

Your Story, Your Turn

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Disclosures

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The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
or list

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HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

GUIDING QUESTIONS

- What is your “HD story”?
- Why is your story important?
- How do you use your story to:
 - **Educate** your community?
 - **Connect** to HDSA’s ongoing work?
 - **Influence** decision makers?



WHAT IS YOUR “HD STORY”?

Your story is who you are, where you’re from, and where you’re going.

- Why are you here today?
- Who are you fighting for?
- What changes do you want to see?

WHY IS YOUR STORY IMPORTANT?

HD is a BIG part of your life, but many people are not as familiar with HD.

Use your story to:

- Educate
- Break down barriers
- Advocate



#LetsTalkAboutHD

WHY IS YOUR STORY IMPORTANT?

Advocacy = Storytelling

- Allows you to **connect** to others
- Often more **memorable** than statistics
- Put's a **face** on something unknown
- Helps inspire others to share their story

Myths about HD Advocacy

- Advocacy is just talking to politicians
- You have to be 18+ to share your story
- You have to be an extrovert to share your story as an advocate

HOW DO YOU USE YOUR STORY?

To be effective, you should:

- Know your message
- Find the right example(s)
- Convey passion
- Support with facts



How do you use your story to
EDUCATE YOUR COMMUNITY?

HOW DO YOU USE YOUR STORY TO EDUCATE YOUR COMMUNITY?

WHY IMPORTANT?

- Support System
- Your network has influence
- Feel good



HOW DO YOU USE YOUR STORY TO EDUCATE YOUR COMMUNITY?

- Talk to your immediate family/friends
- Encourage questions from others
- Work with local community institutions
 - Schools
 - Churches/Temples/Mosques
 - Community Centers
 - Police Stations

HOW DO YOU USE YOUR STORY TO EDUCATE YOUR COMMUNITY?

Malia organized a jog-a-thon at her elementary school, and raised money and awareness for Huntington's Disease.



HOW DO YOU USE YOUR STORY TO EDUCATE YOUR COMMUNITY?

Jolene presented at the HDSA Iowa Chapter Education Day and the University of Iowa HDSA Center of Excellence's screening of the film *The Lion's Mouth Opens* about advocacy and how to get involved in Iowa.



HOW DO YOU USE YOUR STORY TO EDUCATE YOUR COMMUNITY?

In addition to holding education days and events, Lauren educates local law enforcement about Huntington's Disease.





How do you use your story to

CONNECT TO HDSA'S ONGOING WORK?

HOW DO YOU USE YOUR STORY TO CONNECT TO HD SA?

WHY IMPORTANT?

- Reach more people
- Local Chapters and Affiliates often have space on their Chapter Boards for folks who want to get involved
- You can help raise money for HD SA's ongoing projects

HOW DO YOU USE YOUR STORY TO CONNECT TO HD SA?

- Walk-a-thon
- Flower Sales
- Auctions
- Race Cars



HOW DO YOU USE YOUR STORY TO CONNECT TO HDSA?

Morgan has facilitated the *Barbara Lee's Fast Track to a Cure for Huntington's Disease* car race for 8 years - raising funds and awareness for HD.



HOW DO YOU USE YOUR STORY TO CONNECT TO HD SA?



Cheryl sold Amaryllises at her **children's** school to raise money and support HD SA.



How do you use your story to

INFLUENCE DECISION MAKERS?

HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?

WHY IMPORTANT?

- Policy makers control the programs the HD community relies on
- Policy makers rely on you for information – they want to hear from you

HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?



Local Government

- Mayor, City Council, School Board
- Plans your area's economic and environmental development



State Government

- Governor, Attorney General, State Legislature
- Education, implementation of welfare, maintain state highways, regulation of industry



Federal Government

- President, Congress, Supreme Court
- Make laws that affect the entire country, declare war, borrow money, establish post office, issue patents, trade with foreign nations

HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?

Raise HD Awareness at the State and Local level

- Educate your elected officials on Huntington's Disease
- Call, email, and write to your State Representatives and Senators
- Invite Local and State officials to the events that you plan!

HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?

Three Branches of Government FEDERAL LEVEL



The U.S. Capitol

LEGISLATIVE
(Makes Laws)



Congress



Senate



**House of
Representatives**



The White House

EXECUTIVE
(Enforces Laws)



President



Vice President



Cabinet



The U.S. Supreme Court

JUDICIAL
(Interprets Laws)



Supreme Court



Other Federal Courts

Congress

114th Congress (Jan. 2015- Dec. 2016)

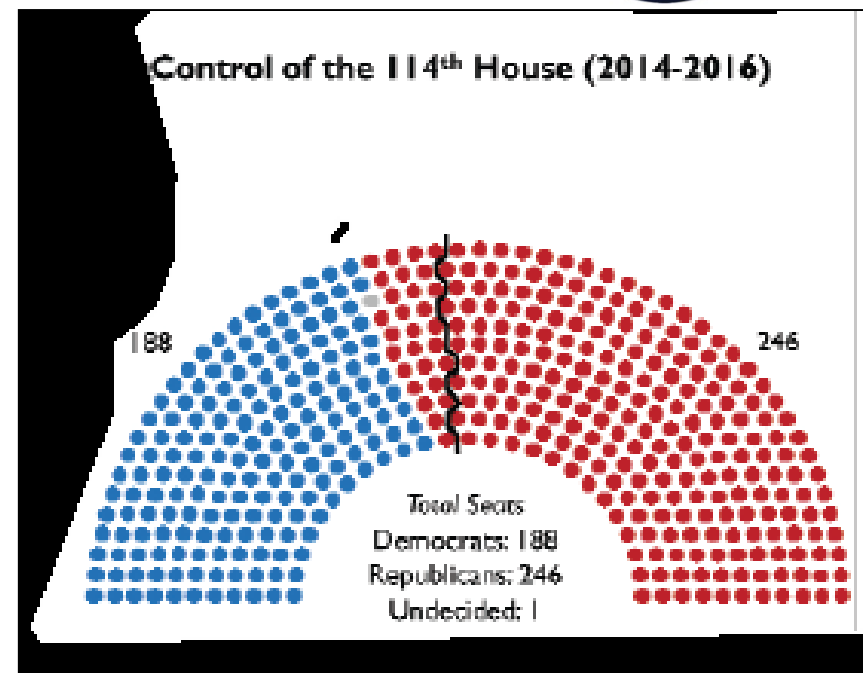


HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?



U.S. House of Representatives

- 435 voting Members from 50 states
 - Elected every 2 years
 - Controlled by Republicans (since January 2011)
 - 218 votes needed to pass a bill (*Majority*)

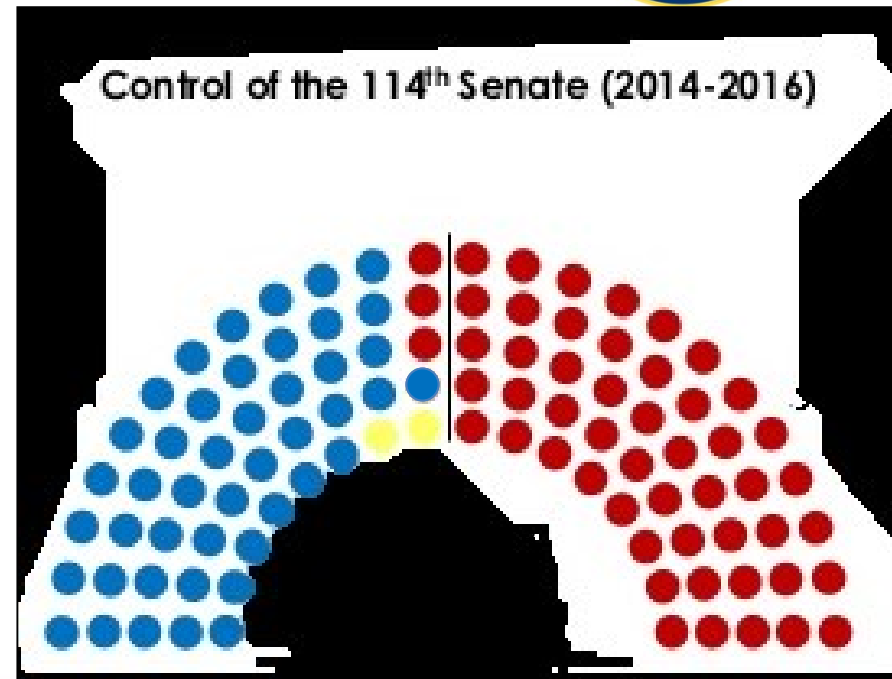


HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?

U.S. Senate



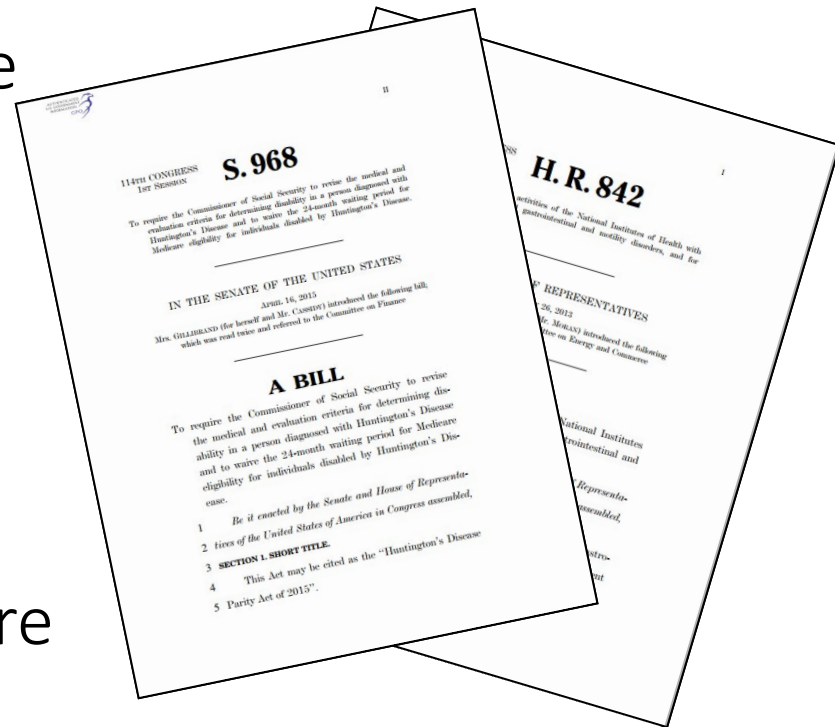
- 100 Senators from 50 states (2 each)
 - Elected every 6 years
 - Controlled by Republicans (since January 2015)
 - 60 votes *usually* needed to pass a bill
 - Unanimous consent
 - Filibuster
 - No representation for the 5 U.S. Territories and Washington, D.C.



HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?

The Huntington's Disease Parity Act (S. 968/H.R. 842)

1. Forces Social Security to revise their outdated criteria for determining disability for individuals with HD, and
2. Waives the Medicare 2-year waiting period to ensure individuals with HD get the care they need, when they need it.



HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?

The Huntington's Disease Parity Act

	House (H.R. 842)	Senate (S. 968)
Sponsors:	Representatives Kinzinger (R-IL) and Pascrell (D-NJ)	Senators Gillibrand (D-NY) and Cassidy (R-LA)
Number of States with at Least 1 Cosponsor:	45	15
Cosponsors:	253 Cosponsors <ul style="list-style-type: none">• 152 Democrats• 101 Republicans• 103 Original Cosponsors	19 Cosponsors <ul style="list-style-type: none">• 15 Democrats• 3 Republicans• 1 Original Cosponsor

HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?

Contact your Congressman and Senator

- Emails/Letters
 - I Care/Faces of HD Campaign
- Meet in person
- Connect on social media



HOW DO YOU USE YOUR STORY TO INFLUENCE DECISION MAKERS?

Advocacy Tips

- Keep it brief/highlights
- Emotion should move, not overwhelm
- Make a specific ask
- Follow up

HD PARITY ACT S.968/H.R. 842

For more information on how you can help pass the HD Parity act please visit www.hdsa.org/takeaction



HOME RESOURCE & ACTION CENTER KEY ISSUES MORE INFORMATION

Huntington's Disease Parity Act

Social Security Disability

People with HD applying for Social Security Disability Insurance (SSDI) are routinely denied or experience long delays due to the Social Security Administration's (SSA) use of outdated, medically inaccurate guidelines.

As a result, the outdated guidelines cause individuals with HD to experience long delays and multiple denials of critical SSD benefits.

Medicare Benefits

The Huntington's Disease Parity Act (H.R. 842/S. 968) will improve access to Social Security Disability benefits and Medicare coverage for individuals with Huntington's Disease (HD). The legislation will ...

- Direct the Commissioner of SSA to revise its outdated medical and evaluation criteria for determining disability, thus enabling individuals with HD to receive the essential disability benefits that they are often

In Their Own Words...

Support The Huntington...

HD Advocates and community members tell us why they want and need the Huntington's Disease Parity Act (H.R. 842/S. 968) passed TODAY!

Get Involved!

Click below to take action and support the HD community!

The Time Is Now!

Don't Wait Another Day! Join the Fight Today To Pass the HD Parity Act!

Tweet Your Member of Congress About the HD Parity Act!

Use Twitter to Engage with your Members of Congress about the Huntington's Disease Parity Act!

Share your HDSA advocacy Story!

Share your perspective about the importance of legislation to help the Huntington's disease community and inspire others to get involved!

Passing the Parity Act

Shared by Destiny Hand - 6/29/2015

Hi, my name is Destiny Hand and Huntington's Disease has been in my life as long as I can remember. I grew up taking care of my mom when I was a child and now...

QUESTIONS?

www.hdsa.org/takeaction

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