

# WORKSHOP



# REACHING CONGRESS IN TWISTED TIMES

Jane Kogan, MSW  
Advocacy Manager

Peggy Tighe, J.D.  
Partner



## 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

# Disclaimer

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2011 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.

# OVERVIEW

## TEAM

- Our Team
- How it Works

## CHALLENGES

- Divided Government
- Economic Crisis
- Hill Staff – Power and Pummeled

## STRENGTHS

- Successes
- Power of the People
- Messages

## WHAT YOU CAN DO

- Turn up the Volume

# **\*\*TEAM\*\***

**HDSA**

Jane Kogan

Deb Lovecky

**Strategic Health Care**

Peggy Tighe

Melissa Benish

# **YOU**



# HOW OUR TEAM WORKS...



# HOW OUR TEAM WORKS...



# \*\*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

	HOUSE	SENATE
REPUBLICANS	240	47
DEMOCRATS	193	51
INDEPENDENTS	0	2
VACANCIES	2	0
MAJORITY	218	60



# ECONOMIC CRISIS/ MEDICARE CONNECTION

MAY 16, 2010 – U.S. hit the DEBT CEILING, 14.3 TRILLION \$, legal limit congress established for U.S. debt.

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

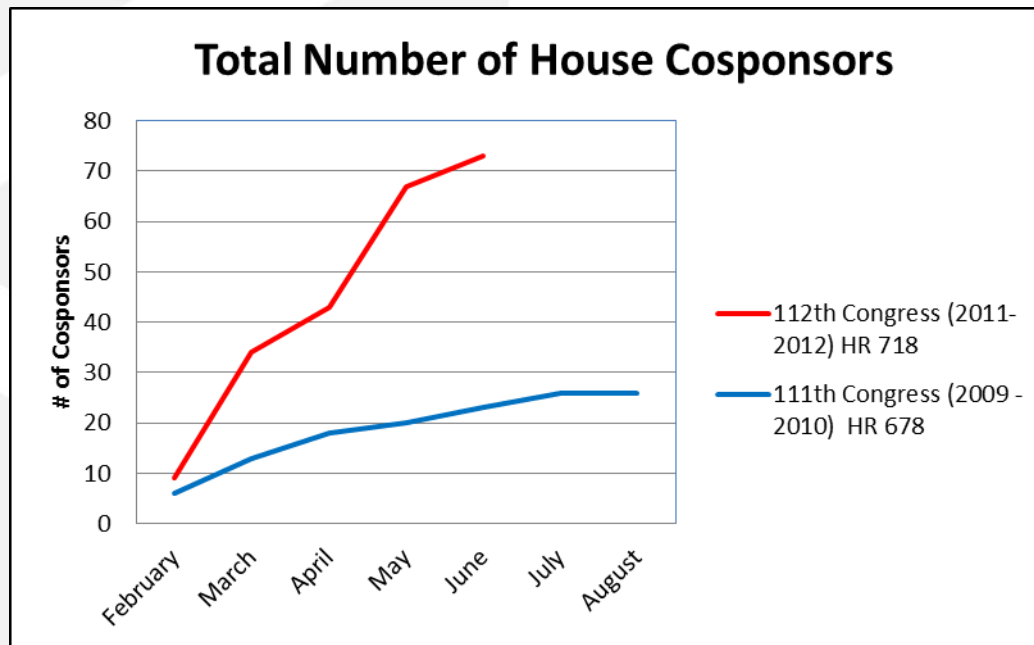


# OUR SUCCESSES

Amid the noise, HDSA remains strong...

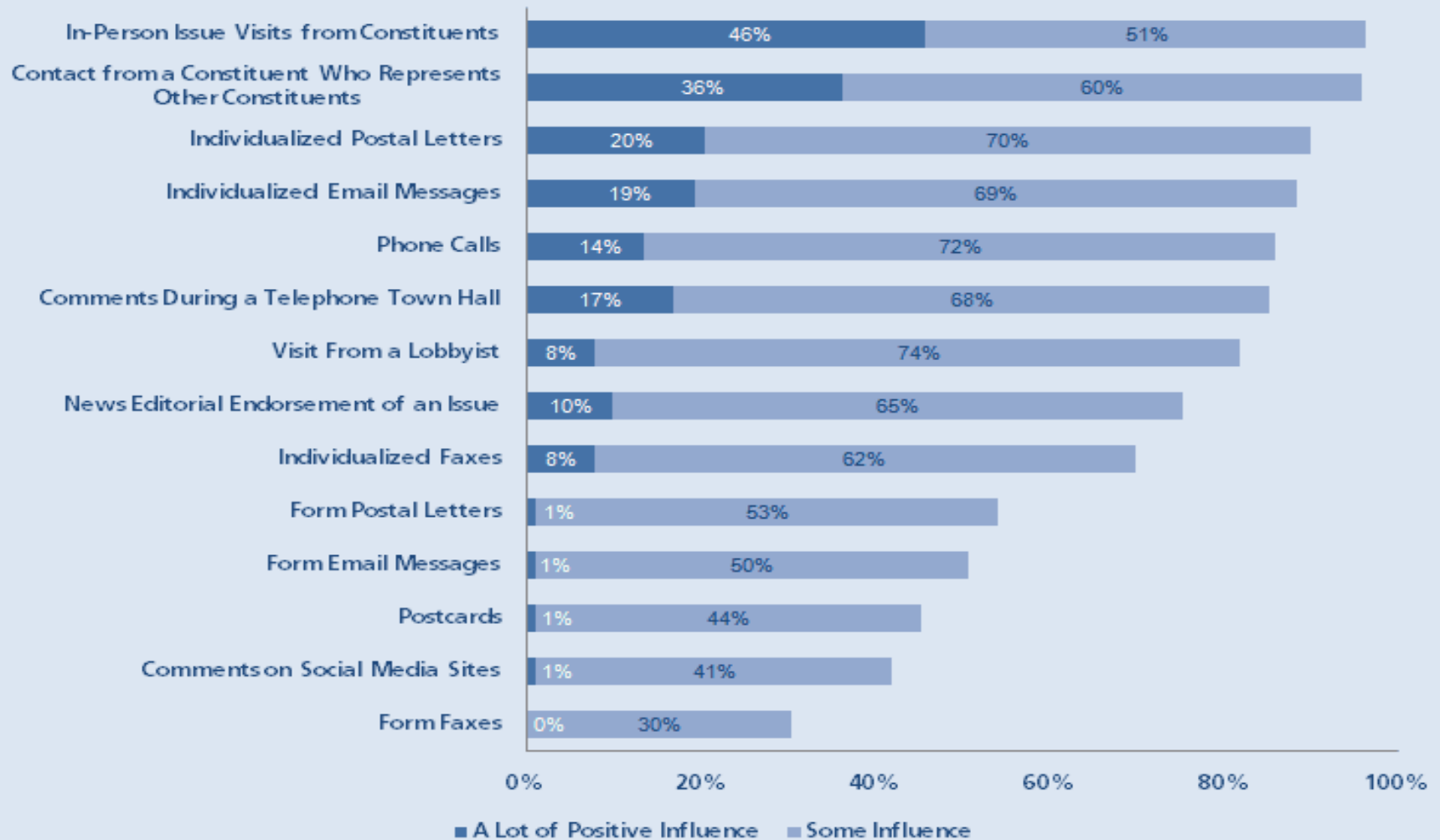
House Cosponsors: 73 (6/13/11)

Senate Cosponsors: 6 (6/13/11)



# POWER OF 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?\*



# 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





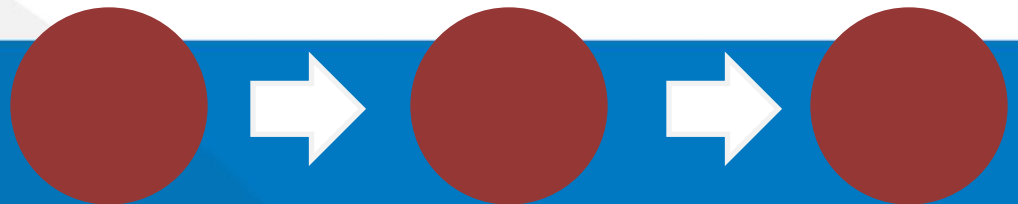
# CONNECT THE DOTS...

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

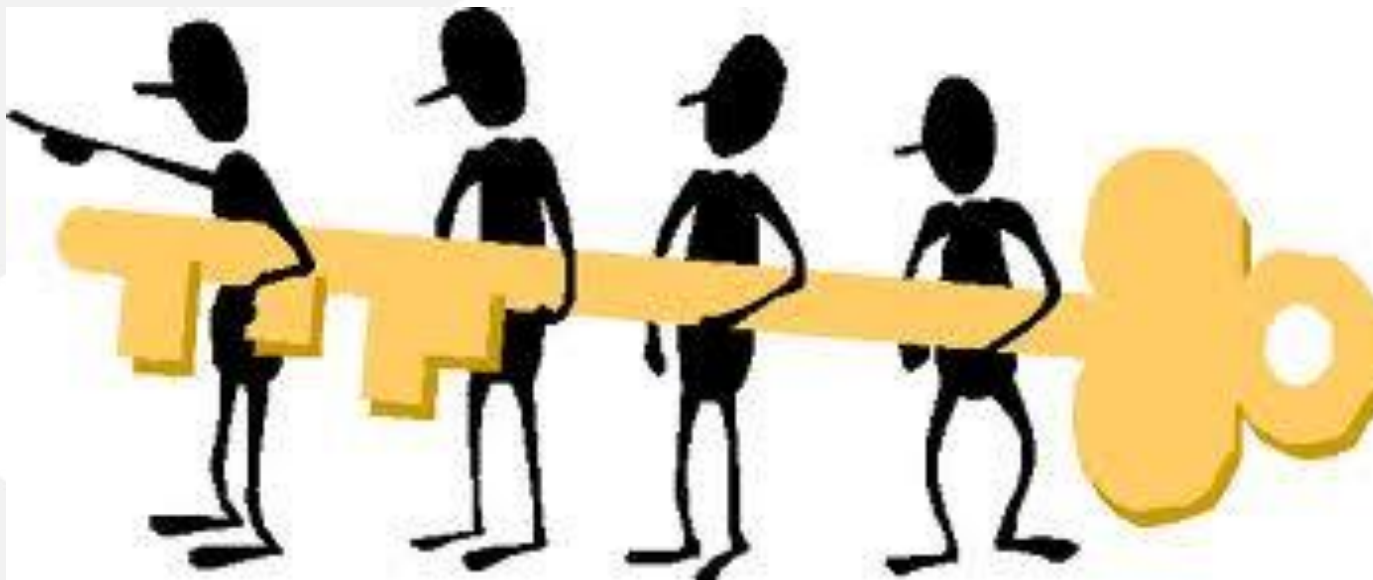
- ❑ DIRECT the Commissioner of the Social Security Administration to immediately REVISE the outdated criteria using current medical science.

**AND**

- ❑ Immediately WAIVE the 2 year waiting period for people with Huntington's Disease.



## \*\*WHAT YOU CAN DO\*\*





**TURN UP THE VOLUME**

**LET'S GET LOUD**

# TARGET LIST

Title	Last	Party	State	Title	Last	Party	State	Title	Last	Party	State
Congressman	Alexander	R	LA	Congressman	Garrett	R	NJ	Congressman	McGovern	D	MA
Congresswoman	Berkley	D	NV	Congressman	Hinojosa	D	TX	Congressman	McNerney	D	CA
Congressman	Berman	D	CA	Congresswoman	Hirono	D	HI	Congressman	Murphy	D	CT
Congressman	Bishop	D	NY	Congressman	Holden	D	PA	Congresswoman	Napolitano	D	CA
Congressman	Blumenauer	D	OR	Congressman	Inslee	D	WA	Congressman	Olver	D	MA
Congressman	Buchanan	R	FL	Congressman	Israel	D	NY	Congressman	Paul	R	TX
Congressman	Cassidy	R	LA	Congressman	Issa	R	CA	Congressman	Perlmutter	D	CO
Congresswoman	Chu	D	CA	Congresswoman	Jackson Lee	D	TX	Congressman	Pitts	R	PA
Congressman	Clay	D	MO	Congressman	Johnson	D	GA	Congressman	Poe	R	TX
Congressman	Cleaver	D	MO	Congressman	Jones	R	NC	Congressman	Polis	D	CO
Congressman	Connolly	D	VA	Congresswoman	Kaptur	D	OH	Congressman	Rogers	R	AL
Congresswoman	DeGette	D	CO	Congressman	Kind	D	WI	Congresswoman	Roybal-Allard	D	CA
Congressman	Dent	R	PA	Congressman	Lance	R	NJ	Congressman	Sires	D	NJ
Congressman	Ellison	D	MN	Congressman	Lewis	D	GA	Congresswoman	Sutton	D	OH
Congresswoman	Eshoo	D	CA	Congressman	Lipinski	D	IL	Congressman	Terry	R	NE
Congressman	Farr	D	CA	Congressman	Luetkemeyer	R	MO	Congressman	Thompson	D	MS
Congressman	Fleming	R	LA	Congressman	Markey	D	MA	Congressman	Thompson	D	CA
Congressman	Frelinghuysen	R	NJ	Congressman	McDermott	D	WA				



# 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

- *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