THE NEWSLETTER FOR PROFESSIONALS INTERESTED IN **ENCEPHALITIS**

CONNECT PROFESSIONAL

EDITION 11 **SUMMER 2023**

ENCEPHALITIS SOCIETY

The brain inflammation charity

WWW.ENCEPHALITIS.INFO

WELCOME

Welcome to the latest edition of Connect Professional.

It barely seems like yesterday that we were putting the finishing touches to the last edition of our magazine, such has been the speed at which 2023 has seemingly flown by.

And what a six months it has been! We have so much to reflect upon and look forward to for the rest of the year.

We write this at a significant time in the history of the United Kingdom, just days after the Coronation of King Charles III.

The Encephalitis Society was fortunate to enjoy an audience with His Majesty when he visited our hometown of Malton, North Yorkshire, in April (See Page 3). His Majesty showed a great interest in our work and it was a honour to have the opportunity to spend a few minutes with him.

Much of our good news begins, as always, with our Scientific Advisory Panel. We have welcomed six new members to our professional panel who we believe will add so much to our work in the future (See Pages 4 and 5).

Research was at the heart of the 10th annual World Encephalitis Day in February. The release of some ground-breaking research about the mental health impact of encephalitis was firmly at the heart of our media campaign which reached over 111 million people worldwide (See pages 18 and 19).

We must take this opportunity to thank everyone who took part in World Encephalitis Day this year. It was inspiring to have so many people wearing red or taking time out of their busy schedules to ensure a building or landmark went #Red4WED.

World Encephalitis Day also saw the release of Why Encephalitis Matters which looks at the growing threat of encephalitis, the challenges we face, and potential solutions. This was the cherry on the cake that was our 2023 campaign and we urge you to find the time to read the full report (See Page 7).

Looking ahead, by the time you receive this newsletter, Encephalitis Research Month will almost be upon us (See Page 8). We need your support with this online campaign - whatever you can to help us raise awareness or money to help young researchers would be most welcome.

Finally, we are now turning our attention to Encephalitis 2023. The keynote and guest speakers are now confirmed and we are putting the finishing touches to the rest of the events for the conference in December (See Pages 9 to 11).

It is important to note that the Call for Abstracts is now open and we are also welcoming bursary applications for professionals from low-and-middle income countries.

Finally, for professional members of the Encephalitis Society, we are delighted to say there is a 20 per cent discount on the cost of a ticket.

We hope to see you there!

Dr Ava Easton
Chief Executive
Encephalitis Society
@encephalitisava

Dr Nicholas Davies
Chair - Scientific Advisory Panel
Encephalitis Society

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Registered charity number (England and Wales): 1087843

Registered charity number (Scotland): SCO48210

Registered company number: 04189027

#ThirdSectorAwards
Fundraising Team of the Year category
Shortlisted 2022
ThirdSector Awards
ansvar

2022
charitytimes Awards
Recognising leadership and professionalism
Winner

Pictured overleaf: King Charles III talks to Adele Mackinlay and Phillippa Chapman from the Encephalitis Society

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Society's Royal appointment

The Encephalitis Society was invited to meet King Charles III during his surprise visit to our home town in April.

The King and the Queen Consort visited Malton in North Yorkshire on Wednesday, 5th April, where they spoke to representatives from several local businesses and charities.

Phillippa Chapman, our Deputy Chief Executive, and Trustee Adele Mackinlay, had the the honour of representing the Encephalitis Society.

"It was a delight to meet His Majesty," said Phillippa. "He was very friendly and very interested in finding out more about encephalitis."

Phillippa spoke to His Majesty about how the Encephalitis Society provides support, our work in low-and-middle income countries, and the impact of climate change on encephalitis globally.

ROYAL CONVERSATION... King Charles III talks to Adele Mackinlay, left, and Phillippa Chapman

“It was all a bit of a blur but very exciting and memorable for both Adele and I and, most importantly, wonderful for the Encephalitis Society.”

Phillippa added: “We are very grateful to Jo Ropner, the Lord Lieutenant of North Yorkshire, who put our name forward to be one of the charities invited to meet King Charles III."

A copy of Dr Ava Easton's book, Life After Encephalitis, was also requested for King Charles III.

Seed funding available

Two grants of up to £10,000 are being offered to researchers based in Europe, thanks to the Encephalitis Futures – International Research Seed Funding project.

Now in its fourth year, the funding from the Encephalitis Society is designed to encourage innovative research projects into encephalitis.

It is open to applicants of all levels, from medical students, junior doctors and early researchers, through to anyone returning to research, post-doctoral researchers and equivalent professionals from any European country.

“Our seed funding grants are aimed at researchers who are looking to develop a smaller or pilot project and then go on to secure future funding for potential large-scale projects,” said Dr Ava Easton, Chief Executive of the Encephalitis Society.

“Since its launch, we have awarded £59,914 to six researchers from five countries, including a number of grants going to early career researchers in resource-limited settings.

"We see this funding as being an important step in meeting our aim of improving the quality of life for all people affected by this often-devastating condition.”

We will be emailing our Professional Membership with more information during Encephalitis Research Month in June.

Webinar ticks all the boxes

Tick-borne encephalitis was the topic of our second online Masterclass in April.

Our panel of speakers covered all aspects of the condition, including its epidemiology, prevention, diagnosis, vaccination, outcomes and travel health.

The webinar attracted 443 attendees from 47 countries.

Dr Ava Easton, Chief Executive of the Encephalitis Society, said: "We are very happy with the level of interest in the Tick-borne encephalitis Masterclass from around the world. It tells us there is an appetite for webinars of this nature.

"We are currently busy working on plans for future Masterclasses, so watch this space."

Meet the professionals

Several new experts have joined the ranks of our Scientific Advisory Panel over recent months.

It now means the Encephalitis Society has a 24-strong panel of world leaders covering neurology, neuropsychology, epidemiology, neuropsychiatry, and neuroimmunology, among other related fields.

"We are delighted to add so many accomplished health professionals to what was already a great team," said Dr Ava Easton, our Chief Executive.

"Our Scientific Advisory Panel is now the strongest it has ever been, featuring a who's who of global experts in all areas of encephalitis research.

"They will now be meeting to exchange information and progress research into encephalitis with the aim of improving diagnosis, treatment and after-care for patients."

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

Professor Frank Leypoldt

Neuroimmunology
Institute of Clinical Chemistry and Laboratory Medicine,
Department of Neurology,
Kiel University, Germany

Professor Leypoldt is currently Head of the Department of Neurology at the University-Hospital Schleswig Holstein, Kiel. He is a speaker and Principal Investigator in a large collaborative German research project (GENERATE) and European research initiative as well as part of the European and German guideline committees.

During the past 10 years, he has studied causes, phenotypic spectrum, mechanisms and treatment of autoimmune encephalitis (AE), viral triggers of brain autoimmunity, passive infusion animal models of AE, cerebrospinal fluid (CSF) and serum diagnostics, overlapping syndromes of AE and demyelinating diseases, CSF biomarkers, on brain metabolism and comparative genetic predisposition in AE and treatment response.

Dr James Sevjar

Neuroepidemiologist,
Division of High-Consequence Pathogens and Pathology
National Center for Emerging and Zoonotic Infectious Diseases,
Centers for Disease Control and Prevention,
USA

Dr Sevjar leads the Neuroepidemiology Unit at the Center for Disease Control and Prevention's Division of High-Consequence Pathogens and Pathology.

He is board-certified in neurology, with an area of focus in infectious diseases. His current research focus centres on the epidemiology, pathogenesis, clinical features, and outcomes of infections of the nervous system, including encephalitis.

Dr Sevjar is also an Assistant Professor of Medicine at Emory University School of Medicine, Atlanta, USA, and Consultant Neuroepidemiologist at Duke-NUS Graduate Medical School, Singapore.

LATEST**NEWS**

Professor Carsten Finke

Heisenberg Professor for Cognitive Neurology,
Consultant Neurologist,
Department of Neurology,
Charité Berlin, Germany

Professor Finke is a faculty member of the Berlin School of Mind and Brain and member of the Einstein Center for Neurosciences, Berlin.

He is also a founding member and member of the scientific council of the German Network for Research on Autoimmune Encephalitis (GENERATE). His research focuses on cognitive deficits and associated brain imaging alterations in neurological disorders with a specific interest in neuroimmunological diseases, especially autoimmune encephalitis. The aim of this research is to identify early (imaging) biomarkers that help to improve the diagnosis and treatment and, ultimately, the outcome of these disorders.

His group uses a broad range of methods, including advanced structural and functional MRI studies in humans and animal models, comprehensive neuropsychological assessments as well as immersive and non-immersive virtual reality setups.

Dr Matteo Gastaldi

Neurologist,
Neuroimmunology Research Unit,
IRCCS Mondino Foundation
Pavia, Italy

Dr Gastaldi is a neurologist specialising in the treatment of antibody-mediated disorders of the nervous system, including autoimmune encephalitis.

He is the Head of the Neuroimmunology Research Unit in Pavia and the Co-head of the Neuroimmunology Diagnostic Laboratory. He is also involved in patient care and once a week attends a neuroimmunology clinic dedicated to patients with antibody-mediated disorders of the nervous system.

Assist Professor Kiran Thakur

Winifred Mercer Pitkin Assistant Professor,
Columbia University Irving Medical Center,
New York, USA

Assist Professor Thakur leads the program in Neuroinfectious Diseases at Columbia and is the Director of the Post-Doctoral Fellowship Program in Neuroinfectious Diseases.

She has a specialised interest in emerging and re-emerging neurotropic infectious diseases and collaborates with scientists globally on the surveillance, diagnosis, and management of neuroinfectious diseases.

In addition to her scientific efforts, Assist Professor Thakur serves as a neurology consultant for the World Health Organization and the Center for Disease Control and Prevention's Clinical Immunization Safety Assessment project on COVID-19 Vaccination safety.

Assoc Professor Maarten Titulaer

Associate Professor of Neurology,
Co-director Academic Center for Neuro Inflammatory Disorders,
Erasmus University Medical Center,
Rotterdam, the Netherlands

Assoc Professor Titulaer runs a national reference clinic for the diagnosis and treatment of autoimmune encephalitis.

In his current role at Erasmus University Medical Center, he combines epidemiological studies of large cohorts with detailed analysis of individual patients. His aim is to provide individual treatment options, based on patients' signatures extracted from precise phenotypes, including validated biomarkers, and relevant knowledge of pathophysiological mechanisms.

From Malawi to Malton: Doctor's special HQ visit

A doctor shared his perspective of working in Malawi during a special visit to the Encephalitis Society.

Dr Gareth Lipunga, who is studying for an MA in Integrated Immunology at the University of Oxford, spoke to the team about his work, neurology, health care and the impact of encephalitis in the southeastern African country at the end of March.

He was invited to our headquarters in Malton, North Yorkshire, by Dr Ava Easton who had worked alongside him with the Brain Infections Global research group in Malawi in 2020.

“I was delighted that Gareth could join us and talk about his work and the health system in Malawi,” said Ava. “It gave the team a fascinating insight into the challenges he and his colleagues face as well as some of the solutions that are being introduced.

“It also helps us as an organisation to understand what we can do to help anyone from Malawi who contacts us for support.”

Malawi, which has a population of approximately 18 million people, is a lower-middle income country which provides public health care to the public.

“Healthcare is free, but resources are few because of the size of the population,” said Dr Lipunga, adding that there is only one doctor for every 20,000 patients, only two neurologists in the whole of Malawi, one for adults and another for paediatrics, and a need for infectious diseases clinicians.

“We have a number of clinical challenges. There is a varying skillset and knowledge across healthcare workers, a high workload for everyone and limited lab diagnostics.”

He also pointed to the costs associated with administering Aciclovir, which is used to treat suspected viral encephalitis.

HOUSE CALL... Dr Gareth Lipunga (inset) and with the Encephalitis Society team

“Aciclovir costs £3 a dose and a patient needs three-to-four doses per day. That is £15 a day, which when you consider the average Malawi earns £1.50 a day, per family, is a cost barrier.”

There is hope, however.

He spoke about the work of Brain Infections Global, the £2 million scheme which is aiming to improve the management of acute brain infections in Malawi, India and Brazil.

Led by Professor Tom Solomon CBE, President of the Encephalitis Society, among many others, it has introduced lumbar puncture packs, clinical training and algorithms into Malawi hospitals, helping health professionals to diagnose patients.

“We have also introduced Brain Infections Champions as someone who advocates for people with brain infections. So, if we do the simple things well and continue to make small strides, we will have a broader effect on health care for people with a brain infection.”

Brush up on your neurology skills with the NeuroPRACTICE team

Are you looking to refresh your knowledge of neurology in clinical practice?

NeuroPRACTICE on Friday, 7th July, is an intensive one-day update on the latest in management of common neurological presentations. The course will focus on the key skills required for clinical assessment, investigation, and management of common neurological and neurosurgical presentations.

The course, organised by the University of Liverpool's Neurosciences Research Unit, is aimed at primary and secondary care healthcare professionals and relevant to anyone seeing common neurological presentations (including GPs, ANPs, A&E doctors, junior doctors and more).

Topics that are discussed in the course generally cover

- Chronic pain and fibromyalgia
- Tingling and numbness
- Dizziness
- High yield neurological examination
- Clusters and hemicranias

NeuroPRACTICE takes place at The Walton Centre, Liverpool, L9 7LJ on Friday, 7th July.

SIGN UP TODAY: www.liverpool.ac.uk/neurosciences-research-unit/neuropractice

A growing global threat

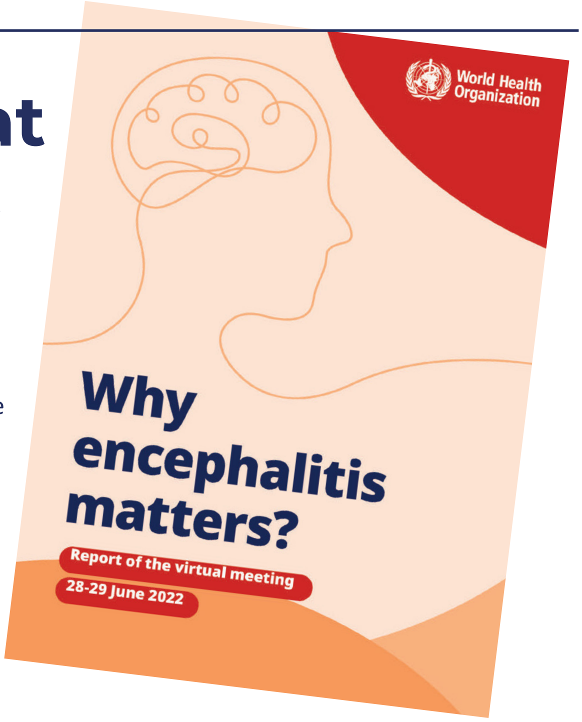
Ambitions to tackle the global impact of encephalitis took a big step forward with the release of a crucial new report from the World Health Organization (WHO) on World Encephalitis Day.

Why Encephalitis Matters, a wide-ranging report from a June 2022 meeting involving representatives from the WHO, Encephalitis Society and other organisations, looks at the growing threat of encephalitis, the challenges we face, and potential solutions.

It follows on from last year's publication of the Global Impact Report, which was put together by the Encephalitis Society and its scientists.

In future editions of Connect, we will look at different aspects of the report, beginning with the reasons why encephalitis is a growing global threat.

The following stats are all taken from the Why Encephalitis Matters report.*



Encephalitis affects almost 500,000 people globally annually – although scientists believe this to be an underestimated figure due to inaccurate reporting systems. Encephalitis can be caused by more than 100 organisms.

Encephalitis has high fatality rates

The mortality rates can vary depending on the cause, but can be as high as up to 40% in some types of autoimmune encephalitis.

Why is encephalitis a growing global threat?

This is due to:

- increased population density in under resourced communities
- intensive farming practices
- vaccine hesitancy
- increasing identification of autoimmune causes
- climate change
- low socioeconomic status
- a significant risk of outbreaks associated with emerging and re-emerging viral causes of encephalitis

Encephalitis has an impact on survivors and their families

- Developmental delay (35%), abnormal behaviour (18%), cognitive impairment (17.5%) and motor impairment (17%) have been reported in children
- Up to 62% of adults may suffer neurological sequelae, including epilepsy, memory problems, behavioural issues, fatigue or sleep disturbance, personality changes, cognitive impairment, pain and abnormal sensations, motor impairment, movement disorders and challenges with daily living skills
- 4.8 million disability-adjusted life years globally**
- High costs, time consuming and poor mental and physical health for carers

The cost impact of encephalitis

Owing to its high morbidity and mortality, encephalitis is associated with significant costs to individuals, the health system and society.

The costs can vary depending on location, but can be high as US$ 2 billion/hospitalisation annually in the USA.

Coming in the next edition of Connect Professional: challenges in diagnosis and access to treatment.

The Why Encephalitis Matters report can be read at www.encephalitis.info/global-impact-report

*World Health Organization. (2023). Why encephalitis matters? Report of the virtual meeting, 28-29 June 2022. World Health Organization. https://apps.who.int/iris/handle/10665/366223. License: CC BY-NC-SA 3.0 IGO

**Disability-adjusted life years are calculated by adding the years of life lost due to premature death and the years of healthy life lost due to disability

Encephalitis**Research**Month

JUNE 2023

ENCEPHALITIS RESEARCH MONTH

investing in hope

June is Encephalitis Research Month - and we need your help!

Launched in 2019, this campaign is designed to highlight the need for more funding into encephalitis research.

As many of you know, there is a funding gap in research into encephalitis compared with other neurological conditions.

This is despite encephalitis having a higher incidence rate in many countries than other neurological conditions, such as multiple sclerosis/ALS, bacterial meningitis, motor neurone disease and cerebral palsy.

Throughout June, we will be talking online about all things encephalitis research - from the current state of encephalitis research, through to success stories, profiles of leading researchers, events, what lies ahead for the future of encephalitis research, and much more.

Our hope is to inform both the general public and medical and health professionals, and we would love your support no matter how big or small.

How Can I Get Involved?

Support us on social media

We will be posting about different aspects of research throughout June. If you see one of our posts, please share or retweet it!
Follow us on Twitter: @encephalitis

Become a Professional Member

We want to continue to build our Professional Membership in order to increase global awareness of encephalitis, save lives and build better futures by driving research.
If you are not a member of the Encephalitis Society, sign up for free today at www.encephalitis.info/professional-membership

Make a donation

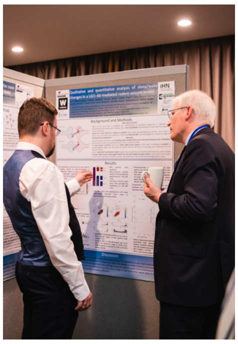
During June, we hope to raise £20,000 to help us fund our research grant schemes.

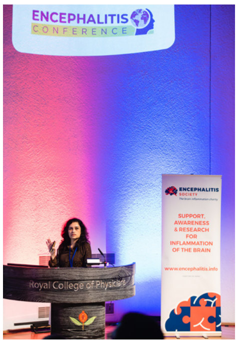
We have partnered with The Big Give so for every £1 that is donated, we will receive another £1 towards our Encephalitis Research Month appeal.

Any money raised will go towards our projects that support young researchers around the world, including:

- Encephalitis Futures International Seed Funding Programme
- Medical Research Council joint-funded clinical research training PhD Fellowship
- Academic Clinical Fellowship
- International research exchange projects

Find out more and make a donation today: www.encephalitis.info/Big-Give





Encephalitis 2023: All you need to know

Tickets are now available for Encephalitis 2023.

Our conference will once again be hosted by the Royal College of Physicians in London on the 4th and 5th of December - with attendees also having the option to join us online.

With six months to go, we have taken great strides towards finalising the 2023 programme.

Already confirmed are the keynote and guest speakers, the debate topic and satellite meetings.

Brand new for 2023 is a Breakfast Meeting where two guest speakers, including Professor Sarosh Irani, will offer a clinical introduction to both autoimmune encephalitis and infectious encephalitis.

Meanwhile, the Call for Abstracts is now open and we have three travel bursaries and a number of free online tickets available for health professionals from low-and-middle income countries.

We hope you can join us!

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.

FREE PLACES: We have a limited number of free places for professionals from low-and-middle income countries. Please select LMIC Attendance in-person/virtual tickets when registering.

Encephalitis 2023: At a glance

ABSTRACT WINNER... Dr Marie Vermeiren and colleagues from Erasmus University Medical Center, Rotterdam

Call for Abstracts - now open!

We are now inviting abstracts for Encephalitis 2023.

Abstracts should be related to encephalitis and will be considered in any field or subject area with cash prizes for the winning presentations.

All abstracts will undergo peer review by the Scientific Panel Conference Sub-Committee and may be accepted for:

ORAL PRESENTATION - refers to abstracts accepted for oral presentation at the podium on the 5th December.

POSTER PRESENTATION - poster presentations will be displayed at the conference and in the booklet distributed to all attendees.

Posters may also qualify for a presentation during the Data Blitz Satellite Meeting on the 4th of December.

Please submit your abstract by the 15th July.

Visit www.encephalitis.info/abstracts

New!

Breakfast of champions

Are you interested in enjoying something substantial for breakfast on the morning of the conference?

We will have two talks offering a basic clinical introduction to infectious and autoimmune encephalitis.

They will be led by Professor Sarosh Irani, Head of the Oxford Autoimmune Neurology Group, and Professor Benedict Michael, Director of the Infection Neuroscience Laboratory at the University of Liverpool.

The talks can be joined in-person or online and are included with the conference ticket.

Professor Sarosh Irani

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

Satellite meetings kick off conference

Encephalitis 2023 begins on Monday, 4th December, with an afternoon devoted to supporting the next generation of researchers.

Our 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 Associate Professor Deanna Saylor, this workshop is aimed at researchers from junior to intermediate level who are beginning their research 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

There will also be an opportunity to hear from clinical academics who have been successful in securing funding in both high and medium-to-low income countries.

SCIENTIFIC PANEL... Professor Arun Venkatesan and Professor Benedict Michael

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.

Debate to pose autoimmune encephalitis question

REFEREE... Dr Thomas Pollak

The gloves will come off with the return of the much-anticipated Debate at Encephalitis 2023.

This year's topic, which will be debated on the 5th December, is: "This house believes that too much time and money is being spent identifying new antibodies in autoimmune encephalitis."

Dr Thomas Pollak, of the Institute of Psychiatry, Psychology and Neuroscience, King's College London, has the honour of chairing what will undoubtedly be a heavyweight meeting of minds.

Bursaries to support doctors from low and middle-income countries

Three bursaries are available for health or medical professionals from low and middle-income countries who want to attend Encephalitis 2023 in London.

Each bursary includes:

- financial assistance for travel and subsistence;
- three nights' accommodation in London;
- free entry to the satellite meetings and the conference

Applications for bursaries must be submitted by the 30th June. Apply today at www.encephalitis.info/conference-bursary

For anyone who is unable to join us in London, we also have a number of free places for health and medical professionals from low and middle-income countries.

Please select LMIC Attendance in-person/virtual tickets when registering for a ticket via www.encephalitis.info/conference

FOCUS: Karolinska Institute

Associate Professor Federico Iovino writes about the work of the Iovino Laboratory at Karolinska Institute's Department of Neuroscience

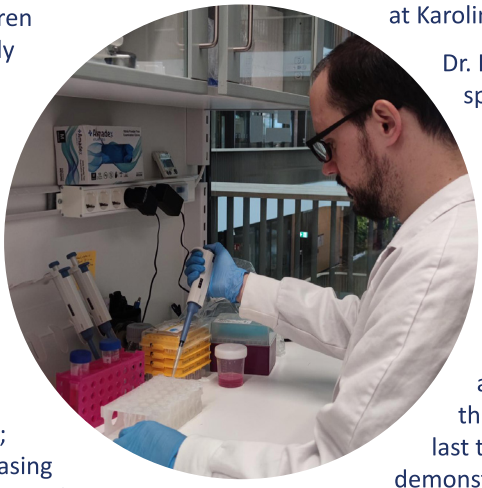
Understanding the molecular mechanisms of bacterial meningoencephalitis to establish new therapeutic and prophylactic approaches for the prevention of permanent neurological disabilities

Associate Professor Federico Iovino of the Karolinska Institute

A child is brought into the hospital. He experiences sudden high fever, a severe headache that does not go away, an incredibly stiff neck for no apparent reason; he may also feel nausea, confusion, even seizures. He is quickly hospitalized, and diagnosed meningoencephalitis. Even with prompt medical treatments, he/she will likely suffer severe brain injuries that will dramatically affect his/her life.

Bacterial meningoencephalitis is the severe inflammation of the brain and meninges occurring as a consequence of a bacterial infection. The World Health Organization defines brain infections as devastating because, even if the infection is adequately treated and cleared, **permanent neurological disabilities** occur in more than half of the survivors. What does that mean? That the child of our story, even if he/she survives, will suffer from permanent disabilities like hearing loss, seizures, cognitive and motor delays, and psychiatric disorders that will likely carried for the rest of his/her life.

The major cause of bacterial meningoencephalitis globally is *Streptococcus pneumoniae* (the pneumococcus). People at high-risk are particularly infants and children below five years old because of their not-fully developed immune system, and the immunocompromised and elderly because of their weaker immunity towards infections. Pneumococcal infections are routinely treated with β-lactam antibiotics, like penicillin. However, these antibiotics have a poor penetration across the blood-brain barrier, the protective barrier that isolates the brain from the rest of the body. Even if the drug successfully accesses the brain, we may be fighting an antibiotic-resistant bacterial strain that will resist the treatment; and antibiotic resistance in hospitals is increasing rapidly. That is why, usually, patients are given multiple antibiotics at the same time, so there is a higher chances of curing the infection.

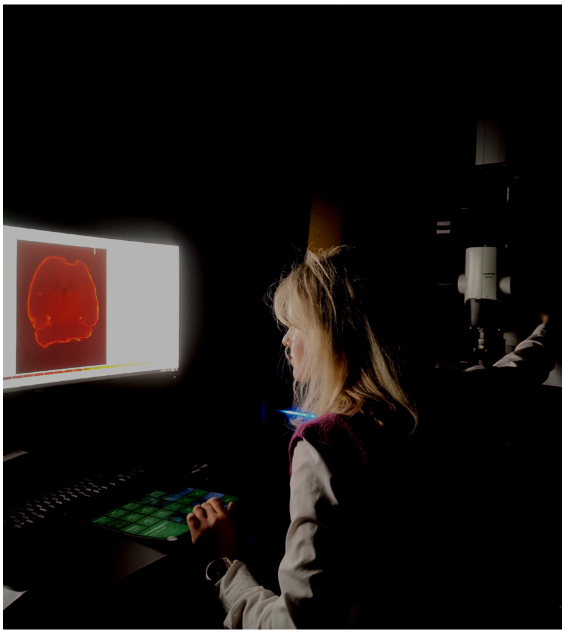


Dr Miguel Tofino

Before and during the days of antibiotic therapy, neurons are continuously damaged by the infection. This will result in neurological sequelae, which have an enormous impact on patients and their social environment. That is why it is so important to investigate new strategies to protect the nervous system from the damage caused by the infection; and that is exactly the main focus of the research done by Dr. Federico Iovino, Associate Professor and Principal Investigator at Karolinska Institutet.

Dr. Iovino is a medical microbiologist specialized in *S.pneumoniae* and pneumococcal meningoencephalitis, who has recently been awarded with the World Expert recognition by Expertscape. “I have always been impelled to develop new therapies to protect the brain from infections”, says Federico. “That’s why, in my group, we strive to understand the deep molecular mechanisms that control this terrible effect of the bacteria on the cells of the brain”. The last two studies by the Iovino Group have demonstrated that, indeed, the accumulation of bacteria in the brain during meningoencephalitis causes neuronal damage and deterioration of neurological functions (1), and, for the first time in the biomedical research field, the specific molecular mechanism by which pneumococci attack neurons, a process that leads to their death (2). This is important because, nowadays, there are no

Associate Professor Federico Iovino and the Iovino Laboratory team



Dr Kristine Farmen undertakes a microscopy analysis

therapies available that specifically target and protect neurons from pathogens. The Iovino Group is now further investigating these mechanisms **with the goal to protect neurons from bacteria even before antibiotics treat the infection.**

But what about prevention? Because the best therapy is always preventing the damage beforehand, instead of treating it after it has happened; a strategy that, unfortunately, has not been an easy endeavor in this disease. There are vaccines available to treat pneumococcal infections: the so-called pneumococcal conjugated vaccines (PCV). Yet these vaccines protect only against less than twenty serotypes (biological variants) of the pneumococcus, a minority indeed of the more than one hundred known serotypes of this pathogen. In fact, **despite vaccination programs, 2.5 million bacterial meningo-encephalitis cases worldwide still occur every year,** most of which are caused by S. pneumoniae.

That means that we need more and better preventive strategies. In this sense, the Iovino Group is trying to understand the biology of microglial response towards pneumococcal infection. Microglia, the resident immune cells of the brain, can recognize bacteria by sensing specific bacterial proteins, and initiate the process to kill them. Federico's group aims to identify the pneumococcal proteins responsible for triggering this process and use them as i**mmunostimulatory agents to enhance the immune response against bacterial pathogens**, so the immune system can kill the bacteria more efficiently. As many of these proteins are very similar among all pneumococcal variants, a protein-based "vaccine" can offer a broader protection against S. pneumoniae than traditional vaccines.

"I am grateful to all the passionate and dedicated scientists who work in my group; they are the engine of the laboratory, the ones to push forward all our projects", says Federico, and he continues: "Our duty as researchers is to help society by providing new knowledge that, hopefully, will lead to new and better therapies and vaccines to prevent these terrible neurological disabilities that so tremendously affect the lives of patients and their loved ones; in this way, the Encephalitis Society represents the link between our research and the patients that drive our passion, and it's an incredible source of inspiration for my group and all researchers in this field".

The Iovino Group at the Department of Neuroscience at Karolinska Institute is composed by Federico Iovino (Associate Professor and Group Leader), Miguel Tofiño Vian (postdoctoral researcher), Kristine Farmen (PhD student), Vittorio Iannotti (researcher, research assistant), Davide Rizzato (master student intern), Hannah Haller (master student intern), Jacob Wildeman (master student intern), Sen Kuilboer (master student intern).

Read more about the work of the Iovino Laboratory at

www.ki.se/en/neuro/iovino-laboratory-neuro-infections-and-neuro-inflammation

(1) *Generoso, J., Thorsdottir, S., Collodel, A., et al.*
Dysfunctional Glymphatic System with Disrupted Aquaporin 4 Expression Pattern on Astrocytes Causes Bacterial Product Accumulation in the CSF during Pneumococcal Meningitis
ASM Journals, mBio. Vol 13, No. 5
https://journals.asm.org/doi/10.1128/mbio.01886-22

(2) *Tabusi, M., Thorsdottir, S., Lysandrou, M., et al*
Neuronal death in pneumococcal meningitis is triggered by pneumolysin and RrgA interactions with β-actin
PLoS Pathog. 17(3):e1009432
https://doi.org/10.1371/journal.ppat.1009432

Swede dreams are made of this

Dr Ava Easton, Chief Executive of the Encephalitis Society, recently achieved a long-held ambition to visit the renowned Karolinska Institute in Sweden. She writes about her experiences.

In 2018, I was presenting in Stockholm for a pharmaceutical company and as the car drove me back to the airport I passed the prestigious Karolinska Institute! I was annoyed with myself that I had not planned ahead and visited, or at least wangled my way in to convert anyone I could on all things encephalitis. Too late now though!

Fast forward to December 2022 and the Encephalitis Conference at the Royal College of Physicians in London where I was approached by a professor from the Karolinska Institute and invited to Stockholm to present my work on patient outcomes and quality of life post-encephalitis. Dreams do come true after all!

And so it transpired that on Monday, 13th March, I flew out to Stockholm and was honoured to find I was to be the inaugural international speaker for the Iovino lab, a team run by Federico Iovino, the very same professor who extended me the invite at the conference.

The following day, I received presentations from all the laboratory team on their work surrounding various aspects of bacterial meningoencephalitis. This was followed by lunch at the delightful Svarta Rafven restaurant, also located in the Institute.

That afternoon, it was time for my presentation: Brains on Fire: Patient Outcomes and Quality of Life Post-Encephalitis. I am not overly prone to nerves when speaking, but admit I was a little distracted when I realised one of the attendees was none other than Professor Tomas Hokfelt, a very famous professor from the Karolinska Institute who is renowned for his work on neurotransmitters and neuropeptides in the brain. In 1977, he discovered that non-neurotransmitter peptide molecules like somatostatin can exist with neurotransmitters in the same peripheral and central neurons. It was a small but very engaged group with lots of questions, so much so that we ran over our session by half an hour!

MEETING... Dr Ava Easton and the team from the Karolinska Institute, Sweden

That evening, I regrouped for dinner with Professor Iovino and two of his laboratory team. The following morning, I flew back to the UK, invigorated by such a wonderful visit to Stockholm. I hope I got the encephalitis word out and raised awareness of the impact of this condition on the people whose lives it touches. I certainly learned a lot whilst there and plan on understanding better the impact of bacteria on the brain.

I returned home to a lovely email from Professor Iovino which said: "It has been an absolute pleasure to have you here. The Encephalitis Society is creating a bridge between research and patients, for us it's fundamental to be aware why we work, to make better health for everyone. Thanks for sharing with us your results, patient stories and the fantastic work of the society."

Are you looking to set yourself a physical challenge in 2023?

We have several charity places available in upcoming long-distance events in England over the coming months for anyone who wants to stretch their legs in support of the Encephalitis Society.

For anyone in different parts of the world who wants to enter an event closer to home, the Encephalitis Society is here to help with advice and any assets you may need.

Email fundraising@encephalitis.info

May
27/28: London to Brighton Challenge

June
10/11: Lake District Challenge
24/25: Cotswold Way Challenge

July
09/10: Peak District Challenge
22: North Downs 50 Challenge

August
05: South West Coast 50 Challenge

September
02/03: South Coast Challenge
09/10: Thames Path Challenge
09: Thames Bridges Trek
10: Great North Run
23: Chiltern 50 Challenge

October
15: Great South Run
28: London Halloween Walk

Retrospective Pediatric Cohort Study Validates NEOS Score and Demonstrates Applicability in Children With Anti-NMDAR Encephalitis

ABSTRACT

BACKGROUND AND OBJECTIVES

Anti-N-methyl-D-aspartate receptor encephalitis (NMDARE) is the most common form of autoimmune encephalitis in children and adults. Although our understanding of the disease mechanisms has progressed, little is known about estimating patient outcomes. Therefore, the NEOS (anti-NMDAR Encephalitis One-Year Functional Status) score was introduced as a tool to predict disease progression in NMDARE. Developed in a mixed-age cohort, it currently remains unclear whether NEOS can be optimized for pediatric NMDARE.

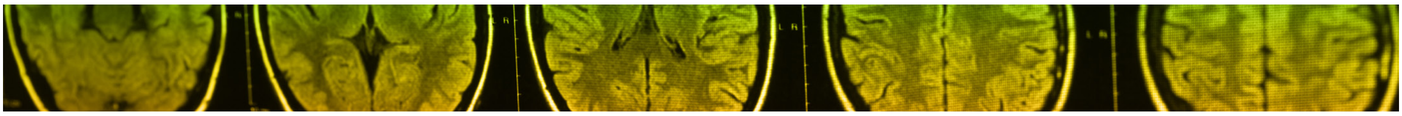
METHODS

This retrospective observational study aimed to validate NEOS in a large pediatric-only cohort of 59 patients (median age of 8 years). We reconstructed the original score, adapted it, evaluated additional variables, and assessed its predictive power (median follow-up of 20 months). Generalized linear regression models were used to examine predictability of binary outcomes based on the modified Rankin Scale (mRS). In addition, neuropsychological test results were investigated as alternative cognitive outcome.

RESULTS

The NEOS score reliably predicted poor clinical outcome (mRS ≥3) in children in the first year after diagnosis ($p = 0.0014$) and beyond ($p = 0.036$, 16 months after diagnosis). A score adapted to the pediatric cohort by adjusting the cutoffs of the 5 NEOS components did not improve predictive power. In addition to these 5 variables, further patient characteristics such as the “Herpes simplex virus encephalitis (HSE) status” and “age at disease onset” influenced predictability and could potentially be useful to define risk groups. NEOS also predicted cognitive outcome with higher scores associated with deficits of executive function ($p = 0.048$) and memory ($p = 0.043$).

Nikolaus M., Rausch P., Rostásy K., et al. (2023)
Retrospective Pediatric Cohort Study Validates NEOS Score and Demonstrates Applicability in Children With Anti-NMDAR Encephalitis
Neurol Neuroimmunol Neuroinflamm ;10(3):e200102. doi: 10.1212/NXI.0000000000200102. PMID: 36948591; PMCID: PMC10032577.



Use of anti-seizure medications in different types of autoimmune encephalitis: A narrative review

ABSTRACT

Seizures are the main manifestation of the acute phase of autoimmune encephalitis (AE). Anti-seizure medications (ASMs) play an important role in controlling seizures in AE patients, but there is currently a lack of consensus regarding the selection, application, and discontinuation of ASMs. This narrative review focuses on the use of ASMs in patients with AE driven by different antibodies. The PubMed, Embase, and MEDLINE databases were searched up until 30 October 2022 using prespecified search terms. We identified 2,580 studies; 23 retrospective studies, 2 prospective studies and 9 case reports were evaluated based on our inclusion criteria. Anti-N-methyl-D-aspartic-acid-receptor (anti-NMDAR) encephalitis is the type of AE that responds best to ASMs, and long-term or combined use of ASMs may be not required in most patients with seizures; these results apply to both adults and children. Sodium channel blockers may be the best option for seizures in anti-leucine-rich-glioma-inactivated-1 (anti-LGI1) encephalitis, but patients with anti-LGI1 encephalitis are prone to side effects when using ASMs. Cell surface antibody-mediated AE patients are more likely to use ASMs for a long period than patients with intracellular antibody-mediated AE. Clinicians can score AE patients’ clinical characteristics on a scale to identify those who may require long or short term use of ASMs in the early stage. This review provides some recommendations for the rational use of ASMs in encephalitis mediated by different antibodies with the aim of controlling seizures and avoiding overtreatment.

Du J., Guo Y. and Zhu Q. (2023)
Use of antiseizure medications in different types of autoimmune encephalitis: A narrative review.
Front. Neurol. 14:1111384. doi: 10.3389/fneur.2023.1111384

RESEARCH**SUMMARY**

Autoimmune Encephalitis Misdiagnosis in Adults

ABSTRACT

IMPORTANCE Autoimmune encephalitis misdiagnosis can lead to harm.

OBJECTIVE To determine the diseases misdiagnosed as autoimmune encephalitis and potential reasons for misdiagnosis.

DESIGN, SETTING, AND PARTICIPANTS This retrospective multicenter study took place from January 1, 2014, to December 31, 2020, at autoimmune encephalitis subspecialty outpatient clinics including Mayo Clinic (n = 44), University of Oxford (n = 18), University of Texas Southwestern (n = 18), University of California, San Francisco (n = 17), Washington University in St Louis (n = 6), and University of Utah (n = 4). Inclusion criteria were adults (age 18 years) with a prior autoimmune encephalitis diagnosis at a participating center or other medical facility and a subsequent alternative diagnosis at a participating center.

A total of 393 patients were referred with an autoimmune encephalitis diagnosis, and of those, 286 patients with true autoimmune encephalitis were excluded.

MAIN OUTCOMES AND MEASURES Data was collected on clinical features, investigations, fulfillment of autoimmune encephalitis criteria, alternative diagnoses, potential contributors to misdiagnosis, and immunotherapy adverse reactions.

RESULTS A total of 107 patients were misdiagnosed with autoimmune encephalitis, and 77 (72%) did not fulfill diagnostic criteria for autoimmune encephalitis. The median (IQR) age was 48 (35.5-60.5) years and 65 (61%) were female. Correct diagnoses included functional neurologic disorder (27 [25%]), neurodegenerative disease (22 [20.5%]), primary psychiatric disease (19 [18%]), cognitive deficits from comorbidities (11 [10%]), cerebral neoplasm (10 [9.5%]), and other (18 [17%]). Onset was acute/subacute in 56 (52%) or insidious (>3 months) in 51 (48%). Magnetic resonance imaging of the brain was suggestive of encephalitis in 19 of 104 patients (18%) and cerebrospinal fluid (CSF) pleocytosis occurred in 16 of 84 patients (19%). Thyroid peroxidase antibodies were elevated in 24 of 62 patients (39%). Positive neural autoantibodies were more frequent in serum than CSF (48 of 105 [46%] vs 7 of 91 [8%]) and included 1 or more of GAD65 (n = 14), voltage-gated potassium channel complex (LGI1 and CASPR2 negative) (n = 10), N-methyl-D-aspartate receptor by cell-based assay only (n = 10; 6 negative in CSF), and other (n = 18). Adverse reactions from immunotherapies occurred in 17 of 84 patients (20%). Potential contributors to misdiagnosis included overinterpretation of positive serum antibodies (53 [50%]), misinterpretation of functional/psychiatric, or nonspecific cognitive dysfunction as encephalopathy (41 [38%]).

CONCLUSIONS AND RELEVANCE When evaluating for autoimmune encephalitis, a broad differential diagnosis should be considered and misdiagnosis occurs in many settings including at specialized centers. In this study, red flags suggesting alternative diagnoses included an insidious onset, positive nonspecific serum antibody, and failure to fulfil autoimmune encephalitis diagnostic criteria. Autoimmune encephalitis misdiagnosis leads to morbidity from unnecessary immunotherapies and delayed treatment of the correct diagnosis.

Flanagan E.P., Geschwind M.D., Lopez-Chiriboga A.S., et al. (2023)
Autoimmune Encephalitis Misdiagnosis in Adults
JAMA Neurol; 80(1): 30–39.
doi:10.1001/jamaneurol.2022.4251

Japanese encephalitis: A rapid review of reported prevalence of infection, clinical disease and sequelae in immunologically naive populations to inform Australia's response

IMPLICATIONS FOR AUSTRALIA

There is limited research on JEV and JE in immunologically naive populations. Based on the research available, it is uncertain what proportion of immunologically naive people in Australia are at risk of JE. However, the proportion of JE cases who develop sequelae and/or die remains very high.

Other than the presence of a reservoir and vector distribution, risk factors for JEV infection and progressing to JE and death are not well understood. Australia has progressively expanded vaccine eligibility throughout 2022 based on our emerging understanding of groups at higher risk. However, the evidence from human studies to support this decision-making has been very limited and of variable quality.

Ongoing serosurveillance at a state and national level will support a better understanding of JEV in the local context, including the distribution of and risk factors for infection. Results from New South Wales suggest 8.7% of serosurvey participants had evidence of prior JEV infection, indicating that many people may have been infected during the outbreak, but also that there is widespread population vulnerability to infection. Results from additional serosurveys will inform further vaccine prioritisation.

In the setting of finite vaccine supply, mass vaccination has not been feasible ahead of the current mosquito season. Alternative and additional public health actions are required to mitigate the potential for significant outbreaks of JEV. Apart from sporadic cases and small outbreaks of Murray Valley encephalitis, South-Eastern Australia has not experienced a mosquito-borne illness with the severity of JE, so there are varying levels of awareness regarding the need for mosquito bite protection. Consequently, a strong targeted public education and prevention campaign is essential to reduce the risk to travellers and residents in high-risk areas.

Further research, including serosurveillance, is needed to understand the possible impacts of JEV within the Australian context. Cases of JE have been reported in South-Eastern Australia in January 2023. While the future is uncertain, this suggests that JEV may become endemic to Australia. The public health implications of this cannot be understated. While a minority of individuals who are infected with JEV will develop JE, for these individuals, the consequences can be devastating. At a population level, if JEV were to move unmitigated through the Australian community, the associated morbidity and mortality could be significant.

Thomson T.N., Marsland M.J., Minko C., et al. (2023)
Japanese encephalitis: A rapid review of reported prevalence of infection, clinical disease and sequelae in immunologically naive populations to inform Australia's response
Australian and New Zealand Journal of Public Health; 47 (2);100041,ISSN 1326-0200, https://doi.org/10.1016/j.anzjph.2023.100041.

Global uncertainty in the diagnosis of neurological complications of SARS-CoV-2 infection by both neurologists and non-neurologists: An international inter-observer variability study

Tamborska et al. (2023) invited 146 clinicians from 45 countries on six continents to assess ten scenarios of acute neurological complications of COVID-19, assign a diagnosis and rank the association with SARS-CoV-2 using standardised case definitions.

The highest correct proportion were cerebral venous sinus thrombosis (CVST) (95.8%), Guillain-Barré syndrome (GBS) (92.4%) and headache (91.6%) and the lowest for conditions presenting with altered mental status - encephalitis (72.8%), psychosis (53.8%) and encephalopathy (43.2%). Association between SARS-CoV-2 and neurological syndromes was underestimated in over 10% of cases. Non-neurologists achieved similar diagnostic accuracy to neurologists.

The conclusion of the study was that case definitions can help with reporting of neurological complications of SARS-CoV-2 for any clinicians, not only neurologists. However the underestimate of association of SARS-CoV-2 with neurological syndromes and misdiagnosis of encephalitis, psychosis and encephalopathy shows the need for a refine of the case definitions and training.

Tamborska A.A., Wood G.K., Westenberg E., et al. (2023)
Global uncertainty in the diagnosis of neurological complications of SARS-CoV-2 infection by both neurologists and non-neurologists: An international inter-observer variability study
Journal of the Neurological Sciences. 449: 120646, https://doi.org/10.1016/j.jns.2023.120646

Ten out of ten

"I want to say thank you to all the buildings that have gone #Red4WED. I want to say thank you to our encephalitis family. We are incredibly privileged to have your support. World Encephalitis Day 2023 has been amazing."

So said Dr Ava Easton, our Chief Executive, at the end of another whirlwind World Encephalitis Day, which reached more than 111 million people around the globe.

Celebrating its 10th year, our awareness day on the 22nd February saw 249 buildings in 29 countries light up red with hundreds of supporters (and some four-legged friends) also sharing red-themed photographs on social media.

"Awareness-wise, we have reached more people than ever before during a single campaign in the 10-year history of World Encephalitis Day," said Ava.

"This was partly due to targeting the media in new markets, including India, the Philippines, and Germany, alongside our more familiar territories in the USA, UK and Australia.

"Our aim going forward is continue building in-roads in all these countries while looking for opportunities elsewhere."

This year's media campaign centred on some important new research from teams based in Mexico and England which looked at mental health issues during and after encephalitis, including suicide and self-harm.

Ava said: "The team thought long and hard about whether to talk about such a difficult subject for World Encephalitis Day.

"But we needed healthcare professionals to be aware that mental health is more likely to suffer for patients affected by encephalitis during their recovery and rehabilitation.

"Mental health problems, including thoughts of suicide and self-harm, are often highly treatable with the right help and support, including from the Encephalitis Society."

She added: "It was also very inspiring for the team to see the courage of our supporters who put themselves forward to talk to the media about such a difficult subject."

Meanwhile, 437 people from 30 countries took part in BrainWalk, our annual step challenge. In total, they walked a combined 65 million steps during February and raised £40,000 in support of the work of the Encephalitis Society.

And, in a growing development, we also partnered with 13 businesses who added their support to our campaign.

Other World Encephalitis Day highlights included a special online virtual gathering, a themed music playlist, an episode of The Encephalitis Podcast, and gatherings in Perth, Australia, at Piccadilly Circus in London, and much more.

WorldEncephalitisDay

Our media campaign for World Encephalitis Day 2023 centred on two new groundbreaking pieces of research, which looked at the mental health impact of encephalitis. The lead authors of the respective papers, Dr Thomas Pollak and Dr Jesus Ramirez-Bermudez, spoke to journalists about their findings. Continue reading to find out more:

Encephalitis patients are at a high risk of suicide and self-harm

Encephalitis patients are at a high risk of suicide and self-harm, two new, groundbreaking research papers, published for World Encephalitis Day 22nd February 2023, have identified. The two papers, from authors in the UK and Mexico, reveal important statistics relating to suicide, self-harm and mental health.

The Mexico paper titled 'Suicidal thoughts and behaviors in Anti-NMDAR Encephalitis: Psychopathological features and clinical outcomes' was published in the Journal of Neuropsychiatry and Clinical Neurosciences. The research, led by Dr Jesus Ramirez-Bermudez, gained data from 120 patients with a headline outcome being 12.5% of patients had suicidal behaviours during early stages of the illness with nearly half (5.83%) carrying out a suicide attempt. Within the paper's conclusions it was noted; 'According to our study, suicidality is not uncommon during the acute phase of ANMDARE, including both first episodes and relapses. Clinicians must be aware of this potentially lethal risk, particularly in those presenting with symptoms of psychotic depression. Although the persistence of suicidal thoughts and behaviors after immunotherapy is rare, we encourage a long-term risk assessment for suicidal and no suicidal self-directed violence throughout the different stages of the disease'.

The second paper 'Mental health outcomes of encephalitis, an international web-based study,' which was written by a team of leading specialists including senior author Dr Tom Pollak of Kings College London and published on a pre-print platform, surveyed 445 respondents from 31 countries and found that 37.5% of survivors of encephalitis reported they had thought about or attempted (4.4%) suicide. The summary and recommendation of the paper was; 'Overall, the large international survey indicates that psychiatric symptoms following encephalitis are common. Overall, these results highlight a need for increased provision of proactive psychiatric care for these patients and represent a call to action for increased research on mental health outcomes of encephalitis so that this patient group can be better supported. Given the treatment-responsiveness of many mental health symptoms and diagnoses, this is likely to represent a global opportunity for reducing morbidity and mortality in this challenging condition.'

Dr Thomas Pollak

Dr Jesus Ramirez-Bermudez

Tellez-Martinez, A., Restrepo-Martinez, M., Espinola-Nadurille, M., Martinez-Angeles, V., Martinez-Carillo, F., Easton, A., Pollak, T., Ramirez-Bermudez, J. (2023)
Suicidal thoughts and behaviors in anti-NMDAR encephalitis: psychopathological features and clinical outcomes
Journal of Neuropsychiatry and Clinical Neurosciences: https://neuro.psychiatryonline.org/

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
(This article is a preprint and has not yet been certified by peer review. It reports new medical research that has yet to be evaluated and so should not be used to guide clinical practice)

Virtually speaking

It is now three years since we launched our first Online Peer Support Groups in response to the Covid-19 pandemic.

We introduced them to bring our encephalitis community together during the long, difficult lockdowns that we all had to endure.

Since those early meetings, our virtual gatherings have grown to become a permanent and popular fixture on our calendar for many supporters of the Encephalitis Society.

They have grown from a single weekly meeting to now include regular gatherings for people in different areas of the world, as well as special meetings for groups, such as carers or people who have been bereaved as a result of encephalitis.

So, if you believe your patient could benefit from one of our meetings, please continue reading to find out more.

What are our Online Peer Support Groups?

These meetings, also known as virtual gatherings, are an opportunity to meet like-minded people in a safe and welcoming environment.

How do they work?

Interested parties should visit our website for details about upcoming meetings, find the one they would like to attend, and email peersupport@encephalitis.info. We will then send them a link to the online meeting.

What do we talk about?

Anything and everything! Attendees can talk about their experiences of encephalitis, ask for advice about their recovery, or it can be something as silly as talking about good recipes to try! (This was a particularly hot topic during the boredom of the multiple lockdowns).

We want to create a warm, welcoming environment for people to be themselves.

What type of meetings are there?

We have a mix of weekly, monthly and regional meetings.

We hold a weekly meeting every Thursday, which is open to everyone and is perhaps the best way to become introduced to joining us online.

We have regional meetings for:

- London, England
- North West of England
- Scotland
- Wales
- Northern Ireland
- Republic of Ireland
- Australia and New Zealand

Our monthly meetings are themed, and include:

- People directly affected by encephalitis
- Parents/guardians of children affected by encephalitis
- People who have experienced bereavement
- Carers, family members, and support groups

My patient is nervous about attending

This is understandable. But fear not! There is always a volunteer or a member of the Encephalitis Society team on hand to make everyone feel welcome. Also, you can join in and listen and talk only when you feel comfortable.

What are the benefits of Online Peer Support Groups?

Our attendees tell us that meetings have increased feelings of connection, given them an emotional release through sharing their stories and experiences, feelings of validation – and helped them to make new friends!

Details about upcoming meetings can be found at www.encephalitis.info/virtual-gatherings

Animations available in different languages

Understanding Encephalitis - our series of animations which cover different aspects of the condition - are now available in four new languages.

Over the past two years, we have been putting together several short animated films which provide a background into areas such as diagnosis, symptoms, recovery and the impact of mental health.

They are aimed at people recovering from encephalitis, their families and friends, and have also been used as an awareness tool among the general public.

Now, thanks to a grant from the UK's National Lottery Community Fund, this nine-strong series of films have been translated from English into:

- Hindi
- Polish
- Punjabi, and
- Tagalog

"Our Understanding Encephalitis animations have become very popular tool with anyone wanting to learn about such a complicated condition," said Alina Ellerington, our Director of Services.

"Our aim was always to have them translated into different languages so more people around the world will be able to benefit."

She added: "Our hope is that healthcare professionals who may be caring for someone who speaks Polish, Hindi, Punjabi or Tagalog can now refer their patients to these films."

Plans are now underway to carry out further translations of the Understanding Encephalitis animations, with French the first on the list.

The Understanding Encephalitis animation series includes:

- What is encephalitis?
- What are the symptoms of encephalitis?
- How is encephalitis diagnosed?
- How is encephalitis treated?
- What are the effects of encephalitis?
- What happens during encephalitis recovery?
- What to do at home for encephalitis recovery?
- Encephalitis for families and carers
- Encephalitis and mental health

Share the animations: www.encephalitis.info/patient-resources

Stories offer encouragement for a life after encephalitis

Online and in-person places can now be booked for My Brain: My Story on Saturday, 7th October.

This year's event will take place at The Grand Hotel, York, England, and will include a series of talks from members surrounding their experiences of encephalitis.

For anyone unable to travel to the historic city of York, the event will be broadcast online. A recording of the talks will also be made available to anyone who books a place.

Alina Ellerington, our Director of Services, said: "We know that beginning life after encephalitis can be a lonely experience for many. By sharing their experiences at My Brain: My Story, our speakers aim to be honest about the difficulties they have faced during their recoveries, but also to offer words of encouragement and let our newer members know that they are not alone in their journeys."

Tickets for My Brain: My Story are available from www.encephalitis.info/mbms-2023

Women in Science:
Professor Kiran Thakur

In a new ongoing feature for Connect Professional, we are asking eminent female medical professionals to share their experiences of working in science. This edition's interviewee is Assistant Professor Kiran Thakur, the Winifred Mercer Pitkin, MD Assistant Professor of Neurology at Columbia University Irving Medical Center, who is also a new member of the Encephalitis Society's Scientific Advisory Panel

Name:

Kiran Thakur

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?

The field of neuroinfectious diseases is ever-expanding with novel pathogens routinely discovered, which makes it a very exciting though challenging field! There are so many unanswered questions around preventive measures, diagnosis, and management. Many individuals with neurological infections including encephalitis are vulnerable and marginalized. I was inspired by the individuals I cared for in my training and continue to take care of, particularly those from underserved populations, whose devastating conditions including encephalitis have impacted their lives so significantly. To have a larger impact, beyond the individual patient, I wanted to do clinical research to improve our understanding of neurological infections and better care for the populations of patients with these serious conditions.

Assistant Professor Kiran Thakur

Where did you study?

I was an undergraduate at the University of Michigan-Ann Arbor where I was an English major. Being an English major has been so important as a scientist as I love to write and I am constantly writing! I then went onto medical school at Tufts University School of Medicine where I was rotating as a student with Professor Gordon Plant at the National Hospital for Neurology and Neurosurgery, University College London. This is where I really fell in love with neurology and will never forget the patient presentations in weekly grand rounds. I then went on to do my medicine internship at the Osler Residency Program at Johns Hopkins Hospital in Baltimore, Maryland, and then neurology residency at Massachusetts General Hospital and Brigham and Women's Hospital in Boston, Massachusetts. Then, I went back to Baltimore to fellowship in neuroinfectious diseases and neuroimmunology at the Johns Hopkins Hospital. This is when I began to acquire research skills in neuroinfectious diseases and travelled internationally, learning about a broad array of neuroinfectious diseases.

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

I think of myself as lover of all things neuroinfectious diseases and what I see clinically really inspires and drives the questions I try to answer in my clinical research activities in neuroinfectious diseases. My clinical research has focused on implementation of novel tools to diagnose and manage neuroinfectious diseases more effectively. I have a specialized interest in emerging and re-emerging neuroinfectious diseases, including tick-borne and mosquito-borne infections that cause encephalitis. In the US and abroad, I focus on diverse populations which have been historically neglected in our healthcare system.

> Love what you do and be passionate about it. Learn the skills that will allow you to answer the questions you want to answer early on in your career and continue your education throughout life.

What inspires you in the workplace?

First and foremost, the individuals I take care of and their family members. This drives me to study encephalitis and other neuroinfectious diseases every day. Working with trainees who are excited to learn and who will be the next generation to move the field forward also is truly inspirational. My colleagues and friends who are not only incredible clinicians and scientists, but also wonderful human beings are also a great joy for me. Most important is my family who are my biggest supporters and advocates. I have two young children aged five and eight, and they inspire me every day to be a better human being, and love to teach science in my daughter's second grade classroom!

What kind of prejudices, if any, did you have to face?

I think there are still very significant ongoing prejudices against women in science. There have been barriers I have had to overcome, some which involve subtle microaggressions, others more apparent. One piece of advice would be to choose and find collaborators, mentors and sponsors carefully and identify colleagues who have your best interests in mind when you are starting out your career. Those around you should take great joy in your individual successes and take pride in your growth towards independence as a scientist.

In your opinion, which changes, if any, are needed in the scientific system to be more attractive to women in science and possible future scientists?

I think we have to create an environment that fosters collaboration and team science more effectively. Too much of science is based on the individual successes, but no one can do science alone. Team-based projects with shared responsibilities and power dynamics especially across borders are so fundamental and fulfilling. These types of studies in clinical research are often the most effective. Women in particular are skilled at being effective leaders of large clinical studies and need to be fostered and given opportunities to lead this type of work. Women are essential to the growth and prosperity of neuroscience research!!!

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

Love what you do and be passionate about it. Learn the skills that will allow you to answer the questions you want to answer early on in your career and continue your education throughout life. Don't be afraid to pivot as needed as science is often unpredictable. Embrace failure, as it is typical in science and one must learn from all the bumps in the road! Work with people who support you and embrace your love of science and who foster your growth, but don't coddle you and provide critical feedback. Most importantly perhaps, don't forget to enjoy life. You will be surprised by what inspires your next scientific questions—oftentimes it is outside of the laboratory!

About Assistant Professor Kiran Thakur

Dr Thakur is the Winifred Mercer Pitkin, MD Assistant Professor of Neurology at Columbia University Irving Medical Center - New York Presbyterian Hospital.

She leads the program in Neuroinfectious Diseases at Columbia and is the Director of the Post-Doctoral Fellowship Program in Neuroinfectious Diseases.

After graduating from the Harvard Neurology Residency Training Program, Dr Thakur completed post-doctoral fellowship training in neuroinfectious diseases and neuroimmunology at the Johns Hopkins Hospital.

Dr Thakur has a specialized interest in emerging and re-emerging neurotropic infectious diseases and collaborates with scientists globally on the surveillance, diagnosis, and management of neuroinfectious diseases. Dr Thakur is funded by the US National Institutes of Health, and the US Center for Disease Control and Prevention.

In addition to her scientific efforts, Dr Thakur serves as a neurology consultant for the World Health Organization and the Center for Disease Control and Prevention Clinical Immunization Safety Assessment project on COVID-19 vaccination safety.

JUNE 2023
ENCEPHALITIS
RESEARCH MONTH
investing in hope

ONE DONATION...

TWICE THE IMPACT

This Research Month, we are aiming to raise an incredible £20,000 to fund life-saving research projects.

Double your donation

Throughout June, donations made to the Encephalitis Society will be doubled – thanks to match funding from the Big Give.

All money raised will go towards supporting young researchers and projects related to encephalitis around the world.

Be a Changemaker and help us to fund life-saving research into encephalitis.

www.encephalitis.info/big-give

ENCEPHALITIS SOCIETY
The brain inflammation charity