AUTOIMMUNE ENCEPHALITIS ALLIANCE

2019 NEWSLETTER • Issue 1

In this issue...

Announcing New Leadership

The AE Alliance has accomplished so much with a small staff and a dedicated board. Yet there is so much to be done to change the trajectory of this disease – to ensure rapid diagnosis, appropriate treatment and advanced research so that no one faces this disease alone. To achieve this mission requires taking the AE Alliance to the next level.

As the Chair of the Board of the AE Alliance, I am excited to announce that after an extensive recruitment process we have hired an Executive Director who has the experience to drive organizational growth, the empathy to understand patient and family needs and the strategic vision to achieve results that improve diagnosis, treatment and care. **I now have the pleasure of introducing the AE community to Caterri Woodrum.** Caterri brings amazing experience, empathy, passion and excitement to the Autoimmune Encephalitis Alliance.

Caterri Woodrum

Until recently, Caterri was the Chief Executive Officer of the North Carolina Museum of Art Foundation, Inc. Over the past fourteen years, she oversaw the Museum's operations and finances and the Foundation's fundraising and earned income support efforts. The Museum has an annual budget of $25 million and during her leadership completed a $50 million capital campaign. She oversaw a staff of 175 and had two governing boards to manage. It was immediately clear in talking with Caterri that she is adept at managing complex projects and organizations and brings a proven record of accomplishment in guiding and funding strategic endeavors, expansions and reorganizations.

> *Caterri brings amazing experience, empathy, passion and excitement to the Autoimmune Encephalitis Alliance.*

When asked "Why the AE Alliance?", Caterri offered several compelling stories. She grew up in and around hospitals and doctors, with her father a hospital administrator. Her early career included more than a decade working for a pharmaceutical company on orphan drugs. It was here she gained valuable insights into rare disease and the complications of research and treatment. She knows personally the impact and trauma of illness.

Two years ago she decided to shift her focus and align her career with organizations that improve the health of our communities, with particular interest in diseases impacted by dysfunctional immunity. She is a board-certified health and wellness coach through the National Board of Health and Wellness Coaches, following training at the Institute of Integrative Nutrition, Manhattan, NY and Duke Integrative Medicine, Durham, NC.

Caterri lives with her husband, Jeff, in Orange County, NC. She is an avid gardener and advocate for the protection of pollinators – monarch butterflies and bees – and has extensively landscaped her property with pollinator friendly plants.

I look forward to you meeting Caterri and I know she looks forward to engaging with the whole AE community. She will start working full time in January. You can meet her at the AE Family Weekend and Florence Forth road race in Durham, NC on March 7, 2020.

Will

Will McDow,
Board Chair

Meet the Board

The AE Alliance Medical Advisory Board (MAB) brings together internationally renowned AE experts to allow the Alliance to provide patients, families and medical professionals with trusted, evidence-based information and practices.

The MAB includes members with different areas of expertise, including adult and pediatric neurology, rheumatology and immunology. The goal of the MAB is to ensure the Alliance has access to the most up-to-date information on the diagnosis, treatment and outcomes for AE, as well as ongoing research initiatives.

First offical MAB meeting in Philadelphia earlier this year.

With the assistance of the MAB, the Alliance will:

1. develop programs and resources for patients, families, and the medical community
2. support research and
3. disseminate best practices for the diagnosis and treatment of AE. We are excited to have the leading experts in the field collaborating with the Alliance to make these goals attainable. Each of the MAB members serves on one of three subcommittees focused on education, research, and clinical care.

Dr. Heather Van Mater,
Medical Advisory Board Co-Chair

Education Subcommittee

The education committee is responsible for advising the Alliance on patient and professional education initiatives. The committee members will assist the Alliance in the development and dissemination of evidence-based materials and programs for both patients and their families, as well as resources for medical professionals.

Research Promotion and Dissemination Subcommittee

The research subcommittee advises the Alliance on the strategic direction for participation and funding of research projects. The members will establish protocols to review research proposals, ensuring the quality of the scientific research methodology and potential for impact on the AE community.

Clinical Care and Standards of Excellence Subcommittee

The subcommittee assists the Alliance in advocating for standards of care for patients with AE through drafting of guidelines, standards of care and necessary services.

The MAB met in person for the first time in May 2019 and began defining the goals for the upcoming year. This was an excellent opportunity to discuss potential priorities and directions for each subcommittee and to share common experiences and challenges. The board members are excited to work with the Alliance on these common goals and advance the care for all those affected by AE.

Medical Advisory Board

Education

Led by
Dr. Heather Van Mater

- Dr. Tania Celluci
- Dr. Russel Dale
- Dr. Helen Egger
- Dr. Eyal Muscal

Research Promotion and Dissemination

Led by
Dr. Anusha Yeshokumar

- Dr. Eric Lancaster
- Dr. Jonathan Kuo
- Dr. Sean Pittock
- Dr. Myrna Rosenfeld
- Dr. Maarten Titulaer

Clinical Care and Standards of Excellence

Led by
Dr. William Gallentine

- Dr. Susanne Benseler
- Dr. Mark Gorman
- Dr. Sarosh Irani
- Dr. Eyal Muscal
- Dr. Kendal Nash
- Dr. Cynthia Wang
- Dr. Elizabeth Wells

ASK OUR PANEL

Q:

My daughter was diagnosed with AE almost a year ago, she was treated with IVIG and steroids and has made significant recovery especially physically. We all are still experiencing anxiety and depression, and she is seeing a psychiatrist and psychologist. In your experience, what does the psychological recovery look like for most AE patients? She is currently taking three psychiatric medications without much response. Is this normal and will it last forever?

A:

Thanks so much for your question, as it is one that is very commonly asked. Psychiatric symptoms in AE can be quite debilitating. Often a prominent feature of the initial presentation, these symptoms can be quite challenging to manage.

Prior to the initiation of immunotherapy, a lack of response to typically used psychiatric treatments is often reported. However, used in combination with immunotherapy, these medications are a mainstay in the symptomatic treatment of AE. We often see better responses once immunotherapy has been initiated.

Have a question for our panel?

Contact us online at:
aealliance.org/contact

As you described in your question, even in patients with excellent response to immunotherapy in other domains (like cognition) quite often, many patients continue to struggle with psychiatric symptoms.

It is very important to approach these symptoms from multiple angles:

1. Be sure your doctor does not feel your psychiatric symptoms are part of ongoing AE (typically will have other symptoms—worsening cognition, seizures, abnormal movements, etc.)
2. Take your medications as directed by your doctor (do not self-wean or adjust psychiatric medications or immunotherapy)
3. Be sure to be enrolled in cognitive behavioral therapy. This last one is very important. Going through the diagnostic odyssey and prolonged treatment often associated with AE can be quite traumatic for patients and their families. Receiving appropriate psychotherapy (including family members in some circumstances) on how to deal with these experiences, the uncertainties of the disease, the lost time, and the remaining symptoms are essential to improved psychiatric outcomes.

Patients who receive cognitive behavioral therapy, in addition to medications, have better outcomes than those who receive either alone. All that being said, patients can get better. Quite often, it does take time and commitment to working very closely with your mental health providers.

Lastly, many patients may require long-term use of psychiatric medications. Persistence of psychiatric symptoms alone should not necessarily be interpreted as a failure of immunotherapy or relapse. These symptoms need to be interpreted in the context of the rest of the illness by your treating physicians. Even if psychiatric medications are required long-term, the overall number of psychiatric medications used are often able to be reduced over time, especially in cases where cognitive behavioral therapy is also used.

Dr. William Gallentine, *Stanford Children's Health*

Therese Fledderjohn

“Every day I arise, not knowing how our day will unfold, but with the hope that the treatment our son is currently receiving will bring his miracle. Before the symptoms, Alex was quiet and kind. He had the quickest wit and funniest personality. His brain was like a sponge, and his retention for taking in his studies and the world around him was unbelievable.

This road we travel began in 2009. Alex was misdiagnosed for seven years. Finally, he was diagnosed by his sixth neurologist with anti-NMDA receptor encephalitis in 2016.

> *I was with my son 24-7, and I would have to share what he was experiencing because he couldn’t.*

Alex experienced neurological symptoms, and they increased in severity and number. He experienced motor neurological symptoms, cognitive symptoms, demonstrated global confusion and with fear in his voice would say over and over again, “I don’t know what is going on.” We embraced him with hugs, love and much reassurance that he would not be alone and that we would walk by his side every step of the way. Along with the neurological symptoms, he had sleep disruptions, including severe insomnia, changes in his visuospatial functioning and gastrointestinal symptoms, including rectal bleeding. He had decreased appetite and quickly lost 20 lbs. Things continued to worsen without a correct diagnosis. He didn’t remember who he was; he had a hard time walking, his balance was off, and lost his ability to write. He would have twisting and writhing movements, later to find out they were choreoathetoid movements. He also experienced psychosis, catatonia, extreme muscle pain, agitation, and aggression.

The Zebra is the symbol for rare diseases in the world of medicine and has become Team Fledderjohn’s mascot. These magnets encourage doctors to look for the zebras amongst their patients.

After a few years, no answers, only more questions. I couldn’t count the endless appointments with the medical field, including many physicians, psychologists, OT, PT, etc., and hospital stays. And the endless nights without sleep.

Like many, he was misdiagnosed with a mental illness by several medical professionals, and as we all know, that’s hard because those labels stick. Other doctors were thinking it could be a neurodegenerative disease and several tests were done. At one point, we were told that these degenerative diseases progress rapidly, so be prepared.

Knowing in my heart that I needed to keep searching for the answer until it was found. I wanted peace for my son! I researched day and night and asked about so many different diseases. I would have a list and share it with his doctors. Could it be this? Or this? Or this? Some doctors were professional and seemed to care and would listen, and some would not. I was with my son 24-7, and I would have to share what he was experiencing because he couldn’t.

I have files, folders, and a box full of paperwork that follows and marks our journey that has defined our life for the past 10 years.

You struggle and fight for your loved one over and over again to get a diagnosis and the proper treatment. At one point, it was suggested that we join a support group. Yes, that would be great, but with no diagnosis, which one do we join? A church friend was sharing that Alex "just has a brain problem." And insurance proclaiming it was *only* a "brain protein condition." The mislabeling meant some testing was denied. When we finally got the right tests and the right diagnosis, the shift was huge for all of us.

I am the most extroverted in my immediate family, but I am not sure that one would define me as an extrovert. But when it comes to my son and advocating about this disease, I guess you would label me an extrovert. I have to be the LOUDEST, the CLEAREST and the BEST on this stage as an advocate for my son and others who suffer from anti-NMDA receptor encephalitis. Especially when early diagnosis and aggressive treatment greatly improves outcomes, while delayed diagnosis and treatment can lead to permanent brain injury or loss of life.

The Fledderjohn family.

"**After seven years of misdiagnosis**, our son, **Alex** was finally properly diagnosed with **Anti-NMDAR Encephalitis** by his sixth neurologist. Since then, Alex has relapsed. This horrible disease requires more **awareness** and **educational avenues** for both the medical community and the public. **Please help** any way you can."

Our son, Alex, had a smile that brightened any place he entered. He was an avid reader and loved to learn.

Q&A session at the AE Awareness gathering in West Chester Hospital.

With much struggle, he finished the last class he needed to graduate from Ohio State University with a BA in Psychology. He chose Psychology because he wanted to help people live better lives and be the best they could be. Unfortunately, after this disease, he cannot do that for himself (let alone for others). So we as "Team Fledderjohn" will advocate for him and help others as he wanted to help them. As Ralph Waldo Emerson said, "The first wealth is health."

On August 17, 2019, we had an AE Awareness gathering and fundraiser in honor of Alex, which was held at West Chester Hospital in Ohio. Two leading UC Health doctors, Dr. Stephen Rush (psychiatrist) and Dr. Elizabeth Dragan (neurology) spoke, along with Kimberley de Haseth from AE Alliance and a resourceful Q&A session followed.

From one caregiver to another…never stop researching…never stop asking questions…never stop looking for the answers…never stop hoping. Knowledge is strong medicine.

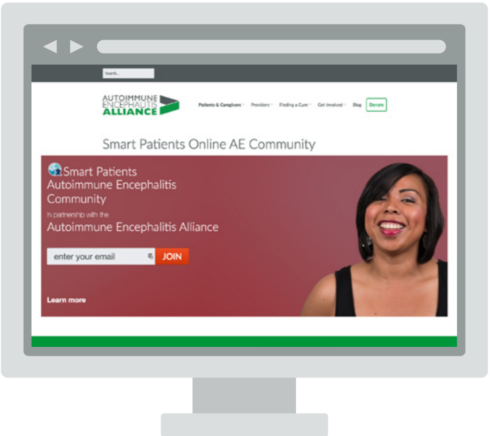
The road traveled was a long, dark, scary, lonely and isolated one. We must continue on, but remember, as we walk on, walk on together.

You are not alone!

In September 2018, AE Alliance partnered with Smart Patients to create the online AE Support Community, giving those affected by AE a safe place to share experiences and resources. Over the past year, this community has grown to nearly 500 patients and caregivers.

One of the reasons the McDow and Egger families founded AE Alliance, was to ensure that no one would face AE alone. The online AE Support Community embodies that spirit. It is heartwarming to read how many people are supporting one another in their most difficult times.

For those of you unfamiliar with this resource, Smart Patients is an online peer support resource for patients, family and caregivers. AE Alliance chose to partner with the Smart Patients team because their custom-built, disease-specific forum offers a truly safe, comforting and engaging online experience for patients and caregivers. The conversations are arranged using tags and are completely searchable, so you can easily find what you're looking for. It is free to join and easy to post questions.



Join the online AE Support Community:

aealliance.org/patient-support/smart-patients-online-ae-community

AEALLIANCE.ORG
920 Urban Avenue
Durham, NC 27701

PRSRT STD
U.S. POSTAGE
PAID
RALEIGH, NC
PERMIT #2483

John Doe
100 Street Name
Durham, NC 27701