



**EPILEPSY  
FOUNDATION**

2018 - 2019  
Year of Service  
Training Manual

# A Message from the President & CEO

April 2018

Dear Epilepsy Advocate:

Welcome to the Epilepsy Foundation's 2018 - 2019 Year of Service! By working together, we can help educate millions of Americans about epilepsy and improve the lives of people living with the condition.



The Epilepsy Foundation's Year of Service is a fun and easy way to raise awareness in your community about the seriousness of epilepsy. This is important because, even though 3.4 million Americans have epilepsy, the public knows little about epilepsy and seizures.

**The Year of Service is about more than raising public awareness about epilepsy. It is also designed to help you advocate with elected officials and other policymakers about the need to improve access to care, fund epilepsy programs and research, foster biomedical innovation, and end discrimination against people with epilepsy. The Year of Service is a great way to join the rest of our community in working towards these goals.** Your participation in the Year of Service is about more than just speaking up for yourself; it's about speaking out on behalf of the entire epilepsy community. You know the condition better than anyone; you live with it. The Year of Service challenges you to take on a leadership role, to speak up and speak out. Take the opportunity to raise awareness with the public about epilepsy to reduce stigma and end discrimination. Inform policymakers about the condition and what they can do to help the epilepsy community. Encourage others to join in with you and speak up and speak out. Your role as an advocate is tremendously important, as the strength of the Epilepsy Foundation, and the entire epilepsy community, lies in its vocal supporters, like you.

In the pages that follow, we provide a guide for how you can be an effective epilepsy advocate. #SeizeTheDay to talk about epilepsy, #SeizeTheDay to take action, and #SeizeTheDay to recruit your community to join your efforts. Thank you for participating in the Epilepsy Foundation's Year of Service! We look forward to working with you to ensure a better tomorrow for everyone affected by epilepsy and seizures.

Sincerely,

A handwritten signature in black ink that reads "Philip M. Gattone". The signature is written in a cursive, flowing style.

Philip M. Gattone, M.Ed.  
President & CEO

# About the Year of Service

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The Epilepsy Foundation's Year of Service raises public awareness and support for improving access to care, epilepsy research and programs, and ending discrimination against people with epilepsy. As teens, you know first-hand the challenges that come with living with epilepsy. We hope that after your training you will feel empowered to raise your voice in your community. It's time to #SeizeTheDay and get started with your Year of Service today!

## **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 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. **Join the 'Speak Up, Speak Out' advocacy network at: [bit.ly/SUSOEFA](http://bit.ly/SUSOEFA).**

## **Mark your Calendars**

The Year of Service manual outlines a series of activities you will organize over the next twelve months to raise awareness about epilepsy and seizures in your communities. Below you can review the activities and dates, and start planning!

### **#SeizeTheDay to Talk About Epilepsy**

Goal: Raise awareness about epilepsy and seizures in your community to help reduce stigma and end discrimination. Help your community understand seizure first aid — what seizures are, how to recognize them, how to react, and where to learn more.

Timeframe: May 1 – July 31, 2018

### **#SeizeTheDay to Take Action**

Goal: Embrace your role as an epilepsy advocate. Engage with your local, state, and federal elected officials and tell them about epilepsy, why they should care, and how they can help the epilepsy community.

Timeframe: August 1 – August 31, 2018 & December 1, 2018 – March 31, 2019

### **#SeizeTheDay to Recruit for the Cause**

Goal: Encourage your local epilepsy community to join you as an advocate for epilepsy. Help your local office recruit next year's TSU participant.

Timeframe: September 1, 2018 – October 31, 2018

### **#SeizeTheDay to Participate in National Epilepsy Awareness Month**

Goal: Participate and encourage others to participate in the Epilepsy Foundation's National Epilepsy Awareness Month activities.

Timeframe: November 1 – November 30, 2018

Though all of these activities cover a different aspect of our agenda, each is important to our mission of epilepsy advocacy. Additional information and greater detail is provided throughout the rest of this manual. Hopefully, this will give you a better idea of what you are capable of doing in the coming year and will get you thinking about your own Year of Service plans!

For more information, visit [www.epilepsy.com](http://www.epilepsy.com), contact your local office, or reach out to [tsu@efa.org](mailto:tsu@efa.org).

# #SeizeTheDay to Talk About Epilepsy

Ideas, Tips, & Helpful Resources

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Goal: Raise awareness about epilepsy and seizures in your community to help reduce stigma and end discrimination. Help your community understand seizure first aid — what seizures are, how to recognize them, how to react, and where to learn more.

Timeframe: May 1 – July 31, 2018

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## Seizure First Aid Awareness

Approach your community leaders to find out if they know what to do in the event of a seizure. Talk to your teachers, school nurses, and first responders to make sure they understand how to recognize a seizure and how to react. Don't forget about your friends and neighbors!

## Spread the Word

Share educational materials on epilepsy and seizure first aid with your community. The Epilepsy Foundation's online store features informative pamphlets, and even a comic book about epilepsy. These materials are inexpensive and some can be downloaded as a PDF to print at home.

Visit the Epilepsy Foundation online store: [epilepsy.com/store](http://epilepsy.com/store).

Be open about living with epilepsy and encourage others to do the same. The more people that know someone with epilepsy, the better people will understand the condition. This will make it easier for them to identify a seizure and will help to reduce stigma and end discrimination.

You could also make a short YouTube video, or a series of videos, describing what it's like to live with epilepsy.

## #SeizeTheDay to Share Your Story

You are the expert on living with epilepsy. You, better than anyone, understand the struggle and the needs of the epilepsy community.

There is no better way to educate others than to share your personal experience.

# #SeizeTheDay to Take Action

Ideas, Tips, & Helpful Resources

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Goal: Embrace your role as an epilepsy advocate. Engage with your local, state, and federal elected officials and tell them about epilepsy, why they should care, and how they can help the epilepsy community.

Timeframe: August 1 – August 31, 2018 & December 1, 2018 – March 31, 2019

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## **Stay Informed Through the ‘Speak Up! Speak Out!’ Advocacy Network**

As a member of the Speak Up! Speak Out! advocacy network you receive our monthly newsletter, which features the latest state and federal policy and advocacy updates. You also receive action alerts on state and federal issues, making it easy for you to engage in the policy process and support the Epilepsy Foundation’s advocacy activities in a timely manner.

Visit the ‘Speak Up! Speak Out!’ homepage at: [advocacy.epilepsy.com/home](http://advocacy.epilepsy.com/home).

## **Petition for Support**

Start a petition asking government officials to take action on policy changes that can improve the lives of people living with epilepsy. Ask family, friends, neighbors, and co-workers to sign onto the petition and help you spread the word. Show your decision makers that your community cares about epilepsy!

You can promote the petition electronically via email or on your favorite social media outlets.

## **Meet With Your Congressional Representatives**

Schedule an appointment while your Representatives are home in their district office, or, if you’re feeling ambitious, plan a trip to Washington, DC. You can also invite your Representative to attend a community meeting with other families living with epilepsy.

Take the opportunity to educate your Representatives about epilepsy. You are the experts! Tell them your story, express your concerns, and explain to them how they can help.

To familiarize yourself with the Epilepsy Foundation’s policy priorities go to: [advocacy.epilepsy.com/policy-priorities](http://advocacy.epilepsy.com/policy-priorities).

## **Meet With Your Local and State Representatives**

In addition to targeting your Representatives in Washington, D.C., you can address your Governor or state officials. Remember to contact your local Epilepsy Foundation office for details on your state’s legislative issues affecting epilepsy.

# #SeizeTheDay to Take Action

Ideas, Tips, & Helpful Resources

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## **Find Other, Creative Ways to Reach Your Representatives**

Contact your elected officials through letters, emails, or tweets. You can also invite them to an event.

## **Don't Forget -- Be In Contact With Us!**

Let the Epilepsy Foundation know when you meet with or contact your elected officials, so we can follow up with them.

### **How To:**

#### **Schedule an appointment with an elected official:**

1. Call/email the scheduler. If you don't have the scheduler's direct contact, reach out to the member's office and ask for the scheduler. Find your elected officials' contact information at: [advocacy.epilepsy.com/Elected?7](http://advocacy.epilepsy.com/Elected?7).
2. Identify yourself as a constituent.
3. Request a meeting with the elected official. If he or she is unavailable, meeting with the legislative assistant who focuses on health issues is also a good option.
4. Establish a purpose for the meeting.

#### **Be prepared for your appointment with an elected official:**

1. Do your research, and know your facts – read through the Epilepsy Foundation's policy priorities to find relevant and important facts and figures about epilepsy. The Epilepsy Foundation's current policy priorities can be found at: [advocacy.epilepsy.com/policy-priorities](http://advocacy.epilepsy.com/policy-priorities).
2. Be comfortable telling your story about living with epilepsy. Write down your key points ahead of time.

#### **Have a successful appointment with an elected official:**

1. Be prepared, punctual, and dress the part.
2. Relax, and be sure to tell your story. It is important to establish a personal connection.
3. It's ok if you don't know the answer to a question. You can refer the question to your local office or the national office.
4. Thank them for their time and ask for a photo.

# #SeizeTheDay to Recruit for the Cause

Ideas, Tips, & Helpful Resources

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Goal: Encourage your local epilepsy community to join you as an advocate for epilepsy. Help your local office recruit next year's TSU participant.

Timeframe: September 1 – October 31, 2018

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## Gather Community Support

Start a club devoted to epilepsy awareness and education at school, or host an event in your community.

Connect with your local office to find other families affected by epilepsy in your area. There is strength in numbers.

### **Encourage Other Families Affected by Epilepsy to #SeizeTheDay to Speak Up! and Speak Out!**

Raising awareness about epilepsy and advocating on behalf of those living with the condition are tremendously important – they are critical to reducing the stigma surrounding epilepsy and securing better services and access to care – but you do not have to do it alone.

Enlist the support of your family, and others living with epilepsy and their families. Encourage them to educate others about the condition, and meet with their elected officials.

They can also join the Speak Up! Speak Out! network at [advocacy.epilepsy.com/home](http://advocacy.epilepsy.com/home). Ask them to take action and advocate for the issues that are important to you and the epilepsy community.

## **Find the Next Teens Speak Up! Participant**

The success of TSU hinges on our teen advocates. Each year, a group of vocal, active teens from around the country gather in Washington, DC to advocate for epilepsy with Members of Congress.

We need your help to find the next TSU participant to represent your local office. Share your TSU experience with other teens with epilepsy and encourage them to apply.

## **Be in Touch With Your Local Office**

Your local office is a great resource as you go through the Year of Service. They chose you to represent them in Washington, DC and want to see you succeed.

Don't be afraid to ask for guidance and support for your Year of Service projects. You can also speak on behalf of the local office to help gather support for their programs.

# #SeizeTheDay to Participate in National Epilepsy Awareness Month

Ideas, Tips, & Helpful Resources

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Goal: Participate and recruit others to participate in the Epilepsy Foundation's National Epilepsy Awareness Month activities.

Timeframe: November 1 – November 30, 2018

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## Participate in National Epilepsy Awareness Month

November is National Epilepsy Awareness Month. Each year the Epilepsy Foundation organizes a nationwide campaign to raise awareness about epilepsy, seizure recognition, and first aid.

Take on a leadership role in this year's campaign by being active throughout the month. Enlist the support of others in your communities and networks to generate support and advocate for epilepsy.

Ask your school and local government officials to recognize November as National Epilepsy Awareness Month.

## Get Epilepsy Some Publicity

Reach out to your local news outlets (print, broadcast, etc.) and ask them to promote National Epilepsy Awareness Month. Ask a local community leader or celebrity to speak out for epilepsy or create a publicity opportunity that gets the attention of local press. Write a "Letter to the Editor" for your local newspaper. Media attention is a great way to raise awareness and educate the public about epilepsy.

## Use Your Own Social Media Tools

You don't have to rely on others to give press to your story. Join the Epilepsy Foundation's social media campaign and:

- Dedicate your Facebook status or tweets to epilepsy facts.
- Gather all your friends and family to help make #epilepsy a trending topic on Twitter.
- Post informative videos to YouTube.
- Blog about how epilepsy affects your daily life.



# Year of Service Agreement

As a 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 May 1, 2018 and ending March 31, 2019. As part of my Year of Service, my responsibilities include (but are not limited to) taking a leadership role in the following initiatives:

**1. #SeizeTheDay Talk About Epilepsy (May 1 - July 31, 2018)**

Description: \_\_\_\_\_  
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**2. #SeizeTheDay to Take Action (August 1 – August 31, 2018 & December 1, 2018 – March 31, 2019)**

Description: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**3. #SeizeTheDay to Recruit for the Cause (September 1, 2018 – October 31, 2018)**

Description: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**4. #SeizeTheDay to Participate in National Epilepsy Awareness Month (November 1 – November 30, 2018)**

Description: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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 office at [tsu@efa.org](mailto:tsu@efa.org).

Date: \_\_\_\_\_

Signatures

Teen Advocate: \_\_\_\_\_

Parent Signature: \_\_\_\_\_

Local/National Representative: \_\_\_\_\_