶ March (3)
 - ▶ February (3)
 - ▶ January (2)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

MONDAY, OCTOBER 03, 2011

Making sense of Huntington's organizations, and a call for unity

HDSA, HDF, HDDW, CHDI: a mini alphabet soup of Huntington's disease organizations serves the families afflicted by this devastating brain disease, leaving at least some people confused about each entity's purpose.

While these organizations often collaborate admirably in their common goal of treatments and a cure, they sometimes conflict, competing for attention and resources and/or disagreeing about the best approach to stopping HD.

Sometimes that conflict occurs *within* an organization, for example, between the grassroots and the leadership.

These patterns are only human, and they apply even to enterprises striving for the utmost in objectivity, including the doctors and scientists seeking to unravel the mysteries of HD.

My experience

I've observed and participated in conflicts ever since I formally joined the HD movement in April 1998. In the San Diego chapter, we tried our best to put the cause ahead of politics. In cases of conflict with the national office, we acted according to what we saw as the best interests of our local HD community.

Lately I've read complaints in HD Facebook discussion groups about, in the words of one veteran of the HD movement, an "obvious disconnect between the HD community and the HDSA at a national level as voiced in numerous posts online."

I aim here not to judge or analyze any particular conflict, but, instead, to provide a brief outline of the specific goals of HDSA – the largest and best-established group – and the other HD organizations.


Gaining perspective

I want to help clear up the confusion of the alphabet soup – and suggest how the apparent "disconnect" might be repaired.

I believe that we act most effectively, and harmoniously, when equipped with accurate information and historical perspective. Providing perspective is part of my job as a professional historian. We cannot plan the future without understanding the past.

I've studied carefully and have had contact with all four organizations: as an HDSA chapter board member and 2011 HDSA Person of the Year; as a regular correspondent with one of the HDF board members and a student of its activities; as a participant in an HDDW observational trial and collaborator of the organization's founder; and as the keynote speaker at

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the 2011 CHDI research conference.

I recognize the powerful influence of my own perspective on this article: as an HD-positive person whose mom died of the disease in 2006, I desperately await a treatment that will save me from losing my mobility and my mind. I expect conflict and even welcome certain kinds of it; opposing ideas often meld into a better one.

But conflict should not lead us to splinter off into so many different directions that we dissipate our energies and lose momentum towards our ultimate goal. I believe that our community must stay focused on care and ultimately the cure. If not, the HD-affected and HD-positive are doomed.

HDSA

HDSA (the [Huntington's Disease Society of America](#)) was founded in 1967 by Marjorie Guthrie, the widow of folk singer and political activist Woody Guthrie, the most famous American to die of HD.

The very first organization to support HD families, HDSA began as a series of support groups and remains the only organization to offer such help. In the Guthrie tradition, HDSA advocated for HD families and, in the 1970s, helped push Congress to set up a commission to study how to eradicate HD.

After the discovery of the huntingtin gene in 1993 created the possibility of effectively treating HD, HDSA emphasized greater fundraising for scientific research. In 1997 it created the "[Coalition for the Cure](#)," which funded HD research projects to the tune of millions of dollars. Scientists competed for grants based on their qualifications and peer review, that is, a careful examination of their proposals by other scientists. Between December of 2005 and January of 2005, HDSA's "Generation 2000" program brought in \$23 million for the Coalition ([click here](#) to read more).

Initially, some in the HD community became angry that HDSA had deemphasized its primary mission of supporting care for HD patients and their families. Partly in response to this, starting in the late 1990s HDSA created Centers of Excellence for Family Services and Research, which gave greater visibility and some additional funding to local HD clinics around the country, practically all of them associated with universities.

With the founding of the CHDI Foundation, Inc., in 2003 (see below), HDSA's role in research diminished substantially. Although it continues to fund some important research, it focuses largely on chapter development, education, family services, fundraising, and advocacy.

HDSA, headquartered in New York City, has a number of development field officers and assistants in various regions of the country. But the organization's lifeblood is the thousands of individuals active in some 40 chapters and affiliates and 21 Centers of Excellence: affected family members, support group members, volunteers, physicians, nurses, social workers, and others.

In late June, a record total – more than 1,000 people – took part in the 26th annual HDSA convention in Minneapolis, an indication of the organization's grassroots strength.

At the same time, however, some in the community have criticized the national office in what they see as its inability, or unwillingness, to back local projects or provide assistance to financially strapped families.

Some have also questioned why such a small portion of the HDSA budget goes to research – just seven percent (about \$370,000), according to the [2009-2010 annual report](#). That is a far cry from the early 2000s. Research is the smallest part of the budget, with 26 percent going to family services,

20 percent to fundraising, 20 percent to chapter development, 17 percent to education, and ten percent to “management and general.”

As illustrated below, the CHDI Foundation now provides more research dollars in one year than HDSA did in a decade.

In an interview with me in May, HDSA CEO Louise Vetter acknowledged that the organization’s national board recognizes the need for local assistance but, with a current annual budget of only \$8.5 million, lacks the wherewithal to help more than it currently does ([click here](#) to read more). She added that HDSA is striving to increase the budget to as much as \$20 million. A bigger budget would allow HDSA to increase support for both research and local projects.



Louise Vetter (photo by Gene Veritas)

Despite these frictions, HDSA remains the “go-to” organization for HD families.

In conjunction with the Centers of Excellence, HDSA is the only organization that provides the large array of services essential to the HD community: clinical care, genetic counseling, genetic testing (with an established protocol), support groups, educational and other chapter events, chapter fundraisers, public and legislative advocacy, caregiver assistance, medical publications (including the important *Physician’s Guide to the Management of Huntington’s Disease*), and the administration of highly crucial clinical trials and observational studies.

(No HD organization provides nursing home care or any published guide on how to find a good facility. Families often must choose a facility for their loved ones on their own.)

HDF

Founded by psychoanalyst Milton Wexler, the HDF ([Hereditary Disease Foundation](#)) began in 1968 as the Los Angeles chapter of HDSA. In 1974, Wexler broke off from HDSA to formally start the HDF.

The HDF arose out of the very first major conflict in the HD movement. Wexler, the husband of an HD-affected woman and father of two at-risk daughters, started his own foundation because he believed private research funding, and not just the government support sought by Marjorie Guthrie, should play a part in the quest to find treatments. His and Marjorie's strong personalities also clashed.

HDF established offices at the Wexler family base in Los Angeles and also in New York. As a scientific foundation, it had no chapters, support groups, or clinics. It had one goal: to promote research towards treatments and a cure. Towards that end, Milton Wexler held seminars with some of the leading scientists of the late twentieth century.

Like the HDSA, the HDF issues grants on a competitive basis. Its single focus allowed it to put a high level of funding in research. In 1990, for example, it spent almost \$600,000 on research – nearly double the amount of HDSA.

The HDF spearheaded the search for the all-important gene that indicates HD. Wexler's daughter Nancy, a Ph.D. in clinical psychology, spent years collecting thousands of blood samples from the world's largest HD extended family in Venezuela.

This research led to the discovery, in 1983, of a genetic marker for the HD gene, thus permitting the development of indirect genetic tests indicating a person's probability of carrying the defective huntingtin gene. In 1993 the actual location of the gene was discovered, leading to a 100-percent accurate genetic test. ([Click here](#) to read more about Nancy Wexler.)

To a large degree, Nancy Wexler and the HDF's work laid the basis for a revolution in HD research over the past two decades. In the 1990s and early 2000s, HDF began efforts to discover specific treatments.



Nancy Wexler (left), the late Milton Wexler, and Alice Wexler (photo by Mariana Cook)

Toward that end, in 1997 the HDF foundation received a “substantial anonymous gift” to set up an internal program known as “The Cure Huntington's Disease Initiative” (CHDI). (This first CHDI should not be confused with the current CHDI Foundation.) According to the HDF summer 2002 newsletter, “the CHDI approaches HD as a problem in practical drug discovery.” It supported research projects for “studying potential new drugs, developing screening methods for quickly assessing the effectiveness of new drugs, and studying the mechanism of disease and potential drug targets” ([click here](#) to read more).

In 2003, with CHDI picking up steam, the HDF put more than \$20 million into research ([click here](#) to read more).

But, like HDSA, the HDF has seen better times in terms of its finances. According to the winter 2010 HDF newsletter, the foundation last year awarded \$800,000 in grants and contracts ([click here](#) to read more) – less, in real terms, than its 1990 amount. Again, the presence of the CHDI Foundation, discussed below, partly explains this decline.

Despite their initial differences and later frictions, HDSA and HDF maintained a reasonable working relationship.

Today HDF remains on the cutting edge of HD research, attracting great attention from the scientific world at its biennial meetings.

Nancy's older sister Alice chronicled the early story of the HDF and her family's struggle against the disease in the acclaimed 1995 book *Mapping Fate*, from which I have drawn some of the information for this vignette of the HDF. In 2008, she published another important book, *The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease*, which helps to explain why HD carries such a terrible stigma.

Everybody in the HD movement should read Alice Wexler's books.

HDDW

HDDW (Huntington's Disease Drug Works) started in 2003 under the leadership of Dr. LaVonne Goodman, a physician to HD families and the president of the HDSA Northwest chapter, and her husband Dr. Nathan Goodman, one of the participants in the historic Genome Project. HDDW is based in Seattle. It has no chapters, support groups, or family services.

While HDSA and HDF sought a long-term solution to HD, the Goodmans instituted a "treatment now" program using safe supplements and medications approved by the federal Food and Drug Administration for other conditions and shown to be effective in HD mice.

For several years, Dr. Goodman monitored a small group of HD patients, but without conclusive results.



Dr. LaVonne Goodman (photo by Gene Veritas)

I have taken the supplements for about six years and, although there is no scientific proof that they have helped me, I remain free of the classic symptoms of HD ([click here](#) to read more about my strategies for avoiding HD).

Because Dr. Goodman questioned the conventional wisdom of HDSA and many scientists and doctors, she stirred controversy. She even had to resign as a chapter president.

Several years later, however, Dr. Goodman resumed her collaboration with HDSA and has been a featured speaker at the national convention. She chairs the Northwest chapter's efforts in family services and education. She has also collaborated with CHDI and the Huntington's Study Group (HSG), an international coalition of physicians and researchers conducting HD research.

The mother of two at-risk children from a previous marriage, Dr. Goodman today attends to several dozen HD patients in the Northwest.

She now focuses on preparing the community for clinical trials, absolutely essential for testing potential drugs for safety and efficacy. On July 30, she co-organized the [Inaugural Clinical Research Symposium](#) in Seattle with support from the Northwest chapter and the pharmaceutical firm Lundbeck.

Dr. Goodman is also working to establish HD "standard of care guidelines" to supplement HDSA's *Physician's Guide* by taking into account care strategies utilized by HD experts around the world. According to Dr. Goodman, the new guidelines "can improve the quality of care delivered by busy doctors who have limited HD experience and need time-efficient guides" ([click here](#) to read more).

CHDI

The [CHDI Foundation, Inc.](#), grew out of the HDF's CHDI program. It is backed by the same anonymous donors.

In the HD community, the CHDI Foundation is probably the least known of the organizations, despite its enormous impact since arriving on the scene in 2003.

Like the HDF, the CHDI Foundation focuses on one goal: finding treatments and a cure for HD. It has offices in three cities, but no support groups, chapters, or family services. The foundation's goals are implemented by CHDI Management, Inc., presided over by Robi Blumenstein, an attorney who built a successful career in merchant banking.

In addition to the HDF, the anonymous donors had previously provided support to the HDSA. In each of the past several years the CHDI Foundation has donated \$1.2 million to HDSA.

The donors, however, wanted to try a different research approach from those of HDSA and the HDF and decided to start a new organization.

With the establishment of the foundation and its management firm, the acronym "CHDI" no longer had any official meaning, although in this blog I have continually referred to its original meaning, the "cure Huntington's disease initiative."

In the simplest of terms, CHDI Management is a virtual biotech company. I have visited all three of its offices: the administrative headquarters in Manhattan (which also has two researchers) and the research offices in Princeton, NJ, and Los Angeles. CHDI Management has no labs – not even a microscope.

Its impressive staff of "drug hunters" – many of them recruited from the highly competitive pharmaceutical industry – conceive, fund, and manage specific research projects carried out in labs at pharmaceutical companies and universities. In all, CHDI Management scientists work with more than 600 researchers.

CHDI Management scientists travel frequently to consult with the scientists implementing the projects. For several years, I have tracked one of these projects at Isis Pharmaceuticals, Inc., in nearby Carlsbad, CA. With a revolutionary approach, Isis and CHDI Management aim to attack HD at its genetic cause. ([Click here](#) to read more.)

At the Princeton office, the scientists are helping design effective clinical trials and ways to measure the effectiveness of the proposed drugs.

Like HDSA and HDF, CHDI Management holds regular conferences. Although some might disagree, I described the CHDI Management meeting as the "Super Bowl" of HD research because of its international reach and intense focus on practical steps towards a victory in the fight against HD.



Scientists at the 2011 CHDI Foundation's research conference (photo by Gene Veritas)

CHDI Management's annual budget varies according to the needs of the researchers and the projects. In the current year, it plans to spend approximately \$100 million. In the fight against HD, it is the largest private initiative ever.

CHDI Management raised HD's profile in the world of science and put drug discovery into overdrive. Pharmaceutical giants such as Pfizer began to pay greater attention to HD. Whereas no specific treatment strategy existed after the discovery of the gene in 1993, the HD research community has now identified an astounding 700-plus potential targets (ideas for drugs) to attack HD. Much of that progress has resulted from CHDI Management's massive commitment.

Crucially, CHDI Management has the resources to transform the most promising of those targets into actual drugs and help guide them into clinical trials.

A potentially positive division of labor

About a year ago a scientist starting work on an HD project hinted to me that the lack of a single disease organization might hamper efforts to discover and implement treatments. Why, he seemed to ask, couldn't our community get its act together?

I understood his point. Drug companies likely would find it easier to deal with one organization. It would also create a perception of unity, as opposed to one of squabbling.

But there is also a positive side to having multiple organizations: the competition of ideas and strategies. Thanks to the current schema, the organizations are less likely to become complacent in their search for treatments and a cure. Unlike the volunteers in the field, disease organization employees earn a living from that quest, and they are more likely to feel passion for their work in an environment of freely flowing ideas, constructive criticism, and healthy competition.

The unique history and focus of each organization also benefit the HD community by creating a sort of division of labor. CHDI and HDF (and also the HSG) do the heavy lifting on research, while HDSA raises awareness and provides the grassroots infrastructure for patient care and clinical trials. HDDW plays a constructively critical, supportive role in the entire process.

Also, sometimes the institutions overlap one another, especially when it comes to research. Many of the scientists receive funding from two or more organizations and attend their respective conferences. What counts most for scientists is not the origin of their funding, but the fact that the money allows them to conduct the research necessary for finding treatments and a cure.

A call for unity

As someone who began my journey with HD at an HDSA support group and worked many years in the trenches as an anonymous volunteer, I sympathize with those at the grassroots who express frustration about HDSA and/or about the other organizations.

However, as someone who has held important leadership positions in my profession, I also understand the challenges of administration.

I believe strongly that several things must happen in the HD community.

With leadership comes great responsibility. The leaders of the HD organizations should always be open to dialogue with the grassroots. They should display a willingness to learn from and even adopt the innovations of the grassroots.

People at the grassroots have a great responsibility, too. They should remember that these organizations must respond to needs expressed from around the country and even from overseas, as CHDI expands the scope of its efforts in the quest for treatments and a cure. Grassroots activists need to resist the very human temptation to adopt an "us versus them" attitude with respect to the leadership, while, however, also maintaining a constructively critical approach and making their voices heard.






Collaboration, negotiation, debate, dialogue, and the search for common points of interest are hard, but I believe that in the end they can bring us more quickly to a victory against HD.

But dialogue needs to be informed.

The members of the HD community should continually strive to learn about the disease organizations. At the same time, each one of us needs to constantly evaluate his or her part in the fight against HD.

In the end, from the presidents to the family stressed out by HD to the volunteers, we all need to remember: *Together* we can beat this disease!

(Note: This article was originally posted on October 3, 2011, and updated on October 4, 2011, to correct several factual errors.)

Posted by [Gene Veritas](#) at [1:51 PM](#)     

Labels: [advocacy](#) , [at-risk](#) , [brain](#) , [caregiver](#) , [CHDI](#) , [clinical trial](#) , [cure](#) , [genetic testing](#) , [Guthrie](#) , [HD-positive](#) , [Huntington's](#) , [Isis Pharmaceuticals](#) , [observational trial](#) , [research](#) , [support group](#) , [treatment](#)

3 comments:

Anonymous said...

Hello Gene, thanks for your blog. There is much I could say this. I choose not to get caught up in the he said, she said on Facebook, or anywhere else. When I fund raise for HDSA I do it from my heart. I do it in the memory of so many of those family members I have lost, and for those who currently have HD. And I agree that each one of us in the HD community needs to take

a look and see what we are doing to help in the fight against HD. It is my prayer that the people who are in positions to help ARE doing the right thing.

6:13 PM, October 03, 2011

⌘ **Jimmy Pollard said...**

My involvement in this wonderful community is as a professional; my family is not directly touched by Huntingtons Disease. Having participated in and observed this community for 25 years now and as a fan of your blog, I find this entry especially interesting.

Yes, there are efforts that overlap and duplicate. There are organizations with clearly defined missions and some with broader less well defined aims. Some devote their resources to cure (scientific research), some to care (How many hours could we spend defining that word?) and some to both. And on Facebook there are more initiatives than I can keep up with! I confess that at times I am confused, amused, bewildered, skeptical and even cynical on occasion.

At these times, though, I have come to reflect on the assessment that collectively there are more folks making more contributions of all kinds than ever before. This gives me hope for better care and a quicker route to an effective treatment. The fact that a very large portion of these efforts is generated by people one-half to one-quarter my age is very, very inspiring,

The scientific research is in good hands. On the care axis, i pray that every player in the community has the confidence and courage to always reflect and discern whether our efforts are as truly effective as we believe or say they are and that we are willing to listen to other points of view and suggestions for improvement, as challenging as they may appear to be. As the saying goes, I am my brothers keeper. But not because I know what is best for him.

Your call for unity prompts me to celebrate all that so many folks are doing and strengthens my own resolve to ask myself whether or not my work really is having its intended effect.

For that, Gene, thanks! Together, we will get there!!!

8:50 PM, October 03, 2011

⌘ **Anonymous said...**

Thank you, Gene, for putting your professional historian's skills to good use to explain the origins and goals of the various HD organizations. I feel connected to HDSA and excited about the research that goes on at CHDI, but I didn't know about the

other organizations.

--Beverly

10:48 AM, October 06, 2011

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