



Why Hasn't Your Congressman Cosponsored HR 678?



HR 678 is a bill in Congress that would make it easier for people with HD to receive Social Security and Medicare. This bill will become law only if we speak up!

Just 20 of the 435 Representatives in Congress have cosponsored (endorsed) HR 678. The odds are pretty good that your Congressman is not one of them. We need you to persuade your Congressman to cosponsor HR 678.

It won't be easy. More than 2,500 bills have already been introduced in Congress and each week the average Congressman receives 10,000 email messages. Because of this high volume of mail, it is very important to be persistent.

Start by writing a personal letter or email. Then follow-up with a call to the member of the staff responsible for health care.

Follow-up regularly and frequently with the staff person. If you stop reaching out, the issue will fall off their radar screen.

If you're not getting the response you want, try using some of the tactics on the reverse to "increase the pressure" on your Congressman.

You can also reach out to the HDSA for assistance. Your Congressman's support is crucial and we want to help you get it.

For your Representative's name and contact information visit www.house.gov. For a copy of HR 678 visit <http://thomas.loc.gov> or www.hdsa.org.

Please contact Joseph LaMountain, our staff in Washington, at joseph.lamountain@gmail.com or 202.288.5124 with questions or comments.

We Can Do It!

SAMPLE LETTER/EMAIL

Dear _____:

I am writing to ask you to cosponsor HR 678. This bipartisan bill will dramatically improve the lives of the 30,000 Americans affected by Huntington's Disease, a degenerative, neurological disease that has greatly affected my life.

I have a strong personal interest in HD. [Please include 2-3 sentences about how HD has affected you and your family. Please mention any specific problems with Social Security and Medicare, if applicable.]

As my Representative in Congress, I strongly urge you to cosponsor H.R. 678, and look forward to your written response on this issue.

Your Name
Address



5 Ways to Persuade your Congressman to Cosponsor HR 678

- (1) Why Not HR 678?** - Find out which bills your Congressman has already cosponsored. You can get a real-time list by visiting <http://thomas.loc.gov> and clicking "Try the Advanced Search." From here, you can find what bills your Representative has cosponsored. It would be hard to explain why a Congressman has cosponsored a bill supporting AIDS, arthritis and breast cancer but not HD.
- (2) Letter to the Editor** - Write a letter to the editor of your local newspaper. Message: Why hasn't Congressman Smith cosponsored HR 678? Mention your previous contacts with the office, your personal story and your request to have the Congressman cosponsor the bill. Be sure to include some of the other bills that he or she has cosponsored.
- (3) Pop the Question** - Visit the Congressman's website (or call his Scheduler in DC) and find out when his/her next public appearance will be. Go to the event and ask a question (in front of everyone). Something like this: "My family is affected by HD. I've contacted your office several times but have not gotten an answer. You've cosponsored bills on AIDS and breast cancer. Why won't you cosponsor HR 678 and help people with HD?"
- (4) Bulk Up** – There's strength in numbers, so get others involved. Have everyone you know sign a letter asking the Congressman why he won't cosponsor HR 678. Or set up a phone tree and generate at least one call a day to the staff person responsible for health. Or send a group letter to the editor of your local newspaper. Or arrange a group visit to his district office. Or ask everyone to hand out 10 copies of this flyer.
- (5) Be a Squeaky Wheel** - If you don't go away, you will eventually wear them down. You will receive every answer in the book about why the Congressman "can't" support HR 678. Answer every question with a rational response or counter whatever argument they make. Or simply ask, "Why not?"

Background Information on HR 678 and HD

HD is a genetic 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 rare, affecting 30,000 Americans while another 200,000 are at risk of inheriting the disease from a parent.

Many people disabled by HD applying for Social Security disability benefits have experienced multiple delays and errant denials due to the continued use of outdated and medically insufficient listings 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 Huntington's Disease Society of America is urging Congress to enact HR 678, which would:

- (1) Revise Social Security's outdated criteria for determining disability for people with HD
- (2) Remove the two-year waiting period to receive Medicare after qualifying for Social Security disability benefits.