



HDSA Convention Advocacy Workshop

Disclaimer

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2009 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

Presenter Disclosures

Joseph LaMountain, Jane Kogan and Melissa Benish

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose or list

Introductions



HDSA Advocacy Team:

Jane Kogan

Joseph LaMountain

Melissa Benish

But the most important
person here is....

YOU!!!

Learning Objectives

1. Power of grassroots advocacy
2. Background on HD Parity Act (HR 678)
3. Effectively communicating with Congress
4. Get fired up to make a difference in your community!



A Look Back...

36 Months ago HD
campaign started (Jun 07)

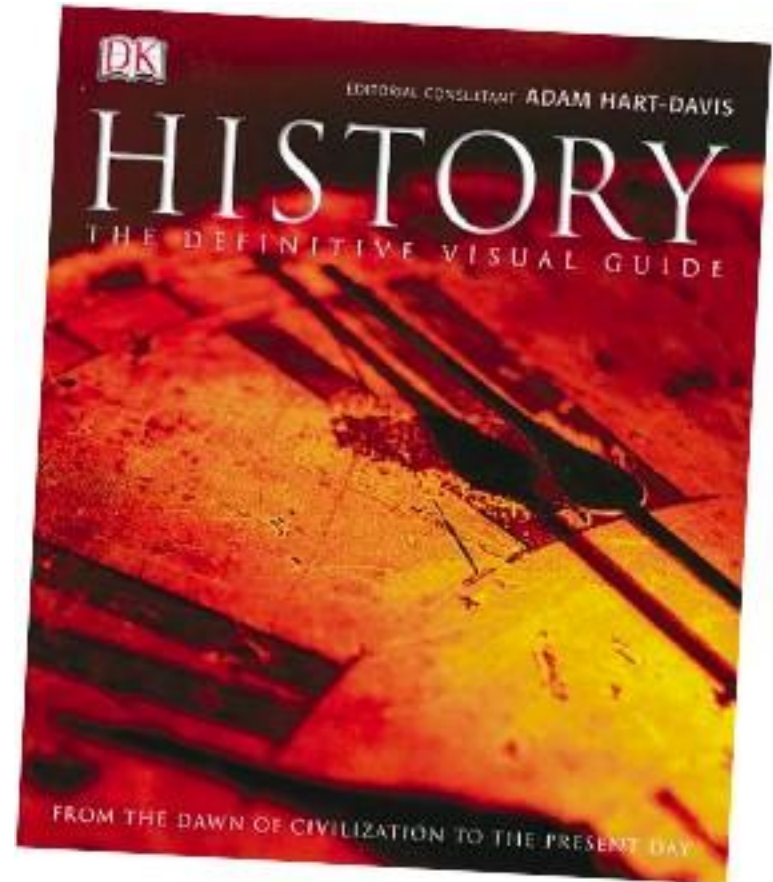
24 Months: Parity Act
Introduced (Jun 08)

9 Cosponsors (Dec 08)

31 Cosponsors (Sep 09)

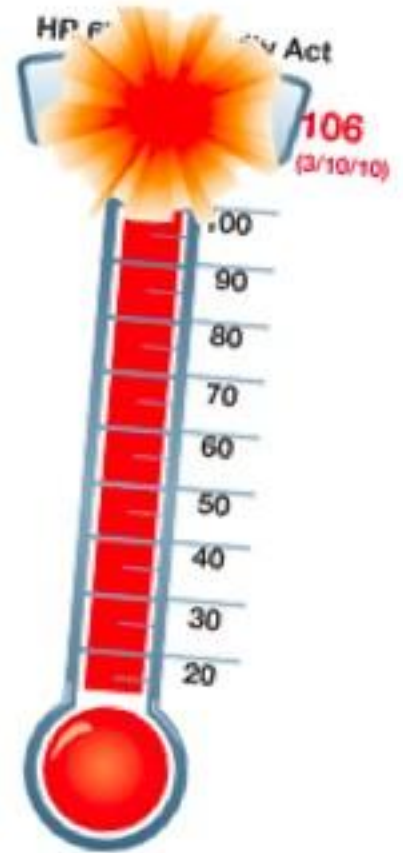
67 Cosponsors (Dec 10)

Today ???????



Fired Up????

134
cosponsors



The Power of Advocacy

Yeah, Right...



Grassroots advocacy is required for success.

BUT, grassroots advocacy is really hard and time consuming. Why?

Americans are cynical. Hard to believe your voice matters.

Incredible competition for Washington, DC's attention and engagement.

Our Opportunity

- Here's why we stand out.
- Passion and Persistence.
- Others give up and we keep pressing forward.
- We have compelling stories.
- If we don't tell it, who will?
 - Our passion is key to advocacy success



The Power of Advocacy is Here

129 Cosponsors on HD
Parity Act.

How did we do it? People
affected HD got involved.

For some it was easy, for
others it was hard.

If they can do it, so can
you and your family.

We need to get everyone
in the HD family engaged
in this campaign.



The HD Parity Act

What is HD Parity Act / HR 678?

Introduced in House by
Reps. Bob Filner (D) and
Brian Bilbray (R)

Would do two things:

- (1) Easier for people with HD to obtain Social Security Disability Benefits
- (2) Eliminate 2-year waiting period to receive Medicare after being receiving SS disability status.



Improving Social Security

People with HD have difficulty obtaining Disability benefits (not alone).

SSA Medical guidelines are 30 years old, don't reflect current medical knowledge.

HR 678 would take cognitive & psychiatric impairment into account when deciding if someone is disabled.

“Easy” part of legislation



Ending 2 Year Wait



Once receive SS Disability, two year wait for Medicare.

Reason: To save Medicare \$\$, exhaust private benefits.

2-year wait prevents people with HD from getting care.

HR 678 would allow people with HD to get Medicare immediately after disability.

“Hard” part of the legislation.

Why is it so hard???

Everyone “agrees” two-year wait should be removed for all diseases

But bills to do that have not advanced and will not become law any time soon.

Cost is a major factor.

Representatives don’t want to “play favorites” by supporting “disease specific” bills.



Ending the Wait for HD...

5 reasons to do it alone:

- Less expensive: \$20M a year vs. \$10B for all
- Helps the neediest first.
 - Achievable politically
 - ALS has an exemption, already “playing favorites.”
- More support HD waiver (134 cosponsors) than overall removal (110).



Communicating with Congress

Keep this in mind...

Never forget that your Congressman works for you, and is elected to represent your interests in Washington. Don't be intimidated and don't take "no" for an answer.

Congressman Bob Filner
HD Day on the Hill
March 2010



How much competition?

Each US Representative office receives 10K emails every week.

4,600+ bills introduced in House as of February 1.

3 million CapWiz email messages sent by constituents.

Capitol Hill is drowning in information



A Day in the Life of a Hill Staffer

Typically 22-28 years old

First job out of college

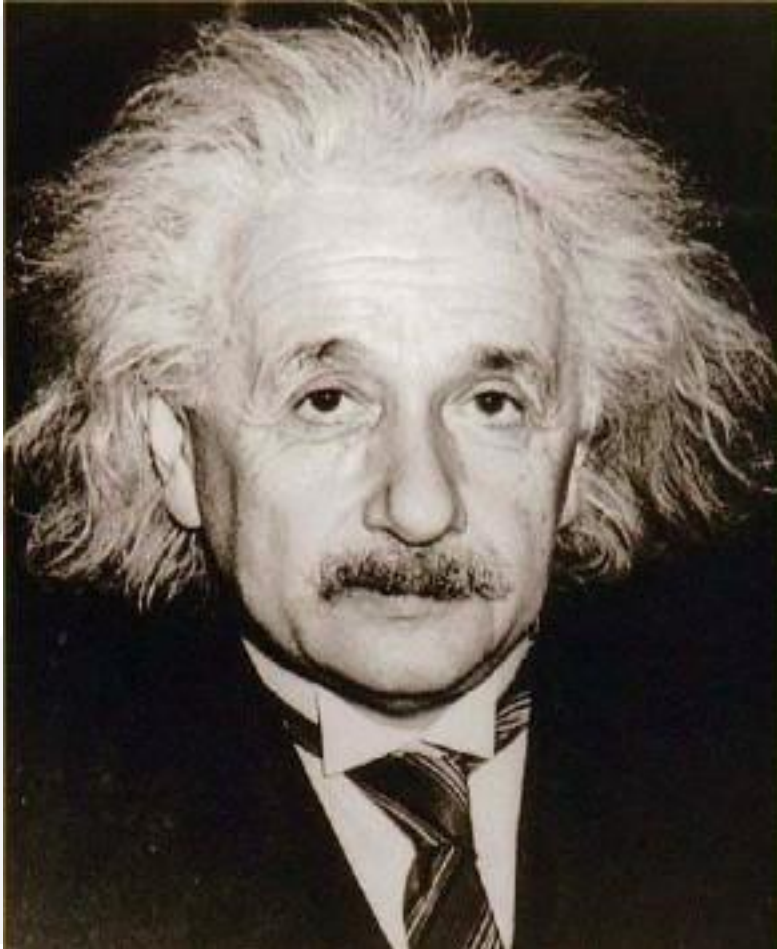
“In House Expert” for Member
on up to 10 issues.

Can take up to 15 meetings a
day - - running from hearings, to
meetings and back to a hearing.

Staff receives 100's of emails
each day.



4 Things to Remember



1. You're the expert. Hill staff know little about HD.
2. Tell your personal story. Connect with the person on a emotional level.
3. Get to the point. Attention spans are very short.
4. Don't stop until you get a "yes" from your Representative's office.

Patience and Persistence are Key



Communication with Congress is not a one-shot deal.

Follow-up by phone, email and in person meetings is essential.

If you stop communicating, you'll get lost in the sauce.

Get more voices involved, show that others support our cause.

We need to build a movement.

Discussion

Let's role play a conversation/
meeting with a congressional
staffer.

How can you build an HD
movement at home in support
of the HD Parity Act?

Visit....

www.hdsa.org/advocacy

for more information and materials.