

All-Star Advocacy

Presented by:

Jason Gromley, Esq.

Vice President, Strategic Health Care

Jennifer Simpson, LMSW.

Manager of Advocacy and Education, HDSA

Teresa Casale

Rock Star Advocate, HDSA



Disclosures

Jason A. Gromley, Esq.
Jennifer Simpson, LMSW
Teresa Casale

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

No relationships to disclose
or list

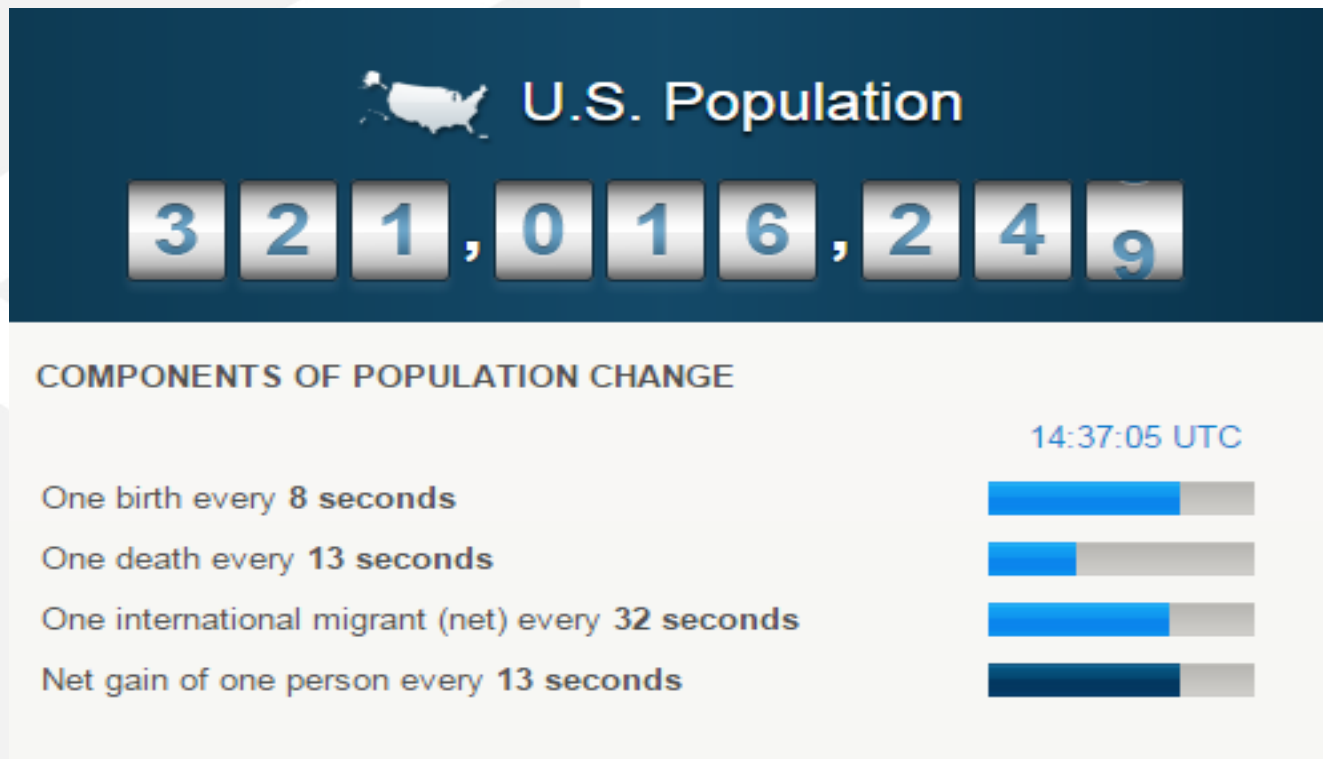
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HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

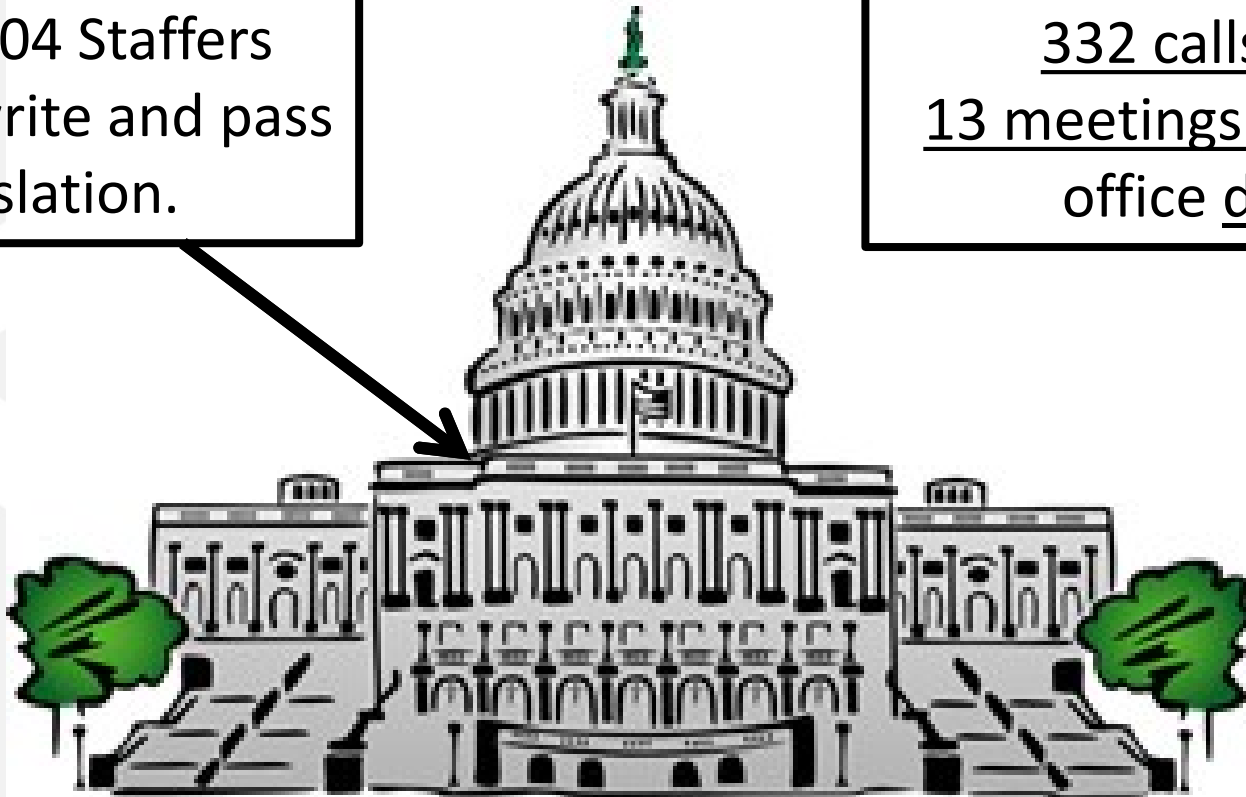
There are...

- Approximately **320 million people** living in the United States
- About 700,000 of those people live in your Congressional district

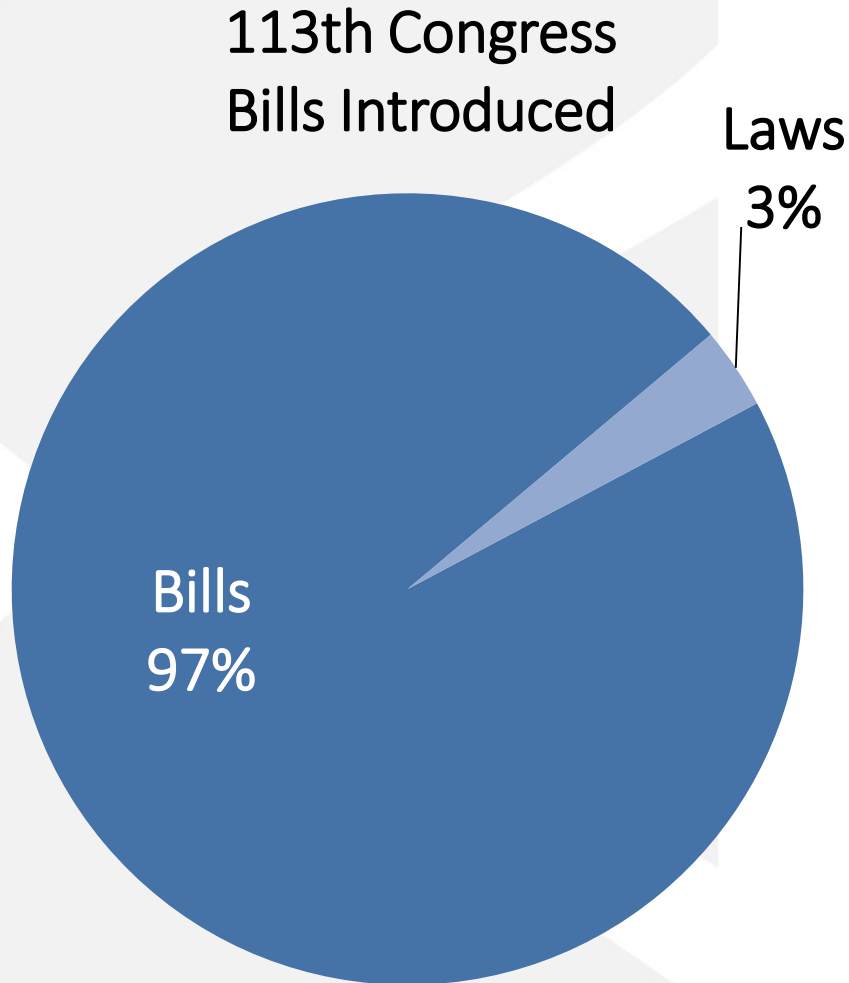


100 Senators,
435 Representatives,
and 9,404 Staffers
work to write and pass
legislation.

5,868 emails,
1,473 letters,
332 calls, and
13 meetings with each
office daily.



But, Few Bills Become Law



Last Congress

- **8,913** bills were introduced
- Only **297** became law.
 - 103 were Administrative Laws (like naming a highway or post office)
 - Only 194 “substantive”

It's Time to Advocate

- It can be hard to stand out from the millions of other advocates and causes, but it is also exactly why you are needed.



Advocacy



What does it
take?

Personal Education

Elected Officials

Community Education

Advocacy

Publicity

Fundraising

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Personal Education

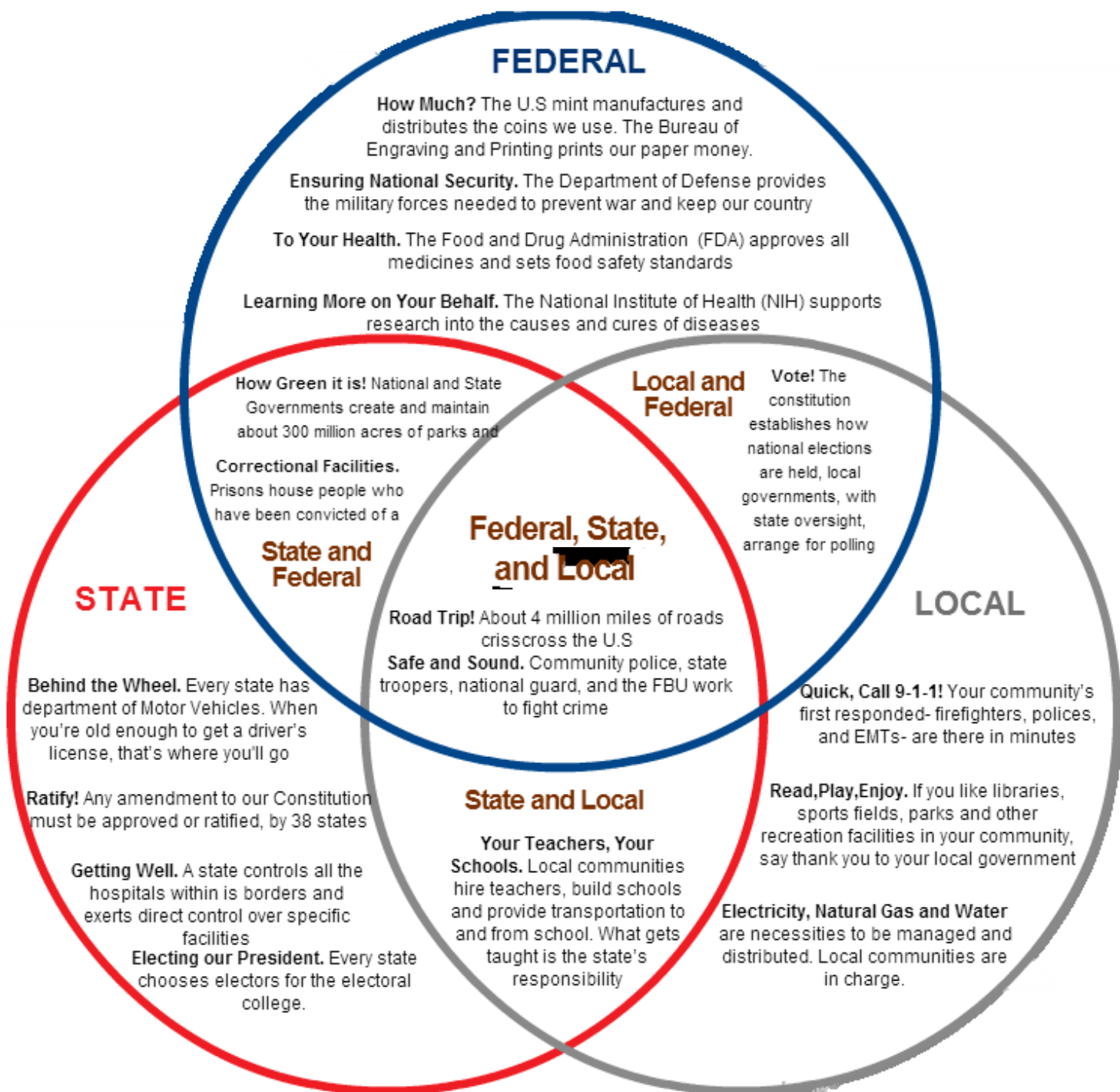
Engage yourself

- Stay up to date on HD news and events across your state and the country
 - Clinical trials
 - On-going research
 - Support groups in the area

Personal Education

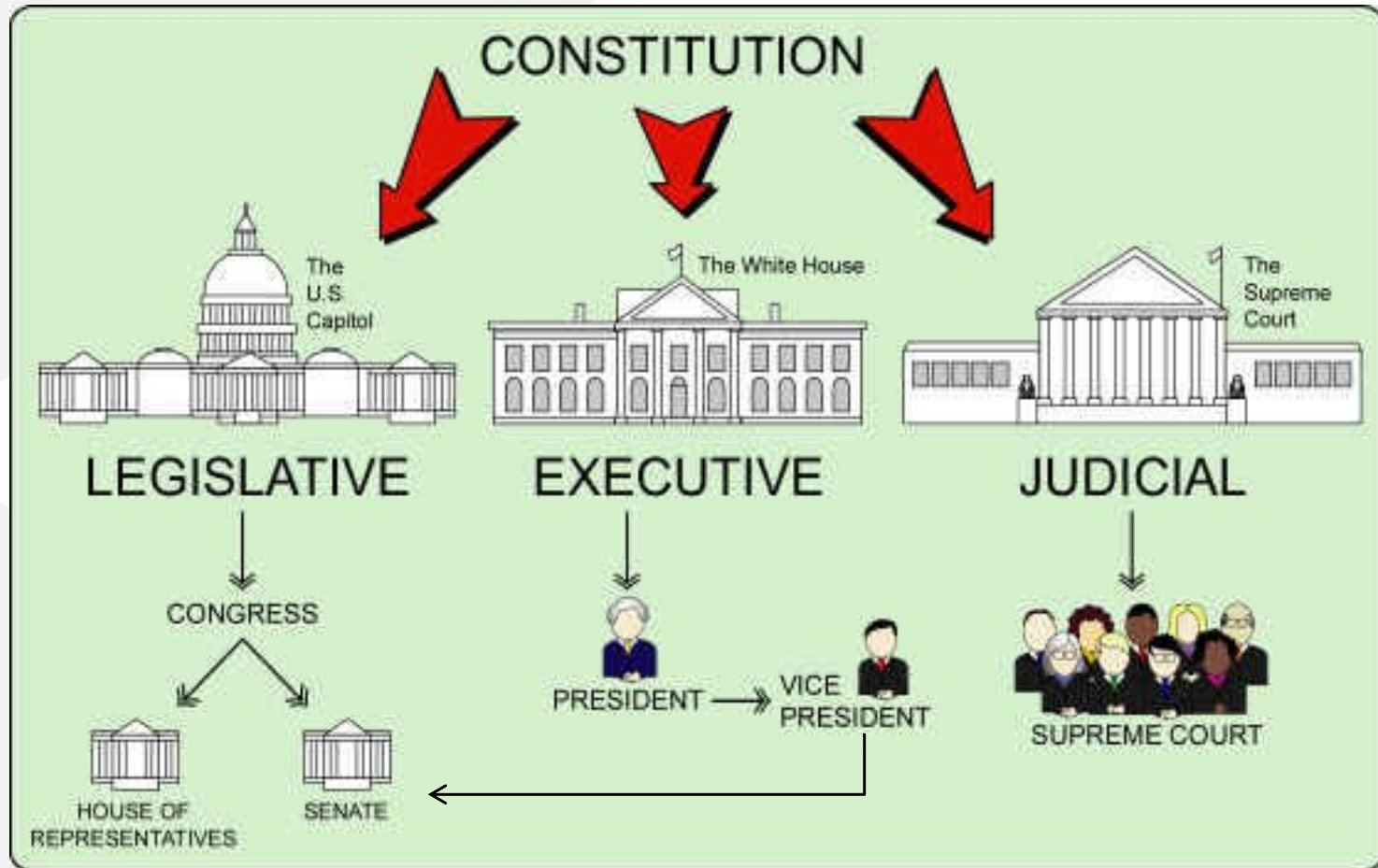
Engage yourself

- Important to understand the political process before interacting with Congress
- The Basics:
 - Federal vs. State Government
 - 3 Branches of Government
 - How a bill becomes a law
 - The Huntington's Disease Parity Act



Personal Education

The Federal Government

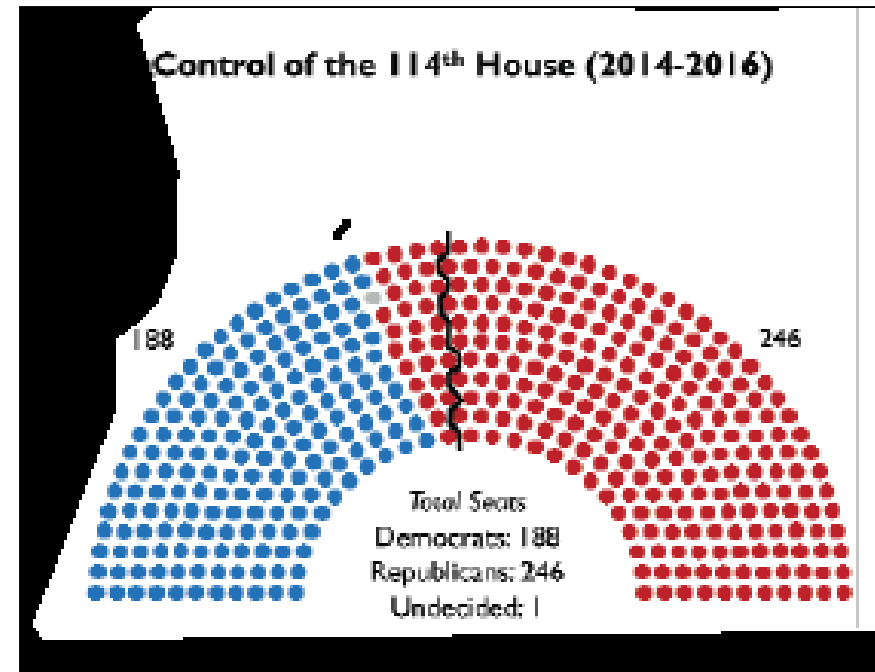


Personal Education



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*)

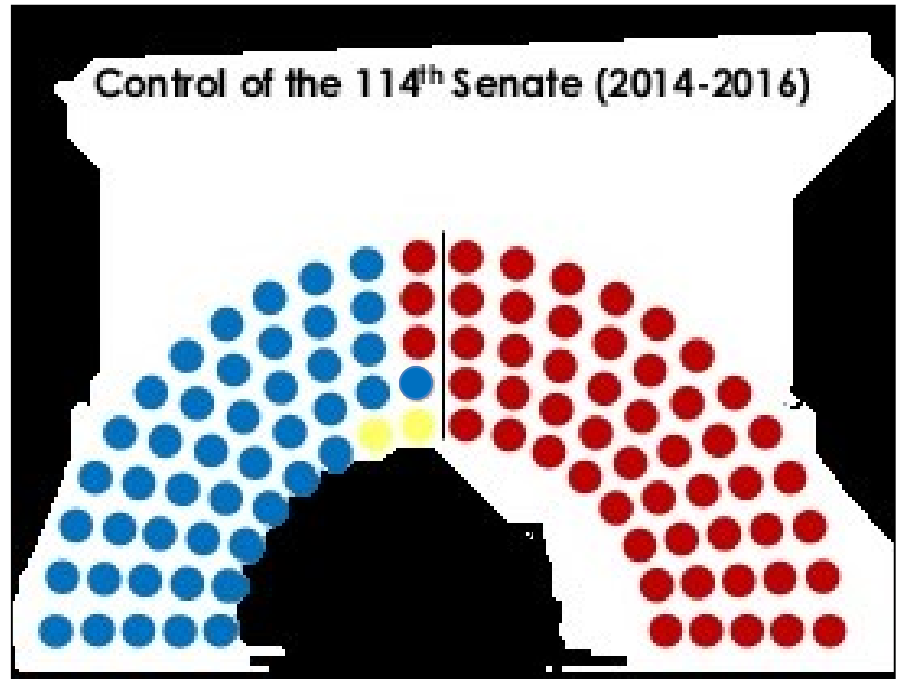


Personal Education

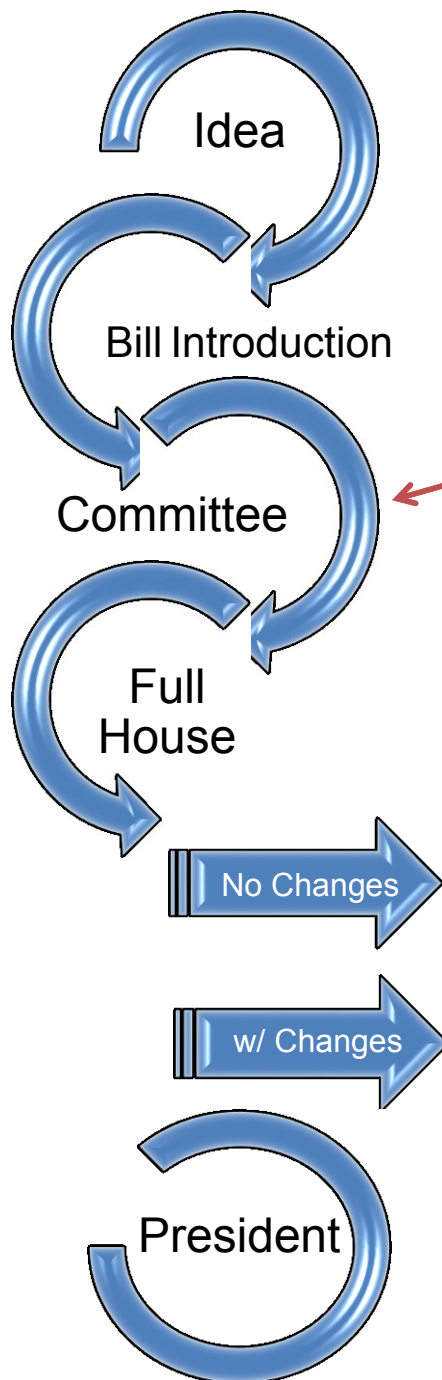


U.S. Senate

- 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 a Bill Becomes a Law



A Member, staffer, or Constituent comes up with an idea to fix a problem (Let's look at the House).

HDPa is Here!

A Representative introduces a bill and the bill is then assigned to the appropriate House Committee.

The appropriate Subcommittee makes any changes to the bill, and votes to send the bill to the full Committee – which votes to send the bill to the full House.

The bill will be debated in the House and voted on. If it passes, it is sent to the Senate to repeat the process.

If there are no changes in the Senate, then the bill is sent to the President.

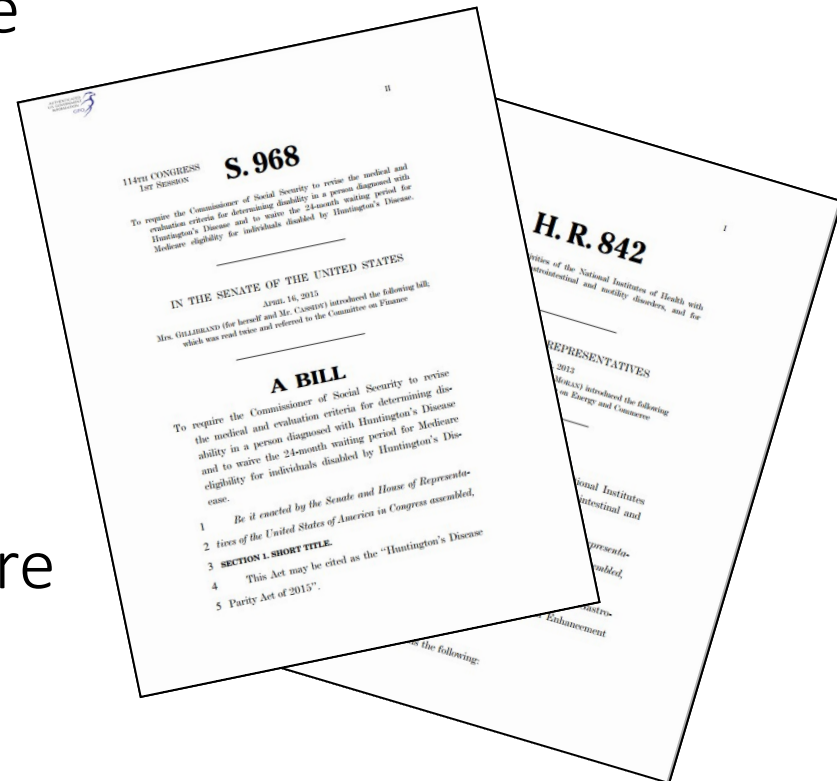
If there are changes, then the bill is sent back to the House for them to vote on it as well.

The President can sign the bill and it becomes a law, veto the bill (which can be overridden by a 2/3 vote in Congress), or take no action.

Personal Education

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.



Personal Education

The Huntington's Disease Parity Act (S. 968/H.R. 842)

	House (H.R. 842)	Senate (S. 968)
Sponsors:	Representatives Kinzinger (R-IL) and Pascrell (D-NJ)	Senators Gillibrand (D-NY) and Cassidy (R-LA)
Cosponsors:	174 Cosponsors <ul style="list-style-type: none">• 111 Democrats• 63 Republicans• 103 Original Cosponsors	7 Cosponsors <ul style="list-style-type: none">• 6 Democrats• 1 Republican• 1 Original Cosponsor
States:	40	5

Personal Education

Elected Officials

Community Education

Advocacy

Publicity

Fundraising

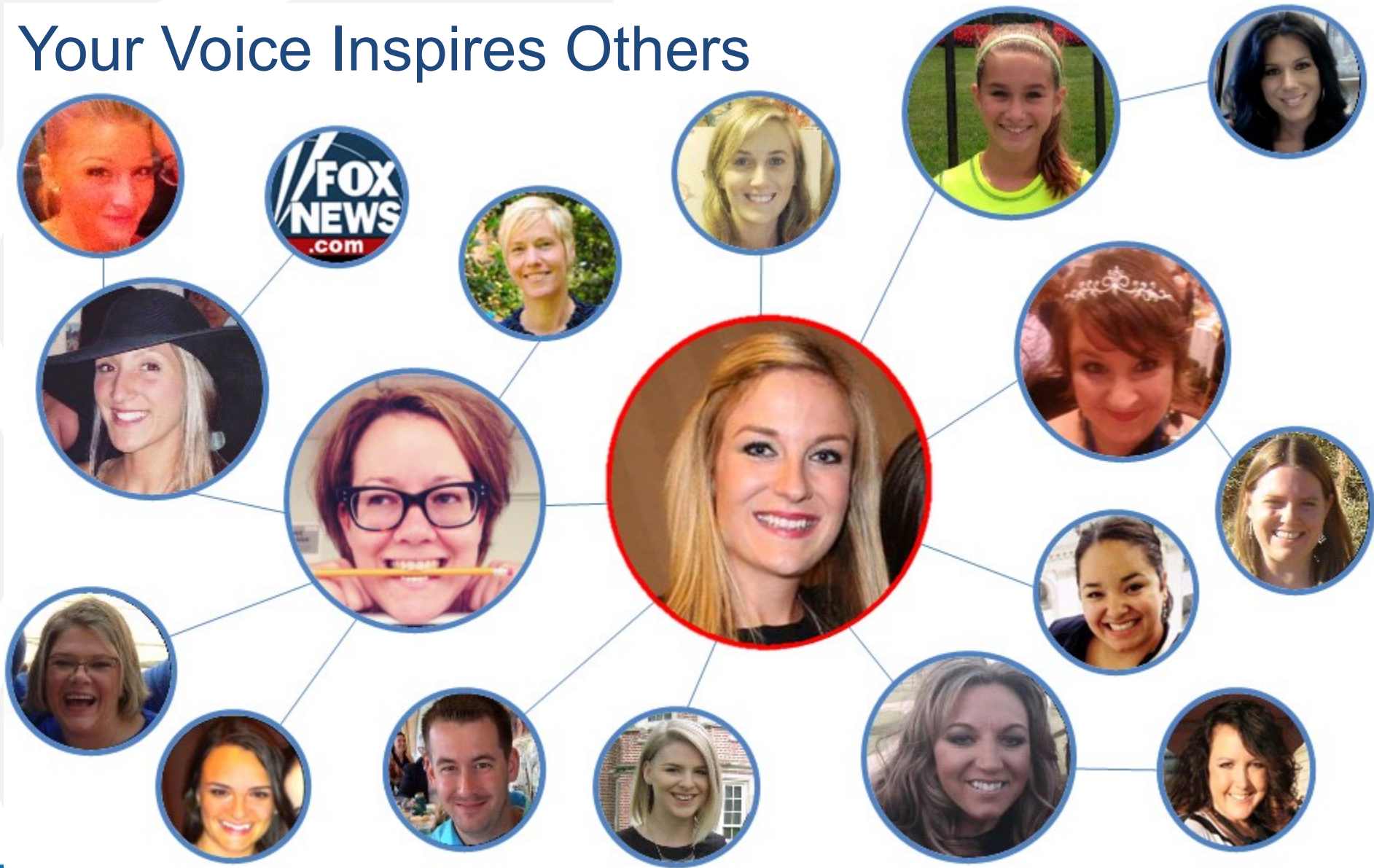
Community Education

Engage your friends, family and community

- Share your story
 - What is HD?
 - How does it affect you?
- Coordinate with others
 - Learn from their experiences



Your Voice Inspires Others



MaryAnn Emerick



Touched thousands of people by sharing her HD story with FoxNews.com.

Bill Johnson

Since 2001 Bill has participated in the San Diego Rock n' Roll Marathon to raise money and awareness of HD.

“Running to Cure HD” has raised almost \$700,000 for HD SA



Ramona Johnson surrounded by family and friends at San Diego's Rock n' Roll Marathon

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Fundraising

Engage donors

- Fundraising accomplishes three goals...
 1. Increased funds
 2. Increased awareness
 3. Increased engagement
- HD SA Local chapters are great sources of support and information

Fundraising



Hope
Walk/5k



Bowl-a-thon

Pancake
Breakfast



Auction



Car Wash



Bake Sale

Morgan McLane

Facilitated the Fast Track PGH car race for 8 years, raising almost \$100,000 and local awareness for HD



Barbara Lee's Fast Track to a Cure for Huntington's Disease

Greater DC Chapter

For the last 3 years the Greater DC Chapter of HDSA has put on the “Blue Tie Gala” to raise awareness and money for HDSA



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Publicity

Social Media

- Tag your local officials and Congressmen in posts asking for support, giving thanks, or requesting attendance at events



Local Media

- Alert the local news to HD events for your Chapter
- Write letters to your editor explaining what you're facing, and what needs to change to make it better
 - Short, sweet, and with a concrete goal in mind.

Publicity

Engage larger media



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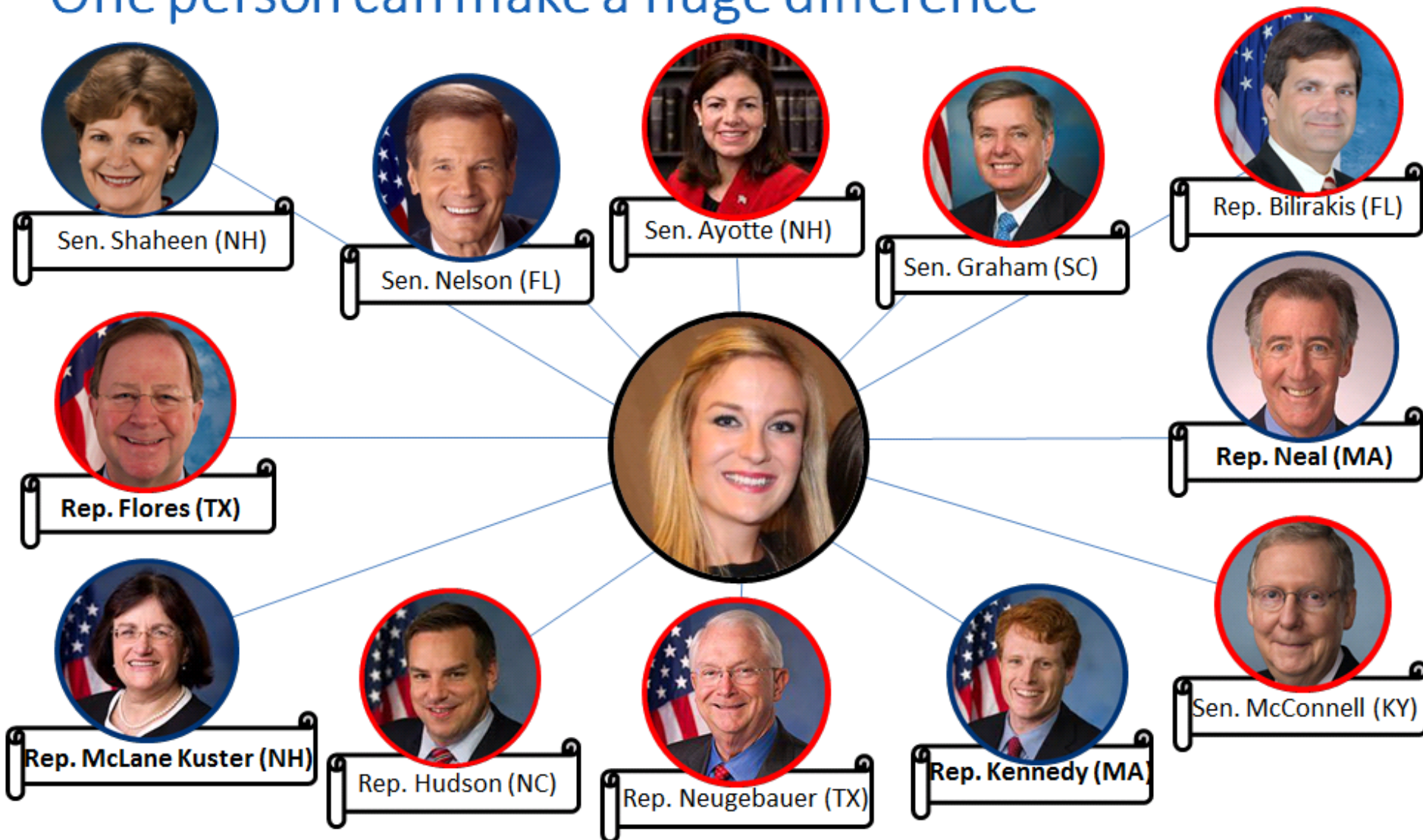
Fundraising

Elected Officials

Engage your elected leaders

- Educate them about HD
- Invite them to your events
- Work with HDSA to promote the Huntington's Disease Parity Act (H.R. 842/S. 968)

One person can make a huge difference



Elected Officials

Email/Write/Call Your Representatives and Senators

Questions to Answer

- Who are you?
- Why are you contacting?
- What are you asking for?
- Why is this important to you?

Keep it simple!

- You are a concerned constituent
- You need them to cosponsor and pass H.R. 842/S. 968
- Share your story!
- Ask for cosponsorship again!

Elected Officials

Schedule a District Meeting

www.hdsa.org/hdparity

- Set up a meeting in your Representative/Senator's local office:
 - Identify who your Representative/Senator is
 - Request through their website
- Prepare for the meeting:
 - Jennifer and Jason will provide you with everything you need!
Email jsimpson@hdsa.org



Elected Officials

DC Fly-In

- Meet with your members in Washington, DC
- Make it a group event!
 - NYA Fly-In
 - Family Trip
- HDSA and Jason's team are here to help!



Elected Officials

Tips for Meetings

Do

- Be yourself – let the Member or staffer get to know you
- Bring a friend
- Describe how the HD Parity Act would help you/your family
- Follow up after the meeting

Don't

- Don't answer questions about the bill if you do not know the answer
- Don't expect a decision on the bill while you are in the

Next Steps

- Today at 5:15pm in Landmark D
 - Texas Meet and Greet
- Today at 7:00pm in Landmark A
 - NYA Talent Show
 - Pie me in my face for \$5.00!
- Today and Tomorrow
 - Stop by the HD Advocacy
- Next Week
 - Email jsimpson@hdsa.org and get engaged!



Personal Education

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Feeling like an All-Star Advocate?

YOU ARE!

Advocacy is for everyone!

You don't have to commit a lot of time – even a quick email or phone call helps.

It's most important to be persistent, patient, and passionate.



QUESTIONS?

Jennifer Simpson: jsimpson@hdsa.org
Jason Gromley: jason.gromley@shcare.net