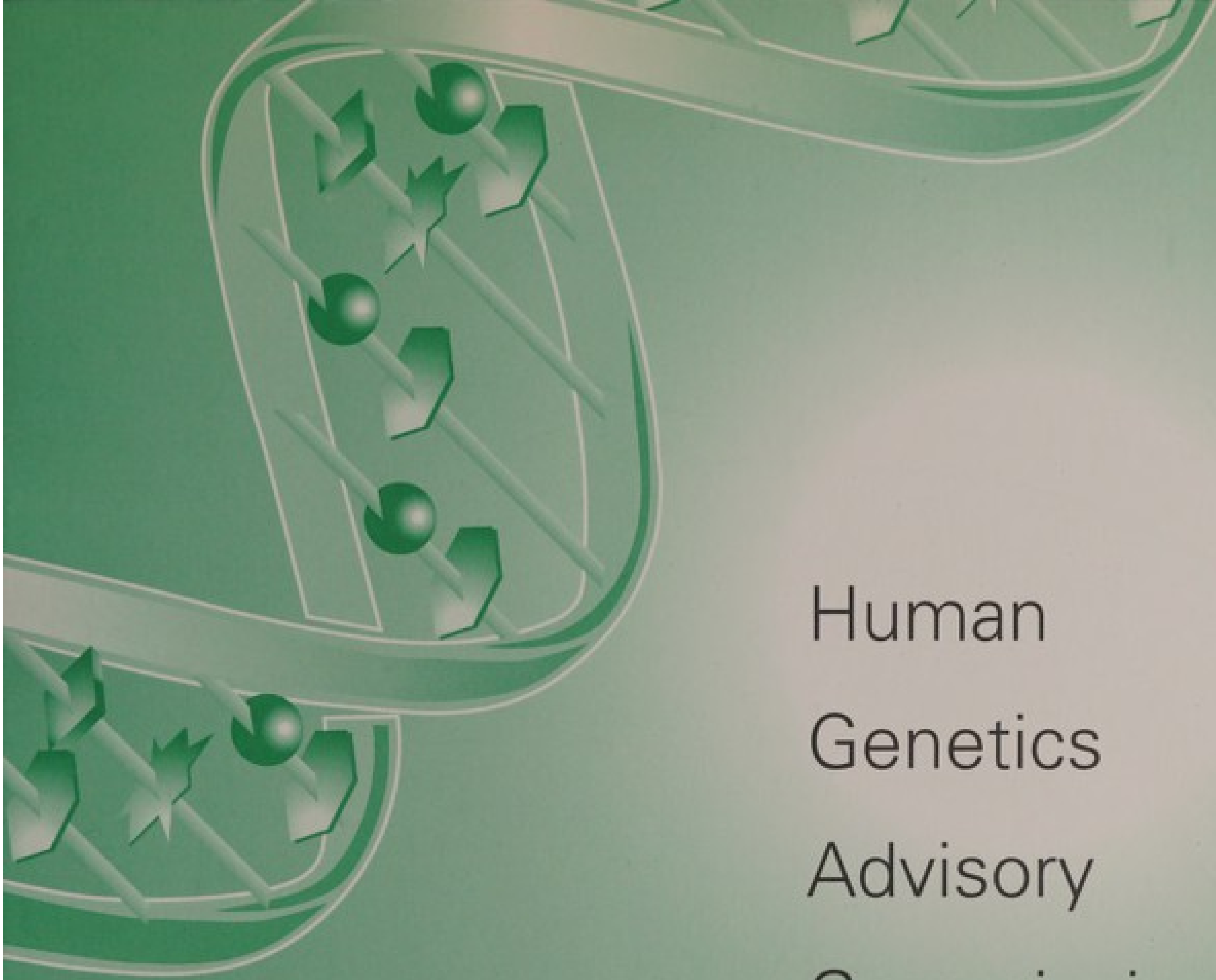
Annual report : 1998 / Human Genetics Advisory Commission.



Human
Genetics
Advisory
Commission

FIRST ANNUAL REPORT
MARCH 1998

CONTENTS

Annexes

FOREWORD

Exciting advances have been made in genetics over recent years. They have the potential to offer major improvements to the quality of life. However, some developments have also raised concerns. Given the huge potential of genetic advances, it is important to consider the ethical and social consequences now, and not be taken unaware. The Human Genetics Advisory Commission has been given the task of advising Ministers on these issues.

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. We are committed to open and public debate and will try to ensure that it is well informed. This should help to enable the Government and Parliament to address difficult and complex issues with the right information, understanding and analysis. Against this background, we have tackled a number of discrete topics in the last year and I have pleasure in presenting our first annual report.

We have published a report on the implications of genetic testing for insurance and, working with the Human Fertilisation and Embryology Authority, issued a consultation paper on cloning. We are indebted to the many individuals and organisations who have willingly assisted us in our task. My thanks go to our small but effective Secretariat who have supported us so ably.

Professor Sir Colin Campbell
Chairman
Human Genetics Advisory Commission

March 1998

OBJECTIVES AND METHODS OF WORKING

Objectives

1.1 The Human Genetics Advisory Commission was established, in December 1996, as a non-statutory advisory body. 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 was also asked to advise on ways to build public understanding of the new genetics (see full terms of reference at Annex A).

1.2 The Commission takes an impartial view and envisages that its published advice to Ministers will encourage well informed and open debate, which contributes to a constructive dialogue between relevant interests and will lead ultimately to public confidence in systems that emerge to address human genetics issues.

Methods of working

1.3 The Commission recognises that there is much existing expertise in the field of genetics. A great deal of work has already been done and a number of specialised bodies are already considering specific issues. A key element of the HGAC's work is, therefore, communication and consultation. The Commission believes that only by consulting widely can it ensure that its advice to Ministers reflects the range of opinion on the issues under consideration. Communication and consultation also enables it to keep abreast of the latest developments, both in scientific and other areas - in the UK and abroad.

1.4 Genetics is a fast moving area where what may merely be a research project one year might have practical applications the next. The HGAC endeavours to anticipate developments and works flexibly and responsively towards it goal.

1.5 The Commission met on the following occasions, during its first year of operation:

27 February 1997
15 May 1997
29 September 1997
24 November 1997
15 December 1997
5 February 1998.

Priorities

1.6 The Commission is charged with setting its own priorities, although from time to time, it may be requested to provide urgent advice to Ministers. At the HGAC's first meeting on 27 February 1997, it identified **insurance, cloning** and **communication and consultation** as its first priorities. Details of the Commission's work in these areas are covered in the three sections following.

1.7 In addition to these three areas, the Commission is pursuing other issues to a longer timescale - including employment and privacy. In particular, privacy is recognised as an underpinning issue in establishing confidence in the new science.

INSURANCE

2.1 The potential impact of genetic testing on the availability of life insurance cover in the UK has attracted a great deal of interest. There is concern that individuals who are required to disclose the results of a genetic test to an insurance company may run the risk of being unfairly discriminated against, and either be refused cover or asked to pay a disproportionately high premium. An additional concern is that, if insurance companies are permitted to insist on disclosure of the results of genetic tests, this may deter people at risk of a treatable disorder from taking genetic tests and receiving early treatment. Concern has also been expressed that genetic test results cannot generally be used for accurate prediction of insurance risks. It may be possible to use genetic test results to make some predictions, but at the present time insurance companies, like others, cannot generally do so.

2.2 Insurers are concerned about "adverse selection", whereby individuals who believe that they have unusually bad prospects may be more likely to seek to insure themselves for larger amounts if they do not have to share genetic information with insurers. This might, it is claimed, raise the cost of insurance by undermining the good faith between the insurer and the insured.

2.3 At its first meeting in February 1997 the Human Genetics Advisory Commission agreed that the issue of genetic testing for insurance merited early consideration. This area had already been highlighted by the House of Commons Science and Technology Select Committee in its report "Human Genetics: The Science and Its Consequences" (1995).

The work of the HGAC insurance group

2.4 An insurance working group, chaired by Professor Cairns Aitken, was set up to explore the implications of genetic testing for insurance, concentrating on life insurance (see Annex B for membership details).

2.5 The group met thirteen times, taking oral evidence from thirty three experts and collecting much written material. In preparing its report, the Commission paid attention to a broad range of opinion from actuaries, underwriters, the Genetic Interest Group and other patient associations, clinicians, representatives of consumer groups and industry. It was clear from those who were consulted that the advance of genetic science will pose significant challenges for the insurance industry in the coming years.

HGAC consultation paper on "The Implications of Genetic Testing for Life Insurance'

2.6 On 9 July, the HGAC issued a detailed consultation paper for consideration by the representatives of the insurance industry and others.

HGAC advice to Ministers

2.7 Based on the responses to this paper and the other evidence that the Commission received, it published its advice to Ministers on the implications of genetic testing for insurance on 17 December 1997 (copies are available from the HGAC Secretariat or can be found on the HGAC Website at *http://www.dti.gov.uk/hgac)*.
The Commission recognises that this is not only a technically complex area, but one in which there are significant differences of view.

2.8 The HGAC's primary conclusion was that, despite the significant progress made by the insurance industry over the past eighteen months, there was still insufficient reliable evidence on the extent to which genetic test results can be used to predict life expectancy or indeed the onset of ill health. The Commission concluded that it is not, at the moment, justifiable for insurers to require disclosure of genetic test results. The HGAC therefore recommended a two-year moratorium on asking clients seeking life insurance products to disclose genetic test results, and that any relaxation of the moratorium should be conditional on the availability of information on the actuarial implications of specific genetic test results for specific insurance types that are sufficient to avoid unfair or unreasonable discrimination. They also recommended the establishment of a robust appeals procedure based on the availability of accurate and reliable information which could afford normal standards of consumer protection. The report also recommended that Government and industry should work together on approaches to monitor the situation and on ways to encourage active research into the actuarial implications of genetic test results.

Reason for focusing on life insurance

2.9 The Commission focused on life insurance partly because this appeared to be the greatest area of public concern. It is important to individuals, to society and, indeed, to the insurance industry itself that people are not denied life insurance without good reason. The protection of dependants is normally the main reason for taking out life insurance but, in addition, in the UK home purchase by means of a mortgage is generally linked to life insurance. Although the HGAC concentrated on life insurance, it believes that advances in genetics will also have implications for other types of insurance, such as health insurance. It is for this reason that the Commission would not wish to see disclosure of genetic test results required for other insurance types without due consideration and public consultation.

Next steps

2.10 In 1998, the Commission will keep under review developments in this area. The HGAC is aware that a range of organisations is actively considering the issues. For example, the publication of the HGAC's advice to Ministers coincided with the publication of the Association of British Insurers Code of Practice on genetic testing. The Government is expected to respond to the HGAC's recommendations on life insurance in the first half of 1998. The Commission will take a particular interest in securing public confidence in systems that emerge to address the issues and will be undertaking further investigative and consultative work.

CLONING

3.1 In February 1997, Dolly the Sheep, the first vertebrate cloned from a cell of an adult animal, generated considerable public interest; some of it exaggerated and speculative. Although hailed as a remarkable scientific development, concern was raised both nationally and internationally about the implications and use of this technology, particularly the possibility of cloning human beings. The reactions have been world-wide and resulted in several international initiatives on this subject.

3.2 At it's second meeting, in May 1997, the Commission decided to explore ways of holding a public consultation exercise into the implications of cloning developments. It was agreed that the HGAC should collaborate with the Human Fertilisation and Embryology Authority (HFEA), which is responsible, among other things, for the licensing of human embryo research.

The work of the HGAC/HFEA Cloning Working Group

3.3 A joint working group, consisting of members of both bodies and chaired by Reverend Dr John Polkinghorne, was established (see Annex B for membership details). This working group was set up to consider the planning, drafting, distribution and analysis of a joint HGAC and HFEA consultation paper on the issues for human genetics arising from advances in cloning technology.

3.4 The group found that considerable confusion has been caused because the term "cloning" is used to describe a number of entirely different concepts. It is important to distinguish between "reproductive cloning", where the intention is to produce identical individuals, and what may broadly be called "therapeutic cloning", which may be used to describe techniques such as producing replacement skin for treating victims of serious accidents or disease. The former is effectively banned in the UK under the Human Fertilisation and Embryology Act (1990). The latter term also includes techniques which, although not therapeutic in themselves, may lead ultimately to therapeutic benefits.

"Cloning Issues in Reproduction, Science and Medicine - A Consultation Document"

3.5 The consultation paper was published on 29 January 1998 (Copies are available from the HGAC Secretariat or on the HGAC Website). Comments have been invited, to the HGAC Secretariat, by 30 April 1998. Over 900 copies have been circulated to date. Consultees included specialists drawn from organisations with scientific, legal, clinical and ethical concerns.

3.6 The paper seeks views on the ethical implications raised by the possibility of human cloning, including the safety of the technique if it were applied to humans and the ethical concerns raised by cloning in specific circumstances. It also invites views about more abstract concepts such as individuality and human dignity.

3.7 The working group will reconvene later this year to consider the results of the consultation exercise. They will revise the paper in the light of comments received, as the basis of advice from the HGAC and HFEA to Ministers.

COMMUNICATION AND CONSULTATION

4.1 Communication and consultation are ongoing priorities for the HGAC, enabling it to keep developments in genetic science under review, inform itself about the range of opinion on the issues and make human genetics accessible to a wider audience. The Commission has used a number of methods to communicate and consult.

4.2 In the first half of 1997, the Commission held a series of consultative meetings with the aim of developing its thinking on the issues. The objectives were to initiate an exchange of information with interested parties, to discuss current and emerging developments and also to discuss the public knowledge of human genetics; along with ways of building public understanding of the subject. Given the HGAC's remit of keeping under review scientific progress, the first consultative meeting was with scientists (22 April) to discuss current and expected developments in the field of genetics. Other meetings with journalists (9 May), industrialists (2 July) and those interested in the social policy implications of human genetics (4 July) followed. A number of common themes emerged from these meetings. At all four meetings, concern was expressed about the possible misuse and misinterpretation of genetic tests, and the potential for discrimination. The need to consider genetics in the wider context (for instance, looking at privacy and ethical issues) was seen as important, as was informing the public and those who advise them (eg health care professionals and others). The consultative meetings were valuable in guiding the Commission's work and the HGAC appreciates the input of those who attended.

4.3 Building on the knowledge imparted at consultative and other meetings (such as the insurance working group meetings), the Commission issued two consultation papers to seek a wider range of views. The insurance consultation paper was based around specific questions and was aimed primarily at the insurance industry, whereas the ongoing consultation exercise on cloning is aimed at a much wider audience. The HGAC will continue to collaborate with the **Human Fertilisation and Embryology Authority** on cloning. The HGAC's consultative documents have set out background information, in an effort to be informative and separate science fact from science fiction. Another point that was made during the Commission's consultative meetings, and which was emphasised during the development of the consultation paper on cloning, was that the language used can have an impact on the public's perception. This is especially true of emotive issues such as cloning.

4.4 The Commission has also endeavoured to keep abreast of developments by means of informal presentations prior to its main meetings. At its first meeting, the HGAC heard from Professor Marcus Pembrey (Institute of Child Health) about "What is genetics and where is it going?". Other presentations included two on developments and implications of cloning technology by Dr Ian Wilmut (Roslin Institute) and Dr Rosa Beddington (National Institute for Medical Research). The Commission also heard from Ms Theo Harris (Sickle Cell Society) about the problems faced by those coping with genetic diseases.

4.5 The HGAC has also been in contact with those at the leading edge of science, policy formers and others. For instance, the Chairman met Dr Ron James of PPL Therapeutics, the company that collaborated with the Roslin Institute on cloning of Dolly the sheep, to discuss the implications of this scientific development. HGAC members met John Battle MP (Minister for Science, Energy and Industry) before their meeting on 15 December and the Chairman met Sir Aaron Klug (President of the Royal Society) and Dr Michael Clark MP (Chairman of the House of Common's Science and Technology Committee) during 1997.

4.6 The HGAC is fortunate that Revd Dr John Polkinghorne of the **Advisory Committee on Genetic Testing (ACGT)** and Professor Norman Nevin of the **Gene Therapy Advisory Committee (GTAC)** are members of the Commission. The HGAC has a broader remit than these two specialist committees, which advise Health Ministers, and complements their work. The dual membership of the GTAC and ACGT chairmen ensures that there is no duplication of effort.

4.7 The **Nuffield Council on Bioethics** is also a key organisation in the UK involved in considering the ethical issues arising from developments in genetics. Members of the HGAC and the Nuffield Council met in February 1998 to discuss their workplans and ensure that they are complementary. This task is made easier because the current chair of the Nuffield Council on Bioethics, Dr Onora O'Neill, is also a member of the HGAC.

4.8 The Commission believes that it needs to be flexible and responsive, given the pace of developments in genetics and related issues. Therefore, although it focuses its efforts on particular topics, it welcomes hearing from those involved in other areas of work that fall under the HGAC's remit. For instance, Members were interested to hear about the development of the International Centre for Life in Newcastle (from Mr Alistair Balls and Dr Matt Ridley) and to receive a report from the Welsh Citizen's Jury that had been considering the question of "What conditions should be fulfilled before genetic testing for people susceptible to common diseases becomes available on the NHS?".

4.9 One point about human genetics that has been made to the HGAC is the need for greater public discourse to assist in the policy making process. The Commission is committed to listening and making itself accessible to wider public views and recognises the need to explore a variety of methods to achieve this. The HGAC considers, on an on-going basis, how best to involve the public, in consultation with other bodies that have experience in this area. A key element is to ensure that those involved in discussions are appraised of the facts; which is not always easy when dealing with complex and fast moving technologies. To this end, the Chairman and other members of the Commission have given a number of presentations about developments in genetics and the work of the HGAC to a range of audiences and participated in public discussions on behalf of the Commission. Examples include the Ashmolean Club, a conference on "Advances in Healthcare and Ethical Constraints" at the University of Hertfordshire and a conference on "The Implications of Genetic Testing for Insurance". Other audiences have included industrialists, academics and school children.

4.10 The Commission considers openness as vital in establishing public confidence and wider public debate. The Commission publishes reports, which are available from the Internet, along with the press notices that are issued after each main HGAC meeting. The publication of the HGAC's advice to Ministers on insurance and the joint consultation document on cloning were both accompanied by press briefings. Human genetics attracts media interest and in response the Chairman and other members of the Commission gave radio and television interviews, as well as providing articles for journals and other publications.

4.11 In the course of its work, the HGAC has found that better information is needed in the UK about the ethical, legal and social implications of advances in genetics. In 1997, the **Wellcome Trust** announced plans to fund research into the ethical, legal and social implications (ELSI) of developments in biomedicine, and sought advice from the HGAC and others on the content of this research programme. The HGAC recognises this work as important, as results of the programme are likely to provide useful information for the Commission and others. Members of the HGAC attended a conference on "Biomedical Advance and Public Policy - Bridging the research gap" organised by the Wellcome Trust in January 1998.

INTERNATIONAL DEVELOPMENTS

5.1 Genetics knows no boundaries. Although cultural and social contexts differ and one nation has little influence over the culture and politics of another, there are areas of common agreement and concern, and much can be learnt from the experiences in other countries. Thus, the HGAC has been developing international contacts.

5.2 The Chairman has held discussions with representatives of bodies examining the issues in other countries. In addition to meeting Dr Harold Shapiro, the Chairman of the US National Bioethics Advisory Commission, he attended the Third Standing Conference of European National Ethics Committees in January 1998. He also attended, for example, a meeting organised by the British Council and *Nature* about the approaches adopted in Britain and France to deal with bioethics.

5.3 During the course of the HGAC's work on insurance and cloning, information from other countries has been collected. The HGAC has been keeping a watching brief on international developments in genetics and biomedicine, such as the UNESCO "Universal Declaration on the Human Genome and Human Rights" and the Council of Europe "Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine".

5.4 The UNESCO Declaration, which was adopted by the General Conference of the United Nations Educational, Scientific and Cultural Organisation in November 1997, contains principles prohibiting unjustified discrimination, emphasising principles of consent and confidentiality and encourages the development of educational activities to improve awareness of the implications of developments in genetics. It is not legally binding, but UNESCO hope that it will, in the future, form the basis for a binding convention on the human genome. The Council of Europe Convention, which sets out general standards for the protection of the human being in the context of developments in biology and medicine, was opened for signature in April 1997. The Convention prohibits unjustified discrimination on the grounds of genetic heritage and includes a moratorium, for a minimum of five years, on germ line gene therapy in humans. A protocol to the Convention prohibiting the cloning of human beings is now open for signature and further protocols, including one on genetics, are also being developed.

5.5 The HGAC has also been closely following the progress of the European Commission's draft Directive on the Legal Protection of Biotechnological Inventions ("the Patent Directive"). It received a report from the Patent Office in September and has met with their representative. The proposed Directive aims to establish a clear legal framework for the protection of biotechnological inventions without prejudice to other legislation, and seeks to harmonise relevant patent laws across the European Union. Although concern has been expressed about the effects the Directive might have on research and development in the field of genetics, it is expected to result in little change to the system currently in place in the UK. The HGAC has indicated that it regards it as important to ensure that no regulations are agreed which might have the effect of inhibiting continuing research. The proposed Directive was presented to the European Parliament on 9 March 1998 and their opinion is awaited. Implementation should follow within two years of adoption ie no earlier than 2000.

ISSUES FOR THE COMING YEAR

6.1 Tasks for 1998 include analysing the public response to the **cloning** consultation exercise and developing advice to Ministers on this subject, in collaboration with the Human Fertilisation and Embryology Authority. HGAC will also be undertaking further investigative and consultative work on genetics and **insurance.** In addition to these existing areas of work, the Commission has identified the implications of genetic testing for **employment** as its next priority, and is now considering how to take this issue forward.

6.2 Communication and consultation will continue to be reflected in all aspects of the Commission's work, with a **consultative conference** planned for the Autumn. The Commission has found **international dialogue** useful and plans to build on its existing network in the coming year.

6.3 Further HGAC meetings have been arranged in 1998 for 7 May, 30 June, 23 September and 16 December.

ANNEX A

TERMS OF REFERENCE OF THE HGAC

The terms of reference of the Human Genetics Advisory Commission are to:

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

ii. 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;

iii. 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 in 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.

Notes:

The Advisory Commission was set up in December 1996 and its functions and operation will be reviewed after 2 years.

The HGAC is jointly funded by the Department of Trade and Industry (DTI) and the Department of Health and is supported by a joint secretariat based in the Office of Science and Technology (part of the DTI).

ANNEX B

MEMBERSHIP OF THE HGAC

Chairman

Professor Sir Colin Campbell
Vice Chancellor - University of Nottingham

Members

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

Dr Micheala Aldred *
Director - Retinoblastoma Society

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

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

Professor Norman Nevin *
Chairman - Gene Therapy Advisory Committee

Dr Onora O'Neill *
Chairman - Nuffield Council on Bioethics

Revd Dr John Polkinghorne
Chairman - Advisory Committee on Genetic Testing

Dr George Poste
Chief Science and Technology Officer - SmithKline Beecham Pharmaceuticals

Ms Moira Stuart
Reporter/presenter - British Broadcasting Corporation

** Members of the HGAC Insurance Group, chaired by Professor Aitken*

Secretariat

Dr Amanda Goldin
Ms Mileva Novkovic
Mrs Natalia Hill
Mr Chris Hepworth

Observers

Mr Chris de Grouchy (until Jan 1998)
- Office of Science and Technology

Mrs Pat Sellers (from Jan 1998)
- Office of Science and Technology

Mrs Marcia Fry - Department of Health

MEMBERSHIP OF JOINT HGAC/HFEA CLONING WORKING GROUP

Chairman

Revd Dr John Polkinghorne

Members

Professor Christine Gosden[†]
Professor of Medical Genetics, Liverpool Women's Hospital

Dr Anne McLaren[†]
Principal Research Associate, Wellcome/CRC Institute

Dr George Poste

[†] Members of the Human Fertilisation and Embryology Authority

ANNEX C

USEFUL ADDRESSES

HGAC Secretariat
Office of Science and Technology
Albany House
94-98 Petty France
LONDON SW1H 9ST
Tel: 0171 271 2131, Fax: 0171 271 2028

email: chris.hepworth@osct.dti.gov.uk
Website http://www.dti.gov.uk/hgac

Members of the HGAC may be contacted via the Secretariat.

Advisory Committee on Genetic Testing/Gene Therapy Advisory Committee
c/o Department of Health
Room 401 Wellington House
133-135 Waterloo Road
LONDON SE1 8UG
Tel: 0171 972 4017, Fax: 0171 972 4196
Website
http://www.open.gov.uk/doh/genetics/htm

ACGT and GTAC are two separate committees that advise Health Ministers on genetic testing and gene therapy issues respectively

Association of British Insurers (ABI)
51 Gresham Street
LONDON
EC2V 7HQ
Tel: 0171 600 3333, Fax: 0171 696 8998
Website http://www.abi.org.uk

The trade association for insurance companies in the UK

British Medical Association
BMA House
Tavistock Square
LONDON WC1H 9JP
Tel: 0171 387 4499, Fax: 0171 383 6400
Website http://www.bma.org.uk

A voluntary professional association for doctors and an independent trade union. A scientific and educational body.

Genetic Interest Group (GIG)
Farringdon Point
29-35 Farringdon Road
LONDON EC1M 3JB
Tel: 0171 430 0090, Fax: 0171 430 0092

GIG is a national alliance of organisations which support children, families and individuals affected by genetic disorders

Human Fertilisation and Embryology Authority (HFEA)
Paxton House
30 Artillery Lane
LONDON E1 7LS
Tel: 0171 377 5077, Fax: 0171 377 1871
Website http://www.hfea.gov.uk

A statutory body that regulates IVF and donor insemination treatments, human embryo research and the storage of gametes and embryos

Nuffield Council on Bioethics
28 Bedford Square
LONDON WC1B 3EG
Tel: 0171 631 0566, Fax: 0171 323 4877

An independent body which examines the ethical issues arising from developments in medicine and biology

The Wellcome Trust
183 Euston Road
LONDON NW1 2BE
Tel: 0171 611 8888, Fax: 0171 611 8545
Website http://www.wellcome.ac.uk

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.

ANNEX D

REFERENCES

General

Universal Declaration on the Human Genome and Human Rights Adopted November 1997. United Nations Educational, Scientific and Cultural Organisation.

Council of Europe. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine Strasbourg: Council of Europe. ETS 164. 1996

Human Genetics: The Government's Response Government Response. Cm 3306. June 1996. HMSO.

Human Genetics: The Government's Response Third Report. House of Commons Science and Technology Committee. HC231. April 1996. HMSO.

Human Genetics: The Science and its Consequences Government Response. Cm 3061. January 1996. HMSO.

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

Genetic Screening: Ethical Issues Report by the Nuffield Council on Bioethics. December 1993.

European Parliament and Council Directive on the legal protection of biotechnological inventions COM(97)446 final.

Insurance

The Implications of Genetic Testing for Insurance Human Genetics Advisory Commission. December 1997. Available from the HGAC Secretariat.

Genetic Testing: ABI Code of Practice Association of British Insurers. December 1997.

The Government's Response to the Science and Technology Committee's Second Report, Session 1996-97, Association of British Insurers' Policy Statement on Life Insurance and Genetics HC455. March 1997. HMSO.

Policy Statement on Life Insurance and Genetics The Association of British Insurers. February 1997.

Cloning

Cloning Issues in Reproduction, Science and Medicine HGAC/HFEA. January 1998. Available from the HGAC Secretariat.

The Cloning of Animals from Adult Cells Government Response to the Fifth Report of the House of Commons Select Committee on Science and Technology, Session 1996-97, Cm 3815. November 1997. HMSO.

Cloning Human Beings Report and Recommendations of the US National Bioethics Advisory Commission. June 1997.

The Cloning of Animals from Adult Cells House of Commons Science and Technology Committee, Session 1996-97, Fifth Report. March 1997. HMSO.

Human Fertilisation and Embryology Act 1990 November 1990. HMSO.

ANNEX E

GLOSSARY

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

Adverse selection - if high risk people take out insurance this drives up the prices of premiums, so that low risk people are deterred from taking out policies and withdraw from the pool, thus worsening the risk pool and increasing costs.

Chromosomes - nucleic acid-protein structure in the nucleus of a cell. Chromosomes are composed chiefly of DNA, the carrier of hereditary information. Chromosomes contain genes, working lengths of DNA that carry the genetic code for specific proteins, interspersed with large amounts of DNA of unknown function. A normal human somatic cell contains 46 chromosomes; a normal human gamete cell contains 23 chromosomes.

Cloning - copying and propagation without altering the nuclear genome.

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.

Embryo - the developing organism from the time of fertilisation until significant cellular differentiation has occurred, when the organism becomes known as a "fetus". In humans, the term "fetus" is used for an embryo after the eighth week of development until birth.

Gene - a working length of a chromosome composed of DNA. Each of the body's 100,000 genes carries the instructions that allow the cell to make one specific product such as a protein.

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.

Mitochondria - cellular organelles that provide energy to the cell. The mitochondrion contains some of its own genes.

Moratorium - temporary ban.

Non-statutory - not required under the law.

Nucleus - the cell structure that houses the chromosomes, and thus the genes.

Premium - the amount paid by the policy holder for insurance.

Therapeutic cloning - 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.

Underwriter - person who decides whether to accept a risk and calculates the premium to be charged.

The HGAC Secretariat may be contacted at:

Office of Science and Technology
Albany House
94-98 Petty France
LONDON SW1H 9ST

Tel: 0171 271 2131
Fax: 0171 271 2028
email: chris.hepworth@osct.dti.gov.uk
Website http://www.dti.gov.uk/hgac

Human Genetics
Advisory Commission

March 1998. Department of Trade and Industry.

http://www.dti.gov.uk/
DTI/Pub 3315/1.5k/3/98/NP.
URN 98/169