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International Autoimmune Encephalitis Society

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FOR IMMEDIATE RELEASE:

**THE INTERNATIONAL AUTOIMMUNE ENCEPHALITIS SOCIETY
AE AWARE CAMPAIGN**

The International Autoimmune Encephalitis Society (IAES) established the month of February as Autoimmune Encephalitis Awareness Month in 2020 and instituted the AE Aware Campaign during the inaugural year. AE Aware is an on-going media campaign designed to bring the public's attention to this treatable illness that is often misdiagnosed as psychiatric, and to decrease the enormous amount of misdiagnosis, so lives can be saved.

Autoimmune encephalitis (AE), a rare disease that occurs when the immune system starts to produce antibodies that are not supposed to be there. These antibodies mistakenly identify healthy brain cells as foreign, thus triggering an autoimmune response to destroy those cells. The body's own immune system is attacking the brain, causing inflammation that can lead to a variety of issues: seizures, hallucinations, memory loss, psychosis, impaired cognition, and paranoia, among other symptoms.

AE can be caused by a variety of different types of antibodies, the most common of which are anti-NMDA (N-methyl-D-aspartate) receptors and LGI1 (leucine-rich glioma inactivated 1) receptors. Many types of AE can be reversed when treated properly. Approximately 80% of patients diagnosed with anti-NMDA AE make a full recovery after aggressive treatment and 1-2 years of rehabilitation to re-wire and re-train the brain.

In addition to aggressive treatment, early diagnosis is one of the main factors in preventing permanent brain damage and death. Prior to AE being identified in 2007, patients were often misdiagnosed as psychiatric cases and legally committed. Undiagnosed, this disease will continue to progress from catatonia to coma to death. The more people who know about AE, the more people will be diagnosed quickly.

IAES established February as Autoimmune Encephalitis Awareness Month to incorporate two important calendar awareness days, World Encephalitis Day, February 22nd and Rare Disease Day February 28th (The last day of the month).

IAES is encouraging those affected by Autoimmune Encephalitis to shine a light on AE by sharing their stories in the media to make the public more AE Aware. Patients, caregivers and loved one who have been touched by AE can contact their local newspapers and television stations to share the story about their experiences battling autoimmune

encephalitis and by incorporating hashtags #AEaware #IAES, #AEwarrior and #Raredisease in their public and social media campaign efforts.

In medicine the term “zebra” is used when referring to a patient with a rare disease. It will take our international herd’s participation to be heard and make the world #AEaware.

What experts in the field of autoimmune neurology had to say:

“Parents, pediatricians and family practitioners should consider AE in any child with an acute or sudden change in neurologic function or behavior. This may include acute regression and language loss in a younger child or acute onset of psychosis in a teenager. AE May be as prevalent as viral encephalitis and requires prompt investigation and therapy,” said Eyal Muscal, MD, Texas Children’s Hospital Houston, Texas

“Improved diagnosis of autoimmune neurologic disorders has been greatly facilitated by the discovery of antibodies that are highly specific diagnostic biomarkers. Autoantibody testing in serum and CSF helps confirm the diagnosis and assist in the prediction of immunotherapy response, cancer association and prognosis. Early recognition is crucial. Immunotherapy and symptomatic therapy can be effective, said A. Sebastian López-Chiriboga, MD, Head of Autoimmune Neurology Clinic, Mayo Clinic Jacksonville, Florida. Additionally, he went on to say, “Evaluation by physicians with expertise in managing these disorders is important as other conditions such as neurodegenerative disorders, infections, psychiatric disorders or other metabolic or genetic conditions can mimic autoimmune encephalitis and the potential side effects of unnecessary immunotherapy can be very serious, thus achieving a correct diagnosis is extremely important.”

Veronica Cipriani, MD, MS, Assistant Professor of Neurology who heads the new Autoimmune Neurology Clinic at University of Chicago explained, “Autoimmune encephalitis, or immune mediated inflammation of the brain, is a syndrome that can present with a variety of neurologic and psychiatric symptoms. This diagnosis should be considered in any patient with acute to subacute onset of neurologic or psychiatric symptoms without a clear explanation. These patients often encounter emergency room physicians or primary care physicians before seeking care from a neurologist, so all physicians should understand when a patient should be referred to our clinic. She went on the say, “It is important to recognize when a patient could have autoimmune encephalitis, because it is imperative to treat it early and aggressively. Our understanding of autoimmune encephalitis is rapidly evolving as more antibodies are discovered and clinical syndromes are being described in medical journals, but there is still much we need to learn.”

Tabitha Orth, IAES President, recently interviewed Michael Sweeney, MD, Assistant Professor, Child Neurology and Neuroimmunology University of Louisville and Norton Children’s Hospital about topics that can most assist raising awareness of autoimmune encephalitis among the medical community and public.

“What can you share with us about how autoimmune encephalitis is often misdiagnosed or under recognized, Dr. Sweeney?”

“This is a complicated question, said Dr. Sweeney, “There are no formal diagnostic criteria for autoimmune encephalitis and there are many mimics. There is no real way to determine how often this is missed. The disease may present subacutely or develop over a period of time. This may result in what is perceived as a delay in diagnosis. The diagnosis may also come after an infection or occur in the setting of a cancer. Every patient with autoimmune encephalitis presents with a different constellation of symptoms and thus it is very feasible that cases are missed.”

“Do you believe that early diagnosis and treatment results in best outcomes for these patients?”

“Despite the lack of research in this area, I do believe that to be accurate.” Continuing Sweeney explained, “AE is a highly treatable group of disorders and it is true that many/most of the symptoms of autoimmune encephalitis can be reversed. I am careful when speaking about this as a generality. For example, when someone with anti-NMDA receptor encephalitis is seen back in clinic, they often have persistent mood changes, difficulties with memory, some with ongoing seizures. Even though these patients may appear back to “normal” on the outside, they often have persistent neuropsychiatric problems that persist for years, if not forever.”

“What is your opinion regarding patients with first time psychosis, should they receive a lumbar puncture for overall mental and physical health?”

“I do agree that patients with first time psychosis should have a thorough evaluation”, replied Sweeney, “This should include a history and examination by someone with experience in the diagnosis of acute psychiatric disorders. There are a number of different diseases, including autoimmune encephalitis, which may present with psychosis.”

“International Autoimmune Encephalitis Society often hears from patients or their loved ones who share their distressing story of how the patient was initially misdiagnosis with bi-polar disorder or schizophrenia due to the dominant psychiatric symptoms present when the patient first became sick. Many patients’ first contact with the medical community at disease onset is either with a Psychiatrist or Emergency medicine physician. Because AE is not commonly identified, patients may be put on a psychiatric hold and eventually legally committed. IAES is so focused on raising awareness among these medical professionals. What can you share with us about this Dr. Sweeney?”

Dr. Sweeney, “Psychiatric symptoms can be the first symptoms to present in autoimmune encephalitis. These are typically then accompanied by additional symptoms, such as abnormal movements, seizures, or autonomic symptoms. We must put aside any preconceived notions about mental health disorders and keep an open mind when first examining patients with psychiatric symptoms.”

In earnest, Dr. Sweeney went on to say, “Emergency medicine doctors are often the first to encounter these patients and should become familiar with the presentation. They do indeed have the difficult task of evaluating patients with acute mental status changes. In their world, they are flooded with patients that have acute mental status changes. It can be very easy to miss a zebra when you see so many patients with common diseases.”

In closing, Dr. Sweeney concluded, "In general, I would like to make it clear that in neurology, especially neuroimmunology, there is no "one-size-fits-all" approach. Each patient with an autoimmune disease that affects the brain has presented differently and has responded differently to medications. The heterogeneity of these diseases is what has made it so difficult to understand in the first place and even more difficult to study in a methodical way."

Tabitha Orth, President of IAES explained, "IAES is the only family/patient centered organization for autoimmune encephalitis and provides services world-wide. We assist members every step of the way from getting an accurate diagnosis to recovery, and the many challenges experienced throughout that journey. Helping patients and families understand the disease, it's treatments and empowering them through education allows people to feel in more control of the health crisis they have been thrown into."

In addition, she said, "Our varied advocacy services, assisting in overturning an insurance denial for example, were not available to AE patients prior to IAES being established. Our organization's model has earned us a gold standard reputation by the people we serve. IAES is devoted to raising awareness of autoimmune encephalitis, across the many specialties of medicine that come in contact with these disorders and with the public. Timely and accurate diagnoses and treatment is a key component for the best possible outcomes."

The International Autoimmune Encephalitis Society (IAES) - a 501 (c)3 non-profit organization founded in Delaware, U.S.A. in 2016 providing services worldwide.

Visit www.autoimmune-encephalitis.org to learn more

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