Joint Committee on Medical Genetics

The Royal College of Physicians **The British Society for Human Genetics** **The Royal College of Pathologists**

Royal College of Physicians, 11 St Andrews Place, Regents Park, London NW1 4LE

Summary of the first meeting of the Joint Committee on Medical Genetics 5th January 1999

1. Terms of Reference:

1 To promote and maintain the highest standards of practice in both clinical and laboratory applications of genetics in medicine.
2 To discuss and co-ordinate advice to Government and other bodies on policy and services issues relating to genetics in medicine.
3 To report and receive information from the parent bodies.
4 To co-ordinate advice on workforce planning.
5 To initiate working groups on specific topics of particular importance. This would be subject to agreement by the parent bodies when significant expenditure was envisaged but the Joint Committee would be free to authorise small working groups.
6 To assist parent bodies in the development of their academic activities.
7 To provide a unified forum for these activities.

2. Membership of the Committee January 1999:

*Three **President/Registrars** of RCP & RCPath, **Chairman**/Deputy of BSHG*

Dr Ian Gilmore (Registrar RCP)
Dr Julie Crow (Registrar, RCPath)
Professor Andrew Read (chairman BSHG)

*Five nominees of **Royal College of Physicians** (including chair of JCHMT SAC and one trainee)*

Professor Peter A Farndon - (**Chairman, Joint Committee)**
Dr Alan E Fryer
Professor R F Mueller
Dr Angus J Clarke
Dr Angela F Brady

*Five nominees of **Royal College of Pathologists** (including chair of SAC and one trainee)*

Dr Tony Andrews
Mrs Margaret Fitchett
Professor Noor Kalsheker
Professor Sue Malcolm
RCPath trainee (vacant)

*Five nominees of **British Society for Human Genetics** (including one from each of the four constituent groups)*

Mr John Barber
Dr Rob Elles
Dr Lorraine Gaunt
Dr Helen E Hughes
Mrs Penny Guilbert

*One representative from **Royal College of Paediatrics and Child Health***

Dr Jill Clayton-Smith

One representative from ***Scottish Royal Colleges of Physicians***
Professor Mike Connor

One representative from ***Genetics Interest Group***
Mr Alistair Kent

One representative from ***Faculty of Public Health Medicine:***
Dr Virginia Warren

One representative from ***Royal College of General Practitioners:***
vacancy

One representative from ***Royal College of Obstetricians and Gynaecologists***
Professor Peter Soothill

One observer from ***Department of Health***
Mr Anthony Taylor

Chief Medical Officer's specialty adviser *(also reporting to the Chief Scientific Officer)*
Professor Dian Donnai

3. Executive group

The committee agreed to the formation of an executive group to deal with urgent matters:
Chairman (or an RCP nominee when not in the chair), the Chairman of the RCPath SAC, and the Chairman of the BSHG.

4. Relationship with existing committees

The Joint Committee (through its chairman) will be considering its relationship with other existing committees, particularly to avoid duplication.

5. Reports of committee business

As well as the Joint Committee reporting to the Councils of the RCPath and the BSHG, and to the Clinical Medicine Board of the RCP, it was agreed that a summary of its proceedings would be placed on web-sites shortly after meetings.

6. Human Genetics Advisory Commission

Mr Anthony Taylor gave an overview of bodies providing advice to the Government on genetics. The Cabinet Office had set up a committee to consider how governmental advice about biotechnology should be obtained. A report was expected in May.

Mr Taylor outlined the work of the Commission and the Genetics Advisory Committees which had covered the following topics: the development of cloning, the insurance implications of genetic testing (there was now a group working with the insurance industry), the employment implications on genetic testing, wider educational aspects, patenting, genetic testing services made available to the public for late onset disorders, and guidance to research ethics committees on gene testing. On-going work was concerned with pre-natal testing and the genetic testing of children.

7. Gene Patents and Genetic Testing

Dr Rob Elles spoke to a paper entitled "Gene patenting and molecular genetic testing - strengths, weaknesses, opportunities, threats", with particular regard to screening for BRCA1 and BRCA2 mutations.
Members expressed concern about the controls which could be exerted by commercial interests if patents for genes were recognised in Europe and the UK. They feared also that patent restrictions could also disrupt the provision of a comprehensive service in the UK. The committee felt that patents involving gene sequences did not involve genuinely inventive steps, rather a routine application of the existing art. It was emphasised that it would seem inappropriate for individual laboratories to enter into licence arrangements at the present time whilst discussions were in progress between the Department of Health and companies.

The Committee was concerned that resources would be removed from the UK if patent holders restricted the freedom of NHS laboratories to perform certain genetic tests, and that it would be difficult to afford capital-intensive new technologies in NHS labs if they were restricted by patentees to testing very rare diseases. Demographic information may not be available for service provision if the testing was centred overseas, and that it would be difficult to obtain genotype/phenotype information.

The Joint Committee is preparing a statement for the Department of Health.

8. UK Genetic Testing Network

The aims of the UK Genetic Testing Network (see http://www/bham.ac.uk/bshg for the document) were discussed. A reaction to the report was awaited from the Department of Health.

Members discussed the proposals in the paper which had recommended that ideally two centres should offer a service for any given rare disease. They agreed to enlist the support of the Advisory Group on Scientific Advances in view of its aims to transfer research into service, and the Chairman undertook to bring this to the attention of that committee.

Concern was expressed that families with rare single gene disorders often had access to DNA tests as part of research projects but when these ended, facilities for testing ceased. It was agreed that data should be collected about this unmet need. Professor Mueller agreed to take this initiative forward.

9. Clinical Governance

It was noted that the Council of the Clinical Genetics Society has set up a small working group to gather together existing material which could form the basis for a National Service Framework. Discussions would be required to ensure that the various bodies who had responsibility for clinical governance were working together to ensure an NSF could operate, but as yet, clear lines of communication did not appear to have been established. One of the problems envisaged was whether all Regions would be able to afford the quality of care.

The committee were concerned about the possibility of duplication as it was believed Professor Harris was also setting up a group to review the Recommendations of the Confidential Enquiry Report and produce guidelines The Confidential Enquiry concerned counselling and referral by non-geneticists, but it was not clear that the proposed guidelines would exclude reference to clinical governance of genetics services. It was agreed that the Chairman would try to clarify the situation.

10. Institute of Public Policy Report

The report “Brave new NHS? the impact of new genetics on the health service” was discussed. Most of the points made in the report were well known to all geneticists but concern was expressed that the genetics community had obviously not been completely successful in explaining the structure of the services available to the general public. It was felt that the report appeared to over-emphasise the role of primary care and the potential clinical effectiveness of testing for disease susceptibility genes. The role of the Regional Genetics centres appeared to be solely for rare genetic disorders, a view which the committee felt needed to be addressed. They refuted the claims that the NHS had not taken sufficient account of the impact of genetics. The Chairman would write to the IPPR and an appropriate ministerial contact.

11. Publication of Report on "Commissioning Clinical Genetics Services"

The RCP Committee on Clinical Genetics final report on commissioning clinical genetics services has been published (available from RCP London).

12. General Genetics Knowledge/Education of Non-genetics Professionals

The Genetics Advisory Commission (and the IPPR report) had identified a lack of knowledge of most non-genetics professionals. The Chairman proposed that a working group be set up to ascertain needs and attitudes of non-genetic professionals before proceeding further. Dr Clayton-Smith agreed to take forward this initiative.

13. Services for Adults with Inherited Metabolic Disorders

For discussion at the next meeting.

14. Manpower and Training

RCPath SAC: There are currently four consultants in cytogenetics and four NTNs who are laboratory clinicians. However, there was no planning for clinical scientists and the RCPath, which had a Manpower Committee to monitor the various pathologies, was beginning to look at this wider aspect.

RCP JCHMT SAC: regional specialty advisers are attending some SAC meetings to help co-ordination. Training in cancer genetics is being discussed with medical and clinical oncologists. A working group had been set up to prepare guidelines for the appraisal and assessment of trainees. The SAC was interested in the distribution of trainees but it had no responsibility for manpower.

Dr Helen Hughes advised that she had been in liaison with SWAG for the RCP Committee on Clinical Genetics. At present there were fifty trainees in clinical genetics with a consultant expansion of around 10% per annum. SWAG had felt that this rate of expansion would be unlikely to continue and thus the situation would be reviewed each year. Dr Hughes emphasised the importance of making sure that SWAG had accurate information. The total stock of NTNs in September 1998 was 59, when the total number of consultants was 81.

15. For Information

Members noted the list of initiatives and publications relating to genetics.
The European Society of Human Genetics is holding four workshops on ethical and legal issues in genetics with the aim of providing guidance for practice.

16. Dates of Future Meetings

13th May 1999
22nd September 1999