

## **Minutes of the Clinical Genetics Society Council Meeting held March 9th 2011, Institute Of Child Health, London.**

Present: Frances Flinter, Peter Turnpenny, Mandy Collins (arrived 4:40 pm), Daniela Pilz, Elisabeth Rosser, Rob Hastings, Annie Procter, Geoff Woods, Sarah Smithson, Judith Goodship, Meena Balasubramanian, Kay Metcalfe, Sahar Mansour (arrived 5:10).

In attendance: Natalie Canham, Bronwyn Kerr (left 6:45), Carole Brewer (left 6:45), Adam Shaw, Shane McKee (arrived 4:50).

### **1. Welcome and apologies:**

Carole Brewer and Shane McKee were congratulated on being elected to Council and welcomed to their first meeting.

Apologies had been received from Alan Fryer, Michael Wright and Emma Hobson.

### **2. Minutes of the previous meeting.**

The minutes of the previous meeting were discussed. One amendment was made, to line 3 page 2 – the SAC is responsible for Job Planning

### **3. New members**

Four new members have joined since the last meeting: Alice Stellman, Kate Baker, Nicola Ragge, Claire Bonshek

### **4. Matters arising**

#### **• ACCEA**

There will be fewer awards available this year but there is no feedback on the recent applications. The outcome of the current round is not yet known, but hopefully will be available before the 2012 round commences. Different processes are operating in the devolved countries, which is regrettable.

#### **• Role of Council Members**

Covered under Section 5 of the Agenda.

### **5a. Constitution:**

This has been redrafted and circulated to both the council and membership. No comments have been received from the membership so far. The revisions will be discussed at the AGM and, hopefully, the changes will be ratified.

There was some discussion as to whether the use of “retiring” in section 21 meant retiring from Council or retiring from work. It was agreed that it meant retiring from Council.

If the changes are ratified the amended constitution will be put on the website and will be reviewed in four years (2014).

### **5b. ‘Roles of the Clinical Geneticist’ Document:**

It was suggested that the terms Dysmorphology Meeting and GenEthics Meeting are preferable to the terms Dysmorphology and GenEthics Clubs. Otherwise the document was approved.

There was some discussion about recontacting patients. It was agreed that this could be interpreted in three ways;

1. Recontacting individuals when they reach child-bearing age.
2. Reviewing cases after a period of time, however the department may not be paid if an individual or family are not re-referred.
3. Recontacting families because of new developments.

It was felt that not all departments would have the resources or ability to provide all these services, particularly the last.

The document is designed to explain what we do. It does not need to be approved by the Commissioners, but should provide information to them.

It was agreed to add the words “of interpretation” to complexity of results.

Action: Amend document (PT)  
Put on website (AS) to be reviewed in a maximum of four years.

**5c. Guide to Job Planning:**

This aims to help with local negotiation. Other examples of national roles were added such as membership of the National Screening Committee, UK GTN and the Nuffield Council on Bioethics.

Action: Amend document (PT)  
Put on website (AS) to be reviewed in a maximum of four years.

**5d. Declarations of interest**

These have been received from some council members but not all.

Action: To request again (ER)  
To send to Carole and Shane (ER)

**5e. International Work:**

A document from PT had been circulated.

The RCP is creating a portfolio of Specialist Societies with an International Interest but Clinical Genetics, so far, is not on it. We have a lot to offer to geneticists and paediatric trainees and there is an opportunity to develop our input. Training goes both ways, UK trainees can learn from being on a short-term placement as well as individuals from other countries visiting the UK. There is a need for an individual to coordinate this input. The RCP provides information for individuals working abroad wanting to enquire about long term training in the UK.

The Travel Fund agreed at the last meeting has not yet been used. It was agreed that money could be made available for visits of CGS members to developing countries for educational purposes, as well as for trainees wishing to gain experience. It was agreed that initially awards would be kept flexible in terms of numbers and types of awards available. It was also agreed that recipients should write reports to go into the newsletter.

Actions:

1. NC to flag in newsletter. SS to send grant application form to SM.
2. SM, DP and PT offered to run a group to collate information on UK centres willing to host visitors.
3. PT to feedback to RCP about the work we are beginning.

**5f. Councils/Lead Clinicians Conference:**

Challenging times are ahead of everyone because of financial pressures. A joint meeting of Council and Lead Clinicians could be very important in addressing issues around clinical governance, mainstreaming and commissioning. PT suggested that such a conference be arranged for January/February 2012.

There was some discussion about this. It was felt that the content should include discussion on devolved nations and commissioning issues. It was felt that it should be over two days to allow enough time for travelling and discussion. It was also agreed that there needs to be a strong agenda so people feel committed and involved.

Actions:

1. BK/CB to discuss in Lead Clinicians meeting in May.
2. PT/ER/BK/CB to work on the agenda and date and venue.

### **5g. Ethics Group.**

Formalising a way to address ethical issues would be useful for the specialty. Such a group could also have a role in addressing media questions and issues. PT has spoken to Anneke Lucassen, Mike Parker and Angus Clark and all are in agreement. There was some discussion as to where such a group should be based as the issues are also relevant to laboratory and public health genetics. It was felt that BSHG would be more relevant, so that representatives all of all its constituent parties could be involved..

Action: PT to make a formal approach to BSHG about this.

### **6. IT Issues – no update.**

18 week targets – no update

Lead Clinician's group – nothing to add to previous discussions. BK is stepping down as Head of the Lead Clinicians Group; CB is taking over the role. Bronwyn was thanked for all her hard work.

Developing Standard For Health Reviews – no update

### **7. Revalidation:**

A report had been submitted and there was no further discussion or comments.

### **8. Academic Subcommittee:**

There has not been a meeting of the sub-committee. There was some discussion as to whether a telephone conference might be an effective way of getting everyone together. A date has been set for a trainee meeting on April 12 but unfortunately no supervisors are able to attend the meeting; funding has been provided by CGS for a visiting speaker.

### **9. Ongoing initiatives**

International Scholarship:

The current scholarship recipient is in the UK.

It was agreed that we could offer two scholarships, perhaps for three years with no scholarship in the fourth year when the CGS Meeting is in Holland. It was agreed that it would be advertised as up to two being awarded. There was some discussion as to whether the recipients should attend CGS or BCHG. If both attend the CGS Meeting they will not both be able to have a spoken presentation because of the pressures on a one day conference.

Actions:

1. DP, GW, KM and ER to assess applications.
2. ER to send information to International Societies.
3. AS to put flier on website indicating that applications to be received between May 1st and July 31st, 2011 to attend CGS in Newcastle in 2012.

### **10. Clinical Governance:**

Reports had been submitted.

There was some discussion as to the implications of publishing protocols and pathways on the website as this can be accessed by the public. It was agreed that a statement would be placed on the website stating that these protocols and pathways are guidelines only and that they are not validated by CGS and are not to be seen as NHS standards. Each document should also have a date for review.

Action: AS to produce a statement and ensure that review date is appropriate.

The Patient Involvement Survey developed by Liverpool is also on the website. Patient surveys will be discussed at the Lead Clinicians Meeting in May.

Audit: GW has developed a questionnaire for BRCA testing. This is straightforward to use and provides useful information.

The aim is to do one audit per year starting with a straightforward one to engage interest. It will be sent out soon.

Quality metrics were discussed in the report.

Complaints/risks/critical incidents are recorded in different ways by different trusts. The data can provide valuable information.

Clinical governance committee membership: SS's Council term of office ends today. She will work with her successor. KM volunteered to lead the group. She has one year of Council office remaining but it was agreed that she could continue in a clinical governance role after this if she wished.

#### **11a Trainee Report:**

A report had been circulated. There was some discussion as to whether the Travel Fund discussed earlier should be expanded to provide small grants. At present the fund will remain for travel expenses only, though this will be reviewed. It was noted that several organisations provide small pump priming grants and are probably more appropriate for this than CGS.

Study leave – some deaneries have listed “mandatory courses” which will be funded. This list does not always correspond to the recommended courses, however, deaneries are changing. It is probably appropriate for trainees to contact the SAC if problems arise.

Action: Everyone to email names of organisations providing small pump-priming grants to JG who will compile a list for the website.

#### **11b SAC Report and discussion led by SS (not KM as stated in agenda).**

A report had been submitted. The new curriculum will come into force from September and all new trainees will be on it. Formal feedback is requested and the curriculum will be reviewed each year. Sixty questions have been produced for the knowledge-based assessment. Five sample questions will be available, but they will not be formally piloted.

The exam will be launched February 2012. The costs have been kept as low as possible – just under £500.

Mary Porteous is standing down as the Chair of the SAC.

#### **11c Manpower Issues:**

Reports had been submitted.

Not all the data in the workforce report is appropriate, obtainable or reliable. It was noted that not all data has been submitted in the same format. It is important for this data to be as accurate as possible as commissioning and planning decisions are based upon it.

Action: BK/CB to discuss whether Lead Clinicians Census could help in clarifying some of the data errors. However, the deadline for the RCP document (Physicians Working with Patients) is 22 March.

#### **12a JCMG.**

A report had been circulated. The new Chair will be nominated by BSHG, as Trevor Cole is coming to the end of his term of office. There was no further discussion.

#### **12b UK GTN.**

A reports had been submitted. Shehla Mohammed is now Clinical Director. There was no further discussion.

#### **12c BSHG:**

A report had been submitted, a meeting is to be planned together with other specialities to discuss mainstreaming. Re-structuring BSHG was discussed at the AGM but was not supported.

#### **12d CGG:**

No report had been submitted and there was no discussion.

**12e HGC:**

is about to publish a report on pre-conception genetic testing.

**12f HGSG:**

Information had been circulated. The remit of the group is still not clear and concerns remained about the attitude to Clinical Genetics as the focus seems to be on laboratory/pathology issues. FF's role on the committee is as an individual and will continue after she demits office as President.

**13 Budget:**

A report had been submitted. The accounts were tabled. They have been audited and the financial situation is healthy. There were no questions about the accounts and they were formally approved by Council. They will be presented to the AGM on 10 March.

Action: MC to e-mail accounts to ER.

**14 Website: A link to the newsletter will be developed.**

Action: AS

**15. Conference Report.**

A report had been submitted. The conference on 10 March should break even. There was some discussion about the composition of the scientific committee with reference to a constitution in terms of office. Committee members' names should be on the website.

Action: DP/JG to discuss and present a proposal for the running of the scientific committee at the next meeting.

AS to put details on website

**16. Carter Lecturer.**

Veronica Van Heynigen will be speaking in 2011. There is a list for the nominating committee to consider for the 2012 lecture.

Action: PT to convene meeting of nominating committee.

**17. Genetic testing of children:**

A revised version of this document is now on the BSHG website.

**18. Consent and Confidentiality:**

Discussions with the GMC continue.

Note added after meeting – has been approved and is with RCP Publications department.

**Any other business**

1. RCP Consultant Physicians Working with Patients. This document is being updated.
2. Rare diseases UK: A letter of support had been provided. There is due to be an article in the newsletter.
3. E bulletin: PT proposed sending an E bulletin twice a year, probably in June and December. Contributions should be sent to ER/PT.
4. Welcome letter for new members

Action: PT

6. A card for retiring members was suggested by PT; it was discussed that there would need to be good communication with Lead Clinicians to ensure that everyone retiring was identified.

7. Document templates.

Action: FF to send to PT.

8. Clinical Genetics Groups convenor for RCPCH: KM has performed this role for several years. It involves organising and sharing the genetic session at the RCPCH Conference. The post is important in strengthening relationships with the RCPCH.

Action: To be discussed with the membership at the AGM and a request for volunteers made.

9. RCP needs a representative on committee to discuss its Transitional Care project. AP expressed a keen interest.

Action: To be mentioned at the AGM and additional volunteers to be sought.

### **Thanks and farewells**

Sarah Smithson, and Bronwyn Kerr were attending their last meeting. Emma Hobson had been unable to attend. They were all thanked for their hard work and contributions. Francis Flinter was thanked for her extremely hard work as president.

**Date of next meeting is September/October. PT to coordinate.**