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/Templs/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.
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 HDSA?

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 HDSA’s ongoing projects
HOW DO YOU USE YOUR STORY TO CONNECT TO HDSA?

• 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 HDSA?

Cheryl sold Amaryllises at her children’s school to raise money and support HDSA.
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

**LEGISLATIVE**  
(Makes Laws)  
\[ \downarrow \]  
Congress  
\[ \quad \downarrow \quad \]  
Senate  
\[ \quad \downarrow \quad \]  
House of Representatives

**EXECUTIVE**  
(Enforces Laws)  
\[ \downarrow \]  
President  
\[ \quad \downarrow \quad \]  
Vice President  
\[ \quad \downarrow \quad \]  
Cabinet

**JUDICIAL**  
(Interprets Laws)  
\[ \downarrow \]  
Supreme Court  
\[ \quad \downarrow \quad \]  
Other Federal Courts
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)

Control of the 114th House (2014-2016)
• **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

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<tr>
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<th>House (H.R. 842)</th>
<th>Senate (S. 968)</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>Number of States</strong></td>
<td>45</td>
<td>15</td>
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<tr>
<td><strong>with at Least 1</strong></td>
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<td>Cosponsor:</td>
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<tr>
<td><strong>Cosponsors:</strong></td>
<td>253 Cosponsors</td>
<td>19 Cosponsors</td>
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<tr>
<td></td>
<td>• 152 Democrats</td>
<td>• 15 Democrats</td>
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<tr>
<td></td>
<td>• 101 Republicans</td>
<td>• 3 Republicans</td>
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<tr>
<td></td>
<td>• 103 Original Cosponsors</td>
<td>• 1 Original Cosponsor</td>
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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
QUESTIONS?

www.hdsa.org/takeaction

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