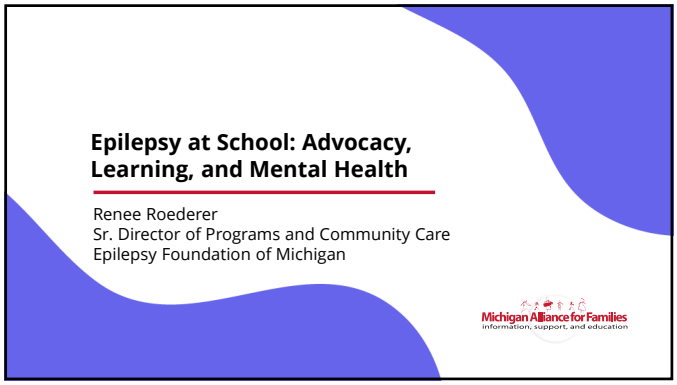
Epilepsy at School: Advocacy, Learning, and Mental Health
Renee Roederer
Sr. Director of Programs and Community Care
Epilepsy Foundation of Michigan
Michigan Alliance for Families
information, support, and education

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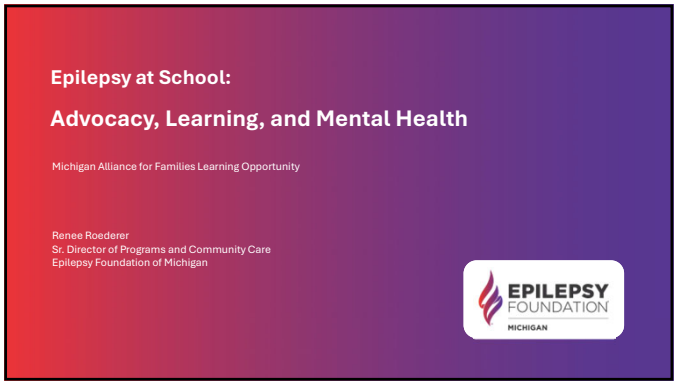
Epilepsy at School:
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EPILEPSY FOUNDATION
MICHIGAN

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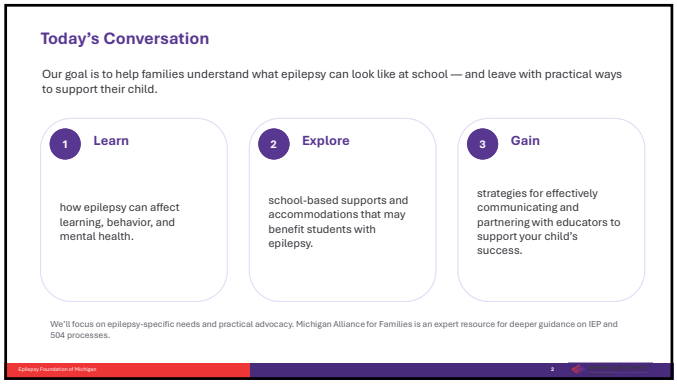
Today's Conversation
Our goal is to help families understand what epilepsy can look like at school — and leave with practical ways to support their child.
1 Learn
how epilepsy can affect learning, behavior, and mental health.
2 Explore
school-based supports and accommodations that may benefit students with epilepsy.
3 Gain
strategies for effectively communicating and partnering with educators to support your child's success.
We'll focus on epilepsy-specific needs and practical advocacy. Michigan Alliance for Families is an expert resource for deeper guidance on IEP and 504 processes.
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Epilepsy Can Affect Much More Than Seizures

A student may be seizure-free during the school day and still experience very real effects of epilepsy.

Learning
Understanding and keeping up with instruction

Memory
Taking in, storing, and retrieving information

Attention
Focusing, shifting focus, and staying engaged

Energy
Fatigue, sleep disruption, and recovery

Emotional Well-Being
Stress, anxiety, mood, and confidence

Relationships
Friendships, stigma, belonging, and participation

Sometimes a family knows something isn't working at school — but it can be hard to name exactly what it is.

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A Very Brief Epilepsy 101

A seizure is...

- a temporary change or disruption in the way the brain sends electrical signals.
- something that can affect awareness, movement, sensation, emotion, behavior, or memory.
- not always obvious to people watching.

Epilepsy means...

- a tendency to have recurrent unprovoked seizures.
- many different seizure types and epilepsy syndromes — not one single experience.
- an individual condition: two students with epilepsy may need very different supports.

At school, useful questions may include: 1) What does this student's epilepsy look like? 2) What do they need to be safe and feel safe? 3) And what helps them learn best?

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Seizures Don't All Look Alike

- Some seizures involve loss of consciousness and convulsive movements.
- Some involve staring, altered awareness, confusion, or brief pauses in activity.
- Some involve unusual movements, sensations, emotions, or behaviors.
- A student may be able to speak during some seizures and unable to respond during others.
- School staff should know the student's typical seizure pattern and follow the individualized Seizure Action Plan.

Recognition matters because a seizure can be missed — or a behavior can be misunderstood.

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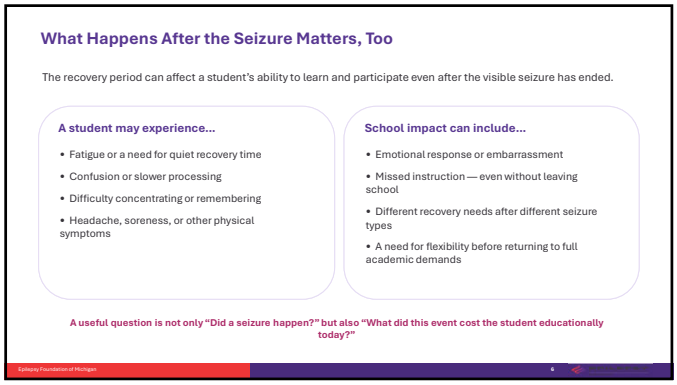
What Happens After the Seizure Matters, Too
The recovery period can affect a student's ability to learn and participate even after the visible seizure has ended.
A student may experience...
• Fatigue or a need for quiet recovery time
• Confusion or slower processing
• Difficulty concentrating or remembering
• Headache, soreness, or other physical symptoms
School impact can include...
• Emotional response or embarrassment
• Missed instruction — even without leaving school
• Different recovery needs after different seizure types
• A need for flexibility before returning to full academic demands
A useful question is not only "Did a seizure happen?" but also "What did this event cost the student educationally today?"
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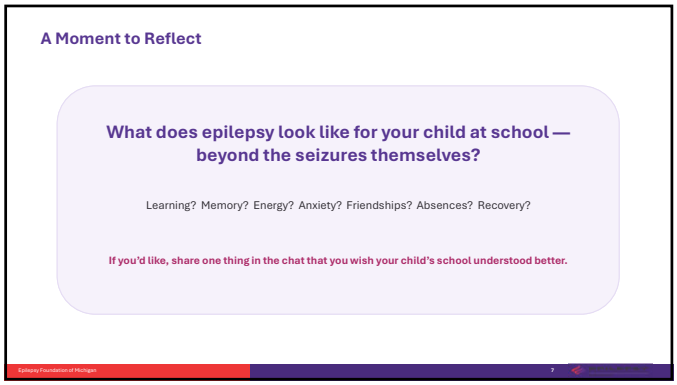
A Moment to Reflect
What does epilepsy look like for your child at school — beyond the seizures themselves?
Learning? Memory? Energy? Anxiety? Friendships? Absences? Recovery?
If you'd like, share one thing in the chat that you wish your child's school understood better.
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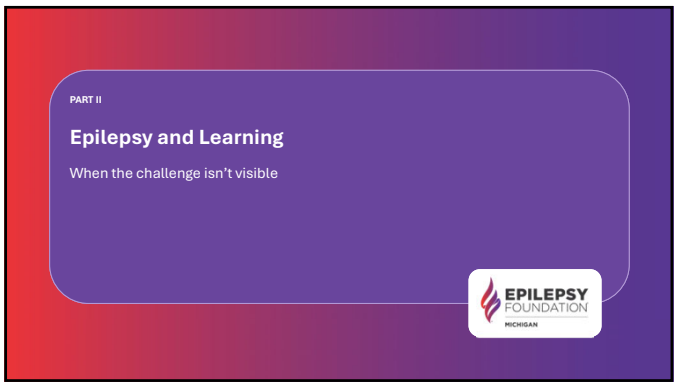
PART II
Epilepsy and Learning
When the challenge isn't visible
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Why Might School Become Harder?

Epilepsy-related factors

- Seizure activity — including seizures that are not obvious to others
- Recovery before or after seizures
- Medication side effects
- Sleep disruption and fatigue
- Missed instructional time

Other factors that may overlap

- Memory, attention, or processing challenges
- Co-occurring ADHD, anxiety, depression, or other conditions
- Stress related to unpredictability or stigma
- Executive-function demands
- Changes in confidence or participation

The cause may be layered. Support does not require families to solve every layer before asking for help.

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The Pattern May Be Inconsistent

- A student may know material one day and struggle to retrieve it another day.
- Performance may change depending on time of day, fatigue, seizure activity, or medication effects.
- A student may understand a concept but have difficulty organizing, initiating, or completing the work.
- Absences and recovery time can create gaps that compound over time.
- Inconsistency can be misread as lack of effort — especially when a student has strong abilities in other areas.

Inconsistent performance is still real performance data.

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Memory and Epilepsy

What families may notice

- Forgetting instructions that were just given
- Difficulty recalling information during a test
- Needing repeated exposure to new material
- Remembering the concept but not the details
- Difficulty retrieving a word, fact, or step under pressure

Questions worth asking

- Is the difficulty new or changing?
- Does it happen after seizures or at certain times of day?
- Does written information help?
- Would repetition, cueing, or extra processing time help?
- Is a neuropsychological or educational evaluation worth discussing?

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When Memory Is the Challenge: Supports to Discuss

- Provide written directions in addition to verbal instructions.
- Break larger assignments into smaller, clearly sequenced sections.
- Allow extra time for assignments, quizzes, or tests when appropriate.
- Use repetition, review, and opportunities to relearn material after absences or seizures.
- Support organization with schedules, checklists, planners, or teacher check-ins.
- Consider a quieter or alternate testing location when distraction or processing is a concern.

The best support is the one that matches the student's actual barrier.

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Executive Function: The "Management System" of Learning

Starting
Getting going without becoming stuck

Planning
Seeing the steps needed to reach a goal

Organizing
Managing materials, information, and tasks

Working Memory
Holding information in mind while using it

Shifting
Moving between tasks, ideas, or expectations

Time Management
Estimating, prioritizing, and using time

Executive-function difficulty can look like motivation or behavior when the underlying problem is task management.

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What Executive-Function Difficulty Can Look Like

At school

- "They know how to do this — but the work isn't getting finished."
- Assignments are completed but not turned in.
- Multi-step projects become overwhelming.
- Transitions between tasks are difficult.
- The student loses track of materials or deadlines.

At home

- Homework takes much longer than expected.
- Starting work becomes a nightly struggle.
- The student needs repeated reminders.
- Planning for the next day is difficult.
- Frustration escalates when there are too many steps.

Try replacing "Why won't they?" with "What part of this task is getting in the way?"

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Practical Supports for Learning

- Give instructions clearly and provide written expectations.
- Break assignments into manageable sections and identify priorities.
- Offer organizational supports — schedules, checklists, planning time, or regular check-ins.
- Provide extended time or an alternate location for testing when appropriate.
- Build in brain breaks or a discreet way to request a pause.
- Give advance notice of changes in routine when possible.
- Make sure substitute staff know the student's relevant plans and supports.

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After a Seizure or Absence: Have a Re-entry Plan

1	**What was missed?**	Identify the essential instruction, assignment, or assessment.
2	**What truly needs to be made up?**	Avoid turning one health-related absence into an unmanageable backlog.
3	**What is the student ready for today?**	Recovery can affect concentration, memory, energy, and processing.
4	**Who helps prioritize?**	A designated adult can reduce the burden of figuring everything out alone.
5	**When do we regroup?**	If recovery or absences are becoming a pattern, revisit the support plan.

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PART III

Supporting the Whole Child

Mental health, belonging, and functional seizures

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Epilepsy and Emotional Well-Being

Why emotional strain can grow

- Seizures are unpredictable.
- A student may worry about having a seizure in front of peers.
- Restrictions or missed activities can affect independence and confidence.
- Academic difficulty can create additional stress.
- Medication, sleep, and co-occurring conditions may also affect mood.

What support can look like

- Regular, caring check-ins
- Access to a trusted adult at school
- Early attention to changes in mood or behavior
- Support for participation and belonging
- Communication among family, school, and healthcare team

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Why Anxiety Can Make Sense

A young person may be wondering...

"Will I have a seizure in front of everyone?"

"Will someone film it or make fun of me?"

"Will people treat me differently if they know?"

"What if I miss something important again?"

"Can I participate safely — or will adults stop me?"

Validation matters: anxiety may be a response to very real uncertainty, stigma, or loss of control.

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When to Pay Attention to Changes

- Withdrawal from friends, family, school, or activities they previously enjoyed
- Increasing school avoidance or fear related to attending school
- Changes in sleep, mood, irritability, or confidence
- Frequent statements of hopelessness, worthlessness, or feeling like a burden
- Sudden academic decline or difficulty functioning that is not explained by missed instruction alone
- Any concern about self-harm or suicide requires prompt professional support

You know your child. A meaningful change from their usual pattern is worth taking seriously.

21

Belonging Matters

What can threaten belonging

- Fear of having a seizure in public
- Feeling different from peers
- Being excluded "for safety"
- Embarrassment about rescue medication or accommodations
- People talking about the student rather than with them

What can strengthen belonging

- Adults who model calm, respectful responses
- Peers who understand seizure first aid
- Opportunities to participate fully when safe
- Privacy choices led by the student and family
- Interests, friendships, and identity beyond epilepsy

22

If Your Child Is Experiencing Stigma or Bullying

- Talk with your child and ask what happened, how often it is happening, and how it is affecting them.
- Document incidents and communicate with the appropriate school personnel.
- Ask the school how its anti-bullying, anti-harassment, and anti-discrimination procedures apply.
- Do not tolerate seizure mimicking, filming, posting, or sharing a student's private medical information.
- Consider whether epilepsy education for staff or peers could reduce fear and misinformation — with the student's privacy and preferences centered.
- Keep checking in. The first intervention may not be the last one needed.

Ask. Document. Communicate. Involve the school team. Keep checking in.

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A Brief Note About Functional Seizures

Functional seizures are...

- real, involuntary events.
- not caused by the abnormal electrical activity associated with epileptic seizures.
- not intentional and not "faking."
- diagnosed and treated with appropriate medical and behavioral-health expertise.

Important to know

- A young person can experience both epilepsy and functional seizures.
- Events may look similar from the outside.
- Clear guidance from the treating team is important when more than one event type occurs.
- School staff need a consistent, individualized response plan.

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Supporting a Student With Functional Seizures at School

- Coordinate among the student, family, treating healthcare providers, therapist, and school team.
- Use an individualized written action plan describing typical events and recommended responses.
- Prioritize safety during an event and follow the plan when event type is uncertain.
- Support return to ordinary school activity as soon as is appropriate for the individual student.
- Consider IEP or 504 supports when symptoms affect access, learning, attendance, or participation.
- Train the adults who may interact with the student — including substitutes, coaches, and paraprofessionals.

Clear plan + consistent response + communication + support returning to school life.

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Who Can Be Part of the Support Team?

Student
Their experience and preferences belong at the center.

Family
Patterns, history, priorities, and advocacy.

Medical Team
Diagnosis, treatment, seizure guidance, recovery needs.

School Nurse
Health planning and school-based coordination.

Educators
Learning, classroom functioning, participation, progress.

Mental Health Team
Emotional, behavioral, coping, and functional-seizure support.

No one person has to hold the whole picture alone.

26

Connection Is Protective

Young people need more than symptom management.

They need places where they can belong, build confidence, practice independence, develop friendships, and be known for more than epilepsy.

That can happen at school, at camp, in support groups, in clubs, in families, in faith communities, in sports, and anywhere a young person is welcomed as a whole person.

Support the condition. Protect the personhood.

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PART IV

From “Something Isn’t Working” to “What Might Help?”

Practical advocacy and school supports

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Start With the Child’s Experience

Before choosing an accommodation, try to name the need.

1	**What is happening?**	Describe what you and your child are noticing — academically, socially, emotionally, and physically.
2	**When does it happen?**	Look for patterns around seizures, recovery, time of day, absences, medication changes, fatigue, or particular tasks.
3	**What makes it harder?**	Consider workload, transitions, missed instruction, stress, or unclear expectations.
4	**What helps?**	Notice strategies that already make learning, recovery, organization, or communication easier.
5	**What does my child say?**	Ask what feels supportive, what feels uncomfortable, and what they want adults and peers to understand.

Advocacy often begins by making an invisible pattern visible.

29

Document Patterns — Not to “Prove” Your Child, but to See the Picture

Things families might track

- Seizure activity and recovery
- Absences, late arrivals, or early departures
- Medication changes or significant side effects
- Fatigue and sleep concerns
- Academic changes
- Emotional or behavioral changes

Also record what helps

- Extra time or reduced workload
- Quiet recovery space
- Written instructions
- Check-ins with a trusted adult
- Organization support
- Specific times or settings where the student does better

Patterns make conversations with the school and healthcare team more concrete.

30

Seizure Action Plan

A good plan helps staff know...

- What the student's typical seizures look like
- What to do during and after a seizure
- When rescue medication should be used, if prescribed
- When emergency services are — and are not — needed
- Who should be contacted

Remember

- Safety planning and educational planning overlap, but they are not the same thing.
- A student can have an excellent Seizure Action Plan and still need academic, emotional, or accessibility supports.
- Plans should be individualized and updated when needs change.

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504 Plans and IEPs: Know That Support May Be Available

Section 504

Some students with epilepsy may need accommodations to ensure equal access to school and school activities.

Examples may include changes in timing, setting, communication, attendance procedures, recovery supports, or other access needs.

IEP / IDEA

Some students may qualify for special education when a disability affects educational performance and the student requires specially designed instruction.

Eligibility and the IEP process are individualized. Michigan Alliance for Families is an excellent resource for understanding these processes.

Our focus today: identify the epilepsy-related need clearly enough to bring it into the school conversation.

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What Could an Accommodation Address?

If the challenge is...	A team might discuss...
Fatigue / recovery	Rest or recovery time; flexible return to academic demands
Memory	Written directions; repetition; cueing; access to notes
Processing speed	Extended time; reduced time pressure; alternate testing setting
Absences	Catch-up plan; prioritization; flexibility with deadlines
Anxiety	Breaks; designated support person; predictable communication plan
Organization	Checklists; planner support; regular adult check-ins
Seizure safety	Seizure Action Plan; trained staff; access to prescribed rescue therapy

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Practical Supports Families Can Discuss With the School Team

- Clear written instructions and expectations
- Extra time on assignments or tests when needed
- Smaller sections for large or multi-step assignments
- A plan for catching up after seizures, illness, or absences
- Brain breaks or a discreet signal for requesting support
- Advance notice of schedule changes when possible
- Alternate testing location or reduced-distraction setting
- Regular communication with a designated school contact

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Communication Is an Accommodation, Too

Decide ahead of time

- Who is the family's primary school contact?
- Who needs updates about seizure or medication changes?
- How will the family learn about missed instruction?
- How will the student ask for help privately?
- What information should substitutes, coaches, and transportation staff receive?

Revisit when

- Seizure type or frequency changes
- Medication changes affect functioning
- Absences or recovery time increase
- Academic performance changes
- Anxiety, mood, or participation changes
- The student says the plan is no longer working

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The Goal Isn't to Predict Every Problem

The goal is to create a team that knows how to respond when needs change.

A strong plan is not a promise that nothing difficult will happen.

It is a shared understanding of what the student needs, who will communicate, and how the team will adjust when the current plan is no longer enough.

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When You Need Help: Two Partners

Michigan Alliance for Families

- Special education information and family support
- IEP and eligibility process guidance
- Understanding family and student rights
- Resources for navigating school systems

Epilepsy Foundation of Michigan

- Epilepsy-specific education and resources
- School and individual advocacy support
- Seizure Recognition & First Aid training
- Connection to programs, groups, and community support

You do not have to become an expert in everything before you ask for support.

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PART V

From Advocacy for Your Child to Advocacy with Your Child

Building student voice, self-advocacy, and independence

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What Is Self-Advocacy?

"An individual's ability to effectively communicate, convey, negotiate or assert their own interests, desires, needs, and rights."

It also involves making informed decisions and taking responsibility for those decisions.

Self-advocacy grows through practice — not all at once.

Adapted from Anthony K. Van Reusen and colleagues

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Supporting Student Voice

- Involve students in IEP, 504, health-plan, or school-support conversations in developmentally appropriate ways.
- Ask students what they want and need after a seizure.
- Invite them to identify what helps them learn, recover, organize, and participate.
- Support their choices about what they want peers to know about epilepsy.
- Encourage them to practice asking questions and requesting support.
- Keep their broader interests, goals, strengths, and identity visible in every conversation.

Students with epilepsy are not just their medical condition.

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Ask: "How Do YOU Want to Be Supported?"

What helps you feel safe?	**What makes things harder?**
Who do you want to know about your epilepsy?	**What do you want friends to know?**
What should adults do after a seizure?	**What makes you feel respected?**

Self-advocacy includes more than safety. It includes how a young person wants to be treated, included, and cared for.

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Self-Advocacy Is Bigger Than Epilepsy

Help young people build

- Confidence to talk about what works for them
- Resilience as they adapt to change
- Skills for asking questions and making choices
- Friendships and peer relationships
- Comfort naming when something feels unfair or inaccessible

Keep making room for

- Interests that have nothing to do with epilepsy
- Clubs, sports, arts, volunteering, and community
- Leadership and public advocacy — if they want it
- Dreams about education, work, relationships, and adulthood
- Joy, humor, experimentation, and ordinary adolescence

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Growing Toward Independence

Health
Understand epilepsy, medications, appointments, and when to ask for help

Education
Know learning needs and how to request supports

Daily Life
Build routines, organization, transportation, and self-management skills

Work
Explore strengths, interests, accommodations, and workplace communication

Community
Develop relationships, participation, and access to resources

Decision-Making
Practice choices, problem-solving, and self-advocacy

Independence does not mean doing everything alone. It means building skills, making choices, and knowing how to use support.

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PART VI

You Don't Have to Figure This Out Alone

Epilepsy Foundation of Michigan programs and support

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Epilepsy Foundation of Michigan

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OUR MISSION

Improve the lives of people affected by epilepsy through education, advocacy, research, and connection.

OUR VISION

So no one faces epilepsy alone.

We serve individuals and families across the entire state of Michigan.

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Here for You Helpline

Call us when you have questions about...

- Understanding diagnosis or treatment
- School issues and advocacy
- Emotional well-being and mental health resources
- Employment, transportation, or financial concerns
- Finding epilepsy specialists or community resources

What you can expect

- A compassionate, knowledgeable person who will listen
- Time to talk through what you are navigating
- Information and resources tailored to your situation
- Invitations into EF-MI programs and community
- Follow-up when appropriate

Here for You Helpline: 1-800-377-6226

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Programs for Young People, Families, and Schools

Kids Camp & Family Camp
Safe, inclusive camp experiences that build confidence, connection, and belonging.

E-SMART
Teen self-management program supporting skills, goals, and resilience.

Back to School Resources
Education for families and schools around learning, rights, safety, and support.

Seizure Recognition & First Aid
Training for schools, colleges, workplaces, community organizations, and families.

Individual Advocacy
Epilepsy-specific support when a family is navigating a difficult school or life situation.

Education & Resources
Guides, webinars, referrals, and practical information across the lifespan.

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Connection and Support

Parents Call & Connect
Weekly connection for parents and caregivers.

Young Adults Call & Connect
Peer connection for young adults navigating epilepsy and independence.

Adults & Caregiver Groups
Multiple virtual groups for different ages and life stages.

U.P. Virtual Meetup
Connection for people across Michigan's Upper Peninsula.

Mindfulness Moments
Monthly opportunities to practice mindfulness and coping.

Project UPLIFT
An evidence-based program supporting mood and quality of life.

Ask us which group or program might fit your family right now.

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Questions & Conversation

Your child deserves to be safe, understood, included, challenged, and supported at school.

You don't have to know every answer before you advocate.

Listen to your child. Notice patterns. Ask questions. Build a team. Reach out when you need support.

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We are here to support you!

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- /MichiganAlliance

For more information visit
www.michiganallianceforfamilies.org

Call 800-552-4821
En Español 313-217-1060
248-963-0607 للغه العربيه
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Michigan Alliance for Families

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Michigan Alliance for Families

In collaboration with The Arc Michigan

Michigan Alliance for Families is an IDEA Grant Funded Initiative of the Michigan Department of Education, Office of Special Education (MDE-OSE); the Michigan Department of Lifelong Education, Advancement, and Potential (MiLEAP); and Michigan's Federal Parent-Training and Information Center (PTIC) funded by the U.S. Department of Education, Office of Special Education Programs(OSEP).

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