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Let's fix the law to help Huntington's families

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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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 [GENE VERITAS](#)

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WEDNESDAY, APRIL 13, 2011

Let's fix the law to help Huntington's families

Because Huntington's disease leaves people unable to work or care for themselves, they can qualify for Social Security and Medicare benefits. However, as many in the HD community can affirm, government bureaucracy and widespread misunderstanding of the disease make it difficult to obtain those benefits.

The [Huntington's Disease Society of America](#) (HDSA) and HD advocates around the country are working to push through legislation in the U.S. Congress that would finally bring relief from these problems.

The *Huntington's Disease Parity Act of 2011* (House Bill 718 and Senate Bill 648) would enact two major legal changes to help HD patients.

Correcting a gross inaccuracy

First, the legislation would require the Social Security Administration (SSA) to update its long-outdated and inaccurate disability criteria for HD.

The current SSA definition considers HD only as a movement disorder. The *HD Parity Act* takes into account two other main types of symptoms: cognitive loss (difficulties with memory and thinking) and behavioral or psychological problems.

"The designation of this disease by the Social Security Administration as 'Huntington's Chorea' is both outdated and medically inaccurate, as this term fails to recognize the behavioral and cognitive impact of Huntington's Disease, while also providing an incomplete characterization of the full spectrum of Huntington's Disease for purposes of Social Security Disability Insurance and the Medicare program," the text of the bill states. ([Click here](#) for the full text of the bill.)

The term "chorea" refers to the shaking and dance-like movements suffered by many – but not all – HD patients.

Secondly, the bill would waive the two-year waiting period for patients to receive Medicare benefits, thus bringing assistance quicker to families in dire straits because of the disease's severe impact on household finances.

How families struggle

Misty Oto, a board member for the San Diego chapter of HDSA and a leading advocate of the bill, witnessed the travails of her HD-stricken mother, brother, and aunt as they struggled to obtain benefits.

Her brother's symptoms had caused him to miss SSA appointments, misplace paperwork, and write illegibly on his application for benefits, according to Misty. Finally, with the help of Reps. Bob Filner (D-San Diego) and Brian Bilbray (R-San Diego), the SSA reviewed the application. (Filner and Bilbray were the original co-sponsors of the bill in 2009.)

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](#)

However, because of the 24-month waiting period, he died before obtaining actual benefits.

Below, you can watch the complete interview I conducted with Misty on April 8.



Gene Veritas interviews Huntington's disease advocate Misty Oto on HD Parity Act

from [Gene Veritas](#)

13:44

[Gene Veritas interviews Huntington's disease advocate Misty Oto on HD Parity Act](#) from [Gene Veritas](#) on [Vimeo](#).

The 'Let's Talk about HD' campaign

In its 2010 edition the HD Parity Act gained a total of 152 co-sponsors in the House of Representatives. But the bill stood no chance of passage because of the lack of a companion bill in the Senate.

The situation improved dramatically on March 17, when Sen. Kirsten Gillibrand (D-NY) introduced S. 648.

Working at the grassroots, HDSA and advocates of the bill are now seeking to drum up support in the House and especially the Senate in order to bring the legislation up for a vote.

In May, Huntington's Disease Awareness Month, HDSA will promote the legislation by launching a "Let's Talk About HD" campaign.

Each week HDSA will focus on a different call to action related to the bill, and on May 31 it will sponsor a national call-in day to Congress. You can watch an HD Awareness Month video by [clicking here](#).

Aggressive advocacy needed

Allan Rappoport, a former HDSA-San Diego board member who has helped HDSA strategize on passage of the bill, stressed that the HD community needs to unite to achieve success.

"It's not up to your Congressman to learn about HD," Allan told me. "It's not up to your Congressman to push that bill through. It's not up to your Congressman to care, because your Congressman and your Senator have got thousands and thousands of people and issues that they're dealing with.

"It's up to the constituents, us in the HD community, to educate them, to keep after them.... And they're not irritated by that.... They expect and they want you to be aggressive. They need you to tell them that this is important."

To learn more about the background to the bill and how people can best lobby their Representatives and Senators, watch the full interview with Allan below.



Gene Veritas interviews Huntington's disease advocate Allan Rappoport on HD Parity Act

from [Gene Veritas](#)

16:33

[Gene Veritas interviews Huntington's disease advocate Allan Rappoport on HD Parity Act from Gene Veritas on Vimeo.](#)

Please act now

So far, only the Lou Gehrig's disease community has obtained a waiver of the two-year Medicare waiting period for people afflicted by that condition, also known as amyotrophic lateral sclerosis.

Passage of the *HD Parity Act* is crucial for the HD community. Not only will it remedy a difficult situation for HD families. It could also inspire other disease communities to seek similar improvements in their benefits situation.

The campaign for the bill also will raise the profile of HD in the Congress and the public arena.

So please write, call, or e-mail your [Representatives](#) and [Senators](#) *today*, and ask your extended family, friends, and acquaintances to do so, too.

To learn more about the bill, visit the advocacy webpages of [HDSA](#) and [HDSA-San Diego](#).

(HDSA is also sponsoring a Caregiver's Corner webinar on Social Security Disability Insurance appeals and denials at 1 p.m. EDT on April 27. For more information, please [click here](#)).

Posted by [Gene Veritas](#) at 1:35 PM



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