

AEA NEWSLETTER

JUNE 2021



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FRIENDS,

This edition of our AEA Newsletter is dedicated to the many partners and supporters who have helped us serve the AE Community over this challenging past few months. Their contributions of time, funding, and encouragement inspire and fuel our continued efforts in our mission.

I would like to start with a big thank you to **Daniel and Helen Egger**, two of our founders, and **Bob and Suzi Given**, previous board member and AE survivor and his spouse, for their financial support and encouragement of our new **AEA website**. This was a mammoth project possible only because of their generosity and dedication to excellent educational tools and information for the AE community. Hopefully, you have gotten acquainted with our site over the last few weeks.

And speaking of the website, I would like to highlight our own **Kimberley de Haseth**, AEA Program Director, who spent countless hours working with our **Medical Advisory Board and Clinicians Network** (who assisted in writing and/or vetting medical data), and our web development team. Kimberley was singularly focused on ensuring the best possible web experience for the many patients and caregivers who rely on this information at a critical time in their lives and the many physicians who seek collaboration with others treating autoimmune encephalitis. Kimberley is compassionate, dedicated, multi-talented, and driven to serve each and every one of you. I could not ask for a better partner in our efforts here at the Alliance.

In the pages of this newsletter, you will get the opportunity to meet our web development team led by **Beverly Murray** of **R+M Agency**. Beverly knows first-hand the challenges of dealing with an autoimmune disorder and brought to this effort a true understanding of our goals and objectives. She and her team at R+M (**Chris Holleman**, **Blair Hamlett**, **Melissa Vega**, and one of their business partners, **Mike McTaggart** of **Global Digital IT**), have worked diligently to bring our vision for this site to fruition. We thank them from the bottom of our hearts.

In March, we held our 9th annual **Florence Forth Road Race**, both in-person in Durham, NC, and virtually across the globe. Despite COVID-19, which necessarily created certain limitations to safeguard participants, this race was a huge financial success for the AEA. But this race doesn't just happen on its own! Thanks to the extraordinary efforts of two of our founders, **Will and Leslie McDow**, and a highly dedicated AEA Board member and friend, **Carrie Painter**, thousands of people have enjoyed the Florence Forth Road Race over the years while supporting the Alliance's programs and services. This race is truly a labor of love for all three of these individuals, and we owe them our appreciation for organizing the most significant fundraiser the AEA conducts annually. I wish to personally thank each of them for their extraordinary dedication, as well as you, the AE community, for participating in this important event.

Each of you should be aware of our signature research fundraising effort now in its second year, the **Research Network**, and its companion, the **AEA Community Seed Grant Program**. This is one of the most compelling and essential undertakings of the Alliance. I wish to extend a huge thank you to those in the AE community and the AEA Board who chose to support this vital program. Your giving last year, along with the efforts of an exceptionally dedicated young AE survivor, **Alexander Berman**, and his family and friends, enabled the Alliance to fund three research seed grants spotlighted over May in our campaign communications. And because of the continued generosity of highly motivated AEA board members and individuals from the AE community this year, we ended our May Research Network campaign with sufficient funding to sponsor at least two more research grants in our next cycle!

Regarding the AEA Community Seed Grant Program, I would like to extend a special thank you to the AEA Medical Advisory Board Research Committee, which served as the grant review team this year. **Dr. Anusha Yeshokumar, Dr. Eric Lancaster, Dr. Jonathan Kuo, Dr. Maarten Titulaer, Dr. Myrna Rosenfeld, and Dr. Sean Pittock** invested significant time developing the framework for this vital AEA program and reviewing the numerous applications received in this inaugural grant cycle. These are renowned professionals in the AE field, and their commitment to fostering promising research and research investigators is to be admired.

It is often said that it takes a village to raise a child. This applies equally to a non-profit. Many individuals committed to changing the course of AE for those impacted by this disease join us in this effort – more than I can possibly credit in this writing. The AE Alliance is blessed with a dedicated board, medical advisory board, staff, and key supporters and partners whose combined efforts are fueling the growth of our programs and services in support of the AE Community. I'm sure you join me in appreciation for all their efforts.

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EXECUTIVE DIRECTOR AND CEO



COMMUNITY SEED GRANT WINNERS

Last year we launched the Research Network at the start of the COVID-19 pandemic, and our AE community rallied behind this effort by donating to advance AE research. In December 2020, we asked physicians and researchers to submit their research proposals through the AEA Community Seed Grant Program, and we received submissions from eight countries! With your support, we can financially support three of these research studies focused on the diagnosis, management, and outcomes of individuals with autoimmune encephalitis.

Our 2021 AEA Community Seed Grant Winners:

Soon-Tae Lee, MD, PhD - Seoul National University Hospital – South-Korea

Development of optimal clinical approaches in seronegative autoimmune encephalitis

Juna de Vries, MD, PhD – Erasmus University – The Netherlands

Patient Reported Outcomes while Manipulating the Immune System in Autoimmune Encephalitis

Amaia Muñoz Lopetegi, MD - Hospital Clinic of Barcelona - Spain

Subclinical activity in anti-LGI1 encephalitis: diagnostic tests and prognostic implications

We want to thank the Medical Advisory Board's research committee members for reviewing and scoring all the submitted proposals and putting forth a recommendation for the AE Alliance's governing board.

JOIN THE RESEARCH NETWORK

Although current therapies in AE are effective in many patients, recovery is often prolonged, and relapses and persistent damage can occur. Research investment is needed to improve our understanding of the disease, shorten the disease course and create long-lasting disease stability. Join the Research Network and further expand our grant program. Together, we are changing the course of AE.



DR. SOON-TAE LEE

SEOUL NATIONAL
UNIVERSITY HOSPITAL
SOUTH-KOREA



Dr. Soon-Tae Lee has been awarded the AEA Community Seed Grant to investigate the Development of optimal clinical approaches in seronegative autoimmune encephalitis. Learn more about his study and how this will affect those affected with seronegative autoimmune encephalitis (AE).

[LEARN MORE](#)

You have been awarded the AEA Community Seed Grant, can you tell us more about the study you plan to do?

Seronegative autoimmune encephalitis is AE without any identifiable pathogenic antibody. Although it is the major subtype of AE, very little has been systematically investigated in the disease. Accordingly, not only the patients/families but also the treating physicians confront diagnostic uncertainty, difficulty in deciding appropriate immunotherapy, and inability to predict the final prognosis. This study will investigate the clinical spectrum of seronegative AE, efficacy of multiple immunotherapeutic agents, optimal duration of immunotherapy and MRI follow-ups, and outcome prediction score. Our team of neurologists, radiologists, and clinical coordinators will collaborate to develop a large-scale clinical data set from our institutional cohort of seronegative AE, and will analyze them to find out the answers for the aims.

How will your study help patients and families affected by seronegative AE?

Compared to the seropositive AE, there has been much more unmet needs for seronegative AE. The etiology of the disease is heterogeneous, and we don't know what is the best treatment and what factors decide the prognosis. I hope this study will help patients with seronegative AE to have more evidence-based treatments and predictable care, as like those with seropositive AE.

Tell us more about yourself and your affiliation?

I am a Professor in Neurology, Seoul National University Hospital, Seoul, South Korea. Seoul National University Hospital is a national referral hospital for rare disease including autoimmune encephalitis. Since 2014, I am operating a prospective cohort of autoimmune encephalitis and the only antibody diagnostic lab for the disease. My research is focused on novel treatments of autoimmune encephalitis. Although treatments of autoimmune encephalitis are improving rapidly, many patients still have poor responses to the current immunotherapies, resulting in long-standing disease burdens. To develop better therapeutic protocols, I research the mechanism of refractoriness and conduct clinical trials using novel immunotherapeutic agents in the disease.

BECOME A MONTHLY DONOR

Monthly giving means strong and steady monthly funding that AE Alliance can count on and plan for, allowing AE Alliance to make meaningful long-term commitments to families in need, physicians and researchers. You simply decide on an affordable amount that meets your budget and your desire to help.

DONATE NOW

DR. JUNA DE VRIES

ERASMUS UNIVERSITY
THE NETHERLANDS



Dr. Juna de Vries has been awarded the AEA Community Seed Grant to investigate the Patient Reported Outcomes while Manipulating the Immune System in autoimmune Encephalitis. Learn more about her study and how this will affect those affected with autoimmune encephalitis.

[LEARN MORE](#)

You have been awarded the AEA Community Seed Grant, can you tell us more about the study you plan to do?

First of all, I want to express my gratitude for being awarded for the Seed Grant provided by the AEA Community. Also, on behalf of our research team led by Maarten Titulaer at Erasmus MC in Rotterdam the Netherlands.

At the moment we are working on the implementation of The PROMISE study, which is an acronym for 'Patient Reported Outcomes while Manipulating the Immune System in autoimmune Encephalitis'. The aim of this study is to determine the clinical outcome and disease burden in treated patients with autoimmune encephalitis in the months and years after diagnosis. We want to measure cognitive outcome, fatigue, effects on mood, behavior, daily-life functioning and quality of life.

We are currently developing the questionnaires, and based on the current literature and our expert opinion we pre-selected a set of questions covering the aforementioned outcomes. This April 30th we had a very valuable focus group meeting with 12 patients with anti-NMDAR, anti-LGI1 or high titer anti-GAD65 encephalitis. In this group conversation they told each other about the impact the encephalitis still has on their lives, which was very moving to hear. We noted the items mentioned in this meeting, and added the missing items to our set of questionnaires.

First, we will start with a cross-sectional estimation of clinical outcome and disease burden in the Dutch population of patients aged 16 years or older with autoimmune encephalitis. Besides the questionnaires we also will complete a neurological examination, the mRS, the CASE and a neuropsychological test. From these data we will select the relevant items in the questionnaire to create a shorter questionnaire encompassing the different domains e.g. functionality, quality of life, behavior, mood, and fatigue, which can be used in the prospective phase of the study.

We aim to provide a questionnaire that takes approximately 40-80 minutes to complete. With this slim version of the questionnaire we are going to follow-up newly diagnosed patients with autoimmune encephalitis or a fairly recent diagnosis, meaning in the last two years. These patients we will measure over time for several years.

How will your study help patients and families affected by AE?

By estimating the clinical outcome and disease burden in autoimmune patients more precisely, awareness is raised for the residual symptoms these patients suffer. This will lead to more targeted rehabilitation programs to support patients as best as possible. Furthermore, we as physicians can better inform the patient and their caregivers about what to expect from the future.

Another goal is to use these outcome measures in clinical trials or patient registry comparisons. By measuring clinical outcomes in a standardized way, studies will be able to measure outcomes relevant to the patient. As these items are more sensitive and statistically powerful, trials can contain less participants, highly increasing trial options in these rare diseases and providing earlier tailored care for the patients. This will optimize the care for the autoimmune encephalitis patients in the future.

Tell us more about yourself and your affiliation?

In May 2018 I started my fellowship in neuro-immunology at the group of Maarten Titulaer at the Erasmus MC in Rotterdam, the Netherlands and specialized in autoimmune encephalitis. Since May 2020 I work there as a neurologist. My focus is on clinical care for patients with autoimmune encephalitis and other neuroinflammatory diseases. Besides my clinical work, I also perform clinical research in the field of autoimmune encephalitis. My goal is to improve the care, future perspectives and treatment strategies for patients with autoimmune encephalitis. I am married with Eric van Breda, who works as a psychiatrist, and together we have three children, Fedja 7, Amelie 5 and Lucy almost 1 year-old.

DR. AMAIA MUÑOZ LOPETEGI

HOSPITAL CLINIC OF BARCELONA
SPAIN



Dr. Amaia Muñoz Lopetegi has been awarded the AEA Community Seed Grant to investigate the Subclinical activity in anti-LGI1 encephalitis: diagnostic tests and prognostic implications. Learn more about her study and how this will affect those affected with autoimmune encephalitis (AE).

[LEARN MORE](#)

You have been awarded the AEA Seed Grant, can you tell us more about the study you plan to do?

The study is aimed at characterizing the post-acute stage of the encephalitis associated with LGI1 antibodies (anti-LGI1), which is the second most frequently reported AE. It affects patients usually older than 60 years, and produces a limbic encephalitis, with different types of epileptic seizures and prominent cognitive decline. The importance of recognizing anti-LGI1 encephalitis is that its prompt diagnosis and treatment usually associate with neurologic improvement and likely prevents permanent symptoms.

Even though the most acute stage of the disease is well characterized, the later stage of the disease is much less known, and it is even unclear whether these patients may have subclinical active disease with manifestations that may have an impact on cognitive recovery.

In order to better understand the disease, we will follow patients during a year with serial visits that include an extensive panel of neurologic, cognitive, and psychiatric investigations, along with comprehensive clinical and video-polysomnographic sleep assessment, electroencephalography and neuroimaging.

Preliminary results in these patients are revealing the presence of unsuspected alterations during routine outpatient clinic assessment, and also show that symptoms considered resolved, such as epileptic seizures, are in fact still present during sleep evaluations, which may negatively impact on cognitive function and memory. These symptoms and tests (e.g., V-PSG, prolonged EEG) can be used as prognostic biomarkers guiding treatment in the post-acute phase of the disease.

How will your study help patients and families affected by AE?

This project will address one of the most complicated questions in AE, that is how to assess and treat patients after they are discharged from the hospital or rehabilitation, but have not reached complete recovery (they are unable to return to work, or they have difficulties in their daily activities). Our preliminary data indicate that a substantial number of patients with anti-LGI1 encephalitis still have an active disease, rather than a slow recovery process or permanent residual deficits. This would indicate that the immune response is still causing damage, producing symptoms that may be subtle or difficult to detect, but can be demonstrated by studies not used in routine clinical practice.

This study will provide clinical and paraclinical biomarkers (e.g., sleep studies, prolonged EEG assessment) for disease follow-up, that will permit clinicians to identify patients that need adjustment of symptomatic medications or more immunotherapy, thus shortening the process of recovery and improving overall prognosis.

Tell us more about yourself and your affiliation?

I am a neurologist and PhD research student. I received my MD degree from the University of the Basque Country (Spain). During my residency program in Neurology at the Donostia University Hospital (Spain), I did a 6-month stay at the Erasmus University Medical Center in Rotterdam, The Netherlands under the mentorship of Dr. Maarten J Titulaer, who is known for his work in the field of immune mediated encephalopathies. Upon completion of my stay in Rotterdam I was accepted to the PhD program at the University of Barcelona and was also named junior faculty at its affiliated hospital, Hospital Clinic of Barcelona. At the Hospital Clinic I work in the Sleep Unit where I attend the Sleep Disorders Unit outpatient clinic and I read polysomnography and EEG recordings for both clinical and research studies. My PhD research is being carried out in the Neuroimmunology group, directed by Dr. Josep Dalmau. My studies are focused on sleep disorders in autoimmune encephalopathies. My goal is to become an independent, translational researcher.



Seronegative Autoimmune Encephalitis Survivor and Author of wherearemypillows.com

**Would losing 29 IQ points concern you? What about the sudden inability to work?
What about in the context of someone with a history of autoimmune encephalitis (AE)?**

“Well... I’m considering whether the root of everything might be adult ADHD instead.”

I was stunned. I had heard many dubious things on my 6 year journey of medical mismanagement, yet doctors still managed to find comical ways to deliver fresh sucker punches. Apparently, receiving the seronegative AE diagnosis in 2019, experiencing a full remission of symptoms, finding a fulfilling full-time career, but having a sudden regression while on Rituxan alone raised alarm bells for the wrong reasons: Not whether I was in the midst of a genuine relapse, but whether AE was ever the right diagnosis to begin with. In fact, if this doctor had her way, future immunotherapy would be stopped altogether.

That second opinion went nowhere fast.

Contrast that with today: I have experienced a remarkable recovery of cognitive capacity as measured through repeat neuropsychiatric testing. I'm making considerable progress towards picking up the shards of months shattered by loss of income, failed potential, and floundering through the medical system. I no longer feel like I'm being overtaken by dementia.

Yet none of these improvements would have occurred had I yielded to the doctors who advised that further medical care was unnecessary.

In early 2021, several "second opinions" later, a new clinician made an assessment that will truly knock your socks off: I was suffering an AE relapse. Not stress, permanent sequelae, or a pseudo relapse. And astonishingly, this was not going to be fixed by a psychostimulant.

In fact, I would end up receiving an aggressive combination of immunotherapies necessary to control inflammation that had gone unmitigated for months. By this time I was distraught across multiple dimensions, least of which came from the mental anguish of knowing I had needlessly suffered— knowing full well that a skilled doctor would have intervened earlier, before letting me deteriorate to the point of autonomic instability. The result? My body started healing, and we reversed the majority of my dementia-like symptoms.

Now, in retrospect, it may seem like a no-brainer: Patient received delayed diagnosis and treatment. Patient's symptoms fully remit, but return shortly after treatment regimen is modified. Patient suspects medications should not have been modified, enters a full-blown relapse, and does not recover. That is, until she finds the right doctor who treats her with therapies that target the original disease process.



But what I'd like you to recognize is that there were no direction signs off the beaten path. To those of you with a nagging gut instinct that you're receiving inadequate medical care, debating whether you should keep searching for answers, keep that in mind. It was rarely obvious to me what I should do next—particularly with an AE-riddled mind, rattled by dispiriting remarks from medical professionals I had placed my trust in. It was one agonizing moment after another, disaster after disaster, vindication withheld until I landed at the feet of a widely-respected AE doctor, miles away from home.

I highlight the grim elements of my journey not to evoke sympathy, but to provide a voice for countless others who are falling through the medical cracks. I've now spoken to hundreds of AE patients and caregivers, many receiving exceptional care, but equally as many with stories more painful than mine. Stories of neglect, of preventable outcomes, of stranded families broken under immense strain, with devastating—sometimes fatal—consequences.

So I'm acutely aware that I've experienced a level of treatment and healing that many have not yet found. For that, I am beyond grateful.

I owe my life to the astute, compassionate doctors who saw the forest for the trees, who encouraged me to keep searching for answers even while I had reached the limits of their individual expertise, who ultimately stepped up to the helm of the ship to provide disease-appropriate care.

But arguably more critical was the AE community. I wouldn't be capable of writing this were it not for those I met at conferences, through my blog, in online forums, and in support groups including the ones run by the AE Alliance. I extend my heartfelt gratitude to those who nudged me forward while I crawled through a frightening and seemingly endless limbo.

Today, I laugh at the zigs and zags of my medical adventure. I cry with those of you in this community, through our setbacks and successes. And I also share my story, to embolden others to keep their head up in the face of innumerable obstacles. AE is a nasty beast; but it's also one that can be disarmed if you look hard enough for its vulnerabilities. Reach out to the AE Alliance, join a support group, or send me a message if you need help. You are never alone, no matter what stage of the journey you're in.

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WITH DR. GENALYNNE MOONEYHAM

What medications are used in general for psychiatric symptoms in AE, are there side-effects we need to be aware of?

For the depression symptoms, do SSRI's really work and can they be mixed with antipsychotics?

Autoimmune Encephalitis (AE) may present with a wide variety of clinical symptoms. While there are no psychiatric care medications that are specifically designed to treat AE, they may still serve as a helpful addition to an immunomodulatory medication plan when clinically indicated for symptom control.

Patients with AE may experience symptoms of psychosis. This may include paranoia, delusions (falsely held fixed beliefs), abnormal body sensations, and auditory or visual hallucinations. These symptoms may be the direct result of antibodies that are actively attacking the brain, the eyes, or the spinal cord. Medications that block the dopamine receptors (partially or fully) can be used to reduce these symptoms. These medications are often referred to as “antipsychotic” or “psychotropic” medications. We monitor patients for the development of any abnormal involuntary motor movements (extrapyramidal effects), sedation, or changes in the way that their body processes glucose (sugars). Physicians may monitor your thyroid hormone function, weight, blood pressure, and blood glucose when they prescribe antipsychotic medications to you.

AE may also cause significant changes in mood and behavior. Sometimes this may look like depression, anxiety, or OCD (Obsessive Compulsive Disorder). Medications that target serotonin and norepinephrine receptors can be helpful in reducing these types of symptoms. Your doctor may prescribe an “SSRI” (Selective Serotonin Reuptake Inhibitor) or an “SNRI” (Selective Norepinephrine Reuptake Inhibitor) to treat features of depression, anxiety, obsessive thoughts, or compulsive behaviors. SSRIs do not usually require blood labs for monitoring. However, in some scenarios, your doctor may monitor your sodium level and your platelet level. Providers may ask you safety questions like whether you might be having thoughts of suicide. They may provide you with resources like the National Suicide Prevention Lifeline (1 800 273 8255) or local emergency numbers that can be used as a part of your safety plan when treating depressive symptoms. We want all patients to know that **help is available... you are not alone.**

Sometimes antidepressant medications can lead to features of mood elevation which can become problematic. This is known as “mania” and refers specifically to an extended block of time when an individual may feel as if they have high energy or do not need much sleep. They might also spend more money than usual, talk more than they ordinarily would, or even take risks that would be out of character for them. These changes in mood and behavior can be an unintended result of using antidepressant medications in a small group of people. Because of this, clinicians will monitor their patients closely for any abrupt changes in their mood.

Some patients also experience “mania” because of the actual disease process involved in AE or because of mood elevation that can occur when steroids are being used in the treatment plan. Elevated mood states like mania or hypomania can be treated by using medications known as “mood stabilizers”. These medications may include lithium, antipsychotics, or anti-seizure medications that can help to reduce the fluctuations in mood/behavior. Mood stabilizers can be a very effective category of medication, but they do require close monitoring. Providers will often order medication levels to be sure that the dose is in a safe zone. Clinicians may also check liver and kidney monitoring labs depending on which mood stabilizer is prescribed.

Patients with AE may experience a set of symptoms known as catatonia. Catatonia symptoms can include drastic reductions in an individual’s ability to move, eat, or even speak. However, catatonia symptoms can also include periods of unexpected agitation, impulsivity, and motor movements that would be considered unusual for the social setting. This is a very complex set of symptoms and it requires careful management by a psychiatrist. Medications that target the GABA receptors of the brain are needed to treat this condition. Benzodiazepines are considered the first line of treatment for catatonia. It is important to note that benzodiazepines are listed as a controlled medication class because they can be associated with physiological dependence, addiction, and/or withdrawal side effects. However, with appropriate supervision by your physician, this medication category can be a very effective way to treat catatonia features.

Who manages these medications and when would you start to taper these medications?

Patients with AE will often require a multi-disciplinary care team. This may include a psychiatrist who can help with making decisions on how to start, monitor, and safely taper psychiatric care medications when clinically indicated.

How do you treat obsessive thinking medically and does talk therapy help?

Obsessive thought patterns and compulsive behaviors can be very overwhelming. Some patients will also experience “intrusive thoughts” which are particularly distressing. These intrusive thoughts can even include religious themes, sexual themes, contamination themes, or a fear that

you may have done something wrong even when you have not. Cognitive behavioral therapy (CBT) is a form of therapy which can be very helpful for treating anxiety, depression, and OCD. When CBT is combined with medications like SSRIs, the potential for synergy occurs. Many patients find that their symptoms are greatly improved when a combination of medication and therapy is utilized.

What can a patient use to manage sleep disturbances?

Sleep disturbances are common in AE and there a number of medication options that may be helpful. This may include over the counter medications like melatonin, doxylamine succinate, or diphenhydramine as a temporary measure. Prescription medications may also be necessary. Alpha agonists are a category of prescription medications that were traditionally used to manage high blood pressure, but clinicians have found that they are also helpful in addressing sleep disturbances or symptoms of impulsivity. Another category of medications are known as “sleep hypnotics” and they require close supervision by a clinician.

Disclosure: Dr. Mooneyham is an employee of the National Institute of Mental Health. The views expressed do not necessarily represent the views of the National Institutes of Health, the Department of Health and Human Services, or the US Government. Please note that the information contained is not meant to substitute for clinical decision making. All medication decisions should be made in close coordination with your care provider.



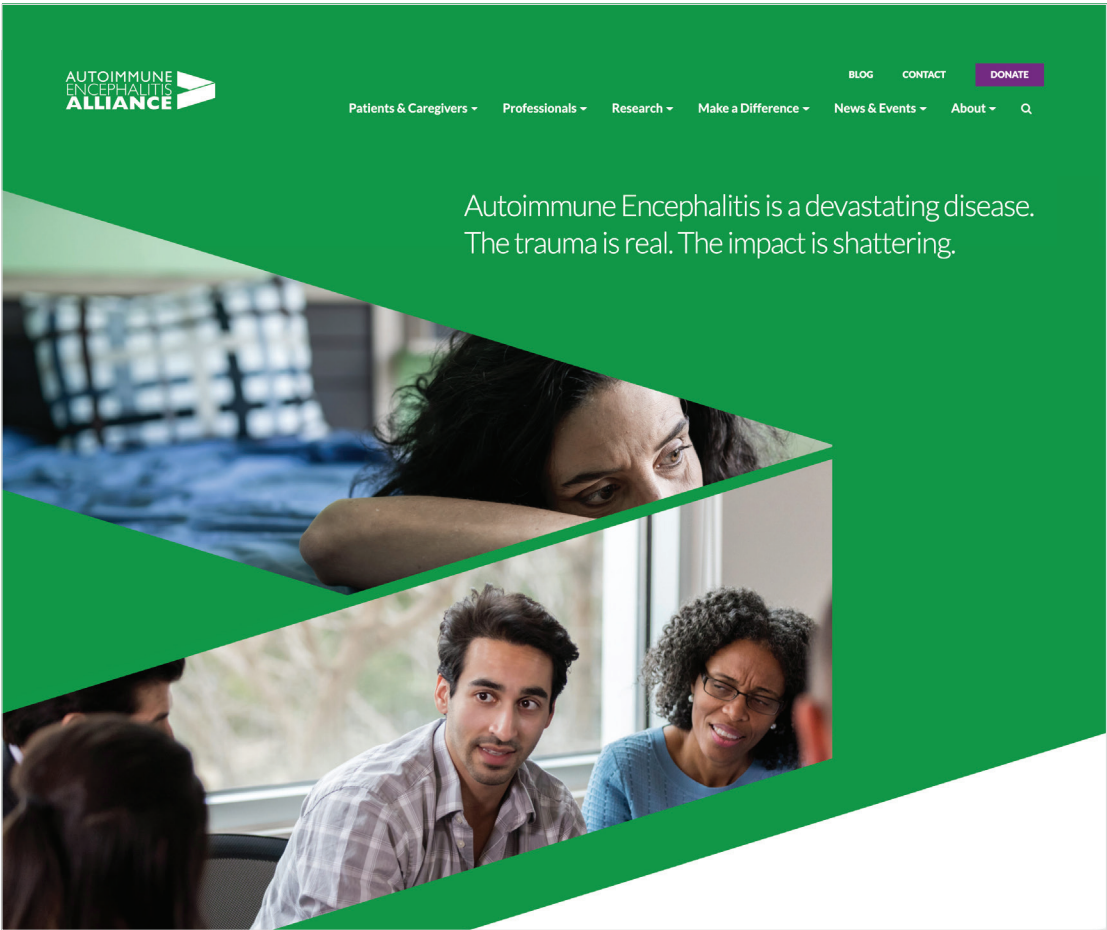
Submit a Question for our Experts



WE HAVE A NEW WEBSITE!

We are excited to announce the launch of our new Autoimmune Encephalitis Alliance website. Your journey with autoimmune encephalitis as a patient or a caregiver inspired the structure of this site. It contains helpful information and resources to support you every step of the way.

VISIT SITE



Key Highlights to Explore

Learn More About the Different Types of AE

Reviewed by AE experts



Check out our Resource Library

This online AE library contains more than 600 resources



Download the Recovery Toolkit

Practical information for when you leave the hospital



Develop Healthy Lifestyles in Living with AE

Rebuilding strength, assessing lifestyle, and building consistent and supportive habits to live productive and healthy lives



Make A Difference

Find multiple options to get involved and raise awareness of AE



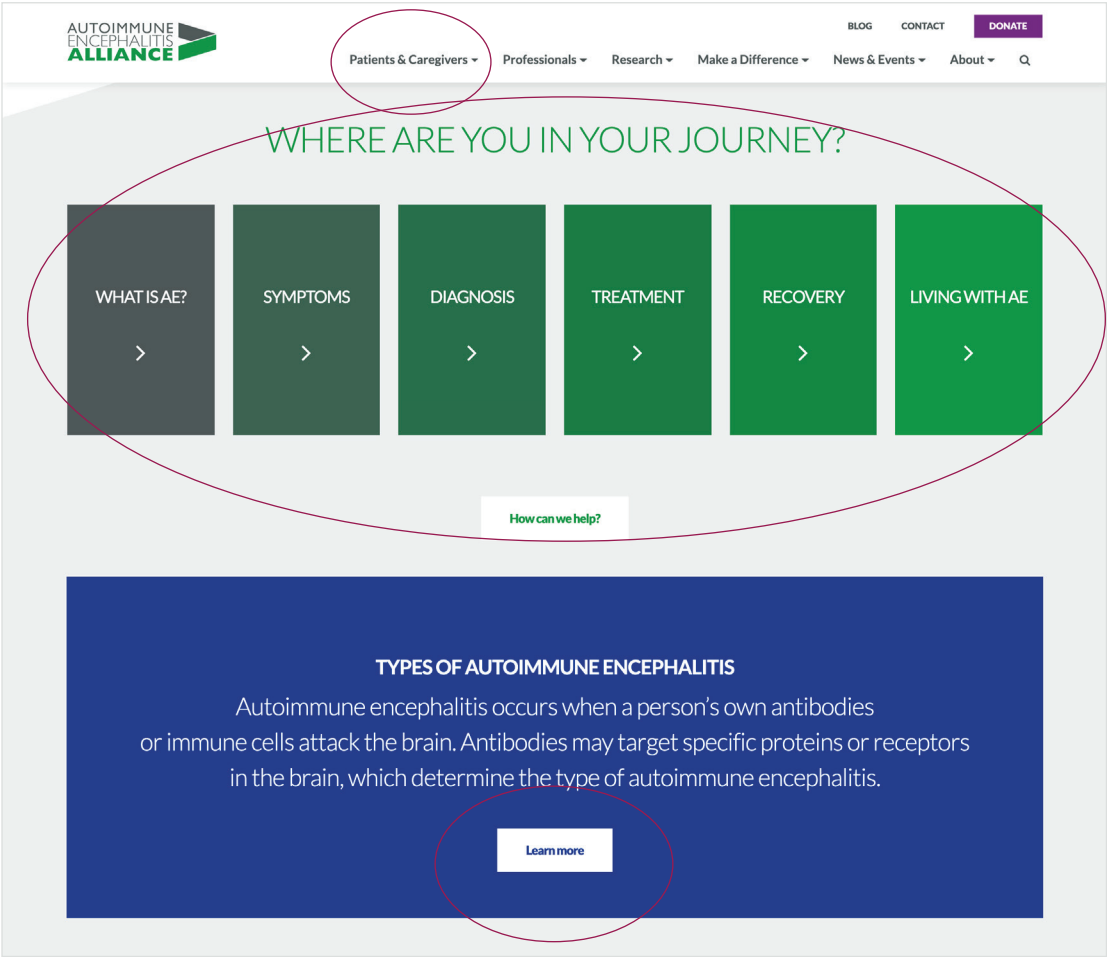
Special Thanks

We wish to thank the following physicians for reviewing and contributing to parts of our website, ensuring you have access to the most up-to-date information on diagnosis, treatment, and outcomes for AE: Dr. Hesham Abboud, Dr. Morten Blaabjerg, Dr. Tania Celluci, Dr. Sarah Crisp, Dr. Divyanshu Dubey, Dr. Jeffrey Gelfand, Dr. Sarosh Irani, Dr. Sergio Muñiz-Castrillo, Dr. Soon-Tae Lee, Dr. Myrna Rosenfeld, Dr. Heather Van Mater, Dr. Anusha Yeshokumar.

We also extend a heartfelt thank you to Lisa Lauter and Alanna Yee for closely collaborating with us on the Recovery Toolkit. This kit contains first-hand and practical information for newly discharged hospital patients.

R+M AGENCY

We chose to partner with **R+M Agency** because of their strong reputation for design excellence and their commitment to helping nonprofits like the AE Alliance build top-notch web experiences. R+M is selective about their partnerships, and so are we. After talking for hours with designers Chris, Blair, Melissa, and Beverly about autoimmune encephalitis and its impact on patients and caregivers, we got down to the business of designing our new AEA website. The site focuses on the patient and caregiver journey, and depending on where you find yourself in that journey, you'll find tools and resources that support you at that specific juncture. Let's walk you through it.



Let's say you want to learn more about your loved one's diagnosis. Click on Diagnosis, and this will take you to the page containing information and references about this stage in your AE journey. On the top of the page, you can easily find where you are in the journey and can click on a different stage if needed. At the bottom of the page, you can find additional resources that support that stage of the journey. And you can also go to the next or previous stage of your journey.

AUTOIMMUNE ENCEPHALITIS ALLIANCE

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How We Can Help You What is AE? Symptoms **Diagnosis** Treatment Recovery Living with AE

Diagnosis

Overview

A diagnosis of autoimmune encephalitis (AE) is based on the presence of *symptoms and findings on physical examination that are consistent with AE and test results that show inflammation in the brain*. In addition, your doctor must make sure that you do not have other more common conditions (such as infections, neurologic diseases and mental health conditions) that may explain your symptoms and test results. Given the large number of conditions that can look like AE, many tests are usually required and making a diagnosis can take many weeks. Criteria now exist to help doctors diagnose AE in adults and children.

Additional Resources

- Types of Autoimmune Encephalitis >
- Find a Clinical Trial >
- Caregiver Support Services >
- Join the AE Community >
- Find a Doctor >

< Symptoms Treatment >

A great tool that you will find on each of the Patient & Caregiver pages is the **Resource Library**. The Resource Library contains over 600 resources (scientific papers, blog posts, webinars, and videos), so you can get more information on a specific topic. You can search on the audience, type of resources, subject matter, and type of AE.

RESOURCE LIBRARY


Audience

Type

Subject Matter

Topic

Submit



BLOG POSTS

Meet Dr. Amaia Muñoz Lopetegi!

Audience: Patient, Professional

Subject Matter: [Patient Support](#) | [Research](#)

Topic: research

New to the AE journey are the pages that fall under Living with AE. These are all about rebuilding strength, assessing lifestyle, and building consistent and supportive habits to live productive and healthy lives.

AUTOIMMUNE ENCEPHALITIS ALLIANCE

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What is AE?

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Living with AE

Living with AE



Overview

A diagnosis of autoimmune encephalitis can be devastating. The journey through diagnosis and treatment can be frightening. Recovery can be long and frustrating. Once complete, the autoimmune encephalitis survivor is left to rebuild strength, assess lifestyle, and build consistent and supportive habits to live productive and healthy lives. The Alliance is here to help.

If you already know what type of AE you or your loved one has, you can quickly access these pages from the homepage and on the different pages in the AE journey. Each type of AE page has information on the specific diagnosis, testing, treatment, and outcomes. It will also list a few important scientific papers if you would like to learn more. Our AE experts review each of these pages to ensure you are getting the most current information available.

TYPES OF AUTOIMMUNE ENCEPHALITIS

Autoimmune encephalitis occurs when a person's own antibodies or immune cells attack the brain. Antibodies may target specific proteins or receptors in the brain, which determine the type of autoimmune encephalitis.

Learn more

Additional Resources

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Find a Doctor
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Types of Autoimmune Encephalitis

CASPR2-Antibody Encephalitis

What is it?

CASPR2 (Anti-contactin-associated protein-like 2) antibody is a neural specific antibody associated with varied autoimmune neurological disorders including autoimmune encephalitis and autoimmune epilepsy.

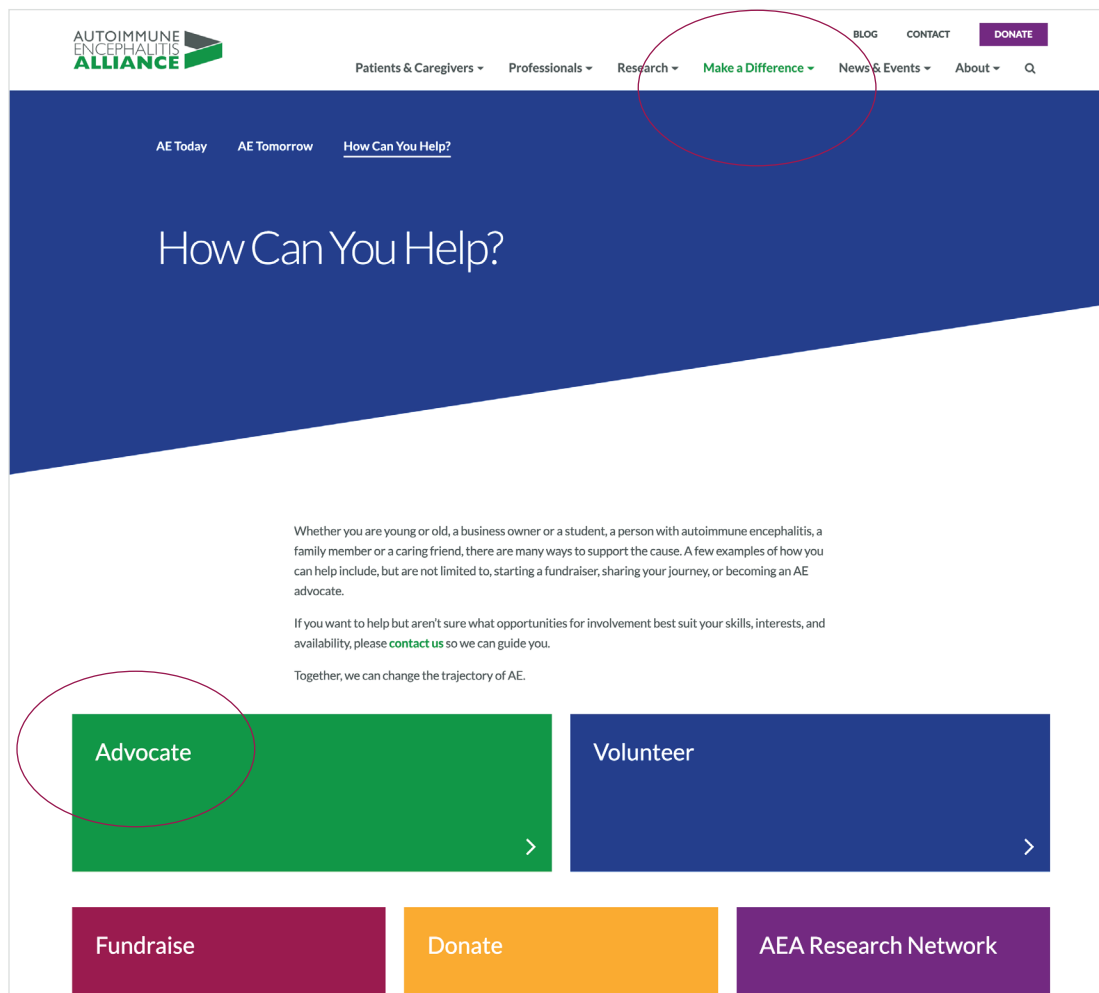
CASPR2 is a cell adhesion molecule expressed in both central and peripheral nervous system. The CASPR2 autoantibodies function by blocking interaction with its binding partner contactin-2. These interactions are essential to prevent repetitive firing, and maintain resting potential of nerves, their disruption can lead to hyper-excitability.

Since its discovery in 2011 it has been utilized by neuroimmunology laboratories throughout the world. It has helped in diagnosis and appropriate treatment of many patients, some of whom would've not been diagnosed or misdiagnosed in the absence of this biomarker.

Who is affected?

People of all ages can be affected by this antibody; however, rates are higher among older adult patients compared to children. It affects men more frequently than women (more than 70% patients are men).

You can find another item of interest under Make A Difference in the menu at the top of the page. AE is a rare disease, and we need to work together to make an impact. **This page shows you how you can help us improve the lives of those suffering from this disease.**



As you can see, the team at R+M Agency did a fantastic job designing a website that follows you in your journey and gives you tons of resources and tools. Our goal was to equip you with everything you might need to advocate for yourself or your loved one. We hope you will take advantage of these great resources and provide us feedback on how we can further assist you.

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R+M creates experiences to get people talking about brands that positively impact our health, well-being and social responsibility. As a Certified B Corporation, the brand experience agency is committed to using business as a force for good. R+M achieves more than 90 percent of their growth from referrals; a result of partnerships built on trust, going above and beyond, challenging the status quo and mutual respect.

DR. EYAL MUSCAL

TEXAS CHILDREN'S HOSPITAL



After taking some time off after college, Dr. Muscal realized that medicine offered the appropriate mix of a “healing” profession with a scientific emphasis. More reflection and a few years “off” made it clear that he would be a frustrated teacher and that he did not have the patience or skills to be a scientist. He is now a pediatric rheumatologist at Texas Children’s Hospital in Houston, TX, where he treats children affected by autoimmune encephalitis, amongst other conditions.

Dr. Muscal’s interest in caring for children with autoimmune encephalitis was sparked close to a decade ago when a young girl was admitted to the ICU with what turned out to be autoimmune encephalitis. Early on in her admission, it was apparent that there were glaring gaps in the care of children with autoimmune encephalitis. And it became to Dr. Muscal that we needed to enhance multi-disciplinary family-centered approaches to care and invest in immune-mediated central nervous system disease research.

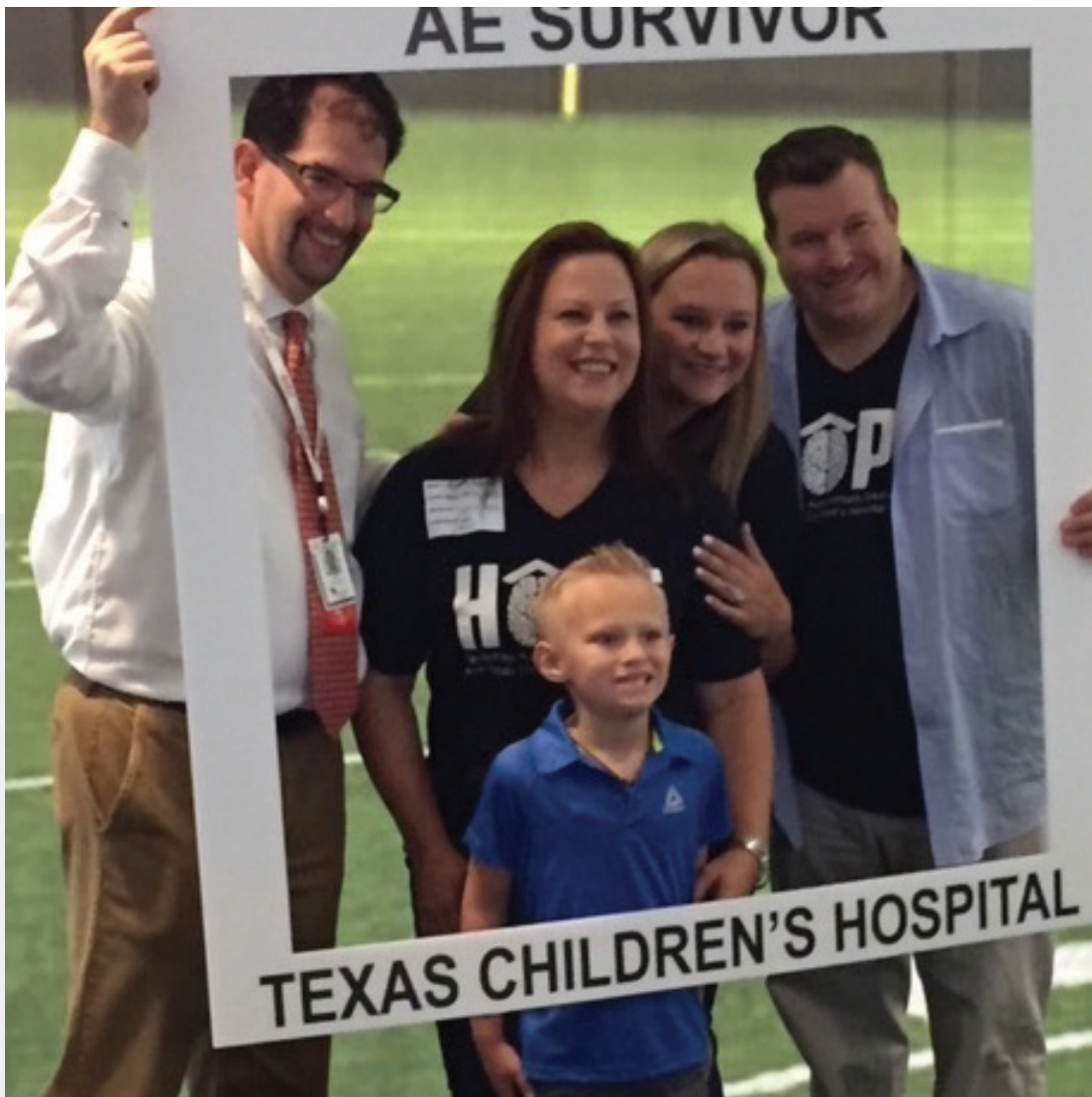
Muscal is a big proponent of consensus-driven multi-disciplinary care that early on involves neurology, rheumatology, critical care, psychiatry, and rehabilitation services. They have built internal best care practices at Texas Children’s Hospital and, before the pandemic, also held monthly task force meetings to improve their care algorithms and approaches.

Dr. Muscal is currently engaged in autoimmune encephalitis quality improvement efforts and clinical research related to immune-mediated epilepsy syndromes (FIRES). He is looking forward to collaborating with other pediatric centers regarding a multi-center autoimmune encephalitis registry later this year. He firmly believes that the pediatric autoimmune encephalitis community (including multiple specialties) needs to enroll more patients in registry studies to understand variabilities in presentation and care better, leading to treatment studies. It is also vital to ensure that we are sharing samples in national autoimmune encephalitis biorepositories.

Muscal hopes that translational neuroimmunology research related to biomarker and antibody discoveries eventually allows us to have targeted therapies for different autoimmune encephalitis phenotypes. The pandemic experiences with virtual meetings and platforms may also allow clinicians and researchers to meet more often in “real-time” to complete projects in a more timely fashion.

When Dr. Muscal is not caring for his patients, he finds himself shuttling his two middle school daughters to sports events and hoping that practices and tournaments are devoid of COVID. With what little free time he has left after that, he enjoys reading modern fiction and watching British crime/police shows.

DR. MUSCAL AT THE AE FAMILY DAY OF HOPE



2021 HIGHLIGHTS

So far, 2021 has been a busy year. We have already hosted **ten support group meetings** and our online **Smart Patients** community grew to almost 700 members. A few highlights:

- We launched our West AE Support Group in February. This group is led by Rachael Bikbov, a seronegative AE survivor. Please email us at support@aealliance.org to join.
- The **World Encephalitis Day Conference** held on February 20th was a great success. We had people join from 17 countries as we learned more about AE from experts across the globe.
- We hosted the first virtual Florence Forth run on the weekend of March 5th – 7th; 272 runners participated in over 22 states and Mexico!
- We reinvented our annual in-person Florence Forth run held on March 6th in Durham, NC to comply with COVID-19 restrictions and regulations. The runners enjoyed being out on the course again. We raised \$35,000 for our programs supporting AE patients and their families.
- Together with the HESA group, we organized the Building Bridges Conference held April 10th, aimed at physician and medical students. This conference aimed to enhance patient care and improve outcomes for those affected by AE by promoting a multidisciplinary approach to diagnosis, treatment, and recovery.

FLORENCE FORTH 2021



Upcoming Support Group Meetings

Connect with fellow survivors and caregivers, email us at support@aealliance.org to join the online meeting.

Southwest AEA Support Group

June 12th

Midwest AEA Support Group

June 26th

West AEA Support Group

August 11th

Join a Support Group



Online Smart Patients AE Community

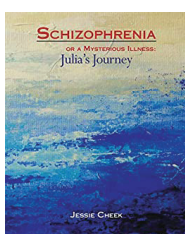
We are looking for volunteers to help us manage our online Smart Patients AE community. All you need is a computer, an internet connection, and a passion for helping others affected by AE. The Smart Patients online AE community provides our AE community with a safe online platform to connect with others, from anywhere, at any time. If you are interested in becoming an Online Community Engagement Volunteer, please email us at kimberley@aealliance.org to learn more about the responsibilities and time commitment involved.

Contact to Volunteer



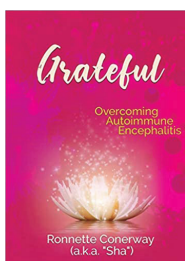
FOR THE THE AEA COMMUNITY

Books by AE survivors and their families



Schizophrenia, or a Mysterious Illness, Julia's Journey
by Jessie Cheek

PURCHASE



Grateful - Overcoming Autoimmune Encephalitis
by Ronnette Conerway

PURCHASE

FOR PROFESSIONALS



Neuroimmunology: Multiple Sclerosis, Autoimmune Neurology and Related Disorders
by Dr. Amanda Piquet and Dr. Enrique Alvarez

This book features several chapters in autoimmune neurology by several leaders in the field (Dr. Zekeridou, Dr. de Vries, and Dr. Titulaer), including chapters on autoimmune encephalitis. Neuroimmunology serves as a resource for those in training, including residents and fellows, to provide clear clinical reasoning and background in a rapidly advancing field.

PURCHASE

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Have questions?

Want to connect with other members of the AE community?

Need guidance?

CONTACT US

