

The Encephalitis Society Annual Seminar

Conference details: December 2014, London, UK. **Report by:** James Pamment, Oliver Zangwill Centre for Neuropsychological Rehabilitation, and edited by Dr Ava Easton, The Encephalitis Society

When the opportunity arose to come to this year's Encephalitis Society Professional Seminar I was delighted to attend and brought along high expectations of increasing my knowledge base in an area of research and clinical practice that I am admittedly fairly new to. A day of highly stimulating talks, packed with innovative research from across the globe highlighted the day's theme of a wider community, endeavouring to share information relevant to best practice.

The seminar had a wide ranging audience allowing multi-disciplinary, service user and family perspectives to fuel lively post talk debates and questions. This diverse range of perspectives added to the quality of the day by offering what felt like extremely comprehensive discussions on thoroughly engaging topics.

The afternoon started with a very warm welcome from Dr Ava Easton CEO and Professor Tom Solomon, Chair of the Encephalitis Society Professional Panel. We were given an exciting sneak preview of the events the Society had planned for its 21st birthday celebrations next year; including a 21 day road-show visiting a different location in the country each day, raising awareness of Encephalitis and the work of The Society.

It was then time to kick off the talks, with Dr Arun Venkatesan from the John Hopkins University, presenting 'Acute encephalitis: prognostic factors and novel therapies'. Dr Venkatesan highlighted factors that through his work in acute settings have shown to contribute to poor outcomes and how this might inform patient care during hospitalisation. The audience was given an overview of Encephalitis hospitalisation rates of 250,000 patients from the US dating between 2000-2010. Predictors of mortality within this data set suggest that there is a need to focus on the very young and old. Dr Venkatesan then honed in on factors identified through his work on patients admitted to the Johns Hopkins Hospital. Research showed that patients that had thrombocytopenia, cerebral oedema or status epilepticus were at a greater risk of death. The focus of the talk then went on to the question; what can we do as clinicians to further reduce these risk factors? Dr Venkatesan then put forward persuasive evidence to suggest that a ketogenic diet can be effectively used to treat status epilepticus in patients with encephalitis, and may also have a protective anti-inflammatory effect.

Next, Dr Jennifer Lemon, University of Liverpool presented a talk looking at how qualitative, semi-structured interviews with parents might be a useful tool in deciding which outcomes are important to measure in children. Dr Lemon highlighted the need for a core set of outcomes that help understand a condition that is complex and varied. The



parent's perspective of how outcomes change over time were shown to be a key theme. Transcripts with parents documented how the focus of concern shifts through the different stages of the illness. Initially they have concerns about mortality and impairments whilst their child is in acute care, then the focus moves to the impact of problems back in their child's normal setting and anxieties about the future. Dr Lemon ended the talk by stating that there is currently a lack of standardisation of outcomes and previous encephalitis trials have focused more on impairments rather than the impact of problems on the child's day to day life.

Dr Defres, also based at the University of Liverpool then followed with a talk titled 'Understanding and improving the outcome of encephalitis'. Dr Defres explained that the aim of The EncephUK study was to determine the clinical predictors of encephalitis for a diagnostic tool for the junior doctor on the frontline. However, this is quite an undertaking given the knowledge of how tricky it can be to diagnose

Encephalitis. But poor outcomes resulting from delays in recognising symptoms and starting treatment, dictate the need for this important research to be carried out and completed.

Dr Thomas Miller, University of Oxford, continued the afternoon seminar with a talk showing the research directions on patient related outcomes in VGKC limbic encephalitis. Describing memory as a 'broad church', Dr Miller introduced his work on creating 'PROMS' (Patient related outcome measures) as part of a multi-pronged approach that can drill down to patient problems. Dr Miller found using a questionnaire in combination with semi-structured interviews a useful way of picking up the social narrative that can be lost in a questionnaire alone. Dr Miller stated that PROMS are useful in explaining the 'how & what' people experience. Dr Miller's talk was insightful in his opinion that a more holistic model of measuring patient experience can be used to better guide research and drug treatment targeting a more patient driven agenda.

After a short break it was then time for Professor Peter Kennedy CBE, Head of the Neurology department at Glasgow University, to deliver his highly anticipated keynote address on 'Human African Trypanosomiasis (sleeping sickness) in sub-Saharan Africa'. One of only a handful of medical doctors working on the disease, he is the world's leading expert on nervous system infection in sleeping sickness, and has spent much of his career devoted to raising awareness of sleeping sickness in Africa and beyond. His acclaimed popular science book on the topic 'The Fatal Sleep' has also been highly commended by the BMA and generates money for charities in Africa. Professor Kennedy introduced the audience to the historical context of a disease that currently puts 70 million people at risk of developing it in Africa. During the period 1894-99, the bite of the tsetse fly was discovered by Sir David Bruce to be the mode of transmission of the causative trypanosome parasites in animal Trypanosomiasis. Over the following decade different forms of trypanosomes, also transmitted by the tsetse fly, were shown to be the cause of Human African Trypanosomiasis (HAT), both forms occurring in sub-Saharan Africa. Professor Kennedy pointed out that recurrences and the periodic re-emergence of HAT have been due to several factors, in particular wars and socio-economic instability which lead to inadequate patient surveillance and vector control. Professor Kennedy then provided an overview of the current highly toxic drug treatment and promising drugs that are in the pipeline, whilst clearly pointing out the major challenges involved in treating an at-risk population living in some of the poorest rural areas of Africa. The talk was summed up