Help Pass the National Plan for Epilepsy Act!

What is the National Plan for Epilepsy Act?

This legislation has been introduced in Congress and when passed, would require the federal government to establish and maintain a National Plan for Epilepsy. This would be a comprehensive plan to improve coordination of epilepsy programs and to improve program coordination, increase investment, and better prevent, diagnose, treat, and cure the epilepsies-ultimately improving quality of life for individuals and families affected by epilepsy.

Thanks to the support of more than 125 bipartisan cosponsors and 190 epilepsy organizations, we are seeing real progress. On August 4, 2026, the U.S. Senate unanimously passed a modified version of the bill. Shortly after, on September 15, the House Energy & Commerce Subcommittee on Health held a hearing featuring powerful parent advocate testimony. To get this bill signed into law, we are urging Congress to pass final, identical legislation before the end of December 2026.

We need to keep up this incredible momentum! Every voice matters. If each member of the epilepsy community completes at least one of the actions below, our collective impact will be undeniable. Even if you've never advocated before, these simple steps will guide you through exactly what to do.

How Can I Take Action?

If you have 2 minutes

Post on Social Media

X, formerly known as Twitter, is the platform that members of Congress use the most. Choose from these sample posts on X to help spread the word.

Tip:
First check whether your Senators and Representative are cosponsors of S. 494/H.R. 1189 (see how under the If You Have 1 Hour or More: Schedule a Meeting with your Members of Congress section). Search each lawmaker's official website or X profile to find their handle, then replace @[Senator1], @[Senator2], and/or @[Representative] with the correct tags- only tag members who are not already cosponsors.

- I'm asking @[Senator1], @[Senator2], & @[Representative] to support and pass the bipartisan #NationalPlan4Epilepsy Act (S. 494/H.R. 1189). Help improve epilepsy care and coordination nationwide by advancing this critical legislation.
- More than 125 members of Congress and 190 epilepsy organizations already support the #NationalPlan4Epilepsy Act. @[Senator1], @[Senator2], & @[Representative], please cosponsor and pass S. 494/H.R. 1189.
- Epilepsy affects nearly 3.4 million Americans. @[Senator1], @[Senator2], & @[Representative], please pass the bipartisan #NationalPlan4Epilepsy Act (S. 494/H.R. 1189) by the end of 2026.

If you have 5 minutes

Email Your Members of Congress

• Scan the QR Code or visit https://bit.ly/NP4E

• Enter your Name, Address, and Zip Code

• A pre-written email will come up. We strongly encourage you to personalize the message: add about your epilepsy journey or connection and why the National Plan is important to you.

• Click "Send Message" and the email will be sent to your members of Congress!

• Share the link with family and friends on social media so they can take action too.



If You Have 1 Hour or More

Schedule a Meeting with your Members of Congress

1. Look up your members of Congress here:

congress.gov/members/find-your-member. Entering your full address and zip code will provide the most accurate results. Click on each member, which will give you their official website. Their official website should always end in "senate.gov" or "house.gov."

2. See if your members of Congress are already a cosponsor of the National Plan for Epilepsy Act:

Go to https://www.congress.gov/ and in the search field at the top of the page, enter "HR 1189" (for Representatives) and "S 494" (for Senators). Once you get into H.R. 1189 or S. 494, click on the "Cosponsors" tab and see if your members of Congress have already cosponsored the bill. If they are already cosponsors, you can reach out to thank them—but do not need to take further action. If they are not cosponsors, proceed to scheduling a meeting!

3. Schedule the Meeting:

Visit your member of Congress's official website and look for the "Contact" or "Office Locations" page to find their phone number and online request form.

When you visit your member of Congress's website, you may also see a pop-up message to signup for their e-newsletter. Sign up to receive updates on your elected official's legislative priorities.

1. **Call to request a meeting**: Say "Hello, I'm a constituent and would like to schedule a meeting with the staffer who manages healthcare to discuss the National Plan for Epilepsy Act."
2. **Submit online**: Follow up via the web form on your representative's official site. Using both methods speeds up response time.
3. **Once connected with a staff member**: Restate who you are and why you're calling, then work with the staffer to schedule a meeting on a day and at a time that works for you.
4. **If it's going to be a virtual meeting**, make sure you have the virtual meeting link to log into the meeting. If it's going to be in-person, make sure you know the exact location of the meeting.

4. Get Ready for Meeting:

Meetings usually last 15-20 minutes long. It is important to stay concise and to the point. You can follow this meeting format:

a. Introduction: Reintroduce yourself as a constituent and share your personal connection to epilepsy (e.g., a person living with epilepsy, a family member, ane epilepsy doctor or researcher, or someone who works for an epilepsy organization).

b. Talk About Epilepsy: This is a great opportunity to ask them what they know about epilepsy and/or seizures and share important facts with them about the condition. **You can find key facts and talking points on page 4 to help guide the conversation**. Use this as a jumping off point to talk about the National Plan.

c. Make the Ask: Say that as a constituent, you want your member of Congress to cosponsor the National Plan for Epilepsy Act and **work together to pass the bill by the end of December.** For Representatives, the bill number is H.R. 1189 and for Senators, the bill number is S. 494.

d. Talk About Why the National Plan is Important: This is an important part of the meeting where you can talk about how epilepsy has impacted your life and why a National Plan is important to you. Be honest and talk about challenges you have experienced, as this will emphasize the need for a National Plan.

e. Get Contact Information: Make sure you get the email address and phone number of the staff person you met with so you can follow up.

5. Follow-Up:

Within a week of your meeting, call or email the staff person to thank them for their time and remind them that you would like your members of Congress to cosponsor and pass the National Plan for Epilepsy Act. Capitol Hill staff are busy, so you may have to follow up a few times.

Key Talking Points and Stats

You can share details about epilepsy like this:

- Epilepsy is the underlying tendency of the brain to produce seizures- which are sudden, abnormal bursts of electrical activity that disrupt brain function.
- In addition to seizures, epilepsy can also cause fatigue, learning and memory problems, mood or behavior changes, anxiety or difficulty concentrating, which can significantly impact daily life.
- Nearly 3.4 million Americans including 456,00 children and youth live with active epilepsy in the U.S.
- 1 in 26 people will develop epilepsy at some point in their lifetime.
- The term "epilepsies" reflects the many types of epilepsy that exist including rare and genetic epilepsies. There are many different causes of the epilepsies, many types of seizures, and they can have very different impacts on a person's life. Those with a rare epilepsy tend to be impacted more severely, have a higher rate of drug resistance, and higher risk of epilepsy-related death.

Important details about the National Plan for Epilepsy Act:

- The bill is bipartisan, led and cosponsored by both Republicans and Democrats.
- In the Senate, Senators Eric Schmitt (R-MO) and Amy Klobuchar (D-MN) lead the bill, and the bill number is S. 494.
- In the House of Representatives, Representatives Jim Costa (D-CA-21) and Greg Murphy, M.D. (R-NC-3) lead the bill, and the bill number is H.R. 1189.
- As of October 2026, more than 125 members of Congress have cosponsored the bill, and 190 epilepsy organizations support it.
- The bill would require the federal government to make and maintain a National Plan for Epilepsy. This would be a comprehensive plan to improve coordination of epilepsy programs- with the goals of better preventing, diagnosing, treating and curing the epilepsies and improving the well-being of people with epilepsy and their families.
- With help from an Advisory Council of federal agency representatives and people from the epilepsy community, the government would have to develop recommendations for priority actions and submit those recommendations to Congress for consideration.
- The bill does not authorize any new funding, i.e., it is a zero-cost bill.
- On August 4, the U.S. Senate passed a modified version of the bill [If this is a Senate meeting, you can thank them!]. On September 15, the House Energy & Commerce Subcommittee on Health held a hearing that discussed the National Plan and featured a parent advocate testifying in support of the bill.

You can also use statistics like this:

- The annual economic healthcare burden of epilepsy and/or seizures in the U.S. is $54 billion.
- More than 30% of adults and 20-25% of children with epilepsy do not respond to current treatments.
- There are no biomarkers for the vast majority of the epilepsies and few effective technologies to track real-time patient data.
- Clinicians cannot predict drug efficacy, adverse side effects or long-term prognosis for any given person with epilepsy.
- Epilepsy can be fatal, with 1 in 1,000 people with epilepsy dying from Sudden Unexpected Death in Epilepsy (SUDEP) every year.

Contact Us!

Thank you in advance for your advocacy!

If you have questions, contact:

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