# 

# February 12–19, 2024



SeizureActionPlans.org #SAPAW2024





Managed by



# THIS TOOLKIT

This toolkit provides tools and resources to share the messages and information of the Seizure Action Plans Coalition and specifically, Seizure Action Plans Awareness Week (February 12 – 19, 2024).

#### FOR AWARENESS PARTNERS

During Seizure Action Plan Awareness Week 2024 we ask that you share a minimum of two social media posts that direct people to SeizureActionPlans.org and use the hashtag #SAPAW2024.

We encourage you to share additional messages about seizure action plans, rescue medications, seizure response and first aid and to encourage your constituents to take action using the tools and resources of your organization and/or those available at SeizureActionPlans.org.

If your organization has tools, resources, videos and/or testimonials that should be added to the Resources pages at SeizureActionPlans.org, submit them to us at <u>info@seizureactionplans.org</u> so they can be included.

#### FOR PEOPLE WITH EPILEPSY

We hope you will take this opportunity to learn about seizure action plans and to share messages about your seizure action plan with your family, friends, co-workers, etc. Sharing your experiences can help inspire those who don't have seizure action plans to put them in place.

# FOR HEALTH CARE PROVIDERS

We hope you will take this opportunity to renew your commitment to talking to your patients about seizure action plans. We encourage you to refer your patients to the tools and resources available at SeizureActionPlans.org.

#### FOR SCHOOL PERSONNEL

School personnel can take this opportunity to renew your commitment to Seizure Recognition and First Aid Training at your schools.

#### **CREATE YOUR OWN MESSAGES**

Organizations and individuals are encouraged to use the posts in this toolkit as written or to make them your own!! If you create your own posts about Seizure Action Plans we recommend that you....

- Use the messages found under KEY MESSAGING provided in this toolkit
- Provide links to the Seizure Action Plan Coalition website: SeizureActionPlans.org
- Use the hashtag #SAPAW2024

This toolkit has the following components:

KEY MESSAGING SOCIAL MEDIA POSTS SAMPLE GRAPHICS

# **KEY MESSAGING**

The following messages are the key takeaways of the Seizure Action Plan Coalition. These are talking points about Seizure Action Plans and Seizure Response and Safety.

#### ABOUT SEIZURE ACTION PLANS

A Seizure Action Plan - or SAP - incorporates tailored guidelines on how to respond during a seizure. It includes key information that can help people react quickly and reduce the harm a seizure can do.

About one-third of people with epilepsy will eventually develop refractory epilepsy or drug-resistant epilepsy. This makes a seizure action plan an important management tool.

In a recent study, only 30% of adult patients responded that they have a seizure action plan and only 45% of pediatric patients had a seizure action plan.

The use of a seizure action plan can offer more control to patients and caregivers by providing consistent, patient-specific guidance regarding seizure management.

A seizure action plan can provide clarification on patient and caregiver concerns, such as understanding what to do during a seizure, when watchful waiting is appropriate, when to intervene with at-home rescue medications, when to call 911 or go to the hospital, and much more.

All adults and children with epilepsy need a seizure action plan. People with a new epilepsy diagnosis and those with ongoing frequent seizures should work with their healthcare provider to create a seizure action plan.

Seizure-free patients who have risk factors for breakthrough seizures may also benefit from a seizure action plan.

It is especially important for those who need help to identify their individual seizure pattern, live far from medical facilities, and/or have intractable epilepsy syndromes (ie, Lennox-Gastaut, Dravet), who are at high risk for seizure clusters, status epilepticus, or have frequent nocturnal generalized tonic-clonic seizures, to have a seizure action plan.

Discuss with your healthcare provider if you need a seizure action plan. Visit SeizureActionPlans.org for more information about seizure action plans and resources available to you.

The development of a Seizure Action Plan should involve and be shared with the patient, caregiver, and healthcare providers to create a customized plan tailored to the patient.

Promoting understanding and defining the use of rescue medications within a seizure action plan may reduce potentially unnecessary emergency healthcare needs, resulting in decreased direct and indirect costs.

If the patient has a rescue medication, when and how to administer the rescue medication should be clearly explained in the Seizure Action Plan.

A seizure action plan can be helpful in guiding home management of seizures, which may reduce visits to the emergency department.

Sharing action plans with caregivers increases their comfort level for seizure care.

In addition to parents and caregivers, school staff, coworkers, babysitters, and medical personnel including emergency medical technicians may benefit from a person's seizure action plan.

#### FOR HEALTHCARE PROVIDERS

Developing a Seizure Action Plan is an opportunity to educate the patient and caregiver on the patient's specific seizure type(s) and which situations call for emergency action.

Seizure action plans can be useful for educating patients and their caregivers about the seizure medications and the status of their epilepsy.

The format of the seizure action plan should allow for modification at future office visits based on patient and caregiver current health status, lifestyle changes, or if a treatment change occurs.

The seizure action plan should be reviewed by the patient and healthcare providers regularly to ensure that it is understood and to determine whether it needs to be updated.

#### FOR SCHOOL PERSONNEL

All school personnel who have contact with a student who has seizures should annually review the student's seizure action plan.

ANYONE, not just the school nurse, can respond to a student's seizure. On-demand and in-person Seizure Recognition and First Aid Training for School Personnel is available nationwide.

#### **GENERAL SEIZURE RESPONSE MESSAGES**

One in 10 people will have a seizure in their lifetime. Basic First Aid, CPR, the Heimlich are all taught to people of all ages to respond to medical emergencies. Seizure Recognition and Response should be commonplace.

# SOCIAL MEDIA POSTS

The sample social media posts below are customizable for you or your organization. Our goal for Seizure Action Plan Awareness Week is to generate a strong online dialogue around #SAPAW2024; to spread awareness about seizure action plans; and, to engage with diverse communities who may not be aware of why having an action plan is necessary.

#### TWEETS

Having a Seizure Action Plan is important. SHARING that Seizure Action Plan with your family and friends is critical. Learn more at SeizureActionPlans.org. #SAPAW2024

When was the last time you shared your Seizure Action Plan with your family and friends? Learn more at SeizureActionPlans.org. #SAPAW2024

You know CPR and the Heimlich but do you know how to respond in case someone has a seizure? Be Seizure Prepared. Get trained today.

Ever woken up in the back of an ambulance after a seizure? Sharing your Seizure Action Plan with family and friends can help them understand when a call to 911 is necessary – and when it is not. Learn more at SeizureActionPlans.org. #SAPAW2024

Nationwide, 470,000 children and teens have been diagnosed with epilepsy, and yet only a shocking 45% of pediatric patients have a seizure action plan. Having a plan in place can save lives. Visit SeizureActionPlans.org for more information. #SAPAW2024

#### SAMPLE POSTS LEADING UP TO SEIZURE ACTION PLAN AWARENESS WEEK

Save the dates! Seizure Action Plan Awareness Week is February 12-19. We're helping patients, caregivers and healthcare providers spread awareness about epilepsy and the importance of having an action plan in place. Learn more at SeizureActionPlans.org and join the conversation with #SAPAW2024

We need your help to spread the importance of having a seizure action plan in place! Seizure Action Plan Awareness Week is coming up, February 12-19. Join the conversation with #SAPAW2024 and learn why having a seizure action plan can be life-changing at SeizureActionPlans.org.

#### SAMPLE POSTS for SEIZURE ACTION PLAN AWARENESS WEEK

The following sample posts are audience targeted. You can share them via Facebook and Linkedin depending on your audience(s).

#### For People with Epilepsy

A Seizure Action Plan EMPOWERS your friends and family to know what to do if you have a seizure. Learn more at SeizureActionPlans.org. #SAPAW2024

When you fail to plan you plan to fail. A Seizure Action Plan sets you up for success by empowering your friends and family to know what to do if you have a seizure. Learn more at SeizureActionPlans.org. #SAPAW2024

When was the last time you shared your Seizure Action Plan with your family and friends? Learn more at SeizureActionPlans.org. #SAPAW2024

Would your co-workers know what do to if you have a seizure at work? Prepare them by having and sharing your Seizure Action Plan. Learn more at SeizureActionPlans.org. #SAPAW2024

Having a Seizure Action Plan is important. SHARING that Seizure Action Plan with your family and friends is critical. Learn more at SeizureActionPlans.org. #SAPAW2024

Have you come out of a seizure in the back of an ambulance because your friends and family didn't know they didn't have to call 911? Share your Seizure Action Plan to educate and empower your family and friends. Learn more at SeizureActionPlans.org. #SAPAW2024

You have a rescue medication – good! None of your family or friends know about it or how to use it – not good! Share your Seizure Action Plan to educate and empower your family and friends. Learn more at SeizureActionPlans.org. #SAPAW2024

#### For Parents of Children with Epilepsy

A Seizure Action Plan can ensure your child's safety at school and empowers their teachers and administrators to respond appropriately in the event of a seizure. We have tools and resources for your child's school at SeizureActionPlans.org. #SAPAW2024

If you have a school aged student with epilepsy, their Seizure Action Plan should be updated yearly or any time there's been a change in their care plan and these updates should be reviewed with school staff. Seizure Action Plans give peace of mind to parents, students, and teachers! We have tools and resources for your child's school at SeizureActionPlans.org. #SAPAW2024

Educate and empower your family and friends to respond if your child has a seizure. Share your child's Seizure Action Plan today. We have tools and resources for your child's school at SeizureActionPlans.org. #SAPAW2024

Do your family and friends know when to call 911 if your child has a seizure – and when NOT to? Educate and empower those around your child by sharing their Seizure Action Plan. We have tools and resources for your child's school at SeizureActionPlans.org. #SAPAW2024

Sharing is caring! Share your child's Seizure Action Plan so others are educated and empowered to help your child if they have a seizure. We have tools and resources for your child's school at SeizureActionPlans.org. #SAPAW2024

#### **For Healthcare Providers**

Clinicians are essential to helping patients and families create Seizure Action Plans that work! Are you discussing your patients' Seizure Action Plans at every appointment? We have tools and resources at SeizureActionPlans.org. #SAPAW2024

Clinician input is essential to the Seizure Action Plan. Are you talking about Seizure Action Plans at your appointments? We have tools and resources at SeizureActionPlans.org. #SAPAW2024

The Seizure Action Plan Coalition has tools and resources for your patients. Share it with them this week, and all year long. We have tools and resources at SeizureActionPlans.org. #SAPAW2024

#### For the General Public – Seizure Safety Messages

Are you trained in CPR? Can you do the Heimlich? It's equally important to know what do is someone has a seizure! Get educated and empowered to respond! Tools, resources, and trainings are available at SeizureActionPlans.org. #SAPAW2024

True or False: Every time someone has a seizure you should call 911. Get the facts and learn how to respond at SeizureActionPlans.org. #SAPAW2024

# Seizure Action Plan Coalition Awareness Partners

Awareness Partners are encouraged to share their involvement with the Seizure Action Plans Coalition with their constituents.

#### Sample Post

has signed on as an Awareness Partner for the Seizure Action Plan Coalition. We're helping patients, caregivers and healthcare providers spread awareness about epilepsy and the importance of having an action plan in place. Learn more at SeizureActionPlans.org and join the conversation with #SAPAW2024.

#### Other ways that Awareness Partners can engage with the Seizure Action Plan Coalition

Consider including a posteach month on your content calendar about SAPs and the SAPC.

Consider placing the Seizure Action Plan Coalition Awareness Partner Logo on your organization's website - linking to SeizureActionPlans.org - all year long.

Include information about the Seizure Action Plan Coalition in an upcoming email, newsletter or on your website.

Share resources from your organizations with the Seizure Action Plan Coalition.



### **SAMPLE GRAPHICS**

#### **Facebook Cover Photo**

Show your support of the Seizure Action Plan Coalition and Seizure Action Plans Awareness Week by uploading the SAPAW2024 Facebook cover photo on your Facebook page.







# **Seizure Action Plan Video**

The video below was created for the Seizure Action Plan Coalition in 2021.

Full length video(1:08): https://youtu.be/seGffFUyVcA

Short promo video (30): https://www.youtube.com/watch?v=GHiMexK12WM



There are <u>several videos available on the Seizure Action Plans Coalition website</u> from our Awareness Partners.