

# Advocacy Training Session



Workshop

Peggy Tighe, J.D.  
Partner





# Peggy Tighe, J.D.

*Partner, Legislative Affairs, Strategic Health Care*

- Prior to joining SHC, Peggy was senior lobbyist for Congressional Affairs at the American Medical Association.
- A strong advocate for individuals with Huntington's Disease, Peggy has worked with the HDSA community for 6 years.
- Peggy has also done extensive work with GINA (Genetic Information Nondiscrimination Act).
- Past President of Women in Government Relations
- Peggy has devoted 20 years to federal and state advocacy.

## Presenter Disclosure

Peggy Tighe has had no personal financial relationships with commercial interests to disclose or list relevant to this presentation during the past 12 months

## Disclaimer

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2012 HDSA convention program is for informational use only.

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.

# AGENDA



**WHERE ARE WE?**



**WHERE IS  
CONGRESS?**



**WHERE DO WE  
GO FROM HERE?**

# WHERE ARE WE?



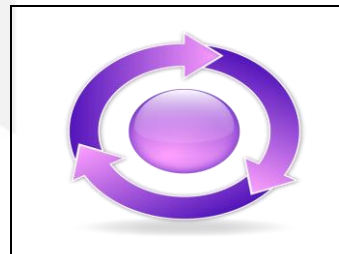
**S.648/H.R. 718**



**HDSA by the Numbers**

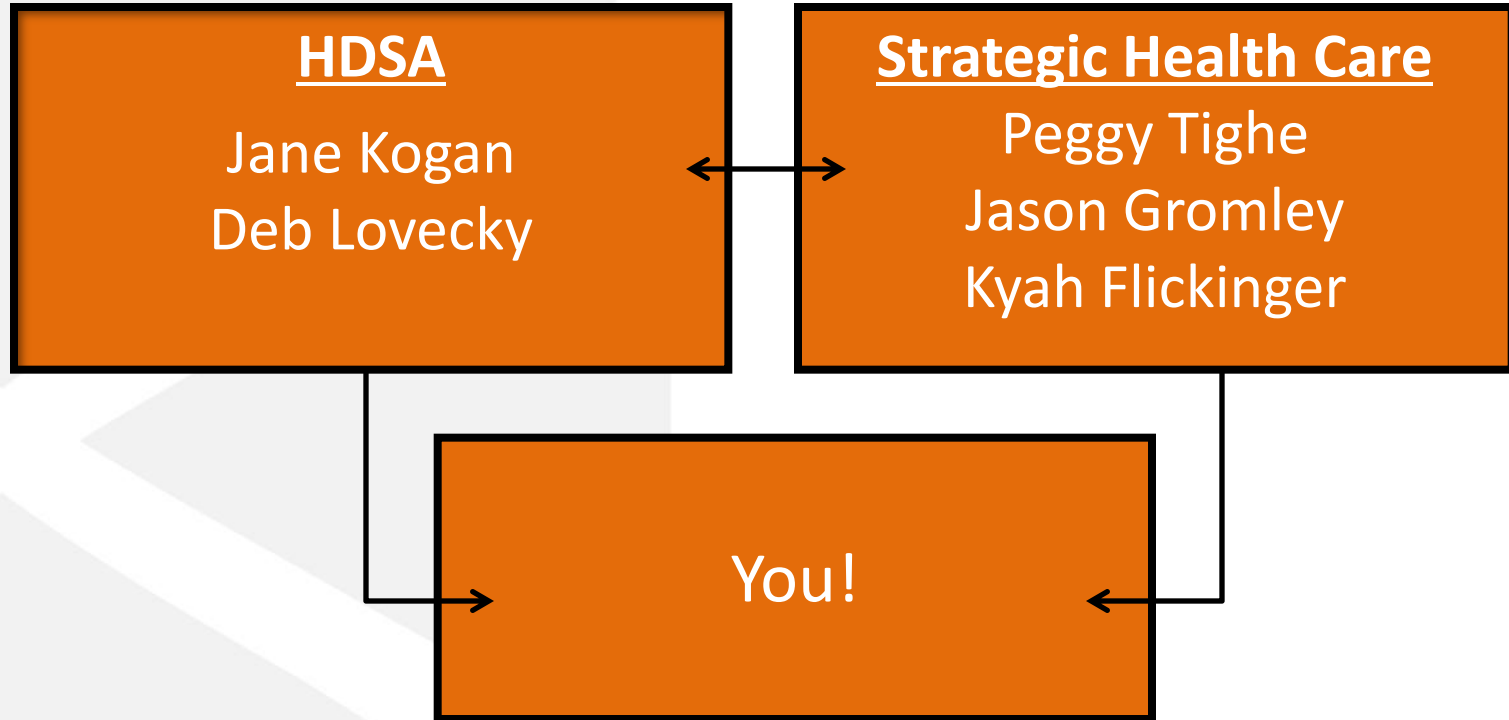
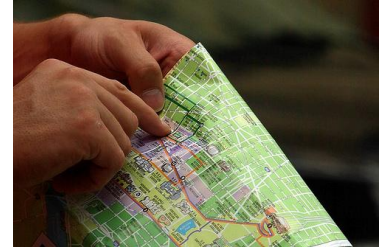


**Social Security/  
Medicare**



**Bringing It All Together**

# Our Team



# LEGISLATION



## Senate Bill – S.648

- 11 Co-sponsors
- Recent 2012 additions include Sen. Daniel Akaka (D-HI), Sen. Mark Begich (D-AK), Sen. Debbie Stabenow (D-MI)



## House Bill – H.R. 718

- 127 Co-Sponsors
- Recent 2012 additions include Rep. Gerry Connolly (D-VA), Rep. Chris Murphy (D-CT), Rep. Bill Cassidy (R-LA), and Rep. Mazie Hirono (D-HI)





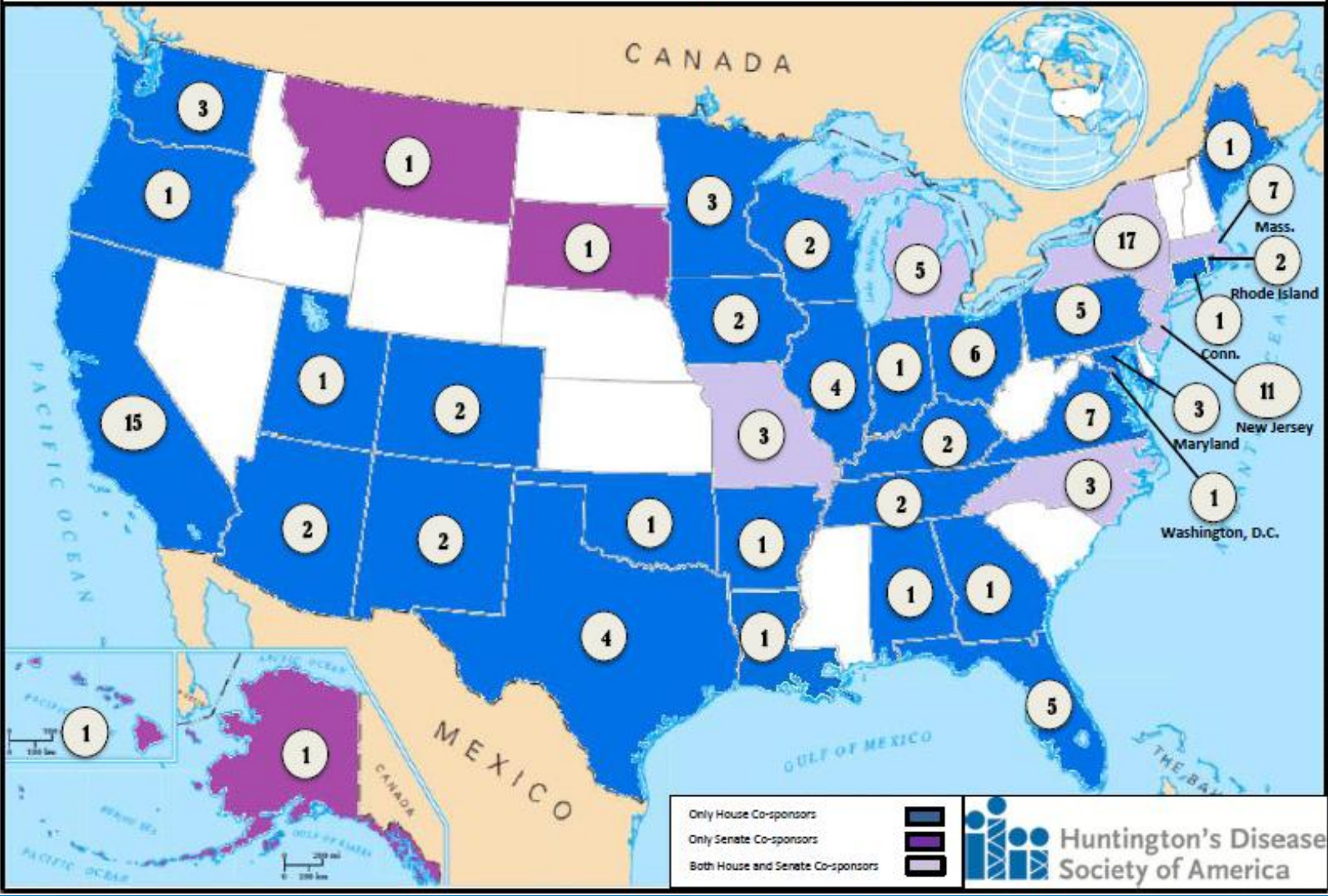
# HD vs. Other Health Related Bills



Bi-Partisan Health Related Bills							
Bill	Bill #	First Introduced	House	Senate	Democrats	Republicans	Total
Pancreatic Cancer Research and Education Act	H.R.733 & S.362	111 <sup>th</sup> Congress	239	48	194	93	287
Combating Autism Reauthorization Act	H.R.2005 & S.1094	111 <sup>th</sup> Congress	100	38	102	36	138
Huntington's Disease Parity Act	H.R.718 & S.648	111 <sup>th</sup> Congress	127	11	100	38	138
National Pediatric Acquired Brain Injury Plan Act	H.R.2600	112 <sup>th</sup> Congress	113	Not introduced	61	52	113
Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act	H.R.2969 & S.1454	110 <sup>th</sup> Congress	91	14	73	32	105

*\*As of May 21, 2012*

# Huntington's Disease Parity Act of 2011 (HR718/S648) Co-Sponsors By State



# Social Security/Medicare



## Social Security Disability

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

## Medicare

- 2 year waiting period for our family members is particularly devastating
- Delay in meaningful healthcare coverage means people are waiting to be treated until eligible for Medicare, increasing system costs.



# Bringing It All Together

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

- Direct the Commissioner of the Social Security Administration to immediately consult with the Institute of Medicine and REVISE the outdated disability criteria for HD using current medical science.

**and**

- Immediately waive the 2 year waiting period for people with Huntington's Disease, similar to the waiver for ESRD and ALS.

# WHERE IS CONGRESS?



**Congress**



**Supreme Court**



**Elections**



**Congressional Staff**





# Defining Issues: '11-'12 Congress

- 1. Reducing The National Debt**, Congress' 2011-12 Focus, health care and hospitals are key targets.
- 2. Moderates leaving Congress**, lack of bipartisanship, polarization.
- 3. Game-changing issues** to be decided in 2012 = Gridlock
  - Supreme Court on ACA
  - Election

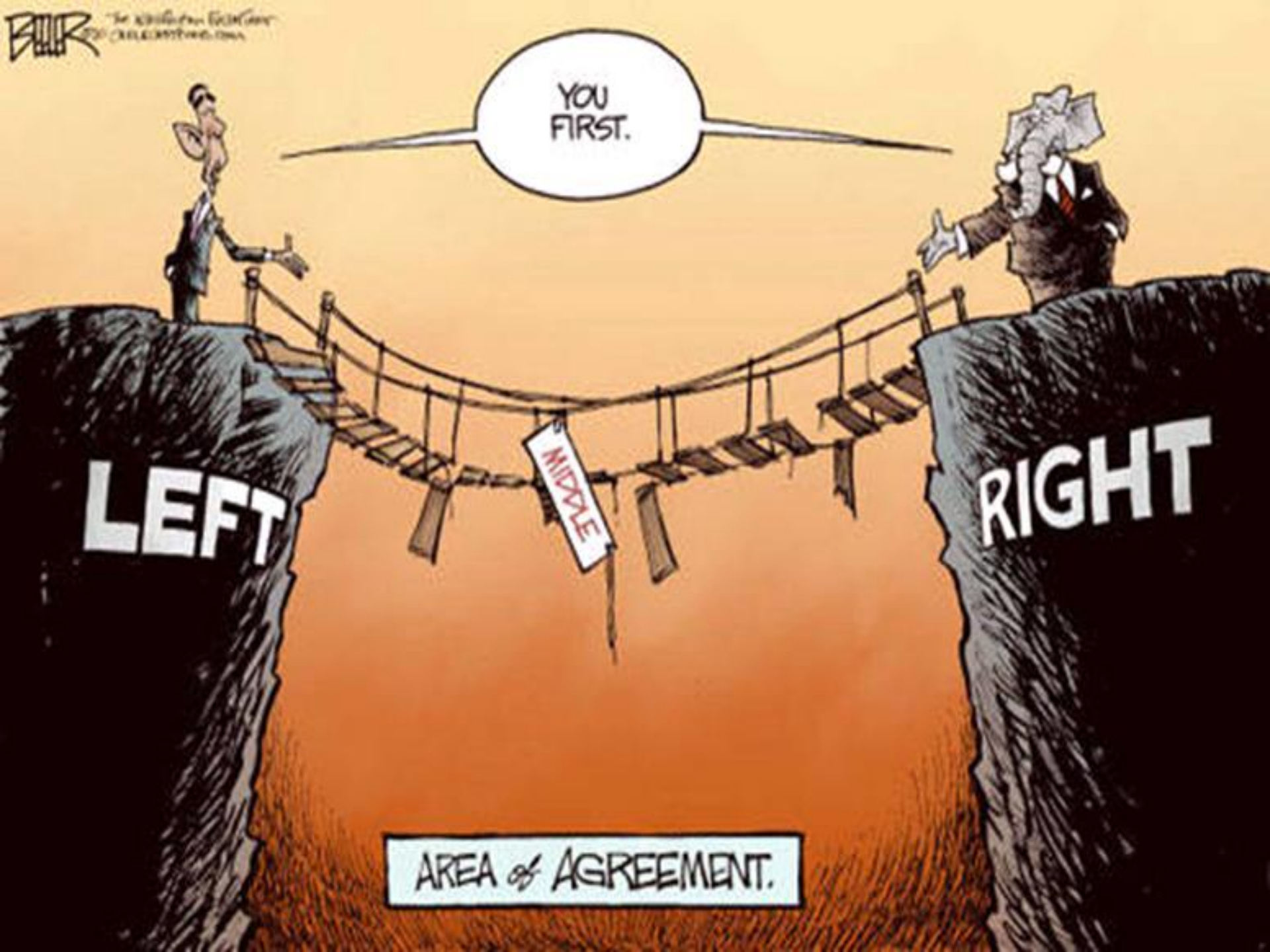
YOU FIRST.

LEFT

RIGHT

MIDDLE

AREA OF AGREEMENT.



# Balance of Power



	HOUSE	SENATE
REPUBLICANS	242	47
DEMOCRATS	190	51
INDEPENDENTS	0	2 (VT, CT)
VACANCIES	3 (AZ, NJ, DC)	0
MAJORITY	218	60*

\* 51 gives agenda setting power and Chairman roles. 60 is the “effective” majority because of the Senate’s filibuster rules resulting in most bills requiring 60 votes for passage.



# The Supreme Court



- **Individual Mandate**  
Get "minimum essential coverage" or pay tax.
- **Medicaid Expansion**  
States expand programs to all non-elderly with incomes below 133 % of Federal Poverty Level (FPL)
- **Anti-Injunction Act**  
Requires a tax to be in effect before the Court can rule on it. Could delay a ruling until 2014.
- **Severability**  
If one part of the law falls, entire law may fall with it.

# Legal Scholars Divided



**Jeffrey Toobin, CNN Analyst, writer for the New Yorker**

“If I had to bet today, I would bet that this court is going to strike down the individual mandate.” (March 27<sup>th</sup>, 2012)

**David Faigman, Professor at University of California Hastings Law School**

“The inevitable march of history not only supports this law, but goes beyond this law.” (March 27<sup>th</sup>, 2012)



# Election Uncertainty

## Congress

- Who is in charge and by what margin?
- House remains in R control?
- Senate flips to R control?
- Olympia Snowe (R-ME) retirement and former Senator Bob Kerrey (D-NE) running again gives Democrats hope that they could retain Senate

## White House

- Obama wins - Vetoes Congress' ACA repeal attempts or finds ways to compromise in 2013 and beyond?



# Control of the House and Senate

**Economy/Gas Prices**

**Contraception &  
Religious Issues**



**Presidential Race**

**Primaries and  
Retirements**

# Congressional Staff



## Hill Staffer Profile

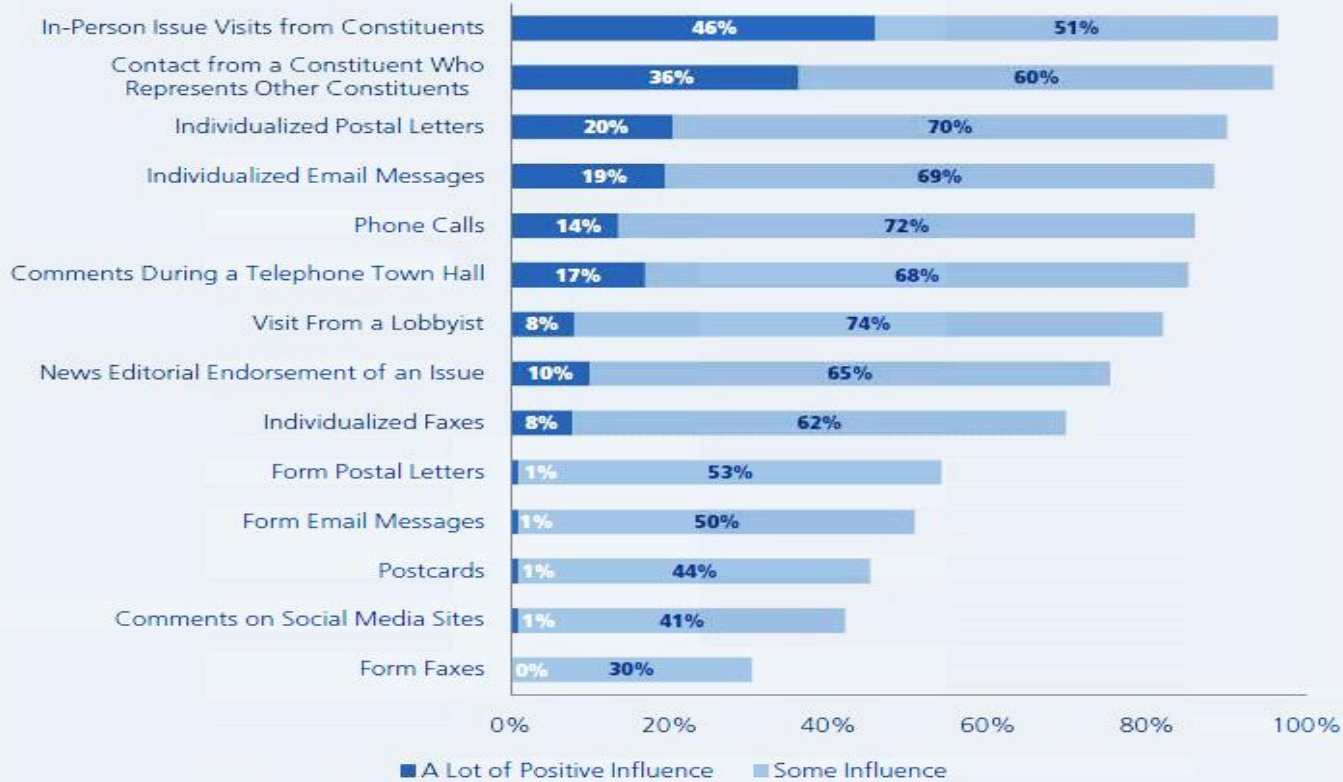


- **Age:** 22-28 years
- **Experience:** Often First Job
- **Issue Count:** “In house expert” on up to 10 issues
- **Events:** Up to 15 meetings a day, hearings, press conferences, and other events
- **Email Count:** Hundreds per day
- **Area:** May/may not be from state or district
- **Workload:** Underpaid and overworked
- **Power:** Incredible

# Power To The People



**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?\***



\*Question was asked only of senior managers and mail staffers. Their responses are aggregated (n=194).

# WHERE DO WE GO FROM HERE?



The Basics



Myth vs. Fact



What Not to Do

# Keep It Simple



However you communicate (by email, letter, or call), be sure to -

**1. Tell Them What You're Going To Tell Them**

I Want Your Boss To CO-SPONSOR The Bill.

**2. Tell Them**

**3. Tell Them What You Told Them**

Create a Dialogue, don't give a speech **AND**  
"make the ask."



# Common Myths and Facts



## MYTH: “Not My Committee”

The Congressman/woman does not sit on the committee of jurisdiction, and therefore can not cosponsor the legislation.

**FACT:** Any member can sign onto any piece of legislation

- » Co-sponsoring would impact lawmakers’ constituents
- » Members can stand up for individuals with HD

## MYTH: “Committee Member Cannot Cosponsor”

The Congressman/woman sits on the committee of jurisdiction, and thus will not cosponsor the legislation

**FACT:** We need members on committees to further legislation

- » Their support is important



**MYTH: “No Offset”**

There is no offset included in the bill; therefore the Congressman/woman cannot cosponsor the bill.

**FACT:** HDSA has identified potential offsets

- » Cost is minimal, ranging \$21 million to \$26 million

**MYTH: “Disease Specific”**

Congress does not favor ‘disease specific legislation’. Eliminating the two year waiting period for a specific disease (HD) will open the door for requests for other diseases.

**FACT:** There are 2 disease specific laws already

- » SSA’s guidelines are 30 years out of date
- » Impacts patients in prime working years

# What **Not** To Do



- I am a constituent/voter and I will vote for you, against you if you do/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
- Assume they know nothing and can't help you.
- Spend more than a few minutes "chatting/making small talk."
- Tell your story, but forget to make the ask.

# Questions, Comments, Tips?



# Resources

- The Congressional Deskbook, The Practical and **Comprehensive Guide to Congress**, Fifth Edition, Michael L. Koempel and Judy Schneider, 2007
- Tom Daschle, Scott S. Greenberger, and Jeanne M. Lambrew, **Critical: What We Can Do About the Health-Care Crisis**, Thomas Dunne, 2008.
- **The System: The American Way of Politics at the Breaking Point** with Haynes Johnson, Little, Brown and Company, 1996.
- Sunlight Foundation, **Keeping Congress Competent: Staff Pay, Turnover, And What It Means for Democracy**, Daniel Schuman, Dec. 21, 2010
- **Strategic Healthcare.net** - <http://www.strategichealthcare.net/>
- **HHS - Healthcare.gov** - <http://www.healthcare.gov/>
- **Kaiser Family Foundation** - <http://www.kff.org/>
- **Robert Wood Johnson Foundation** - <http://www.rwjf.org/healthpolicy/>
- **American Action Forum** - <http://americanactionforum.org/>
- **The Heritage Foundation** - <http://www.heritage.org/issues/health-care>
- **White House** - <http://www.whitehouse.gov/healthreform>

