



# HDSA Grassroots Advocacy

PRESENTED BY: Chris Becker

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*Improving the lives of everyone with Huntington's disease & their families.*



**We support family members in claiming their own power to alter the relationships of institutions holding power.**

**Together we create a string of wins in pursuit of our goal to improve the lives of everyone with HD and their families.**

# Types of Advocacy

*All are important.*



Self



Individual



Systemic

*Each has different goals and outcomes.*

# Deploy Three Pillars to Achieve Success



Create  
Awareness



Drive the  
Conversation



Influence  
Legislation &  
Policy

# Key Areas of Focus



Speed  
Innovation



Increase  
Access to Care



Reduce  
Financial  
Burden

# How Does an Idea Become Law

Any member can introduce a bill during each session of Congress. Once the session ends, all bills die.

Once introduced, bill assigned to the appropriate committee.

House 20. Senate 16

The House allows multiple committees, Senate one.

Committee leadership determines if the bill will have a hearing and markup.

If bill advances from committee it can be called for a floor vote.

Which ever chamber passes the bill sends it to the other chamber.

Both chambers must pass the bill.

Once passed both chambers need to meet to work out the differences before sending to the President.



# Important Health Care Congressional Committees

## AUTHORIZING

### SENATE

**Finance:** Chair Mike Crapo (R-ID)  
Ranking Ron Wyden (D-OR),

**HELP:** Chair Bill Cassidy (R-LA)  
Ranking Bernie Sanders (D-VT)

### HOUSE

**Energy & Commerce:** Chair Bret  
Guthrie (R-KY),  
Ranking Frank Pallone (D-NJ)

**Ways & Means:** Chair Jason Smith  
(R-MO),  
Ranking Richard Neal (D-MA)

## FUNDING

### SENATE

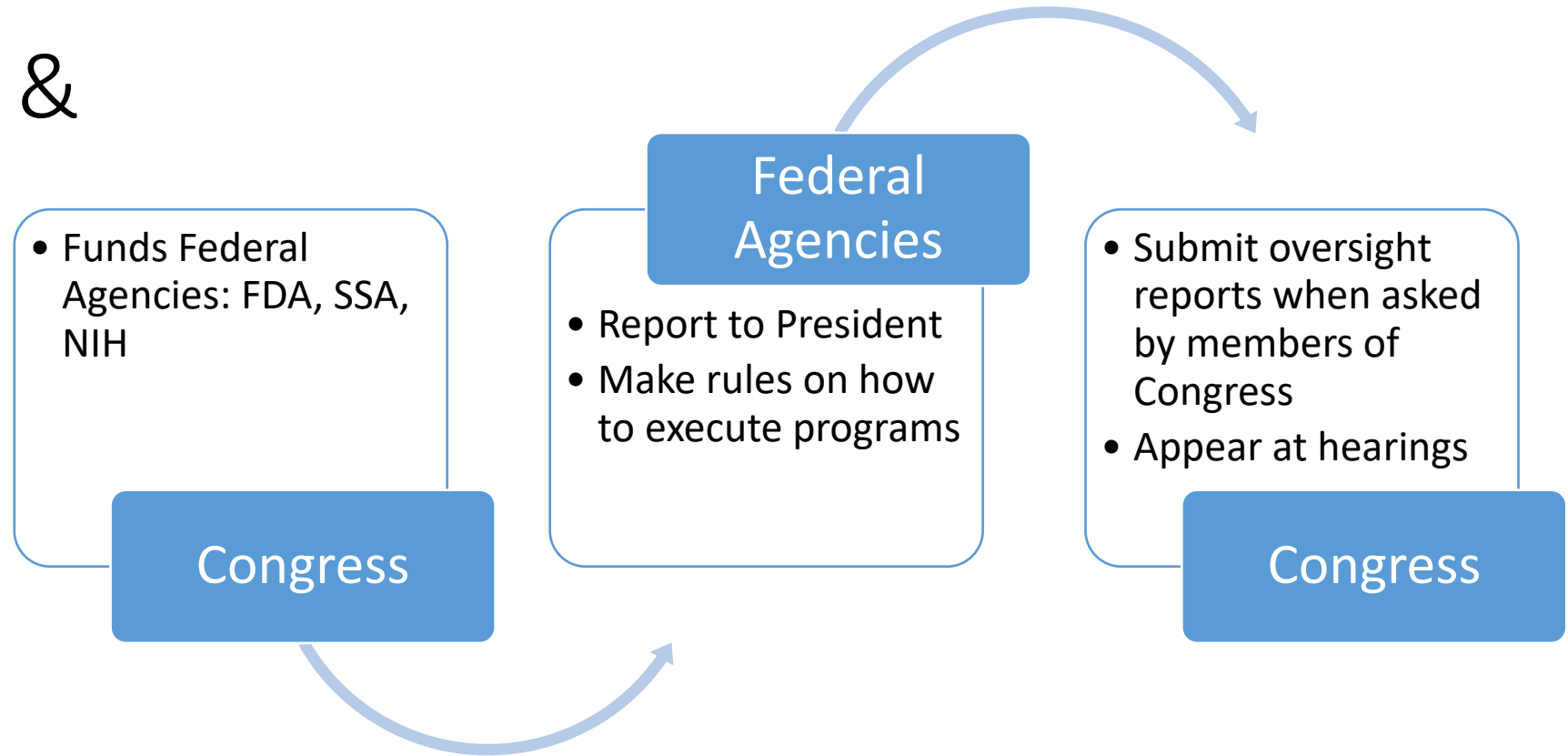
**Appropriations:** Chair Susan Collins (R-  
ME)  
Ranking Patty Murray (D-WA)

### HOUSE

**Appropriations:** Chair Tom Cole (R-OK)  
Ranking Member Rosa DeLauro (D-CT)

# Different Roles of Executive Branch & Congress

*Affects Advocacy Strategy*



Advocacy works behind the scenes relying on Congressional champions to carry our message.

# Speed Innovation

## *Two-Pronged Education & Outreach Strategy*

Branch of Government	Goal	Activities
FDA	Ensure voice of people with the lived experience of HD is incorporated into regulatory decision making	<ul style="list-style-type: none"><li>• 2024 HDSA HD Symptom &amp; Treatment Impact Survey</li><li>• 2024 in-person meeting with FDA decision-makers re: Act for ALS</li><li>• 2024 EL-PFDD Meeting</li><li>• 2025 VOP Report</li></ul>
Branch of Government	Goal	Activities
Congress	Encourage FDA to use the authority Congress has given it to speed innovation in rare disease therapies.	<ul style="list-style-type: none"><li>• 2024 &amp; 2025 August Recess Campaign</li><li>• HDSA Advocacy Leaders Constituent Meetings</li><li>• Nov. 2025 orchestrated VoterVoice email Campaign</li><li>• Committee on Aging Hearing<ul style="list-style-type: none"><li>• Tell Us Your Story Campaign</li></ul></li><li>• HD Day of Action April 13</li></ul>

# Your Advocacy in Action

## Email Campaign

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**4372** Families  
**1762** People living with HD  
**4146** Community  
**10,280** Total

## Constituent Meetings

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**9** Meetings with Senators including  
**5** with Republican members of HELP  
**2** E&C: Rep. Guthrie & Pallone  
**48** Meetings with Members during Rare  
Disease Week  
**19** Emails/Letters sent by Members

## April 13 Day of Action

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**2162** emails  
**165** phone calls

**Due to pressure put on the agency by the patient advocacy community: the director of CBER was replaced.**

# Legislation HDSA is Tracking in 119<sup>th</sup> Congress

## Access to Quality Healthcare

- Alleviating Barriers for Caregivers Act
- Telehealth Coverage Act
- Expanded Telehealth Act

## Access to Medication and Medical Devices

- Providing Realistic Opportunity to Equal and Comparable Treatment for RARE Act
- HELP Copays Act
- Safe Step Act

## Reduce Financial Burden

- SSI Savings Penalty Elimination Act
- Credit for Caring Act



**HDSA ADVOCACY LEADERS HELD  
70 MEETINGS IN 24 STATES**

## HDSA August Recess Campaign

Raise awareness of legislation HDSA is supporting with your two U.S. Senators and U.S. Representative while they are at their home district during the August Congressional recess.

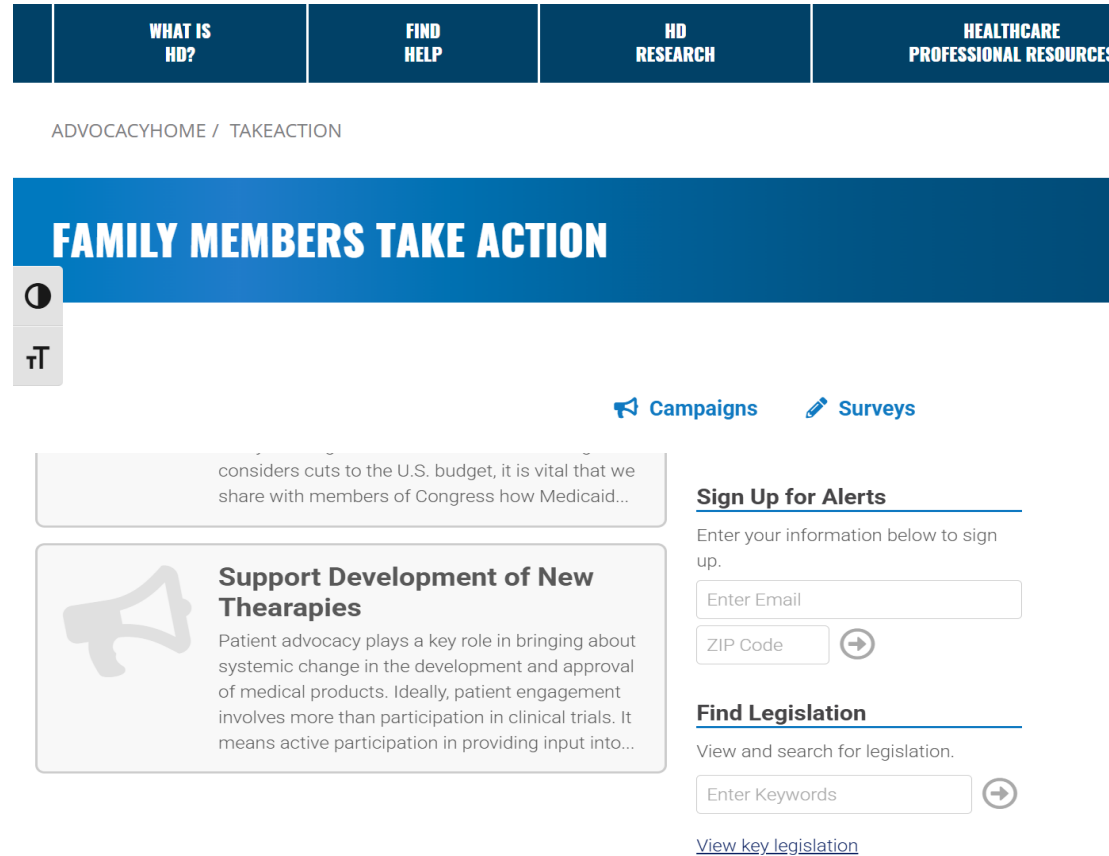


# Into Action Needs YOU!



TAKE ACTION

HDSA Advocacy Hub



WHAT IS HD? FIND HELP HD RESEARCH HEALTHCARE PROFESSIONAL RESOURCES

ADVOCACYHOME / TAKEACTION

## FAMILY MEMBERS TAKE ACTION

📢 Campaigns 📝 Surveys

considers cuts to the U.S. budget, it is vital that we share with members of Congress how Medicaid...

### Support Development of New Therapies

Patient advocacy plays a key role in bringing about systemic change in the development and approval of medical products. Ideally, patient engagement involves more than participation in clinical trials. It means active participation in providing input into...

### Sign Up for Alerts

Enter your information below to sign up.

Enter Email

ZIP Code  →

### Find Legislation

View and search for legislation.

Enter Keywords  →

[View key legislation](#)

<https://hdsa.org/advocacyhome/TakeAction/>



# Join HDSA Advocacy Leaders Program

**Join with HD families** around the country to provide members of Congress with concrete ways they can support:

- Speed development of new therapies
- Access to care
- Reduce financial burden

**HDSA Advocacy Leaders Meet 3<sup>rd</sup> Wednesday every month**  
Email [pfoxworth@hdsa.org](mailto:pfoxworth@hdsa.org) to be added to meeting notification





Huntington's Disease  
Society of America

Thank you for your interest!  
*Together we can bring about systemic change.*

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