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A Compassionate Allowance, and faster Social Security benefits, for the juvenile Huntington's disease community: a key step for advocacy

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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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A Compassionate Allowance, and faster Social Security benefits, for the juvenile Huntington's disease community: a key step for advocacy

In a key step for Huntington's disease advocacy, children and youths stricken with the juvenile form of HD will receive Social Security benefits faster, thanks to a Social Security Administration's (SSA) decision last month.

Now that juvenile onset Huntington's (JHD) is listed as eligible for a Compassionate Allowance (CAL), a ruling SSA Commissioner Michael J. Astrue announced on April 11, those who are eligible for and apply for desperately needed benefits will see their applications approved much more quickly.

"This is an important victory for all families facing juvenile onset Huntington's disease," said Louise Vetter, the CEO of the Huntington's Disease Society of America (HDSA), which lobbied to obtain the CAL. "Currently, applicants usually go through a long decision process and are sometimes denied benefits that are only won after arduous, long appeals."

HDSA CEO Louise Vetter (photo by Gene Veritas)

When the CAL takes effect on August 13, an individual with JHD will receive approval of his or her application for disability in as little as a few days instead of the months the process currently takes. The change results from the CAL's simpler application criteria, based on "minimal objective medical information," an HDSA press release stated.

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)
    - A Compassionate Allowance, and faster Social Secur...
  - ► April (2)
  - ► March (3)
  - ► February (3)
  - ► January (5)
- ► 2011 (33)
- ► 2010 (26)
- ► 2009 (21)
- ► 2008 (7)
- ► 2007 (7)
- ► 2006 (4)
- ► 2005 (17)

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An estimated 10 percent of the approximately 30,000 Americans afflicted with HD have juvenile onset. JHD joins 165 other conditions, including 52 announced in April, considered so devastating that they merit a CAL.

Streamlining the process

"Over the past several years, we have been working with SSA to streamline the disability application process for HD, and to advocate for a CAL designation for HD through letters, testimony at hearings, face-to-face meetings, as well as legislation such as the Huntington's Disease Parity Act (HR 718/S 648)," the HDSA release stated.

The fast-track application for Social Security Disability Income (SSI) means that JHD families should receive their benefits one month after completing a short, online application, explained Jane Kogan, HDSA's advocacy manager. The main requirements will consist of a genetic test for the disease and diagnosis for JHD, she added.

SSI benefits generally amount to monthly payments of several hundred dollars, depending on the applicant's financial and living circumstances.

SSI applicants must still demonstrate very low income levels to qualify, thus leaving many JHD families without SSI, Kogan observed. (Click here and here to see for SSA eligibility guidelines.) Low-income JHD families can also qualify for Medicaid.

The fast-track process also will cover a JHD youth applying for Social Security Disability Insurance (SSD), although such cases are extremely rare because JHD prevents people from working enough quarters to qualify, Kogan said. Many JHD individuals never work, with some dying in childhood. Even if a worker qualified, he or she would still have to wait two years to receive the first SSD check – a period that HD advocates want Congress to eliminate with the passage of the HD Parity Act, as described below.

"This is *just* a way to simplify the application process," Kogan said of the CAL, a concept implemented by the SSA starting only in 2007. "It's one way the SSA is trying to streamline its application process for conditions that are obviously disabled."

SSA will publish guidelines for the CAL, including age requirements and criteria defining JHD, on its site on August 13. With the assistance of HD specialists, HDSA provided the SSA with documentation defining JHD and how it causes disability.

HDSA is currently preparing 21 Centers of Excellence, its 38 social workers, and medical professionals to assist JHD families to use the fast-track process. It has also developed a Disability Toolkit (click here to learn more).

Aiming for broader goals

The CAL designation for JHD does not help most of those afflicted by Huntington's. "We will continue our dialogue with the SSA until adult-onset Huntington's disease is also added as a CAL condition," Vetter said.

Despite those limitations, it represents an important advance for the HD movement.

"This is a small, but significant victory for the HD community," Dr. Martha Nance, the director of the HDSA Center of Excellence for Family Services and Research in Minneapolis and a contributor to the JHD documents, stated. "Recall that we have been working for a number of years to get legislation passed to facilitate the disability process for people with HD. Unfortunately, those advocacy efforts, while important and ongoing, have been slow."

"HDSA decided to try a different approach, which was to go directly to the Social Security Administration, to get them to understand the unique needs of this particular disease," she added. "We decided to focus first on JHD, because it seemed like a more uniform group/set of circumstances/life situation. We are thankful to the SSA for 'getting it,' and for being responsive to the needs of our families!"

HDSA and its advocates hope to use the political momentum from the CAL victory to achieve their broader goals in the area of public benefits.

"This is a very, very partial answer to a very small part of the problem," Kogan explained. "The current (SSA) guidelines for HD don't even include JHD."

"We're hoping this energizes people and that by showing up and speaking persistently, things do get done," Kogan continued. "Just to make this (the CAL) happen, a number of people submitted their stories, when we first testified, and more recently, last summer, we surveyed the community about disability, and a number of people shared their stories."

Jane Kogan

The HD Parity Act

A major goal, of course, is the passage of the HD Parity Act, which has numerous sponsors in both the House and the Senate but which has not been brought up for a vote. As noted above, this bill would eliminate the two-year waiting period for SSD benefits. It also would change the SSA's woefully outdated criteria for HD, which only use chorea (tremors and dance-like movements) as a basis for disability but do not include the cognitive and behavioral symptoms. (Click here for details on the bill.)

Kogan also noted that the potential CAL for adult onset HD is "much trickier" because of the far more nuanced, slower onset in comparison with JHD. This fact further reinforces the need for the Parity Act.

As the HD community awaits passage of the bill, affected individuals may be able to qualify for Social Security benefits more easily by using a diagnosis of "mixed dementia," Kogan noted (click here to learn more).

Kogan stressed that people should contact their representatives and senators now to push for passage of the bill. Because of the 2012 elections, politicians are in “election mode” over the next several months and want to show results for their constituents, she said. The CAL is a “newsworthy” item that advocates can promote and politicians can “latch onto,” she added.

Also, the CAL also provides the HD community with a powerful symbol for the observation of HD Awareness Month, May, now in progress.

Posted by Gene Veritas at 10:34 PM

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