

Federal Cuts & Changes Impacting the Epilepsy Community

Now more than ever, it is critical for the epilepsy community to SPEAK UP and speak with ONE VOICE to try and protect epilepsy programs and research. On April 14, 2025, 118 epilepsy organizations—representing people living with epilepsy; caregivers and loved ones; physicians, care providers, and epilepsy centers; epilepsy researchers; and others—issued [a statement](#), united in opposition to recent actions by the Administration and Congress to cut vital federal epilepsy programs (Note: Organizations that signed on after the deadline are added to the version on epilepsy.com; if you still want to sign on, email lweidner@efa.org).

This toolkit builds on that statement by offering resources and information to support people and organizations in the epilepsy community who want to educate and advocate about recent and looming federal cuts and other changes that are negatively impacting the epilepsy community. This toolkit has resources you need to get started, including background on the issues and action steps you can take—whether you only have a few minutes or have a few hours. Actions range from emailing your members of Congress through an action alert (very quick!) to posting on social media (kind of quick!) to requesting and holding meetings with your members of Congress (this will take a while!).

This is a rapidly evolving landscape. The information included here is current as of May 22, 2025, and we will update the toolkit as needed. This toolkit is for use by the entire epilepsy community. If you have questions or need further support when making your ask, feel free to contact any or all of the following government relations leaders who developed this toolkit:

- Laura Weidner, Chief Advocacy & Government Relations Officer, Epilepsy Foundation of America at lweidner@efa.org
- Katie Collins, Epilepsies Action Network and Vice President, G2G Consulting at kcollins@g2gconsulting.com
- Johanna Gray, Deputy Director of NAEC and Principal, Artemis Policy Group at jgray@artemispolicygroup.com

Background

In March 2025, various actions taken by Congress and the Administration began to cut or otherwise change certain epilepsy programs and research. Some of the changes came in the form of funding cuts, while others came in the form of staff cuts and/or restructuring. Some cuts have already happened, while others are still only possible and looming. Below is a summary of these cuts and changes.

Cuts & Changes That Have Already Happened

Reductions in Force at the U.S. Department of Health and Human Services

In late March 2025, as part of a broader department restructuring, the U.S. Department of Health and Human Services (HHS) sent Reduction in Force (RIF) notices to approximately 10,000 full-time federal employees. This was in addition to early retirement and “Fork in the Road” offers which further decreased the size of the federal workforce. The following epilepsy-related work has been impacted:

- **Centers for Disease Control & Prevention (CDC)’s Epilepsy Program staff within the CDC’s National Center for Chronic Disease Prevention and Health Promotion Epilepsy Program were eliminated.**

The CDC Epilepsy Program is the only public health program related explicitly to epilepsy with a national scope and community programs that examine, test, and share strategies to improve the lives of people with epilepsy and their loved ones. In addition to staffing cuts, in the Administration’s Fiscal Year (FY) 2026 budget request, the Administration proposes to eliminate funding for all chronic disease programs at the CDC, including the Epilepsy Program. Congress has started working on the FY 2026 spending bills, and it is to be seen whether they also propose to eliminate or reduce funding for the CDC Epilepsy Program.

- **Nearly 20% of staff at the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH) were RIFed.**

Within NIH, several institutes fund epilepsy-related research that has helped better understand, diagnose, and treat epilepsy—most notably, the NINDS. On the funding side, the Administration’s FY 2026 budget request proposes \$27 Billion for the NIH—which would be a decrease of nearly \$18 Billion from current levels.

Congressionally Directed Medical Research Programs (CDMRP)

In its final FY 2025 funding bill, Congress cut appropriations for the Congressionally Directed Medical Research Program (CDMRP) by 57%. This has completely eliminated specific funding for research related to Tuberous Sclerosis Complex (TSC), post-traumatic epilepsy, and traumatic brain injury (TBI) and psychological health. It seems like some of these conditions may be able to compete with other diseases for research funding, but there is no longer specific funding dedicated and guaranteed to them.

Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)

Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) was terminated in early April 2025. For more than 20 years, this committee has governed the Recommended Uniform Screening Panel (RUSP), which helps to ensure that newborns have access to screening, diagnosis, and intervention for serious medical conditions. Some conditions on the RUSP list can cause seizures and there are many other rare disorders that cause seizures and epilepsy in infants and children that could be added.

Cuts & Changes That Are Possible & Looming

Medicaid

In April 2025, Congress passed a FY 2025 Budget Resolution that outlines budgetary levels for FY 2026 and beyond. It instructs the Senate Finance Committee (the committee in the Senate that has jurisdiction over Medicaid, Medicare, and tax

revenue) to increase the deficit by not more than \$1.5 trillion over the next ten years and instructs the House Energy and Commerce Committee (the committee in the House that has jurisdiction over Medicaid and Medicare) to cut at least \$880 billion over the next ten years.

In May 2025, Congress has been working on a reconciliation package that includes those cuts. The House bill institutes work requirements, cost sharing, and more frequent eligibility checks for Medicaid beneficiaries, as well as changes to Medicaid provider taxes. The Congressional Budget Office (CBO) has estimated that the Medicaid provisions in the House bill will result in 7.6 million people becoming uninsured; uninsured numbers are higher if the other healthcare provisions are included. About 40% of adults with epilepsy and more than one-third of children and youth with special health care needs rely on Medicaid and the proposed cuts could, if enacted, impede access to needed care, treatments, and/or long-term services and supports. The House passed its bill on May 22 and then the Senate started working on its bill.

U.S. Department of Education

By mid-March 2025, the U.S. Department of Education (Dept. of Ed.) had lost about half its workforce through early retirement or “Fork in the Road” offers or RIFs. Seven of the twelve regional offices are expected to be closed (Boston, Chicago, Cleveland, Dallas, New York, San Francisco, and Philadelphia). The RIFs cut many in the Dept. of Ed.’s Office of Civil Rights which safeguards the civil rights of students with disabilities. Then on March 20, 2025, President Trump signed an Executive Order calling on the Secretary of the Dept. of Ed. to take all necessary steps—to the maximum extent appropriate and permitted by law—to facilitate the closure of the Dept. of Ed. and return authority over education to States and communities. The Dept. of Ed., however, cannot be closed without congressional approval. If Congress approves closing the Dept. of Ed., some of its functions could be moved to another federal agency and the civil rights of students with disabilities would remain—but the expertise and broad oversight would be minimized. Even after just the staff reductions, there have been news stories of civil rights investigations being stalled, and these delays are likely to increase if there are further cuts.

- **Rehabilitation Act, Section 504:** Enacted in 1973 (pre-dating the Americans with Disabilities Act), the Rehabilitation Act was the first time that discrimination on the basis of disability in federal programs was deemed illegal. Section 504 of the Rehabilitation Act states that no person should be excluded from, denied benefits of, or subjected to discrimination under any program or activity that receives federal assistance.

Under Section 504, a student with epilepsy can be a student with a disability for purposes of Section 504 if the student’s epilepsy substantially limits one or more of the student’s major life activities. Federal departments and agencies—including HHS, the Dept. of Ed, the U.S. Dept. of Labor, and the U.S. Dept. of Housing and Urban Development—have since issued regulations and guidance implementing Section 504 for their programs. There are currently two major Section 504 lawsuits underway:

o *A.J.T. v. Osseo Area Schools*: This lawsuit was brought by parents of a teenager with severe epilepsy against the school district, after the school district denied some of their accommodation requests. The case is looking at whether the Americans with Disabilities Act and Rehabilitation Act require children to satisfy a bad faith or gross misjudgment standard when seeking relief for discrimination relating to education. The Supreme Court agreed to hear the case and the oral argument occurred on April 28, 2025.

o *Texas v. Becerra*: 17 state Attorneys General have challenged a Section 504 regulation issued by HHS in 2024. When the lawsuit was first filed, the complaint stated that it was questioning parts of the 2024 HHS Section 504 regulation—but all of that regulation or all of Section 504 could be invalidated. Since then, in a joint status report issued on April 11th, the 17 Plaintiff States clarified that they are no longer challenging the constitutionality of Section 504 nor seeking to restrain federal funding disbursements under Section 504. However, the States continue their challenge to the HHS Section 504 regulation that was issued in 2024.

Cuts to NIH Indirect Costs

In early February 2025, the Administration proposed to cap indirect costs on NIH grants at 15%. Indirect costs, also known as facilities and administrative costs, include expenses essential for medical research, such as laboratory equipment, utilities, and administrative support. Lawsuits have been filed and judges have issued injunctions barring the NIH from capping indirect costs at 15%. However, the federal government is appealing those decisions and the Administration’s FY 2026 budget request included this proposal. There will likely be advocacy and potential action on both sides of this issue during the congressional budget process.

Here is how you can take action

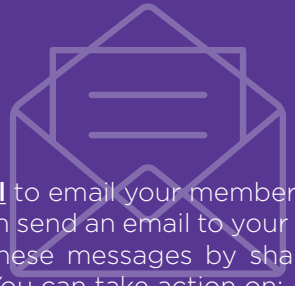
5 minutes

Email your Members of Congress

The easiest and quickest way to take action is to **use the Epilepsy Foundation's tool** to email your members of Congress about your concerns. Just enter your address and a few clicks later, you can send an email to your U.S. Senators and Representative. We strongly encourage advocates to personalize these messages by sharing information about their own experiences as a member of the epilepsy community. You can take action on:

- [Advisory Committee on Heritable Disorders in Newborns and Children](#)
- [CDC Epilepsy Program](#)
- [CDMRP](#)
- [Department of Education](#)
- [Medical Research](#)
- [Medicaid](#)
- [National Plan for Epilepsy](#)

If your organization has its own action alert system, build and send your own action alert! You are welcome to use language from the Epilepsy Foundation's **action alerts** (links above).



10 minutes

Share with your network on social media

You can amplify the epilepsy community's statement **opposing cuts to the CDC, medical research, and ACHDNC** by posting on your social media channels. Graphics and sample social media content can be accessed in this public folder: <https://bit.ly/accep25>



15 minutes

Reach out about 504

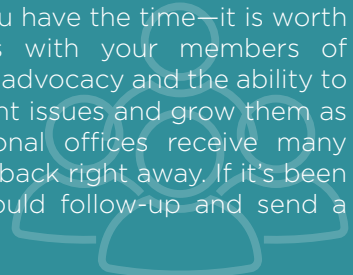
If you want to help **protect the 2024 Section 504 regulation**, the best action you can take is to contact your state's Attorney General. If you live in one of the 17 states that brought the lawsuit, you can ask the state Attorney General to drop out of the lawsuit. If you live in a state that is not part of the lawsuit, you can still contact your state Attorney General and tell them what they can do to protect Section 504 and the new rules. Check out [The Disability Rights Education and Defense Fund \(DREDF\)'s webpage](#) to support people taking action to protect Section 504. Scroll down to the "What can I do to help?" section and it has links/ways to contact your Attorney General and talking points.



1+ hour

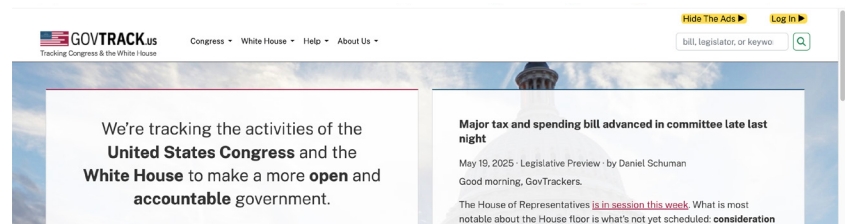
Request meetings with your congressional offices

If you have more time, requesting and holding a meeting with your congressional offices gives you more time to explain your concerns, ask questions, and ask for their support. For each member of Congress you reach out to, it can take at least one hour total to request the meeting, get the meeting scheduled and hold the meeting. But if you have the time—it is worth it!! Establishing and strengthening relationships with your members of Congress and their staff fuels impactful year-round advocacy and the ability to reach out to your members of Congress on different issues and grow them as epilepsy champions. Remember that Congressional offices receive many meeting requests, so don't worry if you don't hear back right away. If it's been longer than a week without a response, you should follow-up and send a reminder about your request.



Identify your Members of Congress!

One great way is the [Govtrack.us](https://govtrack.us) tool available here.



On the Govtrack.us homepage, enter your address in this box:

Find your representative and senators:

Enter your home address:

415 N. Main St., Hannibal, Missouri

Go »

♥ I'm at Home · 🌐 View a Map · ☰ Find Members of Congress »

Senators

Each state elects two senators to the United States Senate for staggered 6-year terms. Senators represent the entire state. Virginia's senators are:



Mark Warner

Senior Senator for Virginia
Since Jan 6, 2009 (next election in 2026)
Democrat

[Official Website](#) · 202-224-2023

[View Legislative Profile & Get Alerts »](#)



Timothy "Tim" Kaine

Junior Senator for Virginia
Since Jan 3, 2013 (next election in 2024)
Democrat

[Official Website](#) · 202-224-4024

[View Legislative Profile & Get Alerts »](#)

Representative

The United States is divided into 435 congressional districts, each with a population of about 710,000 individuals. Each district elects a representative to the U.S. House of Representatives for a two-year term. Representatives are also called congressmen/congresswomen.



Donald Beyer

Representative for Virginia's 8th congressional district
Since Jan 6, 2015 (next election in 2024)
Democrat

[Official Website](#) · 202-225-4376

[View Legislative Profile & Get Alerts »](#)

Check the map below to make sure we've located your address accurately.

And you will get to a page that looks like this

This gives you links to the websites and phone numbers for your two U.S. Senators and your U.S. Representative. You should only contact your Members of Congress – they want to hear from constituents (people who live in their state/district).

Phone call tips / talking points

Call their office or the U.S. Capitol switchboard at 202-224-3121 (voice) or 202-224-3091 (TTY) to be connected. Once you are connected to your congressional office, below is a phone script to use. Update the parts highlighted in []

"Hi, my name is [FIRST AND LAST NAME]. I am a constituent and live in [CITY, STATE]. I am also a member of the epilepsy community and [LIVE WITH EPILEPSY, HAVE A LOVED ONE WITH EPILEPSY, AM AN EPILEPSY HEALTHCARE PROVIDER OR EPILEPSY RESEARCHER, AND/OR WORK AT AN EPILEPSY ORGANIZATION].

Can you please share the name and contact information for the staff person who handles health care issues and then connect me to them? I would like to schedule a meeting with them. Thank you!"



Once you are connected to the staff person who handles health care issues, below is a phone script. Please note that it's possible that you will be connected to the staff person right away or you may have to leave a message. We have provided phone scripts for both scenarios.

If you are connected to the staff person:

"Hi, my name is [FIRST AND LAST NAME]. I am a constituent and live in [CITY, STATE]. I am also a member of the epilepsy community and [LIVE WITH EPILEPSY, HAVE A LOVED ONE WITH EPILEPSY, AM AN EPILEPSY HEALTHCARE PROVIDER OR EPILEPSY RESEARCHER, AND/OR WORK AT AN EPILEPSY ORGANIZATION].

I would like to schedule a virtual meeting with you to discuss how recent and looming cuts are having a negative impact on epilepsy programs and research. Can you share some dates and times that you are available for a meeting?

[Be sure to select a date and time for the virtual meeting, as well as discuss what virtual platform—Zoom, etc.—will be used and how you will get a link for the meeting.] Can you please share your name and contact information in case I need anything before the meeting? Thank you for your time and I look forward to our meeting!"

If you have to leave a message:

"Hi, my name is [FIRST AND LAST NAME]. I am a constituent and live in [CITY, STATE]. I am also a member of the epilepsy community and [LIVE WITH EPILEPSY, HAVE A LOVED ONE WITH EPILEPSY, AM AN EPILEPSY HEALTHCARE PROVIDER OR EPILEPSY RESEARCHER, AND/OR WORK AT AN EPILEPSY ORGANIZATION].

I would like to schedule a virtual meeting with you to discuss how recent and looming cuts are having a negative impact on epilepsy programs and research. Please call me back at [PHONE NUMBER] or email me at [EMAIL ADDRESS] in order to schedule this meeting. Thank you!"

Email tips / sample language to request a meeting

You can paste info into the “contact me” webform on a member’s official website (this should have a “house.gov” or “senate.gov” in the URL) or email it directly to the health staff person whose contact info you got by calling the office!

When emailing an office, consider whether you should use your personal or professional work email address. Some employers have strict rules about engaging in advocacy/lobbying, and if that is the case, you should use your personal email address.

Here’s sample language; be sure to update the parts highlighted in [yellow box]

“As a constituent and someone [LIVING WITH/AFFECTED BY/CARING FOR THOSE WITH] the epilepsies, I am writing to request a virtual meeting with [YOU / THE APPROPRIATE HEALTH CARE STAFF PERSON] to discuss how recent and looming cuts are having a negative impact on epilepsy programs and research.

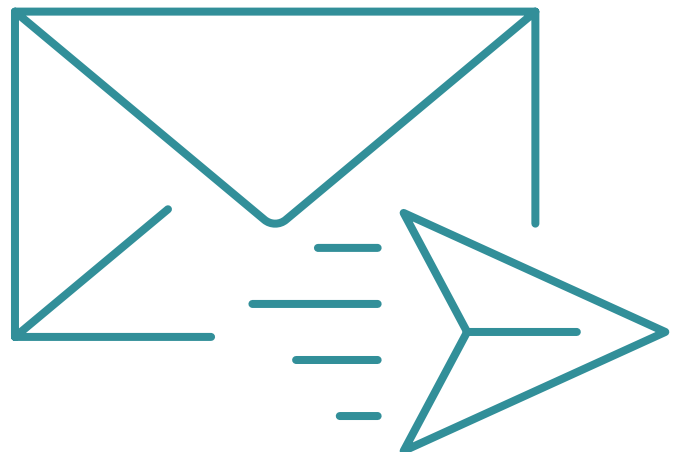
I’m writing on behalf of nearly 3.4 million Americans living with active epilepsy, including 456,000 children, and [ADD NUMBER IN YOUR STATE, as found on the last page of this toolkit] people in [STATE]. Epilepsy is a disease or disorder of the brain which causes reoccurring seizures. It is a spectrum disease comprised of many diagnoses including an ever-growing number of rare epilepsies. Epilepsy, seizures, and their severity are different person-to-person, but epilepsy often impacts many aspects of life including needed health care, employment, education and transportation.

[YOU CAN ADD A SENTENCE OR TWO ABOUT HOW EPILEPSY HAS IMPACTED YOUR LIFE. YOU WILL HAVE MORE TIME IN YOUR MEETING TO ELABORATE ON THIS.]

I am concerned about some of the recent and possible federal cuts that are hurting people with epilepsy and their families, as well as progress to better understand and treat epilepsy. For instance, I am concerned about [LIST WHICH CUTS YOU ARE MOST CONCERNED ABOUT, e.g., CDC Epilepsy Program cuts, NINDS cuts, cuts to medical research funding at the CDMRP].

As a constituent, I would appreciate time to discuss my concerns. Please contact me at [YOUR EMAIL/PHONE NUMBER] to let me know when you are available to meet virtually.

Thank you for your consideration!”





Tips for Meetings

Often during a meeting with a congressional office, you meet with a staff person who works for the U.S. Senator or U.S. Representative. Sometimes, the Member of Congress will also join for some or all of the meeting. But don't be concerned if the Member of Congress does not join the meeting! Building a relationship with a Congressional staffer is important, as they make recommendations to their boss (the member of Congress) on which bills and policies to support and how they should vote.

Members' and staffers' knowledge of different issues—in this case, epilepsy—varies, so it is always good to ask them if they have background or experience with epilepsy. Some may have personal connections to epilepsy themselves.

Most meetings with congressional offices are 15-20 minutes long, so it is important to keep your planned talking points short. It is completely okay to have notes with you, if that makes you more comfortable. Remember that this is just a conversation and the Members of Congress and their staff are there to listen to you – as their constituent, they work for you! If you are asked a question you can't answer, it is totally fine to say “I do not know” and follow up with them if/when you are able.

High-level outline / talking points for a meeting or phone call with a Congressional staffer:

Since it is important to be concise in meetings with congressional offices, an effective format for meetings is the “**Hook, Line, and Sinker.**”

Hook

- How you relate to them – who you are and where you're from; How does this issue relate to your life?

Line

- How will the proposed change help or harm you and the broader epilepsy community?

Sinker

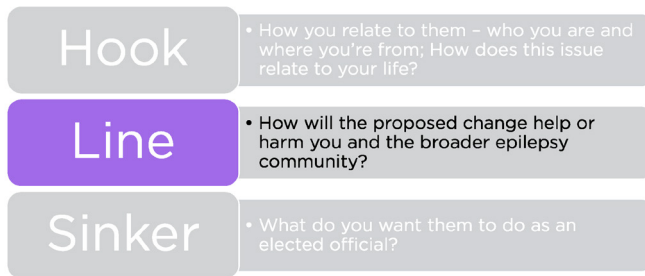
- What do you want them to do as an elected official?

Hook

Introduce yourself, where you live, and your connection to epilepsy (a person living with epilepsy or his/her caregiver, an advocate, a researcher, a person who works at an epilepsy center, etc). Share 2-3 minutes about how epilepsy has impacted your or your loved one's life/lives.

Example: *“I am meeting with you today because I am concerned with how recent and possible federal cuts to epilepsy programs and research are going to hurt the epilepsy community and progress in better understanding and treating epilepsy.”*

- Ask the staff person to introduce themselves.



Line

Select which issue(s) that matter most to you. Sample talking points are below.

CDC Epilepsy Program Cuts

- In early April 2025, Reductions in Force notices were issued to staff within the Centers for Disease Control and Prevention (CDC)'s Epilepsy Program. In addition, the Administration's Fiscal Year 2026 budget request proposes eliminating funding for all chronic disease programs at the CDC—including the Epilepsy Program.
- The CDC Epilepsy Program is the only public health program specifically related to epilepsy with a national scope and community programs that examine, test, and share strategies to improve the lives of people with epilepsy and their loved ones.
- This vital program supports seizure recognition and first aid training, including for school personnel; research to better understand the burden and risk factors of epilepsy; self-management programs that improve the health and well-being of people with epilepsy; and Project ECHO so that epilepsy specialists can help primary care doctors in rural communities.

Share any other reason(s) that the CDC Epilepsy Program cuts are concerning to you.

Research Cuts

- About NIH:
 - o In early April, Reductions of Force (RIF) notices were issued to nearly 20% of staff at the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH). In addition, the Administration's Fiscal Year 2026 budget request proposes cutting funding for the NIH by nearly \$18 Billion.
 - o The Administration has also proposed capping indirect costs of NIH grants at 15%.
- About CDMRP:
 - o In the final Fiscal Year 2025 funding bill, appropriations for the Congressionally Directed Medical Research Program (CDMRP) were cut by 57%.
 - o This has completely eliminated specific funding for research related to Tuberous Sclerosis Complex or TSC, which is a rare form of epilepsy, post-traumatic epilepsy, and traumatic brain injury (TBI) and psychological health.
 - o These conditions may be able to compete with other diseases for some funding, but there is no longer specific funding dedicated and guaranteed to them.
- Why Research Cuts Are Bad:
 - o There are nearly 3.4 million Americans with active epilepsy.
 - o Epilepsy and/or seizures impose an annual economic healthcare burden of \$54 Billion on the U.S.
 - o While progress has been made, in at least 50% of epilepsy cases, the cause remains unknown and at least 30% of people with epilepsy are not able to achieve seizure control with existing treatments.
 - o These epilepsy research staff and funding cuts will halt our progress in better understanding and treating epilepsy and working towards cures.

Share any other reason(s) that the research cuts are concerning to you.

Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)

- In early April 2025, the Advisory Committee on Heritable Disorders in Newborns and Children was terminated.
- For more than 20 years, this committee has governed the Recommended Uniform Screening Panel (RUSP), which helps to ensure that newborns have access to screening, diagnosis, and intervention for serious medical conditions.
- Some conditions on the RUSP list can cause seizures and there are many other rare disorders that cause seizures and epilepsy in infants and children that could be added.

Share any other reason(s) why eliminating the ACHDNC is concerning to you.

Medicaid

- About 40% of people living with active epilepsy between 18-64 years old receive coverage through Medicaid.
- Almost one in five children and youth have special health care needs, including about 4% of children with epilepsy and seizure disorders. More than one-third of children and youth with special health care needs are covered by Medicaid.
- People with epilepsy who experience gaps in Medicaid coverage have a higher number of negative health events including hospitalizations and ER visits.
- The House reconciliation package's Medicaid provisions would institute work requirements, cost sharing, and more frequent eligibility checks for Medicaid beneficiaries, as well as changes to Medicaid provider taxes.
- The Congressional Budget Office has found that these Medicaid changes would result in 7.6 Million people becoming uninsured and even more becoming uninsured when the other healthcare provisions are taken into account. I urge you to oppose any cuts to Medicaid.

Share any other reason(s) why possible cuts to Medicaid are concerning to you.

U.S. Department of Education

- The Reductions in Force and Executive Order calling for closure of the U.S. Department of Education put the rights of students with disabilities including epilepsy in jeopardy.
- States and local communities already have control over the majority of education decisions, including curriculum and graduation requirements, teacher licensure standards, and the development of Individualized Education Plans (IEPs) and 504 Plans.
- Removing federal oversight of critical civil rights laws such as the Individuals with Disabilities Education Act (IDEA) leaves students vulnerable to state variation and being denied their rights and education.
- Students with disabilities must continue to receive support from a department whose roles and functions are designed to ensure that every student can achieve academically.

Share any other reason(s) why closing the U.S. Department of Education is concerning to you. and accessible healthcare are important to you.

Section 504

Note: The best action you can take related to Section 504 is contacting your state Attorney General, as described above on page 4. If you want to highlight Section 504 in your meeting with your congressional office(s) as well, below are talking points you can use.

- The HHS 504 regulation issued in 2024 helps make healthcare more accessible for people with disabilities including epilepsy. For instance, it helps ensure that:
 - o Medical treatment decisions by those that receive federal financial assistance are not based on biases or stereotypes about individuals with disabilities;
 - o Recipients using examination tables and/or weight scales have at least one accessible version of the equipment within two years of the effective date;
 - o People with disabilities can receive care and support in the most integrated setting;

- o Value assessments used in healthcare are not discriminatory against people with disabilities; and
- o Health-related websites and mobile applications are accessible.

Share any other reason(s) why Section 504 and accessible healthcare are important to you.

National Plan for Epilepsy

- By directing the Secretary of Health and Human Services to establish and maintain a National Plan for Epilepsy, this bipartisan bill will enable necessary federal coordination to ensure a unified approach that facilitates better outcomes for people with epilepsy and prioritizes development of more effective epilepsy treatments.
- It's important to protect current epilepsy programs and funding and the National Plan will help make epilepsy a national priority.
- CDMRP Cuts: Please restore specific funding for the following epilepsy-related programs within the CDMRP: Tuberous Sclerosis Complex, Post-Traumatic Epilepsy, and TBI and Psychological Health.
- ACHDNC: Restore the Advisory Committee on Heritable Disorders in Newborns and Children.
- Medicaid: Do not support any cuts to the Medicaid program in budget reconciliation.
- Dept. of Education: Preserve the U.S. Department of Education to ensure the civil rights of students with disabilities.
- National Plan for Epilepsy: Cosponsor and pass the National Plan for Epilepsy (S. 494/ H.R. 1189).
- Section 504: Preserve Section 504 and its regulations, including the HHS rule issued in 2024.

Share any other reason(s) why a National Plan for Epilepsy is important to you. and accessible healthcare are important to you.

As you conclude your meeting, be sure to say thank you and get their contact information (email address and phone number) so that you can follow up with them.

Hook	• How you relate to them – who you are and where you're from; How does this issue relate to your life?
Line	• How will the proposed change help or harm you and the broader epilepsy community?
Sinker	• What do you want them to do as an elected official?

Follow-up After Your Meeting

Be sure to send the staff person you met with a follow-up email to thank them for their time, remind them of your ask(s), and provide your contact information. This also helps continue developing and strengthening your relationship with the staff person and the corresponding congressional office.

Sinker

Whatever issue(s) you discussed during your meeting, ask for your member(s) of Congress's support as detailed below.

- CDC Epilepsy Program Cuts: Please restore and preserve the CDC Epilepsy Program and its funding in Fiscal Year 2026.
- NINDS Cuts: Please preserve funding for the National Institutes of Health including the NINDS in Fiscal Year 2026.

Active Epilepsy Prevalence by State

	Estimated Number of Children (ages 0-17) with Active Epilepsy ¹	Estimated Number of People (all ages) with Active Epilepsy ²
Alabama	7,500	54,100
Alaska	1,100	7,200
Arizona	11,200	77,000
Arkansas	4,900	32,800
California	59,800	427,000
Colorado	7,800	56,800
Connecticut	4,500	35,900
District of Columbia	800	7,500
Delaware	1,300	9,700
Florida	27,300	223,900
Georgia	16,700	110,200
Hawaii	2,000	14,000
Idaho	2,600	16,800
Illinois	18,600	136,600
Indiana	10,600	69,500
Iowa	4,400	31,400
Kansas	4,400	29,900
Kentucky	6,800	49,500
Louisiana	7,900	54,900
Maine	1,700	14,100
Maryland	7,900	59,900
Massachusetts	8,400	71,600
Michigan	13,600	108,900
Minnesota	7,400	53,700
Mississippi	5,100	35,700
Missouri	8,300	61,200
Montana	1,400	10,800
Nebraska	2,800	19,600
Nevada	4,400	31,600
New Hampshire	1,500	13,100
New Jersey	12,000	92,700
New Mexico	3,400	23,200
New York	26,600	215,200
North Carolina	15,200	110,100
North Dakota	1,000	7,300
Ohio	16,900	126,400
Oklahoma	6,400	41,100
Oregon	5,400	42,900
Pennsylvania	16,900	133,000
Rhode Island	1,300	11,100
South Carolina	7,100	53,400
South Dakota	1,300	8,900
Tennessee	10,000	73,900
Texas	47,200	292,900
Utah	5,300	29,300
Vermont	700	6,300
Virginia	11,000	84,800
Washington	10,200	74,600
West Virginia	2,500	21,500
Wisconsin	7,900	59,600
Wyoming	800	5,900

¹ Zack MM, Kobau R. National and State Estimates of the Numbers of Adults and Children with Active Epilepsy — United States, 2015. MMWR Morb Mortal Wkly Rep 2017;66:821–825. DOI: <http://dx.doi.org/10.15585/mmwr.mm6631a1>

² Zack MM, Kobau R. National and State Estimates of the Numbers of Adults and Children with Active Epilepsy — United States, 2015. MMWR Morb Mortal Wkly Rep 2017;66:821–825. DOI: <http://dx.doi.org/10.15585/mmwr.mm6631a1>