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**Contributors**

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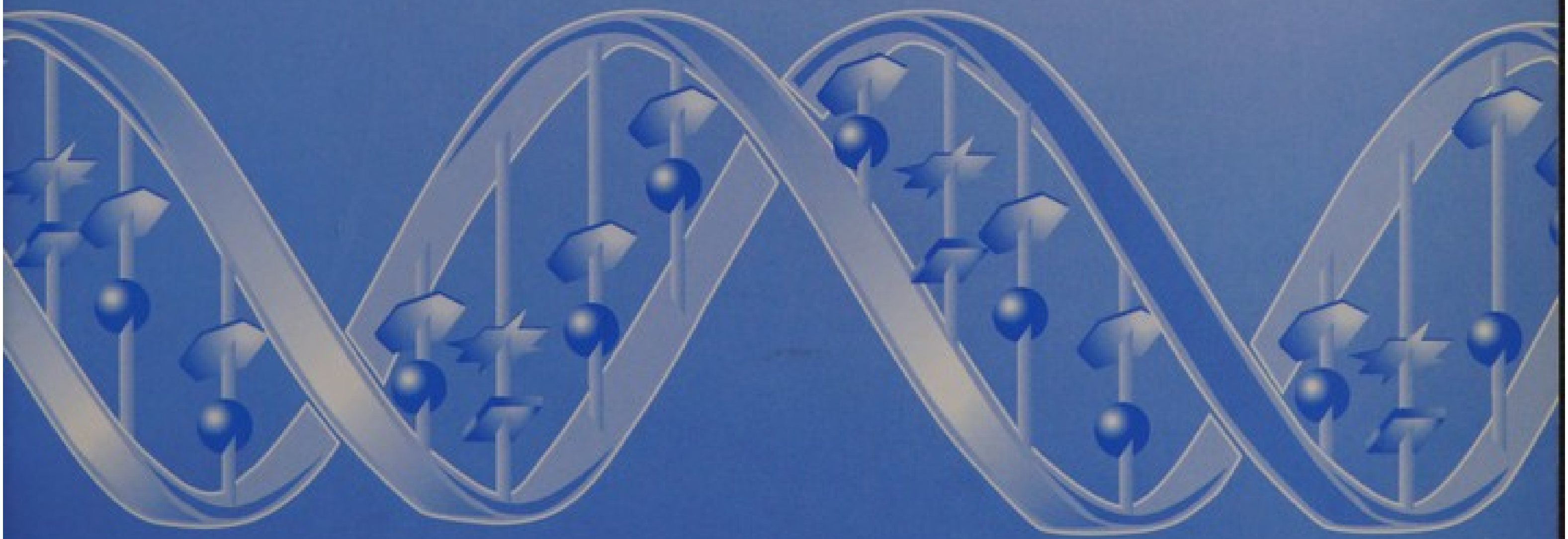
# Human Genetics Advisory Commission



## SECOND ANNUAL REPORT
## MAY 1999

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# FOREWORD

The Human Genetics Advisory Commission (HGAC) had a busy year since publishing its first Annual Report in March 1998.

When the HGAC held its first meeting, in February 1997, scientists in Scotland announced that they had cloned a sheep and called her Dolly. There was widespread concern that this development might lead to human cloning. The topic therefore was an immediate priority for the Commission. Throughout, cloning issues have attracted considerable attention and the science has moved on. For example, there has been independent confirmation that Dolly was cloned from a cell of an adult sheep and reports that scientists in Hawaii have produced cloned mice using similar nuclear replacement technology.

Following extensive public consultation the HGAC, together with the Human Fertilisation and Embryology Authority, published a joint report, *Cloning Issues in Reproduction, Science and Medicine*. It recommended that the safeguards already provided in the Human Fertilisation and Embryology Act 1990 be recognised as being wholly adequate to forbid human reproductive cloning in the United Kingdom (although the Government may wish to consider the possibility of introducing legislation *explicitly* banning reproductive cloning regardless of the technique used). It also recommended keeping the door open to new research and that consideration should be given to extending the regulations which closely control embryo research to allow development of cell nucleus replacement technology (CNR), which does not involve human reproductive cloning, to treat serious illness. Our report and its recommendations have been well received and we look forward to the Government response later this year.

HGAC continues to take an interest in third party access to genetic test results. The Government has responded to our first report *The implications of genetic testing for insurance* and we are monitoring developments. We are currently considering the implications of genetic testing for employment.

The changes arising from developments in genetics are unpredictable, and we need both to take advantage of the benefits and safeguard against perceived threats. We are told that advances in genetic science will revolutionise health care provision over the next ten years, yet we need to consider the concerns raised by these developments. If we are to realise the promise of this technology it is necessary for it to be used sensibly.

Genetics is an issue that continues to command international media and public interest. We support wide participation in open public debate about developments, taking account of the complex nature of a modern society. This process of social negotiation should inform our decisions about the role of the law in regulating the development and application of genetic science.

Our work benefits greatly from the willingness of individuals and organisations who alert us to their views, share their experience and provide us with information, both as part of formal consultation activities and through day to day contact. We are grateful to all those that give their time and expertise so generously.

We would also like to thank Sir Colin Campbell, who resigned as chairman in February 1999, for the great amount he has undertaken and achieved since the Commission was established in December 1996. Sir Colin's skill in explaining to a wide range of audiences the complex issues associated with the developing science of human genetics will be greatly missed.

HGAC will continue to make information about its work including consultation documents and reports available on its website: http://www.dti.gov.uk/hgac

Onora O'Neill

*The Baroness O'Neill*
*13 May 1999*

# INTRODUCTION

1.1 The Human Genetics Advisory Commission (HGAC) was established by Government in December 1996 as a non-statutory advisory body in response to a House of Commons Select Committee report.[1] It provides independent advice to UK Health and Industry Ministers on issues arising from developments in human genetics that have social, ethical and/or economic consequences. The Commission also advises on ways to build public understanding of the new genetics. The terms of reference are at Annex A and the membership is at Annex B.

1.2 The Commission has a facilitative and advisory role. It aims to improve the level of informed debate about the implications of developments in human genetics. To this end, it endeavours to make the issues accessible to as wide an audience as possible. Listening to views and consulting widely continues to be integral to the work of the Commission. It has undertaken two consultation exercises this year: one on cloning and the other on employment and genetic testing. In addition, its first national conference, *Human Genetics - Learning for the Millennium and Beyond,* held in October 1998, helped to broaden HGAC's network of contacts and enable it to become better informed about the perspectives, hopes and concerns of education professionals. The proceedings of the Conference have been submitted to Health, Industry and Education Ministers, suggesting that the work might helpfully complement the Government's current public consultation on developments in the biosciences. The Minister for Science first announced this Government led public consultation at the end of 1997. Its purpose is to explore the perceptions of people not currently engaged in the debate about the biological sciences, and in particular to find out their information needs, and how Government and its advisers can best meet them. The findings will be made public once the exercise is completed later this year.

1.3 Throughout the year the Chairman and other HGAC Members have accepted speaking engagements on behalf of the Commission and participated in public discussion. This helps HGAC to reach a varied audience and also provides an opportunity to communicate to others the HGAC's work. In addition, the Members have accepted a number of invitations to provide articles and contributions to journals, magazines and books. Examples of published work and speaking engagements can be found at Annex C. All HGAC reports have been published and are available on request free of charge or can be accessed via the internet.

1.4 HGAC has continued to take an interest in research into the ethical, legal and social implications (ELSI) of developments in biomedicine, recognising the importance of the right information, understanding and analysis to address difficult and complex issues arising from advances in human genetics with confidence. Links with key players such as The Wellcome Trust, the Economic and Social Research Council, the Medical Research Council and the Nuffield Council on Bioethics have been maintained during the year, and we welcome their continuing commitment to developing programmes of work in this area.

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[1] ***Human Genetics: The Science and its Consequences;*** Third report. House of Commons Science and Technology Committee. July 1995. HC231. HMSO

1.5 HGAC is part of the framework of regulatory and advisory bodies that advise Government on biotechnology. Other key bodies that consider human genetics issues include the Advisory Committee on Genetic Testing (ACGT), the Gene Therapy Advisory Committee (GTAC) and the Advisory Group on Scientific Advances in Genetics (AGSAG). All these bodies report to Health Ministers and the chairman of each committee is a member of the HGAC, to help ensure that our complementary work programmes are well co-ordinated.

1.6 On 17 December 1998 the Government announced a review of the framework for overseeing developments in biotechnology. The review is being conducted so the Government can be sure it is receiving the best possible advice and that the system is comprehensive and robust, but flexible enough to respond to future developments in this area. The review will address any gaps or unnecessary overlaps in the current framework; consider whether the systems could be simplified and made more transparent; and consider how ethical and stakeholder interests are taken into account. It is being co-ordinated jointly by officials from the Cabinet Office and the Office of Science and Technology, and will report in Spring 1999 (at the same time as the public consultation on developments in the biosciences is expected to be completed see paragraph 1.2 above). The HGAC has submitted its views to the review and noted that biotechnology is a rapidly developing subject which raises such a host of technical, regulatory, scientific and ethical questions that there will undoubtedly be a need for a committee or committees with remits sufficiently wide to respond quickly and flexibly to unexpected developments.

# REPORT FOR 1998/99

HGAC held 5 meetings during 98/99: on 7 May, 30 June, 23 September, 16 December 1998 and 11 February 1999. Dates of meetings are publicised on the website, as are press notices detailing business discussed, which are issued following each meeting. The Commission is charged with setting its own priorities, although from time to time it may be requested to provide urgent advice to Ministers. Working Groups have been established to undertake detailed work on particular topics, for example insurance, cloning and employment. All Working Groups report to the Commission, where reports are fully considered before approval for publication and presentation to Ministers.

## 2.1 Insurance

2.1.1 *The Implications of Genetic Testing for Insurance,*[2] a report published by the HGAC in December 1997, recommended that a permanent ban on the use of genetic test results in insurance would not be appropriate, but that safeguards were required to ensure that the results of genetic tests could only be used by insurers when a quantifiable association between a given pattern of test results and events actuarially relevant for a specific insurance product had been established. The Government responded to the HGAC report in November 1998 and fully accepted the HGAC's analysis and these recommendations.[3]

2.1.2 The HGAC had further recommended that a two year moratorium on the use of genetic tests should be applied by the insurance industry. The Government did not consider that an all-embracing two year moratorium was appropriate.

2.1.3 One of the proposals in the Government response to the HGAC's report on insurance and genetic testing was to establish a mechanism to review the use of genetic test results for insurance purposes. The Government has now set up the Genetics and Insurance Committee, which held its first meeting in April 1999. The HGAC is monitoring developments.

2.1.4 In response to HGAC's call for increased collaboration between geneticists, clinicians, actuaries and others, the actuarial profession has set up a UK Forum on Genetics and Insurance to encourage closer working. This forum should complement the work of the Government's Genetics and Insurance Committee.

2.1.5 During this year the HGAC responded to a request from the Royal Commission on Long Term Care for the Elderly (LTC) for information on the implications of genetic developments for the future life expectancy and health in the UK. The Commission has noted the LTC's conclusion that private insurance does not represent a viable means of providing for long term care for all.[4]

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[2] ***The implications of genetic testing for insurance;*** HGAC 1997

[3] ***Government response to the Human Genetics Advisory Commission's report on the implications of genetic testing for Insurance;*** November 1998 Department of Trade and Industry, Office of Science and Technology and Department of Health.

[4] ***With respect to old age;*** March 1999 A report by the Royal Commission on Long Term Care Cm 4192-I

## 2.2 Cloning

2.2.1 The HGAC jointly with the Human Fertilisation and Embryology Authority (HFEA) held a public consultation exercise between January and April 1998. Over 1,000 copies of the consultation document were distributed, although the document also reached a larger audience through the HGAC website and by others copying and circulating the paper. Nearly 200 responses were received - about 40% from individual members of the public and the rest from a wide range of constituencies, including professional bodies, religious organisations and lay groups, many of whom had organised their own discussion groups or otherwise canvassed views. Some examples of activities inspired by this consultation which encouraged further public debate are highlighted in this section.

**The Wellcome Trust commissioned research into public attitudes to cloning, based on seven focus groups representing various interests within society. Presented their findings, along with their own views on the consultation document.**

2.2.2 The joint Working Group was reconvened, again under the chairmanship of Reverend Dr John Polkinghorne, to consider the responses to the consultation. Both parent bodies gave long and careful consideration to the submissions, also taking account of new developments announced during the year in this fast-moving area, before finalising the resulting report for publication.

**A branch of the Workers' Education Association ran a course on modern genetics which included discussion of consultation document by all 29 students, with the tutor encouraging them to submit their own comments.**

2.2.3 The report, *Cloning Issues in Reproduction, Science and Medicine,* was published in December 1998, and submitted to Health and Industry Ministers. It analyses the responses to the consultation exercise and discusses recent scientific advances which shed more light on the potential for cell nucleus replacement (CNR) technology. The analysis showed that reproductive cloning - producing whole human copies, already outlawed in the UK- has little support. The report recommends that the safeguards already provided in the Human Fertilisation and Embryology Act 1990 be recognised as being wholly adequate to forbid human reproductive cloning in the United Kingdom. However, it suggests that the Government may, nevertheless, wish to consider the possibility of introducing legislation *explicitly* banning reproductive cloning regardless of the technique used, when there is an opportunity to do so in the legislative programme.

**University of Kent Centre for Applied Ethics organised a conference attended by 20 members of the University and the general public, included prepared contributions form Biochemistry and Philosophy staff representatives and the Directors. Included formation of working groups to consider specific issues. Response reflected the consensus and disagreement involving broad spectrum of opinion.**

**The Parish of St James' with St Philip's downloaded the consultation from the website, gathered 25 members for discussion, summarised their views in a paper which was submitted to HGAC and posted on their own website.**

2.2.4 In addition, the Report suggests that CNR techniques might be used for specific puposes other than human reproductive cloning. These techniques hold promise for the treatment of serious illnesses such as Parkinson's and Alzheimer's diseases and might be used in research into, and eventually development of, new treatments for replacing diseased or damaged tissue with compatible tissue grown by cloning processes. Such research would constitute research on human embryos within the permitted 14 day period, prior to cell differentiation. CNR techniques might also be used in research into therapies for mitochondrial disease. The Report recommends allowing for these potential benefits and that consideration should be given to specifying in regulations two further purposes for which embryo research can be carried out under the close regulation required by the Human Fertilisation and Embryology Act 1990:

- developing methods of therapy for mitochondrial disease; and
- developing methods of therapy for diseased or damaged tissues or organs.

The Report also recommends that the issues be re-examined in five years, in the light of developments and public attitudes towards them.

2.2.5 The Report was posted on the HGAC website and around 1,500 copies have been issued so far. Publication of the Report attracted a great deal of media interest both nationally and internationally. Its recommendations have been widely welcomed, with widespread support for continuing the ban on human reproductive cloning and for recognising the potential benefits of CNR technology. The Government is giving careful consideration to the Report's recommendations and will be responding later this year.

**St Mary Redcliffe Journey into Science organised public debate involving sixth formers from four Bristol schools.**

## 2.3 Employment

2.3.1 The implications of genetic testing for employment is the Commission's current priority. Many employers request some health information about a prospective employee before confirming the appointment. Some employers also conduct health screening of current employees for a number of purposes, including surveillance to identify the occurrence of certain work-related diseases. Developments in genetic testing may offer employers new means for selecting staff and monitoring their health status. While some genetic testing could be of benefit for both employer and employee alike, there is concern that access to genetic test information may be open to abuse.

2.3.2 A Working Group, chaired by Doris Littlejohn, was set up to:

- report to the HGAC on the potential value of genetic testing in the workplace and highlight any concerns raised by such developments;
- help raise awareness of the implications of genetic testing amongst employers and employees and help stimulate co-ordinated debate; and
- inform the public that wider concerns about this issue are being considered.

In taking forward this work, the Working Group seeks to build on work already undertaken by the Nuffield Council on Bioethics,[5] and draw on the work of others including the Trade Union Congress and the Health and Safety Executive. It will also consider how genetic testing might be deployed in the employment field and whether such use would be justifiable.

2.2.3 As an essential first step in its work, the Group set out to establish the current position regarding genetic testing and employment. To that end, it undertook a written consultation exercise during Summer 1998 targeted at those with an interest in and knowledge of the area and invited further information at a consultative meeting held in the Autumn. The Group has continued taking evidence and expects to finish its work within the next few months. The Commission intends to submit a report to Ministers for publication later this year.

## 2.4 *Human Genetics - Learning for the Millennium and beyond:* HGAC's first national conference

2.4.1 The Commission held a consultative Conference, *Human Genetics - Learning for the Millennium and beyond,* in October 1998, to contribute to the public understanding of human genetics. The Conference, held at the Royal Society, London, set out to listen to and learn from those involved in education, whose work with schoolchildren, lifelong learning groups, patients and their relatives touches on issues raised by human genetics. Over 100 people participated and the programme was designed to take account of their interests and elicit practical suggestions to meet identified needs. In addition to HGAC Members, we invited some excellent guest speakers to set the scene in the morning: Professor John Burn (Department of Human Genetics, University of Newcastle); Professor Lewis Wolpert (Anatomy Department, University College, London) and Professor John Durant (Assistant Director of the Science Museum and Professor of Public Understanding of Science at Imperial College). This was followed by syndicate work in the afternoon, and concluded with rapporteurs presenting their syndicate's findings at a final plenary discussion session.

**Nuffield Foundation**
**"The Science Curriculum in the New Millennium"**

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[5] ***Genetic Screening: Ethical Issues;*** 1993 A report by the Nuffield Council on Bioethics

**Y Touring**
**Dramatic Genetics - Science Through the Arts**

2.4.2 Conference delegates highlighted a number of common concerns of those involved in education about developments in human genetics and the issues they raise. Recurring themes included: the need for greater co-ordination of activities and initiatives between Government, education professionals, charities and other interested groups; the challenge of keeping pace with developments - how to "educate the educators"; the need to raise the "genetic literacy" of the general public; how best to access reliable information and the responsibility of the media to report objectively.

**Science Museum**
**Science Museum professional development for Teachers**

2.4.3 We received positive feedback from delegates. They considered that the conference met its objectives and was excellently organised. They also reported that they were both informed and entertained by the speakers, provided with helpful information by those exhibiting at the conference, and offered an opportunity to network and participate in debate. Some examples of genetics and education initiatives are highlighted on this page. Contact details can be obtained from the Secretariat.

2.4.4 The Conference has helped the Commission to broaden its network of contacts and become better informed about the perspectives, hopes and concerns of education professionals. It has also helped to bring together individuals and organisations with an interest in the common themes that emerged from the Conference.

**Progress Educational Trust**
**The Progress Guide to Genetics**

2.4.5 The proceedings of the Conference have been published and copies passed to Industry, Health and Education Ministers. They were also circulated to all participants and to those with an interest in the issues raised, inviting information about any further work that may have been undertaken following the Conference. It is hoped that the contacts made that day will continue to develop and that the event has helped to draw to the attention of those responsible some of the issues identified by the syndicates. The report can be accessed from the HGAC website.

**Wellcome/Genetic Interest Group**
**Genes and You - cross-curricular materials for Key Stage 4**

# THE YEAR AHEAD

3.1 HGAC's immediate priority is to complete and publish its third report, *The implications of genetic testing for employment.*

3.2 The Commission will also be holding a series of consultative meetings over the next few months to maintain and establish contacts with key interests, identify potential new issues in the field of human genetics and prioritise new issues for consideration. Once confirmed, details will be posted on HGAC's website.

3.3 In the meantime we are monitoring developments relating to insurance and genetic testing and await with interest the conclusions of the Government's review of the framework for overseeing developments in biotechnology.

3.4 Further copies and information about HGAC is available from:

HGAC Secretariat
c/o Office of Science and Technology
94-98 Albany House
Petty France
London SW1H 9ST

Tel: 0171-271 2131
Fax: 0171-271 2028

e-mail: mileva.novkovic@osct.dti.gov.uk
http://www.dti.gov.uk/hgac

# ANNEX A

## TERMS OF REFERENCE OF THE HUMAN GENETICS ADVISORY COMMISSION

(i) to keep under review scientific progress at the frontiers of human genetics and related fields;

(ii) to report on issues arising from new developments in human genetics that can be expected to have wider social, ethical and/or economic consequences, for example in relation to public health, insurance, patents and employment; and

(iii) to advise on ways to build public confidence in, and understanding of, the new genetics.

The Advisory Commission will report to Ministers periodically; reports will be published. It will establish contact with people from different sectors in the United Kingdom and will keep in touch with public views on human genetics. It will also keep abreast of developments in other countries.

# ANNEX B

## MEMBERSHIP OF THE HUMAN GENETICS ADVISORY COMMISSION

### Chairman

Professor Sir Colin Campbell
(to 5 February 1999)
*Vice Chancellor - University of Nottingham*

‡* The Baroness O'Neill
(Acting Chair from 5 February 1999)
*Principal, Newnham College, Cambridge*

### Members

‡* Professor Cairns Aitken CBE
*Professor-emeritus of Rehabilitation Studies, University of Edinburgh*

‡* Dr Micheala Aldred
*Director - Retinoblastoma Society*

‡* Professor Martin Bobrow CBE
*Professor of Medical Genetics - University of Cambridge*

‡* Mrs Doris Littlejohn CBE
*President - Central Office of Industrial Tribunals, Scotland*

‡ Professor Norman Nevin
*Chairman - Gene Therapy Advisory Committee*

† Reverend Dr John Polkinghorne KBE FRS
*Chairman - Advisory Committee on Genetic Testing*

† Dr George Poste CBE FRS
*Chief Science and Technology Officer - SmithKline Beecham Plc*

Ms Moira Stuart
*Reporter/presenter - British Broadcasting Corporation*

‡ Insurance Working Group Member

† Cloning Working Group Member. Professor Christine Gosden and Dr Anne McLaren were HFEA members of this joint working group.

†* Employment Working Group Member. Dr David Wright *(Consultant Occupational Physician)* is a co-opted member of this Group.

All appointments were made in December 1996 for a period of two years in the first instance, which in December 1998, were extended by a year.

# ANNEX C

## EXAMPLES OF PUBLISHED WORK AND SPEAKING ENGAGEMENTS

During 1999, the HGAC has continued to make itself accessible to others by presenting and publishing information about its work. A range of audiences has been addressed. The Commission has also continued to meet with others in order to hear about their work in this field. The HGAC Website has enhanced access to information about the Commission's activities.

### Speaking Engagements

'Genetics Now - Advances and Anxieties'. Presentation to Genetical Society, Spring Meeting at Nottingham University on 2 April 1998.

Address on Genetics to Life Science Students at Nottingham University on 8th April 1998.

Presentation onAddress the work of HGAC at Nottingham City Forum on 5 May 1998.

'Should Insurers Know Our Genes?' Speech on Genetics Testing and Insurance at 26th International Congress of Actuaries, NEC Birmingham on 9 June 1998.

'Biotechnology - Looking Forward' . Address to the Round Table, Borschette Centre, Brussels on 26 June 1998.

'Some Public Policy Implications of Cloning'. Address to British-North American Committee at Bath Spa Hotel on 21 June 1998.

Presentation to Tokyo University on 7 September 1998 on the work of the HGAC.

'Genetics Hopes and Fears'. Speech to the British Council conference at Nagoya on 9 September 1998.

Presentation to Osaka Bar Association on 10 September 1998 on the work of the HGAC.

Presentation on the work of the HGAC to Science and Religion Forum Annual Conference at University College, Chester on 15 September 1998.

Address to the Disability Rights Task Force in September 1998 about the work of the HGAC.

'Genetics in Medicine'. Address to an audience of clinicians, doctors, and students at St George's Hospital, London on 16 November 1998.

'Why Might Employers and Employees Wish to use Genetic Testing'. Speech to The Recruitment Society, The Grafton Hotel, London on 21 January 1999.

## Publications

Commentary provided by Sir Colin Campbell and Ruth Deech for publication with the cloning consultation paper in the Autumn 1998 issue of the German ethics periodical, 'Jahrbuch fur Wissenschaft und Ethik'.

Top Sante Magazine Article on cloning in May 1998 featured an interview with Sir Colin Campbell.

A contribution from Sir Colin Campbell, 'What Issues in Genetics Research Most Concern 13 Experts Right Now', was published in "The Chronicle of Higher Education" 3 July 1998.

'A Commission for the 21st Century', introduction to Modern Law Review's special edition on Genetics by Sir Colin Campbell September 1998 (vol. 61 no.5). This article was reproduced in a popular paperback, 'Law and Human Genetics' (Hart 1998 ISBN 1 84113-006-0).

## Other

Sir Colin Campbell and Professor Bobrow gave evidence to Sir Stewart Sutherland, Royal Commission on Long Term Care of the Elderly (June 1998).

HGAC met representatives form the European Group of Ethical Advisers in Science and Technology (June 1998).

Moira Stuart and Sir Colin Campbell visited Newcastle Gene Dome (October 1998).

Sir Colin Campbell attended the 2nd International Summit of National Bioethics Commissions in Tokyo, 3-4 November 1998.

Sir Colin Campbell chaired the first meeting of Institute of Actuaries', 'A Genetics And Insurance Forum', at Staple Inn, London on 17 November 1998.

# ANNEX D

# REGISTER OF MEMBERS' INTERESTS

HGAC members have declared the following personal or business interests deemed relevant to their appointment to HGAC, including, as a minimum, personal direct and indirect pecuniary interests* in accordance with the Cabinet Office recommendations in "Quangos - Opening the Doors" 1998.

| | |
|---|---|
| **Professor Sir Colin Campbell (to 5. 2.99)** | None |
| **The Baroness O'Neill** | Chairman, The Nuffield Foundation<br>Trustee, World Humanity Action Trust |
| **Professor Cairns Aitken** | None |
| **Dr Michaela Aldred** | Member, Retinoblastoma Society Management Committee<br>Trustee, Genetic Interest Group<br>Head of Molecular Genetics Service Laboratory, Leicester Royal Infirmary |
| **Professor Martin Bobrow** | Governor, The Wellcome Trust Limited<br>National Chairman, Muscular Dystrophy Group of Great Britain |
| **Mrs Doris Littlejohn** | None |
| **Professor Norman Nevin** | None |
| **Dr George Poste** | Non-Executive Chairman, Cerebrus Holdings Plc<br>Non-Executive Chairman diaDexus (USA)<br>Board Member, SmithKline Beecham Plc<br>Member, Scientific Advisory Board, Healthcare Ventures, Princeton, New Jersey, USA<br>Member, Scientific Advisory Board, Celera Corporation, Rockville, Maryland, USA<br>William Pitt Fellow, Pembroke College, University of Cambridge<br>Research Professor, University of Texas Medical Center, M.D. Anderson Cancer Center, Houston, Texas, USA<br>Research Professor, University of Pennsylvania, Philadelphia, USA<br>Member, Governing Committee, Beckman Center for Genetics and Molecular Medicine, Stanford University, California, USA |
| **Revd Dr John Polkinghorne** | None |
| **Ms Moira Stuart** | None |

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* Indirect pecuniary interests arise from connections with bodies which have a direct pecuniary interest or from being a business partner of, or being employed by, a person with such an interest. Non-pecuniary interests include those arising from membership of clubs and other organisations.

# ANNEX E

## USEFUL ADDRESSES

**Advisory Committee on Genetic Testing (ACGT)**
A non-statutory advisory body which advises Health Ministers on developments in genetic testing, taking account of ethical, social and scientific aspects. It establishes requirements, especially in respect of efficacy and product information, to be met by manufacturers and suppliers of genetic tests.

**Gene Therapy Advisory Committee (GTAC)**
A non-statutory advisory body which advises Health Ministers on developments in gene therapy research and their implications. It reviews and if appropriate approves individual protocols for gene therapy research. It works closely with the statutory body for medical products, the Medicines Control Agency and with research ethics committees.

**Genetics and Insurance Committee (GAIC)**
A non-statutory advisory body, has been set up by Government to:

- develop and publish criteria for the evaluation of specific genetic tests, their application to particular conditions and their reliability and relevance to particular types of insurance;
- evaluate particular tests against those criteria and promulgate its findings; and
- report to Health, Treasury and DTI Ministers on proposals received from insurance providers and the subsequent level of compliance by the industry with the recommendations of GAIC.

ACGT, GAIC and GTAC contact details:

Department of Health
Room 401, Wellington House
133-135 Waterloo Road
London SE1 8UG
Tel: 0171 972 4017
Fax: 0171 972 4196
e-mail: mstraugh@doh.gov.uk
http://www.open.gov.uk.doh/genetics/htm

**Advisory Group on Scientific Advances in Genetics (AGSAG)**
A non-statutory advisory body which advises the Department of Health's Chief Medical Officer and the Director of Research and Development on the likely implications for public health and for the NHS of scientific advances in genetics. It also advises the NHS Executive Board on the establishment of innovative genetic services and their evaluation and on the longer term development of genetic services in the light of appropriate evaluations. The secretariat is jointly provided by the Department of Health and the MRC.

Department of Health
Room 403A, Skipton House
80 London Road
London SE1 6LH
Tel: 0171 972 5631
Fax: 0171 972 5666
e-mail: ron.kirby@doh.gov.uk
http://www.open.gov.uk.doh/genetics/htm
(see also MRC entry below)

**Association of British Insurers (ABI)**
The trade association for insurance companies in the UK.

51 Gresham Street
London EC2V 7HQ
Tel: 0171 600 3333
Fax: 0171 696 8998
http://www.abi.org.uk

**British Society for Human Genetics**
The main academic and professional society for human geneticists.

Clinical Genetics Unit
Birmingham Women's Hospital
Birmingham B15 2TG
Tel: 0121 627 2630
http://www.bham.ac.uk/bshg/about.htm

**Economic and Social Research Council (ESRC)**
The UK's leading funding agency for research and training into social and economic issues.

Polaris House
North Star Avenue
Swindon SN2 1UJ
Tel: 01793 413000
Fax: 01793 413002
http://www.esrc.ac.uk

**The Human Fertilisation and Embryology Authority (HFEA)**
A statutory body that regulates IVF and donor insemination treatments, human embryo research and the storage of gametes and embryos.

Paxton House
30 Artillery Lane
London E1 7LS
Tel: 0171 377 5077
Fax: 0171 377 1871
http://www.hfea.gov.uk

**Genetic Interest Group (GIG)**
A national alliance of organisations which support children, families and individuals affected by genetic disorders.

Unit 4D, Leroy House
436 Essex Road
London N1 3QP
Tel: 0171 704 3141
Fax: 0171 359 1447
e-mail: mail@gig.org.uk
http://www.gig.org.uk

**Institute of Actuaries**
The professional body representing the interests of those qualified to apply mathematical principles to solving long-term financial problems, primarily in connection with pensions, life insurance and investment.

Staple Inn Hall
High Holborn
London WC1V 7QJ
Tel: 0171 632 2100
Fax: 0171 632 2111
e-mail institute@actuaries.org.uk
htpp://www.actuaries.org.uk

**Medical Research Council (MRC)**
Aims to improve health by promoting research into all areas of medical and related science. Funded mainly by Government, but it is independent in its choice of which research to support.

20 Park Crescent
London W1N 4AL
Tel: 0171 636 5422
Fax: 0171 436 6179
http://www.mrc.ac.uk

**Nuffield Council on Bioethics**
An independent body which examines the ethical issues arising from developments in medicine and biology.

28 Bedford Square
London NW1 2BE
Tel: 0171 631 0566
Fax: 0171 323 4877

**The Wellcome Trust**
A charity which aims to support the infrastructure of medical research in the UK and to promote consideration of the broader social and ethical implications of contemporary biomedical advance. Its information centre and exhibitions are open to the public.

183 Euston Road
London NW1 2BE
Tel: 0171 611 8888
Fax: 0171 611 8545
htpp://www.wellcome.ac.uk

# ANNEX F

# GLOSSARY OF TERMS

**Actuary** - a professional person qualified to apply mathematical principles to solving long-term financial problems, primarily concerned with pensions, life insurance and investment.

**Cell nucleus replacement (CNR)** - medical and scientific applications of cloning technology which do not result in the production of genetically identical fetuses or babies. These techniques may be undertaken to advance fundamental research and therefore not all such applications will lead to immediate therapeutic utility.

**Cloning** - producing a cell or organism with the same nuclear genome as another cell or organism.

**DNA** - Deoxyribonucleic acid, found primarily in the nucleus of cells (some DNA is also found in the mitochondrion). DNA carries the instructions for making all the structures and materials that the body needs to function.

**ELSI** - Ethical, Legal and Social Implications of the Human Genome Project.

**Embryo** - the developing organism from the single-celled stage until significant cellular differentiation has occurred, when the organism becomes known as a "fetus".

**Genetic test** - a test, based on DNA research, that can be used for diagnostic or pre-symptomatic testing.

**Gene therapy** - the genetic modification of body cells of an individual patient, directed to alleviating disease in that patient.

**Human reproductive cloning** - the creation of human beings genetically identical to one another or to any other human being.

**Mitochondrial disease** - disease due to mutations in DNA outside the nucleus. Since mitochondria are inherited exclusively from mothers, mitochondrial diseases show matrilineal inheritance. They include Kearns-Sayre Syndrome and Leber's Hereditary Optic Neuropathy.

**Non-statutory** - not required under the law.

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Human Genetics
Advisory Commission

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