



2020 – 2021

**YEAR OF
SERVICE
MANUAL**

YEAR OF SERVICE MANUAL

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

-Margaret Mead

ABOUT OUR POLICY PRIORITIES

The Epilepsy Foundation advocates on behalf of people with epilepsy and their family members and caregivers to overcome the challenges of living with epilepsy and accelerate therapies to stop seizures, find cures and save lives.

Our policy priorities include:

- Ensuring access to quality, affordable, physician-directed and patient-centered health care;
- Funding for epilepsy programs, research and treatments at the state level and federal institutions including the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and Food and Drug Administration (FDA);
- Safeguarding disability rights and ending discrimination; and
- Fostering biomedical innovation through incentivizing development of new therapies and the promotion of research to gain a better understanding of causes, consequences, and outcomes, and, ultimately, cures for all the epilepsies.

WHY SHOULD YOU ADVOCATE?

YOUR VOICE MATTERS

The Foundation's programs, services, advocacy, and research initiatives have made significant progress, but there is still a lot of work to be done on the local, state, and federal levels to raise awareness about epilepsy and the issues affecting the epilepsy community.

Congress and state legislatures are constantly considering and putting in place policies that can affect the epilepsy community. The best way to make sure that your needs are considered in these decisions is by sharing your story and explaining how these policies would affect you. As teens, you know first-hand the challenges that come from living with epilepsy. Your experiences help inform your story. Without speaking up and telling your story, elected officials may never know what epilepsy is, what living with epilepsy is like or even know that an issue is important to you.

ABOUT THE YEAR OF SERVICE (YOS)

WHETHER YOU'RE FRESH OFF CAPITOL HILL OR TRYING TO GET THERE, WHERE DO YOU START?

The Year of Service allows you to take on a leadership role and advance your advocacy to the next level. You will explore ways to raise public awareness and help create positive change for the epilepsy community on your own terms, keeping several goals in mind. Historically, the Year of Service has been completed after participating in the Teens Speak Up! program. However, the Epilepsy Foundation has opened up the Year of Service to teens between the ages of 13-17 years old, who wish to become young epilepsy advocates and potential Teens Speak Up! participants.

For those who have participated in the Teens Speak Up! program, your advocacy does not stop in Washington, D.C. The Year of Service empowers you to put what you have learned into action and to keep the momentum going year-round. As described below, there are many opportunities to keep strengthening the relationships you formed on Capitol Hill and to make a difference in your state and communities. You should use your story and advocacy training to your advantage. As you've learned, your story is powerful—but it only has power when you share it.

For those who are volunteering to become young epilepsy advocates, the Year of Service provides an opportunity to begin to learn about advocacy and become an epilepsy advocate. The Epilepsy Foundation will consider your Year of Service activities if you are nominated to attend the Teens Speak Up! program. If you are selected to attend the program, your Year of Service will culminate in a trip to Washington, D.C. to receive formal advocacy training and meet with your legislators on Capitol Hill.

Regardless of whether you have completed the Teens Speak Up! program, it is very important that throughout your Year of Service, you work with your local Epilepsy Foundation office. Your local Epilepsy Foundation can provide guidance on the types of advocacy and volunteer opportunities they need help with. If you're going to meet with elected officials on the local, state, or federal level, your local office needs to know so they can help prepare you and inform you about what is happening. If you are completing the Year of Service in an area without a local office, do not worry. The national headquarters of the Epilepsy Foundation can work with you to determine what kind of activities you should be engaging in. Contact the national office via tsu@efa.org.

WHAT CAN YOU DO RIGHT NOW?

JOIN THE EPILEPSY FOUNDATION'S SPEAK UP! SPEAK OUT! ADVOCACY NETWORK

As a member of the Speak Up! Speak Out! (SUSO) advocacy network you will receive our monthly advocacy newsletter, the Capitol Circuit, and action alerts on state and federal issues, making it easy for you to stay informed and engage in the policy process in support of the Epilepsy Foundation's advocacy activities in a timely manner. With just a few clicks, you can send e-mails to your state and federal elected officials at critical points—like when an important bill is about to be voted on. By staying in touch year-round with your elected officials, your relationships and impact will be strengthened.



Sign up at bit.ly/SUSOEFA.

Make sure you're following the Epilepsy Foundation on social media.



@EpilepsyFdn & @EndEpilepsy



@EpilepsyFoundationofAmerica & @EndEpilepsy



@epilepsyFdn & @endepilepsy

GOALS FOR YOUR YEAR OF SERVICE PROJECT

- 1 First and foremost, collaborate with your local Epilepsy Foundation office.** This is a partnership. You should be working together to find opportunities where you can volunteer. This will be different in every office depending on local dynamics and what's happening in your state. If you're taking part in the Year of Service in a state without a local office, please make sure to reach out to the National Office via tsu@efa.org to collaborate.
- 2 Put on 2-3 awareness events!** This is a time to get creative! We encourage spreading out several awareness events throughout the year and recommend putting one on during November which is National Epilepsy Awareness Month. You can use this as an opportunity to share your story in a comfortable setting and even fundraise for your local office. (See past examples in the next section.)
- 3 Engage with your local, state, and federal officials** to tell them about epilepsy and why and how they can help the epilepsy community. You can do this in many ways. Federal legislators often have town halls that you can attend in person or sometimes it is a telephone town hall. You can also set up meetings with your officials (federal legislators go home during congressional recesses, so in-district meetings are possible) or invite them to one of your awareness events! You should involve the local office in any meetings with elected officials. They can help provide guidance on any important legislation affecting the epilepsy community.
- 4 Help identify and recruit other epilepsy advocates.** Involve your friends and family! If you're completing the Year of Service as a previous Teens Speak Up! participant, be an ambassador for advocacy and for the event and help your local office find their teen representative for the upcoming year. If you're completing the Year of Service to be nominated as a potential Teens Speak Up! representative, it's important to involve your community.

PAST EXAMPLES OF YEAR OF SERVICE PROJECTS

You can get as creative as you want to complete your Year of Service goals. But sometimes a little inspiration helps along the way. Check out some examples of what past Teens Speak Up! representatives have accomplished!

- Helped champion the Seizure Safe Schools bill in their state and/or obtain an epilepsy awareness proclamation at the state or local level.
- Participated in the local office's state advocacy day.
- Attended in-district meetings with elected officials (federal and/or state) during August Recess.
- Testified about the importance of epilepsy funding at their State Capitol on behalf of the local office.
- Testified at the Food and Drug Administration (FDA) about her experience using a vagus nerve stimulation (VNS) device for seizure control.
- Helped educate fellow students and peers about epilepsy and seizure first aid.
- Shared story on social media.
- Created a teen support group.
- Volunteered at or participated in the local office's Walk or special event.
- Attended a local office's summer camp and shared their epilepsy journey.
- Presented their epilepsy journey at a local bookstore.
- Organized an event at school to raise epilepsy awareness and funds.
- Organized a Lemonade for Livy stand or Purple Pumpkin Project event.

SHARING YOUR STORY

YOUR STORY IS YOUR BEST ADVOCACY TOOL. IT IS POWERFUL AND IT DESERVES TO BE HEARD. USE THESE PROMPTS AND TIPS TO HELP LEARN HOW TO SHARE YOUR STORY WITH ELECTED OFFICIALS.

Your story is your best advocacy tool. It is powerful and it deserves to be heard. Sharing your story with elected officials will help amplify and underscore the legislation you're advocating for. Use these prompts and tips to help learn how to share your story with elected officials and stakeholders. You can use the blank space below as workbook.

When meeting with legislators, you will want to mention that you and/or your family are constituents. This will help form a connection.

What is your epilepsy journey? (Share what age you or your loved one were when diagnosed, what kind of seizures you/they experience, what a seizure feels like, number of medications tried, any surgeries, dietary therapies, alternative treatments and any other pertinent information you are comfortable sharing.)

You will need to discuss how a policy will impact your life or your loved ones. This is the time to make an emotional appeal. Share some of your or your loved ones experiences.

Make your ask! You'll either be asking them to sponsor, co-sponsor, support, or oppose the bill.

You are the expert of your experiences but it's still important to practice telling your story before you meet with your elected officials. It might sound silly but saying it out loud or writing it down can help, especially if you're nervous (which you shouldn't be). It will help make sure you've included everything you'd like to say. We do recommend keeping your story simple and short (2-4 minutes).

MEETING WITH YOUR LEGISLATOR

YOU'VE HONED YOUR STORY. NOW YOU'RE READY TO MEET WITH YOUR LEGISLATORS. YOU MAY NEED A PARENT/GUARDIAN'S HELP WITH THESE NEXT STEPS. YOUR PARENT/GUARDIAN SHOULD ACCOMPANY YOU ON YOUR MEETING.

1. You will need to find out who your elected officials are. Look them up here by entering in your full address:
<http://advocacy.epilepsy.com/Get-Involved>.
2. Check their website to determine if they will be hosting a Town Hall. If they are, RSVP to attend. If they are not, you will need to make an appointment for an in-district meeting. Call or email the office to determine a date and time. You can find contact information on their website or call the Capitol Switchboard at 202-224-3121. Each office is structured a bit differently, so as long as you are clear about what you're looking for (scheduling an in-district meeting, for instance), they will direct you to the right person. If you need help, just ask the National Headquarters.
3. Arrive promptly and prepared. It's time to share your story and make your ask. If you don't have an ask, it is still good to meet with the legislator or their staff to build up a relationship with them. You never know when you will need to contact them about a future policy decision. If they ask any questions that you cannot answer, don't panic and don't make anything up. It is perfectly fine not to know the answer. Tell them you will find out that information and send it to them.
4. Lastly, you should follow up with a thank you and any materials they requested.

HELPFUL TIPS AND REMINDERS FOR YOUR YEAR OF SERVICE

POST AWAY!

Social media is a great tool to connect with your elected officials. After your meeting, don't forget to ask for a picture. You can post it on any of your social media channels and tag the elected official, even if you did not meet with the legislator directly. You should also feel free to tag your local Epilepsy Foundation and the national office (see page 6). Check with a parent/guardian first before posting.

STAYING IN TOUCH

Throughout your Year of Service, please keep the National Headquarters apprised of what you're working on. Please share updates, pictures, and media stories by emailing tsu@efa.org.

TIME COMMITMENT

This is an ongoing program requiring a time commitment of approximately 5-10 hours per month, sometimes more if you are planning an event that month, for a minimum of 10-months to one year.

TIMELINE

FOR 2020-2021, THE YEAR OF SERVICE WILL BEGIN MARCH 2020 AND END FEBRUARY 2021. WITHIN THIS TIME FRAME YOU MUST COMPLETE THE FOUR GOALS OF THE YEAR OF SERVICE. BELOW IS A CALENDAR GUIDELINE TO HELP YOU PLOT OUT THE COMPLETION OF YOUR GOALS.

March 2020 – August 2020

- Have a meeting with your local Foundation office as soon as possible after the Teens Speak Up! program or once you decide you want to become a young epilepsy advocate.
- Sign up for the Epilepsy Foundation's Speak Up! Speak Out! Network
- Set up an in-district meeting with your federal legislators during the August recess. Recess means the member of Congress is home and not in Washington, D.C.

September 2020 – November 2020

- Begin planning out your awareness events. Remember: November is National Epilepsy Awareness Month (NEAM).
- Complete at least 2 of your awareness events by the end of November. We recommend doing one during NEAM.
- For November, you can help get a proclamation passed or signed.
- Get your friends and family involved with your events.

December 2020 – February 2021

- Many state legislature sessions will begin in January, work with your local office to determine what advocacy priorities you can help with
- Try to meet with your local elected officials.
- Aim to put on one last awareness event

YEAR OF SERVICE AGREEMENT

As Teen Advocate, I agree to fulfill the obligations as described in the Year of Service Manual. I understand that I am committing to the completion of my Year of Service beginning March 2020 and ending February 2021. If, for any reason, I am unable to complete my Year of Service, I will notify either a representative from my local office or the national headquarters at tsu@efa.org.

Teen Advocate

_____ Date _____

Parent/Guardian

_____ Date _____

Local Office Representative

_____ Date _____

For National Headquarters Use Only:

Received on _____

Please send the signed agreement to tsu@efa.org or mail it to:

Epilepsy Foundation
c/o Government Relations Department
8301 Professional Place West, Suite 230, Landover, MD 20785