All-Star Advocacy

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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.
There are...

Approximately \textbf{320 million people} living in the United States – About 700,000 of those people live in your Congressional district.
100 Senators, 435 Representatives, and 9,404 Staffers work to write and pass legislation.

5,868 emails, 1,473 letters, 332 calls, and 13 meetings with each office daily.
But, Few Bills Become Law

113th Congress Bills Introduced

- Bills 97%
- Laws 3%

Last Congress

- 8,913 bills were introduced
- Only 297 became law.
  - 103 were Administrative Laws (like naming a highway or post office)
  - Only 194 “substantive”
It’s Time to Advocate

• It can be hard to stand out from the millions of other advocates and causes, but it is also exactly why you are needed.
Advocacy

What does it take?
Personal Education

Community Education

Fundraising

Publicity

Elected Officials

Advocacy
Engage yourself

- Stay up to date on HD news and events across your state and the country
  - Clinical trials
  - On-going research
  - Support groups in the area
Personal Education

Engage yourself

• Important to understand the political process before interacting with Congress

• The Basics:
  – Federal vs. State Government
  – 3 Branches of Government
  – How a bill becomes a law
  – The Huntington’s Disease Parity Act
FEDERAL

How Much? The U.S mint manufactures and distributes the coins we use. The Bureau of Engraving and Printing prints our paper money.

Ensuring National Security. The Department of Defense provides the military forces needed to prevent war and keep our country.

To Your Health. The Food and Drug Administration (FDA) approves all medicines and sets food safety standards.

Learning More on Your Behalf. The National Institute of Health (NIH) supports research into the causes and cures of diseases.

Local and Federal

How Green it is! National and State Governments create and maintain about 300 million acres of parks and correctional facilities. Prisons house people who have been convicted of a crime.

State and Federal

Road Trip! About 4 million miles of roads crisscross the U.S.

Safe and Sound. Community police, state troopers, national guard, and the FBI work to fight crime.

Federal, State, and Local

Your Teachers, Your Schools. Local communities hire teachers, build schools and provide transportation to and from school. What gets taught is the state’s responsibility.

State and Local

Quick, Call 9-1-1! Your community's first responders - firefighters, police, and EMTs - are there in minutes.

Local

Read, Play, Enjoy. If you like libraries, sports fields, parks and other recreation facilities in your community, say thank you to your local government.

Electricity, Natural Gas and Water are necessities to be managed and distributed. Local communities are in charge.
Personal Education
The Federal Government
Personal Education

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)
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.
A Member, staffer, or Constituent comes up with an idea to fix a problem (Let’s look at the House).

A Representative introduces a bill and the bill is then assigned to the appropriate House Committee.

The appropriate Subcommittee makes any changes to the bill, and votes to send the bill to the full Committee – which votes to send the bill to the full House.

The bill will be debated in the House and voted on. If it passes, it is sent to the Senate to repeat the process.

If there **are no changes** in the Senate, then the bill is sent to the President.

If there **are changes**, then the bill is sent back to the House for them to vote on it as well.

The President can sign the bill and it becomes a law, veto the bill (which can be overridden by a 2/3 vote in Congress), or take no action.
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.
## Personal Education

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

<table>
<thead>
<tr>
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<th><strong>House (H.R. 842)</strong></th>
<th><strong>Senate (S. 968)</strong></th>
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<tbody>
<tr>
<td><strong>Sponsors:</strong></td>
<td>Representatives Kinzinger (R-IL) and Pascrell (D-NJ)</td>
<td>Senators Gillibrand (D-NY) and Cassidy (R-LA)</td>
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<td><strong>Cosponsors:</strong></td>
<td>174 Cosponsors</td>
<td>7 Cosponsors</td>
</tr>
<tr>
<td></td>
<td>• 111 Democrats</td>
<td>• 6 Democrats</td>
</tr>
<tr>
<td></td>
<td>• 63 Republicans</td>
<td>• 1 Republican</td>
</tr>
<tr>
<td></td>
<td>• 103 Original Cosponsors</td>
<td>• 1 Original Cosponsor</td>
</tr>
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<td><strong>States:</strong></td>
<td>40</td>
<td>5</td>
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Advocacy

- Personal Education
- Community Education
- Elected Officials
- Publicity
- Fundraising
Engage your friends, family and community

- Share your story
  - What is HD?
  - How does it affect you?
- Coordinate with others
  - Learn from their experiences
Your Voice Inspires Others
MaryAnn Emerick

Touched thousands of people by sharing her HD story with FoxNews.com.
Since 2001 Bill has participated in the San Diego Rock n’ Roll Marathon to raise money and awareness of HD. “Running to Cure HD” has raised almost $700,000 for HDSA.
**Fundraising**

**Engage** donors

• Fundraising accomplishes three goals...
  1. Increased funds
  2. Increased awareness
  3. Increased engagement

• HDSA Local chapters are great sources of support and information
Fundraising

- Hope Walk/5k
- Bowl-a-thon
- Pancake Breakfast
- Auction
- Car Wash
- Bake Sale
Morgan McLane

Facilitated the Fast Track PGH car race for 8 years, raising almost $100,000 and local awareness for HD

*Barbara Lee’s Fast Track to a Cure for Huntington’s Disease*
For the last 3 years the Greater DC Chapter of HDSA has put on the “Blue Tie Gala” to raise awareness and money for HDSA.
Personal Education

Community Education

Elected Officials

Fundraising

Publicity

Advocacy
Publicity

Social Media
- Tag your local officials and Congressmen in posts asking for support, giving thanks, or requesting attendance at events

Local Media
- Alert the local news to HD events for your Chapter
- Write letters to your editor explaining what you’re facing, and what needs to change to make it better
  - Short, sweet, and with a concrete goal in mind.
Publicity

Engage larger media

Formerly 'bittersweet' Day takes on a new Shana Verstegen

Shana Martin wasn't excited about her first day of parenthood.

But there's one thing she's looking forward to—Huntington's disease awareness.

The devastation

Advocate fights for new Huntington's disease legislation in mother's memory

MIND AND BODY

Advocate raises awareness about Huntington's Disease - 06:10

Best ways to keep your allergies under control

Eat foods like pulled pork and lose weight?

Mother's Day workouts for expectant mommies

Huntington's Disease Society of America
Elected Officials

Engage your elected leaders

- Educate them about HD
- Invite them to your events
- Work with HDSA to promote the Huntington’s Disease Parity Act (H.R. 842/S. 968)
One person can make a huge difference

Sen. Shaheen (NH)
Sen. Nelson (FL)
Sen. Ayotte (NH)
Sen. Graham (SC)
Rep. Bilirakis (FL)
Rep. Neal (MA)
Rep. Flores (TX)
Rep. McLane Kuster (NH)
Rep. Hudson (NC)
Rep. Neugebauer (TX)
Rep. Kennedy (MA)
Sen. McConnell (KY)
Questions to Answer

• Who are you?
• Why are you contacting?
• What are you asking for?
• Why is this important to you?

Keep it simple!

• You are a concerned constituent
• You need them to cosponsor and pass H.R. 842/S. 968
• Share your story!
• Ask for cosponsorship again!
Elected Officials

Schedule a District Meeting

www.hdsa.org/hdparity

• Set up a meeting in your Representative/Senator’s local office:
  – Identify who your Representative/Senator is
  – Request through their website

• Prepare for the meeting:
  – Jennifer and Jason will provide you with everything you need!
    Email jsimpson@hdsa.org
Elected Officials

DC Fly-In
• Meet with your members in Washington, DC
• Make it a group event!
  • NYA Fly-In
  • Family Trip
• HDSA and Jason’s team are here to help!
# Elected Officials

## Tips for Meetings

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<th><strong>Do</strong></th>
<th><strong>Don’t</strong></th>
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| • Be yourself – let the Member or staffer get to know you  
• Bring a friend  
• Describe how the HD Parity Act would help you/your family  
• Follow up after the meeting | • Don’t answer questions about the bill if you do not know the answer  
• Don’t expect a decision on the bill while you are in the |
Next Steps

• **Today at 5:15pm in Landmark D**
  • Texas Meet and Greet

• **Today at 7:00pm in Landmark A**
  • NYA Talent Show
  • Pie me in my face for $5.00!

• **Today and Tomorrow**
  • Stop by the HD Advocacy

• **Next Week**
  • Email [jsimpson@hdsa.org](mailto:jsimpson@hdsa.org) and get engaged!
Advocacy

- Personal Education
- Community Education
- Fundraising
- Elected Officials
- Publicity
Advocacy is for everyone!

You don’t have to commit a lot of time – even a quick email or phone call helps.

It’s most important to be persistent, patient, and passionate.
QUESTIONS?

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