

Epilepsy Foundation Resource Database Listing Criteria

The Epilepsy Foundation of American (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 outside resources such as GuideStar, Charity Navigator, the Better Business Bureau, 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 affected by seizures and the epilepsies.
- Nonprofit organizations, such as religious groups, social clubs, and community associations which offer services to people 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 that 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.
- Coalitions of healthcare providers, mental health professionals, and allied health services that specialize in working with people affected by seizures and the epilepsies.
- Private practices that provide a specialized program for people affected by seizures and the epilepsies.
- Privately owned websites, blogs, or chat groups that are peer-run groups for rare epilepsy for which no other organization 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 certain groups of persons 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 interest of those they serve.
- Organizations that offer services that do not work with people affected by seizures and the epilepsies.
- 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 EFA includes in the database agree:

- To accept referrals from the EFA.
- 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 EFA.
- That being listed in the database does not grant the organization permission to use the EFA logo.

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

The resource specialist or the helpline director will review these criteria at least twice every year to ensure that the resource database continues to meet the changing needs of the epilepsy community. Where exceptional circumstances that are 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: resources@efa.org or phone: 800-332-1000.

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. Information Specialists will provide referrals to appropriate, available agencies and not recommend one agency over another.

The resource directory information is current to the best of our knowledge. However, you should always call the provider to confirm the information and make an appointment. Be sure to confirm payment information with the provider if payment is required. 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 organizations provide to meet style, format, and space requirements.