

THE NEWSLETTER FOR PROFESSIONALS INTERESTED IN ENCEPHALITIS

CONNECT PROFESSIONAL

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**ENCEPHALITIS
SOCIETY**

The brain inflammation charity

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ENCEPHALITIS 2023 All you need to know about our annual conference

PLUS

COVID-CNS Study

Professor Tom Solomon Q&A

Encephalitis Research Month

WELCOME

Welcome to Connect Professional!

In this edition, you can discover more about our exciting plans for Encephalitis 2023 in London and online on the 4th and 5th December.

As you will see, we have a packed programme over the two days, with some fascinating talks, a lively debate, advice about applying for funding, an opportunity to improve your clinical knowledge of autoimmune and infectious encephalitis, and much more (see pages 8 to 12).

Of course, we would love you to be with us in-person at the Royal College of Physicians in London, but we know that is not always possible – given the global nature of our audience and the busy working lives we lead.

We always like to stress that you can join us virtually from the comfort of your home or office – with recordings made available to all attendees afterwards.

Over recent years, the conference has really taken on a greater international flavour with attendees coming from more and more countries.

As we approach the 30th anniversary year of the Encephalitis Society, it warms our hearts to see the growth an event about which we are passionate, an event that began with only a handful of attendees.

Elsewhere in this edition, you will get to meet the newest members of our Scientific Advisory Panel (see page 4), learn about the success of Encephalitis Research Month (see pages 6 & 7), and read summaries of some of the latest encephalitis research (see pages 14-17).

Also, many of you will be familiar with Professor Tom Solomon, President of the Encephalitis Society. But how well do you really know Tom?

Well, now you can find out more about the man - and the myth! - after he very kindly took part in our Meet the Scientists Q&A (see pages 26 & 27).

Finally, there was a day of celebration and quiet satisfaction for both of us recently.

We were delighted to publish the first research paper inspired by our Global Impact Report.

Global Landscape of Encephalitis: Key Priorities to Reduce Future Disease Burden was authored by Dr Julia Granerod, Dr Yun Huang, Dr Patricia Sequeira, Dr Victor Mwapasa, Dr Priscilla Rupali, Professor Benedict D Michael, Professor Tom Solomon, and ourselves. (See page 17).

This is the first of what we hope will be many such papers to come from our Global Impact Report as the Encephalitis Society works towards our vision of a world without death and disability from encephalitis.

Now all that is left for us to do is wish you happy reading – and we can't wait to see you at Encephalitis 2023!



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Encephalitis Society
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Dr Nicholas Davies
Chair - Scientific Advisory Panel
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Pictured overleaf: Associate Professor Federico Iovino, of the Karolinska Institute, speaks at Encephalitis 2022



San Francisco hosts My Brain & Medicine

The City by the Bay was the picturesque setting for our first ever My Brain & Medicine event outside of the UK.

More than 80 people joined us at the University of California San Francisco Center for Encephalitis and Meningitis (UCSF) at the end of September for an afternoon of talks and discussion about encephalitis.

Speakers included experts from UCSF and supporters who shared their personal experiences of encephalitis.

Dr Ava Easton, our Chief Executive, (pictured) made the journey across the Atlantic and



co-hosted the event alongside, Dr Michael Wilson, of UCSF.

"It was very heartening to witness the passion that so many people have for furthering their understanding of encephalitis. Coming together and sharing our experiences was so powerful - or, as we said on the day, making brain lemonade!"

She added: "This is the first of what will be many more events of this kind in the USA with ambitions to take it to other corners of the world."

Our next US-based My Brain & Medicine will take place in Denver, Colorado, in April, 2024.

Funding recipients to be revealed

Representatives from the Encephalitis Society's Scientific Advisory Panel will announce the recipients of our annual seed funding grants at the end of October.

Applicants were invited to apply for up to £10,000 as part of our Encephalitis Futures - International Research Seed Funding project.

There will be two grants awarded in this round of funding.

Attendees to get sneak peak of major announcement

The times they are a-changing at the Encephalitis Society.

With our 30th anniversary year just around the corner, we will be giving attendees at Encephalitis 2023 a sneak peak at a major announcement for our organisation.

A public announcement will follow a week later.

"What I can say - which is very little - is that this is seismic news about the future of the Encephalitis Society," said Dr Ava Easton, our Chief Executive. "We are naturally proud of our links with the medical community and the conference is an ideal setting to preview our plans for the future."

She added: "Until then, our lips are sealed!"

Nipah virus outbreak

Authorities in India have reported an outbreak of the Nipah virus – the sixth outbreak in the country since 2001.

In mid-September, the Ministry of Health and Family Welfare reported six confirmed Nipah virus cases, including two deaths, in the Kozhikode district, Kerala.

Aside from the first case, whose source of infection is unknown, the other cases were family and hospital contacts of the first case.

At the time Connect went to press, 387 samples had been tested, of which six cases were positive for the virus. There have been no new cases since the 15th September.

Nipah virus infection is spread to humans through contact with infected animals such as bats and pigs. Direct contact with an infected individual can also lead to transmission.

Those affected by Nipah virus infection may experience severe symptoms, including acute respiratory infection and fatal encephalitis.

The only way to reduce or prevent infection in people is by raising awareness about the risk factors and preventive measures.

Case management should focus on providing patients with supportive care measures and intensive support for severe respiratory and neurologic complications.

New experts join panel

The Encephalitis Society's Scientific Advisory Panel continues to grow.

Two new volunteers have recently joined our team of medical professionals - swelling the ranks of encephalitis experts to 26 in total.

This means we now have a who's who of world leaders covering neurology, neuropsychology, epidemiology, neuropsychiatry, neuroimmunology, among other related fields.

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



Dr Greta Wood

NIHR Academic Clinical Fellow - Infectious Diseases, Clinical Infection, Microbiology & Immunology

University of Liverpool, England

Dr Wood is an National Institute for Health and Care Research Academic Clinical Fellow in Infectious Diseases and a Clinical Research Fellow for the national COVID-19 Clinical Neuroscience Study. Her research interests include infection neuroscience, respiratory infection, and digital/Artificial Intelligence.

She is a member of the World Health Organisation Neurology and Public Health Global Forum and leads the Global Brain Health Clinical Exchange.



Dr Stephen Ray

Clinical Lecturer - Paediatric Infectious Diseases

University of Oxford, England

Dr Ray is a Clinical Lecturer at The University of Oxford and a paediatrician, sub-specialising in paediatric infectious diseases at Oxford University Hospitals NHS Trust.

His research aims to improve the diagnosis, management, and outcomes of critically ill children with life-threatening infections, with a focus on brain infections, particularly in Low and Middle-Income Countries (LMIC).

World Encephalitis Day Alliance conference - register for free

Jacksonville in Florida, USA, will be the host city for a three-day conference to celebrate World Encephalitis Day 2024 in February.

Organised by the World Encephalitis Day Alliance (WEDA), it will feature several talks from medical professionals and people whose lives have been affected by encephalitis.

Alina Ellerington, our Director of Services, said:

"We are in the early planning stages of this event which will offer anyone interested in attending a chance to connect with others who have been affected directly and indirectly by encephalitis. If you, or any of your patients, are interested in attending, please sign up today!"

Visit WEDA2024.eventbrite.co.uk to register for a free place.

Vaccine masterclass

Learn more about vaccine-preventable encephalitis at an upcoming online masterclass.

Planned for April next year, it will feature talks from experts in encephalitis and is aimed at medical professionals of all levels.

Professional members of the Encephalitis Society will be informed about tickets closer to the date. Watch this space!

Award nominations

Understanding Encephalitis, our series of short films which cover different aspects of the condition, have been nominated for a Digital Impact Award.

The films which provide viewers with information around different areas of encephalitis are available on our YouTube channel in several languages, including Hindi, Polish, Punjabi, Tagalog, and French.

German versions are also in the works.

At the time Connect went to press, members of the Encephalitis Society team were preparing to don their evening wear for the ceremony in London.

Meanwhile, the Encephalitis Society was also shortlisted at two industry awards ceremonies held in September.

The team was nominated in the Campaigning Team of the Year category at the Charity Times Awards and also for Medium Charity of the Year in the Third Sector Awards.

Ava's tour de France

Dr Ava Easton, Chief Executive of the Encephalitis Society, recently visited Lyon and Toulouse. In this article, she details her visit and the teams she met who are leading encephalitis research in France.

I spent a week based in a sun-kissed Lyon, France, in June. I was fortunate to visit two specialist reference centres and also one of our long-standing corporate partners for a catch-up.

The day after I arrived to 30 degree heat, it was time for a very early start and a 6am train from Lyon Part-Dieu Station to Toulouse. The train takes around four-and-a-half hours, so plenty of time to eat the breakfast I packed, catch a few more z's and also do some work!

I arrived at 11am at the Toulouse University Hospital, where I was greeted by neurologist Dr Marie Rafiq. Marie and I had met previously, first over email and then when she attended the Encephalitis Conference. Marie was joined by Professor Jeremie Pariente and we bonded over some coffee as is the French way.

I was shown around the neurology wards and learnt how their multi-disciplinary teams work, offering authentically joined-up pathways and experiences for the patients that pass their way. They were excited to introduce me to Mr X, an English patient experiencing LG11 encephalitis who was on their wards. He was keen to connect with another Brit and we chatted for some time about home and his current situation. Sadly, he had remained undiagnosed for around six months until the Toulouse team came across him and suggested testing for autoimmune encephalitides.

I was then taken out for a rather splendid lunch where we all took some time out for an hour. In the afternoon, I delivered my lecture on the importance of narrative medicine. After this, I was taken for a tour of their labs and then finally it was time to take the long train journey back, arriving around 10.30pm in Lyon. A long day, but very worth it to see the work of such a committed team.

I had some spare time over the weekend and then on the Monday I was at the Lyon offices of Valneva, a long-standing supporter of our work. Valneva is a pharmaceutical company specialising in vaccines that focus on the development, manufacturing and commercialization of prophylactic vaccines for infectious diseases with significant unmet medical need, including, of course, encephalitis! We had a good catch up



ENTENTE CORDIALE... Enjoying lunch with Valneva

during the morning where I updated the team on our work, then in the afternoon we discussed collaborative options going forward. Naturally, this being France, a delicious meal was again involved to break up the business of the day!

My final visit the following day was to the BetPsy project – a project aimed at biomarkers in autoimmune encephalitis and paraneoplastic neurological syndromes. It is run by Professor Jerome Honnorat and team at the Hôpital Neurologique in Lyon. I was greeted by the kind Lucie Aliouane, who had organised my visit, with the team showing me their offices, giving me a tour of their laboratories and kindly allowing me to update them on the work of the Society. Once again, it was great to see a team so committed to not only the patients in their care, but also their work on the prevention of encephalitis going forward.

I feel very blessed to be welcomed by some many amazing teams around the world as part of my work on behalf of the Encephalitis Society. It really makes a difference to be able to connect with people in-person and see their work in action.

Following the visit, we were able to furnish both clinical teams with patient information brochures and our animation series in French for their patients and their families, as well as reminding them that we serve patients wherever they are in the world.



Ava at Toulouse University Hospital



RESEARCH EXCHANGE... Ava with the team from Toulouse University Hospital

Shining a light on encephalitis research



Projects devoted to furthering the understanding of encephalitis were given a major shot in the arm during Encephalitis Research Month, thanks to the generous donations of supporters.

Our month-long Big Give campaign in June raised a staggering £27,732.74, all of which will now go towards encephalitis research.

We also took our message about the importance of research to social media, talking about everything from the current state of research and upcoming events, through to success stories, profiles of leading experts, and what the future holds.

And with one eye on the Encephalitis Conference in December, we awarded three travel bursaries to researchers in low- and middle-income countries and received 62 abstracts from medical professionals who want to share their findings with us at our hybrid event in London.

Dr Ava Easton, Chief Executive of the Encephalitis Society, said: “We consistently hear that research is something our supporters are passionate about and, thanks to their amazing donations, we will now be supporting projects which will be of benefit to people affected by encephalitis.”

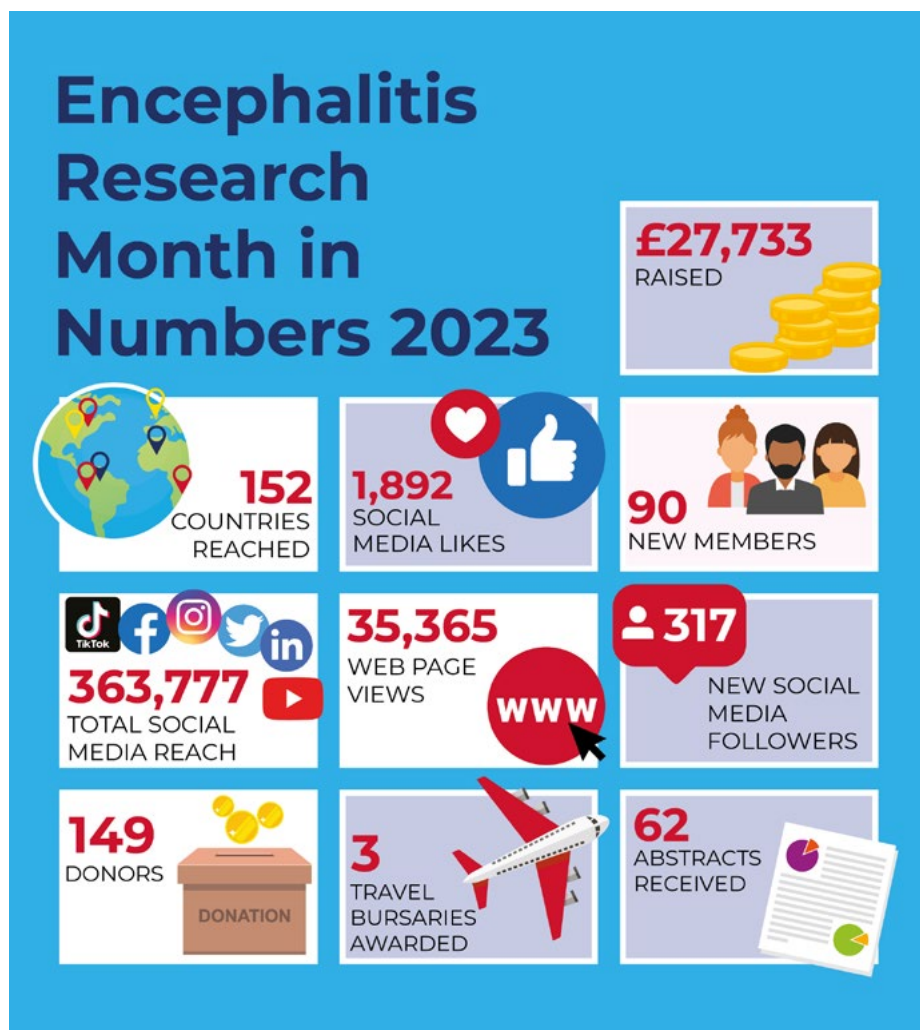
That work will begin at the end of October when members of our Scientific Advisory Panel sit down and decide which applicants will receive up to £10,000 in seed funding towards their encephalitis research project.

of our work as we get to support new, exciting research and, at the same time, nurture the next generation of encephalitis researchers,” added Ava.

Previous grants have benefitted researchers from all over the world, including Dr Tina Damodar in India who is developing a diagnostic test which can differentiate scrub typhus from other causes of acute encephalitis syndrome in children.

Early diagnosis of scrub typhus – a bacterial infection with associated with high mortality and morbidity – could mean the difference between life and death.

Ava said: “Providing seed funding to a researcher such as Dr Damodar can give them the start they need to investigate an area of need. From there, it can lead to further funding as we have seen with some of our previous seed funders.”



“This is one of the most rewarding parts

ENCEPHALITIS RESEARCH MONTH

Projects which will benefit from donations, include:

Seed funding

Our seed funding project gives researchers – particularly those from resource-limited settings – the opportunity to launch pilot studies into different aspects of encephalitis. Since its launch in 2019, we have supported projects in Cameroon, Brazil, Senegal, Uganda, and India, among other countries.

Research exchange

We nurture the next generation of researchers by offering exchanges between doctors from low and middle-income countries and UK centres of excellence.

Academic clinical fellowship

Every three years, we fund one Academic Clinical Fellowship. These junior researchers will split their time working with patients (75%) and obtaining research experience (25%), providing a springboard towards a clinical academic career in encephalitis.

Medical Research Council (MRC) fellowship

We are working with the MRC to offer a jointly-funded clinical research training fellowship which will allow one clinical research fellow to undertake UK-based research project that contributes to improving the diagnosis, treatment, or rehabilitation of patients.

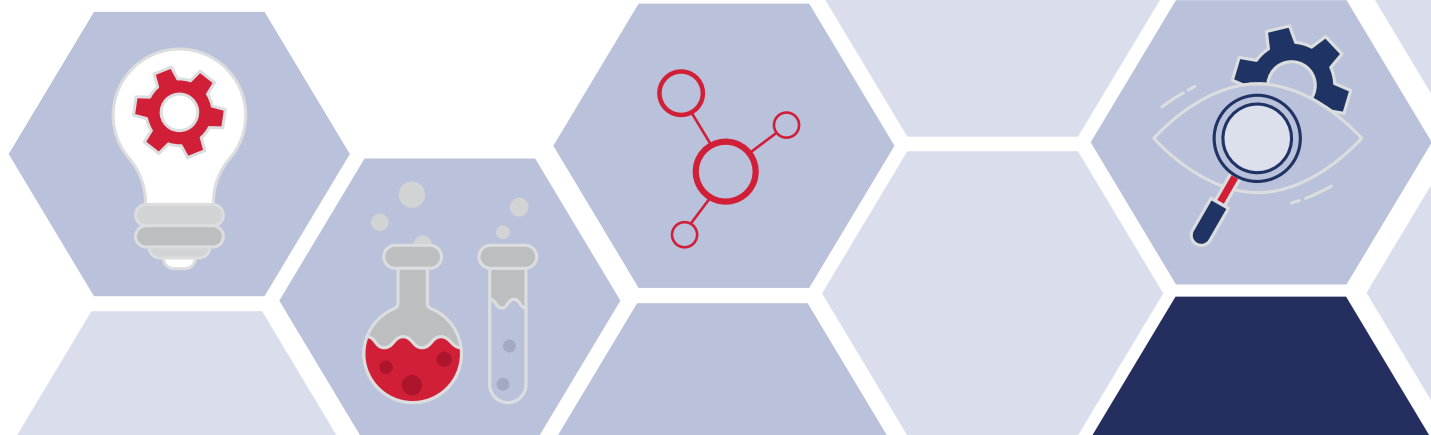
American Brain Foundation (ABF)

We are contributing to the ABF's \$10m, multi-year funding initiative which is aiming to understand neuroinflammation as an underlying mechanism of brain disease

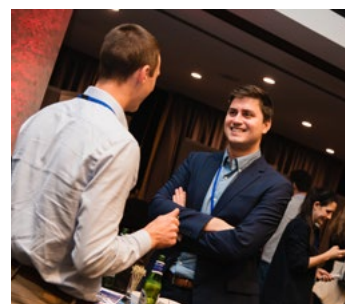
Ava said: "If we are going to continue to see improvements in the diagnosis, treatment and rehabilitation of patients affected by encephalitis, it is of vital importance that we throw our weight behind funding and supporting research wherever we can.

"We are very grateful to everyone who made a donation, submitted an abstract, shared our social posts and who have volunteered to share their experiences with research studies – we can't do any of this without you."

Do you want to support encephalitis research?
Please consider making a donation by visiting
www.encephalitis.info/donate



ENCEPHALITIS CONFERENCE



Encephalitis 2023: All you need to know

Join hundreds of medical professionals from across the world at Encephalitis 2023 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 afterwards for anyone unable to attend.

Encephalitis 2023 begins on Monday, December 4, with an afternoon of satellite meetings, offering tips on applying for grants and fellowships and a Data Blitz Poster Presentation.

The following day starts with a Breakfast Meeting, offering a basic clinical introduction to infectious and autoimmune encephalitis.

Keynote speakers at Encephalitis 2023 include Dr James

Sejvar, of the Centers for Disease Control and Prevention, and Dr Taran Dua, of the World Health Organization, with guest presentations from Dr Sukhvir Wright, of Aston University, and Professor Tom Solomon CBE, of the University of Liverpool.

There will be oral presentations, a debate, with attendees also having an opportunity to view the poster presentations during break times.

This year's programme has been developed by Dr Thomas Pollak who chaired the Encephalitis Conference Sub-Committee alongside members of the Scientific Advisory Panel and Encephalitis Society.

Dr Ava Easton, Chief Executive of the Encephalitis Society, said: "A lot of blood, sweat and tears goes into organising our annual conference. We have put together a programme which we believe will appeal to all medical professionals, whatever discipline you are focused on. We hope to see you there!"

CPD points will be awarded to all attendees.

Encephalitis 2023

Royal College of Physicians, London or Virtual
4th and 5th December

Tickets: www.encephalitis.info/conference

Please note:

To be eligible for a 20% discount, become a FREE Professional Member of the Encephalitis Society by visiting www.encephalitis.info/professional-membership

Ticket holders can view all presentations online for 60 days following the conference.

ENCEPHALITIS CONFERENCE



Satellite meetings support the next generation

Encephalitis 2023 kicks off on Monday, 4th December, with an afternoon aimed at offering a helping hand to the next generation of researchers.

These satellite meetings can be attended in-person at the Royal College of Physicians in London or online and are included in the cost of a conference ticket.

Each meeting will be chaired by professional members of the Encephalitis Society.

HOW TO GET YOUR GRANT OR FELLOWSHIP

1.30pm to 2.30pm GMT

Led by Dr Mark Ellul and Assist Professor Deanna Saylor, this workshop is aimed at researchers who are beginning their careers. Areas covered include:

- how to find grant funding opportunities
- writing tips and guidance on what reviewers look for
- the most common mistakes made by applicants

DATA BLITZ POSTER PRESENTATION

3pm to 5.30pm GMT

Authors of selected conference posters will be invited to present and discuss their research with the Encephalitis Society Scientific Advisory Panel and the audience.

Please note: In-person places are now sold out. Virtual places are still available.

Encephalitis 2023 is kindly sponsored by:



An overview over breakfast

Improve your clinical knowledge of encephalitis, thanks to our brand-new breakfast meetings.

Ahead of our conference on the morning of Tuesday, December 5, we are offering a basic clinical introduction to both infectious and autoimmune encephalitis.

The talks will be led by Professor Sarosh Irani, Professor of Neurology at the Mayo Clinic College of Medicine and Science, Florida, and Professor Benedict Michael, Director of the Infection Neuroscience Laboratory at the University of Liverpool.

“These brand new breakfast meetings were introduced following feedback from previous attendees of the conference,” said Dr Ava Easton, CEO of the Encephalitis Society. “It is a wonderful opportunity to hear from two leaders in infectious and autoimmune encephalitis and what they look out for when treating patients.

Both presentations can be attended in person or online and are included in the ticket price of Encephalitis 2023.



THE BREAKFAST CLUB... Prof Sarosh Irani

ENCEPHALITIS CONFERENCE



FOR:
Dr Sophie Binks



AGAINST:
Prof Harald Prüss

VS

Encephalitis 2023: The Debate

"This house believes that too much time and money is being spent identifying new antibodies in autoimmune encephalitis."

Tuesday, 5th December @ 4pm

Autoimmune encephalitis will be the focus of the second annual debate at Encephalitis 2023.

Dr Sophie Binks, of the Oxford Autoimmune Neurology Group, and Professor Harald Prüss, representing Charité Universitätsmedizin Berlin, will face off in the lively discussion, with attendees then invited to decide who is the victor.

Charged with keeping proceedings civil is Dr Thomas Pollak, of the Institute of Psychiatry, Psychology and Neuroscience, King's College London.

Alina Ellerington, Director of Services at the Encephalitis Society, said: "Everyone loves a hearty debate and we think this year's topic will provoke some good arguments between Harald and Sophie as well as attendees. Who will end up winning the argument - who knows?!"



REFEREE... Dr Thomas Pollak



KEYNOTE SPEAKER
Epidemiological Adventures in Encephalitis

Dr James Sejvar
Centers for Disease Control and Prevention



KEYNOTE SPEAKER
Intersectoral Plan on Epilepsy and other Neurological Disorders

Dr Tarun Dua
World Health Organization



GUEST SPEAKER
Paediatric Autoimmune Encephalitides

Dr Sukhvir Wright
Birmingham Women's and Children's NHS Foundation Trust

Encephalitis 2023 is kindly sponsored by:

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ENCEPHALITIS CONFERENCE

Chair: Dr Ava Easton

Chief Executive, Encephalitis Society, UK

Chair: Dr Nick Davies

Chelsea and Westminster Hospital, London, UK

Session One

KEYNOTE LECTURE

Intersectoral Plan on Epilepsy and other Neurological Disorders

Dr Tarun Dua

World Health Organization

Comparative characteristics in anti-LGI1 and anti-CASPR2 encephalitis

Dr Sophia Michael & Dr Christine Strippel

Oxford Autoimmune Neurology Group, UK

Auto-antibodies neutralizing type I IFNs underlie West Nile virus encephalitis in ~40% of patients

Mr Adrian Gervais

Institut National de la Santé et de la Recherche Médicale (INSERM) U1163,

France

ES funded research: Host mRNA signature in scrub typhus meningoencephalitis

Dr Tina Damodar

National Institute of Mental Health and Neurosciences India



PRESENTERS... Dr Nick Davies and Dr Ava Easton

Chair: Dr Matteo Gastaldi

Neuroimmunology Research Unit, Pavia, Italy

Chair: Prof Carsten Finke

Charite-Universitätsmedizin Berlin, Germany

NMDA receptor encephalitis and multiple sclerosis overlap syndrome - clinical findings and MRI characteristics

Dr Joseph Kuchling

Charité - Universitätsmedizin Berlin, Germany

Cognitive outcomes and associated biomarkers and neuroimaging in COVID-19 encephalitis: analysis of the UK COVID-19 CNS

Dr Greta Wood

University of Liverpool, UK

Highly differentiated LGI1/CASPR2-reactive plasmablasts characterise CSF of encephalitis patients and provide a potential treatment target

Dr Jakob Theorell

Karolinska Institutet, Stockholm, Sweden

Recovery trajectories after severe encephalitis: a prospective multicentre cohort study

Prof Romain Sonnevile

Claude Bernard Bichat Hospital, France

INVITED GUEST LECTURE

Paediatric Autoimmune Encephalitis

Dr Sukhvir Wright

Aston University, UK

Session Two



COVID-19 ANALYSIS... Dr Greta Wood

Encephalitis 2023 is kindly sponsored by:



Prof Angela Vincent
University of Oxford, UK

Dr Thomas Pollak
King's College London, UK

KEYNOTE LECTURE

Epidemiological Adventures in Encephalitis
Dr Jim Sejvar
Centers for Disease Control and Prevention (CDC), USA

**Session
Three**

Functional neurological disorder in the long-term management of adults with autoimmune encephalitis and related disorders
Dr Nicole Lichtblau
King's College Hospital London, UK

Exploring barriers and enablers to vaccine confidence among ethnically diverse communities in Liverpool - Qualitative findings from the MSD Liverpool Vaccine Confidence Project
Ms Charlotte O'Halloran
MSD, UK



GUEST SPEAKER

The Role of Dexamethasone in Herpes Encephalitis; a Crystal Clear Answer

Professor Tom Solomon CBE The Pandemic Institute and The University of Liverpool, UK

The results of a study which could revolutionise the treatment of patients with Herpes Simplex Virus encephalitis will be revealed at Encephalitis 2023.

Professor Tom Solomon, President of the Encephalitis Society, has been invited to share the findings of the DexEnceph study with attendees at the Royal College of Physicians and online.

Researchers have spent several years investigating whether dexamethasone, which can reduce brain swelling, will also benefit the treatment of patients with Herpes Simplex Virus (HSV) encephalitis.

Aciclovir, the standard treatment for HSV encephalitis, can leave some patients with significant memory loss, among other difficulties.

Assoc Prof Kiran Thakur
Columbia University, USA

Prof Benedict Michael
University of Liverpool, UK

The epidemiology and possible aetiology of encephalitis lethargica in a large historical cohort
Dr Jonathan Rogers
University College London, UK

DEBATE: "This house believes that too much time and money is being spent identifying new antibodies in autoimmune encephalitis."

Chair: Dr Thomas Pollak
King's College London, UK

For: Dr Sophie Binks
Oxford Autoimmune Neurology Group, UK

Against: Prof. Dr. Harald Prüss
Charité Universitätsmedizin Berlin, Germany

INVITED GUEST LECTURE

The Role of Dexamethasone in Herpes Encephalitis; a Crystal Clear Answer
Professor Tom Solomon CBE
The Pandemic Institute and The University of Liverpool, UK

The research team wanted to investigate whether dexamethasone improves the outcomes of patients - potentially revolutionising the treatment of HSV encephalitis.

Launched at the end of 2015, the study recruited 94 patients who were divided into two groups - one that received dexamethasone four times a day for four days and the other that did not. Both groups also received aciclovir as part of their treatment.

DexEnceph was led by the Brain Infections Team at the University of Liverpool, in collaboration with the Walton Centre and the Encephalitis Society.

**Session
Four**

Charly awarded PhD for study into behavioural outcomes following childhood encephalitis

Congratulations to Dr Charly Billaud who has recently completed his PhD investigating long-term cognitive and behavioural outcomes following childhood autoimmune encephalitis.

His project also aimed to identify who is most at risk for long-term difficulties by using novel imaging methods.

Charly was the recipient of the 2019 Encephalitis Society Silver Jubilee PhD Fellowship which was co-funded by Aston University in Birmingham, England.

Here he writes about his research and what he has learned over the past four years:

What did your PhD investigate?

My PhD focused on children 18 months to 13 years after they started having autoimmune encephalitis. It looked at psychological aspects of thinking skills and behaviour that are usually not assessed at the hospital; such as how fast a child can complete a task, how much information can a child keep in mind, does a child find it easy to interact with peers etc.

The PhD also used novel methods in brain research that look at subtle structural changes in the brain as well as how it "activates" in a network. The point was to test whether these emerging techniques can predict the psychological measures I used and tell whether difficulties are likely to happen or not in children.

What were your findings?

My findings highlighted that some overlooked difficulties can be experienced by children even years after the onset of the disease.

For example, the group of children that I worked with was more affected by difficulties in completing a set of tasks



Dr Charly Billaud

as fast as we would expect at that age. A portion of children also dealt with hyperactive behaviours, emotional problems and difficulties engaging in prosocial behaviours. These are therefore worth examining for clinicians and families, especially when some of these difficulties can impact their academic career and might warrant support at school for example. The brain analyses also showed that even when a child can have an unremarkable MRI scan, autoimmune encephalitis may leave a subtle impact on the grey matter of some regions. Brain networks of children with autoimmune encephalitis would also tend to organise differently when transmitting information across neurons.

While I found only a minor relationship between networks and the psychological measures, this paves the way for future research to look at brain changes that were not noticed before and could potentially explain why some children still face difficulties after leaving the hospital.

Did anything surprise you during your research?

I was surprised by how well the children did in the brain scanners, as they are commonly thought to be more difficult to analyse, because they tend to move or get tired. The "MEG" machine (the seat and helmet that I used to record brain activity) was actually comfortable enough for them and I'm thankful for the children that did patiently take part!

How does it feel to finish your PhD?

It feels like a relief and an achievement. It took longer than expected as it was challenged by the COVID-19 pandemic, the multiple lockdowns and delayed by changes such as MRI scan renovation at the institute of health and neurodevelopment. I'm grateful for the support I had at Aston University which helped me go through it, and my supervisors who were both good researchers and good people! I am very happy about the overall experience.

What is next for your career?

I expect to become a postdoctoral researcher in neurosciences and keep working in neuroimaging studies with a potential clinical impact.

Addressing vaccine-preventable encephalitis in vulnerable populations

The global incidence of encephalitis is on the rise due to increased recognition of immune-mediated causes, emerging infections, and improved diagnostics. Infectious encephalitis remains a severe syndrome with high mortality and long hospitalisations.

While vaccines are cost-effective public health tools that have been pivotal in reducing encephalitis cases, there are still gaps in vaccination efforts. Among WHO-listed vaccine-preventable diseases, top vaccine-preventable causes are dengue, Japanese encephalitis, rabies, and monkeypox viruses.

The authors contend that focus must be on enhancing vaccine programming to better address encephalitis in vulnerable populations most at risk of vaccine-preventable encephalitis to meet global vaccine coverage targets.

Populations vulnerable to vaccine-preventable infectious that

may lead to encephalitis are listed as those living in endemic and rural areas, military members, migrants, refugees, international travellers, younger and older persons, pregnant women, the immunocompromised, healthcare and laboratory workers, and the homeless.

Identified areas for improving vaccine programming include issues relating to the availability and distribution of vaccinations, vaccine equity, surveillance, and public education and information.

Piamonte BLC, Easton A, Wood GK, et al.

Addressing vaccine-preventable encephalitis in vulnerable populations

Curr Opin Neurol. 2023;36(3):185-197.

doi:10.1097/WCO.0000000000001158.



Autoimmune Encephalitis Criteria in Clinical Practice

BACKGROUND AND OBJECTIVES

To assess the clinical practice applicability of autoimmune encephalitis (AE) criteria (2016).

METHODS

Medical records of 538 adults diagnosed with AE or related autoimmune encephalopathy at Mayo Clinic (not including pure movement disorders) were reviewed and AE guideline criteria applied.

RESULTS

Of 538 patients, 288 were male (52%). The median symptom onset age was 55 years (range, 11–97 years; 16 had onset as children). All had other non-AE diagnoses reasonably excluded.

Of 538 patients, 361 (67%) met at least possible criteria, having all 3 of subacute onset; memory deficits, altered mental status or psychiatric symptoms, and ≥ 1 supportive feature (new focal objective CNS finding, $N = 285$; new-onset seizures, $N = 283$; supportive MRI findings, $N = 251$; or CSF pleocytosis, $N = 160$).

Of 361 patients, AE subgroups were as follows: definite AE ($N = 221$, 61%, [87% AE-specific IgG positive]), probable seronegative AE ($N = 18$, 5%), Hashimoto encephalopathy ($N = 20$, 6%), or possible AE not otherwise categorizable ($N = 102$, 28%). The 221 patients with definite AE had limbic encephalitis ($N = 127$, 57%), anti-NMDAR encephalitis ($N = 32$, 15%), ADEM ($N = 8$, 4%), or other AE-specific IgG defined ($N = 54$, 24%). The 3 most common definite AE-IgGs detected were as follows: LGI1 (76,

34%), NMDA-R (32, 16%), and high-titer GAD65 (23, 12%).

The remaining 177 patients (33%) not meeting possible AE criteria had the following: seizures only (65, 12% of all 538 patients), brainstem encephalitis without supratentorial findings (55, 10%; none had Bickerstaff encephalitis), or other (57, 11%). Those 57 “others” lacked sufficient supportive clinical, radiologic, or CSF findings ($N = 26$), had insidious or initially episodic onset of otherwise typical disorders ($N = 21$), or had atypical syndromes without clearcut memory deficits, altered mental status, or psychiatric symptoms ($N = 10$). Fifteen of 57 were AE-specific IgG positive (26%). Among the remaining 42, evidence of other organ-specific autoimmunity (mostly thyroid) was encountered in 31 (74%, ≥ 1 coexisting autoimmune disease [21, 50%] or ≥ 1 non-AE-specific antibodies detected [23, 53%]), and all but 1 had an objective immunotherapy response (97%).

DISCUSSION

The 2016 AE guidelines permit autoimmune causation assessment in subacute encephalopathy and are highly specific. Inclusion could be improved by incorporating AE-IgG-positive patients with isolated seizures or brainstem disorders. Some patients with atypical presentations but with findings supportive of autoimmunity may be immune therapy responsive.

Orozco E, Valencia-Sanchez C, Britton J, et al.

Autoimmune Encephalitis Criteria in Clinical Practice.

Neurol Clin Pract. 2023;13(3):e200151.

doi:10.1212/CPJ.000000000000200151.

Barriers and facilitators to seeking care for persons with acute brain infections: a cross sectional study

BACKGROUND

Acute brain infections including encephalitis are less common but serious conditions characterized by the inflammation of the brain requiring immediate accurate diagnosis and management. For many infections appropriate therapies exist, but the outcome is often less desirable because of failure to receive appropriate treatment on time due to multiple factors. The aim of the study was to understand the barriers and facilitators towards receiving care for persons with acute brain infections in a low resource setting.

METHODS

The study design was cross sectional exploratory study. Consecutive patients presenting to neurology department of a tertiary referral care center for Neuropsychiatry in South India from July 2020 to September 2020 with the diagnosis of acute brain infections were assessed using the modified Kuppuswamy scale, Glasgow coma scale, the pathway scale: encounter form, patient centered health services in India and

client socio-demographic and service receipt inventory.

RESULTS

A total of 110 participants, both male and female, were recruited for the study. The average age was 39.64 ± 16.5 years, with more female (65.45%) representation. 29% of individuals reported continued use of traditional practices while seeking care for the brain infections. Costs associated with care increased with the increase in duration of infection. There are major barriers and facilitators which either prohibit or facilitate care for persons with acute brain infections.

CONCLUSIONS

Acute brain infections continuing to be a public health challenge in developing country context, and the recognition that the delay in treatment causes significant disability, it becomes imperative to focus on the social, cultural, economic, environmental factors to understand the barriers and facilitators to health seeking among this population.

Nair VS, Thomas PT, Sekar K, et al.

Barriers and facilitators to seeking care for persons with acute brain infections: a cross sectional study

Int J Community Med Public Health. Published 2023 Apr 28. 10(5):1905-10

doi:10.18203/2394-6040.ijcmph20231294.



Japanese Encephalitis: Emergence in Australia

PURPOSE OF REVIEW

Recent changes in Japanese encephalitis (JE) distribution, including its emergence in mainland Australia, call for a review of the epidemiology, diagnosis, treatment and prevention of this important disease.

RECENT FINDINGS

Climate change, urbanisation and changes in vector ecology have driven changes in JE epidemiology including expansion to new areas. Residents of and travellers to endemic areas face potential exposure risks. Surveillance gaps and diagnostic challenges lead to under-appreciation of the true disease burden. Treatment is supportive, but modern vaccines are safe and efficacious.

SUMMARY

The recent emergence of JE in south-eastern Australia highlights its changing epidemiology and the threat this disease poses to other areas with largely naive human populations and with competent mosquito vectors and vertebrate hosts. Awareness of disease features and diagnostic approaches is critical to case detection in travellers and endemic populations, and preventive measures including vaccination should be advised for those with exposure risk.

McGuinness SL, Muhi S, Britton PN, et al.

Japanese Encephalitis: Emergence in Australia.

Published 2023 Apr 5. Curr Infect Dis Rep 25, 111–122

doi:10.1007/s11908-023-00804-w.



Mimics of Autoimmune Encephalitis: Validation of the 2016 Clinical Autoimmune Encephalitis Criteria

BACKGROUND AND OBJECTIVES

The clinical criteria for autoimmune encephalitis (AE) were proposed by Graus et al. in 2016. In this study, the AE criteria were validated in the real world, and common AE mimics were described. In addition, criteria for probable anti-LGI1 encephalitis were proposed and validated.

METHODS

In this retrospective cohort study, patients referred to our national referral center with suspicion of AE and specific neuroinflammatory disorders with similar clinical presentations were included from July 2016 to December 2019.

Exclusion criteria were pure cerebellar or peripheral nerve system disorders. All patients were evaluated according to the AE criteria.

RESULTS

In total, 239 patients were included (56% female; median age 42 years, range 1–85). AE was diagnosed in 104 patients (44%) and AE mimics in 109 patients (46%). The most common AE mimics and misdiagnoses were neuroinflammatory CNS disorders (26%), psychiatric disorders (19%), epilepsy with a noninflammatory cause (13%), CNS infections (7%), neurodegenerative diseases (7%), and CNS neoplasms (6%). Common confounding factors were mesiotemporal lesions on brain MRI

(17%) and false-positive antibodies in serum (12%).

Additional mesiotemporal features (involvement extralimbic structures, enhancement, diffusion restriction) were observed more frequently in AE mimics compared with AE (61% vs 24%; $p = 0.005$). AE criteria showed the following sensitivity and specificity: possible AE, 83% (95% CI 74–89) and 27% (95% CI 20–36); definite autoimmune limbic encephalitis (LE), 10% (95% CI 5–17) and 98% (95% CI 94–100); and probable anti-NMDAR encephalitis, 50% (95% CI 26–74) and 96% (95% CI 92–98), respectively. Specificity of the criteria for probable seronegative AE was 99% (95% CI 96–100). The newly proposed criteria for probable anti-LGI1 encephalitis showed a sensitivity of 66% (95% CI 47–81) and specificity of 96% (95% CI 93–98).

DISCUSSION

AE mimics occur frequently. Common pitfalls in AE misdiagnosis are mesiotemporal lesions (predominantly with atypical features) and false-positive serum antibodies. As expected, the specificity of the criteria for possible AE is low because these criteria represent the minimal requirements for entry in the diagnostic algorithm for AE.

Criteria for probable AE (-LGI1, -NMDAR, seronegative) and definite autoimmune LE are applicable for decisions on immunotherapy in early disease stage, as specificity is high.

Van Steenhoven RW, de Vries JM, Bruijstens AL, et al.

Mimics of Autoimmune Encephalitis: Validation of the 2016 Clinical Autoimmune Encephalitis Criteria

Neurol Neuroimmunol Neuroinflamm. 2023;10(6):e200148. Published 2023 Aug 15.

doi:10.1212/NXI.0000000000200148

First research from Global Impact Report published

The first research paper inspired by our Global Impact Report is now available to read.

Global Landscape of Encephalitis: Key Priorities to Reduce Future Disease Burden, which was published in July, offers a narrative review of key aspects of brain inflammation, including diagnosis, surveillance, treatment, and prevention of encephalitis.

It also highlights priorities to reduce the disease burden for public health, through clinical management and research.

Dr Ava Easton, Chief Executive of the Encephalitis Society, said: "This is another big step forward in our ambitions to realise the findings of our Global Impact Report.

"A long road lies ahead for us, but we are delighted to have released the first of what we hope will be much more research inspired by the report."

She added: "We are now moving forward with a technical briefing, currently being written by the World Health Organization, with the hope of publishing it during our 30th anniversary next year."

Global Landscape of Encephalitis was authored by Dr Julia Granerod, Dr Yun Huang, Dr Nicholas Davies, Dr Patricia Sequeira, Dr Victor Mwapasa, Dr Priscilla Rupali, Professor Benedict D Michael, Professor Tom Solomon, and Dr Ava Easton.



What is the Global Impact Report?

Encephalitis: an in-depth review and gap analysis of key variables affecting global disease burden is a 180-page document which was published at the beginning of 2021. It is known colloquially as the Global Impact Report

What does the report investigate?

It identifies the issues surrounding encephalitis around the world, ranging from epidemiology, incidence, and economic impacts, through to prevention, diagnosis and treatment, and the needs of patients and families.

What are our aims with the report?

We want to bring together leading global health organisations, public health bodies, and policymakers and develop a global response that will result in preventing and reducing the impact of encephalitis around the world.

Who is involved in the report?

The Encephalitis Society and its scientists authored the report and are driving it forwards alongside interested stakeholders, including the World Health Organization.

To read the full Global Impact Report, as well as the World Health Organization's Why Encephalitis Matters report, visit www.encephalitis.info/global-impact-report

Global Landscape of Encephalitis: Key Priorities to reduce future disease burden

Encephalitis affects people across the lifespan, has high rates of mortality and morbidity, and results in significant neurological sequelae with long-term consequences to quality of life and wider society.

The true incidence is currently unknown due to inaccurate reporting systems. The disease burden of encephalitis is unequally distributed across the globe being highest in low- and middle-income countries where resources are limited. Here countries often lack diagnostic testing, with poor access to essential treatments and neurological services, and limited surveillance and vaccination programs.

Many types of encephalitis are vaccine preventable, whereas others are treatable with early diagnosis and appropriate management. In this viewpoint, we provide a narrative review of key aspects of diagnosis, surveillance, treatment, and prevention of encephalitis and highlight priorities for public health, clinical management, and research, to reduce the disease burden.

Granerod J, Huang Y, Davies NW, et al.

Global landscape of encephalitis: key priorities to reduce future disease burden

[published online ahead of print, 2023 Jul 12]. *Clin Infect Dis.* 2023;ciad417.

doi:10.1093/cid/ciad417.

Recruits needed for research studies

Can your patients help with any of the following research projects? If you can support recruitment to these important studies, please get in touch with the Encephalitis Society or contact the relevant recruiting team directly

A clinical study to evaluate whether rozanolixizumab is effective in treating Leucine-rich Glioma Inactivated 1 autoimmune encephalitis (LGI1 AIE)

AIMS LEGIONE is a 34-week study that is evaluating whether an investigational medication called rozanolixizumab is well tolerated and effective in treating LGI1 autoimmune encephalitis. This drug is also being studied in other conditions that involve the immune system.

INSTITUTION UCB

LOCATION LEGIONE will be taking place at sites in several different countries all around the world (Australia, Belgium, Canada, France, Germany, Italy, Korea, Netherlands, Portugal, Spain, Turkey, United Kingdom, USA). Search for the site closest to you by visitin www.aielegione.com/locations

KEY CRITERIA FOR PARTICIPANTS

- Be between 18 and 89 years old
- Have tested positive for anti-LGI1 antibody
- Have symptoms that started within the last 12 months and include facio-brachial dystonic seizures (FBDS) and/or other partial (focal) seizures, unless they stopped as a result of current intravenous methylprednisolone (IVMP) treatment
- Be considered suitable for treatment with IVMP or have started treatment with IVMP

WHAT IS INVOLVED FOR PARTICIPANTS? The study will take place over 34 weeks and includes screening, study treatment period and safety follow-up period.

Clinical studies are completely voluntary, and participants can leave at any time without losing any benefits they would normally be entitled to.

Participants will be reimbursed for reasonable travel expenses as appropriate.

HOW DO PATIENTS SIGN UP? Discover the closest site and get in touch at www.aielegione.com/locations

A clinical trial to compare satralizumab with placebo in people with autoimmune encephalitis

AIMS The purpose of the CIELO study is to assess the effectiveness and safety of satralizumab in participants with anti-NMDAR and anti-LGI1 encephalitis.

INSTITUTION Hoffmann-La Roche.

LOCATION This trial runs in 11 countries: Argentina, Austria, China, Czechia, Denmark, Italy, Japan, Poland, South Korea, Taiwan and United States

KEY CRITERIA FOR PARTICIPANTS

- Be at least 12 years old and have been diagnosed with anti-NMDAR OR at least 18 years old and be diagnosed with anti-LGI1
- Symptoms started no longer than nine months ago.

Who cannot take part:

- Anyone with a history of cancer or certain other medical conditions, or if they have been treated with particular medications.
- People who are pregnant or breastfeeding

WHAT IS INVOLVED FOR PARTICIPANTS? Everyone who joins this clinical trial will be put into one of two groups randomly and given either satralizumab or placebo as a subcutaneous injection at weeks 0, 2 and 4, and then every four weeks until week 52.

Comparing results from the different groups helps the researchers know whether any changes seen are a result of the drug or occurring by chance. Participants will be seen by the clinical trial doctor every four weeks to be given their clinical trial treatment. These hospital visits will include checks to see how the participant is responding to the treatment and any side effects they may be having.

HOW LONG WILL THE TRIAL LAST? The total time in the clinical trial may last for up to five years (including follow-up appointments). Participants are free to stop trial treatment and leave the clinical trial at any time.

HOW DO PATIENTS SIGN UP? For more information about the study or if you would like to contact a center in your country, visit www.encephalitis.info/cielo

Help us support the global encephalitis community

The Encephalitis Society is the only resource of its kind providing direct support and information to people affected by all types of encephalitis, raising awareness about the condition, and furthering understanding of encephalitis through promoting and collaborating on research.

We are funded entirely by the support of our community, philanthropic organisations, trusts and foundations and our team of global fundraisers – people like you who are committed to supporting us.

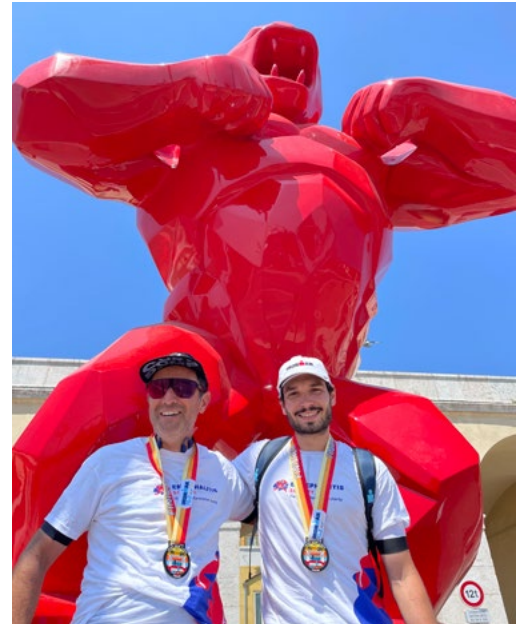
The Encephalitis Society's fundraising team is determined to ensure our services are funded so we can continue to support people around the world who are facing the impact of encephalitis. We are witnessing new and emerging infections that cause encephalitis. For example, we estimate there are over 1.5 million new cases of encephalitis as a result of the COVID-19 pandemic. This increase in demand for our services, coupled with a global cost-of-living crisis that has significantly impacted the Encephalitis Society, means we need your help more than ever!

There are many ways you can support us, both directly and indirectly.

Could you take part in a challenge event for us? Do you know, or work for, an organisation that supports charities? Do you know a trust or foundation the Encephalitis Society can apply for funding from? Do you know an individual who may like to join our Changemakers community?

We are fortunate to have a global community of fundraisers undertaking a range of challenges for us, from sponsored walks and swims through to gaming marathons and birthday fundraisers. We also receive support from corporate partners, trusts, foundations and philanthropists across the world, who ensure the continuation of our support service, sponsor our events and campaigns, and support our appeals and initiatives like Changemakers – which aims to raise £100,000 a year to fund life-saving encephalitis research.

However you may be able to help, it would be amazing to hear from you. Please get in touch!



FLYING DOCTORS... A team from Centre Hospitalier Universitaire de Toulouse recently completed the Nice Ironman to raise awareness of encephalitis



Find out how you can get involved

fundraising@encephalitis.info



**ENCEPHALITIS
SOCIETY**

The brain inflammation charity



FOCUS: COVID-CNS Study

What is COVID-CNS?

The COVID-19 Clinical Neuroscience Study (COVID-CNS) aims to investigate the biological causes of neurological complications, such as stroke, movement disorders, delirium, psychiatric disorders, brain infections and swelling of the brain, in patients hospitalised by COVID-19.

The £2.3m UKRI study is led jointly by researcher from the University of Liverpool and King's College London. Over 800 participants have been recruited from 17 NHS sites across the UK.

Why was it introduced?

Acute neurological and neuropsychiatric complications affect up to 20-30% of hospitalised COVID-19 patients.

During the recent pandemic important questions arose. Why are these patients developing these complications, and others are not? How does COVID-19 get into the brain? Does it cause an excessive immune response? Or interfere with the blood supply to the nervous tissue?

COVID-CNS was initiated to answer these questions, so that suitable patient care and treatments could be chosen and improve patient outcomes.



BRAIN SCANS...Dr Brendan Sargeant, of COVID-CNS

For more information about the COVID-CNS Study, visit

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



COVID-CNS
THE COVID-CLINICAL NEUROSCIENCE STUDY

What are the different working groups?

COVID-CNS has six working groups looking at specific areas linked with brain complications related to COVID-19. The advantage of the working groups is to focus on clinically important questions with experts from different specialties. The working groups are:

NEUROLOGY Aims to evaluate the clinical conditions of brain complications

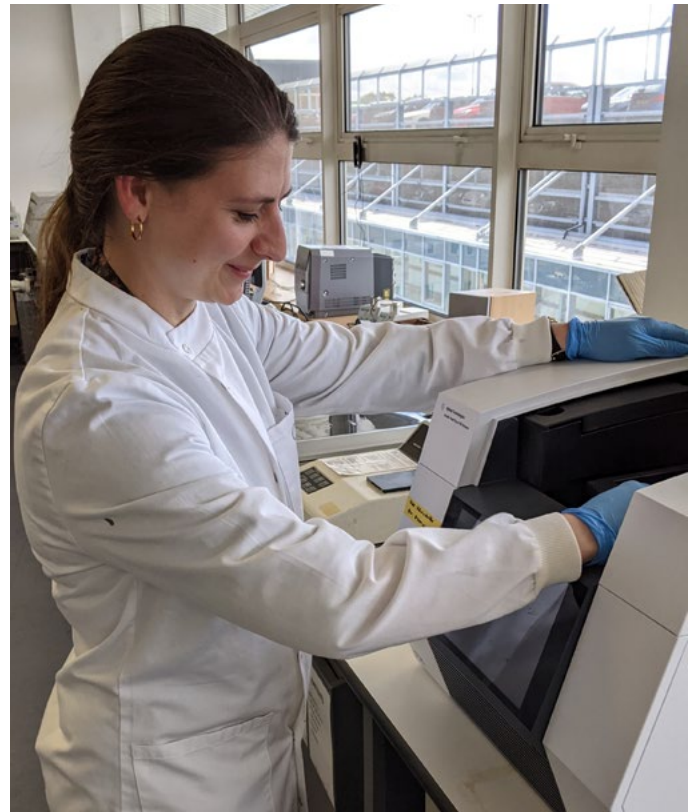
NEUROPSYCHIATRY AND GENOMICS Aims to investigate the range of psychiatric disorders resulting from COVID-19 and their potential mechanisms

NEUROIMAGING Aims to investigate the structural and functional brain changes associated with the neurological and psychiatric symptoms of COVID-19

BIOMARKERS AND IMMUNOLOGY Aims to identify immunological or brain damage-related biomarkers that relate to the development or severity of neuropsychiatric symptoms of COVID-19

NEUROCOGNITION Aims to investigate how COVID-19 affects cognitive function in the brain and nervous system

NEUROVIROLOGY Aims to determine whether there are certain variants associated with neurological diseases of different clinical conditions.



LAB WORK...Dr Cordelia Dunai

What are the findings?

The COVID-CNS study has produced over 45 publications, which are all listed on the COVID-CNS website and provides further information surrounding the study.

The most recent findings have found participants who were previously healthy and developed encephalopathy as a result of COVID-19 infection, presented with a cognitive deficit months after their primary infection. Even at 2-18 months post COVID-19 infection, markers of brain injury (tTau, GFAP, NfL, and UCH-L1) were elevated in the blood; NfL and GFAP were particularly increased in participants with altered consciousness and/or neurological diagnoses. Neurological complications caused by COVID-19 were associated with neuroglial injury, which correlated with uncontrolled immune responses.

Next steps for COVID-CNS?

Using the data collected during COVID-CNS, researchers are working on several ongoing projects focussed on different clinically relevant questions, such as the subset of stroke cases and autoimmune cases.

Following on from COVID-CNS, further work to establish a longitudinal study over three to five years is being carried out. How do complications of the central nervous systems develop in people who have COVID-19? What does this mean for brain recovery on aging brains? What are potential treatments? These are all questions that can be investigated.

How other medical professionals can get involved?

The COVID-CNS study is no longer recruiting patients. However, as COVID-CNS is part of the NIHR BioResource, the data and samples collected is available to researchers' outside of the core team through completing a BioResource Data Access Application Form: bioresource.nihr.ac.uk/using-our-bioresource/academic-and-clinical-researchers/apply-for-bioresource-data

Funders and collaborators



'I have learned to become more compassionate and caring'

Judiel, a nurse from the Philippines, writes about becoming poorly with Anti-NMDAR encephalitis, and the importance of family.

I have been a nurse, here in the Philippines for five years and counting. I am a board topnotcher, working at a JCI-accredited hospital, starting my Masteral, and applying to go to America. With my youth, capabilities, endurance, and dreams - life was limitless. At the age of 25, my life stretched ahead of me.

However, on February 13th, 2021, my life was stolen from me. Everything I had planned and worked for started to vanish. I had no assurance that everything would ever go back to how it was as myself and my identity was lost.

Just before I had started to have severe headaches, fatigue, and fever coupled with the inability to urinate and defecate properly as well as a loss of appetite. My symptoms were so generalized that I was suspected to have COVID, especially as this happened at the height of the pandemic. They also tested for dengue fever, typhoid, spinal cord injury, and even leptospirosis. However, all the tests came back negative, looking at my laboratory results you can see a perfectly healthy woman in her prime years.

It was such a mystery for me, that I felt there was something wrong with me, but I could not decipher what it was. I thought it was all in my head or that the fatigue was making my mind blurry. Maybe I was possessed, or a spell had been put on me to make me sick. I consulted two “manggagamot” (doctors), however, they too could not pinpoint what was wrong with me. After a series of consultations done in the Emergency Room and the Health Clinic, they still could not identify what was causing my symptoms.

On February the 13th 2021 after attending my online class, I started to have delusions and talked as if I was possessed. I was talking nonsense and started having visual distortions – everything looked like an abstract painting. I wanted to talk but I could not put the words into my mouth and my vision was all neon lights with moving objects.

Then I started to scream and howl because of the excruciating pain in my head. I could not understand what my family was saying to me, and I started to become agitated. If you had seen me at that moment, you would have thought I was possessed by evil demons like the ones in Halloween specials. My family, even my sister who is a nurse, did not know what to do with me so they took me to the nearest hospital, and they diag-



nosed me as a psychiatric patient.

My mother, who is an advocate of mine insisted that I was not a psychiatric case. She did not know what was wrong with me, but she knew in her heart that it was not something psychiatric. So, she told my sister to take me to the hospital where I worked. She thought that whatever my diagnosis they would accept me as I worked there. However, when we arrived at the emergency department I was endorsed as a psychiatric case, but they wanted to focus on the high temperature I had. They said they would let my fever go down first and then admit me for psychiatric treatment.

I cannot remember what happened that next morning on February the 14th, apart from my mom telling me to please go to sleep.

Then I woke up on April 21st, 2021. I could not do simple things such as reading, counting, and writing. I could not remember my family; I could not remember who I was. I felt like I was a child trapped in a 25-year-olds body as I needed to re-learn all the things that I knew before. My family told me I had been in a coma for almost two months meaning I had missed my sister's and father's birthdays as well as class and work for a long time.

Please know that we are here for you if you need us. Get in touch with our support team on support@encephalitis.info or +44(0)1653 699599.

PATIENTSTORIES

They also told me that I had been diagnosed with Anti-NMDA autoimmune encephalitis. It is an autoimmune disease causing my immune system to attack the brain causing inflammation. Even tests to confirm such disease must be sent to foreign countries such as France.

Luckily my family was able to get a very capable and smart neurologist. Immediately after being admitted to the hospital, I had lots of tests done and every common disease was ruled out. Therefore, he started possible treatments for brain inflammation because by looking at my ECG you could see continuous seizures as if my brain was being “fried”. They gave me all the antibiotics, anti-viral medication, and even antipsychotic medications they could, but I showed no improvement.

They, then, decided to send my lumbar tap sample to France however this was going to take a month to come back so my neurologist decided to give me steroids, IV IG, and then Rituximab. These treatments posed a great risk to me as they make your immune system low, and we were in the middle of a surge of COVID infections.

Then a miracle happened – I woke up. I was so disoriented and unaware of who I was. Slowly after one month of rehab, I was able to regain my personality. I was able to write, read, count, walk, and go back to my normal life. After two weeks out of confinement, I was able to go back and work as a nurse.

My story might not be the most exciting thing you will read, however, my story showed that in the end no matter how successful or strong you are as a person you will be tested. With my experience, I learned to value the importance of slowing down, especially at this moment when everybody is busy with achieving timelines that have been put in by society.

Slowing down or resting does not make you less of the person you dream to be.

Also, I learned the value of family, at the end of the day, your



family will be the remedy for any problem you have in your life. They are persons in this world who are willing to sacrifice what they have and give the most unconditional love in this world. Lastly, I have learned to become more compassionate and caring as a nurse because my life now has a different purpose.

It is not just a life for me to live but it is in my responsibility to make the gift of life a meaningful one.

Help to light up a landmark

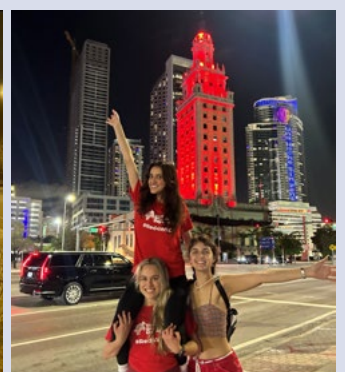
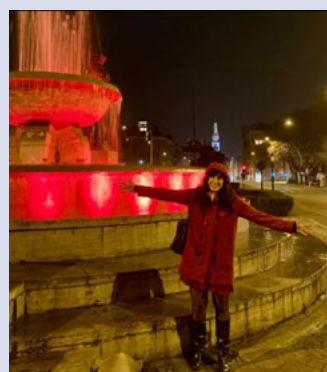
Will you help us turn the world red on the 22nd February, 2024?

On World Encephalitis Day, we are once again aiming to light up as many global landmarks red as possible.

Last year, we smashed our target and ended up with 249 landmarks in 29 countries supporting our annual awareness campaign, including Niagara Falls, the CN Tower in Toronto, Sydney Olympic Park and Piccadilly Lights in London.

However, if we are to top that figure next year, we will need your support.

Dr Ava Easton, our Chief Executive, said: "Lighting up so many landmarks is a huge undertaking for our team and therefore we would love you to identify any landmarks in



the town or city in which you live and ask their operators to support World Encephalitis Day. We have resources which can help, including a toolkit and a template letter, while the team are also happy to answer any questions you may have."

For more information, visit www.encephalitis.info/wed-landmark or email red4wed@encephalitis.info

Guides for patients

The Encephalitis Society provides wide range of information resources which can help patients and their recovery from encephalitis. These resources can be downloaded from our website. Hard copies are also available from our shop or by contacting our support team. All of our resources are free, although postage and packaging may apply.

Encephalitis in adults. A guide

"Encephalitis in Adults: A Guide" is a comprehensive resource designed to offer support and information to individuals affected by encephalitis, as well as their families and friends. This guide encompasses various aspects of encephalitis in adults, serving as a valuable reference for people at different stages of their journey with this condition.

Encephalitis, a complex neurological disorder, not only impacts the affected individual but also extends its effects to family, friends, and even the broader community, including school or workplace environments. Recognizing the far-reaching consequences of encephalitis, this guide aims to provide a holistic understanding of the condition and its implications.

The content of this guide covers a wide spectrum of topics, including a detailed description of encephalitis in adults, the diagnostic process, and the management of the acute phase of the illness. It also delves into the effects of encephalitis, emphasising the challenges faced during recovery and rehabilitation.

While the guide is accessible to individuals worldwide, it is essential to note that certain sections, such as information regarding specific organizations and legislation, pertain primarily to the United Kingdom or specific regions within the UK.

The British Medical Association (BMA) has recognized the value and quality of this guide, marking it as highly commendable. This recognition underscores the credibility and reliability of the information it provides.

Whether you are an individual directly affected by encephalitis, a concerned family member, a friend offering support or a professional seeking insights into this condition, "Encephalitis in Adults: A Guide" stands as a vital resource. You can access a downloadable PDF version of the guide or request a paper copy from our office.

Visit: www.encephalitis.info/encephalitis-in-adults



Encephalitis: after-effects, recovery and rehabilitation

This booklet provides essential information on various aspects of encephalitis, including its effects on individuals, the process of recovery, and the importance of rehabilitation.

Moreover, it offers practical strategies to help individuals cope with the most common difficulties associated with this condition. It aims to be a resource for those affected by encephalitis, their caregivers, and healthcare professionals, offering guidance on managing and improving the quality of life during the recovery and rehabilitation journey.

Visit www.encephalitis.info/encephalitisafter-effects-recovery-and-rehabilitation

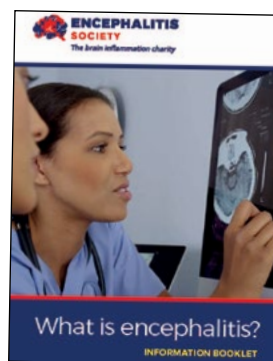
What is encephalitis?

This booklet aims to provide key information about encephalitis, including details on its symptoms, methods of diagnosis, available treatment options, its effects on individuals, and the process of recovery.

By offering this comprehensive overview, the booklet serves as an introduction to encephalitis and its impact on health and well-being.

What is Encephalitis is available in English, German, and Welsh.

Visit: www.encephalitis.info/what-is-encephalitis



Know Your Rights. Neuro-Legal Handbook

This booklet is designed to provide essential information on a range of legal topics.

Its primary audience is individuals who have encountered challenges in obtaining an accurate diagnosis, accessing appropriate treatment, securing support for their recovery or obtaining educational assistance within the United Kingdom.

Visit: www.encephalitis.info/legal-advice

Factsheets

The Encephalitis Society provides a wealth of information to support individuals and their communities affected by encephalitis. Our extensive collection of factsheets is designed to serve a diverse audience, including those directly impacted by encephalitis, their families, friends, caregivers, and healthcare professionals. These factsheets offer valuable insights into encephalitis and its far-reaching consequences.

Our information resources are accessible in various formats to suit your preferences. You can access them electronically through our website, including web pages and downloadable PDFs in the Encephalitis Explained section. If you prefer a printed copy, you can request one from our office.

Our factsheets cover a broad spectrum of topics related to encephalitis, including symptoms, diagnosis, treatment, and the different types of encephalitis. Moreover, we delve into the profound effects of encephalitis on cognitive, emotional, behavioural, physical, and social aspects of life. We also provide guidance on the challenging process of returning to work or education after experiencing encephalitis.

These resources aim to empower individuals and their support networks with knowledge and insights, helping them navigate the complexities of encephalitis and its aftermath with confidence and understanding.

For a full list of our factsheets, please visit: www.encephalitis.info/factsheets

Understanding Encephalitis Animations

Thanks to a generous grant from the UK's National Lottery Community Fund, our nine-part series of films has been translated from English into the following languages: Hindi, Polish, Punjabi, Tagalog, and French.

This development represents a significant milestone in our mission to make vital information about encephalitis more accessible to diverse communities worldwide. We are committed to expanding the reach of our "Understanding Encephalitis" animations further. In the pipeline is the translation of these valuable resources into German, enabling access to an even wider audience.



To explore and share these informative animations, we invite you to visit www.encephalitis.info/patient-resources



Meet the Scientists: Professor Tom Solomon

Name:

Professor Tom Solomon CBE FRCP FMedSci

Occupation:

Neurologist at Columbia University Irving-Medical Center in New York City. Clinically, I work as a Neurohospitalist (inpatient neurologist). I am also a Neuroinfectious Diseases and Global Health researcher.

When did you know you wanted to pursue a career in science?

I didn't! At least not at first! When I was a child, being a scientist meant being someone like Professor Brainstorm – the guy on TV. I wanted to be a doctor, and it was only once I started my medical training that I realised you could do research alongside. There were some really inspiring professors, who were brilliant clinicians also doing amazing research that saved countless lives. So I became interested. But we were told at medical school that most students would become general practitioners, so I never thought I would end up as a scientist.

Where did you study?

I studied medicine in Oxford. Some of my friends started doing laboratory research alongside their clinical training, but that

struck me as rather dull! I wanted to travel to Thailand but was short of cash. One of the professors suggested that if I visit the university's research unit there, I might be able to get some funding to go. I can still remember the thrill of opening the letter from the Anglo-Thai Association, saying they would pay my flight. In Thailand I spent time with the extraordinary Professor Sir Nick White, which had a massive influence on my future direction. I saw the enormity of some of the tropical medicine problems, especially brain infections, and how much scope there was to make a difference. We also had a lot of fun.

For my medical student elective in 1990, I did malaria research in war-torn Mozambique, which somehow resulted in two *Lancet* publications. After four years as a junior doctor, I returned to Southeast Asia, Vietnam, with a 4-year Wellcome fellowship to study encephalitis. Next I started my specialist neurology training in Liverpool, before two years at the University of Texas Medical Branch in Galveston, thanks to more Wellcome funding. Here I studied some of the viruses I had isolated from the patients in Asia. It was much more interesting being in the lab when you were working on samples from your own patients. Returning to the UK in 2003, we set up the Liverpool Brain Infections Group, and started researching not just tropical viruses, but also UK brain infections.

MEET THE SCIENTISTS



Prof Solomon speaks at Encephalitis 2022

What is your area of expertise and how did you choose your field of study?

My expertise is in brain infections, especially those which are emerging viruses. But I did not really choose my field of study, it chose me! I thought I would be studying malaria in Vietnam, but it turned out the patients had Japanese encephalitis. This was an emerging infection, though the term was not widely used at the time.

The Liverpool Brain Infections Group aims to reduce the burden of neurological infections through a range of approaches, from understanding the basic disease processes through developing diagnostics and treatments, and implementing public health programs such as vaccinations.

In 2010, The University of Liverpool made me director of the new Institute of Infection and Global Health, which was my first senior leadership role. When the UK government wanted to establish a new emerging infections research unit, we were well-placed to win the competition; I became the director, and my interests expanded from brain infections to other emerging infections. The unit led a lot of the UK research response to Ebola, Zika, and Covid-19. In 2021 we established The Pandemic Institute in Liverpool bringing together the main academic institutions, hospitals, and civic authorities to tackle emerging infections and future pandemic threats, and I am quite busy now leading that.

What inspires you in the workplace?

The inspiring thing about being a clinical academic is that whereas in clinic you can only help one patient at a time, through research you can have a massive impact on countless lives around the world. Having said that, when things are not going well with the research, maybe because a result was not as expected, or a grant application has been rejected, then it can be really humbling to spend an afternoon in clinic helping people! The bravery of some of our patients and their families, especially those with encephalitis, can be really inspiring.

I am also inspired to see the younger researchers I have supported, especially the women and those from different backgrounds, come through and develop their own careers to



Prof Solomon leads his Roald Dahl's Marvellous Medicine children's show

become brilliant clinical scientists. One of my first PhD students is now Vice-Chancellor of a University in Africa! I am the International Vice President of the UK Academy of Medical sciences where we put a lot of effort into strengthening training and capacity-building with overseas partners.

Is there anything that can be frustrating about research?

It can be frustrating to see some of our greatest advances, for example vaccines, not fully taken up because of misinformation and distrust. Engaging with the public is key here. My first foray into science communication was as the "Running Mad Professor" at the London marathon raising awareness and money for the Encephalitis Society. I now do quite a bit on television and radio. I also wrote a book, Roald Dahl's Marvellous Medicine, describing his fascination with medicine, including his passionate advocacy for vaccination after his daughter died of measles. I created a show, based on the book, for the Edinburgh festival which completely sold out.

In your opinion, are any changes needed in the scientific system to be more attractive to potential future scientists?

We have to get more people from different backgrounds involved in science, especially at an earlier stage; and they need role models. The pandemic has highlighted the importance of science, and some of the brilliant people involved. We now have to capitalise on that, especially in schools.

What advice would you give to people considering a career in science?

Go for it! You'll meet some incredible people, have lots of fun, see the world, and with a bit of luck, maybe even make an important contribution. For those already pursuing a career in science I would say follow your interests, and do not worry too much about a long-term plan. If you get too fixated on this, you will probably miss interesting opportunities along the way. There will be some knocks and disappointments, but ultimately it can be a fantastically rewarding career.

Not in the UK? Not a problem!

Our service-users, our work
and our reach are global!



SUPPORT AND INFORMATION

Our **support helpline** team are available via email, Zoom, phone and online chat. www.encephalitis.info/support

Our information on diagnosis, treatment, recovery and rehabilitation along with a lot of more interesting resources is at your fingertips.

We produce all our **information** in English but our website uses Google Translate and we have key resources translated into a variety of languages.

Want to **meet with others** like you? Simple! We have a range of in-person and online forums:

www.encephalitis.info/meetothers



RESEARCH AND WORKING WITH ACADEMIC, CLINICAL AND RESEARCH PARTNERS

Become a professional member to hear all about our encephalitis research updates, grants and funding, and receive our highly sought-after annual Encephalitis Research Summary!

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We replicate our fantastic My Brain and Medicine patient event with academic or clinical institutions around the world – just email us on research@encephalitis.info to discuss your needs.

We can also work with you to include an adjunct in-country symposium for professionals at your institution!

And much, much, more!

Email: research@encephalitis.info

AWARENESS

Want to help us raise awareness of encephalitis? Then why not get involved with World Encephalitis Day on 22nd February every year!

www.worldencephalitisday.org



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