Issue 2 October 2016

EPIPEG

Epilepsy in infancy: relating to phenotype and genotype

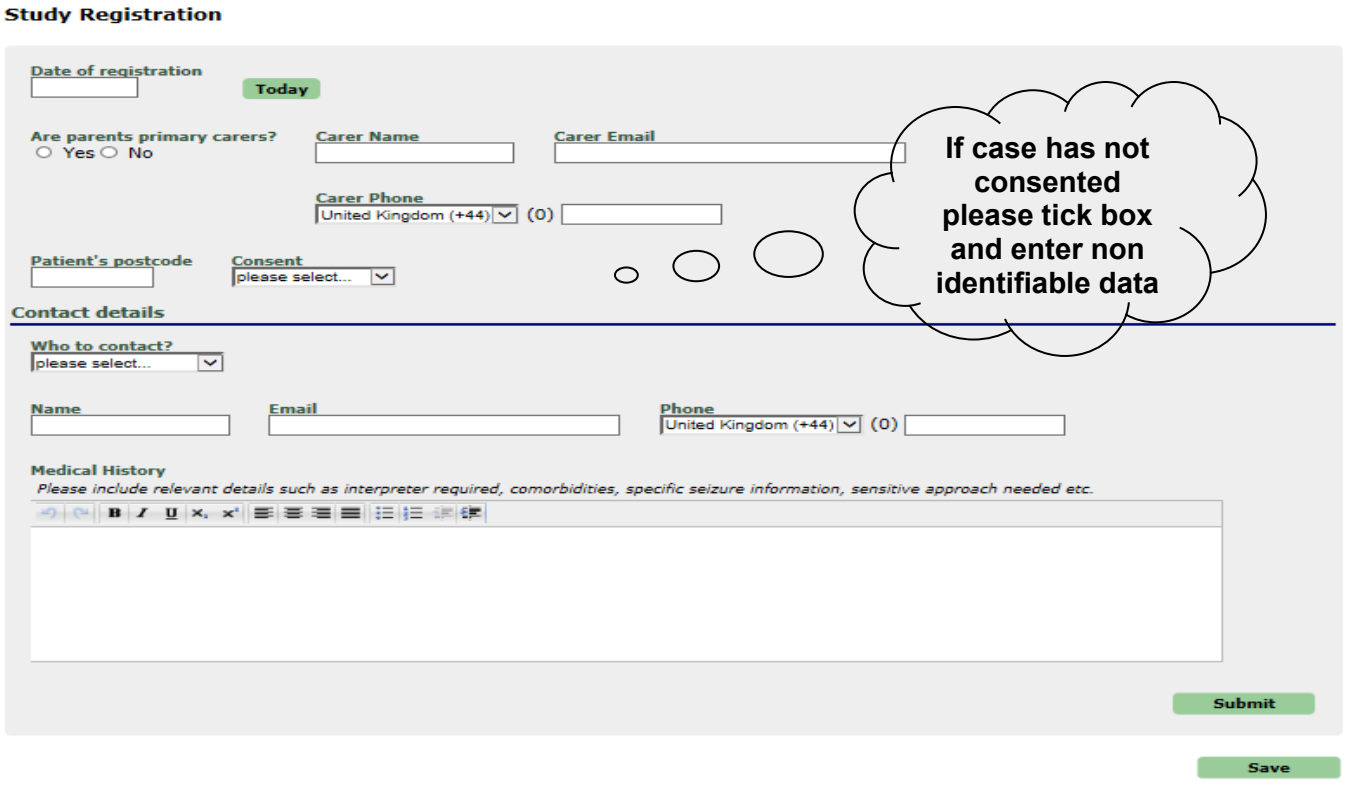
*****NOW RECRUITING*****
28 February 2016 – 31 July 2017

http://www.epipeg.co.uk or click on logo
Database access: https://orioncloud.org/
Phone: 01342 832243 ext 491 or 07827819453
Email: epipeg@youngepilepsy.org.uk

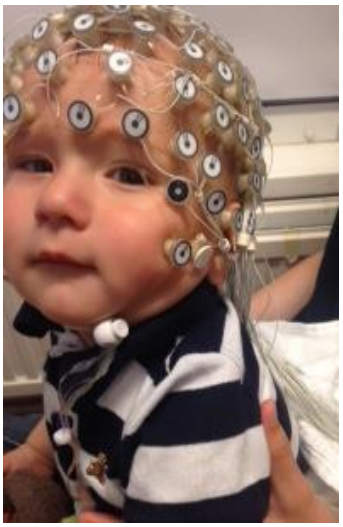
What we ask from you

1. **Take verbal consent for forwarding contact details**
2. **Alert us by registering patient on ORION database https://orioncloud.org (consenting and non-consenting cases – see screenshot below)**
3. **Update any changes in the interim on the database i.e. medication, seizure type/frequency (at clinic)**

   OR email clinic letter to helen.cross@gosh.nhs.uk



Just a reminder that this is an epidemiological study, your results are just as valuable if you have 0% eligible cases as if you had 100%.

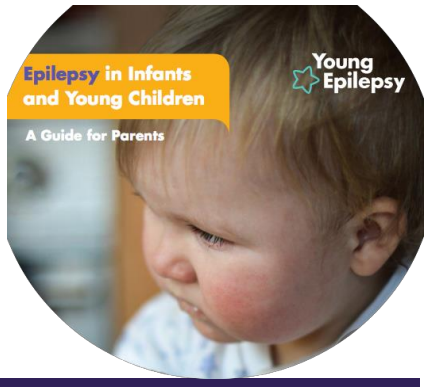


Thank you for your continued support and participation for this very important study.

We are now in the substantive phase now and have a growing number of referrals- thanks to the great effort from sites! Our home visits have been going well with both the families and child enjoying the assessments.

A Guide for Parents

Experts from Great Ormond Street Hospital and Young Epilepsy have designed a guide to give parents and carers essential information about living with, and managing epilepsy in infants. Please follow this link for the interactive guide: http://www.youngepilepsy.org.uk/dmdocuments/Infant-handbook-interactive.pdf



PLEASE EMAIL EEG AND MRI CONTACTS

To ensure gold standard data collection we are using a three-source capture-recapture methodology. Therefore it would be very helpful if you could email epipeg@youngepilepsy.org.uk with the details of where your MRI and EEGs take place.

PLEASE INFORM US ABOUT LOCAL MEETINGS

If there are any meetings you would like us to come to we would be more than happy to talk to you about our project. Please let us know the date, time and place of meeting by email or telephone on 01342 832243 ext 491 or 07827819453.

Eligibility Criteria:

- **4 weeks – 12 months**
- **Newly diagnosed epilepsy, history of ≥2 unprovoked seizures (except febrile seizures ≥15 minutes duration)**
- **If seizure onset in first 4 weeks of life and continuing beyond this age**

Exclusion Criteria:

- **Seizures provoked by acute conditions, such as fever (febrile seizures <15 minutes), infections, trauma, electrolyte disturbances, transient metabolic/endocrine disorders and neonates with seizures that do not recur after 28 days of age**

Please note we have altered the blood pathway please follow new steps from now on

Take bloods and send for baseline testing as part of your usual clinical pathway. Clinicians submitting the samples please submit a standard diagnostic test referral requesting the early infantile epileptic encephalopathy (EIEE) panel through normal route (i.e. their local regional genetics laboratory) and clearly request that a copy of the report is sent to:

Professor Helen Cross,
EPIPEG PI Clinical Neurosciences,
UCL Great Ormond Street Institute of Child Health,
4th Floor PUW South,
30 Guilford Street,
London WC1N 1EH.

We will send a sticker in study pack to put onto sample for your convenience. If appropriate please take a sample for DNA storage from parents and child at the same time and forward to GOSH via usual route for gene panel (no longer via study envelopes).

1. **If the baseline test are non-diagnostic or inconclusive, please forward blood samples to GOSH via usual route for gene panel (no longer via study envelopes). If by this point you have not taken blood from the parents, please do so and send to GOSH along with the child's sample.**
2. **Internally we will review results and determine the need for whole exome sequencing/other.**
3. **We will share results with you.**

Child Brain Research

Sparks
THE CHILDREN'S MEDICAL RESEARCH CHARITY

Charles Wolfson Charitable Trust

The True Colours Trust