



EPILEPSY
FOUNDATION®

MINNESOTA

AN AFTERNOON OF EPILEPSY ADVOCACY

DAY AT THE CAPITOL



EPILEPSY FOUNDATION OF MINNESOTA | EFMN.ORG

Welcome to Epilepsy Foundation of Minnesota's 2026 Day at the Capitol!

We're so glad you're here. Together, we're supporting EFMN's mission to empower Minnesotans impacted by epilepsy and ensure every individual and family has the care, resources, and support they need on their journey.

Today is an opportunity to learn more about EFMN's work and to build confidence in sharing how epilepsy-related issues impact individuals, families, and communities across Minnesota. By engaging with your elected officials, you're helping increase awareness, understanding, and laying the groundwork for future policy change.

This packet is here to guide you through the day. Inside, you'll find the agenda, background information on key epilepsy-related issues, and tools to help you prepare for conversations with elected leaders and their staff.

Thank you for showing up and lending your voice. These conversations matter, and they play an important role in building understanding and momentum, so that no one faces epilepsy alone.

WHAT'S INSIDE

- Program Agenda..... pg. 3
- Fact Sheet: Epilepsy in Minnesota..... pg. 4
- How to Talk with your Legislator..... pg. 5
- Overview of EFMN's Key Issues..... pg. 6

Other helpful materials

- Legislative Meeting Schedule (Receive at check-in table)
- Map (Receive at check-in table)
- Leave behind sheets (Located in your purple folder)
- Note sheets from your visits (Located in your purple folder)

Please give note sheets to EFMN Staff Member after your visits.

PROGRAM AGENDA

April 22, 2026 L'Etoile du Nord Vault
12:30 PM - 4:30 PM Room B15

12:30 - 1:00 PM

Registration & Check in

1:00 - 1:30 PM

Day at the Capitol Program

Featured speakers:



Rep. Julie Greene **Senator Jim Abeler**

1:30 - 4:30 PM

Legislative Meetings

Your legislative meeting schedule and maps of the Capitol Complex are located at the check-in table.

At your convenience, please enjoy complimentary snacks and beverages.

Seating is available in the Vault until 4:30 PM.

PHOTO SHARE

We'd love to see your experience at Day at the Capitol!
Share your photos by emailing them to EFMN.



marketing@efmn.org



EPILEPSY IN MINNESOTA

WHAT IS EPILEPSY?



Epilepsy is a neurological (brain) condition that causes people to have recurring seizures.

Seizures are bursts of uncontrolled electrical activity in the brain that can cause a person to behave or feel differently than they typically would.



WHO HAS EPILEPSY?

- Epilepsy can affect people of all ages.
- It is the fourth most common neurological condition among adults and the most common among children.
- 3.4 million Americans are living with epilepsy.

An estimated
55,000+
Minnesotans live
with epilepsy

1 in 10

people will
have a seizure
in their lifetime

IMPACT OF EPILEPSY

- People with epilepsy, their family, friends, and caregivers are all impacted by epilepsy.
- Unpredictable seizures can disrupt daily life.
- People with epilepsy also face increased rates of:
 - Anxiety and depression
 - Isolation and stigma
 - Unemployment and financial stress
 - Transportation challenges

1 in 26

people will
develop epilepsy
their lifetime

MANAGING EPILEPSY

- **7 out of 10** people manage seizures with medication.
- Seizure Alert Devices are designed to alert caregivers or medical personnel, providing improved safety and peace of mind for people living with epilepsy.
- For those who cannot control seizures with medication, surgery and implant devices may be alternative options.

ADVOCATING FOR THE EPILEPSY COMMUNITY

Quick Look at EFMN's 2026 Key Issues

ACCESS TO AFFORDABLE PRESCRIPTIONS AND MEDICAL SUPPLIES



- Minnesotans with epilepsy may not be able to afford medications and medical devices due to high co-pays and coinsurance.
- Missing medication is the leading cause of seizures and can lead to injury, hospitalization, and in rare cases, death.
- Uncontrolled seizures can impact a person's education, employment, and overall quality of life.

EFMN supports efforts to limit cost-sharing on medications and medical supplies used to treat epilepsy, helping ensure care remains affordable and accessible (HF 3652, SF 3786).

RAISING AWARENESS OF SUDEP & EARLY MORTALITY



- Sudden Unexpected Death in Epilepsy (SUDEP) occurs in 1 in 1,000 people with epilepsy. If seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150.
- Conversations between health care providers and the epilepsy community can help minimize risk for SUDEP.

EFMN is building awareness among legislators about SUDEP and early mortality to emphasize the need for more education, prevention, and healthcare incentives to reduce the occurrence of SUDEP across Minnesota.

ENSURING ACCESS TO ESSENTIAL HEALTH SERVICES



- EFMN's advocacy work is guided by our commitment to ensure that all Minnesotans with epilepsy have the tools, resources, and support they need to thrive.
- For people living with epilepsy, health services extend beyond medical treatment to include supports such as transportation, case management services, financial resources, caregiver services, residential housing with on-site support, service animals, and mental health support.

EFMN is increasing awareness and elevating lived experiences on how gaps in care impact individuals and families across Minnesota.

EFMN'S 2026 KEY ISSUES

ACCESS TO AFFORDABLE PRESCRIPTIONS AND MEDICAL SUPPLIES

- Currently, there is no cost-sharing limit for epilepsy-specific prescriptions and medical supplies, meaning that people with epilepsy may have to pay high co-payments and coinsurance for life-saving prescriptions or related medical supplies.
- When people with epilepsy cannot afford medication, they may miss or ration doses, which can lead to seizures.
- People with epilepsy must often trial several medications or combinations of medications to find what works best – meaning the cost of medications can add up quickly.

Talk with your legislator about why affordability matters, and ask if they would support limiting cost-sharing on epilepsy medications and medical supplies.

RAISING AWARENESS OF SUDEP & EARLY MORTALITY

- Sudden Unexpected Death in Epilepsy (SUDEP) occurs in 1 in 1,000 people with epilepsy. If seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150.
- Status epilepticus, unintentional injuries, and suicide also contribute to early mortality (death) in people with epilepsy
- These causes of death are underestimated in Minnesota due to poor recognition and reporting

What work is already being done to address SUDEP and early mortality?

In 2025, legislation was passed to start the Epilepsy Program at the Minnesota Department of Health (MDH) to improve data collection around epilepsy and related issues including SUDEP and early mortality.

How can SUDEP be prevented?

More research is needed to fully understand what causes SUDEP, which is why it is important to raise awareness. Because SUDEP occurs most frequently among people with uncontrolled seizures, the best way to minimize risk is to optimize seizure control.

Risk counseling is a conversation between healthcare providers and people with epilepsy about their individual risk for SUDEP and how to lower it. It may involve assessing the frequency and type of seizures they experience, their medications, and lifestyle factors.

- Conversations between health care providers and the epilepsy community can help minimize risk for SUDEP, but lack of awareness and inconsistent reimbursement for post-diagnosis education and case management services makes it challenging for healthcare providers and the epilepsy community to have transparent conversations about SUDEP.
- EFMN is building awareness among legislators about SUDEP and early mortality to emphasize the need for more education, prevention, and healthcare incentives to reduce the occurrence of SUDEP across Minnesota.

Talk to your legislator about the importance of increasing awareness of SUDEP and early death in epilepsy.

EFMN'S 2026 KEY ISSUES

ENSURING ACCESS TO ESSENTIAL HEALTH SERVICES

- EFMN's advocacy work is guided by our commitment to ensure that all Minnesotans with epilepsy have the tools and resources they need to thrive, address gaps in care and education, and reduce stigma surrounding epilepsy
- We will advocate to protect and advance access to health care, especially life-saving services for Minnesotans with epilepsy. We will educate lawmakers and key decisionmakers on the public policy changes that are needed to support people living with epilepsy and understand epilepsy's true impact on individuals and families.

Talk with your legislator about why ensuring access to essential health services is important for Minnesotans living with epilepsy and their families.

What types of services do people with epilepsy need?

People with epilepsy need specialized medical care. Additional services depend on how well seizures are controlled and other conditions - transportation, case management services, financial resources, caregiver services, residential housing with on-site support, service animals, and mental health support are other services people with epilepsy may need.

What gaps in care do people with epilepsy often encounter?

Medication costs, inadequate transportation, and lack of knowledge of and access to specialty medical care are some issues most frequently experienced within the epilepsy community.

For more information scan the QR Code or
visit EFMN.ORG/advocacy-2026

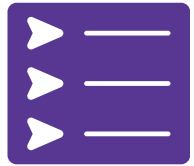


TIPS FOR A SUCCESSFUL CONVERSATION



Be mindful of time

Meetings with legislators (or their staff) are friendly & brief - 15 minutes or less.



Be concise & stick to one message

Your time will be limited. Stick to describing the policies you are advocating for.



Stay personal

Explain how these policies would support you, someone you know, or your community.



Stay friendly

Greet your legislator warmly and thank them at the end. Use formal titles such as Senator Abeler or Representative Greene.



Practice

You don't need a strict script, but practicing your main points can help you feel confident going into your meeting.



Follow up

The legislator may have follow-up questions. You can reference personal experience, information in this packet, or provide EFMN's contact info (advocacy@efmn.org).

HOW TO TALK TO YOUR LEGISLATOR

INTRODUCTION

Introduce yourself, where you live, and why you're here. Provide a one-page fact sheet

"Hi, my name is ___ and I live in ___. I'm here today as part of the Epilepsy Foundation of Minnesota to share my experience with epilepsy and why these issues matter to my family and community. Epilepsy is when someone has recurrent seizures. Here is a fact sheet about epilepsy in Minnesota."

Optional: "I/My child/spouse/friend has seizures, and it impacts me/them by ___."

MAKE THE ASK

Clearly state what you're advocating for. Choose one or all three of EFMN's key Issues to Discuss.

ACCESS TO AFFORDABLE PRESCRIPTIONS AND MEDICAL SUPPLIES

"I want to share an issue that's important to me and to the epilepsy community: access to affordable care.

People living with epilepsy often rely on life-saving medications and medical supplies, and out-of-pocket costs can add up quickly.

Missing medication is the leading cause of seizures and can lead to injury, hospitalization, and in rare cases, death. When seizures are not well controlled, they can also affect a person's education, employment, and overall quality of life

Optional: Talk about how this issue impacts you or someone you care about.

Ask: Epilepsy Foundation of Minnesota supports limiting cost-sharing on epilepsy medications and related medical supplies. Would this be something you would be supportive of?"

RAISING AWARENESS OF SUDEP & EARLY MORTALITY

"I want to share an issue that's important to the epilepsy community and that many people are still unaware of— Sudden Unexpected Death in Epilepsy, also known as SUDEP.

SUDEP occurs in 1 in 1,000 people with epilepsy. If seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150.

Many individuals and families are never informed about this risk, even though education, awareness, and access to appropriate care can help reduce it.

Optional: Talk about how this issue impacts you or someone you care about.

Ask: Would you be open to learning more about SUDEP and supportive of efforts that improve education, awareness, and prevention for Minnesotans with epilepsy?"

ENSURING ACCESS TO ESSENTIAL HEALTH SERVICES

"I want to talk about access to essential health services and why it matters to people living with epilepsy.

For many people with epilepsy, care goes beyond medical appointments and prescriptions. It can include transportation to appointments, case management, mental health support, caregiver services, and stable housing with on-site support. When access to these services is limited or disrupted, it can directly affect health, safety, and quality of life.

Optional: Talk about how this issue impacts you or someone you care about.

Ask: Would you be supportive of policies that maintain access to services like transportation, mental health care, caregiver support, and housing for people living with epilepsy?"

CLOSING

Ask for their support, offer follow-up, and thank them.

Your support can help improve health access, safety, and quality of life for Minnesotans living with epilepsy. Please reach out to the Epilepsy Foundation of Minnesota with any questions at advocacy@efmn.org."

"Thank you for taking the time to meet with me today. Would you be willing to take a photo?"

Questions?

We're here to help.

Reach out to EFMN by emailing:

advocacy@efmn.org