

Dear Principle Investigators and Researchers,

Thank you to all centres that have been extremely busy recruiting patients for the UK Acromegaly Register, PRAGMA, Transitional Care and Apoplexy audits. The Sfe would also like to thank Ipsen and the CET for their continued support.

UK Acromegaly Register Update

There are currently 3295 patients on the register as detailed in the table, which is an overall increase of 109 patients in the past 8 months since the last newsletter! The major task for the remainder of 2014 will be continuing to update these records and to continue with the centralised blood measurements.

For further information about the Acromegaly Register, please see our website on the link below. <http://www.endocrinology.org/about/projects/acromegaly.html>

AGM

The AGM Meeting was held at the Sfe BES conference at The ACC – Liverpool on Wednesday 26th March 2014. Thank you to all of those who attended. The AGM Minutes are attached for reference.

If you have any queries please email them to Natasha Archer natasha.archer@endocrinology.org.

The Society are very keen to assist any centres that are in need of an extra pair of hands to update the Register. Please email Natasha if you require database training or if you need assistance to update patient records.

Ethics - Reminder

Patient consent – When consenting patients please ensure the **PC number** for the patient is entered at the **top** of the consent form. The PC number is the number generated by the database when a patient is added to the register. When consenting a patient either 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.

Current Documents –

Please can you check that you have all the current versions listed below.

- Consent Form – Version 7 - 17th January 2011
- Patient Information Sheet – Version 7 - 17th January 2011
- Letter to GP – 2nd May 2010
- Standard letter to consent by post – March 2007
- Standard letter to re-consent by post – March 2007
- Protocol – 2nd April 2005
- Centralised Measurement form - v2 – April 2013

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. The Society uploads the accrual data monthly on behalf of all centres. If you have any queries about accrual data please contact Natasha.

The UKCRN activity based data funding cut deadline for ALL adopted studies is approaching – please send all Acromegaly consent forms to the Society addressed to Natasha Archer. The deadline for receipt is **Wednesday 15th October** as previously advised.

Apoplexy Audit Update

We are delighted to report that 61 patients have been recruited over a total of 16 centres and the details have been entered onto our database.

Please can we remind people to update the Apoplexy Audit 3 month outcome section of the database. Prior to any data entry, you must ensure that Caldicott Guardian approval is in

place - please forward a copy of the approval to natasha.archer@endocrinology.org for our records.

Please follow the below link to the database – <https://www.bioscientifica.info/sfe/apopaudit/Login.aspx>

For username and passwords to the Apoplexy database please contact Natasha.archer@endocrinology.org with your telephone contact details and Natasha will call you to verify.

PRAGMA Project Update

Post-Radioiodine Management of Patients with Graves' disease

The PRAGMA Study is live and patient recruitment is well underway. We are excited to report 632 patients have been recruited so far and we are awaiting approximately 100 from centres.

Please send all PRAGMA CRF's and PQ's to Natasha by **Friday 17th October**. (address below)

Transitional Care Audit

We have received 233 Young Adult and 200 Parent Mind the Gap questionnaires from 21 centres. – Thank You!

Please ensure that the service provision questionnaire has been completed for both adult and paediatric service.

Thank you for all your continued hard work and support.

Passwords – If you require a password for any of the databases please contact Natasha Archer

Contact details:

Natasha Archer – Clinical Projects Officer

natasha.archer@endocrinology.org

Tel: 01454 642275

Dr Debbie Willis – Policy & Professional Affairs Manager

Debbie.willis@endocrinology.org

Tel: 01454 642251

Please send any postal correspondence to –

Society for Endocrinology

22 Apex Court

Woodlands,

Bradley Stoke.

Bristol. BS32 4JT

Patient Recruitment	Acromegaly	PRAGMA	Apoplexy	Transitional	
Boxes shaded in grey indicate a centre is not involved in that project				YA*	P*
Aberdeen Royal Infirmary	90			7	7
Armagh	-	-	-		
Bath	-	-	-	2	2
Belfast	177	-	-	31	16
Barnsley Hospital NHS	-	25	-	-	-
Birmingham–Qu. Elizabeth	298	52	3	-	-
Birmingham –City Hospital	-	15	-	-	-
Birmingham – Children's				20	19
Bradford	27	-	-	-	-
Brighton	59	31	2		
Bristol - BRI	25	-	-	-	-
Bristol Frenchay	-	-	-	-	-
Bristol Southmead	-	21	-	-	-
Bristol University Hospital	-	-	-		
Carmarthen	-	-	-		
Cambridge-Addenbrookes	103			-	-
Cambridge University	-	-	-	12	11
Cardiff	168	11	3	7	7
Chester	30	-	-		
Cork				19	20
Coventry - Welsgrave	-	-	-	23	23
Dundee - Ninewells	19	21	-	-	-
East&North Hertfordshire	-	-	-		
Edinburgh	173	51	-	17	7
Exeter	64	37	-	4	2
Gateshead	-	15	-	-	-
Gillingham – Medway	-	-	-		
Glamorgan	-	-	-		
Glasgow	40	-	8	12	10
Southern General Hospital	-	-	1	-	-
Western General Hospital	-	-		-	-
Halifax – Calderdale	-	-	-		
Hull	65			-	-
Leeds	117	46	2	1	1
Leicester	104	27	-	18	15
Liverpool – Aintree	94		-	5	5
Liverpool – Alder Hey				8	9
Liverpool - Walton Centre	-	-	1	-	-
Liverpool & Broadgreen	-	-	-		
London - Bart's	345	-		1	
London – King's	43	6	6	9	9
London - UCLH	23	-		-	-
London - Imperial	-	-	-	-	-
London - Royal Free	-	-		-	-
London – St George	-	-	-		
London - Essex Neuro	-	-		-	-
Maidstone	-	-	-		
Manchester - Christie	177	5	-	2	2
Manchester - Hope	112	10		-	-
Manchester - MRI	77	18	-	-	-
Middlesborough-JamesCook	-		2	-	-
Newcastle	144	50		10	10
Norfolk & Norwich	24	-	-		
Northumbria NHCT	-	-	-	-	-
Nottingham University	-	20	2		
Oxford	220			13	13
Pennine Acute	-	49	-	-	-
Plymouth	50	25	2	-	-
Portsmouth	-	-	-		
Preston	24	-	4	-	-
Sheffield	205	-	4		1
Sheffield Children's NHS				07	07
Shrewsbury & Telford	-	-	-		
Southampton	-	-			
Southend Hospital	-		-	-	-
Stoke on Trent	160	-		-	-
Stirling – NHS Forth Valley	-	-	-		
Swansea	-	-		-	-
Truro	-	-	-		
Watford	21	-	-	-	-
West Hertfordshire	-	32	-	-	-
Weston General	-	20	-	-	-
York	20	-	-	-	-
Total	3298	632	60	233	200

NB 3 patients are registered at more than one centre.

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