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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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THURSDAY, FEBRUARY 16, 2012

The quandary of denial in the Huntington's disease community (Part II)

The fear of confronting the devastating, incurable, and ultimately deadly symptoms of Huntington's disease, coupled with its terrible stigma, causes many in the HD community to go into denial. They avoid participation in research trials and other activities crucial for combating the disorder.

In Part I of this two-part series, I revealed how my own family's struggles with HD highlight how denial hampers involvement ([click here](#) to read more).

"How do we untie this terribly complex knot of denial?" I asked. "I am in a quandary about how to act – and to overcome this problem that threatens our march to treatments and a cure."

Here I propose some practical strategies for overcoming denial at the level of the individual, the family, and the larger HD community, including both physicians and the main organization that cares for HD families.

The struggle within

The fight against denial and for participation begins within us.

In the words of Dr. LaVonne Goodman, the founder of [Huntington's Disease Drug Works](#) and physician to several dozen HD patients, we in the HD community "suffer not just from society and intra-family struggle – but also from [internalized stigma](#) that we have 'learned' from others, and incorporated into self."

We need to block this internalized stigma from leading us into denial and preventing us from fighting both the disease and the external stigma.

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](#)



Dr. LaVonne Goodman (photo by Gene Veritas)

On January 30, Dr. Goodman published a [detailed article](#) that identifies stigma as an actual “component of Huntington’s disease.”

“Stigma drives HD families into the closet where we suffer as a marginalized part of society,” Dr. Goodman wrote. “Further, the fear of stigma likely prevents those with early disease from seeking medical care, as it does with mental illness or from signing up for clinical trials. Study has shown that when society becomes aware of HD family status, individuals can experience discrimination in employment, housing, medical care and social relationships. Stigma is damaging even before clinical diagnosis, negatively affecting the quality of life for these individuals and their loved ones.”

Dr. Goodman’s article is a must-read for the entire HD community.

Why care?

We must always remember that we each have an individual responsibility in fighting HD and making others aware of our plight.

“If we don’t speak up for ourselves, why should anybody care about us?” Bill Johnston, the public relations director of the San Diego Chargers and the husband of an HD patient, once told the San Diego support group.

Exercising the power of our own voices helps rebuild our self-esteem, so easily wounded by the depressing symptoms of HD and the terrible stigma. It also builds badly needed awareness about a disease still largely unknown to the public.



*Bill Johnston carrying the Olympic in 2002 to raise HD awareness
(photo by Mike Nowak)*

Renewed participation

While we cannot force people to come to terms with their denial and join the cause, we can set an example by daily renewing our own commitment to participate.

That commitment can include attending a support group or volunteering for the local chapter or affiliate of the [Huntington's Disease Society of America](#) (HDSA). (Many other countries have their own HD organizations; [click here](#) to learn more.)

HDSA chapters need people to help with so much: fundraisers, advocacy, communications and media contacts, support groups, the Centers of Excellence for Family Services and Research, volunteer recruitment, education and awareness-building, and “diplomats” to provide information about clinical trials. No prior experience is necessary, and individuals of all ages and skill sets can pitch in.

Helping shape HDSA: you have till Feb. 24

In recent years, HDSA has experienced a financial and organizational crisis, and [some members of the HD community have criticized it for an apparent lack of concern](#) about the problems of the everyday HD family.

HDSA recognizes such complaints and aims to be more responsive. HDSA CEO Louise Vetter and the national board of directors want the HD community's feedback on a proposed five-year strategy for increasing the size, reach, and impact of the organization.

You can find the link to the proposal and read Vetter's letter soliciting input from the HD community by [clicking here](#). The deadline for comments is February 24, 2012.

Bolstering HDSA, breaking denial

In my next article, I will comment in detail on the HDSA plan. Here I want to highlight the HDSA goal of bringing “new folks into our fight” through an increase in the number of volunteers.

“Many organizations for diseases as rare as HD are many times our size,” the proposal states. “It is imperative that we increase our capacity so that we can do more, fund more research and accelerate the accomplishment of our vision – a world free of HD.”

HDSA wants to train and “deploy an ‘army of HD’ers’ to give voice and action to HD causes and needs.” To do so, over the next five year HDSA aims to increase the number of chapters and affiliates from 45 to 55. It also aims to add at least 200 new volunteers per year. The plan states that HDSA will support the volunteer base “with resources,” presumably in the form of dollars and staff support.

The plan doesn’t specify exactly how HDSA will reach these goals. I believe it’s implicit that the chapters and volunteers, as usual, will need to take the initiative locally.

Nevertheless, the national board recognizes the need to restore some confidence lost in recent years. It wants to improve the bonds between the national office and the chapters and affiliates. Specifically, it proposes “to build a strong, ongoing dialogue ... that fosters a ‘we’ and not ‘us vs. them.’”

By including input from the community and emphasizing dialogue, the planning process presents a golden opportunity for the HD community to both strengthen and shape the future of HDSA and its mission of care and cure.

By bolstering HDSA, we can help encourage the inactive members of our community to break through their denial.

Young people facing HD can also join the recently launched [Huntington’s Disease Youth Organization](#).

The doctor’s impartial role

Breaking down denial requires education about the causes and symptoms of HD, genetic testing and discrimination, family planning, medical care and caregiving, and a wide range of other factors.

The educators in this process are multiple: HDSA, the Centers of Excellence, the support groups, the various HD Facebook groups and other web-based initiatives, social workers, genetic counselors, psychologists, and, most importantly, doctors and other medical personnel.

A doctor is often the first person to assist an individual or family confronting the onset of symptoms or learning about the disease for the first time.

Doctors, probably more than anybody else, can provide hope.

And they can prevent people from going into denial. People respect doctors, and doctors provide an impartial assessment of a person’s medical condition. People are much more likely to listen to a physician than a family member or activist with whom they’ve tangled over HD.

So, doctors need to be properly informed about HD.

A helpful guide

HD specialists and neurologists familiar with HD can skillfully diagnose, treat, and counsel HD people. However, because HD patients form a

relatively small group (an estimated 30,000 individuals in the U.S.), most doctors know little, if anything, about the disease.

HDSA has sought to educate doctors about HD by publishing *A Physician's Guide to the Management of Huntington's Disease*, now in its third edition (2011). Authored by four respected HD specialists, the guide provides an overview of HD symptoms, genetic counseling and testing, treatment and care, juvenile HD, management of late-stage HD, and HD research and clinical trials.

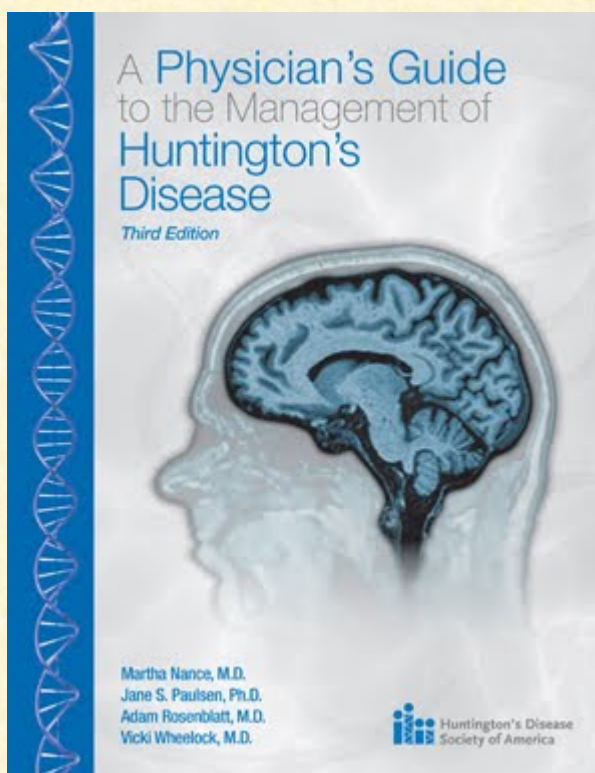
Written in a non-technical style, the guide is an invaluable tool to educate the public.

A free flow of information

HDSA provides free copies of the print guide. However, it limits them to one per family.

Furthermore, the publication is not available online, because HDSA aims to track the physicians requesting the publication as part of the HD educational process.

A number of people in the HD community believe that HDSA should make the guide available as a downloadable PDF. Indeed, some are puzzled that, in the era of the Internet and the e-book, HDSA has not facilitated access to the publication.



I have participated in many conversations about HD on Facebook in which people ask very basic questions about HD, as well as sophisticated ones about medical matters. It would be enormously helpful to point to the document online.

In visits to my primary care doctor for non-HD matters, I've noted how he relies heavily on not just the health plan's computer network, but the wider web.

Imagine a doctor seeing his or her first HD patient who has to call HDSA for a copy of the guide rather than download it.

The freer the flow of high-quality, doctor-generated information about HD, the greater our chances at ending stigma and denial.

(In a future article I will review the *Physician's Guide*.)







Increasing visibility

Because doctors form the front line of diagnosis and treatment, we in the HD community must advocate the bolstering of the HDSA Centers of Excellence, support groups, and HD educational events such as the annual convention of the Northern California chapter.

We also need to participate in HDSA walks and other fundraisers that emphasize raising awareness among the general public. These events may not raise as much money as galas or other big events, but they provide a huge symbolic impact in the local community.

The more visible we can make HD in the local community, the greater the chance someone in denial might be brought to reflect on his or her predicament and the effort to defeat HD.

Then we can build a stronger movement and take one step closer to the goal we all strive for: the end of HD.

Posted by [Gene Veritas](#) at [6:17 PM](#)      

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1 comment:

Anonymous said...

Hello, Gene, I'm a fan of your blog. I think it's great that you're speaking up like this.

I just started a blog, "Confessions of a Genetic Mutant."

I'm adding your link to my blog, and I hope you'll add mine to yours.

<http://anonymoushd.wordpress.com/>

Thanks!

[7:14 AM, February 21, 2012](#)

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