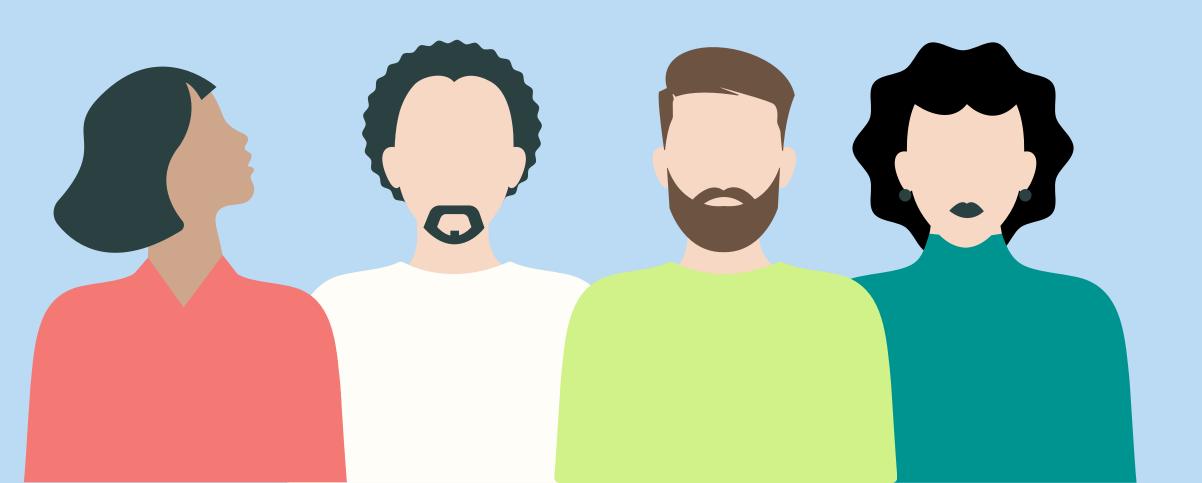
Preparing for Legislative Advocacy

A video series providing strategies for success



Julie Rauch, RN, BCPA
ZebraAdvocate@gmail.com

Policy Research & Issue Identification

Module 2

Learning Agenda



What we'll discuss this afternoon

- Identifing policies that affect your community
- How to research legislation
- Tracking and monitoring bills
- How to identify key stakeholders and allies



Identifying the Needs Of Your Community

Each congressional session, bills are passed that affect access to healthcare and funding for research & drug development

Where To Look



Rare Disease Legislative Advocates

Their policy priorities reflect the most pressing needs of the rare disease community and provide resources, webinar, and policy primers



Take Action Center

They aim to make meaningful, lasting change for chronic disease patients from access to adequate health care to discrimination & the cost of treatment



Action Campaigns, Priorities & Positions

They work to influence policy and legislation to reduce barriers to care & improve the quality of life of individuals living with chronic pain



Prior authorization: a process health insurers use to determine whether a medication, treatment or service prescribed by a doctor will be covered.

Access to Telehealth: Examples include virtual visits via video or telephone, mobile applications and remote patient monitoring.

POLICY ISSUES

Chronic disease patients face battles that healthy Americans do not. From access to adequate health care to discrimination and the cost of treatment—chronic disease patients know America has room for improvement. Policy issues present opportunities to make meaningful, lasting change for everyone.

✓ Jump to an issue...

2025 Policy Platform

Addressing Prior Authorization

Addressing Step Therapy and Non-Medical Switching

Alternative Funding/Third Payer Assistance and Premium Assistance Bans

Bridging the Medicare Gap

Chronic Kidney and Rare Disease Task Forces

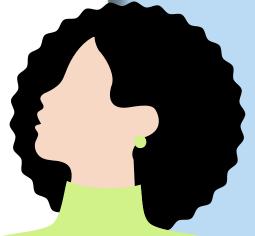
Copay Accumulator Programs

Expanding Access to Telehealth

Living Organ Donor Protections

Putting Patients First in Pharmacy Benefit Management (PBM) Reform

The 340B Program



Example: Access to Telehealth

EXPANDING ACCESS TO TELEHEALTH



What is telehealth?

Telehealth is the use of digital technology to provide health care services remotely. Examples include virtual visits via video or telephone, mobile applications and remote patient monitoring.

Why is telehealth important for people living with chronic diseases?

For individuals living with chronic diseases, telehealth offers timely access to care, provides cost-savings related to travel and time away from work, and improves their overall quality of life. Telehealth also bridges the gap caused by geographic isolation, ensuring that patients, especially those in rural communities, receive regular, specialized care they need without the added burden of travel.

Imagine an individual with diabetes living in a remote area. With telehealth, they can have a virtual consultation with a specialist to discuss their blood sugar levels, get adjustments to their medication, and have access to remote monitoring tools that allow them to send their glucose readings directly to the doctor. This eliminates the need for long travel, allows for timely management of their condition, prevents complications and improves their health.



Republicans and Democrats at both the state and federal level agree that telehealth provides important, affordable care to patients and families.

Nearly three quarters (74%) of physicians now work in practices that offer telehealth. Provider parity, which ensures telehealth services are reimbursed the same as in-person visits, is essential to ensuring patients get the care they need, where and when they need it most.



"I have found telehealth to be very beneficial. Not only is it convenient, but when I am feeling too sick or in pain due to my illnesses, it makes receiving a diagnosis from a doctor a viable option. Previously, when I was too sick to drive to the doctor's or even too sick to get a ride, I would just have to reschedule the appointment for when I felt better." -Dustin Miller, CDC Ambassador, Wisconsin

www.ChronicDiseaseCoalition.org JoinUs@ChronicDiseaseCoalition.org @ChronicRights







Policy Primer

Position Statement





POSITION STATEMENT: TELEMEDICINE

Telemedicine is the use of technology to provide health care from a distance, such as through video conferencing or over the phone. U.S. Pain Foundation supports the use of telemedicine as an important and innovative form of health care delivery.

Telemedicine is typically used to overcome access barriers for patients with limited travel abilities, such as individuals with disabilities or the elderly, and patients in rural communities, who may have to travel long distances for appropriate care. It also can be used to provide immediate care in emergencies, especially if the patient cannot get to an emergency room. Telemedicine can take place using a variety of communications methods, including telephone, email, videoconference, digital imaging, and other forms of technology.

If employed appropriately, telemedicine can provide important benefits to patients. including: increased access to health care, especially for at-risk groups; improved adherence to clinical advice; and reduced cost of patient care. While it cannot replace inoffice assessments provided by medical professionals, patients should have access to telemedicine. Toward this end, telemedicine service should be included in both private and public insurance plans.

The benefits of telemedicine have been well-documented. A study published in the Clinical Journal of Pain reviewed eight Canadian patients with chronic pain who each lived about 200 miles from their respective doctors. Researchers found that both patients and doctors saved time and money by meeting virtually. The visits were follow-ups to review patient progress, change medication, or offer counseling. Another study again found that doctors and patients using telemedicine for chronic pain follow-up care may save time and money.²

Telemedicine may also, in some cases, be more effective than standard care, according to researchers at Indiana University School of Medicine, particularly when all the potential of technology is harnessed for tracking patient well-being.³ A study of 250 patients compared those receiving telemedicine to those receiving traditional care from a general practitioner. The telemedicine group was asked to record their levels of pain by phone or online. Doctors used a special algorithm to adjust medication based on the patients' responses. After one year, patients in the telemedicine group said their pain improved by 30 percent, while patients receiving standard care said their pain worsened.

U.S. Pain Foundation supports legislative action at both state and federal levels to make available benefits of telemedicine to all patient populations, but especially those with limited access to care for physical or geographic reasons.

¹ https://www.ncbi.nlm.nih.gov/pubmed/16691087

² https://www.ncbi.nlm.nih.gov/pubmed/19484320

³ http://www.bostonglobe.com/lifestyle/health-wellness/2014/07/20/telemedicine-may-ease-chronicpain/IENXEzLQInfkzwY1ZXXw4L/story.html

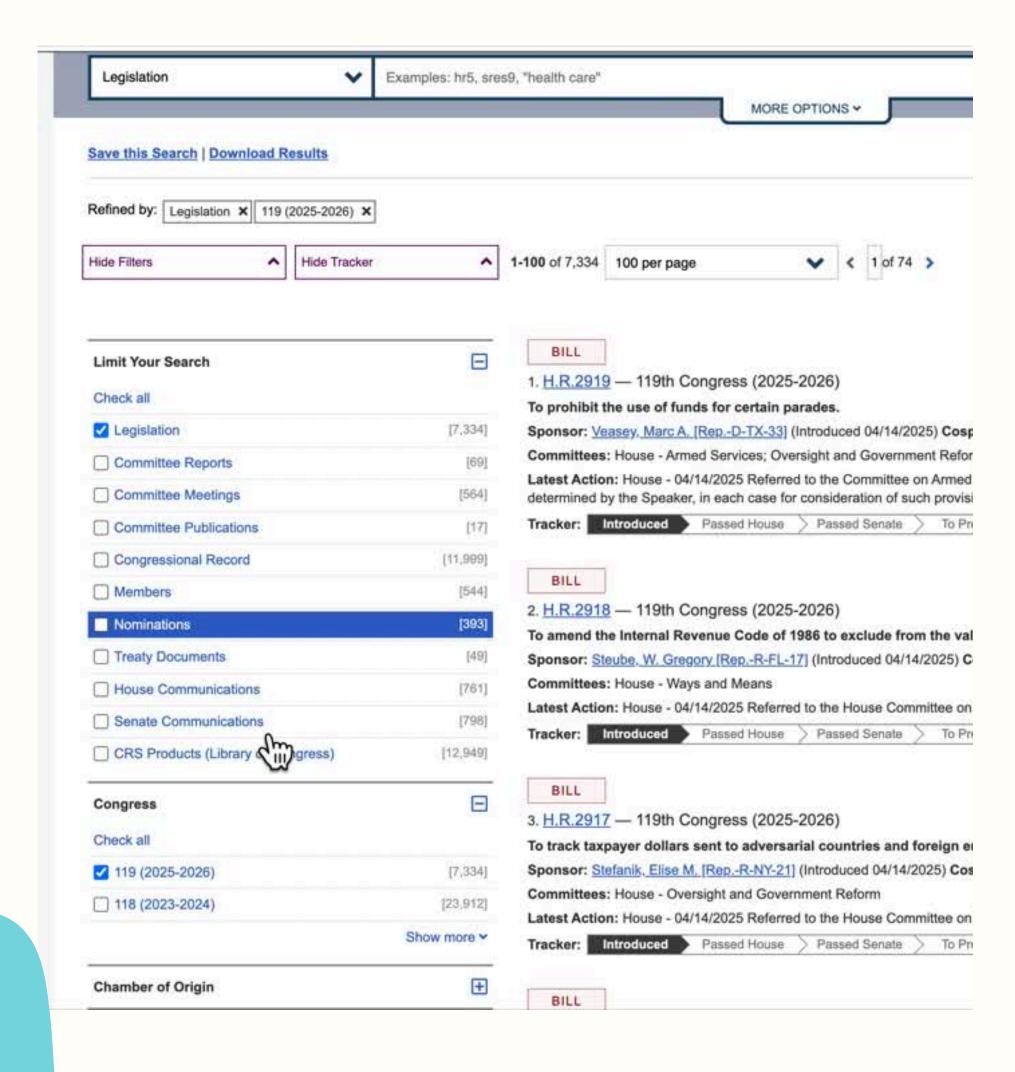




Congress.gov

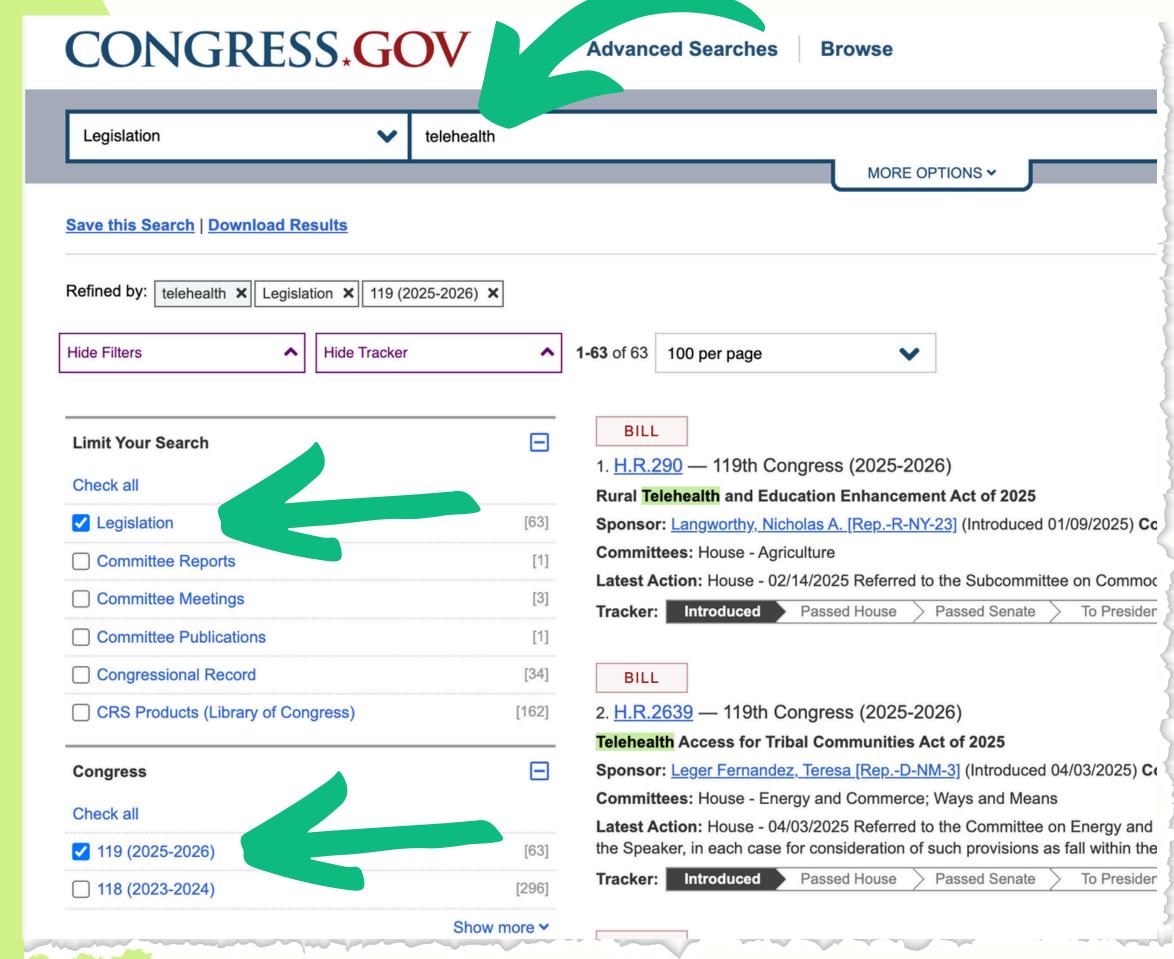
- Chamber- House or Senate
- <u>Bill Type</u>
- Subject-Policy Area
- Committee & Subcommittee
- Sponsor & Cosponsor
- Party of Sponsor





Many people with Chiari, Syringomyelia, and Ehlers-Danlos Syndrome need to see out of state physicians for consultations or second opinions.

Telehealth is a great option if a physical exam is not needed.

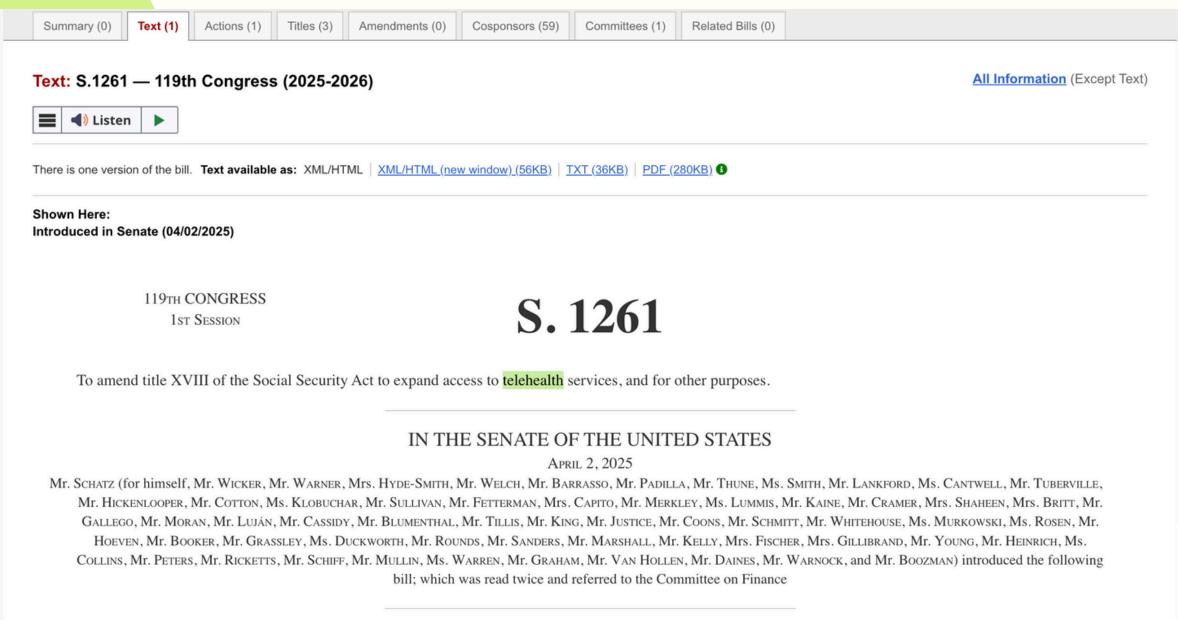


Many people with Chiari,
Syringomyelia, and EhlersDanlos Syndrome need to see
out of state physicians for
consultations or second
opinions.

Telehealth is a great option if a physical exam is not needed.







A BILL

To amend title XVIII of the Social Security Act to expand access to telehealth services, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

Summary (0)

Text (1)

Actions (1

Text (1)

Actions (1)

Titles (3)

Amendments (0)

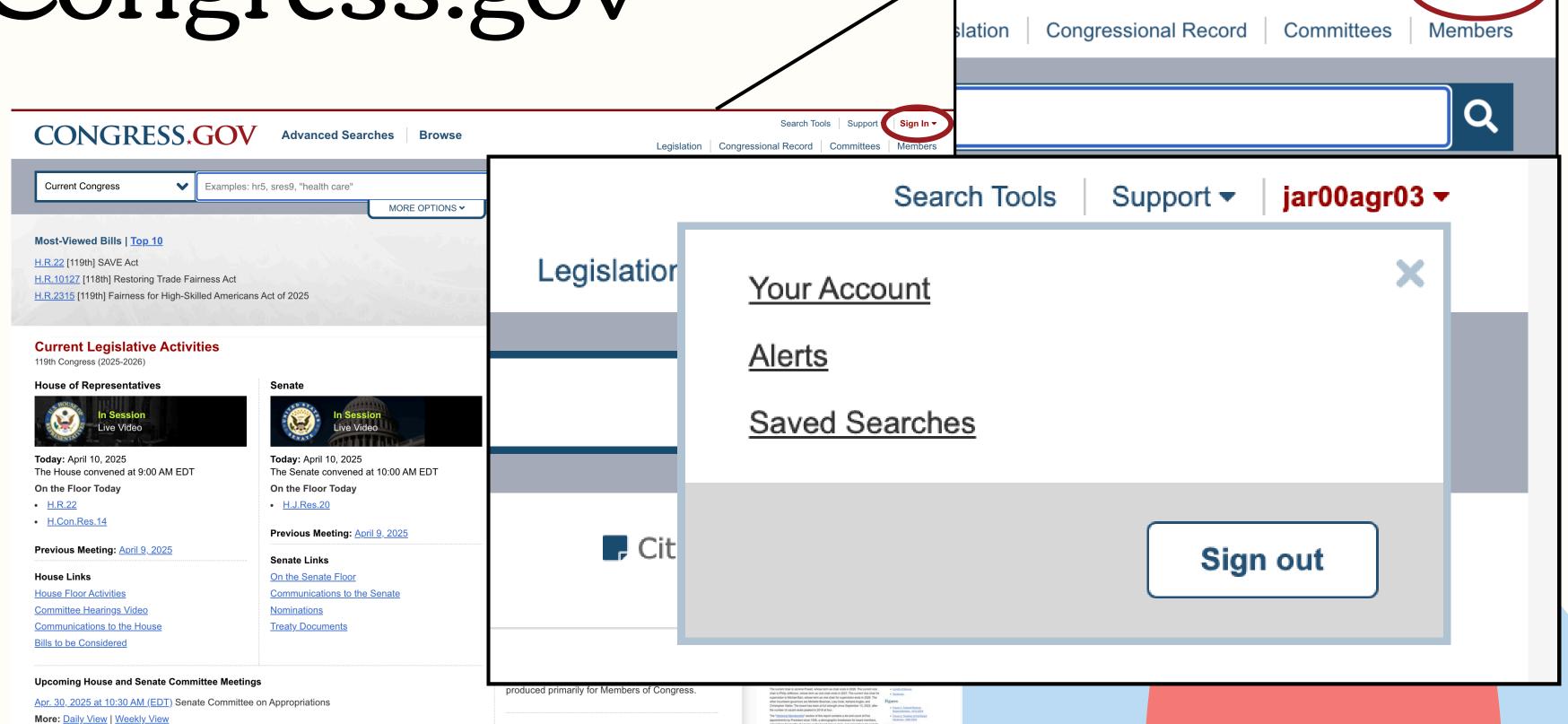
Cosponsors: S.1261 — 119th Congress (2025-2026) All Info Sponsor: Sen. Schatz, Brian [D-HI] | Cosponsor statistics: 59 current - includes 59 original Hide Filters * = Original cosponsor Sort by First to View Expanded V Party of Cosponsor **Date Cosponsored** Cosponsor Check all Sen. Wicker, Roger F. [R-MS]* 04/02/2025 Republican [30] 04/02/2025 Sen. Warner, Mark R. [D-VA]* [27] Democratic Independent [2] 04/02/2025 Sen. Hyde-Smith, Cindy [R-MS]* Cosponsors by U.S. State or Territory Sen. Welch, Peter [D-VT]* 04/02/2025 [2] Alabama 04/02/2025 Sen. Barrasso, John [R-WY]* [2] Alaska [2] 04/02/2025 Arizona Sen. Padilla, Alex [D-CA]* Arkansas [2] 04/02/2025 Sen. Thune, John [R-SD]* California [2] Sen. Smith, Tina [D-MN]* 04/02/2025 [2] Kansas [2] Maine Sen. Lankford, James [R-OK]* 04/02/2025 [2] Minnesota 04/02/2025 Sen. Cantwell, Maria [D-WA]* [2] Mississippi Nebraska [2] Sen. Tuberville, Tommy [R-AL]* 04/02/2025 New Mexico [2] Sen. Hickenlooper, John W. [D-CO]* 04/02/2025 North Dakota [2] Oklahoma [2] Sen. Cotton, Tom [R-AR]* 04/02/2025 [2] South Dakota

Cosponsors (59)

Related Bills (0)

Committees (1)





The Constitution Annotated

Search Tools

Support •

Sign In •

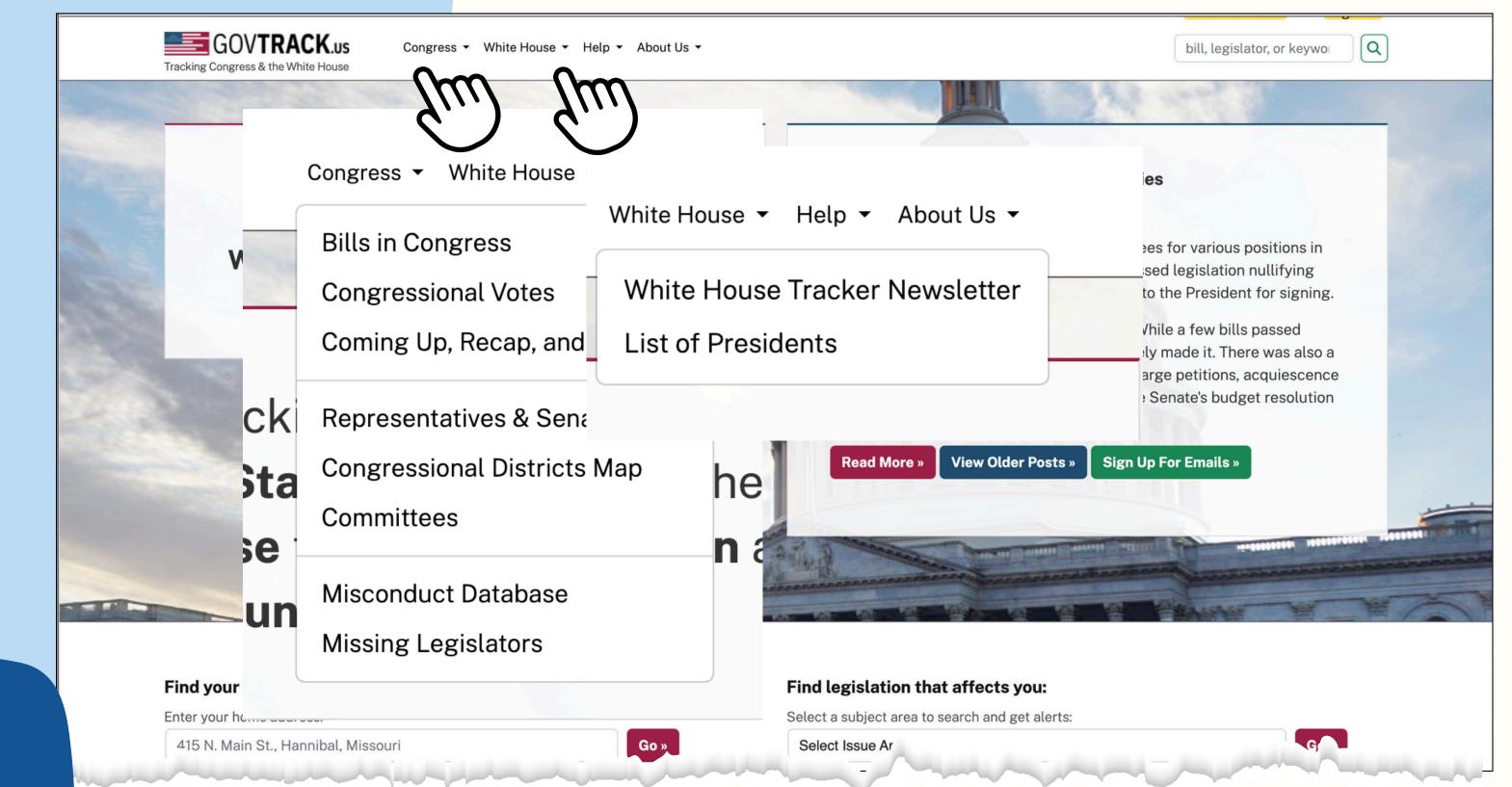
Home > Legislation > 119th Congress > S.1261 Citation 15 OF 63 RESULTS S.1261 - CONNECT for Health Act of 2025 119th Congress (2025-2026) | Get alerts Hide Overview X Sen. Schatz, Brian [D-HI] (Introduced 04/02/2025) Track Changes - Choose one or more (Optional) Help You will be alerted when changes are made to the parameters selected below. Please select one or more of the following: Cosponsors Amendments Confirmed Actions ☐ Committees Related Bills ☐ Titles You will receive an alert for the updates you selected for this bill. Check All OK

Amendments (0)

Cosponsors (

Titles (3)

Get email alerts when changes are made to bills you want to follow.

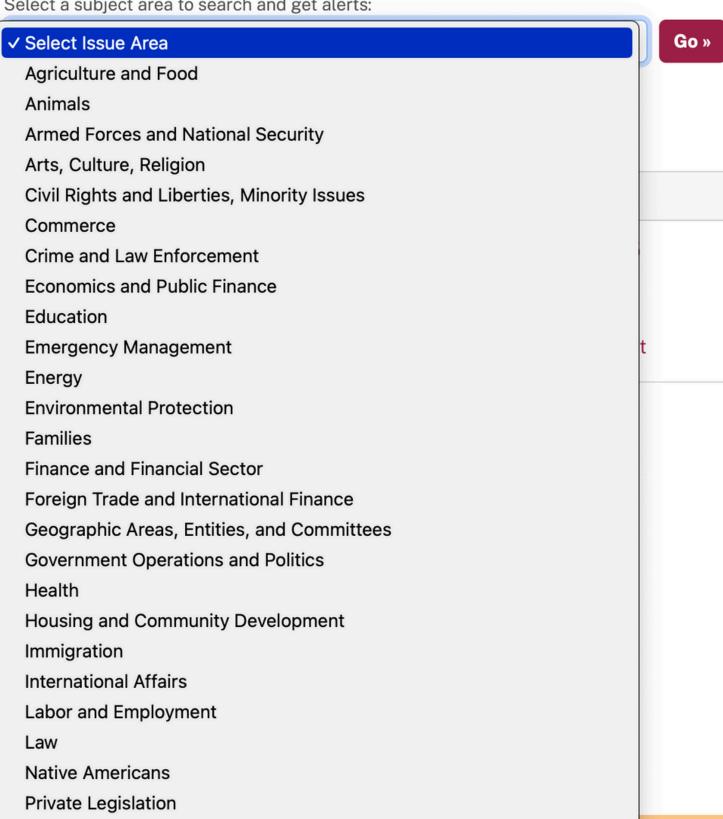




Find legislation that affects you:

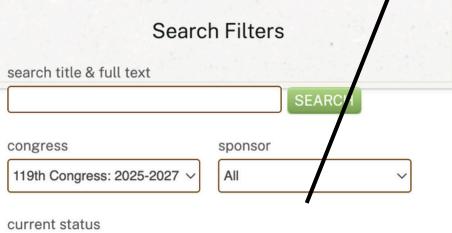
Select a subject area to search and get alerts:

Public Lands and Natural Resources



Advanced Search for Legisl

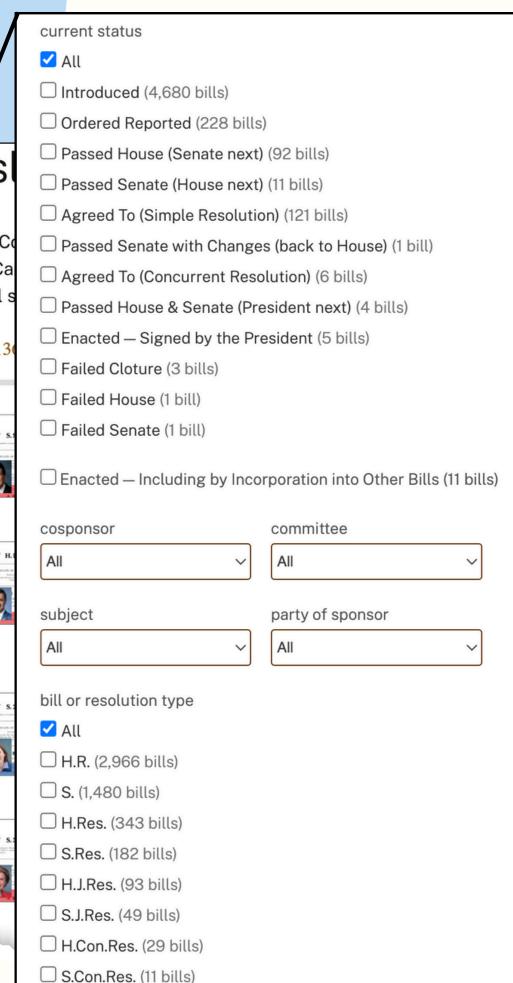
Use this page to find bills and resolutions in the United States Co about enacted laws from 1951-1972 and bills from 1799-1873. Ca announcing a new bill and when Congress publishes its official s



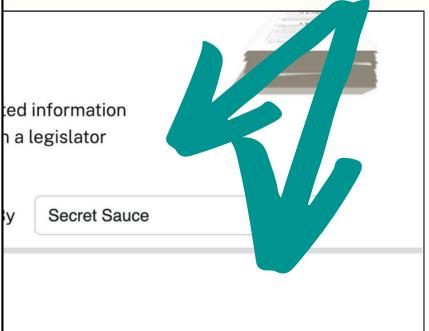


- ✓ All
- ☐ Introduced (4,663 bills)
- Ordered Reported (228 bills)
- Passed House (Senate next) (92 bills)
- Passed Senate (House next) (11 bills)
- Agreed To (Simple Resolution) (121 bills)
- Passed Senate with Changes (back to House) (1 bill)
- Agreed To (Concurrent Resolution) (6 bills)
- Passed House & Senate (President next) (4 bills)
- ☐ Enacted Signed by the President (5 bills)
- ☐ Failed Cloture (3 bills)
- ☐ Failed House (1 bill)





Secret Sauce



Prognosis

74%

rk Act of 2025

sponsors

2R,2D)

Prognosis sponsors (10R,2D) 74%

Prognosis sponsors 2D,1R) 73%

Prognosis sponsors



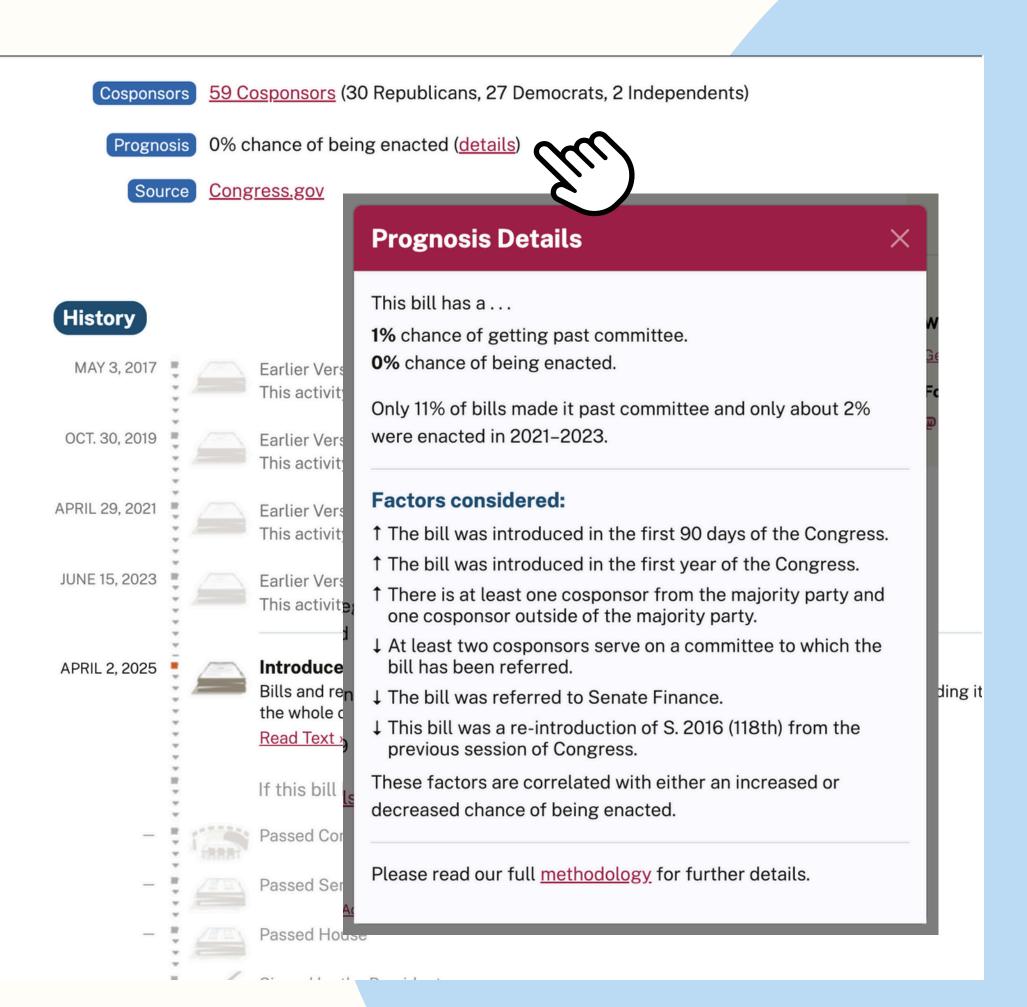
S. 1261: CONNECT for Health Act of 2

Sponsor: Sen. Brian Schat 201

Introduced

April 2, 2025





LegiScan.com Register About Register About

OneVote

Features

GAITS Pro

Datasets

LegiScan API

Bill Tracking

142,335 pieces of legislation tracked from Congress and fifty

state legislatures in the active

Seai

loped

LegiScan AP

Custom Tracking

Build and control a personalized

Bill Tracking

142,335 pieces of legislation being

tracked from Congress and fifty state legislatures in the active

Search

Loain

biennium.

list of only the bills you are interested in, categorized into user-defined Topic or Client & Issue assignments for grouping, corting and reporting

Regardless if you need to focus on a single state, track any of the bills across the nation or are looking to create your own custom legislative data application, LegiScan provides the services that bring all legislative information together into a single uniform interface. With over two decades of servicing clients from public agencies, non-profit associations and national corporations; LegiScan has developed the tools and technology to save time and enhance analysis and communication in the government affairs workflow.

Awareness of legislation and having information about the laws that affect daily life for all Americans is more important than ever. Start Now!

LegiScan GAITS

Turnkey legislative tracking: Research to identify bills, Monitor personalized bill lists, Report and track bill status

OneVote+

Public tracking service for concerned individuals following up to 50 bills from the states and Congress. Personal monitoring list with saved searches from the national legislative search engine and private RSS feeds to stay informed. Receive monitored email alerts, create simple dynamic reports sharable with friends and colleagues.		Introductory subscription service for more active individuals that require tracking legislation from multiple states or expanded to unlimited monitoring list slots. Gaining additional user tracking data fields and simple bill classification groups. Generate PDF reports and alerts for easier printing and sharing.		Unlimited centralized monitoring for single or multiple users. Custom issue management and expanded tracking information including executive summary, regional assignments, and the Insights browser. Advanced dynamic reporting available in PDF, Word & Excel along with daily monitoring and search email alerts.	
Price:		Single State or Congress:	\$25/year		\$100/year
	Register Now!	National (50 States & Congress):	\$1,000/year	National (50 States & Congress):	\$3,000/year

LegiScan API

The RESTful API into the national legislative database for JSON versions of bill, text, vote and search engine results

Custom Tracking

Build and control a perso list of only the bills you are interested in, categorized into user-defined Topic or Client & Issue assignments for grouping, sorting and reporting.

Email Alerts

biennium.

Receive email alerts when new or amended bills match your full text saved searches, and when already monitored bills have hearings, changes or updates, from weekly to daily schedules.

Dynamic Reporting

Create reports based on your monitoring list or issue areas that update bill data automatically and can be shared with others, available for all user levels.

Sample: OneVote, GAITS Pro

Interactive Maps

Nationwide maps allowing interactive browsing of all legislation being tracked from your master monitoring list or just those tagged with your



LegiScan.com



Example Executable Searches

For more examples try the Top 50 Searches trending recently.

- vaccination
 - Simple word search for bills dealing with vaccination
- transgender **OR** gender
 - Legislative texts that include either gender or transgender anywhere in the document
- election AND ballot
 - Legislative texts that include both election and ballot anywhere in the document
- personal ADJ property ADJ tax
 - Bills relevant and affecting personal property tax
- hemp OR cannabis OR marijuana
 - Match legislation containing any of the words hemp, cannabis or marijuana
- abortion OR (pregnancy NEAR termination)
 - Legislation relating to abortion and pregnancy termination
- "National Popular Vote"
 - Generally concerned with the National Popular Vote interstate compact
- ((reform OR repeal) AND "Affordable Care Act") AND (exchange OR connector
 - Search-Fu concerning ACA/Medicaid reforms to exchanges and benefits
- status:introduced AND (alternative ADJ fuel)
 - Find introduced alternative fuel legislation
- type:B AND status:passed
 - All bills affecting code statutes and law that have successfully passed
- action:month AND mask
 - All bills concerning masks that have had activity this month
- intro:week
 - All bills that have been introduced this week



Regardless if you need to focus on a single state, track any of the bills across the nation or are looking to create your own custom legislative data application, LegiScan provides the services that bring all legislative information together into a single uniform interface. With over two decades of servicing clients from public agencies, non-profit associations are national corporations; LegiScan has developed the tools and technology to save time and enhance analysis and communication in the government affairs workflow.

142,335 pieces of legislation being tracked from Congress and fifty state legislatures in the active biennium.

Awareness of legislation and having information about the laws that affect daily life for a Americans is more important than ever. Start

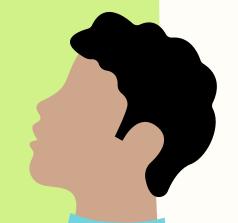
Ou Mission

without bias or conflict; we lelie e that each individual in a demond engagement that you fact that voice, enabled by the data

In to become more engage I aware of the happenings of the leads on the happenings of the leads of a democracy to make deck one on how citizens choose to be reported by the leads of the happenings of the leads o

ity to manage their own government relation clients and issue are legislative data in a manner that enhances analysis and communic most.

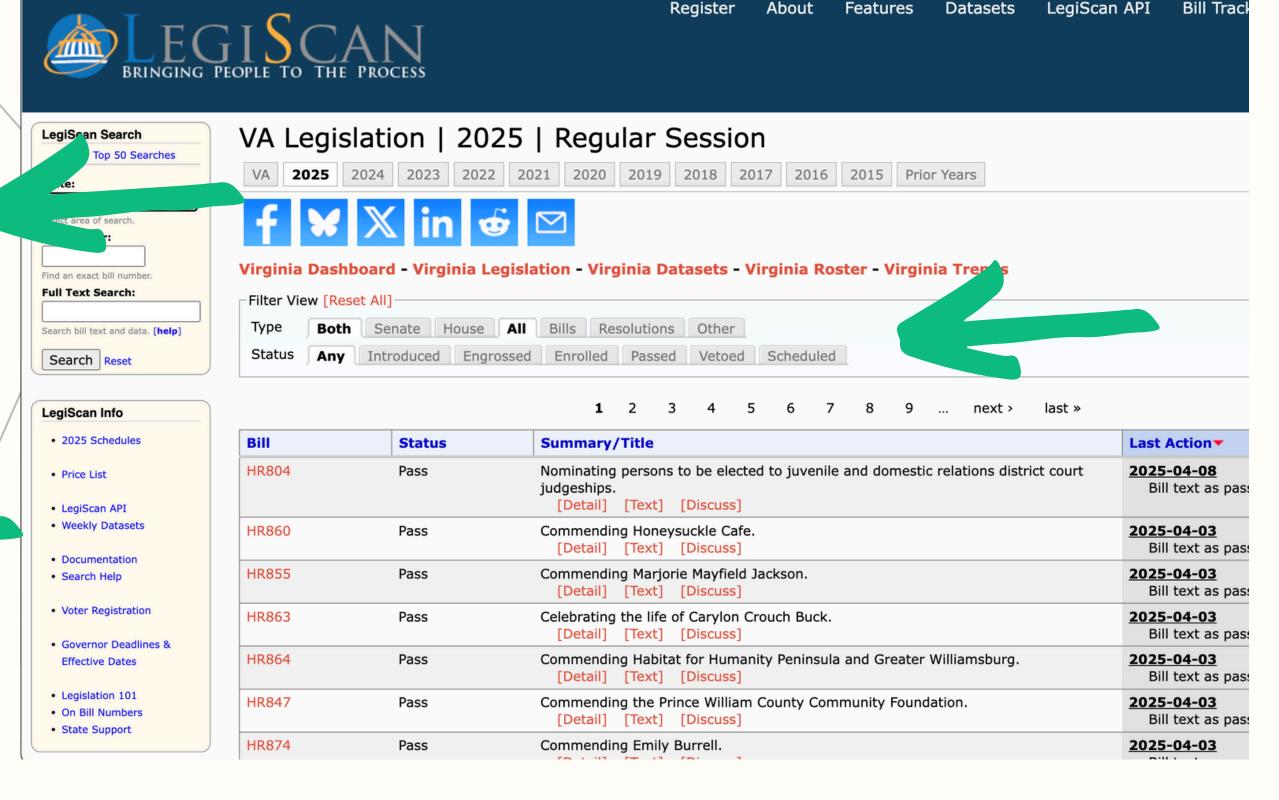
Watch Webinar





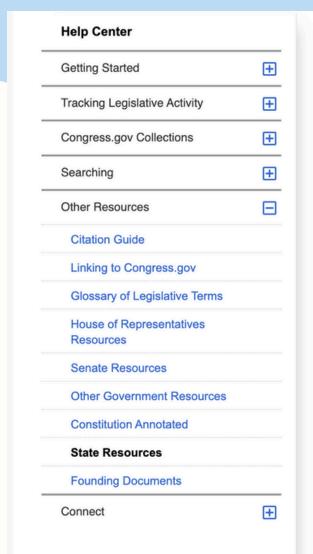
LegiScan.com





Congress.gov

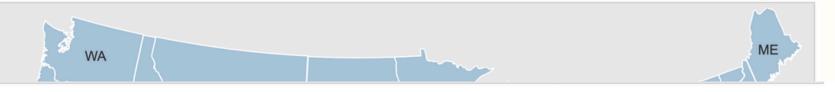
State Government Websites



State Legislature Websites

For U.S. States and Territories

Congress.gov provides legislative information from the House and Senate of the United States Congress. Use the links below to visit similar websites for the U.S. states and territories. Also see <u>state government resources</u>.



Fifty U.S. States and the District of Columbia

Alabama	Kentucky	North Dakota
<u>Alaska</u>	Louisiana	Ohio
Arizona	Maine	Oklahoma
Arkansas	Maryland	Oregon
California	<u>Massachusetts</u>	Pennsylvania
Colorado	Michigan	Rhode Island
Connecticut	Minnesota	South Carolina
<u>Delaware</u>	<u>Mississippi</u>	South Dakota
District of Columbia	Missouri	Tennessee
<u>Florida</u>	<u>Montana</u>	<u>Texas</u>
Georgia	<u>Nebraska</u>	<u>Utah</u>
<u>Hawaii</u>	Nevada	Vermont
Idaho	New Hampshire	Virginia
Illinois	New Jersey	Washington
<u>Indiana</u>	New Mexico	West Virginia
lowa	New York	Wisconsin
Kansas	North Carolina	Wyoming

U.S. Territories

American Samoa

Guam

Northern Mariana Islands

Puerto Rico

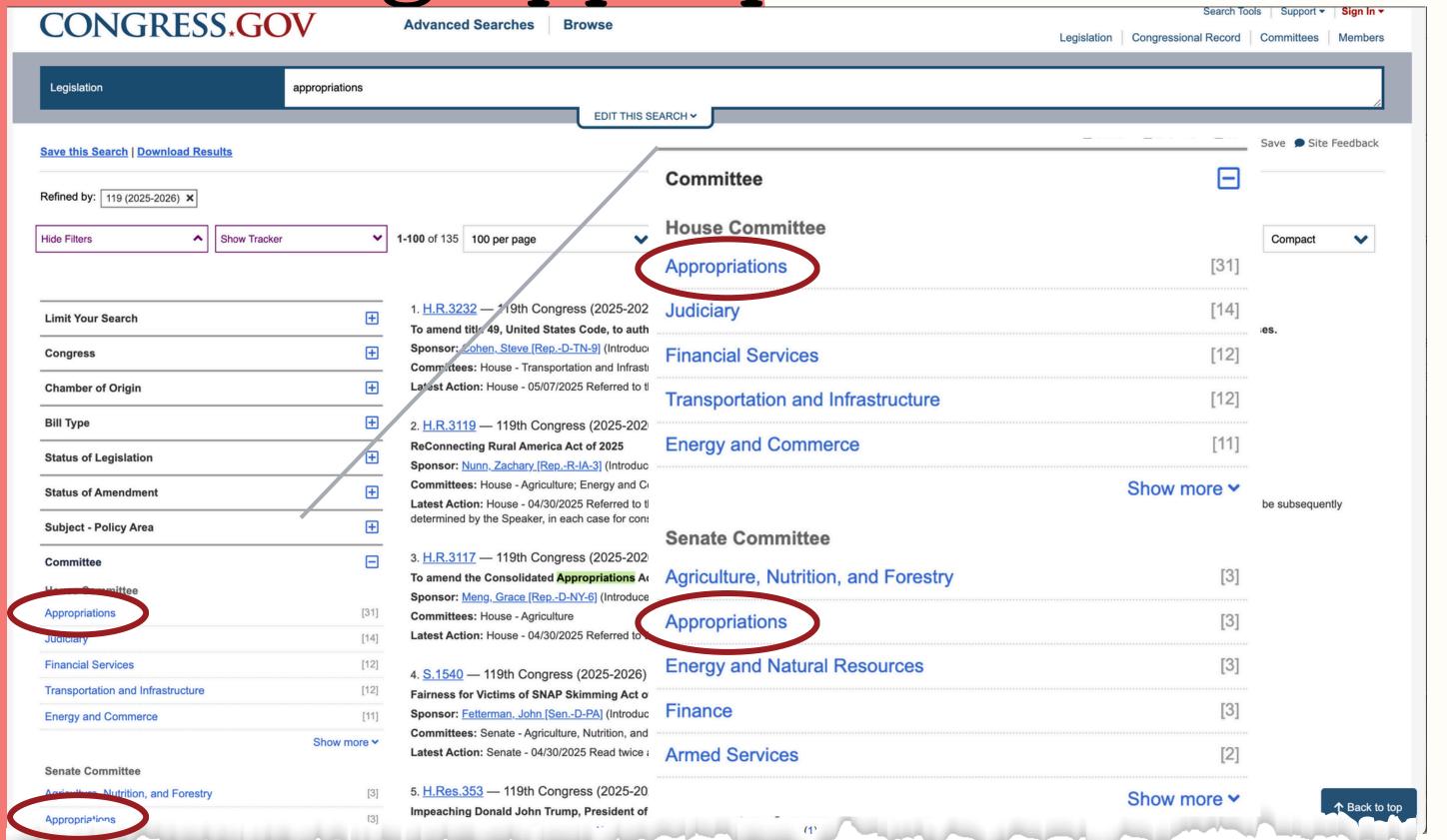
Virgin Islands



Northern Mariana Islands

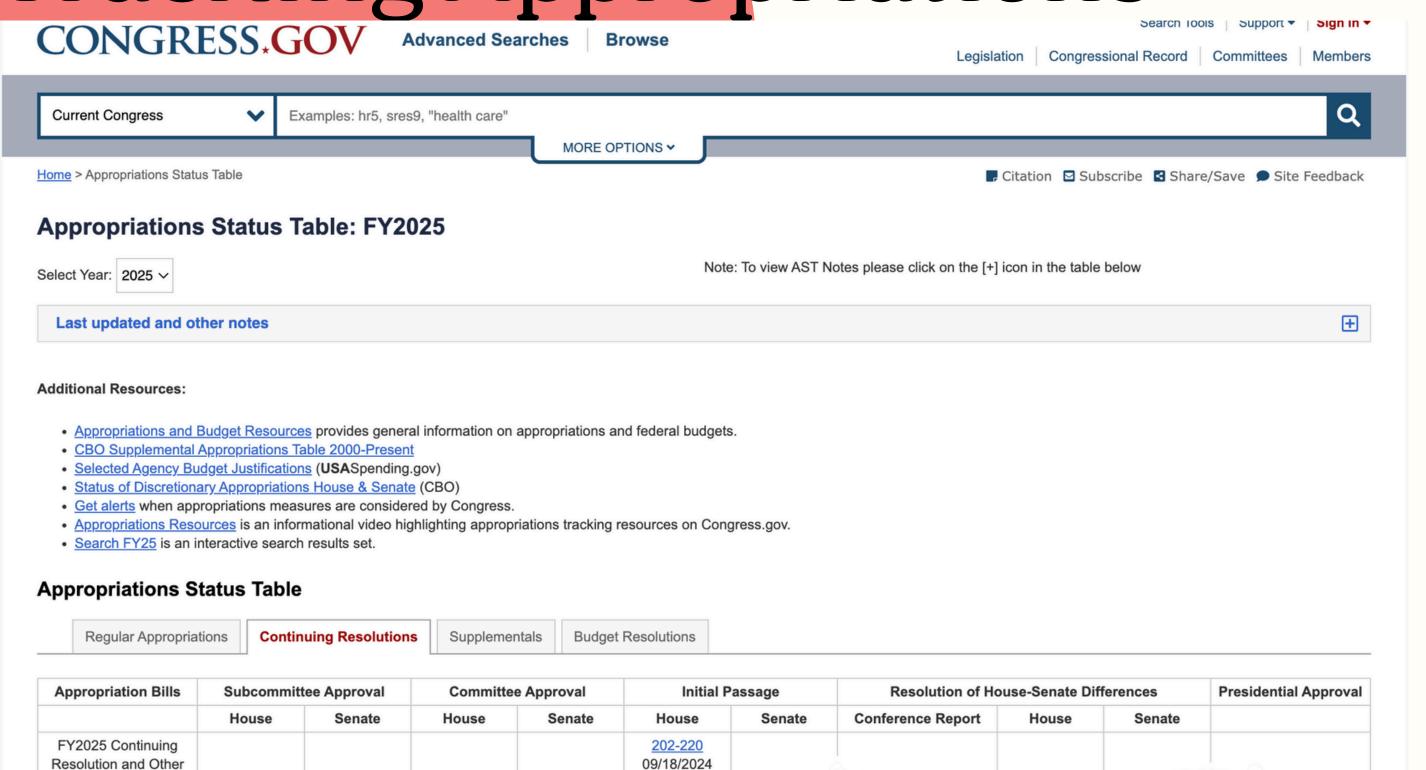


Tracking Appropriations





Tracking Appropriations





Tracking Appropriations







Understanding Appropriations





Key Points

- O1 Every bill addresses a problem and proposes a solution know both.
- Understanding a bill's impact (social, financial, political) is important when advocating.
- Tracking a bill's progress helps you know when and how to act.
- O4 Know who supports and opposes the bill and why to strengthen your strategy.
- Key tools for research: Congress.gov, GovTrack.us, USASpending.gov.



TRACKING LEGISLATION

Step 1: Identify the Bill

Where to Search

- <u>Congress.gov</u> Official source for federal legislation.
- <u>GovTrack.us</u> User-friendly summaries and tracking.
- <u>LegiScan</u> Tracks state and federal bills.

Bill Information:

- **Bill Number** (e.g., H.R.1234 / S.5678)
- Bill Title
- Sponsor(s)
- Date Introduced
- Current Status (e.g., Introduced, In Committee, Passed House, etc.)

Step 2: Understand the Bill's Purpose

Read the Bill Summary and/or Text

Use sources such as: Congress.gov, LegiScan, GovTrack. and USASpending.gov

- What is the main goal of this bill?
- Who does this bill impact?
- · What situation prompted its creation?

Step 3: Track the Bill's Progress

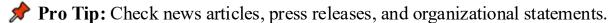
Key Legislative Stages:

- Introduced The bill is submitted in the House or Senate
- Committee Review Assigned to a committee for discussion
- **Floor Vote** Debated and voted on in the chamber (House/Senate)
- Other Chamber If passed, sent to the other chamber for approval
- **Presidential Action** If both chambers pass it, the president signs or vetoes it
- Where is the bill currently in the process?



Step 4: Identify Supporters & Opponents

- Who supports this bill? (Legislators, organizations, advocacy groups, etc.)
- Who opposes this bill? (Opposition groups, industries, etc.)



Step 5: Take Action

How can you advocate for or against this bill?

- Contact legislators
- Mobilize supporters through social media
- · Write an op-ed or letter to the editor.
- Join or organize an advocacy campaign.