# **Programs and Services of Our Member Organizations**



Real Epilepsy Help



epilepsyallianceamerica.org

## Providing real epilepsy help to nearly 1 million Americans living with epilepsy



Epilepsy Alliance America is dedicated to supporting those impacted by epilepsy in local communities by confronting the spectrum of challenges created by seizures. There are currently ten organizations that are members of the Alliance:

- Epilepsy Alliance Louisiana
- Epilepsy Alliance
   North Carolina
- Epilepsy Alliance Ohio
- Epilepsy Association of Western and Central PA
- Epilepsy Florida
- Epilepsy-Pralid, Inc.

- Epilepsy Services of New Jersey
- Sociedad Puertorriqueña de Epilepsia
- Valley Children's Healthcare
- Epilepsy Advocacy
   Network

## What is epilepsy?



Epilepsy is a neurological condition that causes a person to have recurring seizures. A doctor may diagnose you with epilepsy if you have one or more seizures, it is likely you will have more seizures, and the seizure is not directly caused by another medical condition (such as diabetes or an infection).

Epilepsy is a spectrum disorder. The impact of epilepsy varies from person to person.

Epilepsy is not a mental illness, or a sign of low intelligence. It is not contagious. Epilepsy is generally a chronic and/or lifelong condition.

#### What is a seizure?

A seizure is a sudden surge of electrical activity in the brain. Seizures can alter awareness, physical movements, emotions, or actions and generally last a few seconds to a few minutes. Seizures can take on many different forms and affect people very differently.

There are many different types of seizures but they can be classified into two main categories: generalized and focal.

Generalized seizures mean that the entire brain is engaged in the seizure. The person may become unconscious or unresponsive. Generalized seizures may be convulsive or non convulsive. Types include tonic-clonic, absence, myoclonic, and atonic seizures.

Focal seizures involve only certain parts of the brain. The person may remain aware, be confused, have automatic muscle movements, and/or experience changes in taste, sight, smell, or feelings. These seizures are classified by whether or not there is a change in awareness.

## What does "Real Epilepsy Help" mean to us?



If you or someone you love needs help, please contact your local Epilepsy Alliance America member organization to find out more about other local programs and services that are available.

If there is not an EAA member organization near you, please call 800-642-0500 for help!

Epilepsy is a condition that affects individuals and families in different ways. You may face challenges because of the types of seizures you have, the side effects from medications, or other things either directly and indirectly associated with epilepsy.

The Epilepsy Alliance America (EAA) is a group of organizations dedicated to providing support to all those impacted by epilepsy. In this brochure you will find a list of programs that many of our member organizations offer, but there are even more ways that we can help that are not included in this list!

## **Membership Opportunities**

If your organization has a mission that aligns with ours, you should consider becoming a member of the Epilepsy Alliance America (EAA). Membership provides a wide range of benefits and supports such as:

- Connection to a national epilepsy association and a network of individuals and organizations working in the field of epilepsy;
- The opportunity to contribute to and benefit from EAA programs and activities;
- Involvement in EAA's collaborative partnerships and community engagement strategies;
- The invitation to be included in EAA's Committees, Task Forces, Networks, and User Groups;
- Connecting and networking opportunities with the major influencers in the epilepsy community;
- Analyses of legislative and advocacy activity for members to gain insight into pressing policy issues and add their perspectives, views, and voice to these key issues;
- Access to breaking news and opportunities to participate in advocacy efforts and awareness campaigns;
- The opportunity to promote organizational priorities and efforts through EAA's platforms;



## **Epilepsy Alliance America Services**



#### **Camp Programs**

We offer a wide selection of camp programs, including day programs, weekend camps, and weeklong summer camps. These include camps for children, teens, and adults with epilepsy.



#### **Individual/Family Consultation**

We provide customized one-on-one support to individuals and families affected by epilepsy, based on the specific needs that are shared with our experienced and knowledgeable staff.



#### **Medication Assistance**

We provide medication assistance for individuals and families who cannot afford their anti-seizure medications



#### **Seizure First Aid Training**

We train school staff, including nurses, teachers, and support staff, and students of all ages how to recognize and respond to seizures. We also provide training for first responders and other community organizations.



#### **Support Groups**

We host a variety of support groups for children, teens, adults, and parents impacted by epilepsy. These include groups that meet locally, as well as online groups.



#### **Community Education**

We host conferences, workshops, webinars, and more to teach people about epilepsy and how to help their friends and neighbors that are affected by seizures.



#### **Information and Referrals**

We provide information about epilepsy and connect people with other community resources and organizations which can provide additional support. Additional services may include: care coordination, family weekend retreats, health literacy, in-person assistance, individual case management, legislative & school advocacy, medical & diagnostic services, seizure response dog fund. Not all services are available in all areas. Contact your local epilepsy organization to find out which of these programs and services are available in your local community.



#### **Networking/Social Events**

We host networking groups and social events for people of all ages, providing opportunities for those impacted by epilepsy to meet others who are confronting similar challenges.



#### **Seizure Movement Monitor Assistance**

We can help you decide if a movement monitor might detect your seizures and connect you with resources that may be able to provide a monitor for free.



#### **Telephone Support**

Even if you are not sure what help you need, call your local epilepsy organization and we can talk through the programs, services, and community resources that might be right for you.



#### **Employment Assistance**

We help individuals with epilepsy who are seeking employment by offering resume and interview skills assistance, identifying available jobs, and providing training to employers.



#### **Legislative Advocacy**

We can help you make sure your voice and your story are heard, by connecting you with your local legislators.



#### **Residential Services**

We provide a safe home for some individuals who are severely impacted by epilepsy and other coexisting conditions.



#### **Special Education Advocacy**

We can teach you about the rights of children with epilepsy in school and assist with special education services like Seizure Action Plans, 504 Plans, and Individualized Education Plans.

## **Epilepsy Alliance Louisiana**



Main Office 4137 S Sherwood Forest Blvd Suite 210 Baton Rouge, LA 70816

**Phone** 

(225) 298-5490 (800) 960-0587

Website

www.epilepsylouisiana.org

#### Follow us on social media

f Facebook facebook.com/epilepsy.louisiana

Instagram @epilepsylouisiana

Twitter @EpilepsyLA



Camp Programs



Individual/ Family Consultation



Medication Assistance



Seizure First Aid Training



Support Groups



Community Education



Information and Referrals



Networking/ Social Events



**Seizure Movement Monitor Assistance** 



Telephone Support



**Employment Assistance** 



Legislative Advocacy



Special Education Advocacy



Medical Support



Our *Preteen Education Series* is an interactive social media program that encourages kids to take an active role in their health and epilepsy management. We help children develop skills that will prepare them to overcome any challenges life throws their way!

## **Epilepsy Alliance North Carolina**



Main Office Piedmont One, Suite 5541A 1920 West First Street Winston-Salem, NC 27104

**Phone** 

(336) 716-2321 (800) 642-0500

Website

www.epilepsync.org

#### Follow us on social media



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Instagram

@EpilepsyNC



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Medical Support





Shared story of hope: Kim King shares her family's story, with two daughters (Whitney and Mackenzie King) affected by epilepsy by Marty Kelso.

Read the full story at https://epilepsync.org/kim-king/

## **Epilepsy Alliance Ohio**



Main Office

895 Central Avenue, Suite 550 Cincinnati, OH 45202-5757

Additional Location

3857 N High Street, Suite 206 Columbus, OH 43214

**Phone** 

(513) 721-2905

Website

www.epilepsy-ohio.org

#### Follow us on social media

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Seizure First Aid Training



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Community Education



Information and Referrals



Networking/ Social Events



Telephone Support



**Employment Assistance** 



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Residential Services



**Special Education Advocacy** 



Our *Mom's Group* is a support network on Facebook that also meets in person every other month. We provide the pizza, wine, and location so moms can meet other moms and share their challenges and triumphs. Sometimes they just talk and other times we bring in a presenter or plan a fun activity like painting and wine night. It is a great way for moms to connect and they love it!

## **Epilepsy Florida**



Main Office

7300 N Kendall Drive, Suite 760 Miami, FL 33156

Additional Locations

Broward, Palm Beach, Gainesville, Jacksonville, Pensacola, and Naples

**Phone** 

(305) 670-4949

(877) 553-7453

Website

www.epilepsyfl.com

#### Follow us on social media

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Twitter @EpilepsyFLA



Camp Programs / Family Retreats



Individual/ Family Consultation



Medical Support /
Medicine Assistance



Seizure First Aid Training



**Support Groups** 



Community Education



Information and Referrals



Networking/ Social Events



Care Coordination



Telephone Support / Telemedicine



Seizure Response Dog Fund



Legislative Advocacy



Travel Fund



**Special Education Advocacy** 



Our *Telemedicine Program* provides neurological care through "virtual office visits", for individuals that find it difficult or too far to travel to the doctor's office. The doctor and patient video conference using any smart device, such as a smart phone or laptop. It's just the same as an in-person visit, without the hassle.

## **Epilepsy Association of Western and Central PA**



Main Office 1501 Reedsdale Street, Suite 3002 Pittsburgh, PA 15233

Additional Locations

3507 Market Street Suite 203 Camp Hill, PA 17011

**Phone** 

(412) 322.5880 (800) 361-5885

Website

www.eawcp.org

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Special Education Advocacy



Medical Support



Our *Emma's Gift program* can provide free movement detection monitors for individuals who have nocturnal convulsive seizures to alert loved ones when a seizure might be happening. Applications are accepted from anywhere in the United States.

#### **Epilepsy-Pralid, Inc.**



Main Office

2 Townline Circle Rochester, NY 14623

Additional Locations

Binghamton

23 Jackson Ave, Ste 127 Endicott, NY 13760

Rochester

1650 South Ave, Ste 300 Rochester, NY 14620

Syracuse

6493 Ridings Rd, Ste 115 Syracuse, NY 13206

Phone

(585) 442-6420

Website

www.epiny.org

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Twitter @EPI\_NY



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**Seizure Movement Monitor Assistance** 



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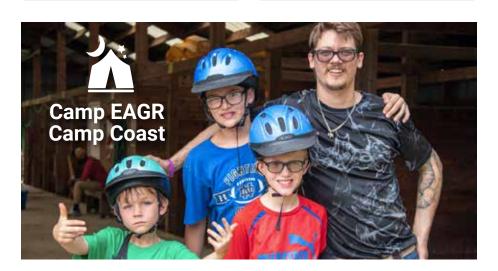
Legislative Advocacy



Special Education Advocacy



Medical Support



We offer two annual sleepaway camps for kids and young adults with epilepsy.

Camp EAGR is a week-long camp for kids age 8 to 17 with epilepsy and their siblings.

Camp Coast is for young adults aged 18+ with epilepsy and other disabilities. The camps provide connections with peers and respite for parents.

## **Epilepsy Services of New Jersey**



Main Office 50 Millstone Road Building 300, Suite 201 East Windsor, NJ 08520

**Phone** 

(800) 336-5843

Website

www.epilepsyservicesnj.org

#### Follow us on social media

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**Employment Assistance** 



Legislative Advocacy



Our *Camp NOVA* is a wonderful opportunity for children and young adults living with epilepsy and other developmental disabilities to enjoy summer camp. Camp NOVA provides an exciting and independent camping experience in an environment filled with fun experiences and memories that last a lifetime.

## Sociedad Puertorriqueña de Epilepsia



Main Office 1100 Calle Marginal Ruiz Soler Bayamon, Puerto Rico 00961-7265

**Phone** 

(336) 716-2321 (800) 642-0500

Website

https://www.sociedadepilepsiapr.org/

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**Employment Assistance** 



Legislative Advocacy



Residential Services



**Special Education Advocacy** 



Our *public awareness efforts* promote the control of epilepsy and education about epilepsy and seizures. We support all people living with epilepsy in Puerto Rico!

## Valley Children's Healthcare



Main Office 9300 Valley Children's Place Madera, CA 93636-8762

**Phone** 

(559) 353-3000

**Website** 

www.valleychildrens.org

#### Follow us on social media

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Twitter @CareForKids



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Residential Services



**Special Education Advocacy** 



Our NICU nurses see the world through a different lens and cradle the sanctity of life everyday. In these difficult times, our team continues to provide high-quality care to our tiniest patients and their families.

## **Epilepsy Advocacy Network**



Locations

616 35th Ave, Suite 3 Moline, IL 61265

303 E Hillcrest Dr., Suite 1 DeKalb, IL 60115

Phone

(309) 472-6264

(815) 909-0241

Website

epilepsyadvocacynetwork.org

#### Follow us on social media



**Facebook** 

https://www.facebook.com/ EpilepsyAdvocacyNetworkQuadCities/



YouTube

https://epilepsyadvocacynetwork.org/contact-us/



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