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**National Advocacy**

**We Want to Hear from You: Take the Foundation's Access to Care Survey**

The Foundation advocates at the federal and state levels for everyone with epilepsy to have access to affordable, quality, provider-directed and patient-centered health care. Information and data inform our advocacy - so we need to hear from you!

*We are conducting a survey to better understand the health care needs of people with epilepsy and what challenges - if any - you are facing*
accessing the health care you need. Share your experiences today to help us improve systems that connect people to epilepsy health care and to better advocate for improved access to care. The survey takes approximately 15 minutes to complete.

This survey should only be completed by people age 18 and over who live with epilepsy or care for someone who lives with epilepsy. If you are under age 18, a parent or family member may complete it on your behalf. We thank you in advance for your participation.

Recent Congressional Efforts to Address Drug Pricing

Congress continues to roll out and consider legislation aimed at addressing high prescription drug prices and rising out-of-pocket costs. In addition to numerous drug pricing bills and packages, last month the House Majority Leadership released the Lower Drug Costs Now Act of 2019 (H.R. 3). The Foundation released updated principles and positions on access to prescription medications over the summer. Using those principles as a guide, the Foundation has weighed in on parts of this bill and other efforts that are most relevant to people with epilepsy. For instance, the Foundation strongly supports the out-of-pocket cap proposed in H.R. 3, but is working on targeted changes to the bill such as adding smoothing, which would help to evenly distribute out-of-pocket costs throughout the year and banning the use of the cost-effectiveness tool known as quality-adjusted-life-years (QALYs), which can be used to discriminate against individuals with chronic and serious conditions, seniors, and people with disabilities. UPDATE: House committee leadership has introduced an amendment that would bar the use of discriminatory measures like the QALY. The Epilepsy Foundation expects it will be adopted and applauds the change.

Safe Step Act Introduced in House of Representatives and Senate

In late September, the Senate introduced the Safe Step Act (S. 2546). Similar legislation had been introduced in the House of Representatives (H.R. 2279) in the spring. Step therapy, or fail first, is a process that requires individuals who have been prescribed certain medications to try and fail one or more medications preferred by the insurer before receiving the originally prescribed drug. This bipartisan legislation would streamline step therapy protocols and require exemptions to step therapy requirements so that people with chronic and serious conditions, like epilepsy, can safely access the most effective medications in timely manner.

Now that the legislation has been introduced in both chambers of Congress, you can take action and make an even greater impact. Tell your elected officials how impactful this legislation would be for the epilepsy community
and share your story. Urge your members of Congress to co-sponsor the Safe Step Act! If your lawmaker is already a co-sponsor, you’ll be able to send them a thank you. The more co-sponsors the bills have, the greater likelihood that it will advance.

Learn more about step therapy at advocacy.epilepsy.com/StepTherapy.

Open Enrollment in 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 2020. It is very important to use the open enrollment time-period to compare your coverage choices and find the plan that best meets your prescription drug needs at the lowest cost.

The annual open enrollment for Medicare prescription drug coverage (part D) and Medicare Advantage began on October 15, 2019 and will run through December 7, 2019 for coverage beginning January 1, 2020. Visit medicare.gov or call 1-800-MEDICARE (1-800-633-4227) to learn more.

Read the 2020 Medicare Part D Open Enrollment FAQ Brochure

The open enrollment period for the Health Insurance Marketplace runs from November 1, 2019 until December 15, 2019 for coverage beginning January 1, 2020. 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.

Tips about the Health Insurance Marketplace

Get Ready to Apply or Re-enroll with this Checklist

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

State Advocacy

Register for a Webinar on Advocating for Seizure Safe Schools

Join us for an educational webinar, “Advocating for Seizure Safe Schools,” on November 5, 2019 at 8 p.m. ET. The Epilepsy Foundation’s Seizure Safe
Schools Act aims to ensure all school personnel, including nurses, teachers, coaches, administrators and volunteers, are prepared, can recognize and can respond appropriately and efficiently to students who experience seizures.

To date, four states – Kentucky, Indiana, Texas, and Illinois – have successfully passed Seizure Safe Schools legislation. The Epilepsy Foundation is inviting state-level elected officials and grassroots volunteers – parents, community organizers, health care providers, etc. – to learn more about our initiative and join the Foundation’s Seizure Safe Schools Act efforts in your state.

Learn more about the legislation and this initiative at [advocacy.epilepsy.com/seizuresafeschools](advocacy.epilepsy.com/seizuresafeschools).

**Epilepsy Foundation New England Testifies in Support of Massachusetts Step Therapy Reform Legislation**

On October 8, the Massachusetts State Legislature held a hearing on step therapy reform legislation (S. 1235 and H. 1853). The legislation would protect individuals with serious and chronic conditions by putting in place exemptions to step therapy protocols and an expeditious appeals process. The Epilepsy Foundation New England attended and had several health care providers and individuals living with epilepsy share their stories and testify in support of the legislation.

**Minnesotans and North Dakotans: Tell Your Members of Congress to Recognize National Epilepsy Awareness Month (NEAM)**

November is Epilepsy Awareness Month and the Epilepsy Foundation of Minnesota (EFMN) wants to jumpstart a conversation in your district. Many members of Congress share updates on important issues to their district through e-newsletters. These newsletters reach thousands of people. The goal is for your member to include Epilepsy Awareness Month in a November edition of their newsletter. As a constituent you can use your voice and support EFMN in asking your U.S. Senators and Representatives of Minnesota and North Dakota to join the conversation about epilepsy and seizures. [Ask your members of Congress to recognize and celebrate Epilepsy Awareness Month today!](#)
We encourage you to invite others to join our Speak Up, Speak Out! advocacy network. Members receive the monthly Capitol Circuit newsletter and alerts about opportunities to advocate for the epilepsy community throughout the year. Growing our advocacy network is critical to achieving our public policy goals as we move through busy state and federal legislative sessions. Make a difference today by sharing our Speak Up, Speak Out! Network on Facebook and Twitter.

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