

WELCOME TOOLKIT



TABLE OF CONTENTS

3	OUR MISSION
4	WELCOME
5	USE OUR RESOURCES
6	TIPS FOR PATIENTS & FAMILIES
8	CHECKLIST FOR MEDICAL APPOINTMENTS
9	MEDICATION CHART
10	JOIN THE AE COMMUNITY
11	EVENTS & FUNDRAISING

The Autoimmune Encephalitis Alliance was started by families and patients affected by autoimmune encephalitis. Founded in 2012 the AE Alliance is a 501(c)(3) non-profit organization based in Durham, North Carolina.

OUR MISSION

The Autoimmune Encephalitis (AE) Alliance strives to **educate physicians** in evidence-based best practices for the diagnosis and treatment of AE. Successful patient care requires a collaborative, multidisciplinary approach.

The AE Alliance endeavors to establish a **supportive community** of patients, families and caregivers, so that no one faces autoimmune encephalitis alone.

The AE Alliance works to **facilitate scientific research** into the causes of AE and its treatment, with confidence that **a cure will be found**.

WELCOME

To the newest member of our community: I want to extend a personal appreciation for connecting with us.

We formed AE Alliance in 2012 in hopes of creating a community of knowledge, resources, and connection. We truly believe that no one should face AE alone.

While many of us want to draw comparisons among experiences, we recognize that each path is different. We respect these differences and use them to inform all our efforts. We share stories of patients recovering from AE. We are constantly expanding our Clinician's Network so that patients can find doctors in their area. We fund critical research. We communicate directly with doctors and patients. We support fundraising efforts like the Florence Forth race/run/walk, where participants can gather to show their commitment to raising awareness of AE.

Diagnosis and treatment of AE are ever-changing, and we strive to remain on the front line of distributing critical care information. It is our sincere hope that as the medical community learns more about AE, it will one day become a curable disease. Sharing your experiences, asking questions, seeking answers and contributing to the community will ensure that AEA can continue to help those in need.

All of our services are free of charge, and we appreciate each and every contribution. Your support sustains our organization and facilitates progress for medical and patient communities alike.

We hope our Welcome Kit will be a helpful resource. On behalf of the AEA board, welcome to the community.

Sincerely,



Will McDow

Co-Founder, AE Alliance
Chairman, Board of Directors

USE OUR RESOURCES

AE SMART PATIENTS

Join our online AE Smart Patients community, a safe, and engaging online community, available from anywhere 24/7



JOIN A SUPPORT GROUP

To join a support group and connect with others affected by AE, please contact us at support@aealliance.org



FIND A DOCTOR

Find a doctor who has experience treating AE using our searchable Clinician's Database at aealliance.org/clinicians



TIPS FOR PATIENTS & FAMILIES

Know Your Healthcare Options

Have a point person. AE requires multidisciplinary care. If your hospital doesn't assign case managers, ask your primary care physician to coordinate communication and care between specialists.

If your insurance plan doesn't cover certain medications, or you have a high-deductible plan, you have options. Talk to your clinician. Some drug manufacturers offer patient assistance programs. Look for online resources and apps that can help save on prescription drugs and treatments, regardless of whether or not you are insured.

Take advantage of hospital resources. Contact the hospital's medical social worker, who can help with social, emotional, environmental, financial and other support needs.

Compare bills from providers with insurance explanation-of-benefit statements, looking for discrepancies. Consider filing bills and explanation of benefits (EOBs) in a 3-ring binder for easy reference.

Insurance denials happen. Don't despair: appeals are often successful. Familiarize yourself with your plan's appeal process, and work with your clinician to formulate a plan. Your clinician may have experience writing letters of appeal and conducting peer-to-peer telephone appeals with insurance company doctors.

TIPS FOR PATIENTS & FAMILIES

Get Organized

Patients with AE will interact with doctors from many medical disciplines. **We recommended using a large 3-ring binder to keep copies of doctor reports, current medications, lab results and other documents in one place.**

Use a monthly planner to document symptoms, changes in medications, or other information pertinent to care. Take the binder and planner with you to all appointments. This can be helpful for caregivers and doctors in monitoring a patient's health.

Use a pill organizer and a medicine chart (see page 9) to manage medications.

Get Support

AE is stressful for patients and caregivers alike. Discuss your feelings **with a hospital social worker or therapist**. Caregivers: **take time for yourself and the things you enjoy** — even if it's just a 15-minute walk around the block. Talk to the hospital social worker about respite care.

Family, friends and neighbors often want to help, but they might not know how. Consider using one of many free websites or apps that make it easy to coordinate meals, childcare, or household chores. Appoint a willing family member or friend to manage it for you.

CHECKLIST FOR MEDICAL APPOINTMENTS

- 3-ring binder or folder of medical documents
- Planner
- A pen and paper to take notes
- Written questions for doctor
- Adult patients: consider bringing another person as an advocate and notetaker
- Something to pass the time in waiting rooms/infusion suites
- Food and drink

JOIN THE AE COMMUNITY

Connect on Social Media

Share our statuses, retweet our tweets, invite others to join us. We also have educational videos you can share with family, friends and your social media community.

 facebook.com/AEalliance

 twitter.com/ae_alliance

 linkedin.com/company/autoimmune-encephalitis-alliance-inc

 instagram.com/aealliance

 vimeo.com/aealliance

Sign Up for Updates

Subscribe to the AE Alliance newsletter to have access to a growing community and the latest in AE research and news. Visit our website to find the newsletter signup form in the footer.

Spread the Word

Take AE Alliance brochures to your treating doctor's office. Ask that the brochures be made available to patients with AE. You can request brochures by contacting us.

Share Your Story

Our blog regularly features powerful patient and family stories. Share your story at aealliance.org/support-the-alliance/share-your-story

Visit AEAlliance.org



EVENTS & FUNDRAISING

Attend Florence Forth

Held annually in Durham, NC, on the first Saturday in March, Florence Forth is the largest annual fundraiser for AEA. Or join us virtually, and run or walk in your own area.

Host Your Own AE Awareness Gathering or Fundraising Event

We have created an AE Awareness Toolbox for you to help with planning your event, order yours at info@aealliance.org

Shop AmazonSmile

Use this link and 0.5% of purchases will go to the AE Alliance:
smile.amazon.com/ch/46-1584730

Have questions?

Want to connect with other members of the AE community?

Need guidance?

CONTACT US

AUTOIMMUNE
ENCEPHALITIS
ALLIANCE

