



ENCEPH UK

Understanding and Improving the Outcome of Encephalitis



ENCEPH UK

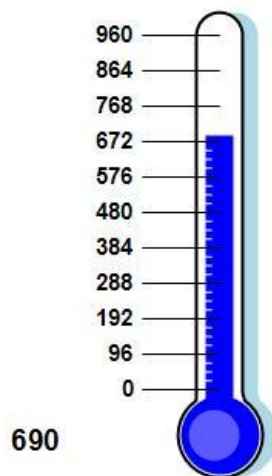
Hello and welcome to our Summer 2014 newsletter for ENCEPH UK.

Since the last newsletter we are now nearly up to the 200 mark for adult patients with suspected encephalitis recruited into ENCEPH UK!

Children with suspected encephalitis continue to be recruited at a steady rate for UK ChiMES with 488 patients giving us a total of **690 children and adults recruited with suspected encephalitis!**

Thank you for your continued support and hard work. Remember to check the recruitment table to see how your site is doing!

Thermometer Chart



Upcoming Event

Monday 1st December 2014

The Encephalitis Society Professional seminar is in its 7th year, hear the latest research development and news from leading professionals from around the globe. See Page 5 for details



Monitoring Visits

Now that the study has been recruiting for nearly two years we are coming out to all the sites for a visit, see below for details and some of the common issues picked up so far...

What to have ready...

One of the team will be in touch with your research team to request a date to visit. The two main things that need to be available are:

1. Case notes. The monitor will indicate which sets of case notes they need available on the day- please make sure they are available and if there is a problem let them know as soon as possible
2. Investigator Site File: make sure there is access to the file

...But remember a monitoring visit is a great way to raise any issues or concerns that you have and talk through any problems or queries with us!



What to look out for...

So far two common issues have come up across the sites:

1. Treatment Chart not filled in. This should be filled in for each patient recruited and is located on Openclinica after the CRF
2. Sample log not filled in. This also needs to be completed for each patient so we can run reports and see what samples we have where



Research Nurse Day

We hope to hold an update day in the North West shortly where we will be able to keep you posted on results and data so far as well as a good opportunity for discussion and feedback. Keep an eye out for a Save the Date email with more details soon.



Recruitment Leader Board

Hospital	Date Opened to recruitment	Number of months opened	Total recruited	Recruit / Month
Royal Liverpool	18/10/2012	22	37	1.68
The Walton Centre	19/12/2012	15	17	1.13
Bradford Royal Infirmary	03/01/2013	18	15	0.83
South Tees	11/07/2013	12	10	0.83
Aintree University Hospital	15/11/2012	21	14	0.66
North Manchester General	01/02/2013	17	9	0.58
Mid Yorkshire	22/03/2013	16	9	0.56
Leeds	19/12/2012	19	10	0.52
Southampton	28/02/2013	17	8	0.47
Birmingham Heartlands	10/06/2013	13	6	0.46
Calderdale & Huddersfield	05/06/2013	13	6	0.46
Manchester Royal	29/07/2013	12	5	0.41
Royal Preston	04/02/2013	17	7	0.41
Morecambe Bay	19/12/2012	19	6	0.31
Guys & St Thomas	15/02/2013	17	5	0.29
St George's	28/11/2013	8	2	0.25
Royal Free	08/02/2013	17	4	0.23
North Cumbria	15/02/2013	17	4	0.23
Arrowe Park	19/02/2013	17	4	0.23
Milton Keynes	12/06/2013	13	3	0.23
Salford Royal	30/01/2013	18	4	0.22
York	24/04/2013	15	3	0.20
Chelsea & Westminster	08/03/2013	16	2	0.12
Hull & East Yorkshire	08/01/2013	18	3	0.16
St Mary's	30/10/2013	10	1	0.10
North Bristol	21/10/2013	10	0	0
Sheffield Teaching Hospital	13/02/2014	5	0	0

Check the UK ChiMES newsletter for the
paediatric recruitment table!

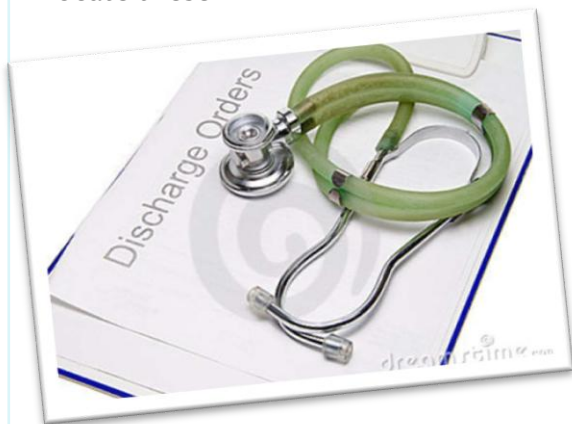
Did you know...?

You can recruit a patient after they have been discharged...

Have you recently found a patient that was eligible for the ENCEPH UK study but they had already been discharged? These patients can still be recruited!

We have ethical approval to recruit patients to the study **12 months** after discharge!!!

All you need to do is send one of our Introductory Letters, Patient Information sheet & Consent Form and one of our self addressed envelopes. Please contact us if you can't locate these



Discharge Questionnaires

Please remember to complete the discharge questionnaires with the patients who are recruited, we have recently seen a fall in these. As a reminder:

- EQ5D5L and SF36 are completed by the patient
- GOSE and LOS discharge are completed by the research nurse with the patient

These can be completed on or around discharge

Recruiting patients

There are great ways of identifying and recruiting patients into the study. Some of our research nurses share their tips below...


- Ask microbiology for daily lumbar puncture reports
- Ask pharmacy for weekly reports on who is prescribed acyclovir
- Screen CT/MRI lists and approach anyone with ?encephalitis
- Attend daily ward rounds
- Ask MAU and I.D ward to ring research nurse if anyone is about to perform an LP
- Ring us if you have any queries or not sure if a patient might fulfill the inclusion criteria



Save the Date

Monday 1st December 2014


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



Encephalitis

Professional Seminar

Monday 1st December 2014
Access the latest research and information from leading professionals



www.encephalitis.info

Encephalitis

Encephalitis is an often life-threatening illness caused by infection, usually viral, or by autoimmune diseases affecting the brain. Subsequently many people are left with an acquired brain injury, the degree and severity of which will vary. The Encephalitis Society is committed to promoting and assisting with research into Encephalitis.

Reasons to attend

- Access the latest research updates
- Earn CPD points
- Networking
- Multidisciplinary audience

Monday 1st December 2014
13:00 – 18:00
MacFarlanes LLP
20 Cursitor Street, London, EC4A 1LT

Book your place now

Places are free to our Professional Members. You can join online directly from our website. Numbers are limited, so get in touch now.

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Registered Charity Number: 1087848
Charitable Company Number: 4189027

The Encephalitis Society is kindly offering **FREE** places to any PI, Co-Investigator or Research Nurse involved with ENCEPH UK so make sure you take advantage of this fantastic opportunity!

Modified Amendment 19



You should all have recently received an email notifying you of our recent modified amendment 19 and the new documents approved.

In order for you to use the new documents the acknowledgement receipt needs to be signed by the PI and returned to us by email or fax

Please send back as soon as possible!



Useful Contacts

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National Institute for
Health Research


Meningitis
Research Foundation

 UNIVERSITY OF
LIVERPOOL


Brain Infections UK.org
A Portfolio of Research Studies



ENCEPH- UK cohort studies