

S U M M E R 2 0 1 3



## ENCEPH UK

Understanding and Improving the  
Outcome of Encephalitis



## Research Nurse Training Day 2<sup>nd</sup> July 2013

This was an exciting and very productive day for adult and paediatric research nurses involved in the ENCEPH-UK Programme of studies.

A number of presentations were given covering clinical aspects, patient perspectives, laboratory aspects and learning more about the conduct of clinical trials.

There were also a number of group work and practical sessions going over case scenarios and other useful training exercise.

Thereby all learned more about encephalitis and meningitis!

See our Facebook page for some of the photos from this event.

<https://www.facebook.com/media/set/?set=a.516062051780908.1073741840.184437834943333&type=1>

## Welcome to the Summer ENCEPH-UK/UK-ChiMES Newsletter

The studies have now been running for about 8 months! Recruiting sites and patients continues. See page 3 to see how your site is faring. In our previous newsletters we introduced you to various team members, and we did warn you it was a big team; there are more!

### Save the Date!

Book signing - Waterstones  
Liverpool One

**28<sup>th</sup> August 2013 - 1730**

Meet the encephalitis society's international ambassador & New York Times best selling author Susannah Cahalan & Prof Tom Solomon as they discuss "Brain on Fire - My month of madness"

The UK Acquired Brain Injury  
Forum – 5<sup>th</sup> Annual  
conference: London

**21<sup>st</sup> November 2013**

Talks include how to improve information & support for GPs and counting the cost of the rehabilitation postcode lottery.

## More of the ENCEPH-UK team!

Here we introduce the leads of the sub-studies for which you are collecting all those samples for!

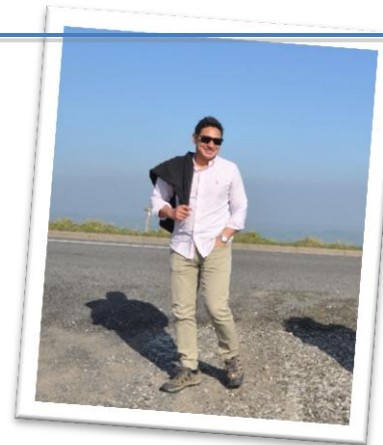


### Dr Mike Griffiths

I am a clinical Lecturer in the Brain infections Group and have clinical roles in paediatric and adult neurology. My research interests lie in the host responses to severe infection, particularly neurological infectious insults, with a focus on identifying diagnostic & prognostic markers as well as better understand the role of host & pathogen responses in determining the outcome of brain infections

### Dr Ben Michael

I am a NIHR Doctoral research fellow investigating the neuro-immunological responses, particularly to infection. Other research interests include the clinical management of central nervous system infections and epileptology. I work closely with the Encephalitis Society, the Meningitis Research Foundation, the International Encephalitis Working Group and the National Patient Safety Agency to promote public and patient involvement in research and clinical practices development.



### Remember our running mad nurse – Claire Matata?

Due to a set-back, illness put a hold on Claire's triple marathon challenge to raise money for the encephalitis society.

However, the date is set for the final marathon which is the Dublin Marathon on 28<sup>th</sup> October.

Please consider supporting her if you're able at <http://www.justgiving.com/user/33389073>



### Remember those targets?

60 sites

960 participants in ENCEPH-UK Prospective studies; 160 in ENCEPH-UK Retrospective study

3000 in UK-ChiMES..... **SEE ON THE NEXT PAGE HOW WE, AND YOU, ARE DOING!**

Adult Site	In set up	Trained	Site Open	Recruiting	No in Prosp	No in Retro
Charing Cross Hospital	✓					
Chelsea and Westminster	✓	✓	✓	✓	1	
Hull and East Yorkshire	✓	✓	✓	✓	1	1
Royal Free London	✓	✓	✓	✓	3	
North Bristol	✓	✓				
Nottingham University Hospital	✓					
Royal Gwent Hospital	✓					
Royal Preston Hospital	✓	✓	✓	✓	5	3
South Tees Hospital			✓		2	
University of North Staffordshire	✓					
University Hospital of Birmingham	✓					
The Walton Centre	✓	✓	✓	✓	4	11
Morecambe Bay	✓	✓	✓	✓	2	
Royal Liverpool University Hospital	✓		✓	✓	25	9
St James' University Hospital- Leeds	✓	✓	✓	✓	6	
Bradford Teaching Hospital	✓	✓	✓	✓	8	
Salford Hospital	✓	✓	✓	✓	2	
Aintree University Hospital	✓	✓	✓	✓	4	1
York	✓	✓	✓		0	
Milton Keynes	✓	✓	✓	✓	0	
Arrowe Park	✓	✓	✓	✓	1	
Huddersfield/Calderdale	✓	✓	✓	✓	3	
North Cumbria University Hospitals	✓	✓	✓	✓	1	
Manchester Royal Infirmary	✓	✓	✓			
National Hospital for Neurology and Neurosurgery	✓					
North Manchester General Hospital	✓	✓	✓	✓	4	1
St George's Healthcare Trust	✓					
Mid Yorks (Pinderfileds)	✓	✓	✓	✓	3	
St Mary's	✓					
Oxford	✓					
Guys and St Thomas	✓	✓	✓	✓	3	1
Southampton	✓	✓	✓	✓	4	
Birmingham Heartlands	✓	✓	✓	✓	1	
Sheffield Teaching Hospital	✓					
South London and Maudsley	✓					
Kings College NHS Foundation Trust	✓					
Health Protection Agency						85
Encephalitis Society						9

# Useful websites

Have you checked out the e-learning modules at [www.braininfectionsuk.org](http://www.braininfectionsuk.org)

And when you need another one of those outcome scores etc go to [www.encephuk.org](http://www.encephuk.org)

Don't forget to support our running mad nurse raising money for the encephalitis society

[www.justgiving.com/claire-matata1](http://www.justgiving.com/claire-matata1)

[www.encephallitis.info](http://www.encephallitis.info)



**The Encephalitis Society**  
Support, Awareness & Research for Inflammation of the Brain



## Happy summer holidays!

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### Focus on outcome scores – what are they?

PROMs (patient reported outcome measures) measure a patient's health status or health-related quality of life at a single point in time, and are collected through short, self-completed questionnaires. What we refer to, as outcome scores are the Glasgow outcome score extended and the Liverpool outcome score.

**The Extended Glasgow Outcome Scale (GOS-E)** was developed to address the limitations of the original GOS, including the use of broad categories that are insensitive to change and difficulties with reliability due to lack of a structured interview format. The GOS-E extends the original 5 GOS categories to 8. The 8 categories are: Dead, Vegetative State, Lower Severe Disability, Upper Severe Disability, Lower Moderate Disability, Upper Moderate Disability, Lower Good Recovery, and Upper Good Recovery. A structured interview has been provided to improve reliability of rating. Good interrater reliability and content validity have been demonstrated for the GOS-E (Compared to the GOS, the GOS-E has been shown to be more sensitive to change in mild to moderate TBI).

The **Liverpool Outcome score (LOS)** is a validated outcome score in children with Japanese encephalitis and has been adapted for adults and for UK use.