



epilepsy
leadership council

ELC TOOLKIT –

ADVOCATING FOR MEMBERS OF CONGRESS TO JOIN THE CONGRESSIONAL EPILEPSY CAUCUS November 2024

The Epilepsy Leadership Council (ELC) has created this toolkit to facilitate ELC members in contacting Members of Congress to ask them to join the Congressional Epilepsy Caucus in honor of National Epilepsy Awareness Month (NEAM) in November 2024. We encourage you to use this toolkit for NEAM and anytime that you are looking to connect with your Members of Congress about the Epilepsy Caucus!

A robust Congressional Epilepsy Caucus is key to achieving so many of our advocacy goals so we hope that all ELC members will take action to build the Caucus membership. This toolkit has everything you need to get started – an FAQ, tips for requesting and holding meetings with Congressional staff, sample emails and action alerts, etc.

Finally, please let us know how it goes! Use [this link](#) to share your advocacy goals, outreach, social media plans, etc.

FREQUENTLY ASKED QUESTIONS

WHAT IS THE CONGRESSIONAL EPILEPSY CAUCUS?

Congressional caucuses bring members of the United States Congress (federal level) together around a shared interest to consider policy solutions. This caucus is a great way to raise awareness, build epilepsy champions and advance federal epilepsy-related policies and funding.

WHO LEADS THE CONGRESSIONAL EPILEPSY CAUCUS?

There are two bipartisan caucuses – one for the U.S. House of Representatives and one for the U.S. Senate. Here are the leaders:



WHO ELSE HAS JOINED THE CONGRESSIONAL EPILEPSY CAUCUS?

For a list of Members of Congress who have already joined the caucus, please see [here!](#)

WHAT SHOULD I DO IF MY SENATOR OR REPRESENTATIVE IS ALREADY PART OF THE CAUCUS?

Please call, email or post on social media to say thank you!

Don't forget to tag the Members of Congress in your social media posts. Here are some sample tweets, though you can use these same messages on other platforms:

X: Thank you [@InsertSenatorOrRepHandle](#) for being a member of the Congressional #Epilepsy Caucus. November is #NationalEpilepsyAwarenessMonth and your support of the epilepsy community means so much to the nearly 3.4 million Americans living with this condition. #NEAM2024

X: Thank you [@InsertSenatorOrRepHandle](#) for being a member of the Congressional #Epilepsy Caucus. This November, please continue to show your support and raise awareness by wearing purple and sharing it! #NEAM2024

IS THERE A ONE PAGER ABOUT THE CONGRESSIONAL EPILEPSY CAUCUS THAT I CAN SHARE WITH CONGRESSIONAL OFFICES?

Yes, see [here!](#) You can send this factsheet to your U.S. Senator or U.S. Representative when making your ask or as follow-up. It has all of the information a congressional staffer would need to discuss and add their Member of Congress to the Caucus.

WHERE CAN I LEARN MORE ABOUT ADVOCACY MORE GENERALLY?

ELC has held a few training webinars with more information about how you can advocate with Congress. You can find them on the ELC website here: <https://www.epilepsyleadershipcouncil.org/advocacy-webinars/>.

WHAT IF I HAVE OTHER QUESTIONS NOT ANSWERED IN THIS TOOLKIT?

If you have questions or need further support when making your ask, feel free to contact the ELC Advocacy Committee co-chairs – Johanna Gray, Deputy Director of NAEC at jgray@artemispolicygroup.com; and Laura Weidner, Chief Advocacy & Government Relations Officer at Epilepsy Foundation of America at lweidner@efa.org. We will support you as much as you need!

HOW TO REQUEST A CONGRESSIONAL MEETING AND SAMPLE MEETING REQUEST

1. Identify your Members of Congress! One great way is the [Govtrack.us tool available here](#). Put 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](#)

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).

1. Contact the office! There are a few ways to contact the office: either by email or by phone.

2. 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.
- Introduce yourself – share your name, that you are calling as one of their constituents (feel free to mention your city/state) and that you are a member of the epilepsy community (e.g., if you live with epilepsy, have a loved one with epilepsy and/or work at an epilepsy organization).
- Ask to be connected with the staff person who handles health care issues (this is usually the staff person in the office who would manage a request to join a health-related caucus). Ask for his/her name and email.
 - If you are connected to that staff person, repeat your introduction and say that you'd like to set up a meeting with them to discuss having [SENATOR/REPRESENTATIVE'S LAST NAME] join the Congressional Epilepsy Caucus.
 - If you have to leave a message, repeat your introduction and say that you'd like to set up a meeting with them to discuss having [SENATOR/REPRESENTATIVE'S LAST NAME] join the Congressional Epilepsy Caucus. Leave your contact info. Be sure to say thank you!

3. 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 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!

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.

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 the bipartisan Congressional Epilepsy Caucus.

I'm writing on behalf of nearly 3.4 million Americans live with active epilepsy, including 456,000 children and **[ADD NUMBER IN YOUR STATE, as found here!]** 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 would like to meet with you to discuss issues affecting people with epilepsy and the importance of the Congressional Epilepsy Caucus.

Please contact me at **[YOUR EMAIL/PHONE NUMBER]** to let me know when you are available to meet virtually.

Thank you for your consideration!

SAMPLE ACTION ALERT LANGUAGE FOR YOU TO USE OR SHARE WITH YOUR COMMUNITY

In addition to, or instead of requesting a meeting with your Members of Congress, we also encourage you send an action alert to activate your community! Again, there are a few ways to do this:

1. Use the [Take Action tool](#) on the Congressional Epilepsy Caucus website!

The easiest way to take action is using the Epilepsy Foundation's tool on the website supporting the Congressional Epilepsy Caucus - <https://www.epilepsiescaucus.org/takeaction!>



Just enter your address and a few clicks later, you can send a personalized email to your Senators and Representative. The tool even identifies if members are already on the caucus, so it's easy to say thank you!

2. Sample email if you want to send emails directly or use your organization's own Take Action tool:

HOUSE VERSION (be sure to personalize words in yellow!)

As a constituent and someone **[LIVING WITH/AFFECTED BY/CARING FOR PEOPLE LIVING WITH]** the epilepsies, I ask Rep. **[LAST NAME]** to join the bipartisan congressional Epilepsy Caucus. Nearly 3.4 million

Americans live with active epilepsy, including 456,000 children and **[ADD NUMBER IN YOUR STATE, as found here!]** 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. Epilepsy and/or seizures impose an annual economic healthcare burden of at least \$54 Billion.

[SHARE HOW EPILEPSY HAS IMPACTED YOUR LIFE AND WHY YOU'D LIKE YOUR REP TO JOIN THE CAUCUS.]

Thank you for considering this request. To join, contact the health staff for either Rep. Murphy (McLean.Piner@mail.house.gov) or Rep. Costa (Kit.Devine@mail.house.gov).

SENATE VERSION (be sure to personalize words in yellow!)

As a constituent and someone **[LIVING WITH/AFFECTED BY/CARING FOR PEOPLE LIVING WITH]** the epilepsies, I ask Sen. **[LAST NAME]** to join the bipartisan congressional Epilepsy Caucus. Nearly 3.4 million Americans live with active epilepsy, including 456,000 children and **[ADD NUMBER IN YOUR STATE, as found here!]** 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. Epilepsy and/or seizures impose an annual economic healthcare burden of at least \$54 Billion.

[SHARE HOW EPILEPSY HAS IMPACTED YOUR LIFE AND WHY YOU'D LIKE YOUR SENATOR TO JOIN THE CAUCUS.]

Thank you for considering this request. To join, contact the health staff for either Sen. Schmitt (Peter_Dudziak@schmitt.senate.gov) or Sen. Klobuchar (ruth_mcdonald@klobuchar.senate.gov).

3. Sample Email to Your Community to Encourage them to Take Action

In either case, here's a draft email or social media post for you to ask your community to take action!

We need your help! As part of National Epilepsy Awareness Month, **[MY ORGANIZATION]** is joining with partners in the Epilepsy Leadership Council to ask Members of Congress to join the Congressional Epilepsy Caucus! Congressional caucuses organize around a shared interest to consider policy solutions and we want as many members of Congress as possible to help us raise awareness, build epilepsy champions and advance epilepsy-related federal policies and funding! Click **here [EF tool - <https://www.epilepsiescaucus.org/takeaction> or your tool]** to take action today!

MEETING TIPS AND TALKING POINTS

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. 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! Be sure to hand them the one-pager at the end of the meeting, so they focus on your conversation instead of reading the paper. 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:

- 1. Introductions** – Introduce yourself, where you live, and your role in the epilepsy community (a person living with epilepsy or his/her caregiver, an advocate, a researcher, a person who works at an epilepsy center, etc). Ask for the staff person to introduce him/herself.
- 2. Epilepsy 101** – Say that in honor of National Epilepsy Awareness Month in November, we are asking for Congressional offices to join the Congressional Epilepsy Caucus. Ask if the staffer is familiar with epilepsy. Here are some facts to have handy (choose one or more that resonate with you!):
 - There are nearly 3.4 million Americans live with active epilepsy, which includes _____ (number – check [here!](#)) in our 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 often impacts many aspects of life including needed health care, employment, education and transportation.
 - Epilepsy and/or seizures impose an annual economic healthcare burden of at least \$54 Billion.
- 3. Make it personal** – Share a 2-3 minute story about your connection to epilepsy / how epilepsy affects your life or someone you care about, if applicable.
- 4. The ask** - Given the large number of Americans living with epilepsy and the broad impact that epilepsy has on their lives, we are asking for Members of Congress to show their support for our community by joining the Congressional Epilepsy Caucus.
 - **(REPRESENTATIVE MEETING DETAILS)** The bipartisan Congressional Epilepsy Caucus in the House was created in February 2023 and is led by Representatives Greg Murphy (R-NC-03) and Jim Costa (D-CA-21). To join, contact staff for Rep. Murphy (McLean Piner) or Rep. Costa (Kit Devine).
 - **(SENATOR MEETING DETAILS)** The bipartisan Congressional Epilepsy Caucus in the Senate was created in February 2024 and is led by Senators Amy Klobuchar (D-MN) and Eric Schmitt (R-MO). To join, contact staff for Sen. Schmitt (Peter Dudziak) or Sen. Klobuchar (Ruth McDonald).
- 5. Conclusion** – Ask if the staff person has any questions about the caucus or epilepsy. Give them the one-pager. Will their boss join the Caucus (if they say the need to check, ask when and how you can follow up; be sure to get their business card and contact information)? Be sure to say thank you!
- 6. Follow Up** – 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 and provide your contact information. This also helps continue developing and strengthening your relationship with the staff person.