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“We've been working with global stakeholders to make Encephalitis a public health priority”

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The Encephalitis Society is a multi-award-winning charity and the leading global resource providing support and information, raising awareness of the condition and collaborating in research. It also funds and collaborates on ground-breaking research and raises awareness through various campaigns including World Encephalitis Day which is held annually on February 22. In an interaction with BioSpectrum India, Dr Ava Easton, CEO of the Encephalitis Society, UK shared her views on the activities of the society and programmes / projects that are being funded by the society in the country.

Established in 1994, what have been the key achievements of the Encephalitis Society till now?

Encephalitis is an inflammation of the brain. It can occur at any age, in any part of the world and is caused either by infection, usually viral, or by a person’s own immune system going wrong. There are over 5,00,000 reported cases of encephalitis around the world each year with mortality up to 40 per cent depending on the cause.

People might be more familiar with meningitis, which is inflammation of the lining of the brain. But this is inflammation of the brain cells, and it is caused either by infection, invading the brain. This can be an ordinary, everyday infection that people will be familiar with, such as the measles or the cold sore virus, or it can be through the immune system attacking the brain in error.

It's often a devastating neurological condition and sadly in many cases can have a high death rate. But for many who survive the condition, it can result in injury to the brain and in some cases, life changing disabilities for people. At the encephalitis society, we operate in three different ways. We provide information and support for people that have been affected by the condition and also for their family, their friends and their caregivers wherever they live in the world.

We raise awareness of encephalitis. And our primary global campaign for that is World Encephalitis Day on February 22. And we also participate in research both funding and collaborating on research around the world to change and to heighten the encephalitis agenda. More recently, we've been working with global stakeholders, including the World Health Organisation, trying to develop a plan to change the landscape of encephalitis around the world, and make it seen more as a public health priority, and that encephalitis really matters, no matter where people live in the world.

What kind of projects have you been working on in the Asia Pacific region?

We're involved in lots of projects, but certainly in Australia you'll be aware that in February and March of last year they had a Japanese encephalitis outbreak. We mobilised very quickly to develop a masterclass for professionals and we did lots of public awareness around then. The Encephalitis Society is doing lots of projects and lots of work around the world to try and change the landscape of encephalitis.

Do you have direct operations in other countries and how do you look at working in other countries besides the UK?

We don't have chapters in different countries. But my team is a global team and they can help and support patients wherever they are in the world. If those patients need specific in-country treatment or support. And we will source that and we will signpost them to who can help in that country.

What is the current status of Encephalitis in India?

In India, outbreaks of acute encephalitis syndrome pose a major public health problem, affecting thousands of people every year. Since 2005, the overall incidence of acute encephalitis syndrome in India has not decreased, with 10,867 - 13,672 cases reported each year to the National Vector Borne Disease Control Programme (NVBDCP) between 2014 and 2017. Overall, incidence of encephalitis is suspected to be 3,00,000 cases a year. Among individuals who develop acute encephalitis syndrome, case fatality is as high as 40 per cent and long-term neurological or psychiatric conditions can occur in 30-50 per cent of patients. More dramatic is the long-term brain damage that these patients suffer leading to Epilepsy, memory loss, loss of attention, personality changes, paralysis, sensory loss such as loss of hearing or vision, depression, speech and movement difficulties.

How are you spreading your activities in India?

We don't have a chapter in India at the moment, but our team at the Encephalitis Society people can contact us and our team will put them in touch with people that it depends on what their needs are. But I think it's important to mention that for World Encephalitis Day we've got famous landmarks and buildings around the world lighting up, and colleagues, Dr Netra and colleagues at the National Institute of Mental Health and Neurosciences (NIMHANS) are lighting up some buildings, and our colleagues at Christian Medical College,Vellore are lighting up buildings.

If I had all the money and all the time in the world, I would have a chapter in every country. But we are a small team trying to do the very best that we can. I hope one day we will get there. That will be our dream. But at the moment we're doing what we can with the small resources that we have.

To develop a novel diagnostic test that can differentiate scrub typhus from other causes of acute encephalitis syndrome (AES) in children, a project from India received seed funding in 2022. What is the current status of the project?

The scrub typhus project was only started on December 1, 2022. They've just received ethical approval, patient samples have been collected and they're currently checking their quality control before processing the rest of the patient samples. So early stages, but good progress being made by then.

We, the Encephalitis society, have funded this project. With a seed funding, the project, we would normally expect to hear the results usually about 12 months from the start of the project. Hopefully by the end of this year we can see some good results.

Similarly in 2021 Dr Priyanka Madaan, Pediatric Neurology Unit, Department of Pediatrics, Post graduate Institute of Medical Education and Research (PGIMER), Chandigarh, India received seed funding for Validation of the Paediatric Autoimmune Encephalitis Severity Score (PASS) in children with autoimmune encephalitis. What is the progress of the study so far?

The start of the project was postponed due to long delays at receiving the necessary authorisations. So that project actually started in October 2022. They've got ethical approval. Their recruitment began in Chandigarh in November with five children and they're currently undergoing assessments. New Delhi is the next centre that's going to begin recruiting very shortly. So again, good progress and we should see some results from both of those studies this year.

Dr Netravathi M, Professor of Neurology – NIMHANS, Bangalore and I are working as part of a consortium called Brain and Flow Infections Global. And, over the last five years, we've been looking at the diagnosis and treatment of encephalitis in low to middle income countries such as Malawi and Brazil. And we've been working in India, so we've worked on and supported that project for the last five years, and it's hoped that we're going to have some results from that study over the next few months. Some are really exciting and really good projects that have been created and that we've been collaborating on in India.

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