Joint Committee on Medical Genetics

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

RCP 11 St Andrews Place Regents Park London NW1 4LE

A summary of the third meeting of the Joint Committee on Medical Genetics held on Wednesday 22nd September 1999

Present

Professor Peter A Farndon	Chairman RCP
Professor Ian Gilmore	RCP Registrar
Professor Andrew Read	BSHG Chairman
Mr John Barber	RCPath
Dr Angela Brady	RCP trainee representative
Ms Caroline Browne	RCPath trainee
Dr Jill Clayton-Smith	RCPCH
Professor Mike Connor	Scottish Colleges
Dr Dennis Cox	RCGP
Professor Dian Donnai	CMO Adviser
Dr Rob Elles	RCPath
Mrs Margaret Fitchett	RCPath
Dr Alan Fryer	RCP
Dr Lorraine Gaunt	BSHG
Mrs Penny Guilbert	BSHG
Dr Helen Hughes	BSHG
Professor Noor Kalsheker	RCPath
Mr Alastair Kent	GIG
Professor Sue Malcolm	RCPath
Professor Peter Soothill	RCOG
Mr Anthony Taylor	DH Observer
Dr Virginia Warren	FPHM
Ms Hilary Irons	RCP Committee Administrator

Apologies Dr Julie Crow (RCPath Registrar), Dr Tony Andrews (RCPath SAC Chairman), Dr Naomi Brecker (NHSE Observer), Dr Angus Clarke (RCP JCHMT SAC), Professor Robert Mueller (RCP).

1 DH/NHSE Review of Genetic Services

Within the last five to six months the profile of clinical genetics had been greatly enhanced within the Department and with Government Ministers. In July there had been a half-day briefing on clinical genetics for Ministers. Resulting from the review of governmental advice, all the present advisory committees would be closed by the end of the year and AGSAG had already been disbanded. However, a new working party had been formed under the chairmanship of Professor Martin Bobrow to look at clinical laboratory services. The report from the February workshop was in final draft form.

2 Membership of the Joint Committee

A plan was needed to stagger the rotation of members. The Chairman would contact the parent bodies to decide how this should be done.

3 Patents and genetic testing

Dr Elles reported that the Department of Health was still negotiating with Myriad but no formal progress had been made. Mr Taylor confirmed that this was the situation and advised that Myriad had postponed a meeting arranged with the Department until January 2000. He advised that Bridgehead Diagnostics was acting as consultants to Myriad rather than offering laboratory facilities of their own. The Department had been given authority to negotiate NHS-wide arrangements with any company which might approach them.

4 Clinical Governance

The document prepared by the Clinical Genetics Society for the British Society for Human Genetics was in final draft.

5 Nuffield Trust Genetics Scenario Project

The Chairman and several Joint Committee members had attended a stakeholder group meeting. They had been asked to speculate on future developments and the general feeling was that it had been a positive experience. The chairman would be attending the December workshop which would aim to pull all the strands of the different groups together.

6 DNA Services
Comments from Regional Genetic Services re the operation of the OAT system

Members had expressed concern about the ability to recover the costs of testing following the replacement of the ECR with the OAT system on lst April 1999. It had therefore been decided to monitor the operation of the new OAT system, and Dr Elles tabled the results of a survey on referrals of genetic tests across regional boundaries during the period 1 April to 30 June 1999. Twenty-seven centres had been contacted and 13 had responded with data and comments. Whilst there had not been a complete halt to the payment of bills it was evident that there was considerable confusion about how the costs of this work would be covered and very little advice had been provided. There was not yet a clear picture and therefore he suggested that the situation should be reviewed in about three to six months' time.

Mr Taylor commented that NHSE was aware that the OAT system was not working well in all areas and he felt that the type of data obtained by Dr Elles would be extremely helpful. Meanwhile, the Chairman would write formally to the Department stating the concerns of the Joint Committee.

7 Genetics knowledge/education of non-genetics professionals

Dr Clayton-Smith gave a progress report on the deliberations of this working party of the Joint Committee.

Members recognised the importance of co-ordinating efforts in order to avoid duplication. They felt that Dr Clayton-Smith should pursue the idea of devising a questionnaire to obtain further information and that the BSHG be asked to support the project. Dr Clayton-Smith said that the group would also be keeping a watching brief on any possible funding for future promotion.

6 Advisory Group on Scientific Advances in Genetics

It was noted that AGSAG had been disbanded.

7 Human Genetics Advisory Committee/Department of Health

Following the review of how the Government obtained advice, two new Governmental Commissions were being set up:

(i) Human Genetics Commission (HGC)
(ii) Agricultural and Environment Biotechnology Commission (AEBC)

Letters were currently being sent out inviting people to be interviewed for membership of the Human Genetics Commission. This process would involve two to three interviews for each of the 15/18 places available. The Commission's remit would also include health interests of the NHS, and genetic education.

The Advisory Committee on Genetic Testing would not be closed until the end of the year as the report on prenatal testing particularly for women at high risk remained to be completed. It was planned that the Joint Committee would receive a copy for consultation. With regard to the template for genetic testing, eg for insurance companies, trials had been carried out and work would continue to the end of the year.

9 Public Health Genetics Unit

The Nuffield Trust Genetics Scenario Project: Nuffield had been equally pleased with the group seminar in which members had participated and plans were on target for the final workshop in December.
Summer school for policy makers: Progress was being made with the curriculum the four-day course which was being planned for next year, probably in early September. Mr Taylor advised that the Department hoped to be able to give support with partial funding, and the NHSE was also hoping to hold skill workshops for Trust managers.
Familial research - to be commenced in early October by Martin Roberts.
Genetic workshop days aimed at health professionals. Well received in the Eastern Region and invitations to take to other Regions would be welcome.

10 Information from the Genetics Interest Group (GIG)

(a) At GIG’s forthcoming conference a report profiling the experiences of families with particular diseases and disorders would be issued. This showed that when patients left the care of paediatricians they lost the holistic approach and there was a need for co-ordination of care in adult life. GIG felt that clinical geneticists had a role to play in ensuring that this happened. A copy would be sent to the Clinical Genetics Society.

(b) A number of GIG groups had produced leaflets for families who had been given recent diagnoses. Copies would be sent to all clinical genetics units and would also be available on the GIG website

(c) Mr Kent referred to the draft of a patient centred checklist of quality indicators and said that he would welcome the comments of the Joint Committee. It was therefore agreed that copies would be sent to all members.

(d) Access to genetic services by minority ethnic populations (report).
(e) Involvement in the production of education and training materials.

11 Services for adults with inherited metabolic disorders

Enquiries had shown that there was no coherent strategy and services varied according to their location. There was no accreditation for the clinical specialty of inherited metabolic disorders and this was an aspect which needed to be resolved. With regard to laboratory services, the main question was the siting and number of laboratories.

The RCP had considered accreditation for metabolic medicine but it had not thought to be sufficient for a separate specialty and the EU was not keen for the creation of new specialties. Concerns about clinical provision were being discussed within the RCPCH, the problem being that it was a specialisation involving only two people at present and the feeling was that perhaps it should be a sub-interest for other specialists.

A list of centres offering at least partial clinical services for adults with inherited metabolic disorders was tabled.

It was agreed that Professor Kalsheker, Dr Clayton-Smith, and Dr Warren would continue their enquiries, finding out those bodies which were concerned with the present situation with the aim of the Joint Committee reinforcing the general view

12 Accreditation proposals for non-medical genetic counsellors

Mrs Penny Guilbert reported that she had passed on to the Association of Genetic Nurses and Counsellors (AGNC) the Joint Committee’s comments on the accreditation proposals which had been received with appreciation. The proposals would concern only those wholly involved in genetic counselling. However, they recognised that it was a multi-disciplinary activity and there would need to be strong links with other practitioners who provided genetic counselling such as midwives.

13 Career structure and prospects for academic medical genetics

The Chairman referred to a discussion document which had been published in the RCP Journal giving advice on how best to accommodate training in academic medicine within the Calman training schemes. He had also learnt that the Academy of Royal Colleges had a working party looking at academic medicine.

Professor Connor advised that his inquiries into academic medical genetics had shown that the numbers of clinical lecturers had fallen and it was difficult to get any plans from medical schools. There was no problem in attracting good recruits into genetic research but a large number returned to specialise in other disciplines, and thus it was difficult to assess how many people were planning to specialise in clinical genetics. An additional difficulty was that these researchers were often categorised under biological sciences.

The Chairman explained his concern that the specialty needed to be proactive in undertaking research which would be useful in interpreting relative risks of "susceptibility genes" when these were identified, and before they were used in clinical practice. He wanted to make sure that the Joint Committee was not missing opportunities to encourage the development of a suitable infrastructure and staff for this research to be carried out. Mrs Maggie Fitchett said that she could provide data from the ACC of people who had undertaken research training.

14. United Kingdom Haemophilia Centre Directors' Genetics Working Party

Dr Fryer agreed to be a member of this external working party as a representative of the Joint Committee.

15 Matters referred from the Royal College of Physicians

(a) Ethical issues

Members were asked to submit ethical issues for consideration by the RCP Committee on Ethical Issues in Medicine.

(b) The Role of Genetics in Future Health Care

Professor Gilmore explained that this Department of Health discussion paper had been submitted to the JCC in July and, in turn, he had asked the Chairman for the Joint Committee's comments. Mr Taylor advised that the document reflected some of the issues considered at the February workshop. Professor Read expressed concern that the document failed to distinguish between the application of genetic tests which required genetic expertise for their interpretation and genetic screening tests which did not. Mr Taylor undertook to pass on the Joint Committee's comments to DH/NSHE.

(c) The relationship between physicians and the pharmaceutical industry

The College was considering updating its 1994 report, particularly those areas concerned with the effects of the biomedical industry on genetics. Members were asked for comments.

(d) National confidential enquiry into genetic counselling by non-geneticists

The Chairman had met with Professor Rodney Harris to discuss some of the points made by CEGEN on clinical governance in genetic medicine, informing him that the Joint Committee had taken on this issue for the specialty.

The President of the RCP had asked for the Joint Committee's comments on the CEGEN paper. Professor Soothill believed that the RCOG would support the idea of proformas in genetics for their ante-natal practitioners. Dr Cox thought that it would not be practical to expect general practitioners to carry out all the recommendations. Mr Kent commented that from the patient point of view there was concern that the recommendations had been drawn up regardless of which practitioner should carry them out. There needed to be a baseline of what should be expected which could be followed according to local circumstances to ensure that families at risk received expert advice. It was agreed that the Chairman should first discuss the paper with colleagues within the RCOG and elsewhere.

The RCPCH had also received a letter from Professor Harris as it was concerned with genetic education and training. The RCPCH had been advised that the Joint Committee was considering the issues. The Chairman recalled that the RCP Clinical Genetics Committee had undertaken a review on undergraduate education which it had been unable to complete as it had been during the transition year. He felt that it might now be appropriate to revisit the scene.

16 Manpower and Training

RCPath SAC

Training log books for molecular genetics and cytogenetics were now ready. The SAC felt that they represented a considerable advance and would be useful for those already trained. It was hoped that everyone in laboratories would be encouraged to use them.

19 Dates of future meetings

Tuesday 11th January 2000