

Dear Principle Investigators and Researchers,

Thank you to all centres that have been extremely busy recruiting patients for the UK Acromegaly Register, PRAGMA, and Apoplexy audit.

*Information – Please note that Dr Debbie Willis is currently on Maternity leave, and is due to return to the society later in the year. We congratulate Dr Willis on the safe arrival of baby Adam.*

### **Acromegaly Project update**

There are currently 3186 patients on the register as detailed in the table. The major task for 2014 will be continuing to update these records, particularly the IGF-1 and GH results. This will be very important for the analysis of medical treatment of Acromegaly which we plan to report on in the near future.

Thank you for all your continued hard work and support.

For further information about the Acromegaly Project, please see our website on the link below.

<http://www.endocrinology.org/about/projects/acromegaly.html>

### **AGM**

The Next AGM Meeting will be held in Liverpool at SfE BES conference 2014 on Wednesday 26th March at 13:30hrs, lunch will be provided from 13:00hrs.

All researchers involved in the project are invited to attend to obtain an update on the project and provide feedback. Please can you confirm attendance to Natasha Archer as soon as possible – [natasha.archer@endocrinology.org](mailto:natasha.archer@endocrinology.org).

### **Data entry payments**

Once a new patient has been added to the database or an annual update completed as per datasets required for data entry payment (sent separately to the centres) please send your completed claim form by post to Natasha Archer.

Please contact Natasha if you require database training or if you need assistance to update patient records.

**Blood Sample Kits** - Please send any enquiries to – [natasha.archer@endocrinology.org](mailto:natasha.archer@endocrinology.org)

### **Ethics**

**Patient consent** – When consenting patients please ensure the **PC number** for the patient is entered at the top of the consent form. Whether consenting in clinic or by post, four copies of the consent form are required, one for the patient, one for the patient's notes, one for the chief investigator and one for the local site file. Please send the chief investigator's copy to Natasha Archer at the Society.

**Amendments** – **Reminder** - Amendments 5 and 6 have been granted approval from the ethics committee. Amendment 5

allows us to obtain information on deceased patients with Acromegaly already known to the local centres where consent was not obtained prior to death. Amendment 6 changes references to the Office of National Statistics to the NHS Information Centre in the study documentation, for our flagging study. Copies of the amendments, REC approval letters and local R & D approval letters should have been added to your project site file.

### **UKCRN**

The project is a UK Clinical Research Network adopted study (ID 6687). As an adopted study we are required to submit accrual data to NIHR as a measure of research activity, for funding to local networks. We upload accrual data monthly on behalf of all centres. If you have any queries about accrual data please contact Natasha.

### **Apoplexy Project Update**

The Apoplexy Audit Database is now live and can start accepting data. Before you enter your data, you must ensure that Caldicott Guardian approval is in place - please forward a copy of the approval to [pamela.turpin@endocrinology.org](mailto:pamela.turpin@endocrinology.org) for our records.

Please follow the below link to the database -

<https://www.bioscientifica.info/sfe/apopaudit/Login.aspx>

### **PRAGMA Project Update**

#### **Post-Radioiodine Management of Patients with Graves' disease**

The PRAGMA Study is now live and patient recruitment is underway. Before you can start recruiting patients please can you ensure that Caldicott Guardian approval is in place for your local centre. Once approved please email a copy to Pamela at the Society for Endocrinology [Pamela.turpin@endocrinology.org](mailto:Pamela.turpin@endocrinology.org). Please let Pamela know if you require any help with gaining Caldicott Approval.

In order for us to undertake the analysis for the PRAGMA study, please can all centres fill in their local reference ranges for FT3, FT4, Free T3 and Free T4. This should save time for centre's rather than completing this for every patient recruited.

Please can all centres send this to Pamela by Friday 14th February.

Patient Recruitment	Acromegaly	PRAGMA	Apoplexy	Transitional	
				YA*	P*
Boxes shaded in grey are to show which projects centres aren't involved in.					
Aberdeen Royal Infirmary	88				
Armagh	-	-	-		
Bath	-	-	-		
Belfast	175	-	-	31	16
Barnsley Hospital NHS	-		-		
Birmingham-Qu. Elizabeth	284				
Birmingham -City Hospital	-	15	-		
Birmingham - Children's					
Bradford	26	-	-		
Brighton	59	31	2		
Bristol - BRI	25		-		
Bristol Frenchay	-		-		
Bristol Southmead	-	20	-		
Bristol University Hospital	-	-	-		
Carmarthen	-	-	-		
Cambridge-Addenbrookes	103				
Cambridge University	-	-	-	9	9
Cardiff	168		3		
Chester	26	-	-		
Coventry - Welsgrave	-	-	-		
Dundee - Ninewells	19	21	-		
East&North Hertfordshire	-		-		
Edinburgh	173	51	-		
Exeter	62	18	-	4	2
Gateshead	-	15	-		
Gillingham - Medway	-	-	-		
Glamorgan	-	-	-		
Glasgow	40	-	-		
Southern General Hospital	-	-	1		
Western General Hospital	-	-	-		
Halfax - Calderdale	-	-	-		
Hull	52				
Leeds	106		1		
Leicester	104	25	-	5	5
Liverpool - Aintree	94		-		
Liverpool - Walton Centre	-	-	1		
Liverpool & Broadgreen	-	-	-		
London - Bart's	316	-			
London - King's	43	4	6		
London - UCLH	23	-			
London - Imperial	-		-		
London - Royal Free	-	-	-		
London - St George	-	-	-		
London - Essex Neuro	-	-			
Maidstone	-		-		
Manchester - Christie	172		-		
Manchester - Hope	106				
Manchester - MRI	77		-		
Middlesborough-JamesCook	-				
Newcastle	144	50			
Norfolk & Norwich	10	-	-		
Northumbria NHCT	-		-		
Nottingham University	-	20	2		
Oxford	220				
Pennine Acute	-	27	-		
Plymouth	48	25	2		
Portsmouth	-	-	-		
Preston	24	-	4		
Sheffield	200	-	4		
Shrewsbury & Telford	-	-	-		
Southampton	-	-			
Southend Hospital	-		-		
Stoke on Trent	161	-	-		
Stirling - NHS Forth Valley	-	-	-		
Swansea	-	-	-		
Truro	-	-	-		
Watford	21	-	-		
West Hertfordshire	-	24	-		
Weston General	-	20	-		
York	20	-	-		
<b>Total</b>	<b>3186</b>	<b>366</b>	<b>26</b>	<b>49</b>	<b>32</b>

NB 3 patients are registered at more than one centre.

\*YA = Young Adult Questionnaires / P = Parent Questionnaires

## Transitional Care Audit

To date we have recruited 34 centres to take part in this national audit. For any centres who wish to participate, please email Pamela [pamela.turpin@endocrinology.org](mailto:pamela.turpin@endocrinology.org) who will send you the relevant information. The closing date for centres to register is Monday 31<sup>st</sup> March, and the closing date for data collection is Monday 30<sup>th</sup> June.

Please do not use the current electronic version of the Mind the Gap Questionnaires as all centres will be sent packs containing the latest version of the young person, parent questionnaires and self addressed envelopes once Caldicott Guardian approval is in place. Please can all centres wait for these hard copy packs to distribute.

**Passwords** - To ensure that we maintain security, passwords to access any of our databases **MUST** be provided over the telephone, please telephone Pamela on 01454 642778 for Apoplexy and Transitional Care, and email [natasha.archer@endocrinology.org](mailto:natasha.archer@endocrinology.org) for any UK Acromegaly Register password queries.

**IMPORTANT:** Please note that you must not allow anyone to use your exclusive passwords for **ANY** of our databases. If it becomes apparent that this is taking place then all access to our systems will be suspended until the issues have been resolved.

## Peer Review

We are now organising Interdepartmental Peer Reviews for 2014.

Please follow the below link to our website to find out more -

[http://www.endocrinology.org/clinical/professionals/prof\\_PeerReview.html](http://www.endocrinology.org/clinical/professionals/prof_PeerReview.html)

Please email Natasha Archer to organise a peer review for your centre.

## Contact details:

For all Clinical Research Projects, please contact

**Natasha Archer** – Clinical Projects Officer

[natasha.archer@endocrinology.org](mailto:natasha.archer@endocrinology.org)

Tel: 01454 642275

**Pamela Turpin** – Clinical Projects Administrator

[pamela.turpin@endocrinology.org](mailto:pamela.turpin@endocrinology.org)

Tel: 01454 642778

**Please send any postal correspondence to –**

Society for Endocrinology

22 Apex Court

Woodlands,

Bradley Stoke.

Bristol. BS32 4JT

**This project information sheet will be distributed on a quarterly basis.**

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