The Capitol Circuit
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Engagement & Input Opportunities

Become an Epilepsy Advocacy Champion

The Epilepsy Foundation is excited to announce the official launch of the Epilepsy Advocacy Champion program. Epilepsy Advocacy Champions are trained, high-level advocacy volunteers who will be empowered to share their
experiences and educate lawmakers to help advance the Foundation's policy priorities and raise awareness about the epilepsies. Champions will build strong relationships with state and federal elected officials and serve as a liaison between their legislators, national headquarters and their local Epilepsy Foundation office. These grassroots advocates will help expand the network of local advocates to increase the epilepsy community's presence in a state or district.

The program is open to those over age 18 who are living with or affected by the epilepsies. Champions will receive specialized trainings, resources, and support from the Foundation's national advocacy team and be eligible to attend a biennial advocacy conference in Washington, D.C. and advocate on Capitol Hill (first one to occur in 2022). Advocates are expected to serve in two-year terms with the possibility of renewal. Learn more and apply here.

Join us on Tuesday, October 20th at 7 p.m. ET for a webinar to learn more about our new advocacy volunteer initiatives.

Take the Epilepsy Foundation's Pulse Survey

The voices and experiences of our community matter. 2020 has been a tough year in a lot of ways and we want to know what sort of challenges you and your loved ones may be facing in order to better serve you. If you are a person living with epilepsy, a family member, health care provider, or other stakeholder, we want to hear from you! Complete this Pulse Survey by October 30. And please share with your networks—the more people we hear from, the better!

NINDS Curing the Epilepsies Crowdsourcing Opportunity

The nation's leaders want to hear from YOU as they set new research goals and explore big, transformative ideas toward a cure and making lives better for everyone touched by the epilepsies. In 2000, the White House initiated a conference called Curing Epilepsy: Focus on the Future to develop research goals (benchmarks) to cure epilepsy. Since then, epilepsy thought leaders have come together every seven years to measure our progress against the goals and set new priorities. The 2020 event has been postponed and will occur in January 2021.

To gather ideas and create a conversation, the American Epilepsy Society (AES) Epilepsy Benchmark Stewards Committee in collaboration with the National Institute of Neurological Diseases and Stroke (NINDS) has launched a crowdsourcing tool called Ideascale where everyone from the person living with epilepsy as well as top doctors can all share their challenges and visions
for change. The "benchmark feedback" and "new idea" campaigns both end on Oct. 30, 2020. Comment on one or both and share with your networks!

- Sign up [here](#) and start adding your stories, photos and ideas or like the ideas of others. Need help? Step by step instructions are [here](#). Watch a how-to video [here](#). Alternatively, you can submit your comments via email to NINDS_IdeaScaleSupport@mail.nih.gov.
- Want more background? A non-scientific summary is [here](#). For scientific background including articles and videos, visit [here](#). Click this [link](#) to learn more about benchmarks vs. new ideas.

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**National Advocacy**

**Congress Avoids Government Shutdown; Deal Unlikely on COVID-19 Package**

On September 30, Congress passed, and the President signed, a continuing resolution (H.R. 8337) narrowly avoiding a government shutdown. The stopgap spending bill extends funding for federal agencies until December 11. The outcome of the election will likely determine whether Congress finalizes spending levels for Fiscal Year 2021 at that point or passes another continuing resolution.

Senate Majority Leader McConnell has announced that the Senate will vote on a scaled back COVID-19 relief package next week, but it does not seem to have the votes to get through both chambers.

**33 National Patient & Consumer Advocacy Groups Unveil 100 Days Agenda**

The first 100 days of any Administration and a new Congress are a key period when elected officials can leverage post-election momentum to start initiating small or major reforms. Lawmakers have a unique opportunity to use that time period to prioritize their top issues which could include peoples’ need for quality, affordable healthcare. To facilitate a focus on health care, thirty-three organizations, including the Epilepsy Foundation, rolled out a patient-first blueprint identifying and recommending key priorities elected officials should focus on in the first 100 days of their terms in 2021, regardless of the outcome of the election. The blueprint highlights several high-level areas including reducing administrative barriers to care, addressing challenges in the courts, and enacting a comprehensive pro-patient legislative agenda. The health and wellbeing of individuals with serious and chronic conditions, and the nation as a whole, depend on the Administration and Congress acting quickly to secure these changes.
Coalition Comments on White House Pre-Existing Conditions and Surprise Medical Billing Executive Orders

In late September, the Administration issued Executive Orders aimed at protecting Americans living with pre-existing conditions and preventing the practice of surprise medical billing. Executive Orders cannot change existing law and usually only direct federal agencies to issue guidance in line with existing law. Protections for people with pre-existing conditions are already in place because of the Affordable Care Act (ACA) and the Administration has declined to defend the ACA in its current legal battle, so it is unclear the full ramifications of the Order. The Executive Order on surprise medical billing is more directive, urging the Secretary of Health and Human Services to work with Congress on a legislative solution by year’s end or take administrative action if that is unsuccessful.

The Foundation joined 17 national patient and consumer advocacy organizations in a letter to the President regarding the recent Executive Orders urging that more concrete action be taken to protect those with pre-existing conditions and offering to work on solutions together.

Open Enrollment for Medicare and the Marketplace

People seeking to buy or change their Medicare or Marketplace plan must do so during open enrollment unless a specific exception occurs like moving out of state or having a baby. Since each year, plans make changes to benefits and costs, and new plans are available, your current plan may or may not be the best plan for you in 2021. It is very important to use the open enrollment time-period to compare your coverage choices and find the plan that best meets your all of your health care needs at an affordable cost.

The annual open enrollment for Medicare prescription drug coverage (part D) and Medicare Advantage begins on October 15, 2020 and will run through December 7, 2020 for coverage beginning January 1, 2021. Visit medicare.gov or call 1-800-MEDICARE (1-800-633-4227) to learn more.

Read the 2021 Medicare Part D Open Enrollment FAQ Brochure

The open enrollment period for the Health Insurance Marketplace runs from November 1, 2020 until December 15, 2020 for coverage beginning January 1, 2021. Learn more about your options at healthcare.gov or 1-800-318-2596 (TTY: 1-855-889-4325). Individuals may be eligible for premium tax credits that will help make coverage more affordable.

Quick Guide about the Health Insurance Marketplace
Get Ready to Apply and Enroll

Already Enrolled? Keep or Change Plans for 2021

Checklist to Apply or Re-Enroll

You can find these resources available at advocacy.epilepsy.com/access-to-care.

Medicare Prescription Drug Discount Cards

On September 24, President Trump announced his plan to send prescription drug payment cards worth $200 each to Medicare enrollees. Since then, there have been media reports that Medicare enrollees may receive letters about the cards as soon as this week, but it is still unclear where the funds for the estimated total of nearly $8 billion will come from and whether the funds have been legally authorized. The Epilepsy Foundation continues to monitor the progress of this policy. Given the many evolving factors and it not being clear if and when the checks will be mailed, we urge people with epilepsy and their families to not rely on or budget for these savings until people have them in hand.

State Advocacy

Foundation Advocates for Open Access to Treatments Across States

Every year, state Medicaid programs review coverage requirements for classes of medications, including anti-seizure medications. The Epilepsy Foundation monitors and engages in public meetings where anti-seizure medications and seizure rescue medications are being discussed and advocates for open access, free from utilization management hurdles like step therapy or prior authorization, to ensure that Medicaid beneficiaries living with epilepsy have access to the full range of treatment options to treat epilepsy and seizures. Recently, the Epilepsy Foundation has submitted testimony in Pennsylvania, Minnesota, Florida, Texas, Missouri, and Tennessee, and we will continue to monitor other states as their public meetings are announced.

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