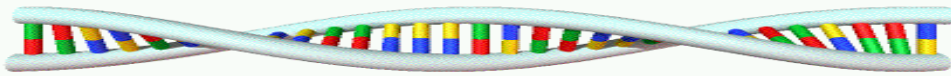


September 2009

Newsletter 16

**UK Stroke
Genetics
Group**

Stroke Genetics Newsletter A DNA Resource for Lacunar stroke



New Study Coordinator - Eithne Smith

As you are probably aware, I have taken over from Sam Febrey as Study Coordinator for the DNA Lacunar Study. I am contactable at the same email address (strokegenetics@sgul.ac.uk) or by phone at 0208 7255403.



I have come here from Cancer Research UK where I worked as a Clinical Data Manager and Clinical Research Associate and am very excited about my new role at St. George's. I am looking forward to working with you all and meeting many of you. If there is anything I help with, please do not hesitate to contact me.

I would like to say a huge thank you to Sam for all her work on the study and her help during the handover.

Chief Investigator:
Hugh Markus

Study Coordinator:
DNA – Eithne Smith
Tel: 020 8725 5403

Contact:
St. George's
University of London
Cranmer Terrace, London
SW17 0RE
Fax: 020 8725 2950

Email:
strokegenetics@sgul.ac.uk



Recruitment: 580 Patients, 1739 Controls

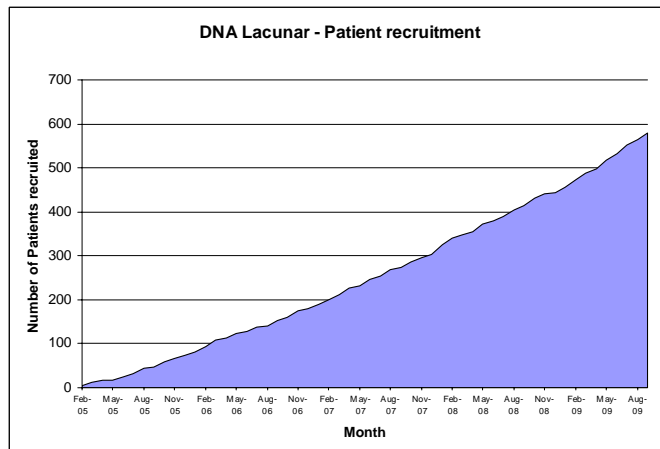
We have now recruited 580 patients to the study so we have passed the halfway point!

79 patients have been recruited since the beginning of May with an excellent month in July, hitting our target of 20 patients recruited per month. Things slowed down during the holiday period in August with 11 patients recruited, so I'm hoping we can reach or even exceed our 20 per month target for the rest of the year.

Leeds, Edinburgh Western General and Torquay have been recruiting very well recently, with 11, 9 and 8 patients respectively since May.

Blackpool and North Staffordshire have recently recruited their first patients, hopefully with many more to come!

Thank you to all sites who are working hard to recruit patients to the study, your efforts are appreciated and keep up the good work!



In this issue:

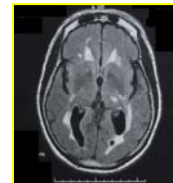
New Coordinator **1**
Patient Recruitment Update

Control Recruitment Update **2**
EDTA Tubes
Study Website
Some Quick Reminders

Data Collection Form Completion Tips **3**
Recruitment Table

Stroke Genetics Newsletter

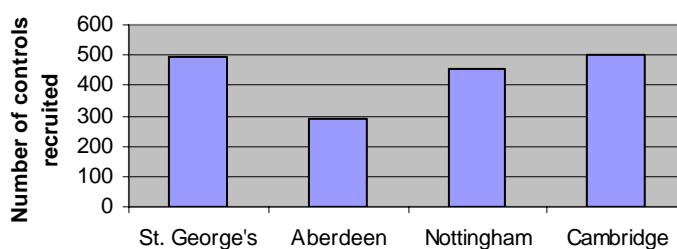
A DNA Resource for Lacunar stroke



Control Recruitment

Control recruitment is still progressing very well. Both St. George's and Cambridge have completed control recruitment, Nottingham have passed the 450 mark and Aberdeen have recruited almost 300. We are now 87% complete, requiring 261 more controls.

DNA Lacunar Control Recruitment



EDTA Tubes

Until recently, we were providing both pink and purple tubes as it was thought there was a problem with the purple tubes cracking when frozen.

However, other studies have been successfully using the purple tubes so I will no longer be sending the additional pink tubes.

If anyone does experience any difficulties or would prefer to continue with the pink tubes please let me know.



Study Website

www.strokegenetics.co.uk

The website is a useful resource for information such as:

- Recruitment figures
- Latest documents
- Presentations from previous investigator Meetings
- FAQs

If there is anything else you would like to see on the website, please let me know.

Some quick reminders...

UKCRN Uploads

Only eligible patients are uploaded to the website. Cases can only be reviewed when all the necessary data has been received, therefore, there may be a delay from when the patient is recruited to when they appear on the UKCRN database.

Changes in P.I.

If there is a change of P.I. at your site, please let me know and forward a copy of the approval letter from your R & D department.

Anonymise Data

All supporting data sent, including MRI CDs should be identified only by the patient's study ID number.

Contracts

Please return the new version of the contract to me as soon as possible so that I can ensure they are all approved quickly. Thank you to all who have already done this.

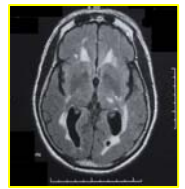
Study Extension Approval Letter

Please send a copy of the letter from your R&D Department approving the extension of the study.

Thank you!

Stroke Genetics Newsletter

A DNA Resource for Lacunar stroke



Data Collection Form Completion Tips

Just a few points that will reduce the number of queries you get from me!

- In the Essential Investigations section, the question 'Stenosis/Occlusion <50%' should be answered Yes if the patient has no stenosis.
- If the Blood Pressure reading provided on page 4 is less than 7 days post stroke and it will not be possible to obtain a later reading, please note this on the page.
- If any investigation has not been done or a piece of information is not known and will not be obtained at a later date, please write ND or NK on the form so that you will not be followed up for this information.

Recruitment Table

UK01 – Southern General, Glasgow	23	UK 14 – King's College, London	9	UK31 – Luton and Dunstable	21
UK02 – Western Infirmary, Glasgow	28	UK15 – Guy's and St Thomas', London	6	UK32 – Yeovil, Somerset	27
UK03 – Western General, Edinburgh	22	UK16 – St George's Hospital, London	70	UK36 – West Herts, Watford	5
UK04 – Freeman Hospital, Newcastle	3	UK17 – Mayday, London	5	UK37 – Blackpool	2
UK05 – Leeds General Infirmary	94	UK18 – Stoke Mandeville, Aylesbury	13	UK38 – Airedale, Skipton	3
UK06 – Hope Hospital, Manchester	6	UK19 – William Harvey, Ashford	9	UK39 – Countess of Chester	23
UK07 – Aintree Hospital, Liverpool	20	UK23 – Charing Cross, London	1	UK41 – Royal Cornwall, Truro	4
UK08 – Walton Centre, Liverpool	13	UK24 – Royal Hallamshire	1	UK42 – Derriford Hospital, Plymouth	7
UK09 – City Hospital, Nottingham	26	UK25 – Royal Bournemouth	6	UK50 – Preston	8
UK10 – Glenfield Hospital, Leicester	6	UK26 – Royal Aberdeen	5	UK80 – Southend	9
UK11 – Addenbrooks Hospital, Cambridge	36	UK27 – St Helier's, Carshalton	8	UK82 – North Staffordshire	3
UK12 – Radcliffe Infirmary, Oxford	3	UK29 – Royal Sussex, Brighton	10	UK83 – Torquay	10
UK13 – Institute of Neurology, London	16	UK30 – Royal Devon and Exeter	19	Total	580

Finally, I would like to thank all sites that have sent in outstanding data and responded to data queries recently, this allows us to review cases for eligibility and provide feedback to sites as early as possible.