

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 for its UK Acromegaly sponsorship, Pfizer for its Transition study grant and also the CET for their continued support.

UK Acromegaly Register Update

There are currently 3362 patients on the register as detailed in the table. The major task for the remainder of 2015 will be continuing to update these records and to continue to collect 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>

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

UK Acromegaly Register – TRAINING DAY Monday 13th July 2015 – Bristol

The Society will be organising a training day in Bristol and would like to invite any new UK Acromegaly users.

This training day is designed for those new to the register, but we would like to extend the invite to other users that feel they would benefit from a refresher.

The training day will provide 'hands on' experience of the register; it is designed to be informal with an opportunity for users to ask any questions throughout the day. You will have the opportunity to work with the register using a test database, you will be taken through each screen and you will be shown how to check and validate errors.

The project will pay travel costs upon receipt of a claim form, and lunch will be provided. There are 9 spaces for this training day,

Please email Natasha.archer@endocrinology if you would like to attend the training day.

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

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.

Ethics – Amendment to study

You may have noticed that the study end date was listed as 31/12/2014. We are currently preparing a substantial amendment to extend the end date to 31/12/2017. (The study is ongoing and the UKCRN has been updated to reflect this).

Centralised Measurements –

Thank you to all the centres that are sending blood samples to the Christie for centralised measurements. Together with the Christie Hospital we are now analysing the data in order to start preparing the first abstract on local Vs central measurements. In order to do this please can we ask centres to ensure they upload their local GH and IGF-I blood results for patients where blood has also been taken for centralised measurements. Please continue to send the samples to the Christie.

If you would like further details on how your local centre can be involved with collecting samples for centralised measurement, please contact Natasha.archer@endocrinology.org.

Important Request – When sending samples to the Christie Hospital please can you ensure that the correct form is used (attached to this email) and that the DOB, PC number and patient number are all noted on the form as these are required to ensure that the centralised measurement can be allocated to the correct patient in the upload of data to the register.

Apoplexy Audit Update

We are delighted to report that 77 patients have been recruited over a total of 16 centres and the details have been entered onto our main database.

26 patients have been added to the 3 month Apoplexy outcome section of the database. Please can we remind people to update the Apoplexy Audit 3 month outcome section of the database for patients already on the main database?

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 has now completed the recruitment stage, and has moved into data analysis. We are delighted to report the final number of patients recruited was 812, which is above the target cohort of 760.

Please can you send back the reference range information requested by Natasha as soon as possible as this information is needed for data analysis.

Transitional Care Audit

We have received 226 Young Adult and 191 Parent Mind the Gap questionnaires from 21 centres. – Thank You!

52 Service Provision questionnaire's were completed, 25 from Adult Endocrinologists and 27

The data is currently being analysed and a report / abstract will be prepared for SfE BES Conference 2015.

At the moment the data is not available for individual centre's to view.

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Please send any postal correspondence to –

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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	20	1	7	7
Armagh	-	-	-	-	-
Bath	-	-	-	2	2
Belfast	182	-	-	31	16
Barnsley Hospital NHS	-	25	-	-	-
Birmingham–Qu. Elizabeth	298	52	10	-	-
Birmingham –City Hospital	-	16	-	-	-
Birmingham – Children's	-	-	-	20	17
Bradford	27	-	-	-	-
Brighton	60	31	3	-	-
Bristol - BRI	25	-	-	-	-
Bristol Frenchay	-	-	-	-	-
Bristol Southmead	-	21	-	-	-
Carmarthen	-	-	-	-	1
Cambridge-Addenbrookes	-	-	-	-	-
Cambridge University	103	25	-	13	12
Cardiff	168	11	3	7	7
Chester	31	-	-	-	-
Cork	-	-	-	12	12
Coventry - Welsgrave	-	-	-	21	19
Dundee - Ninewells	29	21	-	-	-
East&North Hertfordshire -Lister	-	16	-	-	-
Edinburgh	173	51	-	17	7
Exeter	65	36	-	4	2
Gateshead	-	16	-	-	-
Gillingham – Medway	-	-	-	-	-
Glamorgan	-	-	-	-	-
Southern General Hospital - Glasgow	40	-	8	14	12
Western General Hospital	-	-	-	-	-
Halfax – Calderdale	-	-	-	-	-
Hull	68	9	-	-	1
Leeds	122	46	7	1	1
Leicester	104	27	-	18	15
Liverpool – Aintree	-	-	-	5	5
Liverpool – Alder Hey	94	-	-	8	10
Liverpool - Walton Centre	-	-	-	-	-
Liverpool & Broadgreen	-	-	1	-	-
London - Bart's	357	23	-	1	-
London - King's	43	10	9	8	8
London - UCLH	23	-	6	-	-
London - Imperial	-	20	-	-	-
London - Royal Free	-	-	-	-	-
London – St George	-	-	-	-	-
London - Essex Neuro	-	-	-	-	-
Maidstone	-	-	-	-	-
Manchester - Children's	-	-	-	-	-
Manchester - Hope	116	10	2	-	-
Manchester - Christie	177	5	-	2	2
Manchester - MRI	77	19	-	4	6
Middlesborough- JamesCook	-	12	2	-	-
Newcastle	144	58	8	9	9
Norfolk & Norwich	42	-	-	1	1
Northumbria NHCT	-	66	-	-	-
Nottingham University	-	20	7	-	-
Oxford	220	11	-	13	12
Pennine Acute	-	51	-	-	-
Plymouth	54	25	2	-	-
Portsmouth	-	-	-	-	-
Preston	24	-	4	-	-
Sheffield	207	-	4	1	-
Sheffield Children's NHS	-	-	-	07	07
Shrewsbury & Telford	-	-	-	-	-
Southampton	-	-	-	-	-
Southend Hospital	-	-	-	-	-
Stoke on Trent	160	-	-	-	-
Stirling – NHS Forth Valley	-	-	-	-	-
Swansea	-	-	-	-	-
Truro	-	-	-	-	-
Watford	-	-	-	-	-
West Hertfordshire	22	38	-	-	-
Weston General	-	21	-	-	-
York	20	-	-	-	-
Total	3365	812	77	226	191

NB 3 patients are registered at more than one centre.

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

The SfE would like to thank Ipsen, CET, and IDS for their continued financial support.



SfE – Clinical Interdepartmental Peer Review

The Society administers a voluntary interdepartmental peer review scheme for UK endocrine units. The scheme provides an external assessment of clinical governance, standards of endocrine care & service provision, with the aim of supporting endocrinologists and improving services for endocrine patients.

If you would like to find out more or organise a peer review at your centre please visit our website

http://www.endocrinology.org/clinical/professional/prof_PeerReview.html

or contact natasha.archer@endocrinology.org