



## **Huntington's Disease Society Recommendations to Congress**

### **Our Goal**

Secure enactment of HR 678, legislation in Congress that would improve access to treatment and medical care for individuals suffering from Huntington's Disease

### **Background**

Huntington's Disease is a genetic neurodegenerative disease that causes total physical and mental deterioration over a 10 to 25 year period. Eventually, every person affected by HD will lose the ability to live independently. It is a rare disease, affecting 30,000 Americans while another 200,000 are considered 'at risk' of inheriting the disease from an affected parent.

### **The Problem**

Many people disabled by HD applying for Social Security disability benefits have experienced multiple delays and errant denials due to the continued use of the outdated and medically insufficient listing for HD. Furthermore, because most patients develop HD at a relatively young age they do not qualify for Medicare and therefore receive insufficient treatment during the early stages of the disease.

### **The Solution**

The Huntington's Disease Society of America is urging Congress to introduce and enact legislation that (1) revises the Social Security Administration's outdated criteria for determining disability for people with HD and (2) removes the two-year waiting period to receive Medicare benefits after receiving Social Security disability benefits.

### **Rationale**

Revising Social Security Administration criteria would reduce the number of delays and reapplications of genuinely disabled HD individuals by providing a complete and medically accurate description of the disease. Often, by the time persons affected by HD are "under review" for SSA disability, many have already lost their employer-provided health insurance benefits for themselves, and often their families.

Eliminating the 24-month Medicare waiting period in cases of individuals with disabling Huntington's Disease will ensure individuals will get crucial care in the early stages of the disease. In 2000, the Centers for Medicaid and Medicare Services waived this waiting period requirement for people disabled by ALS (amyotrophic lateral sclerosis), a degenerative neurological condition similar to HD.