Epilepsy Foundation of America
Database Listing Criteria

Introduction

The Epilepsy Foundation of America (EFA) Epilepsy and Seizures Helpline provides information and referrals to people affected by seizures and the epilepsies. To provide this service, the EFA maintains an electronic resource database of epilepsy-related national and international resources. The EFA strives to keep these resources current through a scheduled verification process. The EFA reserves the right to determine what organizations and programs will be included in this database. In addition to the criteria listed below, the EFA will gather information from external sources, including GuideStar, Charity Navigator, the Better Business Bureau, the Internal Revenue Service, consumer reports, news sources, and consumer surveys. The final decision to include an organization or program shall be at the sole discretion of the EFA.

Organizations that may be included

- Epilepsy Foundation local chapter and affiliate partner offices and programs.
- Nonprofit organizations, critical for-profit organizations, and governmental entities that provide health programs, social services, educational resources, employment assistance, legal assistance, financial assistance, recreational resources, and other health & human services programs to people, including those affected by seizures and the epilepsies.
- Nonprofit organizations and critical programs that serve people with rare diseases or complex medical conditions, such as seizures, epilepsy, seizure-like episodes, or related neurological complications, may be a symptom, risk, or common co-occurring concern.
- Nonprofit organizations, critical for-profit organizations, and governmental entities that provide support, information, advocacy, navigation, emergency assistance, or care coordination for people experiencing a life-threatening illness or injury, when those services may benefit people affected by seizures and the epilepsies or their caregivers. Services can include those that provide memory programs or applications that assist with memory, transportation, housing, employment, job placement, medication payment assistance, medical expense assistance, rent/mortgage payment assistance, utility payment assistance, and other basic or financial needs.
- Nonprofit organizations, such as religious groups, social clubs, and community associations that offer services to people, including those affected by seizures and the epilepsies, and do not require membership or enrollment as a member to receive services.
- Nonprofit self-help support groups for people affected by seizures and the epilepsies.
- Nonprofit and critical for-profit international organizations that help people affected by seizures and the epilepsies.

- Nonprofit organizations that advocate for policies which support the health and safety of people affected by seizures and the epilepsies.
- For-profit organizations that provide specific, unique services to people affected by seizures and the epilepsies.
- For-profit or nonprofit organizations that provide seizure alert devices, applications, or services designed to detect or identify seizure or seizure-like activity and automatically notify a designated caregiver, responder, or emergency contact, when the device or service offers a specific, verifiable safety benefit to people affected by seizures and the epilepsies.
- Coalitions of healthcare providers, mental health professionals, and allied health services that specialize in working with people affected by seizures and the epilepsies.
- Behavioral health providers who have successfully completed the Epilepsy Foundation's behavioral health training and registered as an Epilepsy Foundation Preferred Provider.
- Behavioral health providers, or practices, which provide specialized services for people affected by seizures and the epilepsies related to functional neurological disorders or non-epileptic seizures.
- Privately owned websites, blogs, or chat groups that are peer-run groups for rare epilepsy for which no other organization or program exists, including programs that provide unregulated services or support groups for rare epilepsy when no other program exists.

Why an organization may not be included

Certain types of organizations that are not ordinarily included:

- Organizations that explicitly deny service or engage in discrimination based on color, race, ethnicity, religion, creed, gender, gender identity, sexual orientation, ancestry, or nationality, or require membership fees that serve primarily to discourage specific groups of people from seeking their services.
- Organizations and governmental entities that offer services or engage in unlawful practices under federal, state, and local laws or the laws within their specific country or have been publicly charged with or convicted of actions not in the best interests of those they serve.
- Organizations that offer services that do not work with, or deny services to, people affected by seizures and the epilepsies.
- Organizations focused on rare diseases, complex medical conditions, or neurological conditions that do not provide services, information, advocacy, navigation, or support

relevant to people who may experience seizures, epilepsy, seizure-like episodes, or related neurological complications.

- Organizations, websites, blogs, support groups, or programs that promote unproven, unsafe, or medically unsupported treatments, emergency interventions, or crisis guidance for seizures, epilepsy, rare diseases, life-threatening illness, or injury.
- Devices, applications, or services promoted for detection, monitoring, tracking, or safety that do not automatically alert a designated caregiver, responder, or emergency contact when a seizure or seizure-like event occurs, if they are presented as emergency-alert, crisis-response, or life-safety services.
- Private practices of medicine, social work, nursing, counseling, psychiatry, psychology, physical or occupational therapy, etc., that do not have a specialty in working with people affected by seizures and the epilepsies.
- Any organization that repeatedly fails to respond to EFA requests for current program information or misrepresents, by omission or commission, pertinent information about their services or any other pertinent matter.
- Any organization that repeatedly refuses to accept referrals from the EFA without cause.
- Privately owned websites, blogs, or chat groups that are not related to rare epilepsy or provide a service that a formal organization offers.

Agreement

Agencies and programs that the Epilepsy Foundation includes in the database agree:

- To accept referrals from the Epilepsy Foundation's Epilepsy & Seizures Helpline.
- To verify their current agency, contact, and program information at least annually.
- That a listing in the database is not a formal partnership with the Epilepsy Foundation.
- That being listed in the database does not grant the organization permission to use the Epilepsy Foundation of America logo.

Completing and submitting the Directory Listing Application is considered acceptance of these terms.

The Resource Specialist or Helpline Director will review these criteria at least twice each year to ensure that the resource database continues to meet the changing needs of the epilepsy community. Where exceptional circumstances exist, or where circumstances not

covered in these guidelines do not currently exist, the Resource Specialist and the Helpline Director will review the organization in question.

The fact that an agency is or is not listed in the database is neither an endorsement nor a lack of approval of their purpose, method, or quality of service.

Questions

Please direct any questions, comments, or concerns to our Resource Specialist via email at resources@efa.org or by phone at 800-332-1000.

Appeal

If an agency would like to appeal the content of the resource record or has been denied acceptance into the resource database, an agency representative may request an appeal by email to resources@efa.org. Please include the full agency name and program name, which is the focus of the appeal, along with an explanation of why you believe the agency meets our Database Listing Criteria. If the appeal is concerning the language used in the resource record, please explain why the language you are requesting is essential to the record. The Helpline Director will review the appeal and respond within two weeks. Any decision by the Helpline Director will be final.

Disclaimer:

The Information Specialist will strive to provide the most accurate and appropriate information and referral possible. However, EFA is not responsible for the quality of service delivered by a referral agency not directly affiliated with EFA. The Information Specialists will provide referrals to the most appropriate, available agencies and will not recommend one agency over another.

The resource directory information is current to the best of our knowledge and abilities. However, you should always call the provider to confirm the information and make an appointment. Be sure to verify eligibility and any payment information. The EFA does not rate or endorse any non-Epilepsy Foundation agency but provides this information as a public service to those in need.

The Epilepsy Foundation reserves the right to edit information provided by organizations to meet style, format, and space requirements.