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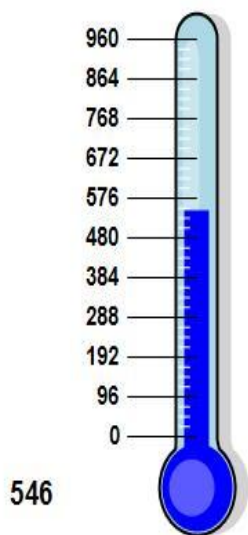


ENCEPH UK

Understanding and Improving
Outcome of Encephalitis



Thermometer Chart



Prospective suspected encephalitis recruitment: Adults and Paediatrics

Welcome to the ENCEPH UK Spring Newsletter!

We have now been recruiting patients with suspected encephalitis in ENCEPH UK for nearly a year and a half and in UK ChiMES for 15 months. There are 56 sites open across the country who are participating and our recruitment total is currently 546.

In this issue we will tell you more about one of our sub studies that some of your patients may have been involved with – the End User Experience. We will also update you on recent news and don't forget to check out where your site stands on our Recruitment Leader Board.

Save the Date!

Liverpool Neurological Infectious
Diseases Course | 21-23 May 2014

www.liv.ac.uk/neuroidcourse



Ever struggled with a patient with a brain infection? Then NeuroID is for you! Date: 21-23rd May 2014

The course features case presentations and talks by UK and international experts, as well as updates on the latest brain infections research including ENCEPH UK. You can register for the course here: www.liv.ac.uk/neuroidcourse

It's a must for any clinician with an interest in neurological infections!

End User Experience Sub Study

Understanding encephalitis from the perspective
of sufferers

What is the End-User Study?

The End-User experience study is a sub-study of ENCEPH-UK. The aim of this research is to explore the experiences of Herpes Simplex Viral (HSV) Encephalitis from the perspective of sufferers and their relatives/carers. The study's main focus is to examine the appropriateness, timeliness and adequacy of care for encephalitis across different stages of the clinical trajectory (prospective and retrospective cohort). This is being done because, at present, we know very little about how encephalitis and its treatment are experienced, alongside the ongoing consequences of the disease for sufferers and the people closest to them.

Paying attention to stories

The study uses a narrative research methodology, which pays close attention to the stories that people tell about their experiences. This approach allows for insight into how people experience events around encephalitis, and how these events are given meaning within their stories. By focusing upon stories we are able to gain an in-depth understanding of individual cases, as well as looking for patterns in the structure and meaning of people's stories. Issues which have been focused upon in the interviews include: how people make sense of a diagnosis of encephalitis, how people experience the care they receive during both the acute phase and after discharge from hospital, and how sufferers and their relatives negotiate the changes to their everyday lives as a result of ongoing difficulties from the disease.

Study Progress

The study has very nearly finished data collection, with just one interview left to complete! We have conducted 28 narrative interviews with 45 participants (23 patients (14 retrospective, 9 prospective) and 22 relatives/carers (13 retrospective, 9 prospective)). The interview data – consisting of hundreds of pages of transcripts from over 45 hours worth of recorded interviews – is now being analysed using a combination of narrative analysis (which looks at how people's stories are constructed) and thematic analysis (which looks for patterns, similarities, and variations across accounts). The results will be written up for publication later this year. It is hoped that the results will go some way to helping health professionals understand the devastating impact of encephalitis as well as how the care around this disease can be improved.



World Encephalitis Day: Does the University of Liverpool have the biggest brain?

To support World Encephalitis Day on February 22nd people from 38 countries and aged from one month to 83 years old took part in a successful new Guinness World Record attempt on the University of Liverpool campus. 650 people took part to create the largest ever brain made out of people.

To find out more and watch the video:
www.liv.ac.uk/worldsbiggestbrain

World Encephalitis Day has been developed by the Encephalitis Society as a time for people to connect and learn more about this devastating condition. The annual event will take place on the 22nd February each year and hopes to raise awareness of Encephalitis and its devastating effects.

Check out the website for more information:
www.worldencephalitisday.org

It has lots of resources to help your work place get involved and support World Encephalitis Day



Other News...

University of Liverpool's Institute of Infection and Global Health awarded 7.5m from National Institute for Health Research to establish two Health Protection Research Units

This exciting development will lead to one Liverpool HRPUs will be in Emerging and Zoonotic Infections, led by Professor Tom Solomon in collaboration with Liverpool School of Tropical Medicine. The other will be in Gastrointestinal Infections, led by Professor Sarah O'Brien in partnership with the Universities of East Anglia, Oxford and the Institute of Food Research

Recruitment Leader Board

Hospital	Date Opened to recruitment	Number of months opened	Total recruited	Recruit / Month
Royal Liverpool	18/10/2012	17	33	4.71
Milton Keynes	12/06/2013	9	11	1.20
The Walton Centre	19/12/2012	15	14	0.93
Bradford Royal Infirmary	03/01/2013	15	13	0.87
Aintree University Hospital	15/11/2012	16	11	0.69
Mid Yorkshire	22/03/2013	12	8	0.67
South Tees	11/07/2013	8	5	0.63
Southampton	28/02/2013	13	8	0.61
Calderdale & Huddersfield	05/06/2013	10	6	0.60
Leeds	19/12/2012	15	9	0.60
North Manchester General	01/02/2013	12	7	0.58
Birmingham Heartlands	10/06/2013	9	5	0.55
Manchester Royal	29/07/2013	8	4	0.50
St George's	28/11/2013	4	2	0.50
Morecambe Bay	19/12/2012	15	6	0.40
Royal Preston	04/02/2013	14	5	0.36
Guys & St Thomas	15/02/2013	13	4	0.31
Royal Free	08/02/2013	13	4	0.31
North Cumbria	15/02/2013	13	4	0.30
Arrowe Park	19/02/2013	13	4	0.30
Salford Royal	30/01/2013	14	4	0.29
York	24/04/2013	11	3	0.27
Chelsea & Westminster	08/03/2013	12	2	0.16
Hull & East Yorkshire	08/01/2013	14	1	0.07
St Mary's	30/10/2013	5	0	0
North Bristol	21/10/2013	5	0	0
Sheffield Teaching Hospital	13/02/2014	1	0	0

Check out the UK ChiMES Newsletter to see how the Paediatric sites are doing!



Neuropsychology

Please keep recruiting for the Neuropsychology substudy!

The neuropsychology part of the study aims to find the different types of cognitive problems (e.g. in memory, language or problem-solving) caused by different types of encephalitis.

Just a tick in the neuropsychology sub study box on the consent form and we can phone the patients to explain what we do. Please help us recruit more patients. Any questions contact Alison or Lara a.e.gummery@liv.ac.uk or lara.harris@kcl.ac.uk

Retrospective Study

Time is running out for the Retrospective Study! We really need you to send out packs to patients who have had suspected encephalitis up to 5 years *prior to your site opening* for recruitment.

REMEMBER: These patients count towards your data accrual with the UKCRN!

If you need any help, guidance or supplies contact the team below

NEW TRIAL - COMING SOON!

COHESIVE- Corticosteroid in Herpes Simplex Encephalitis

Do corticosteroids improve outcomes in *Herpes simplex* virus encephalitis? As many of you will know this is a vexed question! We now have the chance to answer it.

We are planning a randomized controlled trial of dexamethasone in adults with HSV encephalitis which will roll out across all ENCEPH-UK hospitals recruiting adult patients.

The pluses: it's an important question and it's a relatively simple study to add to your portfolio. Unlike ENCEPH-UK, which we know involves lots of patients with *suspected* encephalitis, the new treatment trial will **ONLY** be for those with **PROVEN HSV encephalitis**, so you are likely to see only 1-2 patients per year!

If you haven't already done so, please confirm you would like to know more by emailing: encephuk@liv.ac.uk



Useful contacts

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