

# Genetic Tests and Future Need for Long-term Care in the UK

## Executive Summary

Report of a Work Group of the Continuing Care Conference Genetic Tests and Long-term Care Study Group, chaired by Dr Virginia Warren, BUPA

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## Foreword

Our knowledge of genetic science is expanding rapidly. Genetic testing could grow rapidly over the early decades of the next century. The overall result will be of benefit to people since those people with a predisposition to a certain disease or a combination of impairments could take preventative measures. They could make life-style changes or receive medical treatment or therapy earlier and thus defer the onset of disease, or significantly reduce the risk.

Widespread genetic testing of the population would raise many issues for the insurance industry. Would people with a predisposition to a disease take out insurance more readily and in larger amounts than the average? Would people who know that they have a predisposition to a disease fail to reveal the fact, and thereby adversely select against the insurance office which could lead to substantial underwriting losses?

The public also has worries and doubts about the relationship between genetic testing and

insurance. Would some people with a particular genetic profile be denied insurance cover completely? Would some people only obtain insurance at a very high cost that only a few people can afford?

A joint seminar of the Royal Society and the actuarial profession in September 1996 considered the implications for life assurance. The general feeling was that there were some problems associated with high sums assured, but there were unlikely to be adverse effects for either the insurance industry or the general public. For normal cases of average size, life assurance cover could be obtained by proposers without increases in premium and without reference to genetic test results.

The Association of British Insurers has drawn up guidelines and a Code of Practice on how member offices should use genetic information. Several researchers have suggested that, though the impact of genetic testing will be relatively slight for life assurance, it could have a serious impact on other classes of insurance in future years – medical fees insurance and long-term care insurance have been quoted as particular cases.

The Continuing Care Conference (CCC) is a unique coalition of commercial, charitable and public service organisations with a common purpose to ensure that the public and private funding of long-term care needs of elderly people meets their reasonable expectations and preserves their dignity in old age. Several prominent insurance offices are members. Research, advice and recommendations of good practice are a fundamental part of CCC's *raison d'être*. CCC has sponsored a distinguished multi-disciplinary team of medical doctors, actuaries, geneticists and consultants to consider the effects of genetic testing on long-term care and insurance. CCC was aware that in North America there were calls for making it illegal for insurance offices to take notice of genetic test results when underwriting or pricing long term care insurance. CCC wants to promote a reasoned discussion in the United Kingdom.

The Study Group's report is not exhaustive and concentrates principally on Alzheimer's disease, though outlines are given for diseases which lead to the requirement for long-term care, or are thought to be significantly influenced by the genetic profile. The relationship between genetic and other (environmental) risk factors is explored. This shows that for most diseases which are significant for long-term care, environmental factors are more important than genetic factors.

An actuarial model developed by Dr A S Macdonald was used to estimate the likely long-term care cost that results from susceptibility to Alzheimer's disease according to the Apolipoprotein E (ApoE) gene. For a small percentage of people, around 2%, there is a higher long-term care cost, at just over 10% higher than the average for males, and below 10% for females. Insurance offices and the Association of British Insurers (which has drawn up guidelines and a Code of Practice on how member offices should use genetic information) will now need to consider whether this degree of 'extra' risk can be absorbed into the standard underwriting pool. Under current underwriting practice for long-term care insurance, 10% of extra risk is generally taken as the boundary at which extra underwriting terms are imposed. Many insurers are likely to absorb this degree of extra risk within the standard underwriting pool.

The Study Group members, under the leadership of Dr Virginia Warren, are to be

congratulated on accomplishing this wide-ranging and important study. This study, which concentrates on Alzheimer's disease, will serve as a model for gauging underwriting terms for other diseases and may be of use in care planning. It will encourage other bodies and other study groups to extend the research to other classes of insurance.

Desmond Le Grys  
Director of Research, Continuing Care Conference

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## 1. The Project: Scope, Summary and Conclusions

### 1.1 Terms of Reference

“To research and evaluate the significance of diagnostic and prognostic genetic markers in the financing (both private and state) of long-term care of the elderly, and in relation to the provision of care.” CCC Genetic Tests and Long-term Care Study Group minutes 22.5.98

Objective: to take what information is available on this topic, and present it in a form useful to funders and providers of care.

### 1.2 Scope of the study

This is a pragmatic piece of work. We have sought to find relevant information, and to collate and present it in a way which is accessible to funders and providers of long term care. We have aimed to give you a valid impression, not a detailed appreciation, of the present state of play.

We have done this to the best of our ability, within the constraints of the time and skills available. As you read and use the booklet, please remember that the work was undertaken by a group of active geneticists and insurance specialists, none of whom could make its production a main task. We have been able to work up the section on late-onset Alzheimer's most fully. For all the conditions we would wish the “provider” aspect and also the ethical context to have been more fully explored. For the latter, you may like to see *Mental disorders and genetics: the ethical context*, the report of the Nuffield Council on Bioethics, published in September 1998, and available on the web. (Nuffield, 1998)

Similarly, apart from Angus Macdonald's model of Alzheimer's, we are conscious of the absence of a “healthcare economics” input. You might like to see *Alzheimer's Disease in the United Kingdom: Burden of disease and future care* by Bosenquet N, May J and Johnson N (Health Policy Review paper 12, London: Imperial College School of Medicine Health Policy Unit, 1998) (Bosenquet, N et al, 1998) and *Fit for the Future: The prevention of dependency in later life: a Report of the Prevention of Dependency in Later Life Study Group* chaired by Elizabeth Mills (ed Prophet H, London: Continuing Care Conference, 12, Little College Street, SW1P 3SH) (Prophet, H (ed) 1998)

We realise that many readers will not be familiar with the vocabulary of genetics and hope that you will find helpful the following informative introduction to genetics and a

glossary available on the Internet:

- *Genetics: Basis for medicine in the 21st century*, pages 53-56. Published by Munich Reinsurance Company, 1998. Copies are available from Munich Re, 154 Fenchurch Street, London EC3M 6JJ (Tel: 0171 626 2566)

- <http://www.hhmi.org/GeneticTrail>

### 1.3 Group members:

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### 1.4 Executive summary

Genetics is advancing rapidly as a laboratory science, and will enhance our understanding of the causes and modulators of all diseases. It can be expected to contribute to the treatment (avoidance, amelioration or cure) of many of the conditions which give rise to a need for long-term care. However, it is clear that these advances are not imminent but will start to bear fruit in the medium to long term (ie 5-20 years).

- Increasing genetic knowledge impacts in four ways on conditions that give rise to a need for long term care:
  - it may allow confirmation of diagnosis in affected people
  - it may allow predictive testing in healthy people
  - increased understanding of genetic factors may allow environmental triggers to be identified, hopefully leading to preventive measures

- new genetic knowledge may lead to new forms of treatment.
- Diagnostic genetic testing of people who are already showing symptoms is already widespread and is increasing. It has implications for long-term care if it helps define the prognosis. It may have repercussions for healthy family members if they choose to be tested.
- For predictive testing of healthy people it is important to distinguish two cases:
  - Some tests lead to useful preventive action. Insofar as the preventive measures are effective, these tests are uncontentious, and have no implications for long-term care
  - Some tests simply indicate the probability of future disease without allowing the risk to be modified. Such tests are relevant to long-term care but are fraught with ethical difficulties
- For conditions that are entirely genetically determined, most of the genes have now been identified. Predictive testing is technically possible, and is available, for example for Huntington's disease, within a tightly controlled ethical framework.
- Few conditions are exclusively due to inherited genetic factors. Most are due to a mixture of inherited genetic factors and lifestyle and environmental factors. The genetic variants that confer some of the susceptibility to common conditions such as heart disease, diabetes and schizophrenia are proving difficult to identify, but there is gradual progress with many diseases. Our current knowledge does not allow predictive or diagnostic genetic testing and our knowledge of the lifestyle and environmental risk factors is not complete either. Nevertheless, understanding of the two areas is sometimes sufficient to allow us to indicate to the public and patients how they could reduce their risk of developing disease or alter its course for the better.
- Increasing genetic knowledge will refine health professionals' advice to the public and patients. Three ways in which this might happen can be envisaged:
  - (i) it will be feasible to avoid or ameliorate some diseases by altering genes directly.
  - (ii) it will be feasible to avoid or ameliorate some diseases by altering gene products (proteins) by diet or medication
  - (iii) the main impact of genetic knowledge on treatment over the next few years is likely to be through drug development. We know that some drugs are more effective, or cause fewer side effects, in some patients than others. Often, the explanation of this will turn out to be genetic. Genetic testing should allow some currently available drugs to be used with greater precision, and may be a prerequisite for using some new drugs.
- A small proportion of some cancers is due to pre-conceptual genetic changes (eg up to 10% of all breast cancer). The identification of such a genetic change allows the estimation of the lifetime risk of someone with that genetic constitution developing that disease. Characteristically, early studies are conducted with affected families, and the estimated lifetime risk is high (eg 85% for breast cancer for women with BRCA1). Further studies, which are population based, are then carried out, and the estimated risk

falls (eg to 55% in the case cited). This happens because the number of people in the general population with the genetic susceptibility but no disease becomes apparent. This effect will almost certainly be seen with the e4 allele for ApoE 4 in relation to Alzheimer's disease.

- Long-term care is labour-intensive, whether delivered formally or informally. The demography of the UK is changing. Until about 2011 the increase in the working age population will keep pace with the increase in the 'dependent' population. After that, the ratio will become unfavourable and there will be progressively fewer people to provide formal or unpaid care.
- The Study Group's report is not exhaustive and concentrates principally on Alzheimer's disease, though outlines are given for the major groups of diseases which lead to the requirement for long-term care, or are thought to be significantly influenced by the genetic profile. The relationship between genetic and other (environmental) risk factors is explored. This shows that for most diseases which are significant for long-term care, environmental factors are more important than genetic factors.
- For a small percentage of people with Alzheimers disease, around 2%, there is a higher long-term care cost, at just over 10% higher than the average for males, and below 10% for females. Insurance offices and the Association of British Insurers (which has drawn up guidelines and a Code of Practice on how member offices should use genetic information) will now need to consider whether this degree of 'extra' risk can be absorbed into the standard underwriting pool. Under current underwriting practice for long-term care insurance, 10% of extra risk is generally taken as the boundary at which extra underwriting terms are imposed. Many insurers are likely to absorb this degree of extra risk within the standard underwriting pool.

### **1.5 Future prospects?**

When an understanding of genetics, environmental factors and their interaction is gained, new tools will be able to be developed for clinical medicine:

- some diseases will be able to be avoided or ameliorated by altering genes eg introduction of functioning genes into stem cells in the lungs of people with cystic fibrosis.
- some diseases will be able to be avoided or ameliorated by altering gene products eg a high homocysteine level in the blood is a risk factor for ischaemic heart disease. It appears that eating more folate would reduce this risk in many people by boosting a faulty enzyme (methylenetetrahydrofolate reductase) which in other people keeps the homocysteine level low. Equally, new drugs will be able to be developed to achieve this sort of effect.
- some diseases will be able to be treated with greater precision with currently available drugs. It is observed that some drugs are more effective, or cause fewer side effects, in some individuals than others. Often, the explanation for this will turn out to be genetic.
- drugs will be able to be designed to treat specific conditions in people with specific genomes.

Some of these will reduce demand for long term care. None are currently available.

## 1.6 Recommendations

1) The Genetics and Insurance Committee (GAIC) note that the same genetic test can have different relevance for different insurance products. A test which predicted a long period of morbidity associated with normal, or near normal, life expectancy would have different meaning for long term care insurance than life insurance. GAIC should make multiple assessments of each test, classifying them as appropriate for use, or not appropriate for use, for each class of insurance product.

2) That long-term care insurers should not plan to rate applicants for risk of genetically complex disease unless:

a) it becomes clear that consumer-driven “right to know” testing has become sufficiently common in the UK for serious anti-selection to take place if applicants are not rated,

**AND**

b) actuarially sound data are available to relate the risk of a particular genotype to the risk being insured, and not just to the risk of a specific disease.

3) That those in all sectors involved in funding and providing long term care use the forthcoming years before genetic susceptibility testing has a major influence on clinical practice to introduce relevant teaching. This needs to be a component of all relevant professional training courses, and of current practitioners’ continuing professional development.

4) That research into the interactions between genetic and lifestyle risk factors for disease is supported, with a view to finding the most cost effective way to reduce that risk. More actuarial research is needed.

5) Our model has suggested that 2% of people could possibly be asked a higher premium for long-term care cover on the basis of genetic understanding of their susceptibility to Alzheimer’s disease. The implications of this need exploration.

## 1.7 Key Points about Specific Conditions (listed alphabetically)

*Diseases giving rise to the need for long-term care, and those which produce symptoms in the elderly and which have interesting genetics, were considered. In our full report we codified the information gleaned onto a standard template and have abstracted the key points here.*

### **Alzheimer’s Disease, familial early onset**

- This is very rare, comprising only about 2% of all Alzheimer’s disease.
- Some families show autosomal dominant inheritance with near 100% penetrance, so an individual with an affected parent can deduce that they have a 50/50 chance of

developing the disease personally. Conversely, a family member whose parent (or grandparents) on the affected side is well and aged more than 70 can reassure themselves that they are very unlikely to be at risk.

- Mutation screening is difficult and not currently routinely available in the UK.
- From an insurance viewpoint, this presents similar underwriting problems for family members as Huntington's disease.

## **Alzheimer's Disease, late onset**

### ***Key points relating to Alzheimer's disease and genetic testing***

- Late-onset Alzheimer's Disease (AD) is common but genetically complex. The only unambiguously identified genetic factor is ApoE.
- ApoE4 is associated with an increased likelihood of Alzheimer's. ApoE2 may be protective. This risk or protection is thought to act through an effect on time of onset.
- Susceptibility must be due to a combination / some combinations of other genes and lifestyle risk factors. At present, we have limited information on these.
- Although ApoE4 genotyping is simple, several authoritative recent reports have warned against using it for diagnostic or predictive purposes. In addition to the poor predictive value for an individual, it is a general ethical principle of genetic testing that it should be performed only when a positive result leads to some useful intervention.
- Although in principle undisclosed ApoE testing could allow substantial anti-selection in long-term care insurance, such testing is not generally available within the UK, either over the counter (which would contravene the guidelines of the Advisory Committee on Genetic Testing (ACGT) or clinically. Family history is the major risk factor: an affected first-degree relative doubles the risk of late-onset disease.

### ***Key points relating to the actuarial model***

- According to our model, long-term care costs vary depending on ApoE status. The magnitude of the variation depends on assumptions about a number of factors. Those we have considered are (i) the frequency of the different genotypes in the population, (ii) the extent to which a given genotype is protective against, or risky for, Alzheimer's, (iii) the overall age/sex-specific mortality rate, (iv) how this is modulated in those with Alzheimer's by being in an institution and (v) whether genotype influences mortality rate. We have presented tables which show the effects of varying the assumptions made. These are capitalised at age 60.
- For context, we have also calculated the overall costs of a pension starting at £10,000 per year from age 60, increasing at 3% per year.
- The modelled overall care costs are about 60% of the pension costs for males, and over 90% for females. Females suffer several financial disadvantages; they live longer (so

pension costs are higher) and require more long term care on average. Considering the genetic risk, the e4 allele puts females at greater risk of AD. In addition, the majority of unpaid carers, whose economic value is included in the care costs, are female.

- Pension costs are not very dependent on ApoE genotype. It is clear that increased care costs will not be significantly offset by reduced pension costs.

### **Cancer: Breast Cancer**

- Little breast cancer is due to known genes.
- Even with a strong family history, women reaching late middle age without developing the disease become not much more likely to get it than a woman without such a family history - they “grow out of” their risk.
- Women can potentially reduce the risk of breast cancer by eating healthily, exercising regularly and moderating alcohol intake.

### **Cancer: Colorectal Cancer**

- About 10% of colorectal cancers are largely genetic and a further 10-15% are associated with strong family history or with ulcerative colitis. The remaining 75-80% of cases are sporadic.
- Acquired genetic changes associated with the development of colorectal cancer are increasingly being understood.
- A predominantly vegetable diet would probably reduce risk.
- Population screening for early disease, rather than genetic susceptibility, may be introduced in the UK.
- For genetic cases, predictive DNA testing is possible, but would only be offered to a healthy person if the family history suggested there was a high risk.

### **Cancer: Endometrial Cancer**

- Little endometrial cancer is due to pre conceptual changes in genes.

### **Cancer: Liver and Pancreatic Cancer**

- Inherited genetic contribution to these cancers is small.
- Primary liver cancer is very rare in this country - largely because hepatitis B is not prevalent. Continuing control of this infection rather than anything genetic is the way to keep it rare.

- Secondary liver cancer is very common in the UK, but is a different entity.

### **Cancer: Ovarian Cancer**

- Approximately 5% to 10% of ovarian cancers are familial and three distinct hereditary patterns have been identified. Limited predictive testing is possible in families with breast-ovarian cancer.

### **Cancer: Prostate Cancer**

- Prostate cancer is very common in elderly men. It is often asymptomatic, or causes few problems.
- Many men die with prostate cancer, rather than of prostate cancer.
- In some, it does follow an aggressive course, with local symptoms and distant metastases giving eg bone pain.
- Some initial progress has been made in identifying susceptibility genes, but as yet no predictive testing is available.
- We do not know how best to treat disease of the various degrees of aggressiveness and spread.

### **Cataract**

- About 50 purely genetic forms of cataract have been described, but they are very rare and constitute only a small proportion of all cataracts.
- Cataract should not generate demand for long-term care because it is so treatable.

### **Diabetes Mellitus: Type 1**

- Type 1 diabetes is genetically complex.
- Environmental factors must interact with genetic factors in its causation.
- We do not at present know how to prevent it; this is a research priority as prevalence is rising rapidly and diabetes is an unpleasant and costly condition with many complications.

### **Diabetes Mellitus: Type 2**

- Type 2 diabetes is common (approx 4% of the population).
- At present there is no place for genetic testing in determining susceptibility to Type 2 diabetes. Family history and ethnic identity are the main predictors of risk.

- Heart disease is a common complication (8% of people with diabetes): it is estimated that a quarter of this is attributable to the D allele of the ACE gene. People with type 2 diabetes and at least one copy of this allele can potentially reduce their risk.
- Avoidance of obesity, and adequate exercise are protective.

### **Fragile X**

- There are many causes of mental retardation, including chromosomal, single gene and non-genetic causes.
- Fragile X is the commonest known single-gene cause of moderate-severe mental retardation in males. Females are more mildly and variably affected.
- Various characteristic physical features can suggest the diagnosis in an affected boy; the diagnosis can be confirmed in either sex by a DNA test.
- Fragile X follows a well defined but complex inheritance pattern in families; careful assessment of the full pedigree and DNA data is needed to calculate risks of affected children.
- Examination of the X chromosome may cut short months of uncertainty, developmental assessment and worry for the parents, and inform further reproductive choices.

### **Haemorrhagic Stroke**

- Haemorrhagic stroke comprises about 10% of stroke in the UK. It does not share the genetic causes of blood lipid abnormalities with IHD and ischaemic stroke. It looks similar clinically because the resultant brain damage causes similar patterns of disability in movement, speech etc. • The major risk factor for “primary” haemorrhagic stroke is high blood pressure. “Secondary” haemorrhagic stroke is mainly due to brain tumours, or abnormalities of the blood.
- At one year after first ever haemorrhagic stroke, approx 65% of people will have died, 10% will be alive and dependent, and 25% alive and independent.
- Any genetic influence is via any genetic influence on high blood pressure.

### **Huntington’s disease**

- Huntington’s disease is entirely genetically determined. A person who carries the HD mutation will inevitably develop HD, if they live long enough.
- The age of onset is very variable, and cannot be predicted for individuals.
- All affected people carry the same mutation, for which a simple DNA test is available.
- Predictive testing is strictly controlled, limited to a few specialist genetics centres using

internationally agreed protocols.

### **Ischaemic Heart Disease**

- This is a very common disease and if genetics can be used to allow a proportion of people at risk to avoid the onset of the disease or to reduce the severity of the disease they have got, it will be very important to society as well as to individuals. • It has long been apparent that there were symptoms and signs in common between IHD and ischaemic stroke, and increasing genetic knowledge is confirming the overlaps between the two conditions.
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- While we have gone some way to understanding the genetics of IHD, there is still a long way to go. We are very well informed about the environmental factors that play a part, and people can reduce their risk without waiting for the genetics by addressing them.
- Where the same molecule seems to play a major role in the development of two diseases, (IHD/ischaemic stroke and Alzheimer's), genetic testing for it in one context could bring unwelcome news in the other context. Society needs to consider the ethical and practical implications, including implications for insurance practice.

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### **Manic Depression**

- Family, twin and adoption studies support an effect of genetic susceptibility, but to date

no susceptibility genes have been conclusively identified.

- Information that is available supports the view that some psychiatric disease has a molecular basis, so that in the medium term we can reasonably hope for effective drugs whose design is tailored to the underlying pathogenesis.

### **Multiple Sclerosis**

- A condition which must result from an interplay of genetic and environmental factors.
- We do not currently understand enough to prevent it, or to treat it well.

### **Osteoarthritis**

- A very common condition in which it seems likely that a number of genes will be shown to be involved, together with lifestyle factors.
- It is likely that it will be divided into a number of separate diseases by genetic pathology.

### **Osteoporosis**

- It is likely that osteoporosis is a complex disease which will be revealed to have specific genetic as well as lifestyle components.

### **Parkinson's disease**

- A disease with a genetic element where occupational medicine has given specific clues regarding the interaction of industrial chemicals with genetics, and quite a good understanding of the biochemistry of how symptoms are produced.
- We should know how to ameliorate or avoid disease as understanding develops.

### **Rheumatoid Arthritis**

- A fairly common disease which affects people in young adult life and therefore causes many years of disability. Its drug treatment is not particularly targeted or effective, and tends itself to have serious side effects. So, an insight from genetics could be particularly valuable.
- It appears that certain HLA types confer susceptibility to rheumatoid arthritis.

### **Schizophrenia**

- A moderately common (1% of population) disease with a peak of incidence in young

adults.

- Family, twin and adoption studies support an effect of genetic susceptibility, but to date no susceptibility genes have been conclusively identified.
- Information that is available supports the view that some psychiatric disease has a molecular basis, so that in the medium term we can reasonably hope for effective drugs whose design is tailored to the underlying pathogenesis.
- Following concerns about care in the community, the balance of public provision between community psychiatric and institutional care is currently under review. It must be remembered that some ‘long-term residential care’ for people with schizophrenia happens within the prison service, where cases may not actually be recognised and therefore appropriate treatment not given.

## 1.8 Summary of Relevant Population Attributable Risks

### Introduction

We sought published estimates of the population attributable risk (PAR) due to inherited genetic change, and present these here. The PAR is defined as the proportion of new cases of a disease in a population that can be attributed to a given risk factor. It can be seen that inherited genetic change is responsible for relatively little of the need for long-term care amongst older people generally, and for little of the illness they experience which, while it may not lead to the need for long-term care, reduces their quality of life. It would be inappropriate to set our expectations of ‘genetic medicine’ very high in these respects. However, in some cases it may be revealed that an inherited genetic change is a ‘necessary’ prerequisite for the development of a disease along with a handful of environmental and lifestyle risk factors, each one of which is only ‘optional’. In that case the genetic risk factor will take on disproportionate importance.

### Positions on spectrum

The following numbers refer to positions on a scale where 100% preconceptual is represented as zero, and 100% post-conceptual is represented as 100. The position on the spectrum is estimated rather than absolutely defined. It is represented as a single number or as a range. These numbers have been estimated from a graphical representation in the original report.

AD: early onset	65
AD: late onset	83
Cancer: Breast Cancer	83-98
Cancer: Colorectal Cancer	80-85
Cancer: Liver and Pancreatic Cancer	100
Cancer: Ovarian Cancer	85

Cancer: Prostate Cancer	90-100
Cataract	70
Diabetes Mellitus, Type 1	50-60
Diabetes Mellitus, Type 2	40-45
Fragile X	0
Haemorrhagic Stroke	67-77
Huntington's Disease	0
Ischaemic Heart Disease	63-77
Ischaemic Stroke	63-83
Manic Depression	40-50
Multiple Sclerosis	52-58
Osteoarthritis	53-75
Osteoporosis	70
Parkinson's Disease	75-90
Rheumatoid Arthritis	45-60
Schizophrenia	40-65

### 1.9 Common questions, fears and misconceptions about genetics and genetics and insurance

**Q: If I have the gene will I develop the disease?**

A: For a few rare diseases, this is true. In these cases the gene is said to be 100% penetrant. But for the great majority of diseases, genes are just like any other susceptibility factors: having the “disease” gene increases your risk, but does not inevitably predestine you to get the disease.

**Q: If I do not have the gene I will not get the disease?**

A: This again this is not generally true. There is a degree of uncertainty as many genetic diseases have sporadic, non-genetic forms. If you do not possess the gene causing the disease in your family you are still at the same risk of developing the non-genetic form of the disease as the general population.

**Q: If I have a disease gene will this affect my insurance policies?**

A: No. Currently there are many restrictions on the use of genetic testing for insurance purposes. The ABI, HGAC and ACGT have all issued guidelines on this point, and until the reliability, relevance and actuarial significance of each test has been proven they can not be taken into account for insurance purposes. The HGAC and ACGT have set up an

independent group, the Genes and Insurance Committee (GAIC), to assess each test in relation to each form of insurance. There is a long-standing tradition of use of family history information for assessing applicants for some types of insurance.

**Q: If I reveal a genetic test result will it affect other members of my family?**

A: No. All genetic test results are confidential and can not be used to assess another individual's application.

**Q: Will I be asked to reveal any genetic test results from my relatives?**

A: No. Genetic test results can not be linked to another person for insurance purposes.

**Q: If I reveal a genetic test result to one insurance company can they pass it to others?**

A: No. This is against the confidentiality agreement signed by you as an applicant and also against the guidelines of the ABI, HGAC and ACGT.

**Q: How many tests can be done currently?**

A: Tests are possible for several hundred diseases, but these are all rare. Mostly these diseases have their onset in childhood. Even for those adult-onset diseases where a genetic test is possible, the use of such tests is confined to people who have a strong family history of the disease.

**Q: Will population screening for genetic diseases ever occur?**

A: It already occurs. Babies born in the UK have a heel prick test for Phenylketonuria (PKU) and the test has been used for at least 30 years. This is a quick and easy test. Screening is used if it results in people getting effective treatment who would otherwise suffer some severe disease – babies with PKU would be severely mentally retarded, but if they are detected by early screening and put on a special diet, they grow up normal. This test meets the classic requirements for responsible detection of pre-symptomatic disease (Wilson & Jungner, 1968).

**Q: What if people get themselves tested by buying a test ‘over the counter’?**

A: For ethical, (and, secondarily, financial) reasons, the NHS will not introduce widespread testing services unless knowledge of the result can be used to alter the natural history of the disease for the better. For example; the NHS will not seek to identify those at increased risk of Alzheimer's unless care can be offered to mitigate this risk. If “right-to-know” testing becomes widespread, then, in relation to private insurance and Alzheimer's (and assuming that GAIC validates the test for use in place of family history), it may be appropriate for two risk pools to be used. This arrangement would allow the industry to protect itself from adverse selection, be practical and efficient to administer. It would, however, be disadvantageous to a small proportion of the population, and UK society and the Government will need to consider how the services this group may need will be funded.

**Q: Will all this genetic testing lead to a “cure”?**

A: Hopefully: if a genetic test has been developed this means that a genetic cause of a particular disease has already been found and this may lead to novel cures to correct the defect and prevent symptoms from developing. For example in PKU the “cure” is a dietary one which prevents any symptoms from developing if specific foods are avoided.

**Q: Can genetic tests predict how severely I will be affected if I get a genetic disease?**

A: Sometimes, but usually not. Most genetic diseases are variable, even when people carry exactly the same mutation.

## 2. Appendices

### 2.1 Useful Addresses

Association of British Insurers (ABI)  
51 Gresham Street  
London EC2V 7HQ  
Tel: 0171 600 3333  
Fax: 0171 696 8999  
Web: <http://www.abi.org.uk>

British Society for Human Genetics  
Clinical Genetics Unit  
Birmingham Women’s Hospital  
Edgbaston  
Birmingham B15 2TG  
Tel: 0121 627 2630  
Web: <http://www.bham.ac.uk/bshg>

Genetics and Insurance Committee (GAIC)  
Department of Health  
Room 401, Wellington House  
133-155 Waterloo Road  
London SE1 8UG  
Tel: 0171 972 4017  
Fax: 0171 972 4196  
E-mail: [mstraugh@doh.gov.uk](mailto:mstraugh@doh.gov.uk)  
Web: <http://www.dh.gov.uk/Home/fs/en/genetics.htm>  
(Also contact point for Advisory Committee on Genetic Testing (ACGT), Gene Therapy Advisory Committee (GTAC) and Human Genetics Commission (HGC)).

Human Genetics Advisory Commission (HGAC), Secretariat  
Office of Science and Technology  
Albany House  
94-98 Petty France  
London SW1H 9ST  
Tel: 0171 271 2131  
Fax: 0171 271 2028  
[E-mail: mileva.novkovic@osct.dti.gov.uk](mailto:mileva.novkovic@osct.dti.gov.uk)  
Web: <http://www.dti.gov.uk/hgac>  
(To merge with HGA, December 1999).

Medical Research Council (MRC)  
20 Park Crescent

London W1N 4AL  
Tel: 0171 636 5422  
Fax: 0171 436 6179  
Web: <http://www.mrc.ac.uk>

Nuffield Council on Bioethics  
28 Bedford Square  
London NW1 2BE  
Tel: 0171 631 0566  
Fax: 0171 637 1712  
Web: <http://www.nuffieldfoundation.org>

Public Health Genetics Unit  
Strangeways Research Laboratory  
Worts Causeway  
Cambridge CB1 4RN  
Tel: 01223 740200  
Fax: 01223 740200  
E-mail [phgu@srl.cam.ac.uk](mailto:phgu@srl.cam.ac.uk)  
Web: <http://www.medinfo.cam.ac.uk/phgu>

UK Forum for Genetics and Insurance  
Staple Inn Hall  
High Holborn  
London EW1V 7QJ  
Tel: 0171 632 2136  
Fax: 0171 632 2131  
E-mail: [ukfji@actuaries.org.uk](mailto:ukfji@actuaries.org.uk)

The Wellcome Trust  
183 Euston Road  
London NW1 2BE  
Tel: 0171 611 8888  
Fax: 0171 611 8545  
Web: <http://www.wellcome.ac.uk>

## **Genetic Interest Groups & Consortia**

### ***General***

Genetic Interest Group  
Unit 4D  
Leroy House  
436 Essex Road  
London N1 3QP  
Tel: 0171 704 3141  
Fax: 0171 359 1447  
E-mail: [mail@gig.org.uk](mailto:mail@gig.org.uk)  
Web: <http://www.gig.org.uk>

### ***Alzheimer's Disease***

United Kingdom Alzheimer's Disease Genetics Consortium  
Institute of Psychiatry  
London SE5 8AF  
Tel: 0171 703 5411

### ***Huntington's Disease***

United Kingdom Huntington's Disease Genetics Consortium  
Institute of Medical Genetics  
University Hospital of Wales  
Heath Park  
Cardiff, CF14 4XW  
Tel: 01222 747747  
Fax: 01222 747603

### **Societies for Specific Conditions**

#### ***Alzheimer's Disease***

Alzheimer's Disease Society  
Gordon House  
10 Greencoat Place  
London SW1P 1PH  
Tel: 0171 306 0606  
Tel: 0845 300 0336 (Helpline)  
Fax: 0171 306 0808  
Email: [info@alzheimers.org](mailto:info@alzheimers.org)

#### ***Cancers***

CancerBACUP  
Bath Place  
Rivington Street  
London EC2A 3JR  
Tel: 0171 613 2121 (Info line)  
Tel: 0808 8001234 (Info line)  
Tel: 0171 696 9003 (Admin)  
Tel: 01415531553 (Counselling, Glasgow office)

Cancer Care Society  
Jane Scarth House  
39 The Hundred  
Romsey, Hants, SO51 8GE  
Tel: 01794 830374  
Fax: 01794 518133  
E-mail: [info@cancer-care-soc.demon.co.uk](mailto:info@cancer-care-soc.demon.co.uk)

CancerLink  
11-21 Northdown Street  
London N1 9BN  
Tel: 0171 833 2818  
Tel: 0800 132905 (Helpline)  
Fax: 0171 833 4963  
E-mail: [cancerlink@cancerlink.org.uk](mailto:cancerlink@cancerlink.org.uk)

#### ***Cataract***

Royal National Institute for the Blind  
224 Great Portland Street  
London W1N 6AA  
Tel: 0171 388 1266  
Fax: 0171 388 2034

#### ***Diabetes Mellitus***

British Diabetic Association

Youth and Family Services  
10 Queen Anne Street  
London W1M 0BD  
Tel: 0171 323 1531  
Tel: 0171 636 6112 (Careline)  
Fax: 0171 637 3644

***Fragile X Syndrome***

Fragile X Society  
53 Winchelsea Lane  
Hastings TN35 4LG  
Tel: 01424 813147  
Web: <http://www.fragilex.org.uk>

***Huntington's Disease***

Huntington's Disease Association  
108 Battersea High Street  
London SW11 3HP  
Tel: 0171 223 7000  
Fax: 0171 223 9489  
Web: <http://www.had.org.uk>

Huntington's Disease Association of Northern Ireland  
C/o Department of Medical Genetics  
Floor A  
Belfast City Hospital Trust  
51 Lisburn Road  
Belfast BT9 7AB  
Tel: 01232 263555  
Fax: 01232 236911

Scottish Huntington's Association  
Thistle House  
61 Main Road  
Elderslie  
Johnstone PA5 9BA  
Tel: 01505 322245  
Fax: 01505 382980

***Ischaemic Heart Disease***

British Heart Foundation  
14 Fitzharding Street  
London  
W1H 4DH  
Tel: 0171 935 0185  
Tel: 0171 486 5860

***Manic Depression***

Manic Depression Fellowship  
8-10 High Street  
Kingston-upon-Thames  
Surrey KT1 1EY  
Tel: 0181 974 6550  
Fax: 0181 974 6600

### ***Multiple Sclerosis***

Multiple Sclerosis Resource Centre  
4a Chapel Hill  
Stansted  
Essex CM24 8AG  
Tel: 01279 817101  
Fax: 01279 647179

Multiple Sclerosis Society  
25 Effie Road  
Fulham  
London SW6 1EE  
Tel: 0171 610 7171  
Tel: 0808 800 8000 (Helpline)  
Fax: 0171 736 9861

### ***Osteoarthritis/ Rheumatoid Arthritis***

Arthritis Research Campaign  
Copeman House  
St Mary's Court  
St Mary's Gate  
Chesterfield  
Derbs, S41 7TD  
Tel: 01246 558033  
Tel: 01246 558007

### ***Osteoporosis***

The National Osteoporosis Society  
PO Box 10  
Radstock  
Bath BA3 3YB  
Tel: 01761 471771  
Tel: 01761 472721 (Helpline)  
Fax: 01761 471104

### ***Parkinson's Disease***

Parkinson's Disease Society  
215 Vauxhall Bridge Road  
London SW1V 1EJ  
Tel: 0171 931 8080  
Tel: 0171 233 5373  
(Helpline, Mon-Fri 9.30 – 5.30)

### ***Schizophrenia***

National Schizophrenia Fellowship  
28 Castle Street  
Kingston-upon-Thames  
Surrey KT1 1SS  
Tel: 0181 547 3937  
Tel: 0181 547 3862 - Advice Service)

### ***Stroke***

Stroke Association

Stroke House  
123/7 Whitecross Street  
London EC1Y 8JJ  
Tel: 0171 566 0300  
Fax: 0171 490 2686  
Web: <http://www.stroke.org.uk>

## 2.2 CCC and its members

The Continuing Care Conference (CCC), a unique coalition of commercial, charitable and public service organisations, was established in 1992. Current members are listed below. Its purpose is to ensure that the public and private funding and provision for the long-term care needs of older people meets their reasonable expectations and preserves dignity in old age for all.

In 1998, as part of its ongoing programme, CCC established a study group on genetic tests and long-term care, chaired first by John Castagno, and then by Dr Virginia Warren, Consultant in Public Health Medicine, BUPA. The work group that produced this report was formed under the auspices of the study group.

### **Continuing Care Conference: Current Members**

Abbey National plc  
Age Concern England  
Anchor Trust  
Association of Directors of Social Services (ADSS)  
Assurance Medical Society  
AXA Sun Life  
Bacon & Woodrow  
Barnet Directorate of Community Services  
BUPA  
Care and Repair (England)  
Care Choices Ltd  
City of Bradford Metropolitan Council  
City of Sunderland Social Services Dept  
CGU  
Counsel and Care  
Dirk Bloemers  
Eagle Star Life Assurance Company Ltd  
East Sussex Social Services Department  
Eastern Health & Social Services Board  
Eli Lilly  
ERC Frankona  
Friends Provident  
General & Cologne Life Re UK Limited  
Grace Consulting  
Halifax Financial Services Limited  
Hannover Re  
Help the Aged  
Homeowners Friendly Society  
Housing 21  
IFA Association  
IFACare  
Independent Healthcare Association  
Institute of Actuaries  
J Rothschild Assurance Holdings plc  
Jewish Care

Laing & Buisson  
Local Government Association  
Long-term Healthcare Consultancy Services  
Metropolitan Borough of Stockport  
Metropolitan Borough of Wigan  
Munich Reinsurance Company  
NatWest Life  
Norton Waverley Ltd  
Norwich Union  
Nursing Home Fees Agency  
PPP lifetime care plc  
Prudential UK  
Quality Care & Nursing Home Advice Service (CNHS)  
RB Kensington & Chelsea  
Registered Nursing Homes Association  
Research into Ageing  
Retirement Strategies Ltd  
SAGA Services Ltd  
Salvation Army  
Scottish Provident Institution  
Scottish Widows  
Shropshire County Council  
Skandia Life Group  
SmithKline Beecham Pharmaceuticals  
Social Care Association  
Solihull Social Services  
Standard Life Assurance Company  
Stalwart Assurance Co Ltd  
Swiss Re Life and Health  
Tameside Social Services  
The Health Quality Service  
The Relatives' and Residents' Association  
Teachers' Benevolent Fund  
United Kingdom Home Care Association  
Warwickshire Assoc of Nursing Homes  
Western Health & Social Services Board

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