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After a Social Security setback, HDSA steps up advocacy on Huntington's disability criteria

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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)
 - ▶ December (2)
 - ▶ October (1)
 - ▶ September (2)
 - ▶ August (3)
 - ▶ July (1)
 - ▶ June (2)
 - ▶ May (3)
 - ▼ April (3)
 - [After a Social Security setback, HDSA steps up adv...](#)
 - [Woody Guthrie, Huntington's disease, and our duty...](#)
 - [Reshaping my career and life in the face of Huntin...](#)
 - ▶ March (2)
 - ▶ February (3)
 - ▶ January (2)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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WEDNESDAY, APRIL 23, 2014

After a Social Security setback, HDSA steps up advocacy on Huntington's disability criteria

The [Huntington's Disease Society of America](#) (HDSA) is calling on the HD community and its supporters to urge the Social Security Administration (SSA) to update and expand its listing (description) of the disorder so that patients suffering from all types of symptoms can qualify for disability benefits.

Listings are medical criteria for evaluating disability claims involving diseases and disorders as determined in the Social Security Act. Written decades ago, the current SSA listing for HD mentions only the motor symptoms, the involuntary movements caused by the deterioration of the brain. However, HD also produces cognitive decline and psychiatric and behavioral issues, which usually leave patients disabled. Both of these symptom types often occur before the motor symptoms.

In the past decade, HDSA worked for the introduction of a bill in Congress, the *Huntington's Disease Parity Act*, to change the HD listing and eliminate the two-year waiting period for benefits. HDSA has also directly lobbied the SSA.

Initially, the SSA responded favorably. It took a big step in April 2012 by listing juvenile onset HD as eligible for a Compassionate Allowance, thus quickening the approval of applications for benefits, which can take many months and even years and sometimes require applicants to resort to an arduous appeals process. Later that year, adult onset HD also became eligible for the allowance. ([Click here](#) to read more about Compassionate Allowance, HD, and Social Security benefits.)

However, when the SSA on February 25 released its draft of updated neurological listings – the first such revision in more than 30 years – the description for HD remained woefully inadequate.

A 'glaring omission'

"We were certainly disappointed when the listings ... made no practical advancements in the ability of their (SSA) examiners to have a true picture of the clinical manifestation of Huntington's," said HDSA CEO Louise Vetter in an interview today. "They continue to depend on the motor symptoms. There is a large body of knowledge obviously that gives the cognitive and behavioral symptoms equal importance in the progression of the disease."

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 (photo by Gene Veritas)

On March 27, HDSA issued an analysis of the SSA HD listing that it posted on its website ([click here](#) to read more).

“Based upon HDSA’s analysis, this listing leaves many of the same gaps unaddressed and is worse than the listing we have now,” the society states. The proposed listing puts even more emphasis on the motor symptoms. (To obtain benefits, patients must be examined by at least one doctors and provide any medical documentation requested by SSA.)

The HDSA analysis found an “inconsistency between the listings (that do not mention any non-motor symptoms) and the preamble, which states that: ‘When these disorders result in solely cognitive and other mental function effects, we evaluate the disorder under 12.02/112.02 (for juvenile).’” The number twelve refers to the mental health listings, where general issues with neurological disorders such as HD are also described.

HDSA argues that “unless these other sections are spelled out in the listing itself, the examiner (and even a medical professional who is unfamiliar with HD) won’t know that they should look at the preamble because the person with HD appears fine in person and often lacks the insight to describe symptoms.”

The “glaring omission” of non-motor symptoms in the SSA listing “will cause individuals disabled by non-physical symptoms to be denied,” the HDSA analysis concludes.

One advocate told me privately that the SSA and HD specialists “don’t always speak the same language.” For instance, what HD specialists describe clinically as “apathy,” a hallmark symptom of HD, must be found in the SSA criteria under “anhedonia.”

Educating the bureaucracy

As of this writing, the SSA point person had not responded to my phone message requesting comment on the HD listing. Cheryl Williams of the SSA Office of Medical Listings Improvement is indicated as a contact

person in the *Federal Register*, where the SSA published the proposed neurological listings.

Vetter offered “two plausible explanations” for the inconsistency in the neurological listing.

First, the SSA is “struggling with a change in leadership” after Commissioner Michael Astrue finished a six-year term, retiring in February 2013. Astrue had approved the Compassionate Allowances and even appeared in a video made specially for the [2012 HDSA national convention](#). Since Astrue’s departure, SSA has operated under an acting commissioner, Carolyn Colvin. Thus, “new staff” received the task of revising the neurological listings, Vetter observed.

Second, Vetter noted the complexity and length of a document covering numerous neurological conditions.

“I recognize that it’s a tall order to conveniently define HD,” she said. “This is a bureaucracy looking for simple definitions, and HD is not easily characterized in convenient language. From that perspective, they’re trying to simplify a complex disease. That is inevitably going to lead to some gaps, and we’re calling them out on that.”

Pressing for a meeting

Vetter added that, at some level, the SSA doesn’t sufficiently understand HD. HDSA is seeking “direct dialogue” with the SSA, but so far the SSA has refused to meet.

Vetter speculated that, if the SSA meets with HD community representatives, it fears “the slippery slope” of having to meet with all disease groups.

HDSA, Vetter said, must convince the SSA of the uniqueness and complexity of HD and therefore the need for more “guidance” for the medical examiners who determine whether HD patients receive disability benefits.

“We should be granted an exception,” she declared. “We won’t take no for an answer on this one.”

How to send a message to Social Security

HDSA CEO Louise Vetter has formally submitted the HDSA analysis as a comment for SSA consideration, as have several dozen other HD advocates and family members.

Vetter urged HD advocates, family members, and supporters to also submit comments to the SSA. You can view others’ comments and add your own by [clicking here](#). You can simply state that you support the HDSA’s input on the Huntington’s listing, or you can leave a personalized comment of greater length.

The deadline for comments is April 28.

Removing barriers to understanding HD






Advocacy on this issue forms part of a larger effort by HDSA and the HD community in favor of the *Huntington’s Disease Parity Act of 2013*, a bill that would direct the SSA to update and expand its HD listing and waive the two-year waiting period for HD patients to receive Medicare benefits.

The current setback is “not a reflection on the HD community’s momentum at all,” Vetter said. “I know that we still have many strong advocates in the SSA. They are trying to find a way to accommodate HD in

a complex process. Hopefully they'll be able to accomplish that quickly. I don't think we should be disheartened."

Little by little, HD advocates are "removing barriers" to understanding of the disease, she added.

To learn more about how you can assist with HD advocacy, contact the [nearest chapter of HDSA](#) or write advocacy Jane Kogan, HDSA's manager of education and advocacy, at jkogan@hdsa.org.

Posted by [Gene Veritas](#) at [8:24 PM](#)      

Labels: [advocacy](#) , [apathy](#) , [behavioral](#) , [benefits](#) , [cognitive](#) , [Compassionate Allowance](#) , [Congress](#) , [disability](#) , [HD Parity Act](#) , [HDSA](#) , [Huntington's disease](#) , [lobby](#) , [Louise Vetter](#) , [motor](#) , [neurological](#) , [Social Security](#) , [symptoms](#)

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