



**ENCEPH UK**

Understanding and Improving the  
Outcome of Encephalitis

## Welcome to the ENCEPH UK Spring Newsletter 2015

We're a bit overdue in our newsletters to you all! A sign of how busy we are in this the final year of recruitment into ENCEPH-UK and UK-ChiMES. The UK ChiMES newsletter will highlight the paediatric aspects. In ENCEPH-UK, overall recruitment has been going well, though a couple of sites have dwindled off; we know how difficult it is when there are staff changes, but please do keep on in there!

**We have now entered our last year of recruitment to the Enceph UK study. We have a lot of work to do before 31<sup>st</sup> December 2015 and we want to make sure we have as much complete data as possible before then, so please make sure you are completing all data in a timely and accurate manner. Following on from our site document review reports, we will be sending out data queries to all sites starting next week so please try and complete these within 2 weeks of receiving them.**

The thermometer over the page shows only the cases of encephalitis due to Herpes simplex virus (HSV) because this relates to the power calculations for the study to develop a clinical predictor tool. It shows we've still got a bit to go. Hence our emails about contacting your local laboratories and encouraging them to get data on past positive CSF samples for HSV, to try and optimise these numbers. These patients can be contacted retrospectively and recruited into the prospective study should they agree. Indeed on a clinical note I've had patients keen to be in the study, months after their admission, especially when they are starting to appreciate the sequelae they are experiencing! So please do try and get these lists and send out invitation letters.

In November, we said a sad farewell to Chloe Smith, who has moved over to the Liverpool Cancer Trials Unit, and in February, we also said goodbye to Richard Crew who has now joined the Clinical Trials Research Centre. They are both still working within the University of Liverpool so we'll see them around but we'd just like to say a huge thank you to both of them for their massive contributions to the study. Good luck in your new roles!

Please do enjoy this newsletter, with some updates on where we're at with these studies, publications, and new studies. We look forward to reviewing and analysing this data so please do try and complete as soon as possible.

Thank you again for all your hard work on this.

Dr Sylviane Defres  
Clinical Research Fellow

A handwritten signature in black ink, appearing to read 'S Defres', written in a cursive style.

Professor Tom Solomon  
Chief Investigator

A handwritten signature in black ink, appearing to read 'Tom Solomon', written in a cursive style.

## Recruitment Targets

In this newsletter we are focusing on HSV encephalitis patient recruitment – one of the planned outcomes of the study is a predictor for HSV encephalitis, to be able to achieve this we need to reach a set number of cases within our overall recruitment. The thermometer shows where we are in relation to our target.

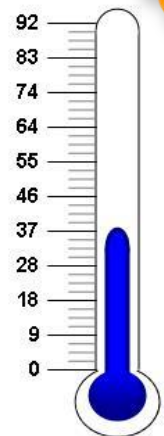
We currently have an estimated 38 cases where we need at least 92 cases to achieve significance. We've got roughly 40% of the cases we need since the study started so it will take a big push to get the other 60% before the study closes.

### Reaching the target

You can help us to reach our target by requesting your microbiology lists for positive HSV PCRs with suspected/ diagnosed encephalitis. You can recruit patients into the Prospective Study up to one year after discharge so please ask your microbiologists/labs to provide you with the lists (if you haven't already) to help boost recruitment!

**We still haven't reached our diagnosed encephalitis target yet so all patients meeting the suspected criteria are important and will help us make an impact on future encephalitis outcomes!**

HSV Encephalitis



38

## Outcome scores

We've noticed that there are a large number of outcome scores missing or 'unknown' from CRFs. Please note that you can complete the GOSE and LOS questionnaires with patients **up to 2 weeks after discharge**, and the questionnaires can be completed over the phone if you don't manage to do them in person before discharge. You can also complete the Modified Rankin Scale from patient notes. Likewise for the follow up time points if you can't get them on the phone, you may be able to deduce scores from clinical notes if they have had a follow up appointment.

If you are unsure about completing assigning a score from the questionnaires you can send over the completed questionnaires to us and we will assign the score here.

If you have any further questions about outcome scores please get in touch.

### NEW SITES OPENED!

Since our last newsletter we've been busy opening sites, we're very pleased that the following sites have now joined the study:

- Royal Infirmary Edinburgh
- University Hospitals of North Midlands
- King's College Hospital



## Leaderboard – Adult Recruitment

Rank	Site	Total recruited	Recruits per month
1	Royal Liverpool	42	1.45
2	Royal Berkshire	8	0.89
3	Walton	19	0.70
4	South Tees	14	0.70
5	Bradford Teaching	18	0.69
6	Aintree	16	0.57
7	Leeds	13	0.48
8	North Manchester General	12	0.48
9	Salford Royal	11	0.44
10	Calderdale & Huddersfield	9	0.43
11	Arrowe Park	10	0.40
12	Royal Preston	10	0.40
13	Mid Yorkshire	9	0.38
14	Sheffield Teaching Hospital	5	0.38
15	Birmingham Heartlands	8	0.38
16	Southampton	9	0.36
17	Manchester Royal	7	0.35
18	Guys & St Thomas	8	0.32
19	North Cumbria	8	0.32
20	Morecambe Bay	8	0.30
21	Oxford John Radcliffe	2	0.25
22	York	5	0.22
23	Royal Free	4	0.16
24	St Georges Hospital	2	0.14
25	Milton Keynes	3	0.14
26	St Mary's Charing Cross	2	0.13
27	Chelsea & Westminster	3	0.13
28	Hull & East Yorkshire	3	0.12
29	North Bristol	0	0.00

Well done to those at the top! If you're at the bottom keep trying to recruit those patients, we have posters and strategies to aid recruitment, if you're struggling get in touch.



# Welcome Anna!

*This month we welcomed Anna Bridge to the Enceph UK Team. She will be working as Data Manager and will be the main contact for queries on the Enceph UK Study.*



My background is in forensic psychology and mental health. I completed my BSc and MSc in Forensic Psychology at the University of Central Lancashire in 2005/6 before undertaking various clinical and research roles in forensic mental health and mental health in the NHS. My last role involved working as a research assistant on a multi-site study investigating the effectiveness of the early intervention for psychosis services in the NHS. My current role as a data manager is based within the Brain Infections Clinical Research Team. Some of my main roles include data entry, chasing up outstanding documents and enrolment for ENCEPH.

Outside of work I love spending time with my partner and our 11 month old daughter Savannah, as well as seeing friends as often as I can. I am highly passionate about health, fitness and nutrition, and enjoy going working out at the gym and running. I also love cooking, spending time outdoors, educating myself on personal development and wellbeing, as well as travelling and exploring other cultures. I dislike junk food, being indoors for too long, and being unorganised!

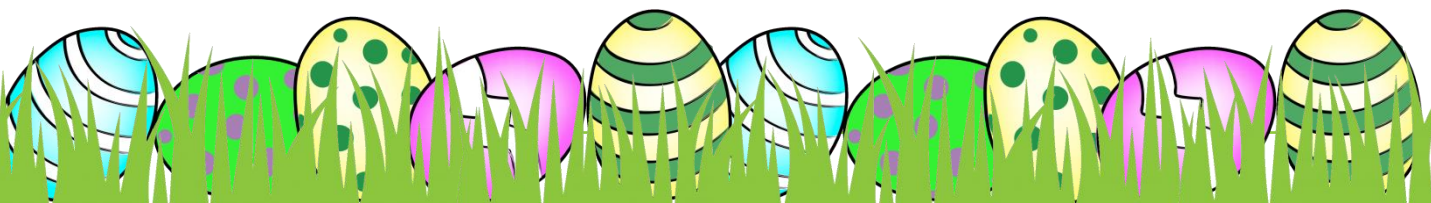
## DexEnceph Update!



We're pleased to say the DexEnceph study setup is going well, the protocol has been approved by the steering committee and will soon be submitted to ethics. We are creating an app to make recruitment simple, and we're hoping to recruit our first patient in October 2015!

We will need to open 100 sites to reach our recruitment targets – so if you would like to be involved in the study please get in touch with Cristina Fernandez via email [cristina.fernandez@liverpool.ac.uk](mailto:cristina.fernandez@liverpool.ac.uk) to be one of the first sites opened.

And remember to let your local labs know about the HSV hotline (07714 271 804) where they can notify all your HSV positive CSF results for ENCEPH UK!



## Upcoming Events

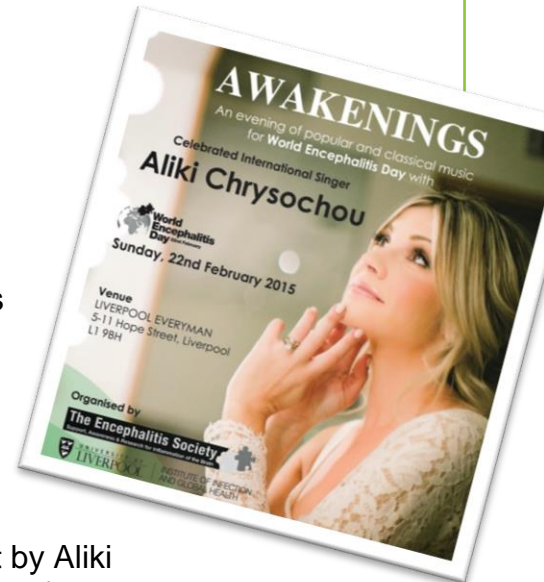
The Encephalitis Society are hosting their annual Family Weekend from 21<sup>st</sup> – 24<sup>th</sup> August, at the Hollowfield Centre in the Peak District, which may be a nice thing to mention to any patients you see between now and then. More information via the link below.

<http://www.encephalitis.info/awareness/news/news-and-events/>

## News

### World Encephalitis Day 2015

We recently celebrated the second World Encephalitis Day on 22<sup>nd</sup> February 2015, following on from the success of last year's launch. This year included a special 'Awakenings' concert with **Aliki Chrysochou** (*Britain's Got Talent*) organized by The Encephalitis Society. Ambassadors **Rebecca Adlington OBE**, **Simon Hattenstone** and **Mathew Bose** were also in attendance with keynote speaker **Professor Tom Solomon**.



If you missed the events, you can listen to the webinars and the concert by Aliki again on <http://www.worldencephalitisday.org/world-encephalitis-day-2015/>

### Brain infections research highlighted as 'most impressive' in Medical Schools Council Report

The Medical Schools Council has highlighted brain infections research at the University of Liverpool as having significant impact on people, policy, and the economy.

The research led to the introduction of vaccines in 11 new countries, reaching 200 million people, and avoiding up to 854,000 cases and 214,000 deaths.

<http://news.liv.ac.uk/2015/02/12/brain-infections-research-highlighted-impressive-medical-report/>



### Moxon Medal Awarded to Professor Tom Solomon

<http://www.liv.ac.uk/infection-and-global-health/news/articles/moxon-medal-awarded-to-professor-tom-solomon/index.htm>

You can also read Tom's article 'The Mystery of the Incredible Human Brain' [here](#).



## Monitoring Reports & Screening Logs

Since Chloe left in November, Hayley has been circulating site document review reports to address missing data as well as requesting screening and sample logs. For the most part we have had a great response from sites, but if you have not yet responded please make an effort to correct all queries and send over your screening log as soon as possible.

## Data Reminders

Time point	Document	OpenClinica™	Send to Enceph UK Team?
Recruitment	Consent form	Enter on OC (if possible)	Yes
	Enrolment form	Enter on OC (if possible)	Yes
	Contacts details form	Enter on OC (if possible)	Yes
Discharge	Outcome scores	Enter on OC (in CRF)	Yes
	Questionnaires	Enter on OC	Yes
Up to 1 month post discharge	CRF	Enter on OC	No
	Treatment chart (as part of CRF)	Enter on OC	No
	Scan reports (MRI/CT)		Yes
	Discharge letter		Yes
3 months post discharge	CRF	Enter on OC	No
	Outcome scores	Enter on OC (in CRF)	Yes
12 month post discharge	CRF	Enter on OC	No
	Outcome scores	Enter on OC (in CRF)	Yes

Below is a table of all the time points in the Enceph UK study and what data needs to be collected by you at each point and what needs to be done with it.

Remember to send all outcome scores to the Enceph UK Team. You can send any anonymised documents by fax to 0151 795 5528 or by email to [encephuk@liverpool.ac.uk](mailto:encephuk@liverpool.ac.uk).

You can send documents with patient identifiable data (this should only include enrolment documents) by fax or, if you have password protected the documents, by email. You can also send patient identifiable data to Sylviane's NHS email at [sdefres@nhs.net](mailto:sdefres@nhs.net) but please let the team know to expect an email to this account.

## Ebola Questionnaire Results

In the last newsletter we asked for responses to a questionnaire about health practitioners joining the aid in West Africa for the Ebola outbreak. You can read the article below about the results of the questionnaire.

**What holds doctors and nurses back from volunteering to fight Ebola in Africa?**



# Focus on...

## Enrolment

Recently we've been having a lot of enrolments come through that have been queried/incorrect and so enrolment has been delayed or invalid. To avoid this in future please read the pointers below.

### **In general:**

- Make sure you are on the delegation log.
- Don't send documents by email unless you can password protect/encrypt the data, or they are going from nhs.net to nhs.net email – you can email [sdefres@nhs.net](mailto:sdefres@nhs.net) but please let us know to expect your email.
- Make sure to include the complete screening number on all documents \_\_ A \_\_\_\_.
- You should send a minimum of 6 pages.

### **Consent form (3 pages):**

- Please do not email/fax/post any forms without the consent form included (or the consent form having already been sent). This would constitute a data breach.
- All parts of the main study should be initialed for consent – otherwise the patient is not eligible to join the study.
- All boxes on the consent form should be completed.
- Make sure the patient has signed and dated the consent form, as well as the member of research staff.
- There are three pages to the consent form, we require them all.
- Make sure the consent form (and the patient information sheet) is the correct version – currently version 7, 12th May 2014.

### **Enrolment form (2 pages):**

- Make sure to complete all boxes on the enrolment form –if 2A) is completed this includes all symptoms (no if unknown or not present).
- Make sure the DOB and date of consent are present and correct.
- Make sure to include the second page, signed and dated.

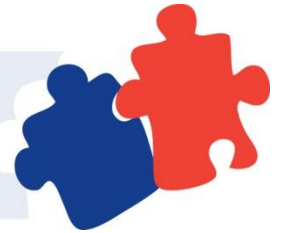
### **Contact details form (1 page patient consent, 2 pages consultee/nominated assent):**

- If the patient has joined the study under consultee/nominated assent please also send the contact details form for the consultee/nominated member of staff.

We are happy to answer any queries, if you are unsure ask – it's better to ask 50 questions than to lose the patient.

# The Encephalitis Society

Support, Awareness & Research for Inflammation of the Brain



World Encephalitis Day

## 5 LIVE WEBINARS, 5 DIFFERENT TYPES OF ENCEPHALITIS, 5 CONTINENTS

Did you know 500,000 people globally will be struck down by encephalitis each year? That's the same as the entire Edinburgh population. And most people have never heard of the condition!

As part of a plan to educate the world on encephalitis and to make sure those affected get speedy diagnosis and treatment, five of the world's leading neurologists and paediatricians hosted webinars from across 5 continents, reaching over 13 million people globally!

## 21<sup>st</sup> Birthday Year of The Encephalitis Society!

The Society is visiting 21 cities around the UK and Ireland in 21 days in August! An incredible challenge to help increase awareness and understanding amongst the general public.

1 <sup>st</sup> August 2015	Aberdeen
2 <sup>nd</sup> August 2015	Glasgow
3 <sup>rd</sup> August 2015	Newcastle
4 <sup>th</sup> August 2015	Leeds
5 <sup>th</sup> August 2015	Manchester
6 <sup>th</sup> August 2015	Liverpool
7 <sup>th</sup> August 2015	Belfast
8 <sup>th</sup> August 2015	Dublin
10 <sup>th</sup> August 2015	Colwyn Bay
11 <sup>th</sup> August 2015	Nottingham
12 <sup>th</sup> August 2015	Norwich
13 <sup>th</sup> August 2015	Cambridge
14 <sup>th</sup> August 2015	Oxford
15 <sup>th</sup> August 2015	Birmingham
16 <sup>th</sup> August 2015	Cardiff
17 <sup>th</sup> August 2015	Bristol
18 <sup>th</sup> August 2015	Exeter
19 <sup>th</sup> August 2015	Truro
20 <sup>th</sup> August 2015	Plymouth
21 <sup>st</sup> August 2015	Southampton
22 <sup>nd</sup> August 2015	London

## We need all the support we can get! Can you help?



Do you own or work for a business in any of the cities above that might be interested in sponsoring the Roadshow?



Could you volunteer in your city? The more people we have volunteering the greater our impact.



Are you aware of a compelling patient story locally that could help us promote the roadshow to local media/press?

If you have any ideas or can help in any way then please get in touch with The Society team on [mail@encephalitis.info](mailto:mail@encephalitis.info) or call 01653 692583, as we would love to chat this through further with you!



## Publications

### The evaluation of a tailored intervention to improve the management of suspected viral encephalitis: protocol for a cluster randomised controlled trial.

Backman R, Foy R, Diggle PJ, Kneen R, Defres S, Michael B, Medina-Lara A, Solomon T. Implement Sci. 2015 Jan 27;10(1):14. [Epub ahead of print]

### Measles-induced encephalitis.

Fisher DL, Defres S, Solomon T. QJM. 2015 Mar;108(3):177-182. Epub 2014 May 26. Review.

### The British antibiotic and silver-impregnated catheters for ventriculoperitoneal shunts multi-centre randomised controlled trial (the BASICS trial): study protocol.

Jenkinson MD, Gamble C, Hartley JC, Hickey H, Hughes D, Blundell M, Griffiths MJ, Solomon T, Mallucci CL. Trials. 2014 Jan 3;15:4. doi: 10.1186/1745-6215-15-4.

## Contacts

For technical queries you can contact Hayley Jelleyman.  
For general queries please contact Anna Bridge.



Enceph UK email:  
[encephuk@liverpool.ac.uk](mailto:encephuk@liverpool.ac.uk)

Clinical Research Fellow  
Sylviane Defres  
[sdefres@liv.ac.uk](mailto:sdefres@liv.ac.uk)

Programme Manager  
Hayley Jelleyman  
[h.e.jelleyman@liv.ac.uk](mailto:h.e.jelleyman@liv.ac.uk)

Brain Infections UK fax number  
0151 795 5528

Administrator  
Greg Gibson  
[greg1@liverpool.ac.uk](mailto:greg1@liverpool.ac.uk)

Data Manager  
Anna Bridge  
[anna.bridge@liverpool.ac.uk](mailto:anna.bridge@liverpool.ac.uk)

Do you have any questions or topics you would like addressing in the next newsletter?  
Do you have any news you'd like to share? Email [greg1@liv.ac.uk](mailto:greg1@liv.ac.uk) before the end of June 2015.



Excellence in Neuroscience



ENCEPH-UK cohort studies



UK-ChiMES  
UK Childhood Meningitis and Encephalitis  
cohort Study

