

19 August 2013

Dear Endocentre lead

I am writing with an update of the BSGE Endocentre project which continues to progress well. There are many different areas of development but all are working to provide the same outcome; namely to provide high quality laparoscopic surgery for women with severe endometriosis form specialists who work in multidisciplinary teams and audit their work. I specifically want to keep you informed about the following issues:

- Annual audit of severe endometriosis - Reminder
- Analysis of data – declaration to publish
- Scientific Advisory Group standard operating procedures
- Endometriosis specialist nurse training
- Specialist Commissioning of surgery for severe endometriosis
- Forthcoming meetings for Endocentre leads
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#### Annual audit of severe endometriosis

I would like to remind you that data entry of all cases of severe endometriosis managed by surgery, which includes dissection of the pararectal space, should be kept up to date for your centre. Please use the simple search in the endometriosis database to keep an eye on your numbers; simply go to Centre>Reports>Pararectal Space Summary then select your time frame and run the report. We are now two thirds of the way through 2013 so your data collection should include at least 8 cases at this stage and hopefully considerably more. Remember all these patients must have symptom questionnaires pre-op and at 6,12 and 24 months post op. The data entry for 2013 will be closed on 31<sup>st</sup> December for annual audit and the figures published in late January 2014. This will determine which centres retain accreditation and which provisional centres will become accredited.

#### Analysis of data

The Endometriosis data that has been collected to date has now been downloaded and passed to our independent scientific chairman for initial analysis. The analysis will inform us all about the total amount of data gathered and how complete the data collection has been. We will be able to see which centres have collected the most cases and which centres have collected the most complete data. As you all know the project is a collective study of all endometriosis centres, as such it should be powerful dataset and hopefully provide useful information for the management of this challenging condition. It will be possible to refine data collection based on this initial data review. In time this will inform improvements to the database.

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### Scientific Advisory Group

One of the fundamental principles of the endocentre project is to collect data from the Endocentres for scientific publication. It is now time to declare the intention to publish collective data. The BSGE does not support individual centres publishing their own cohort data. The literature already contains many individual surgical series whilst the BSGE endocentre project is a collective study. The BSGE aims to publish a large multicentre dataset, which should provide more robust evidence for patients, clinicians and health care providers.

One of the most difficult aspects is establish the appropriate authorship to such publications. Clearly data will have been collected by a large number of people and they cannot all be authors. Data will be analysed by a small group of people and the papers written by an even smaller group. To retain ownership of the whole project the decision is to make the publications 'BSGE publications' rather than owned by a small group of individuals. Hopefully in future years a series of publications will follow and the BSGE 'brand' will become recognised, irrespective of who the individual authors are for each paper. At this stage it is important to set up a structure for this to happen and establish some standard operating procedures (SOP's).

The plan is to establish a Scientific Advisory Group to oversee preparation of publications from the data. I attach a draft of the SOP's for the Scientific Advisory Group and I would be grateful of your constructive feedback via the BSGE secretariat. Atia will collate responses so they can all be reviewed together. Could I have all responses to Atia by the end of September, please. Thank you in advance for your contribution and all the hard work in, both treating these patients, and entering the data.

### Endometriosis specialist nurse training

As you are all aware from January 2014 it is a requirement for all Endometriosis Centres to have an Endometriosis Specialist Nurse. To help Centres introduce this development the BSGE gave 18 months notice of the requirement. In addition, we have posted examples of job descriptions for such a post on the BSGE website in the Endometriosis Centres section dropdown menu. Now I am delighted to announce that the first training course for Endometriosis Specialist Nurses has been developed. It is organised jointly between the BSGE, Endometriosis UK and the Royal College of Nursing. The residential training course is on 19<sup>th</sup> and 20<sup>th</sup> October 2013 in the Best Western Windmill Village Hotel in Coventry. The cost of the course, including accommodation is £200. There is an option for nurse members of the BSGE to apply for a bursary from the BSGE to help with this cost (contact the secretariat for detail of the bursary options). Nurses who need more information can contact Cathy Dean at [Cathy.Dean@rcht.cornwall.nhs.uk](mailto:Cathy.Dean@rcht.cornwall.nhs.uk)

### Specialist Commissioning of surgery for severe endometriosis

Purchasing of surgery for severe endometriosis became part of specialist commissioning in April 2013 and the specification for the treatment pathway becomes active from October 2013. Already there are further developments planned for the specification from April 2014 onwards. Developments will include the introduction of quality measures which will attract supplementary payment. Details of the current specification is available on ([www.england.nhs.uk/wp-content/uploads/2013/06/e10-comp-gynae-endometriosis.pdf](http://www.england.nhs.uk/wp-content/uploads/2013/06/e10-comp-gynae-endometriosis.pdf)). If centres meet all the requirements of the BSGE they will meet all the criteria for specialist commissioners and are highly likely to be successful in their application to be a provider.

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The tariff for complex endometriosis surgery is available on the endometriosis database (go to: Help/Downloads>Complex endometriosis Surgery –Coding and Tariffs May 13). The future tariff will likely be developed from the 2012/13 reference cost grouper and so can be expected to increase significantly. This information can be used to form part of the business case to your own Trust.

Forthcoming Endocentre leads meetings

All Endocentre leads are invited to one of the following meetings to discuss all these developments and hear of up to date progress with the Endocentre project. It is always difficult to find mutually convenient dates and times. However I have chosen meeting dates to coincide with BSGE/RCOG or ESGE meetings, so I hope one of the dates is suitable. The dates are as follows:

Tuesday 17<sup>th</sup> September 8am at the RCOG- Conference Room

Tuesday 19<sup>th</sup> November 6pm at the RCOG- Conference Room

ESGE meeting one Berlin 16<sup>th</sup>-18<sup>th</sup> Date and timing to be announced.

Please confirm your planned attendance to the BSGE secretariat as the meetings will only proceed if there is a suitable size group. The BSGE has to pay for the facilities and this needs to be justified. Please email Atia at [bsge@rcog.org.uk](mailto:bsge@rcog.org.uk) by end of August with confirmation.

With kind regards

A handwritten signature in black ink, appearing to read "D Byrne".

Dominic Byrne

Chairman BSGE Endometriosis Centres Portfolio

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