Caregiver's CORNER

# **HDSA Advocacy:** *What you need to know to be an effective Grassroots Advocate*

*Funded by an educational grant from* Lundbeck

Huntington's Disease Society of America

# Questions

- Questions will be answered after the presentation. however, you may send a question anytime during the presentation.
- To send a question, go to the control panel that appears on the right side of your screen.
- There will be a panel for typing in a question.
- After typing your question, hit the “send” button

# To View this Webinar Again

- Approximately one week after this webinar is broadcast, you will be able to access it for viewing on the HDSA national website.
- To access this presentation, go to www.hdsa.org and scroll down the frequently used shortcuts box on the right hand site. You will see a link to Caregiver’s Corner Webinars. There will be an accompanying Powerpoint presentation that will allow you to print the slides out as well as a PDF file of additional information.
- Older webinars are archived in the *Living with HD* section, and can also be accessed via the front page.

# Panelists

**HDSA Advocates:**
*Lauren Holder*, Winston-Salem, NC
*Denise Wilders*, Pequannock, NJ
*Lindsey Zan*, San Diego, CA

**HDSA Advocacy Manager:**
*Jane Kogan*, HDSA
jkogan@hdsa.org

# Outline

- The Huntington's Disease Parity Act
- Grassroots vs. Legislative Advocacy
- Three faces of HDSA Advocates
- Get Involved!

# What We're Working Towards

**<u>Goal</u>:** Make it easier for people with HD to receive Social Security Disability and Medicare Benefits

***<u>How (Huntington's Disease Parity Act</u>*** **<u>(S. 648/H.R. 718):</u>**

I. Updates guidelines used by SSA to determine Disability for Huntington's disease.

II. Ends 2-year Medicare wait period for individuals disabled by HD.

**<u>Our Strategy</u>:** Advocates contact elected officials, tell their story & secure Congressional support. HDSA follows up with Congress in Washington

# Grassroots & Legislative Synergy

- Grassroots advocates put a face on Huntington's Disease
- Importance of a personal connection
- When Advocates tell their stories, HDSA follows up in Washington.
- HDSA is here to help you be an effective advocate, and to give you tools to succeed

**MEET 3 HDSA ADVOCATES**

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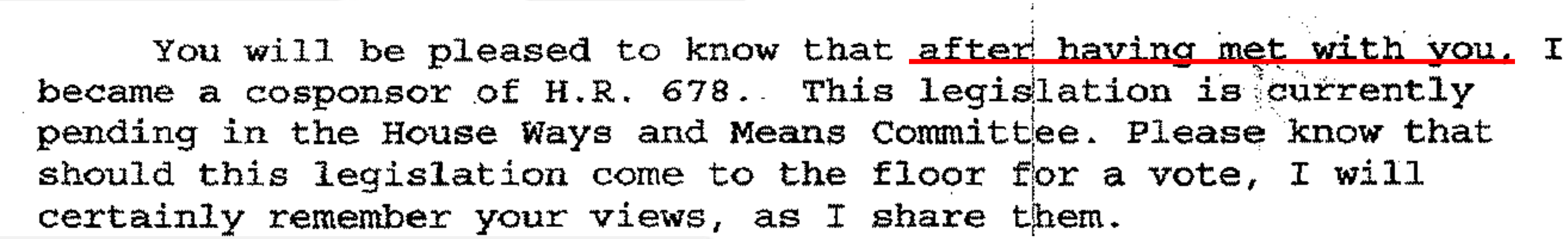
# Denise Wilders

- ✓ You have to ask Congress for them to care…
- ✓ But usually, it takes persistence, perseverance, and follow-up.
- ✓ Cosponsors can be cultivated to become champions.



You will be pleased to know that after having met with you, I became a cosponsor of H.R. 678. This legislation is currently pending in the House Ways and Means Committee. Please know that should this legislation come to the floor for a vote, I will certainly remember your views, as I share them.

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# Lauren Holder

- ✓ If you hit a roadblock, keep trying!
- ✓ Advocate for others
- ✓ Go for the personal meeting
- ✓ Engage your support group

# Lindsey Zan

- ✓ If you don't have a connection, ask five people.
- ✓ Make it a Chapter effort!
- ✓ Engage others.

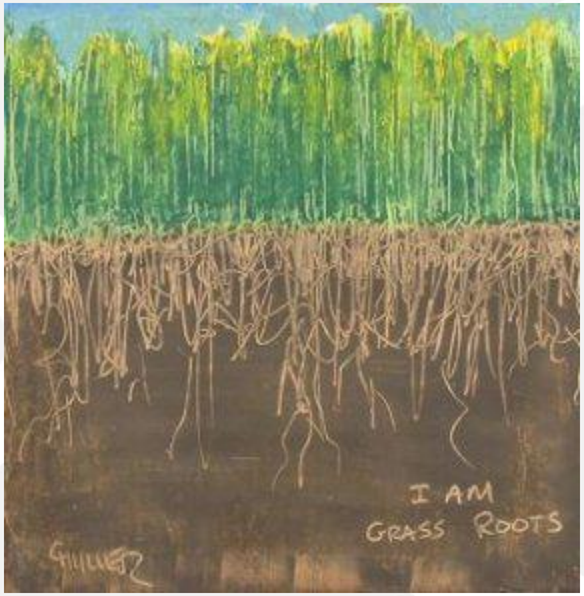
# Common Themes

1. **Persistence is Key:** Don’t stop until you get a definitive answer. If you get a noncommittal response, politely repeat your request. HDSA can help you respond!
2. **YOU Need to Participate:** Members of Congress need to hear from constituents to take action on issues.
3. **HDSA Advocates Are the Experts:** Members of Congress and their staff know little about HD, so you need to share how HD affects you.
4. **Engage Others:** Every person you involve is another voice speaking for HD.

# Next Steps

- Join the HDSA advocacy movement by becoming an E-Advocate at www.hdsa.org/join!
- If you are already an E-Advocate, Ask the people who care about you to get involved!
- **Call Congress on May 31!** Phone numbers and talking points will be posted at www.hdsa.org/callcongress

# Why We Advocate



- The Huntington's Disease Parity Act is important to me because…

<u>You should speak up for the Huntington's Disease Parity Act because your Congress need to hear from **YOU!**</u>

# If We Don't.... Who Will?

# HDSA's E-Advocacy Center

## www.hdsa.org/takeaction

**Contact the Presenters:**

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