

EDITION 13 WINTER 2024

CONNECT

THE NEWSLETTER FOR PROFESSIONALS INTERESTED IN ENCEPHALITIS

PROFESSIONAL



IN THIS ISSUE:
Conference 2024
World Encephalitis Day 2025

Plus...
Seed funding
Latest Research
& much more



**Encephalitis
International**
The brain inflammation non-profit

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Front Page Image:

Encephalitis International Team in London for the 30 Birthday Party

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Welcome to Connect Professional!

In this edition, you can discover what we have been working on recently and all our exciting plans for upcoming events and campaigns. It's been a busy 2024 and we hope 2025 will be just as productive!

Firstly, the Encephalitis Conference will be held on the 2nd and 3rd of December at the Royal College of Physicians in London. We hope to see you there! It promises to be a fantastic event dedicated to encephalitis with cutting-edge insights from global leaders in the field of brain inflammation. We know it is unfortunately not possible for everyone to join us in-person, so rest assured that you can join virtually, or watch the recording afterwards. The conference is growing every year, and this one is sure to be the best one yet.

In this issue, we show the impact of World Encephalitis Day (WED) 2024 and our plans for WED 2025. In addition, you will read about our 2024 Vaccine-preventable Encephalitis Campaign and our other events for patients and carers. We have some exciting news about being PIF TICK accredited and new resources for your patients wherever you are in the world: instant translated online chat, connection scheme and peer support groups. We are excited to share the start of our work to develop online training modules on encephalitis.

We are delighted to announce our joint-funded Academic Clinical Fellow and update on Encephalitis International seed funding programme. There is also information on trials we have been involved in and latest research including CAMKV autoimmune encephalitis, UK research priority setting for childhood neurological conditions and brain changes after COVID-19.

In this edition, we welcome Prof Michael Wilson, Dr Sophie Binks and Dr Tina Damodar to our Scientific Advisory Panel. You can also read a patient's lived experience of anti-LG1 autoimmune encephalitis. Finally, there will be some save the dates for our upcoming events.

Enjoy this edition and hopefully see you in December!



Dr Ava Easton

Chief Executive

Encephalitis International



Dr Nicholas Davies

Chair - Scientific Advisory Panel

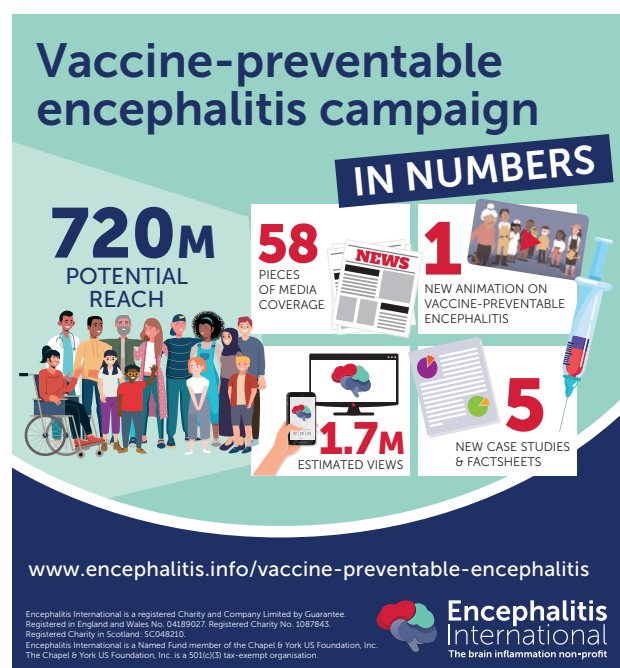
Encephalitis International

Latest News

Vaccine-preventable campaign

Back in April we launched a campaign to raise awareness about the vaccine-preventable encephalitis types: tick-borne encephalitis, Japanese encephalitis, measles associated encephalitis, varicella zoster encephalitis and influenza associated encephalitis. A webinar discussing these types of encephalitis chaired by Assoc Prof Kiran Thakur from Columbia University, USA saw 114 registrations from 40 countries. We were overwhelmed with the success of the campaign which reached a potential audience of 720 million and that was largely down to the bravery of some of our community who shared their stories with the media and on film, a massive thank you to them. We also held the UK premiere of the film *Shot in the Arm* highlighting the harm that misinformation about vaccines can have.

Watch the highlights on our [YouTube Channel](#).



If you wish to view recordings of our webinar,
please visit [Webinars | Encephalitis International](#)

30th Birthday Party

We were delighted to have 150 members of our community join us in May to celebrate our 30-year milestone in London in the beautiful Sales Force building. The venue was kindly gifted to us and what a venue it was! With panoramic views of London, it really was a treat. It was a great opportunity for us to connect with long standing and new encephalitis community members and supporters, and reflect on how we, as an organisation, have progressed over the past three decades. An important part of the evening was also sharing some of our future plans, including the appeal for purchasing our offices based in North Yorkshire, England, an important step to secure the next 30 years of our work.

You can watch the highlights film on our [YouTube Channel](#).

Encephalitis International is PIF TICK accredited

Encephalitis International is proud to be awarded the PIF TICK – an assessed quality mark for print and online health and care information.

To become a 'trusted information creator', Encephalitis International had to undergo an assessment showing it met 10 key criteria.

This means you can be assured that what you and your patients are reading, watching or listening to is evidence-based, understandable, jargon-free, up-to-date, and produced to the best possible standard.

Dr Ava Easton, CEO of Encephalitis International, said "Gaining the PIF TICK shows we have a robust process for developing our health information resources. With so much information online, it can be difficult to know what to trust. This quality mark is a quick and easy way for people to be assured our information is reliable and trustworthy."

The PIF TICK, which launched in May 2020, is run by the non-profit [Patient Information Forum \(PIF\)](#).

Latest News

My Brain & Medicine - Patient Event

My Brain & Medicine (MB&M) is a regular patient event held during 2024 in the USA (Cleveland) in-person and internationally online. This is part of our series of free patient events that we run for our encephalitis community.

In April and July this year, we welcomed experts to share their knowledge of encephalitis with patients and their families, alongside those with lived experience of encephalitis. The talks at MB&M events are aimed at patients, family members, carers and anyone with a specific interest in encephalitis.

My Brain & Medicine, 22 April

MB&M in April was a virtual only event held during our Vaccine-preventable Encephalitis Campaign week. We welcomed six professional speakers: Professor Carsten Finke (Germany), Dr Marie Rafiq (France), Kati Sowada (USA), Professor Ann Yeh (Canada), Dr Brendan Sargent (UK) and Karen Ernst (USA), who spoke about encephalitis, recovery, outcomes, research and vaccine hesitancy. In addition to these speakers, Judiel Diaz, a nurse from the Philippines, shared her lived experience of encephalitis. 359 people from 35 countries worldwide registered. The success of our event was reflected in the attendee feedback we received, such as:

"Brilliant. Loved combination of input from round the world (came across as very high level) & management of the process."

My Brain & Medicine Cleveland, 22 July

In the USA, the My Brain & Medicine event took place in Cleveland. It was jointly hosted by Encephalitis International and the Cleveland Clinic with a mix of professional and lived experience speakers. Dr Ryan Miller, Dr Jenny Linnoila, Dr Aaron Abrams, Dr Hesham Abboud, Dr Justin Abbatemarco, Dr Amy Kunchok, Dr Grace Tworek, Allyson Krueger, Maureen Ivec and Danielle Brown, from the Cleveland Clinic, and Dr Jenny Linnoila from University of Pittsburgh Medical Center (UPMC) talked about the condition and the multidisciplinary longitudinal care for patients with encephalitis. Jackie Stebbins, author and encephalitis survivor talked about self-care after encephalitis and three wonderful members of the encephalitis community shared their experiences: Maria Skliros (infectious encephalitis), Ronald Gadzinski (autoimmune encephalitis) and Bradley Wells (inspirational caregiver).

"Up until now I believe (I do not remember) I have resisted going for support groups when I was told about them. But I do see the value of them after attending this meeting. It was good to meet others in the group who had similar issues and nor feel as isolated as I have for so long".

If you feel that events such as this would be helpful for your patients or their families, please direct them to our website to see upcoming events: www.encephalitis.info/events/

Dates for My Brain & Medicine 2025

28th April, virtual event only

26th September, in-person only, New York, USA in collaboration with Columbia University

Closure of Enceph-IG Trial

We would like to take this opportunity to share the news that, unfortunately, the encephalitis trial 'Enceph-IG' has now closed. This was an ambitious study that aimed to determine whether, in adults with autoimmune encephalitis, treatment with early Intravenous Immunoglobulin (IVIG) leads to a different recovery time and improve the outcome. The study also set to determine the mechanism by which it might do this. This trial was led by Professor Tom Solomon CBE from the University of Liverpool's Brain Infectious Group. Despite its unfortunate early closure, there is still much to be learnt from the study. Dissemination material sharing their experience of running the Trial will follow.

Help with our events/information needed

If you are a neuropsychologist and want to get involved with reviewing our information and/or speaking at our events, please get in touch with us at research@encephalitis.info

2024 Viral Outbreaks

Several viruses made the spotlight in the last few months as a reminder of the complex and often unpredictable nature of viral diseases. As we've learned from past outbreaks—be it polio, HIV, or more recently, COVID-19 – viruses can affect the brain in ways we can't always predict. By staying informed, investing in research, and prioritising prevention, we can work towards minimising the neurological impact of these emerging viral threats.

MPOX

Mpox continues to be a threat today with a rise of number of cases in some countries such as the Democratic Republic of Congo. When you think about mpox (formerly known as monkeypox), you might picture the skin lesions characteristic of the disease. But this viral infection can have far-reaching effects beyond the skin, sometimes impacting the brain itself with rare but severe neurological complications. Encephalitis is the most common neurological complication of mpox infection. Vaccination and early treatment are crucial in preventing severe outcomes of mpox infection. For more information, please read our blog on Mpox: [Mpox and encephalitis | Encephalitis International](#)

Eastern Equine Encephalitis (EEE)

Eastern Equine Encephalitis (EEE) has been a concern over the summer in the United States. While still rare, it is a potentially life-altering and deadly infection that deserves our attention. It is a viral disease transmitted to humans through the bite of infected mosquitoes. Although EEE virus is rare, it has a 30% mortality rate among infected individuals. Even among survivors, half have brain or nerve problems. Also, there is no human vaccine for EEE – so prevention is crucial.

For more information, please read our blog on EEE:

[Eastern Equine Encephalitis \(EEE\) | Encephalitis International](#)

Oropouche

The Oropouche virus disease has now been described as a 'mysterious' and 'emerging' threat by The Lancet¹. Oropouche virus is an arbovirus spread by insect bites – in this case mainly midges and possibly some mosquitoes.

Why is it concerning?

- Cases: In Brazil, cases have jumped from 832 in 2023 to 7284 so far in 2024.
- Geography: Previously mainly in the Amazon Basin, the virus has now been reported in new areas like Bolivia and Cuba.
- Severity: While historically considered mild, 2024 has seen the first reported deaths associated with Oropouche – 2 healthy young women in Brazil.
- Mitigation: There are no vaccines or specific treatments for Oropouche.

For more information, please read our blog on Oropouche: [Oropouche virus – what you need to know | Encephalitis International](#)

1 The Lancet Infectious Diseases. Oropouche fever, the mysterious threat. Lancet Infect Dis. 2024;24(9):935. doi:10.1016/S1473-3099(24)00516-4

Guidelines for Management of Encephalitis

Guidelines for managing both infectious and autoimmune encephalitis are in the process of developing. Groups of global experts have been working tenaciously to produce these for the benefit of any health care provider who care for patients with encephalitis.

Assoc Prof Maarten Titulaer, co-director of the Academic Center for Neuroinflammatory disorders at the Erasmus University Medical Center, Rotterdam and member of Encephalitis International Scientific Advisory Panel reports on the progress of the Guidelines for Management Autoimmune Encephalitis:

"We are well on our way with the guideline process. All data

has been extracted, valued and summarised. Recommendations with the relevant considerations have been written. We are currently in the process of discussing the produced texts and voting to measure the level of consensus. These should be finished by the time of the Encephalitis Conference. The next steps are combining all these recommendations, merge the texts to make them appear in harmony, and create the full manuscript, including introduction, methodology, knowledge gaps and future directions."

Dr Julia Granerod, epidemiologist, reports on the guidelines for managing infectious encephalitis

"The Task Force group who develops the guidelines met in Barcelona at the ESCMID Global conference. The good practice statements and recommendations for the 16 PICOs (questions) have been formulated and agreed. They have put together a draft manuscript which is in the process of being approved by the group. Following approval, this will enter a consultation process with both societies (ESCMID and EAN) before being submitted to their respective journals for publication. Publication is anticipated in 2025."

Latest News

Meet the newest members of our Scientific Advisory Panel (SAP)

The Scientific Advisory Panel provides Encephalitis International (EI) with expert professional resources, advice and assists with clinical and research matters. The Panel will also promote and support the organisation's involvement within research studies and programmes, advocacy and patient and public involvement (PPI) initiatives, partnerships and collaborations.

Dr Sophie Binks

Clinical Lecturer and Honorary Neurology SpR at Nuffield Department of Clinical Neurosciences, University of Oxford

I am a clinical lecturer and honorary neurology registrar in Oxford recently awarded a DPhil in autoimmune neurology, and now establishing myself as a clinician-scientist. My DPhil supervisors and current collaborators are Prof Sarosh Irani, as well as Prof Julian Knight and

Dr Kate Elliott from the Knight Group, Wellcome Centre for Human Genetics, Oxford.

My research focuses on clinical and genetic aspects of autoimmune encephalitides. Previously (2016-2017) I was an Academic Clinical Fellow in Neurology in Oxford investigating clinical and HLA associations of LGI1- and CASPR2-antibody encephalitis, and prior to that I completed an Academic Foundation Programme in Neurology in Brighton.



Dr Tina Damodar

India Alliance (Wellcome Trust/ DBT) Clinical & Public Health Fellow, Department of Neurovirology, National Institute of Mental Health & Neurosciences (NIMHANS), Bangalore, India

Dr Tina Damodar is a Wellcome Trust/ DBT- Clinical & Public Health Fellow at National Institute of Mental Health & Neurosciences (NIMHANS), Bangalore in Southern India.

After completion of MBBS in 2010, she pursued advanced training in Clinical Microbiology and subsequently served as

a registrar in the Department of Neurovirology at NIMHANS. She was awarded the Wellcome DBT fellowship, aimed at developing a clinical algorithm for diagnosing various causes of Acute Encephalitis Syndrome (AES) in children. She also received the International Seed funding from Encephalitis International to investigate host mRNA signatures in children with scrub typhus meningoencephalitis.

Her research goals are focused on streamlining and simplifying the diagnosis of brain infections, with a specific emphasis on those associated with AES in India.

Professor Michael Wilson

Professor, Neurology UCSF Weill Institute for Neurosciences, School of Medicine, San Francisco

I am a neurologist specializing in infectious and autoimmune diseases of the central nervous system.

I see patients with autoimmune diseases like multiple sclerosis and autoimmune encephalitis as well as patients with a wide array of infectious diseases that impact the nervous system like HIV, neurocysticercosis, neurosyphilis, viral encephalitis and fun-

gal infections.

My laboratory applies metagenomic and immune repertoire sequencing techniques as well as phage display antibody discovery technologies to enhance our understanding of the causes and immunopathogenesis of multiple sclerosis as well as autoimmune and infectious causes of meningoencephalitis.

For more information about the Panel, visit: www.encephalitis.info/our-scientific-advisory-panel/



Latest News

Our International Travel

Reported by Dr Ava Easton, CEO Encephalitis International

As I sit typing I am on a train heading to Glasgow to teach on the university MSc and Postgraduate Diploma in Applied/Clinical Neuropsychology course, a lecture I have been delivering for so many years now that neither I or Prof. Jon Evans who runs the course, can remember how long for! This is an example of one of my many domestic travels.

Moving to more international trips, this year I also attended the American Academy of Neurology (AAN) Annual Conference in Denver along with my colleague Calum Goodwin. The AAN Annual Meeting is the world's largest gathering of neurologists and neuroscience professionals. It features scientific research presentations, educational sessions, networking opportunities, and hundreds of exhibitors, with around 11,000 people in attendance in person and a further 3,000 online. I attended and drank in the many lectures as well as using the opportunity to connect with many of our clinician, scientist, and researcher colleagues. An additional advantage for both Calum and I of attending this huge conference is that we can connect in one place with many of our industry friends, having meetings about ongoing projects and strategic discussions about how we can support their research trials and projects. No sooner had I landed back in the UK than I was summoned to Paris by the World Health Organization for a high-level meeting on their roadmap to combat meningitis!

Later in the year I also attended the AAN summer conference in Atlanta. This is a smaller affair over two days in which there was focused discussion on autoimmune neurology and its intersection with neuro-infectious diseases. Prior to this I took the opportunity to pop down to the University of Georgia where I had heard about a Japanese Modelling project and I was hosted for the day by John Drake, head of the Center for the Ecology of Infectious Diseases. After the AAN conference I was meant to attend the Cleveland Clinic for our My Brain and Medicine collaborative event there however the global cyber/IT outage had other plans for me leaving me stuck in Atlanta for a further three days unable to get home. The Next US My Brain and Medicine event will be in New York City next year.



In September I had the pleasure of returning to the Karolinska Institute in Stockholm to deliver a lecture on the history of encephalitis and what the future may hold. My time in Stockholm however was not over as I was then off to attend what I believe was the Nordic's first conference

dedicated to the biology of Autoimmune encephalitis, ably stewarded by Dr Jakob Theorell, Prof Frank Leypoldt and Dr Christine Nilsson, and hosted by the Wenner-Gren Center Foundation for Scientific Research. Here I presented on the last day lecturing about patient outcomes and quality of life post-encephalitis. A wonderful social program was provided allowing opportunity to catch up with colleagues in the field as well as the long days of lectures and discussion. One output from this meeting was a desire to host a patient event in Sweden and we are currently working on this with Nordic colleagues so watch this space! These travels whilst at times exhausting are an important part of our work. Networking and raising the profile of Encephalitis International, contributing to existing and new research and motivating and inspiring clinicians, scientists and researchers in our vision of a world without death and disability from encephalitis, and our mission to rebuild futures around the world by saving lives, accelerating awareness and driving research.

Encephalitis Conference

Encephalitis Conference 2024



Hundreds of medical professionals from across the world will attend the two day conference Encephalitis 2024 this December. Aimed at physicians, scientists, researchers and healthcare professionals, our annual conference is an event where cutting-edge ideas, knowledge and clinical experiences relating to encephalitis are exchanged.

Attendees can join us in-person at the Royal College of Physicians in London or virtually - with all talks available to watch on-demand for 60 days after the event.

This year's programme has been developed by Assoc Prof Kiran Thakur who chaired the Encephalitis Conference Sub-Committee alongside members of the Scientific Advisory Panel and Encephalitis International and feature 26 presentations and 49 posters.

This year, we are proud to announce:

KEYNOTE SPEAKERS

- Professor Michael Wilson, Debbie and Andy Rachleff Distinguished Professor of Neurology at the UCSF Weill Institute for Neurosciences; Director, UCSF Center for Encephalitis and Meningitis, San Francisco, USA
"Metagenomics, Encephalitis and Global Health"
- Dr Marianna Spatola, IDIBAPS Research Institute, University of Barcelona and La Caixa Research Institute, Barcelona, Spain; Hospital of Sion, Switzerland
"Functional Effects of Antibodies in Infectious and Autoimmune Encephalitis"

Encephalitis Conference

GUEST SPEAKERS:

- Dr Ava Easton, Encephalitis International; University of Liverpool, UK
"Brains on Fire: Patient Outcomes and Quality of Life Following Encephalitis"
- Dr Bhagteshwar Singh, Institute of Infection Veterinary and Ecological Sciences, University of Liverpool & Tropical and Infectious Diseases Unit, Royal Liverpool University Hospital, UK
"Improving Diagnosis and Management of People with Brain Infections in Brazil, India and Malawi"

DEBATE "Encephalitis research fails to improve diagnosis and treatment in low-to-middle income countries (LMIC)"

- Dr Mashina Chomba, University Teaching Hospital – Adult Hospital, Lusaka, Zambia
- Dr Gagandeep Singh, Professor & Head, Department of Neurology, DMCH, Ludhiana, India

LATE BREAKING DEX-ENCEPH NEWS

- Professor Tom Solomon, CBE, The Pandemic Institute; National Institute for Health and Care Research Health Protection Research Unit in Emerging and Zoonotic Infections, Liverpool, UK
"Early corticosteroid treatment appears to improve the outcome of HSV encephalitis"

BASIC CLINICAL OVERVIEW OF ENCEPHALITIS

- Prof Benedict Michael, University of Liverpool & The Walton Center, Liverpool, UK
- Prof Sarosh Irani, Mayo Clinic Florida & University of Oxford

CLINICAL CASE PANEL

- Chaired by Assoc Prof Kiran Thakur, Columbia University Irving Medical Center, USA

HOW TO GET YOUR GRANT/FELLOWSHIP

- Chaired by Assoc Prof Deanna Saylor, Johns Hopkins University School of Medicine, USA & University Teaching Hospital and the University of Zambia School of Medicine, Lusaka, Zambia

Please note:

- [Professional Members](#) of Encephalitis International are eligible for a 20% discount and our members from low-and-middle income countries could attend the Conference free of charge

The Conference was kindly sponsored by:

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World Encephalitis Day



Professor Tom Solomon CBE and Dr Ava Easton at the World Health Organization HQ in 2020

World Encephalitis Day

World Encephalitis Day on the 22nd of February, is the global awareness day which has reached millions of people through media features, events and social media since its beginnings.

This year, a global survey commissioned by Encephalitis International has revealed that emergency medical professionals lack confidence in recognising encephalitis – risking delays in recognition, diagnosis and treatment. These findings have been the focus of our media campaign. Following our World Encephalitis Day 2024 appeal: **Don't Delay: Give Today** we raised funds towards providing training opportunities for medical professionals globally.

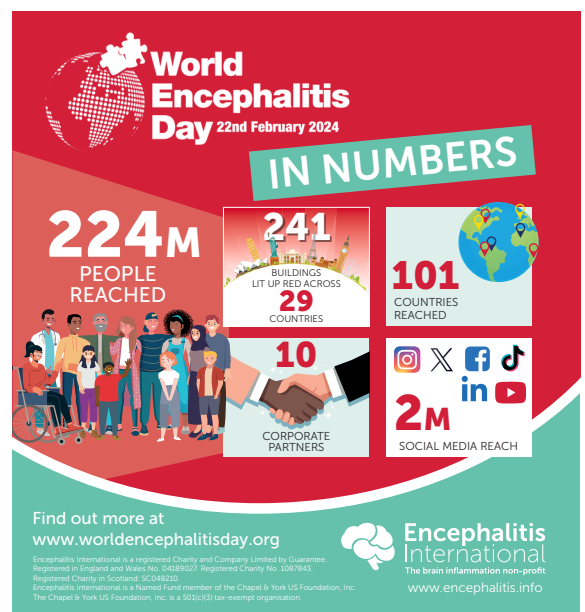
We are proud to now be working on the first ever education modules for healthcare professionals globally. We have formed a working group of experts to help steer the production of the course and are sure their knowledge and expertise will mean we create the best possible product. We will update on the progress of the modules in our future newsletters.

It is our hope that World Encephalitis Day 2025 will play a leading role in our mission to increase global awareness of encephalitis and therefore saving lives and building better futures.

In 2025 we will be inviting supporters to once again take part in World Encephalitis Day by:

- Wearing something #Red4WED
- Lighting up a landmark #Red4WED
- Supporting our appeal by donating or organising a fundraiser

Some of you may be part of the 27,681 people who signed our petition in 2019 to show the World Health Organization that encephalitis matters. This year on World Encephalitis Day we are excited to update you on some important progress on our work with the WHO that will change the global landscape of encephalitis for years to come.



Research Matters

Encephalitis International funded research

Driving research that will benefit everyone affected directly and indirectly by encephalitis is part of our mission. We are pleased to update you on the research we are currently funding.

Academic Clinical Fellowship

We are pleased to be involved in funding an academic clinical fellowship (ACF) with the University of Liverpool. Dr Abdusshakur Muhammad Auwal has started this Fellowship in neurology at the University of Liverpool/Walton Center Liverpool, UK working to understand better the causes and effects of NeuroCovid using functional magnetic resonance imaging (fMRI). Dr Auwal graduated from Usmanu Danfodiyo University, Sokoto in Nigeria at the top of his class and has been working in the NHS since 2020. His research work included collaborating on a project that led to the approval of using two new drugs-Dexamethasone and Tocilizumab for patients with Covid 19. We wish Dr Auwal good luck, and we look forward to updating you on the progress of his study.



Seed funding update

2024 saw the launch of our sixth round of seed funding with a focus on making grants for projects in Asia. We cannot fund large-scale research, but we are very keen to help international groups in various countries get started on new and clinically relevant studies. Our proposal is to provide seed funding for a small or "pilot" project which, if successful, can help secure further funding for potential larger-scale work. This year, we had seven applications from six countries. Our Research Subcommittee (subcommittee formed from members of our Scientific Advisory Panel and our volunteer lay reviewers) scored all the applications and made recommendations for selecting the two funding grants. **The winners will be announced in our next digital newsletter.**

Three of our previous grants have finished this year. **Dr John Kasibante** set up to differentiate viral encephalitis from its mimics in patients with encephalitis of unknown cause in Uganda. **Assoc Prof Priyanka Madaan's** project aimed to develop a tool to measure the severity of autoimmune encephalitis in children to better understand the severity of the disease and aid the decision-making regarding treatments. **Dr Tina Damodar** looked into developing a novel diagnostic test that can differentiate scrub typhus from other causes

of acute encephalitis syndrome (AES) in children.

Dr Kasibante and Assoc Prof Madaan will present on their findings at the Encephalitis Conference.

Dr Damodar reports on her findings below:

"The study at the National Institute of Mental Health & Neurosciences (NIMHANS), Bangalore, has unveiled distinctive transcriptomic signatures that could potentially form the basis of a novel host-based diagnostic test for scrub typhus in children with acute encephalitis syndrome (AES). This research marks a significant advancement in understanding the host immune response to scrub typhus infection, particularly in cases presenting with neurological complications. The study employed high-throughput mRNA sequencing (Illumina HiSeqX) to analyse host transcriptome profiles in a cohort of children with AES due to scrub typhus and viral aetiologies. This analysis led to the identification of over 500 differentially expressed genes, revealing complex immune response patterns specific to scrub typhus infection. A key finding emerged in the significant up-regulation of genes involved in T-cell receptor signalling pathways and NK cell-mediated cytotoxicity, accompanied by enhanced lymphocyte activation. Notably, the research uncovered

downregulation of genes associated with B-cell receptor signalling and humoral immune responses, suggesting a previously underappreciated aspect of the disease's immunopathology. These findings have established the first comprehensive transcriptome database for scrub typhus-associated AES, providing valuable insights into the molecular mechanisms underlying the disease. The distinct immune response patterns identified could serve as potential biomarkers for developing rapid, blood-based diagnostic tests, particularly crucial for resource-limited settings where timely diagnosis remains challenging.

While these findings are preliminary and need further validation in a larger cohort, the results provide compelling evidence for further investigation. Building on these results, the research team plans for a larger-scale validation study across multiple hospitals in the future. The research has facilitated valuable collaborations with multiple hospitals and experts in bioengineering, setting the stage for the development of practical diagnostic tools."

Call for applications for seed funding 2025 will open in the Spring 2025.

Research matters

CAMKV autoimmune encephalitis: a novel autoimmune neurologic disorder

Dr Michael Gilligan, MB BCh BAO, Mayo Clinic Rochester, USA

Autoimmune encephalitis is a disorder characterized by inflammation of the brain and is usually associated with antibodies against neural proteins (1). In the past two decades the discovery of antibodies associated with autoimmune encephalitis has increased exponentially. The most commonly encountered neural antibodies include anti-N-methyl-D-aspartate (NMDA)-receptor or anti-leucine-rich glioma inactivated (LGI1) protein, but in recent years many other neural antibodies have emerged. Traditionally, the process of antibody discovery is lengthy but modern technologies such as protein microarray have transformed our ability to identify antibodies in patients who have 'seronegative' (neural antibody unknown) autoimmune encephalitis. A protein microarray is a glass slide upon which human proteins are printed and incubated with patient serum or spinal fluid samples. This technology can be used to inform researchers which neural antibodies are present in a patient's blood or spinal fluid. In the discovery of the calmodulin kinase-like vesicle associated (CAMKV) antibody, protein microarrays were used to rapidly identify the neural antibody associated with this autoimmune disorder(2).

In a study performed at the Mayo Clinic, Rochester USA, 5 patients were identified with antibodies targeting CAMKV (a neural protein involved in memory formation). The CAMKV protein is highly expressed in region of the brain that are responsible for memory formation (hippocampus) and the control of movement (basal ganglia). All 5 patients had an encephalitis localizing predominantly to the 'limbic system' (an anatomic region of the brain responsible for the control of memory and emotion), and 4 of the 5 patients had evidence of abnormal movements. Other neurologic problems experienced by patients included psychosis, insomnia, and seizures. Brain imaging and spinal fluid testing revealed evidence of inflammation in all patients who were tested.

As with other autoimmune conditions, CAMKV autoimmune encephalitis is more frequently observed in women than men. The onset of the disorder is most common in late middle age

with all patients aged between 50 to 75 years old. Unfortunately, the CAMKV antibody appears to also signal the presence of an underlying tumor in patients (and may therefore be termed a 'paraneoplastic' autoimmune disorder). Among women, the CAMKV antibody is associated with endometrial (uterine) cancer in all patients. In men, the cancer associations are more diverse: 1 patient had bladder cancer, and another had lymphoma.

Importantly, all patients treated with immunotherapy demonstrated an excellent response to treatment with improvement or resolution of neurologic symptoms. In one patient, early detection and treatment of the underlying uterine cancer led to complete improvement in neurologic symptoms. We therefore wish to emphasize the importance of awareness, recognition and early diagnosis of CAMKV autoimmune encephalitis. Should you wish to read more about this novel form of autoimmune encephalitis, you can find our research article at the following link:

<https://onlinelibrary.wiley.com/doi/10.1002/ana.26943>

This research was supervised by Dr Andrew McKeon, MD, Director, Mayo Clinic Neuroimmunology Laboratory. If you are a healthcare professional and wish to enquire about testing your patient for CAMKV antibodies, please email mckeon.andrew@mayo.edu.

1. Gilligan M, McGuigan C, McKeon A. Autoimmune central nervous system disorders: Antibody testing and its clinical utility. Clin Biochem. 2024;126:110746.
2. Gilligan M, Lesnick CE, Guo Y, Bradshaw MJ, Ladha SS, Nowak M, et al. Paraneoplastic Calmodulin Kinase-Like Vesicle-Associated Protein (CAMKV) Autoimmune Encephalitis. Ann Neurol. 2024;96(1):21-33.

NMDAR and SAPIENCE

N-methyl-D-aspartate-receptor (NMDAR) encephalitis is a rare neurological autoimmune disease with severe neuropsychiatric symptoms. Despite good functional neurological recovery, most patients continue to experience cognitive, psychiatric, psychological, and social impairments years after the acute phase.

However, the precise nature and evolving patterns over time of these long-term consequences remain unclear, and their implications for the well-being and quality of life of patients have yet to be examined.

SAPIENCE (Social and psychological long-term impact of NMDA receptor encephalitis) is a new international research study looking at how NMDAR encephalitis affects people's lives long after their initial treatment. While doctors understand the medical aspects of this condition, they know less about how it impacts patients' thinking abilities, mental health, and social lives.

The study will take place in three major hospitals (Berlin, Lyon, and Barcelona) and will gather information in three ways: interviews, psychological testing and online surveys.

Research matters

The ultimate goal is to create better guidelines for doctors to help patients recover and cope with the long-term effects of this disease.

Boeken, Ole Jonas et al. "Assessment of long-term psychosocial outcomes in N-methyl-D-aspartate receptor encephalitis - the SAPIENCE study protocol." BMC neurology vol. 24,1 322. 6 Sep. 2024, doi:10.1186/s12883-024-03842-6.

UK research priority setting for childhood neurological conditions

This study aimed to identify research priorities regarding the effectiveness of interventions for children and young people (CYP) with childhood neurological conditions (CNCs). These include common conditions such as epilepsies and cerebral palsy, as well as many rare conditions. The study identified top 10 research priorities through collaboration between health-care providers, patients, and families. Key priorities included sleep, emotional well-being, communication difficulties, and distressing symptoms.

While many submitted concerns about epidemiology, pathophysiology, and service delivery were considered out of scope, they provided valuable insights for future research and healthcare services. The priorities overlap with previous studies, particularly those from the British Academy of Childhood Disability.

The study acknowledges several challenges in conducting research in this field, including clinical heterogeneity, varying environmental factors, and multiple simultaneous interventions. The findings aim to guide future research funding and improve clinical care.

Cadwgan, Jill et al. "UK research priority setting for childhood neurological conditions." Developmental medicine and child neurology, 10.1111/dmcn.16021. 16 Jul. 2024, doi:10.1111/dmcn.16021.

Brain changes after COVID-19

A large UK study looked at the lasting effects of COVID-19 on brain function in 351 patients who were hospitalised with the virus. They compared these patients to nearly 3,000 people who hadn't had COVID-19 and found that COVID-19 patients showed significant memory and thinking problems that lasted long after their initial infection – similar to the cognitive decline typically seen when aging from 50 to 70 years old.

These problems were seen even in patients who didn't have obvious neurological complications during their illness. The study found signs of ongoing brain cell damage up to a year after infection, along with reduced brain volume in certain areas. These cognitive problems were worse in patients who had more severe COVID-19 or who experienced confusion during their illness.

While some improvement was seen during follow-up, recovery

seemed to plateau, suggesting these changes might be long-lasting. Depression symptoms were also common and linked to the cognitive problems.

The strengths of this study included its use of robust cognitive assessment, high quality clinical data, and multimodality. One limitation is the lack of genetic sequencing data for SARS-CoV-2 variants which means the impact of viral clade on outcomes can only be assessed approximately. Also, current pipeline approaches limit the analysis of certain brain regions, such as the brainstem or basal ganglia.

The researchers conclude that a strong concordance between subjective and objective cognitive deficits, underpinned by neuroanatomical and biochemical changes, indicates that patient experience must be acknowledged by clinicians in the post-infection context. However, care needs to be taken in both inferring cause and effect and extrapolating these results to a broader COVID-19 population. Mechanisms underpinning this potentially immune-mediated construct of depression, cognition, and brain injury must be further understood to allow development of targeted therapeutic intervention.

Wood, Greta K et al. "Post-hospitalisation COVID-19 cognitive deficits at one year are global and associated with elevated brain injury markers and grey matter volume reduction." Nature medicine, 10.1038/s41591-024-03309-8. 23 Sep. 2024, doi:10.1038/s41591-024-03309-8.

COVID-19 and immune-mediated brain injury

This study examined how COVID-19 affects the brain by analysing blood samples from 203 hospitalised patients. Researchers measured markers of brain injury, inflammation, and antibodies in two groups: 111 patients during acute infection and 92 during recovery. They found increased levels of brain injury markers both during acute infection and recovery, particularly in patients with neurological symptoms. During acute infection, inflammatory molecules were increased and correlated with brain injury markers. Although inflammation decreased during recovery, some brain injury markers remained elevated in patients who had experienced neurological complications. The study also found that COVID-19 patients developed antibodies against both the virus and some brain proteins, though these weren't strongly linked to brain injury. However, taken together, these findings suggest that COVID-19 can cause brain damage through the body's immune response rather than direct viral infection of the brain, and that this damage can persist even after recovery. It is hoped that studies such as this can guide future treatments for the neurological complications following COVID-19.

Michael, Benedict D et al. "Para-infectious brain injury in COVID-19 persists at follow-up despite attenuated cytokine and autoantibody responses." Nature communications vol. 14,1 8487. 22 Dec. 2023, doi:10.1038/s41467-023-42320-4.

Patient and Public Involvement(PPI)

Statement of intent

We have now developed a Statement of Intent for Encephalitis International. This document outlines the ways in which we are able to support research in encephalitis, and in doing so, continue to help to improve the lives of those affected by encephalitis. This document demonstrates the vast scope for how we can support researchers and professionals in both the UK and internationally whilst continue to work on behalf of people affected by encephalitis as a patient organisation in encephalitis research. The Statement will be available on our website very soon: www.encephalitis.info/research/

Wondering how we might be able to support your research? Visit the patient and public involvement PPI pages on our website to find out more: www.encephalitis.info/patient-and-public-involvement-in-research/ We can offer expertise at all stages of your project, from helping to shape your research focus, to supporting and co-creating your study dissemination resources.

Hear from other researchers and research teams about how our support benefitted them:

"We're delighted to report that our two remaining Caregiver focus groups sessions have been filled. Thank you so much for all of your efforts and assistance with getting the word out – it has clearly made a massive impact."

"Encephalitis International were excellent in helping recruit for our study. They were thorough and professional in seeking to understand the study design and ethics. They were consistently friendly and helpful in aiding the recruitment process. Finding relevant participants can be difficult when researching I am very grateful for their help!"



STATEMENT OF INTENT:
Encephalitis International supporting
YOUR research



Encephalitis International
The brain inflammation non-profit
www.encephalitis.info

Clinical Trials

We are currently supporting two encephalitis clinical trials: the CIELO trial and the ExTINGUISH trial:

CIELO is looking at assessing the effectiveness and safety of satralizumab in participants with anti-NMDAR and anti-LGI1 encephalitis. Ran by Roche, the trial is currently open across 11 countries. The research team are looking to recruit patients aged 12 or older with NMDAR encephalitis, or patients over 18 years old with anti-LGI1 encephalitis. More information on eligibility of patients can be found at: www.encephalitis.info/cielo-study/



ExTINGUISH Trial of Inebilizumab in NMDAR Encephalitis is aiming to recruit patients in the USA affected by NMDAR encephalitis. **NEW EUROPEAN SITE ACTIVATED: Rotterdam, The Netherlands! A Barcelona site aims to open in 2025!** The trial is looking at evaluating the activity and safety of Inebilizumab in NMDAR encephalitis and assess markers of disease. Call the Trial Hotline on 844-4BRAIN5 (844-427-2465) to discuss your patient with a member of the ExTINGUISH team or visit: www.encephalitis.info/extinguish-trial/. This trial is funded by The National Institutes of Health (NIH)/National Institute of Neurology Disorders and Stroke, via the NeuroNEXT Clinical Trials Network



You can read more information on these trials, as well as other projects that we are currently supporting which are looking to recruit professional here: www.encephalitis.info/prof-research-projects

Resources for Professionals

Diagnosis webinar

This webinar is aimed at all medical professionals involved in the acute management of patients with viral encephalitis.

The webinar presented by Professor Benedict Michael, Vice chair of Encephalitis International Scientific Advisory Panel and MRC Clinician Scientist and Director of the Infection Neuroscience Lab at The NIHR Health Protection Research Unit for Emerging and Zoonotic Infection and an Honorary Consultant Neurologist at The Walton Centre, discussed the initial management of all patients with suspected encephalitis up to the point of diagnosis in an acute care setting. The webinar also included discussion of the challenges of diagnosis.

To view a recording of the webinar, please visit: www.encephalitis.info/webinars/

This webinar information resource was supported from an educational grant from bioMérieux!



Vaccine -Preventable Encephalitis Webinar

In line with the 2024 World Immunization Week (24th – 30th April) and part of the Encephalitis International Vaccine Prevention Campaign, on the 29th April 2024, we held our 'Vaccine-preventable encephalitis webinar'. This webinar aimed to raise healthcare professional's awareness and understanding of vaccine-preventable encephalitis types.

Chaired by [Assoc Prof Kiran Thakur](#) (member of the Encephalitis International Scientific Panel), the webinar covered Japanese encephalitis, Varicella Zoster encephalitis, Influenza associate encephalitis, Measles and encephalitis and Tick-borne encephalitis.

This webinar was an exciting opportunity to hear from experts in their field and keep up to date with current studies and knowledge of vaccine preventable encephalitis.

To view a recording of the webinar, please visit: www.encephalitis.info/webinars/

External resources for professionals with an interest in encephalitis

We now have a dedicated webpage for external resources which may be helpful for professionals working in the field of encephalitis and neurology.

The Neuroscience Resources Centre, is an online hub created by the Infection Neuroscience Laboratory Research Team at the University of Liverpool. The team have developed the hub to bring together a collaborative network of professionals to share expert knowledge and resources.

Visit our website to find out more and discover new professional resources: www.encephalitis.info/other-resources/

Save the Dates (2025)

- 22nd February - World Encephalitis Day
- 29th April – Arboviral Encephalitis Webinar
- May – Launch of Call for Abstracts Encephalitis 2025
- May – Conference Bursary Applications open
- May – Call for Seed Funding 2025 open
- 15th July – Deadline for submitting Conference Abstracts
- 30th September – Deadline for submitting Seed Funding Applications
- 3rd & 4th December Encephalitis Conference 2025, London & virtual

Patient outcomes and quality of life

Our CEO, Dr Ava Easton, can deliver sessions on patient outcomes and quality of life following her 25-year career experience on working with patients globally. If you would like to extend an invite or find out more information, please email

research@encephalitis.info

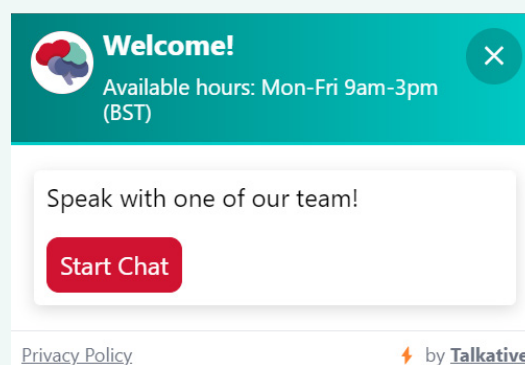
How can we support your patients

Encephalitis International provides a wealth of information and resources that are made available for healthcare professionals to share with their patients. Please read below for further details of a selection of our resources:

NEW! Online chat

We are pleased to share that we now have an online chat function on our website open to anyone in the world instantly translated in different languages. Any patients, caregivers or family members who use this chat will be able to talk with members of our support team.

The online chat can be found in the corner of our website and has made getting in touch with us even more accessible!



Peer-to-peer support meetings

Our Online Peer Support Groups are regular online support groups which help to connect our community across the world (English speaking). They are held via Zoom and hosted by members of our support team and our Encephalitis International volunteers.

We receive regular feedback from those affected by encephalitis and their families, which shows the positive benefits that can result from talking to other people who may understand their experiences of encephalitis.

We have specific meetings for people directly affected by encephalitis, parents/guardians of children affected by encephalitis, family members/carers of adults affected by encephalitis, and young people affected by encephalitis.

We also hold regional online peer support groups, currently held in UK, Canada, Australia and New Zealand.

For any questions regarding these groups, please email: peersupport@encephalitis.info or visit: www.encephalitis.info/online-peer-support-groups

Connection Scheme

We are so pleased to announce the launch of our new Connection Scheme which will allow people to establish one-to-one connection with others who have similar experiences of encephalitis. We hope that this Scheme will help to ease the feelings of isolation that can often be felt following the impacts of encephalitis.

This is an online Scheme, which means that members of our community can connect internationally with each other. If you feel one of your patients would benefit from joining the Scheme, please direct them to our website: www.encephalitis.info/connect-with-others/connection-scheme/ they must be 18 years or older to join.

To enquire about the full range of support schemes that we can offer to people affected by encephalitis and their families, please email: peersupport@encephalitis.info



Patient Support

Animations “Understanding Encephalitis” available in several languages

As part of our patient and encephalitis community resources, we have developed several animations to help explain and raise awareness of encephalitis and its consequences. Our series of animations focusing on ‘Understanding Encephalitis’ have been translated in French, Hindi, Tagalog, Polish, Punjabi, Portuguese and German. You can direct patients to our animations here: www.encephalitis.info/animations/

Encephalitis information leaflets, available online in several languages

Encephalitis International has developed leaflets to give to patients and their families. They explain what encephalitis is and how Encephalitis International can help those affected. They have been translated into German, French, Italian, Dutch, Spanish and Hindi. The leaflets can be printed for patients or viewed online here: www.encephalitis.info/what-is-encephalitis-leaflet

Guides to Encephalitis

Encephalitis International is delighted to announce the new reviewed and rebranded guides to encephalitis: Encephalitis in Adults. A Guide and Encephalitis in Children. A Guide.

The guides walk through every stage of the condition – from initial symptoms and diagnosis to treatment, recovery, and rehabilitation. It also addresses the profound impact on families and provides practical strategies for coping with life changes. Understanding that processing this information can be overwhelming, the guides feature a modular design. This allows readers to focus on specific sections as needed, rather than having to digest all the information at once.

By providing clear, accessible information, the guides empower individuals and their caregivers to better understand their condition, make informed healthcare decisions, and navigate their recovery journey with confidence.

Download the Guides from our website (www.encephalitis.info/guides-for-people-affected) or order a hardcopy from our shop (www.encephalitis.info/shop)



We need your help to continue to support people affected by encephalitis and healthcare professionals like you.

Will you consider making a regular gift to support our life-saving work?

- £10 helps to fund our Encephalitis Research Summary
- £25 enables one life-changing support call for someone in need of help
- £75 delivers a virtual place for one day of our annual Encephalitis Conference

www.encephalitis.info/donate

Patient Story

Anti-LGI1 Autoimmune Encephalitis Lived Experience- Juliette's Story

My name is Juliette. I am 23 years old, and I have just completed my five years of studies in International Hospitality Management. I currently live in Madrid. I am the youngest in my family, having two older sisters. I've been fortunate to travel since my childhood and live abroad in Madagascar, Mauritius, Belgium, Indonesia, and Cambodia. These cultural experiences have contributed to my growth and shaped the person I am today. My story, though short and perhaps more "fortunate" than some others you might read, has a happy ending.

Towards the end of 2021, things took a strange turn. Looking at old photos and despite comments from some close ones, I realized I had lost weight. I was no longer myself, crying frequently, and my mental sharpness had significantly diminished.

In December 2021, my physical weakness intensified with unexplained weight loss. Shortly after my return to school in January 2022, I contracted an almost asymptomatic form of COVID-19. It was at this point those things quickly deteriorated. I don't exactly remember the course of events between late February and late April; it became blurry, almost non-existent, leaving only vague and unpleasant memories. This well-known symptom of memory loss was indeed present.

February marked the true beginning of the illness, with the onset of absence seizures. These moments of "disconnect" were characterized by a temporary sensation of leaving my body, accompanied by an electric shock to the head and a metallic taste in the mouth, similar to episodes of "trances" lasting about 10 to 15 seconds. Initially, these episodes occurred when I was alone, and I didn't talk to anyone about them. However, their frequency increased every day. I later learned that these were focal epilepsy seizures, tiny but impactful. I had crying spells at the psychiatrist's, mixed with fatigue so intense I couldn't explain it. That's probably why he also diagnosed me as depressed.

But I always knew deep down that the problem wasn't that, that it went deeper and that something was destroying me from the inside. This thing had a hold on my body and my thoughts and there was absolutely nothing I could do about it. Orals at school became complicated, and sometimes I felt like I was leaving my body when I stood in front of my classmates during my presentations, until all I could see was an opaque white filter in front of me.

This period was also marked by the onset of insomnia and trembling episodes. The absence seizures took up more space in my life, adding to a kind of depression, a state I had never experienced before. On March 2, I finally shared my concerns with my sisters, addressing the issue of seizures and expressing my fear of going insane (as I couldn't sleep at night, I would walk alone in my apartment). At that time, I hadn't informed my parents yet, fearing to unnecessarily worry them.

Advised by my sisters and friends, I consulted my general practitioner without informing my parents. After verbally describing my "symptoms" she hesitantly mentioned the possibility of a mild depression or epilepsy, recommending a consultation with



Patient Story

a psychiatrist and possibly a neurologist. A few days later, the psychiatrist confirmed depression and prescribed an antidepressant and Valium for sleep disturbances supposedly linked to anxiety.

The anxiolytic proved ineffective, trembling episodes persisted, and my sleep was disturbed. My nights unfolded in a cycle of fragmented sleep, making it difficult to concentrate in class and exacerbating my absence seizures. On March 17, 2022, thanks to a radiologist friend of my family, I urgently obtained an appointment for a cerebral MRI due to the "seriousness" of the situation.

The MRI revealed cerebral edema, possibly explaining my symptoms. My medical journey then accelerated with consultations with a neurologist and an electroencephalogram (EEG), which showed slight signals of epilepsy. The diagnosis became more precise, and I was put on a low dose of Levetiracetam and anxiolytics.

On April 1, I was admitted to the epilepsy department at the hospital for in-depth examinations, including camera surveillance, blood tests, and a lumbar puncture. This period was marked by intense migraines after the lumbar puncture, as well as long moments of disorientation.

On March 17, during an Easter Mass in the south of France, my first epileptic seizure struck. I don't remember the incident; my parents told me everything. But the collapse, the rolling eyes, and the chattering of teeth marked the beginning of the episode. A man, whose son was epileptic, timed my seizure, allowing for a quick intervention. This event was a shock for my family, who had never faced such a situation. Then another seizure occurred, the holidays were cut short, and I was informed of my condition at the hospital where I had undergone my initial tests.

On April 22, I was admitted to the epilepsy department for in-depth tests, including blood tests, extremely exhausting cognitive tests, an electrocardiogram, and an electroencephalogram. The results revealed 'LGi1 autoimmune limbic encephalitis', a rare disease unknown for most.

From May 4, I started my first immunoglobulin treatments, followed by six others until November 2022. These hospitalizations introduced me to hospital life with its challenges, difficult moments of pain, loneliness, and great fears of never returning to my "real" self, but also moments of joy with my family. This experience has undoubtedly left its mark on my family, which has always been there and has bonded us more than anything, all five of us.

From my fourth treatment onwards, I finally felt a significant improvement in my overall cognitive state, inner well-being, but especially in my personality. The treatments finally ended, and my latest tests showed improvement, with my cerebral edema gone and my antibodies negative.

Today, I am doing well. I continue to take my epilepsy medication that I'll probably take forever. I have been psychologically supported and have undergone additional therapies sessions to manage some of the sequelae of encephalitis. I finished all of my immune treatments in July 2023 and my last cognitive check-up in March 2024 (the results were really good).

This journey has not only reshaped my perspective on life but has also underscored the unpredictable nature of challenges that can befall anyone, regardless of age.

It is crucial to raise awareness about rare diseases and epilepsy, which are still too unknown in our society. By increasing awareness, we can better support individuals going through similar challenges and move towards a world where nobody feels isolated in their journey.

Patient stories needed

Can you help us with patient stories? They are invaluable for our encephalitis community members' recovery and our awareness campaigns. We're always looking for patient stories for any types and experience of encephalitis, but for our upcoming climate campaign, we're focussing on dengue encephalitis, chikungunya encephalitis, West Nile encephalitis, Japanese encephalitis, tick-borne encephalitis (USA) and oropouche virus infection. If any of your patients would like to share their story, please get in touch with us on peersupport@encephalitis.info

It would be greatly appreciated!

BECOME A PROFESSIONAL MEMBER OF ENCEPHALITIS INTERNATIONAL

Help us in our mission to rebuild futures around the world by saving lives, accelerating awareness and driving research.

By joining our world-renowned, award-winning organisation, you will be part of a professional community of over 2500 members in more than 100 countries.

Complete the membership form on our website to keep up-to-date with the work that we do and the latest encephalitis related news, campaigns, appeals, events and research:

www.encephalitis.info/professional-membership

WHY SHOULD YOU BECOME A PROFESSIONAL MEMBER OF ENCEPHALITIS INTERNATIONAL?

You can access a wide range of benefits, including:

- Research grants
 - Access to international Seed Funding to support encephalitis research studies
 - Bursaries to attend our events, including discount rates, complementary tickets and accommodation to attend our prestigious encephalitis Conference.
 - Training and development opportunities as well as invaluable networking opportunities.
 - Priority access to our professional member's newsletter and annual Advances in Encephalitis Research Guide.
 - Access the latest information and research from leading professionals via our blogs and podcasts
 - Support for your patients and their families,
- including information resources, events and peer support groups, to help them to understand their diagnosis.
 - Opportunities to get involved in the production of our information, such as our translated factsheets and information guides.
 - Opportunities to present at our meetings and events.
 - Extensive patient and public involvement (PPI) support, including designing research questions, funding applications, recruitment, and co-authoring on dissemination documents.
 - You can benefit from our expertise of patients' and families' experience of encephalitis at all stages of a research project.

You can access all this and more, and membership is FREE!



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