



HDSA Advocacy: *Speaking Up for HD!*

Introduction

- Why are YOU an Advocate?
- When did you become involved?

Cathy Saliga, LCSW
Social Worker
HDSA/KY Chapter
982 Eastern Parkway
Louisville, KY 40217
502-637-4372
csaliga@hdsa.org

“
*Different people do different
things when they feel vulnerable.*

**I TAKE
ACTION**

so I don't feel helpless.

”
Elisabeth Glaser



Advocacy is...

- *speaking up politically, educating, and raising awareness*
- *engaging others affected by HD, building a nationwide movement and getting results*

Why Me? Why Now?

- You are the **expert**. You know more about HD than members of Congress, and it's up to YOU to educate!
- Congress needs to hear from **YOU**. Members of Congress are contacted about thousands of issues. It's our responsibility as voters to tell them what is important to the HD Community.
- **Members of Congress won't act unless they hear from US.**



Your Voice Matters!

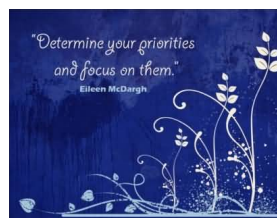
SPEAK UP, BE HEARD.
IF YOU DON'T SAY A WORD, EVERYTHING WILL STAY THE SAME WAY

PLAYREY

HDSA Advocacy: 2015 Priorities

HDSA National Advocacy is focusing on improving access to care and benefits for individuals affected by Huntington's disease at the national level.

The current primary focus of the HDSA National Advocacy Effort is generating support in the U.S. Congress for the ***Huntington's Disease Parity Act of 2015 (H.R. 842/S.968)***



But What About SSA Compassionate Allowances?

- The Social Security Administration's Compassionate Allowances (CAL) program fast-tracks disability decisions for the most serious conditions.
- Juvenile Huntington's disease (JHD) became one of the CAL conditions in August 2012.
- Adult Onset HD became a CAL condition in December 2012.
- Although the Compassionate Allowance designations for HD and JHD will make the disability review process easier, it does nothing about the 24 month waiting period for Medicare. Nor does it fix SSA's outdated guidelines for Huntington's disease.

This is why we still need to advocate for the *Huntington's Disease Parity Act*

The Huntington's Disease Parity Act

Goal: Make it easier for people with HD to receive Social Security Disability and Medicare Benefits

How (Huntington's Disease Parity Act)

- I. Updates guidelines used by Social Security Administration uses to determine disability for Huntington's disease.
- II. Ends 2-year Medicare wait period for individuals disabled by HD.

Our Strategy: Individuals contact elected officials, tell their story & ask their members of Congress to be cosponsors the Huntington's Disease Parity Act, creating a broad, bipartisan base of support for H.R.842 and S. 968.



Co-sponsorship

After a bill gets introduced, it is referred to committee. No vote can happen until after the committee acts.

Asking a Member of Congress to "vote for/against a bill" is meaningless while the Bill is in Committee

For a bill where no action has been scheduled it is important to ask members of Congress to **sign on as co-sponsors and ask their colleagues to cosponsor as well**

The more cosponsors a bill has, the more likely it is to move out of committee

YOUR help is needed to ask your Representative and Senators to cosponsor the Huntington's Disease Parity Act.



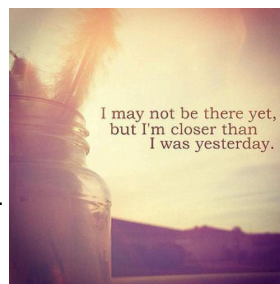


Where we are today

We are at **155** cosponsors of H.R. 842 in the House

Only 1 week after introducing the bill in the 114th Congress, we had as many original co-sponsors of H.R. 842 as we had after almost 22 months of the 113th Congress.

Because of the work of advocates around the country just like you, we have a Republican Senator, Senator Cassidy (R-LA) joining our long-time champion Senator Gillibrand (D-NY) as a lead sponsor of the HD Parity Act in the Senate (S.968). With Dr. Cassidy's support, we now have broad bi-partisan support for the HD Parity Act in the House and the Senate!



Advocating for HD is Easy!

- **Become an E-Advocate** at www.hdsa.org to get updates when Congress needs to hear from HD families
- Go to www.hdsa.org/takeaction to **send a letter** to your Representative and Senators. All you have to do is add your personal story, and click *send*.
- **Use Social Media** to stay informed and advocate for HD
- **Make it local:** Schedule a meeting with your Congressman and Senators in your home state. We'll provide you with materials, and make sure you're prepared for your visit.



What Can You Do To Help?



- You've already taken the first steps! You're at this Education Day!

Use What You Know:

- Emails & Letters to Members
- Petition Drives
- Call-in Days
- Letters to the Editor
- Washington, DC
- District Meetings
- Media Coverage
- Social Media (Facebook, Twitter, YouTube, etc.)



Advocates from the NYA with Senate Majority Leader Mitch McConnell (R-KY)

Local Meeting Tips

Face-to-face communication is the most effective method to influence politicians. Your Reps and Senators are there to serve you – show them what you care about!

- HDSA can help you set up a meeting with your Members locally and walk you through the whole process!
- What do you talk about?
 - What is HD?
 - How has HD impacted your life?
 - What is the HD Parity Act?
 - How would the HD Parity Act change your story or your loved ones?
 - Ask them to cosponsor the HD Parity Act!

Don't know where to begin? Contact jsimpson@hdsa.org to get started!



What You May Hear (and how to respond)

When you write to Congress or meet with a Member, you may receive a basic response that does not address the issue. Here are some examples of these non-responses.

- I will keep your concerns in mind should the legislation come to the Floor for a vote
- I am not a member of [Committee]
- I am a member of [Committee]

When you receive a non-response from a Member, provide polite rebuttal (HDSA can help!) and respectfully repeat your request for support. As a follow-up, send an email to the legislative aide for healthcare thanking the member of Congress for their time and consideration, and again respectfully repeat your request for support.

If you receive a response and do not know how to answer, HDSA can help. For help decoding Congressional responses, contact jsimpson@hdsa.org



Ways to Amplify Your Message



- Keep HD in the conversation by continuing to engage with your Members (even if they have cosponsored)...
 - **Having a Team Hope walk?**
 - Invite your Members of Congress!
 - **Having an HDSA fundraiser?**
 - Invite your Representatives and Senators!
 - **Got a letter to the editor published about the HD Parity Act?**
 - Send it to your Elected Officials!
 - **Were you in the newspaper or on TV?**
 - Share it with your Congressional offices!
 - Be **creative, persistent, and respectful** in all of your outreach – and become a useful resource to the offices for information, events, and ways for the Member to engage.



**BE
POSITIVE,
PATIENT
AND
PERSISTENT**

Working together, we CAN Succeed!

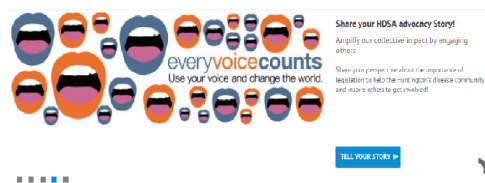
- ✓ **HDSA is here to help!** Contact Jennifer Simpson at jsimpson@hdsa.org or by phone at 800-345-4372 ext 226
- ✓ **Use the HDSA E-Advocacy Center at**
www.hdsa.org/takeaction
- ✓ **Get your friends involved as well**
 - You don't have to have HD in your family to care about helping people!

Persistence + Persistence + Persistence + Persistence
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= SUCCESS



"Take Action" Page



Take action for HD from your computer at

www.hdsa.org/takeaction

Our new e-Advocacy center is easier to use than ever!

You can take action from your computer or your phone!

[In the Spotlight](#) | [Join the E-Advocacy Network](#) | [Like HDSA on Facebook](#)



Final Thoughts

