WORKSHOP

REACHING CONGRESS IN TWISTED TIMES

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STRATEGIC HEALTH CARE
PRESENTER DISCLOSURE

Peggy Tighe and Jane Kogan have had no personal financial relationships with commercial interests to disclose or list relevant to this presentation during the past 12 months.
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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.
**TEAM**

HDSA
Jane Kogan
Deb Lovecky
Strategic Health Care
Peggy Tighe
Melissa Benish

YOU
HOW OUR TEAM WORKS...
HOW OUR TEAM WORKS...

YOU

Huntington’s Disease Society of America

STRATEGIC HEALTH CARE

YOU
**CHALLENGES**

- Divided Government
- Presidential Election
- PPACA Repeal/Threats
- Balance of Power
- Budget Crisis
- Medicare out of $$

*Being Heard Through Political “Noise”*
## Divided Government/Balance of Power

<table>
<thead>
<tr>
<th></th>
<th>House</th>
<th>Senate</th>
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<tr>
<td>Republicans</td>
<td>240</td>
<td>47</td>
</tr>
<tr>
<td>Democrats</td>
<td>193</td>
<td>51</td>
</tr>
<tr>
<td>Independents</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Vacancies</td>
<td>2</td>
<td>0</td>
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<tr>
<td>Majority</td>
<td>218</td>
<td>60</td>
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</table>

Treasury Secretary Timothy Geithner, “if lawmakers don't get it together by Aug. 2, the United States will no longer be able to pay its bills in full.”

CNN, May 17, 2010

The new Medicare trustees report (May 2010) says the trust fund is now likely to run out of money in 2024, five years earlier than predicted last year.

Politico May 23, 2010
**CAPITOL HILL STAFF - POWER**

- Average Capitol Hill Health Care Staffer 22-28 years old
- Capitol Hill, often FIRST job
- "In House Expert" -- up to 10 issues.
- Up to 15 meetings a day, hearings, press conferences, other events
- Hundreds of emails daily.
- Staffer may or may not be from the Members’ state or district
- INCREDIBLE POWER
**CAPITOL HILL STAFF – PUMMELLED**

- Fewer House staff and fewer legislative support agency personnel now than in any time since 1979.
- Total House personal office, committee, and leadership staff numbers are at and all time low.
- Major legislative support agencies - 65% of their ‘79 levels.
- 12,500 federally registered lobbyists, and countless others, provide information and exert influence in Congress.
- ONLY 7-8,000 House personal office, leadership, and committee staff.
**STRENGTHS**

SENATE BILL  
S.648  
Gillibrand (D-NY), Schumer (D-NY), Menendez (D-NJ), Lautenberg (D-NJ) Tester (D-MT), Johnson (D-SD), Kerry (D-MA) . . . more to come!

HOUSE BILL  
H.R. 718  
2009-2010  
153 co-sponsors  
2011 TOTAL  
78 co-sponsors  
TOP TARGETS  
54 09-10 co-sponsors
OUR SUCCESSES

Amid the noise, HDSA remains strong...

House Cosponsors: 73 (6/13/11)
Senate Cosponsors: 6 (6/13/11)
If your Member/Senator has not already arrived at a firm decision on an issue, how much influence might the following advocacy strategies directed to the Washington office have on his/her decision?*

<table>
<thead>
<tr>
<th>Method</th>
<th>A Lot of Positive Influence</th>
<th>Some Influence</th>
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<tr>
<td>In-Person Issue Visits from Constituents</td>
<td>46%</td>
<td>51%</td>
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<tr>
<td>Contact from a Constituent Who Represents Other Constituents</td>
<td>36%</td>
<td>60%</td>
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<tr>
<td>Individualized Postal Letters</td>
<td>20%</td>
<td>70%</td>
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<tr>
<td>Individualized Email Messages</td>
<td>19%</td>
<td>69%</td>
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<tr>
<td>Phone Calls</td>
<td>14%</td>
<td>72%</td>
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<tr>
<td>Comments During a Telephone Town Hall</td>
<td>17%</td>
<td>68%</td>
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<tr>
<td>Visit From a Lobbyist</td>
<td>8%</td>
<td>74%</td>
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<tr>
<td>News Editorial Endorsement of an Issue</td>
<td>10%</td>
<td>65%</td>
</tr>
<tr>
<td>Individualized Faxes</td>
<td>8%</td>
<td>62%</td>
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<td>Form Postal Letters</td>
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<tr>
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<td>50%</td>
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<tr>
<td>Postcards</td>
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<td>Comments on Social Media Sites</td>
<td>1%</td>
<td>41%</td>
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<tr>
<td>Form Faxes</td>
<td>0%</td>
<td>30%</td>
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*For each method, the percentage indicates the likelihood of the strategy having a lot of positive influence or some influence on a Member/Senator's decision.
MESSAGES

SOCIAL SECURITY DISABILITY

- Delays, denials are unfair and harmful
- SSA Medical Guidelines for Huntington’s Disease are 30 years out of date (only chorea).
- Devastating cognitive and behavioral effects occur at least a decade before chorea
- Disability system was meant to help us.

MEDICARE

- 2 year waiting period for our family members is particularly devastating
- There are exceptions for ALS and ESRD
CONNECT THE DOTS...

S. 648/H.R. 718  SOLVE THESE PROBLEMS because the bills....

- DIRECT the Commissioner of the Social Security Administration to immediately REVISE the outdated criteria using current medical science.

AND

- Immediately WAIVE the 2 year waiting period for people with Huntington’s Disease.
**WHAT YOU CAN DO**
TURN UP THE VOLUME
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</table>
KEEP IT SIMPLE

In any communication (email, letter, call)...

1) THANK THEM
   Thanks for taking the time to hear my concerns.

2) TELL THEM WHAT YOU WANT
   I want you to CO-SPONSOR the bill.

3) TELL YOUR PERSONAL STORY
   Tell them why you are an advocate

4) ASK them to CO-SPONSOR
   Will you/your boss co-sponsor the bill?
WHAT **NOT** TO DO...

- I am a constituent/voter and I will vote for you, against you if you don’t do this...
- Discuss anything relative to a fundraiser or contribution to the member of Congress.
- Tell staff they are the age of your children, grandchildren or assume they know nothing.
- Spend more than a few minutes “chatting/making small talk.”
- Tell your story, but forget to make the ask
QUESTIONS, COMMENTS, TIPS.....
RESOURCES


• Tom Daschle, Scott S. Greenberger, and Jeanne M. Lambrew, Critical: What We Can Do About the Health-Care Crisis, Thomas Dunne, 2008.


Sunlight Foundation, Keeping Congress Competent: Staff Pay, Turnover, And What It Means for Democracy, Daniel Schuman, Dec. 21, 2010