ENCEPHALITIS SOCIETY

Changing the Research Landscape

RESEARCH IMPACT REPORT

MAY 2023

ENCEPHALITIS SOCIETY
The brain inflammation charity

www.encephalitis.info

Contents

Our research impact

ENCEPHALITIS SOCIETY
The brain inflammation charity

OUR VISION

Saving Lives. Rebuilding Futures. Global Impact.

OUR MISSION

Rebuilding better futures by driving research, accelerating awareness, and saving lives.

OUR VALUES

Our core beliefs shape our culture and our work:

PASSIONATE:

We are dedicated to making a positive impact in the lives of our beneficiaries

INCLUSIVE:

Our aim is for everyone to be respected for who they are and feel supported and empowered

CHANGEMAKERS:

We create the change in the world that makes life better for our community

FOREWORD:

Changing the research landscape

We are delighted to present the first research impact review carried out by the Encephalitis Society. The Society has been providing a lifeline for all those affected by encephalitis for nearly 30 years and funding research has become a priority for us.

Driving research that will benefit everyone affected directly and indirectly by encephalitis is part of our mission. We are guided by research priorities in areas such as prevention, diagnosis, treatment, recovery and rehabilitation and we will work tirelessly to save lives, rebuild futures and make a global impact. Exciting latest discoveries in the field of diagnosis and treatment can lead to reduced mortality, but there is still a lot to do regarding recovery and rehabilitation of these patients. Progress also needs to be made around awareness, education and training among all healthcare professionals worldwide. It can take a long time to yield results, but we are making progress.

This report gives some examples of the many ways we engaged in research and the difference we made. We have taken this opportunity to look back and consider what our funding and work have meant for the encephalitis research community. Within this report you will find information on how we supported research as well as the different ways in which our work has impacted research and the people affected and their families.

If we look back to when the charity started in 1994, the Society's involvement in research was very limited, with no funds available for research. Gradually, we engaged in research in various ways from supporting professionals, helping recruitment and organising small professional seminars to being the bridge between patients and professionals/researchers, collaborating with prestigious institutions and driving change globally. Many of the projects we have funded or supported over the years have paved the way for further grants and more research. In 2023 we launched a three-year research strategy where we committed not only to spending a considerable amount on research but also to collaborate with prestigious institutions such as Medical Research Council (MRC) and World Health Organization (WHO).

We could not have done this without the support of the encephalitis community. Our research has brought together people affected by encephalitis, their families, researchers, clinicians, scientists, therapists and many supporters from all over the world who all have brought together their knowledge, skills, experiences, passion and dedication to save lives.

For all your efforts we THANK YOU!

Every minute at least one person is diagnosed with encephalitis worldwide. Up to 40% of people will die. We have to change this!

We have committed to spending £941,000 on research in the next three years.

30 YEARS OF ACHIEVEMENTS:

A snapshot of our past research

- We funded the first study to investigate the after-effects and social consequences of encephalitis.
- We funded and supported six PhD studies.
- We funded eight seed projects.
- We were involved in the first randomised control trial (RCT) in herpes simplex virus encephalitis (HSVE) in more than 40 years (DexEnceph study).
- We supported the ENCEPHUK study which looked into the outcomes and clinical predictors of encephalitis.
- During the COVID-19 pandemic, we were involved in some of the biggest international studies on COVID-19: COVID-CNS and COVID NeuroGlobal.
- We established the annual go-to Encephalitis Conferences (406 participants from 55 countries in 2022).
- We organised three masterclass webinars.
- We supported neurology training and provided equipment in two low and middle income countries (LMIC).
- We awarded 10 bursaries to professionals from LMIC to attend the Encephalitis Conference in the UK and three bursaries to professionals from the UK to further their professional development abroad.
- We awarded the 10th Anniversary Research Prize.
- We supported the patient participation involvement (PPI) in more than 10 research studies.
- We helped find participants for more than 100 research projects.
- We contributed to the publication of over 85 articles in scientific journals, two books and six book chapters.
- We published nine research summaries and 10 newsletters for professionals.
- We have over 2,300 professional members.
- We have 24 members from all over the world on our Scientific Advisory Panel.
- Since 2018, we spent £423,142 on research.

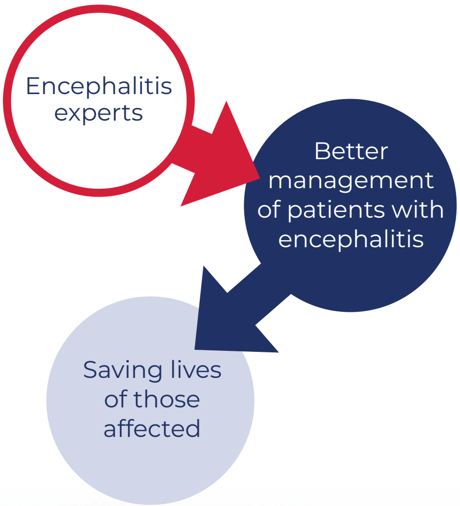
We nurture and inspire the next generation of researchers and clinicians

Our support for the next generation of researchers and clinicians is critical to ensure a future community of encephalitis experts. We fund and support students, junior doctors and professionals allied to medicine to further their knowledge, expertise, dedication and commitment for the ultimate benefit of the patients.

- We supported Dr Emily Talbot's doctoral research thesis into the quality of life of children and adolescents following encephalitis illness. Dr Emily Talbot is now Consultant Clinical Psychologist in the Paediatric Neuropsychology Service at Nottingham University Hospital and her specific clinical and research interests are in encephalitis and epilepsy in childhood, and paediatric acquired brain injury.

- We supported Dr Thomas Miller's PhD on anti-VGKC antibody encephalitis. Dr Thomas Miller is now a Wellcome Clinical Research Career Development Fellow and Honorary Consultant Neurologist at National Hospital for Neurology and Neurosurgery, London pursuing further research into autoimmune types of encephalitis.

- We supported Dr Tehmina Bharucha, an Academic Clinical Fellow in Infectious Diseases and Microbiology in London to travel to the American Society of Tropical Medicine and Hygiene (ASTMH) Conference in Maryland and spend several weeks at the Infections of the Nervous System Section at the National Institute for Health. Dr Bharucha is now undertaking a DPhil in the Department of Biochemistry at the University of Oxford, focusing on identifying biomarkers of Japanese encephalitis virus.



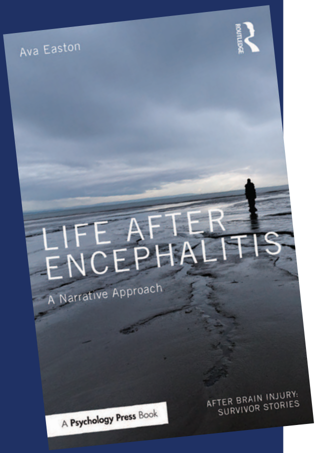
Encephalitis experts

Better management of patients with encephalitis

Saving lives of those affected

We fund the gaps in research into encephalitis and its consequences

We focused where there were gaps in research. Our funded projects have explored the range of neuropsychological outcomes and predictors of cognitive recovery after encephalitis. This is very important as detailed reports on specific neuropsychological outcomes and their characteristics over time are lacking. We know little about the impact of these outcomes on quality of life and what the most effective interventions in maximising people's recovery are.



The Role of Written Narratives in the Recovery of People Affected by Encephalitis

Dr Ava Easton, Encephalitis Society 2005-2012

This study explored the role of written narratives in the recovery of people affected by encephalitis, examining the motivations of readers and writers and the impact upon them. The aim of the study was to understand the purpose and meaning of post-encephalitis narratives for those who read and write them; to explore the impact of these stories upon both authors and readers; to establish in what way (if any) these stories contribute to people's recovery, and their relationships with professionals.

The study was a mixed methods study incorporating a literature review, a quantitative element presenting the findings of a self-report postal questionnaire returned by 406 people, and semi-structured qualitative interviews with 21 respondents. Participants in the study were those directly affected by encephalitis and family members of people affected.

The study found that the experiences of people post-encephalitis are, in many cases, life-changing and complex. Narrative use occurs at both personal and collective levels, helping people to better understand their condition, make sense of and compare their experiences with those of others; and reduce feelings of isolation and loneliness by embracing a sense of belonging. Narratives and people's experiences of them were, however sensitive to context: temporality, memory and gender were key variables. Narratives, however, are not for everyone and for some people their use could cause anxiety and distress.

The study concluded that narratives are an important tool in the recovery of many, but not all people affected by encephalitis, including relatives of people affected. Narratives can also be used by professionals to better understand the experiences of their patients, reflect upon practice, and provide better patient-oriented services.

> *"Encephalitis is undoubtedly a thief, and Dr Easton does an excellent job at explaining why."*
>
> Jules Morgan
> Lancet Neurology

The After-effects and Social Consequences of Encephalitis

2006-2008

A study conducted with the University of York found that many people experience long-term consequences following encephalitis. The study included the SF-36 in the postal survey, which is a questionnaire asking about quality of life. The normal score in the healthy UK population is 50. For the SF-36 Physical Component Score, which looks at physical functioning to do with quality of life, respondents scored an average of 35. For the SF-36 Mental Component Score, which looks at emotional well-being, respondents scored an average of 40. Therefore, post-encephalitic respondents' scores were much lower than 50, indicating that their quality of life was poorer than for the rest of the UK population. These results were also worse than some studies into other forms of acquired brain injury.

Atkin K, Stapley S, Easton A. No one listens to me, nobody believes me: self management and the experience of living with encephalitis. Soc Sci Med. 2010 Jul;71(2):386-393

> *"Well, I've often used the analogy that at just after 3 o' clock in the afternoon probably has had the same impact on me and the family unit as somebody that undergoes a bomb blast, an earthquake, a tsunami. It hits without warning and the devastation and the consequences, the fallout that comes from it can be never ending. And because nobody warns you, it's just basically survival tactics you're using initially on a day to day basis and to make sense of it. But somewhere along the line you have got to pick the pieces up and rebuild and it won't be the same as it was before.*
>
> Philip's wife: 5 ½ years after the illness

Neuropsychological outcomes in herpes simplex encephalitis (HSE)

Cory Hooper, PhD student 2016-2023

Jointly funded with University of Liverpool

Herpes simplex virus encephalitis (HSE) is the most common cause of encephalitis in the western world with a mortality rate exceeding 70% without antiviral medication (acyclovir). Despite significant improvements in mortality rates, patients often have an acquired brain injury (ABI) which can result in severe neuropsychological deficits long after the acute phase of the illness. The project aims to present a comprehensive neuropsychological profile of patients with HSE, analyse the possible cognitive deficits, explore the relationship between neuropsychological outcomes and health-related quality of life and investigate neuroimaging and clinical correlates of long-term cognitive outcome.

*At the time of writing this report, the PhD is in its final stages and Cory is writing up the findings of the project.

UNIVERSITY OF LIVERPOOL

Aston University

IHN Institute of Health & Neurodevelopment

Predictors of cognitive recovery in paediatric immune-mediated encephalitis

PhD student, Charly Billaud 2019-2023

Joint funding with Aston University

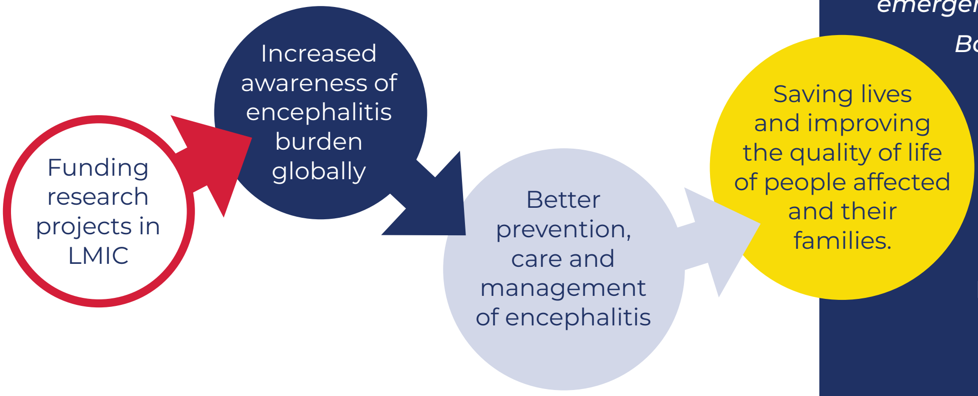
Children with autoimmune encephalitis (AE) have specific clinical profiles. It was suggested that early brain lesions may alter long term development, which is a phenomenon reported in general paediatric brain injuries. Recent research has shown that after acute medical recovery, residual cognitive and behavioural deficits persisted in a substantial proportion of paediatric patients. Given the predominant findings linking AE to abnormal brain function activities this project aims at investigating predictors of long-term deficits using magnetoencephalography, a sophisticated method which can localise functional brain activations with high temporal precision.

**At the time of writing this report Charly is in his final year.*

We drive research in low and middle-income countries (LMIC)

Seed funding

In 2019 we started to provide seed funding for smaller or pilot projects which not only provide acknowledgement and better understanding of the illness in different settings, but also secure future funding for potential large-scale projects or be a first step on the long journey to becoming a well-established researcher. Since the start of seed funding grants stream, we have allocated funding in five low and middle income countries: **Cameroon, Brazil, Senegal, Uganda and India.**



> *"First of all, it was a great honour to be selected for the 2019 Encephalitis Society Seed Funding. At that time, I was starting my PhD thesis and my research had no specific funding. In my country resources are basically limited to governmental grants. In order to have one of those grants, you have to have things like published articles, international experience, a topic of public interest and supervisors recognized by their previous work. The seed funding was essential to start my career as a young scientist and made me able to dedicate myself to my main topic of interest – neurological manifestations of emergent and re-emergent viruses in encephalitis. Based on this background and built network my team were selected for a great national full grant to work with COVID-19 and neurology."*
>
> Dr Aline Matos, Brazil

2019

Aetiologies, clinical presentation and neuro-cognitive outcomes of non-HIV associated encephalitis in Cameroon - exploring a neglected disease in a low-income African country *(extended)*

Project lead - Dr Alain Kenfak Foguena, Jura Bernois Hospital (HJB), Moutier, Switzerland and Filariasis and other Tropical Diseases Research Centre (CRFilMT), Yaoundé, Cameroon

2019

Encephalitis' clinical and laboratory characteristics during a triple epidemic of Dengue, Zika and Chikungunya *(completed)*

Project Lead – Dr Aline de Moura Brasil Matos, Instituto de Medicina Tropical, Medicine School, University of São Paulo, Brazil

2021

Implementing an hospital-based encephalitis surveillance in Senegal to decipher main causes of viral encephalitis in a West-African Low-Income Country *(completed)*

Dr Jamil Kahwagi, Clinique de Neurosciences Ibrahima Pierre Ndiaye, CHNU FANN, Dakar, Senegal

Dr Jean-Michel HERAUD,
Institut Pasteur de Dakar, Senegal

2021

Validation of the Paediatric Autoimmune Encephalitis Severity Score (PASS) in children with autoimmune encephalitis (ongoing)

Project Lead, Dr. Priyanka Madaan, Pediatric Neurology Unit, Department of Pediatrics, Post graduate Institute of Medical Education and Research (PGIMER), Chandigarh, India

2022

Differentiating viral encephalitis from its mimics in patients with encephalitis of unknown aetiology (ongoing)

Dr John Kasibante, Research Department, Infectious Diseases Institute, Makerere University, Kampala, Uganda

2022

To develop a novel diagnostic test that can differentiate scrub typhus from other causes of acute encephalitis syndrome (AES) in children (ongoing)

Dr Tina Damodar, Department of Neurovirology, National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru, India

"After an initial regular inclusion rate, COVID-19 pandemics had a huge impact on activities: decreased availability of healthcare workers for non-COVID activities, fear of patients to attend hospitals. The budget remaining from the Cameroon Encephalitis Study (seed funding 2019) will allow us to start a new project and include up to 50 patients who survived encephalitis to look at the physical, neurological and neurocognitive long term outcomes (12-36 months)."

Dr Alain Kenfak Foguena

"We discovered that Chikungunya virus stands out as a major etiological agent for encephalitis cases with a high death rate. We established a prospective cohort of viral encephalitis in our center. We improved data collection, we now use specific scales for encephalitis follow-up and have a basic cognitive evaluation protocol."

Dr Aline Matos, Brazil

"The project was the first to allow quick detection of virus in encephalitic patients that could inform clinician on potential monitoring and treatment when an herpesvirus was detected."

Dr Jamil Kahwagi, Senegal

Kahwagi J., Seye A.O., Mbodji A.B., et al. Surveillance of Viral Encephalitis in the Context of COVID-19: A One-Year Observational Study among Hospitalized Patients in Dakar, Senegal. Viruses. 2022 Apr 22;14(5):871.

Assist Prof Saylor and the Zambia Neurology Training Team

“This programme has made a significant difference. All across the country patients are sent to us for a diagnosis and treatment. I have looked after a patient who had spent many years bouncing from one hospital to another, was unable to hold a job and eventually was being seen by psychiatry with no diagnosis. Now, she’s held on to a job for more than three months and she’s doing remarkably well. The impact has almost been immediate as there are more people on the ground to provide neurological care with an improvement in the quality of care and in a few years’ time, our influence will spread to the different parts of the country as more people get trained.”

Dr Stanley Zimba, Zambia

Neurology Training programme in Zambia is led by our Scientific Advisory Panel member - Assist Prof Omar Siddiqi, Beth Israel Deaconess Medical Center, Boston, USA and Assist Prof Deanna Saylor, The Johns Hopkins University School of Medicine, USA

We support training and networking opportunities in low and middle income countries

NeuroAccess

NeuroAccess is a collaborative project between the Encephalitis Society and the University of Liverpool that aims to improve the care of patients with encephalitis and other neurological problems in sub-Saharan Africa through improving education in clinical neurology. Projects have been delivered in Mozambique and Zambia since 2013 which resulted in raising awareness, delivering education, and ultimately saving the lives of people affected by encephalitis and other neuro-infectious conditions. We also provided Neuro-Kits, which are essential for the neurological examination.

Zincare, Zambia

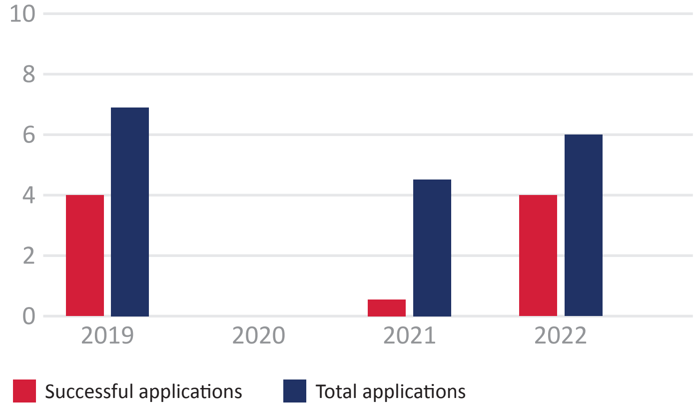
The Encephalitis Society added its support to a new scheme which was helping to train neurologists in Zambia who would then continue to train future generations. The training program included three adult neurology trainees and two paediatric neurology trainees. The country, in south-central Africa, has a population of 16 million people and until recently did not have a single locally trained, full-time neurologist. The Society has provided funds to attend essential training and procure neurological equipment.

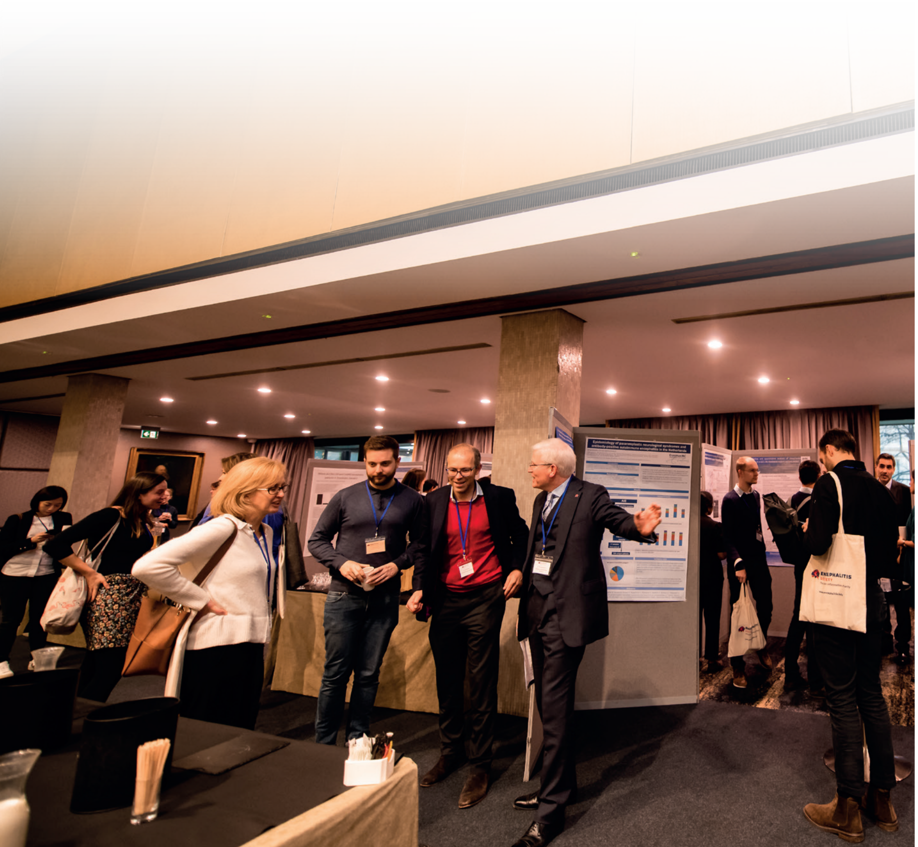
ZINCARE

Encephalitis Conference Bursaries

The Encephalitis Society grants help researchers and academics in LMIC to attend the annual Encephalitis Conference in London and its afferent satellite meetings in-person. This is a great opportunity for participants to learn, make connections with other clinicians and researchers in the field and take the learning back to their countries. This not only adds to the professional growth of an individual but also share knowledge and experience for the ultimate benefit of the patient. Since we launched them in 2019, we welcomed participants from **Brazil, Malawi, Zambia, India, The Philippines, Cambodia** and **Ethiopia** to attend our Conference in-person.

Total applications, ‘Successful applications, total applications’ by ‘Year’





“Attending this year’s conference has definitely broadened my horizons with regard to various aspects of encephalitis. It has re-ignited my passion in research, and it has given an opportunity to interact with the experts on the field of encephalitis. Equipped with new knowledge, I am motivated to apply what I learned from the conference in order to improve the care of patients with encephalitis in my clinical practice. I aim to also share this knowledge to other neurologists here in the Philippines and at the same time, encourage them to participate in activities organized by the Encephalitis Society.”

Dr. Ferron F. Ocampo, The Philippines

Tackling emerging infections

Awareness, information and support for both people affected and professionals involved in their care

Saving lives, preventing illness and improving the quality of life for all people affected.

We respond to emergencies

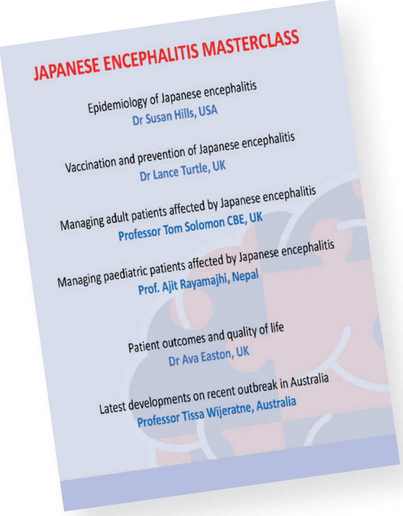
COVID-19 and encephalitis

Since the COVID-19 pandemic emerged at the end of 2019, there has been growing evidence which suggests that it can cause neurological complications, including encephalitis. That is why we dedicated our second round of seed funding (2020) to projects on encephalitis and COVID-19 and funded two projects in the USA.

The first project aimed to elucidate possible routes of CNS infection by the virus and identify brain regions and cell types most vulnerable to either direct infection or the effects of systemic cytokines. The project was led by Dr Emily Happy Miller from Columbia University Irving Medical Center-New York Presbyterian Hospital.

Findings have been published in the journal Brain (Thakur et al, Brain, https://doi.org/10.1093/brain/awab148).

The second project was a pilot study which aimed to dissect the mechanisms through which subsets of neurons, specifically dopamine neurons, are susceptible to SARS-CoV-2 infection. The project was led by Dr Oliver Harschnitz, Memorial Sloan Kettering Cancer Center (New York, USA).



JAPANESE ENCEPHALITIS MASTERCLASS

Epidemiology of Japanese encephalitis
Dr Susan Hills, USA

Vaccination and prevention of Japanese encephalitis
Dr Lance Turtle, UK

Managing adult patients affected by Japanese encephalitis
Professor Tom Solomon CBE, UK

Managing paediatric patients affected by Japanese encephalitis
Prof. Ajit Rayamajhi, Nepal

Patient outcomes and quality of life
Dr Ava Easton, UK

Latest developments on recent outbreak in Australia
Professor Tissa Wijeratne, Australia

Japanese encephalitis (JE) outbreak in Australia

Following the outbreak of Japanese encephalitis in Australia earlier 2022, we mobilised a strategic campaign which included a JE masterclass webinar (411 people from 27 countries attended), a media campaign (which reached 1.5 million via traditional media and up to 1 million via social media), and information resources (1,138 web page views/1 week and 53,000 people/month on social media).

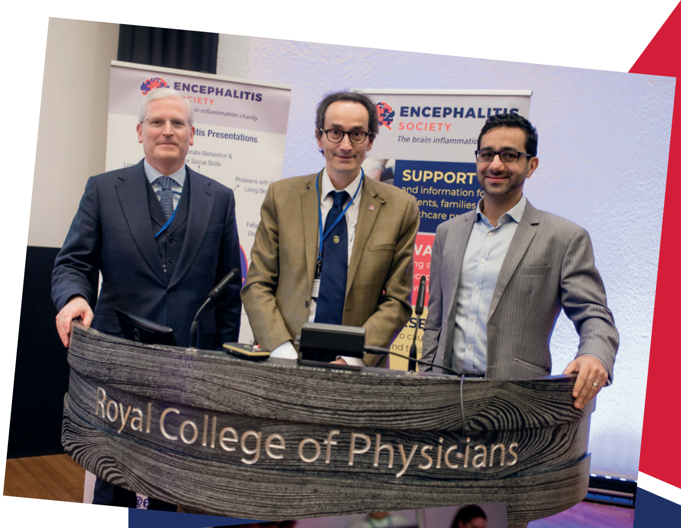
Tick-borne encephalitis (TBE) spread in Europe

In response to the spread of the tick-borne encephalitis virus across Europe, the Encephalitis Society held a TBE masterclass webinar for professionals across the globe. 455 people from 47 countries attended.

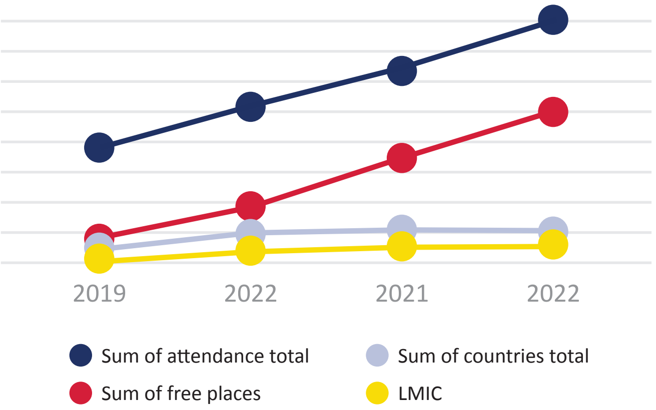
We bring together experts to facilitate exchange of knowledge and expertise

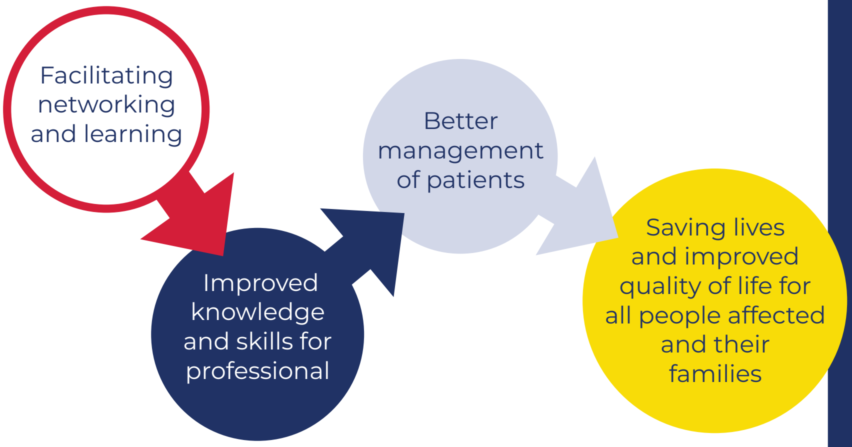
The Encephalitis Conference

The Encephalitis Conference is dedicated exclusively to encephalitis (infectious and autoimmune) and covers epidemiology, pathogenesis, diagnosis, treatment and rehabilitation in both children and adults. There are cutting-edge insights from global leaders in the field covering hot topics, critical research questions, and approaches to the key clinical challenges informed by the latest research. Since moving to a new venue in 2019 – Royal College of Physicians, the Conference has gone from strength to strength: from bigger number of participants, increased countries presence to incorporating satellite meetings and hybrid attendance.



Attendance total increases over time





> *"The conference was absolutely fantastic. It was definitely the best conference I have been attending, the organisation was spot on, and I really felt that it was a welcoming and encouraging atmosphere for everyone. The talks were absolutely first-rate."*

We influence global change

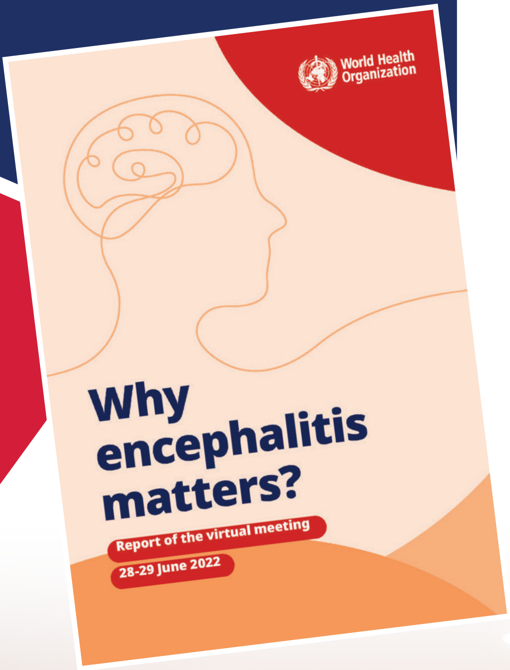
> *“28,000 people in 128 countries called for WHO to agree that #EncephalitisMatters no matter where people live in the world”*

Global impact report

Encephalitis: an in-depth review and gap analysis of key variables affecting global disease burden

A new report from the Encephalitis Society has identified a range of difficulties and solutions to the global impact of encephalitis which could save lives and improve the treatment and after-care of millions of people today and into the future. A working group was put together between the World Health Organization (WHO) and the Encephalitis Society and discussions have been progressing through 2021 and into 2022 resulting in the launch of the report and a global meeting held in June 2022. At this meeting, discussions centred around creating a coalition of leading global health organisations, public health bodies and policy makers to take forward the findings of the Global Impact Report and improve the prevention, diagnosis and treatment of the condition, particularly in low-middle income countries. A report of the meeting was launched during World Encephalitis Day 2023 *(https://apps.who.int/iris/handle/10665/366223)*

Next steps include the drafting of a Technical Briefing which is targeted to policy-makers, health programme managers and planners, health-care providers, researchers, people with the condition specified and their carers and will support the implementation of the WHO intersectoral action plan on epilepsy and other neurological disorders.



World Health Organization

Why encephalitis matters?

Report of the virtual meeting

28-29 June 2022

The authors of the Global Impact Report: Dr Julia Granerod, Prof Benedict Michael, Dr Ava Easton, Dr Nicholas Davies, Alina Ellerington, Prof Tom Solomon CBE

We put patients at the heart of research

The Encephalitis Society believes that research should be carried out with patients and members of the public rather than for them. We build bridges between patients and researchers making sure the research benefits both the research community and the public. Consequently, the Society has been actively involved in patient participation involvement activities by

- Sitting on a project steering group
- Developing or providing feedback on research material
- Becoming a co-applicant
- Becoming a co-researcher

At the time of writing this report we are involved in eight national or global research projects, three guidelines working groups and numerous research articles.

The COVID-19 Clinical Neuroscience Study (COVID-CNS)

The COVID-CNS study is a £2.3m UKRI study jointly led by researchers at the University of Liverpool and King's College London.

Lead: *Prof Benedict Michael, University of Liverpool*
Prof Gerome Breen, King's College London

www.liverpool.ac.uk/covid-clinical-neuroscience-study

Acute neurological and neuropsychiatric complications of COVID-19 affect up to 20-30% of hospitalised patients, including encephalopathy, encephalitis, catatonia, psychosis, stroke, and Parkinsonism. These are often otherwise unexplained (i.e. excluding risk factors / hypoxia / iatrogenic causes) and often occur in younger patients. Survivors frequently report cognitive impairment, fatigue, and depression. The limited regenerative capacity of the brain means these complications may cause lifelong disability.

There was an urgent, unmet need to understand the biological causes of acute neurological and neuropsychiatric complications of COVID-19 and their sequelae.

In collaboration with CoroNerve and ISARIC-4C's, the COVID-CNS study identified patients who had been hospitalised with these complications. The study researchers invited these and new patients to join the COVID-19 Clinical Neuroscience Study (COVID-CNS), part of the COVID-19 section of the NIHR BioResource.

The study aimed to determine the phenotypes, biomarkers and genotypes of these patients relative to previously hospitalised controls including those from ISARIC-4C's and PHOSP-COVID (COVID-19 and non-COVID). They collect data from clinical cases notes and electronic records, then assess neurological/cognitive/psychiatric sequelae post-discharge. They analyse brain injury, virologic, and immunological mechanisms in serum and cerebrospinal fluid, and acute and follow up MRI to study the pathophysiology of these complications.

By understanding these mechanisms, the study wants to be able to stratify patients into clinical care pathways and into trials using existing and novel therapies and apply this knowledge through the WHO-commissioned COVID-19 Neuro Research Coalition Task Force, and through the study's PPI program to have immediate impact on patient care. The NIHR BioResource will provide sustainability and, through linkage to the community cohort, will allow the study to determine if similar, but milder, symptoms are being experienced more widely.

It was felt from the grant development time that patient and public engagement (PPI/E) was a key element in the project. Dr Ava Easton, CEO, Encephalitis Society and Hon. Fellow, Dept Clinical Microbiology and Immunology, University of Liverpool was appointed Chair of the COVID-CNS PPI Panel in 2020.

Brain Infections Global (BIGlobal)

BIGlobal is an NIHR Global Health Research Group on Improving the Management of Acute Brain Infections.
Lead: *Prof Tom Solomon, CBE; The Pandemic Institute; HIHR HPRU in Emerging and Zoonotic Infections, University of Liverpool*
https://braininfectionsglobal.tghn.org/

Acute brain infections, such as meningitis and encephalitis, are a major cause of death and disability globally. There is relatively little global research expertise in tackling them. For many brain infections appropriate therapies exist, but doctors fail to diagnose, and thus treat them properly. Often basic but critical investigations, such as a lumbar puncture and microbiology, to examine the cerebrospinal fluid, are performed poorly, or not at all. Doctors are therefore faced with the choice of blindly overtreating for all possibilities (risking side effects and antimicrobial resistance) or guessing at the diagnosis and treatment (which risks getting it wrong). Newer technologies offer the promise of diagnosing brain infections more accurately, more rapidly, with less reliance on skilled technicians, and ultimately more cheaply. The BIGlobal study was launched in 2018 to address some of these issues, particularly in low to middle income countries (LMIC).

Additionally, in 2020 the COVID-19 pandemic erupted around the world, often hitting low-to-middle income countries hardest. An additional study called COVID NeuroGlobal was put together in addition to the original Brain Infections Global Study. This study aimed to identify risk factors for development of SARS-CoV-2-associated neurological disease, prioritising those which are modifiable in a low-resource setting. This study will be of significance to policymakers making protocols for risk stratification and mitigation for morbidity and mortality with limited resources.

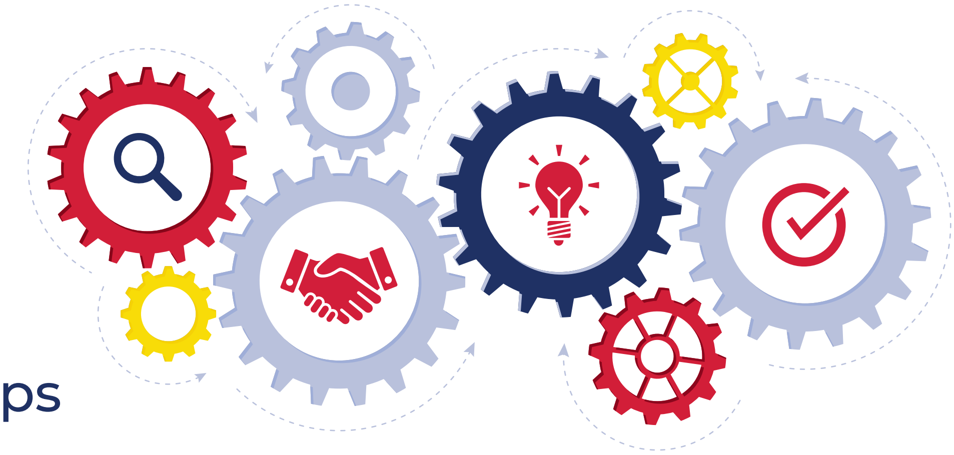
The study currently operates in four countries: Brazil, India, Malawi and the UK.

It was felt from the grant development time that patient and public engagement (PPI/E) was a key element in the project. Dr Ava Easton, CEO, Encephalitis Society and Hon. Fellow, Dept Clinical Microbiology and Immunology, University of Liverpool was appointed Chair of the PPI Panel in 2018.

> *"I am grateful to the Encephalitis Society UK for providing support with participant recruitment for my study. Without your support, I would not have succeeded. I am thankful to all family members who participated in my study. I have been able to create score band descriptors for the FROM-16 questionnaire. This means that doctors and nurses will be able to understand the questionnaire scores and so have a much better idea of how much a family member is being affected by having someone in the family with a health condition, such as encephalitis. The research has also created a new way of using the data to understand better the economic impact of this effect on family members.*
>
> *A big thank you from the research team at Cardiff University!"*
>
> Rubina Shah, Cardiff University

Since 2019 we helped recruiting participants for over 26 projects

Aston University
University of Liverpool
UCL
University of Oxford
Kings College London
Anglia Ruskin University
University of Nottingham
Glasgow University
Edinburgh University
University of Exeter
British Paediatric Neurology Association
USB
University of Surrey
University of Staffordshire
University of Salford
University of Hull
East Anglia University
University of Leeds
Cardiff University
University of Southampton
Manchester Metropolitan University
University of Newcastle
Swansea University



Collaborations and partnerships

The Encephalitis Society comprises a passionate, dedicated and high-achiving, but small team. We recognise that in order to make a bigger and more rapid difference we need to work with others. We collaborate across a network of academic institutions, specialised hospitals and research groups to promote multidisciplinary research and team collaboration.

Joint fellowship with Medical Research Council (MRC)

A new collaboration with the MRC has seen a joint funding for a fellowship being launched in 2023. The MRC is a national funding agency dedicated to improving human health by supporting research across the entire spectrum of medical sciences, in universities and hospitals, in MRC units, centres and institutes in the UK, and in MRC units in Africa.

"This collaboration is the result of many years of hard work, and I am excited that we are joining forces with such a prestigious institution to fight this disease" (Dr Ava Easton, Encephalitis Society)

AMRC

We are members of the prestigious Association of Medical Research Charities (AMRC) and we follow their peer-review and research principles to make sure our research is of high-quality.

We engage with researchers and professionals all over the world

- We share knowledge by presenting at Conferences worldwide and delivering training to various healthcare professionals.
- Every year we publish our Research Summary- Advances in Encephalitis which is distributed to thousands of medical professionals and researchers. *www.encephalitis.info/research-summary*
- Our biannual Newsletter – Connect Professional featuring news, research and events is distributed to over 2300 health professionals. *www.encephalitis.info/Pages/Category/professional-newsletter*
- We broadcasted 28 podcasts since the beginning of the COVID-19 Pandemic on various themes from COVID-19 and mental health to vaccination and measles. *www.encephalitis.info/Listing/Category/our-podcasts*

Professional Membership is offered to all professionals all over the world. The Membership allows a wide range of benefits.

- Bursaries to attend our events.
- Discount rates to our annual Encephalitis Conference.
- Priority access to our professional members newsletter.
- Priority access to our annual Advances in Encephalitis. Research Summary.
- Access the latest information and research from leading professionals.
- Networking and development opportunities.
- Support for research projects.
- Support for patients and their families.
- Training opportunities.
- Opportunities to get involved in the production of our information.
- Opportunities to present to our meetings and events.

Shining a light on research via the media

World Encephalitis Day (WED) on the 22nd of February, Encephalitis Research Month in June and Information Week in October are the Society's global awareness campaigns. These campaigns focus on raising awareness of encephalitis by and for the people affected, large public, supporters and professional involved in management and research of this condition. These campaigns also provide a chance to show the impact of the condition on people's lives by talking about important research with media, and highlighting people's personal experiences.

World Encephalitis Day 22nd February

WED 23

Working with medical and scientific colleagues, we had new research that highlighted the impact on the mental health of those suffering or recovering from encephalitis. This research – which some of our audience may have contributed to – is what we shared with the media on World Encephalitis Day on 22nd February. We believe that by talking about mental health and encephalitis, we shone a light on the fact that these feelings can be preventable and, in most cases, highly treatable. There is also the need for an increased awareness of mental health issues for people with or recovering from encephalitis among healthcare professionals. The more neurologists, doctors, nurses, and family members know that encephalitis can negatively impact on mental health - the better they will be able to look out for the signs.

Abdat, Y., Butler, M., Zandi, M., et al (2023) Mental health outcomes of encephalitis, an international web-based study. medRxiv 2023.02.03.23285344; *https://doi.org/10.1101/2023.02.03.23285344*

Tellez-Martinez, A., Restrepo-Martinez, M., Espinola-Nadurille, M.,et al. (2023) Suicidal thoughts and behaviors in anti-NMDAR encephalitis: psychopathological features and clinical outcomes. Journal of Neuropsychiatry and Clinical Neurosciences: *https://neuro.psychiatryonline.org/*

Our research future

We are very proud of what we have achieved so far and we are aiming to an even better future. Here are some of our plans:

To fund:

Academic Clinical Fellowship

PhD

Seed funding

Research Exchange

American Brain Foundation

To employ:

PPI Coordinator

To engage and support

More researchers, more patients, more supporters

To disseminate and share

More knowledge and experience

For more information on future plans, please see the Encephalitis Society Research Strategy 2023-2026.

www.encephalitis.info/research-strategy

With your continued support, we can make these plans possible, so there will be a brighter future for people affected by encephalitis and their families.

To find out more contact
research@encephalitis.info
or visit **www.encephalitis.info** to donate today

Thank you to all our research sponsors and donors

UCB
SVAR Wieslab
Euroimmun
Valneva
University of Liverpool
UAP
The De Laszlo Foundation
ACNR
CSL Behring
NIHR
The Shears Foundation
Quest Advanced Neurology
Bavarian Nordic
Pfizer
Aston University
Guarantors of Brain
The Lancet Neurology
Routledge
Brain Infectious Global
Oxford University Press
Cambridge University Press

All our members and supporters who believe in us

ENCEPHALITIS
SOCIETY
The brain inflammation charity

Encephalitis Society Scientific Advisory Panel

Dr Nicholas Davies
Chair of the Encephalitis Society Scientific Advisory Panel
Chelsea and Westminster Hospital London, UK

Prof Benedict Michael
Vice chair of the Encephalitis Society Scientific Advisory Panel
NIHR HPRU for Emerging and Zoonotic Infection
The Walton Centre, Liverpool, UK

Dr Bonnie-Kate Dewar
Neuropsychology Services Limited
London, UK

Dr Ava Easton
CEO, Encephalitis Society
University of Liverpool
Liverpool, UK

Prof Carsten Finke
Charité Berlin
Berlin School of Brain and Mind, Humboldt Universität
Berlin, Germany

Dr Jessica Fish
Institute of Health and Wellbeing, University of Glasgow
Glasgow, UK

Dr Matteo Gastaldi
Neuroimmunology Research Unit, IRCCS Mondino Foundation
Pavia, Italy

Prof Sarosh R. Irani
Oxford Autoimmune Neurology Group
John Radcliffe Hospital
Oxford, UK

Prof Peter GE Kennedy CBE
Institute of Neuroscience and Psychology, University of Glasgow
Glasgow, UK
Queen Mary University of London
London, UK

Assist Prof Kiran Thakur
Columbia University Irving Medical Center
New York, USA

Dr Rachel Kneen
Alder Hey Children's NHS Foundation Trust
Institute of Infection & Global Health, University of Liverpool
Liverpool, UK

Prof Frank Leypoldt
Inst. of Clinical Chemistry and Laboratory Medicine, Kiel University
Kiel, Germany

Dr Nick Makwana
Sandwell and West Birmingham NHS Trust
Birmingham, UK

Dr Thomas Pollak
Institute of Psychiatry, Psychology and Neuroscience, King's College London
South London and Maudsley NHS Foundation Trust
London, UK

Dr James J. Sejvar
Division of High-Consequence Pathogens and Pathology
National Center for Emerging and Zoonotic Infectious Diseases
Centers for Disease Control and Prevention, USA
Emory University School of Medicine
Atlanta, USA

Assist Prof Omar K. Siddiqi
Harvard Medical School
Beth Israel Deaconess Medical Center, Boston, USA
University of Zambia School of Medicine, Zambia

Dr Arleta Starza Smith
Nottingham University Hospitals NHS Trust
Nottingham, UK

Prof Tom Solomon CBE
The Pandemic Institute
NIHR HPRU in Emerging and Zoonotic Infections
Brain Infections Group
Walton Centre NHS Foundation Trust and Royal Liverpool University Hospital
Liverpool, UK

Assoc Prof Maarten Titulaer
Erasmus University Medical Center
Rotterdam, The Netherlands

Dr Michel Toledano
Mayo Clinic
Rochester, USA

Dr Lance Turtle
Institute of Infection, Veterinary and Ecological Sciences, University of Liverpool,
Liverpool, UK

Prof Arun Venkatesan
Johns Hopkins University School of Medicine
John Hopkins Encephalitis Centre
Baltimore, MD, USA

Prof Angela Vincent
Somerville College, University of Oxford
Oxford, UK

Dr Steven White
Cromwell Hospital
London, UK

The Encephalitis Society is the operating name of the Encephalitis Support Group
Registered Charity in England and Wales No. 1087843, Registered Charity in Scotland No. SC048210,
Charitable Company registered in England and Wales No. 04189027
Encephalitis Society is a Named Fund member of the Chapel & York US Foundation, Inc. The Chapel & York US Foundation, Inc. is a 501(c)(3) tax-exempt organization.