

**STATEMENT FOR THE RECORD BY**  
**LOUISE VETTER, CHIEF EXECUTIVE OFFICER**  
**THE HUNTINGTON'S DISEASE SOCIETY OF AMERICA**  
**THE HOUSE COMMITTEE ON WAYS AND MEANS**  
**SUBCOMMITTEE ON SOCIAL SECURITY**  
**SUBCOMMITTEE ON OVERSIGHT**

**Social Security Payment Accuracy**

**JUNE 28, 2011**

Thank you Chairman Boustany, Chairman Johnson, Ranking Member Lewis, Ranking Member Becerra, and distinguished Members of the Subcommittees for holding this important hearing on Social Security payment accuracy; I am honored to have the opportunity to submit testimony today for the Huntington's Disease Society of America (HDSA).

On behalf of the thousands of families that HDSA represents, we share your concerns that the Social Security Administration (SSA) has significant flaws in its payment and benefit policies. The system is not only failing the taxpayers who fund these vital programs, but also its intended beneficiaries. For years, HDSA has urged the SSA to update the medical criteria used for determining disability benefits as a means of reducing the backlog of initial disability claims and program costs. Our pleas remain unanswered.

Filing for Social Security Disability Insurance (SSDI) is a complex, burdensome process, especially for those living with a rare disease such as Huntington's Disease (HD). HD is a devastating, hereditary degenerative brain disorder that causes total physical and mental deterioration. Today, 30,000 Americans are known to have HD and an additional 200,000 have a fifty percent chance of inheriting the disease from an affected parent. The debilitating symptoms of HD make it challenging, if not

impossible, for an affected individual to remain employed, resulting in a loss of income and employer-sponsored health insurance benefits.

Documenting a disability like HD can be difficult because of the complexity of the disease. Symptoms of HD typically hit during an individual's prime working years (30 – 45), and can include dementia, obsessive-compulsive behavior, depression, mood swings, inability to concentrate, processing and sequencing difficulty, immobility, as well as the involuntary movements (chorea), for which the disease first became known. Given the often subtle onset of symptoms, it is hard to pinpoint exactly when a person with HD first becomes disabled. Further, the neurological listings under the *Disability Evaluation Under Social Security*, (also known as the Blue Book), have not been comprehensively revised in almost 30 years and only take into account HD's physical impairments. We now know that the often debilitating cognitive and behavioral effects of HD occur at least a decade before the visible physical effects. As a result, people with HD who apply for Social Security disability benefits experience numerous delays and denials due to the continued use of outdated and insufficient medical criteria. Denials based upon severely outdated guidelines should not be acceptable in our disability system.

Because the HD guidelines are almost 30 years out of date, Social Security Disability Insurance (SSDI), eligibility is extremely difficult for individuals with HD. Under the current Blue Book listing, HD is referred to as "Huntington's Chorea," a name that captures the physical impairments typical of the latter stages of the disease but fails to recognize the myriad of symptoms such as the less apparent but equally debilitating cognitive and behavioral symptoms now widely accepted as characteristic of HD. These declines are often more debilitating than motor abnormalities and are often the reason that an individual affected by HD has to stop working during his or her prime working years. Despite this fact, the lack of visible dysfunction of motor abnormalities has caused many people affected by HD to remain undiagnosed and unable to receive badly needed benefits. A revised definition of HD that captures the

complex nature of the disease and its many emotional and cognitive manifestations beyond the “chorea” is needed to reduce the number of delays and reapplications of genuinely disabled individuals.

On July 1, 2010, *11.00 Neurological – Adult* disability guidelines, in which HD is currently listed, expired; but the SSA extended their own deadline for an additional two years and little progress has been made. We believe that in order to successfully facilitate HD applicants through the disability process, medically accurate guidelines for determining disability are needed. By updating the guidelines, the SSA can reduce its ever-growing backlog and overall costs to the program.

In furtherance of this goal, earlier this year Representatives Bob Filner (D-CA) and Bilbray (R-CA) reintroduced *the Huntington's Disease Parity Act* (H.R. 718) in the House of Representatives. Senator Kirsten Gillibrand (D-NY) introduced the Senate companion bill, S. 648. This important legislation directs the SSA to revise outdated, medically inaccurate criteria for determining Social Security disability and waives the Medicare two-year waiting period for people disabled by HD. Currently, 78 Representatives have cosponsored H.R. 718 and 6 Senators have cosponsored S. 648. In the 111<sup>th</sup> Congress, 153 Representatives cosponsored this crucial legislation.

As Congress and the SSA looks for ways to ensure that those who are truly in need of benefits receive the assistance they deserve, we ask that the Administrator expedite the rule-making process and update the medical criteria and outdated guidelines for HD. The SSA is currently failing individuals with HD, our nation's most vulnerable and the very ones that the disability system was meant to protect. Updating the medical criteria for HD will support the SSA's efforts to make timely and accurate disability determinations. Further, it will save time, money, resources and emotional energy on the part of the SSA and the individuals and families it serves.



Thank you again for holding this important hearing and for the opportunity to provide Members of the Subcommittee with written testimony this afternoon.

505 Eighth Avenue, Suite 902, New York, NY 10018 | T. 212 242.1968 T. 1 800.345.HDSA (4372) F. 212 239.3430



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