EPILEPSY
FOUNDATION
MINNESOTA

ADVOCACY
ACTION NETWORK

A guided toolkit on public policy advocacy for the epilepsy community.

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OVERVIEW

No one journeys through epilepsy alone

Thank you!

Thank you for joining the Epilepsy Foundation of Minnesota's (EFMN) Advocacy Action Network.

Day at the Capitol and the Advocacy Action Network

Each year, EFMN hosts an annual Day at the Capitol (DAC) for individuals interested in supporting EFMN's advocacy efforts. Historically, Day at the Capitol is a single-day event that connects advocates with their representatives and lobbies their support for specific bills that build safer communities and increase access to care for individuals and families impacted by epilepsy and seizures.

In 2021, this community successfully advocated for a policy supporting Seizure Smart Schools. In 2023, this community again helped pass vital legislation expanding coverage of Seizure Detection Devices.

This year, Day at the Capitol launches an expanded advocacy initiative. The Advocacy Action Network invites members from our community to support this work by building relationships with their legislators throughout the year to advocate on behalf of EFMN and the epilepsy community.

2024 Policy Priority

During the 2024 Minnesota legislative session, EFMN's priority is to secure funding for an awareness campaign for the recently passed bill that allows FDA-approved seizure detection devices (SDD) to be covered by Minnesota Health Care Programs (MHCP).

The awareness campaign will be vital in spreading awareness about the passage of the bill, which went into effect January 1, 2024, and provide education about epilepsy, seizure detection devices and the new coverage under MHCP so all those eligible can utilize this life-saving device.

Would you or a loved one prefer to communicate with your legislator in Spanish, Somali, or Hmong?

The Legislative Coordinating Commission (LCC) has a new pilot program to provide interpreters/translators! To get an interpreter, your legislator and/or their staff have to make a request with the LCC. This is a brand-new service, so some legislators may not yet know about it. If you'd like help contacting your legislator through an interpreter, please reach out in your preferred language to EFMN's Director of Health Equity, Angela Bowles Edwards at 651-368-6209 (call/text) or abedwards@efmn.org.

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Seizure Detection Devices

Last year, the EFMN community successfully helped pass Seizure Detection Device (SDD) Legislation that allows FDA-approved seizure detection devices to be covered under Minnesota Health Care Programs (MHCP). MHCP includes Medical Assistance, MinnesotaCare, Minnesota Family Planning Program, home and community-based waiver programs, and Medicare Savings Programs.

DID YOU KNOW?

Seizure detection devices can be covered under certain epilepsy treatment plans to decrease the risk of injuries and death. Many people living with epilepsy and seizures may not be aware of their risk of sudden unexpected death in epilepsy (SUDEP), of seizure detection devices, or may not be aware of this coverage option.

The good news

- Minnesota Health Insurance Programs coverage of seizure detection devices went into effect on January 1, 2024.
- Minnesota is the first state to cover seizure detection devices under state health care programs.

Where’s the problem?

- Because Minnesota is the first state to cover these devices under Minnesota Health Care Programs (MHCP), it’s unclear how many people know about this new bill.
- Because seizure detection devices can be life-saving technologies, and many who may be eligible for this coverage are not aware, it is critical to ensure Minnesotans are aware and educated on this topic.

How can you help?

- Join us on March 6th for a virtual day at the capitol program to learn more about this year’s policy priority.
- Follow the steps in this guide to advocate throughout the year by engaging your legislators in conversations about the importance of epilepsy awareness.

PATH TO BECOMING AN ADVOCATE

Find your legislator

Knowing who your legislators are is the first step to building relationships. Your legislators want to hear your story and how their work connects directly to your experiences.

- Visit the "Who Represents Me" webpage to find your legislators. Make sure you track their contact information in the "Who represents me?" worksheet so you can reference it later.

Send an email

Sending an email to your legislators is an excellent way to introduce yourself and let them know your story and what your priorities are as a constituent.

- Prepare the "What's your story" worksheet to help you focus your introduction.
- Use the email template to send separate emails to your legislators.

Write a letter

Writing a letter, or organizing a letter-writing campaign with your friends and network, is another great way to share your story and ask for your legislators' support. Inviting your neighbors and network to write letters can help legislators see how certain policies affect many of their constituents.

- Write individual letters to your legislators using the letter template and mail it to the addresses you identified when researching your legislators' contact information.
- Share the template with your neighbors and friends so they can write their own letters to their legislators as well!

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Call your representative

Calling your legislators to tell your story and make a personal connection makes a difference! Your story provides them with a bigger picture and a first-hand account of how certain policies and issues impact the everyday lives of their constituents.

- Make sure you have your story worksheet filled out and you're comfortable sharing.
- Prepare your script using the phone script provided. Practice beforehand to help ease any nervousness.
- Call your legislator's office but keep in mind, you may be speaking with your legislator directly, with a member of their staff, or leaving a voice message.

Meet in-person or via video call

Whether you schedule an individual or group meeting, this is an opportunity to build a relationship with your legislator that goes above and beyond.

- Call your legislator's office to make an appointment for an in-person meeting or via zoom. Appointments can be made all year round - during the legislative session and when legislators are back home in their districts.
- **Bonus!** Invite your legislator to your regional walk. The goal of the EFMN Advocacy Action Network is to make sure representatives understand how many people are impacted by epilepsy and seizures. We want them to build a connection with our community so invite your legislators to your regional United in Epilepsy walk!

YOUR ADVOCACY PLAN

Tools to help you prepare and execute your advocacy plan

PREPARE:
WHAT’S YOUR WHY?

Print this out or fill out on your device.

Introduction

My name is ______________________________ (first & last name)
and I am a _____________________ (relation to epilepsy. Example: person with epilepsy).

My epilepsy story

(Example: I have had epilepsy since I was 12 years old. At first, I was misdiagnosed with ADHD. Then after 2 years, I was finally diagnosed and given proper medication to help control my seizures.)

Why advocacy is important to me

(Example: After years of uncontrolled seizures, a seizure detection device was recommended… but my insurance didn’t cover it. This is why advocacy is so important to me. With help from the Epilepsy Foundation, I can now get a seizure detection device covered by my insurance!)

PREPARE:

WHO’S MY LEGISLATOR?

Print this out or fill out on your device. Visit the “Who Represents Me” webpage to find your legislators.

My MN State Senator

Name: ____________________
Address: ____________________
Phone: ____________________
Email: ____________________

Notes about my senator:

My MN State House Representative

Name: ____________________
Address: ____________________
Phone: ____________________
Email: ____________________

Notes about my representative:

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PREPARE:
LETTER TEMPLATE

(Month)(Day)(Year)
The Honorable (First name)(Last name)
(Legislator's street address)
St. Paul, MN 55115

RE: Support the Seizure Detection Device Awareness Campaign Bill (HF 4056 or SF 4109)

Dear (Representative or Senator) (Last name):

My name is (your first and last name) and I am a (family member /service provider/advocate/community member) who resides in your district. I am writing to request your support for the Seizure Detection Device Awareness Campaign bill. This important bill funds an awareness campaign to educate Minnesotans with epilepsy about the new Minnesota Health Care Programs (MHCP) coverage of FDA-approved seizure detection devices (SDDs).

SDDs are critical under certain epilepsy treatment plans to reduce the risk of injuries and death. Unfortunately, many people living with epilepsy and seizures are not aware of these devices, the new health care coverage, or their risk of sudden unexpected death in epilepsy (SUDEP) — the leading cause of death for young people with uncontrolled seizures.

(Include a personal story here. Personal stories are very impactful and show your representative why the issue is important to you and how it affects you, your family and/or your community. Be specific about the ways in which the bill would bring about positive change or prevent negative outcomes.)

Your support for this bill could make a significant impact on the lives of many Minnesotans with the potential to reduce financial stress and save lives. I appreciate your consideration and kindly ask that you send me a response letting me know your position on this important bill. (Optional: state here if you are available to discuss the matter further if they have any questions or need more information)

Sincerely,
SIGN YOUR NAME
Print your name
Your street address
City, State, Zip code

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PREPARE:

EMAIL TEMPLATE

Subject: Support the Seizure Detection Device Awareness Campaign Bill (HF 4056 or SF 4109)

Dear (Representative or Senator) (Last name),

As your constituent, I am reaching out to ask that you support the Seizure Detection Device Awareness Campaign bill.

This is an important piece of legislation because it funds an awareness campaign to educate Minnesotans with epilepsy about the new Minnesota Health Care Programs (MHCP) coverage of FDA-approved seizure detection devices (SDDs).

SDDs are critical under certain epilepsy treatment plans to reduce the risk of injuries and death including sudden unexpected death in epilepsy (SUDEP). Unfortunately, many people living with epilepsy and seizures are not aware of these devices or the new healthcare coverage.

(Include a personal story here. Personal stories are very impactful and show your representative why the issue is important to you and how it affects you, your family and/or your community. Be specific about the ways in which the bill would bring about positive change or prevent negative outcomes.)

Spreading awareness of the new Minnesota Health Care Programs coverage for SSDs has the potential to save lives and reduce financial stress for many Minnesotans. I hope to count on your support for this bill and appreciate a response indicating your position. (Optional: state here if you are available to discuss the matter further if they have any questions or need more information)

Thank you for considering my perspective on this vital issue. I look forward to your response.

Your name

County, State

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PREPARE:

PHONE SCRIPT TEMPLATE

Reminder: Be aware that when you call you may be speaking with your legislator directly, with a member of their staff, or leaving a voice message. Make sure to adjust your script accordingly.

Hi, (Representative or Senator) (Last Name), my name is (your name) and I live in your district.

I am calling as an advocate with the Epilepsy Foundation of Minnesota, an organization dedicated to providing education, support, and empowerment for Minnesotans impacted by epilepsy. I strongly support the Seizure Detection Device Awareness Campaign bill (HF 4056 or SF 4109), which would fund an awareness campaign on the new Minnesota Health Care Programs coverage of seizure detection devices to save lives and reduce financial stress for Minnesotans living with epilepsy.

(Share a personal story here. Personal stories are very impactful and show your representative why the issue is important to you and how it affects you, your family and/or your community. Be specific about how the bill would bring about positive change or prevent negative outcomes.)

As your constituent, I strongly encourage you to support the Seizure Detection Device Awareness Campaign.

Thank you for your time and interest.

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PLAN:

ACTION PLAN

Use this action calendar to help you plan your advocacy. Write out your objectives for each action step you plan to take, the date you'd like to complete your action, and who you're planning to contact. Having a plan helps you stay organized and on track. You can print this out or fill it out on your device.

Objective	Action	Date	Elected Official
Invite reps to regional United in Epilepsy Walk	Email	March 25, 2024	Sen. Jane Doe

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EXECUTE:

SUCCESS TRACKER

Action taken this year

Outcomes

Example: Sen. Jane Doe came to the Twin Cities walk!

Notes

Bonus: we'd love to see the action you took this year. Forward this completed sheet to advocacy@efmn.org.

Questions? Reach out to us at advocacy@efmn.org.

WHAT NEXT?

Let’s keep the momentum going

UPCOMING OPPORTUNITIES

United in Epilepsy Regional Walks Announcement

April 20, 2024

Be sure to keep an eye on your inbox on April 20th. We will be announcing this year's United in Epilepsy Regional Walks' locations and dates. Is your team ready to raise support and awareness for EFMN?

Camp Programs

Summer 2024

Registration is now open for all camp programs and spots are filling up fast! Don't miss out on early bird registration prices for Camp Oz. Check out efmn.org/camp for more information.

Shining Stars at Mall of America

September 21, 2024

Register your child for our Shining Stars Program and join the fun! This program connects youth and teens with epilepsy from across Minnesota. The registration form can be found at efmn.org/shining-stars

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QUESTIONS?

Check out these frequently asked questions

FAQ

What is advocacy?

Advocacy includes a large range of activities with the goal of influencing policy. Advocacy raises awareness, influences and changes policies through education, and can help represent people who are unable to represent themselves.

Why is advocacy important?

Advocacy is important because legislators want to hear from the public, especially their constituents, about issues they care about. Constituents are citizens whom a legislator has been elected to represent. Part of a legislator's job is to serve their constituents by representing their interests.

Where can I find more information about the bill?

You will be able to search for the bills on the Minnesota Legislature website using these bill numbers: House file (HF) 4056, Senate file (SF) 4109. Find details about the bill, its status in the House and Senate, and details from any committees or upcoming meetings.

You can also use the MyBills feature to track any bill along with information on any recent or upcoming action on the bill.

What if I need translator services to connect with the legislator?

The Legislative Coordinating Commission (LCC) has a new pilot program to provide Spanish, Somali, and Hmong interpreters/translators. This is a brand-new service, so some legislators may not yet know about it. If you'd like help contacting your legislator through an interpreter, please reach out in your preferred language to EFMN's Director of Health Equity, Angela Bowles Edwards at 651-368-6209 (call/text) or abedwards@efmn.org.

Who should advocates connect with if they have questions?

If additional support is needed or there are further questions, please contact our advocacy team at advocacy@efmn.org.

Questions about getting your seizure detection device covered?

For those interested in learning more about possible seizure detection device coverage for themselves or a loved one, please reach out to clientsupport@efmn.org.

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