

Background Information

The following information is meant to give you a brief overview of the difficulties people with HD face when applying for Social Security disability benefits, why these difficulties exist, and the change we hope to achieve with this new legislation.

HD and disability

While you are probably familiar with some of the disabling aspects of HD, we would like to expand on it here as symptoms often vary between individuals, even within the same family. Huntington's Disease was formerly termed *Huntington's Chorea*, for the involuntary movements thought to be the best indicator of the disease. Recent research, however, has been able to provide scientific support for what people experiencing the effects of HD firsthand have maintained for years; HD's cognitive and psychiatric symptoms often present prior to the physical manifestations of the disease and are just as, if not more, severe and disabling. These symptoms may include personality changes, irritability, mood swings, depression, obsessive-compulsive behavior, loss of inhibition, inability to foresee the consequences of actions, lack of concentration, and decreased motivation. While symptoms may vary, HD is a degenerative disease that eventually renders everybody affected by it disabled.

Under The Current Framework

Individuals, families, social workers, and medical professionals have reported a variety of difficulties in applying for Social Security Disability Insurance (SSDI). While the reasons cited for denials vary slightly, most can be attributed to the lack of accurate medical criteria in the neurological disease listings used by the Social Security Administration (SSA) to determine an individual's disability status. These listings have not been comprehensively revised in more than 20 years. When you consider the vast amount of scientific and medical understanding the last 2 decades have brought, it isn't hard to see why applicants with Huntington's Disease, still incorrectly referred to as Huntington's Chorea in its listing, often do not precisely fit the description of HD disability despite being disabled. Just as the outdated name suggests, the listing emphasizes the physical impairments typical of the latter stages of HD, and says nothing of the triad of psychiatric, cognitive, and physical symptoms now widely accepted as characteristic of HD.

Given that HD is a rare disease, many SSA caseworkers and physicians are generally unfamiliar with the disease. Delays caused by multiple referrals are common, with the end result often being a denial from an SSA official who refers to the listing criteria and does not properly account for HD's disabling cognitive and psychiatric components. Accurate medical criteria are crucial for these officials.

Due to delays and to the backlog of disability requests the SSA is currently experiencing, the application process for someone with HD can take up to 2 years. This is a tremendous amount of time for a disabled individual to go without a determination and the subsequent benefits. Denials of disability worsen the situation for applicants who, since their symptoms are only progressing as time passes, must reapply and consider acquiring a lawyer to aide them. Legal counsel, however, is a luxury many applicants cannot afford if they became unemployed prior to or during the application process.

Summary: An update to the neurological listings for Huntington's Disease needs to include the psychiatric/behavioral, cognitive and motor impairment that typifies people with HD today.

Medical Disability Waiting Period

Currently, there is a 2-year waiting period from the point someone begins receiving disability benefits to when they are eligible to receive Medicare. This waiting period was originally created to avoid the potential overlap between employer-provided and government-provided health insurance. Any necessity for such a waiting period, however, has long expired.

The loss of employer-provided health insurance is unfortunately all too common for individuals with HD, their dependents, and any spouse/family member who must stop working to become a full-time caregiver. By the time many HD disability applicants have navigated the application process and begin receiving disability benefits, they have already lost their health coverage. Due to the age of onset (usually between the ages of 30-50), people with HD do not qualify for Medicare and often receive insufficient treatment during the early stages of the disease. In addition to the financial ruin a lack of insurance can cause a family dealing with a terminal illness, a tremendous financial strain is also put on hospitals and clinics that provide these individuals with state-funded emergency care or at their own expense. The reality is that medical care is a necessity for someone with HD, and a very high percentage of affected families are uninsured while attempting to cope with the financial, physical, mental, and emotional strains this disease causes.

In 2000, Congress passed a landmark bill that granted a waiver of this waiting period for any disability recipient with Amyotrophic Lateral Sclerosis (ALS), or Lou Gehrig's Disease, a neurodegenerative disease similar to HD. If disability recipients with HD were granted a similar waiver, the common and often ruinous gap in medical coverage could be closed and people with HD and their families would benefit from a better quality of life.

Summary: A waiver of the current two year waiting period for Medicare is needed for people with HD to ensure proper and timely treatment of symptoms and a better quality of life for the person with HD and their family.

The Proposed Solution

Simply put, the answer is legislation. The delays and errant denials of disability applications, as well as the lack of well needed medical coverage, for people disabled by HD are unnecessary. Revisions to the HD listing and a waiver of the 2 year waiting period for Medicare are urgently needed and can be accomplished through Congress. In order for this to happen we need to inform our congressional leaders about these issues and ask for their support. For the bill to be introduced it will need at least one "sponsor," and after its introduction our goal is to gain as much political support and as many "co-sponsors" as possible.