Welcome to the ENCEPH UK Autumn 2014 Newsletter!

Since the last newsletter we have recruited a total of 226 adult patients and 508 paediatric patients with suspected encephalitis into ENCEPH UK study! This brings our grand total of patients to **734**.

**Thermometer Chart**

Prospective suspected encephalitis recruitment (adults and pediatrics).

Recruitment for suspected encephalitis is going **really well**. Unfortunately we are lacking certain cases, especially **proven causes of encephalitis** and in particular **HSV**.

See the next page for top tips for patient recruitment.

**Upcoming Events!**

We would like to thank everyone who responded to the Research Nurse Update Day survey.

The responses were positive and we will be holding an event in the new year. Details to follow.

If you think of anything that you would like further information on but didn’t manage to complete the survey please email: encephuk@liverpool.ac.uk
Patient Recruitment – Top Tips

- Ask microbiology for daily lumbar puncture reports
- Ask pharmacy for weekly report on who is prescribed aciclovir
- Attend daily ward rounds
- Ask Medical Assessment Unit and Infectious Diseases ward to ring researchers if an LP is being performed
- Screen CT/MRI list and approach anyone with encephalitis

Patient enrolment reminder

Please make sure that once you have updated OpenClinica you fax the below completed documents:
- Enrolment form – 2 pages
- Consent form – 3 pages
- Contact details form – 1 page

If you are doing a consultee declaration:
- Relations to patient – 1 page

Samples

A new system to track samples that have been received from sites has been created so that we can locate patient samples easily.

It is vital for this system to work that the sample logs are completed on OpenClinica.

If you need any samples collected please email h.e.jelleyman@liverpool.ac.uk
## Recruiment Leaderboard

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Date Opened to recruitment</th>
<th>Number of months opened</th>
<th>Total recruited</th>
<th>Recruit / Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Royal Liverpool</td>
<td>18/10/2012</td>
<td>23</td>
<td>40</td>
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</tr>
<tr>
<td>Royal Berkshire</td>
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<td>4</td>
<td>4</td>
<td>1.00</td>
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<tr>
<td>South Tees</td>
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<td>14</td>
<td>13</td>
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<tr>
<td>Walton</td>
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<td>21</td>
<td>17</td>
<td>0.85</td>
</tr>
<tr>
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<td>03/01/2013</td>
<td>20</td>
<td>17</td>
<td>0.85</td>
</tr>
<tr>
<td>Aintree</td>
<td>15/11/2012</td>
<td>22</td>
<td>15</td>
<td>0.68</td>
</tr>
<tr>
<td>North Manchester General</td>
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<td>19</td>
<td>12</td>
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<tr>
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<tr>
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<td>9</td>
<td>0.50</td>
</tr>
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<td>19</td>
<td>9</td>
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<tr>
<td>Arrowe park</td>
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<td>7</td>
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<tr>
<td>Guys &amp; St Thomas</td>
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<td>5</td>
<td>0.26</td>
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<tr>
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<td>York</td>
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<tr>
<td>Hull &amp; East Yorkshire</td>
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<tr>
<td>North Bristol</td>
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<tr>
<td>Oxford John Radcliffe</td>
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<td>0.00</td>
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<tr>
<td>University College London</td>
<td>28/08/2014</td>
<td>1</td>
<td>0</td>
<td>0.00</td>
</tr>
</tbody>
</table>

We would like to say a big THANK YOU for your continued support with recruitment into ENCEPH UK.

For the paediatric recruitment figures please check the UK ChiMES newsletter.
The outcome scores: Glasgow Outcome Score Extended, Modified Rankin and Liverpool Outcome Score are to be completed at:

- Discharge
- 3 months after discharge
- 12 months after discharge

The final score is to be added to the CRF at the relevant time point: Open Clinica.

A copy of the scores is to be forwarded via fax ensuring the subject ID is on each page of the document.

We appreciate it can be difficult to get a hold of patients at the follow-up points but unfortunately completion of outcome scores is low across the study and it is one of the main outcomes.

When you are speaking to the patient please remind them to complete the questionnaires that have been sent.

Please can you make every effort to contact the patients as we really need this data to be collected. If after 3 attempts you are unsuccessful please email encephuk@liverpool.ac.uk.

If we can assist in any way for these then please do get in touch.

dexENCEPH

dexENCEPH is a prospective randomised controlled trial that will compare the outcomes between patients with herpes simplex virus (HSV) encephalitis that do or do not receive corticosteroids.

Co recruitment with ENCEPH UK will not be a problem. Further information will be coming shortly.

If you are interested in participating in this study or have any questions about it please let us know by emailing Cristina.fernandez@liverpool.ac.uk.
1. You can recruit patients after discharge

If you have identified a patient but they have been discharged prior to you giving them a patient information sheet up to 12 months post discharge.

We have ethical approval to send the below information sheet out to patients to provide them with the opportunity to participate in the study;

- ENCEPH UK Prospective Cohort Study Introductory Letter

2. Notify of patient deaths

Please make sure you let the team know if a patient dies within 2 - 3 days of becoming aware to prevent questionnaires being sent out causing undue distress to family members.

3. Put Subject IDs on ...

- **Questionnaires** you give to patients at discharge
- **Outcome scores** that you complete and fax at 3 and 12

4. Discharge Letters & Scan Reports

This is important so we can classify the patients into groups to see if we have adequate numbers of patients recruited.

5. Screening Logs and Non Enrolled Logs

It is important that you send in your screening logs on a monthly basis so that we can see your site activity and will be able provide targeted support on a site by site basis.
Last but not least...

I would like to introduce Greg Gibson to the team as the ENCEPH-UK/UK Meningitis Administrative Assistant. Greg will be the main contact for patient enrolment, replenishing study supplies and providing general support.

Useful Contacts

Brain Infections UK fax number 0151 795 5528

**Clinical Research Fellow**
Sylviane Defres
sdefres@liv.ac.uk

**Programme Manager**
Hayley Jelleyman
h.e.jelleyman@liverpool.ac.uk

**Data Manager**
Chloe Smith
chloenyc@liv.ac.uk

**Administrator**
Greg Gibson
Greg1@liverpool.ac.uk

**Information systems developer**
Richard Crew
R.Crew@liv.ac.uk
EBOLA questionnaire

Researchers at the HPRU are inviting doctors, nurses and other healthcare workers to help us understand their thoughts about helping with the Ebola outbreak in West Africa, by filling in a simple survey.

https://www.surveymonkey.com/s/HPRUebola

The results will help to identify and, therefore, potentially address any modifiable barriers there might be to people helping in West Africa.

First-hand experience – Andrew Bosworth

To learn about the first-hand experience of Liverpool HPRU PhD student, Andrew Bosworth, who provided support to healthcare workers trying to contain the virus in West Africa, please visit:

http://news.liv.ac.uk/2014/08/07/phd-student-works-on-ebola-frontline-2/e