THE FREEDOM TO UNDERWRITE

by

Spencer Leigh
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"I've got a head full of ideas and it's driving me insane."
('Maggie's Farm', Bob Dylan)

1. INTRODUCTION

"We gazed upon the chimes of freedom flashing."
('Chimes Of Freedom', Bob Dylan)

1.1 This paper is about the Freedom to Underwrite. Of course, there are more important freedoms in the world and possibly it cheapens the term to apply it to underwriting. Nevertheless, the phrase helps to draw together the most important and controversial issues in life underwriting today. Like Bruce Springsteen with 'Born In The USA', I feel like putting a bandana round my head, punching the air and shouting 'The Freedom To Underwrite'. Whether 50,000 fans would gather in a stadium to cheer me on is doubtful.

1.2 As we know from both textbooks and experience, a close relationship between underwriting standards and premium bases is crucial to the well-being of a life office - and yet surprisingly few underwriting papers have been presented to the Institute.

1.3 In 1952 Wilfred Perks delivered a definitive paper titled 'The Treatment of Sub-standard Lives in Practice' (JIA 78, 205). So definitive in fact, that it wasn't until 1965 that another was presented, Arthur Steeds' excellent, 'Some Considerations Affecting the Selection of Risks' (JIA 91, 231). Even though 13 years separated the papers, Arthur was able to write, "In presenting a paper on underwriting to this Institute, I realise how difficult it is to say anything new on this subject."

1.4 Twenty-five years passed until there was another paper on underwriting. That was when I had the honour of presenting 'Underwriting - A Dying Art?' in March 1990. (JIA 117, 443).
1.5 When I wrote the paper, I knew I couldn't possibly make a similar statement to Arthur Steeds' because there had been remarkable medical advances, both in diagnosis and treatment since 1965, and also changes in the way that offices viewed underwriting. I attempted to write a state-of-the-art paper and the title was ironical as I was heading off threats from life office managements that underwriting was unnecessary or could be done totally by computers. Hopefully, the high mortality experienced from the MIRAS business that had been accepted without any medical questions would make offices think twice before doing it again, although, to be fair, there were considerable savings in expenses. Also, the progression to expert systems has not been as rapid as some anticipated. However, five years on, the medical world is moving so fast that many sections of the paper need updating. The challenges to the Freedom to Underwrite are no longer confined to AIDS pressure groups. At times, it seems that almost everyone is telling us how to do our job!

1.6 In the commercial world, an essential requirement to the completion of a contract is an agreement between the parties as to its nature and scope. Each person is deemed to be equally able to assess the value of the bargain offered. Hence, the maxim "let the buyer beware" (caveat emptor). This does not apply to life assurance as the proposer may know more about himself than the insurer could possibly discover. The information could relate to health, habits, occupation, family history and financial standing. Therefore, the law imposes on the proposer the duty of "utmost good faith" (uberrima fides). In my view, only a fool or a rogue would disagree with this principle. Furthermore, the risk selection procedures used by life offices have been accepted by doctors and by the general public for many years.

1.7 Because of this, I believe that, from a theoretical viewpoint and assuming that offices act responsibly, we are invariably right. This is not arrogance because, looked at objectively, anyone would have to concede the arguments. However, that is a different debate and not what we are fighting for here.

1.8 Looking at the issues subjectively, various groups want us to make concessions for social and medical reasons. The rights of an individual are being championed everywhere and so it is unrealistic to hope for Freedom to Underwrite as we approach the year 2000. Indeed, why should insurers be exempt from the vast changes that are happening in our society? If nothing else, this paper demonstrates that the entire nature of life assurance could change from what we have known for the past century or two. Underwriting may never be the same again.

1.9 For a peaceful life, the easiest option is to give in to our critics. However, these Brownie points may cost us dear. As I hope to demonstrate, the Freedom to Underwrite is not something we should relinquish lightly. This paper describes what is happening and how the Freedom to Underwrite is being eroded as a result of AIDS lobby groups, regulations regarding genetic testing, and legislation over disability. And who knows what else is around the corner?

1.10 Forty years ago, when Wilfred Perks wrote his paper, the general public paid no attention to life underwriting. This was true until the mid-1980s, but since the advent of AIDS, life underwriters have come increasingly under the spotlight. We have become the subject of newspaper editorials, and there was even a Private Member's Bill to limit our powers in 1994! As a life underwriter, I should be proud that we have such a high profile but we must be sure that we can defend our position.
1.11 The theory aside, there are no rights or wrongs to many of the issues and it is easy to see things from both sides. Usually it is about drawing the line between equity and equality, and, let's face it, life assurance underwriting is about that very unfashionable word, discrimination, although we call it selection. Discrimination is a word with very negative connotations today, but a distinction should be drawn between fair and unfair discrimination. Fair discrimination is where a proposer's risk has been properly evaluated and is reflected in the premiums. Unfair discrimination is when equal risks are not treated equally. Such action is always unreasonable but I would stress that fair discrimination is essential to good underwriting practice. A life office should strive for an unbiased assessment of the risk. It is sound business practice that the premiums charged should relate to the risk an individual brings to the fund.

1.12 I hope that this paper, which attempts to be objective but inevitably leans towards the insurers, provokes a lively and stimulating debate and, even better, points the way forward. I must emphasise that this paper represents my own views and should not be taken as representing the views of Royal Insurance Life & Pensions for whom I work as Chief Underwriter. Nor does it represent the views of the Association of British Insurers (ABI), where I sit on the Life Assurance and Medical Affairs Committee.

1.13 It should be stressed that the Association of British Insurers is a trade association representing the interests of over 400 insurance companies. Over 95% of the total life business in the UK is written with offices who are members of the ABI. The ABI considers industry matters and makes recommendations to its members, after perhaps seeking guidance from Chief Executives. The ABI cannot enforce its recommendations, but they are usually accepted. I would expect that to be the case with the recommendations they make on genetics and disability, whilst it has already happened with AIDS. The debate tonight may well influence their thinking.
2. DEFINING THE FREEDOM TO UNDERWRITE

"Freedom's just another word for nothin' left to lose,
Nothin' ain't worth nothin' but it's free."
('Me And Bobby McGee', Kris Kristofferson)

2.1 In the early 1980s, before the advent of AIDS, there was total Freedom to Underwrite. A life office could do what it wanted, and this was manifest in three ways:

2.1.1 PROPOSALS - On its proposal forms, a life office could ask whatever was considered relevant - and there was very little controversy. Up to the mid-1960s, offices asked proposers about their ethnic origins and even charged so-called racial extras. Following the Race Relations Act 1968, offices removed the additional premiums from existing contracts and resolved not to charge them for new proposals. No-one would defend racial discrimination now, but the alteration did limit the Freedom to Underwrite at the time.

2.1.2 MEDICAL EVIDENCE - An underwriter could request whatever medical evidence he thought was necessary, usually a report from the proposer's general practitioner (a medical attendant's report or MAR) or a medical examination report by an independent doctor (MER). Again, there were no restrictions regarding the questions on those forms.

2.1.3 UNDERWRITING DECISION - An underwriter could determine whatever decision he thought was appropriate - ordinary rates, a rating, postponement of cover, policy exclusions or outright declinature.

2.2 In various ways, there have been challenges to:

The questions on proposals and supplementary forms
The questions on MARs
The questions on MERs
The decisions made by underwriters
The exclusion clauses put on policies

2.3 As will be seen, the AIDS lobby has won one victory, admittedly not a substantial one, and many interested parties are attacking our Freedom to Underwrite. In the climate of the mid-1990s with the rights of the individual at an all-time high, life offices could alienate many of the public by demanding the Freedom to Underwrite. Even if we believe we have right on our side, we have to be very careful about the presentation of our arguments. The theoretical niceties of §1.7 are unlikely to interest the public.

2.4 The various threats to the Freedom to Underwrite are not exclusive to the UK and they have been raised with different emphasis and different outcomes in many other countries. Hence, this paper looks at the most significant legislation or regulations in place elsewhere. I admit that I have acquired this knowledge in a piecemeal fashion and possibly some members at the meeting will have practical knowledge of the practices in certain countries.
2.5 However, comparison between one country and the UK can only be made after considering all the relevant facts since the provision of insurance, existing legislation and medical practice can vary considerably. Thanks to the National Health Service, nearly everyone in the UK is registered with a GP and hence we are able to request MARs, a facility that exists in few other countries. In the USA, some health insurance is essential if an individual is to survive protracted illness with his capital intact. Again, in the USA, it is common practice to use private investigators to check out claims for non-disclosure: in the UK, they tend only to be used in connection with the more dramatic, potential frauds.

2.6 Pressure groups, however, may take the most favourable solution from 30 or 40 countries and display it as a rôle model. I may sound xenophobic but the UK is a major player on the world stage and I find it odd that we should be asked to follow countries that we wouldn’t dream of following in anything else. As indicated in the previous paragraph, even following the USA has its problems, and a cautious note was added by Dr Robert Pokorski, the Vice-President, Medical Research for Swiss Re America and an important voice for the US industry in the debate on genetic testing. When talking to UK life underwriters early in 1995, he said, “Everybody follows us and the danger is that we are going to do something really stupid.”

2.7 However, we may be directly affected by legislation from the European Union. As at 1st January 1995, we should particularly note trends in Austria, Belgium, Denmark, Finland, France, Germany, Greece, Italy, Luxembourg, the Netherlands, Portugal, the Republic of Ireland, Spain and Sweden, although of course the countries in the Union may come and go. We must ensure that UK Euro MPs are fully briefed on the issues involved.
3. AIDS (UK)

"It's partner found and it's partner lost
And it's hell to pay when the fiddler stops."
('Closing Time', Leonard Cohen)

3.1 The advent of AIDS in the mid-1980s caused new problems for life offices. Not only did they have to consider what action to take, they had to consider what criticism they might receive from AIDS pressure groups.

3.2 From the start, there has been criticism of the questions on the proposal which asked applicants to disclose details of previous HIV tests and whether they had been counselled for HIV. The wording that offices followed in the early 1990s was along these lines:

(1) Have you ever been personally counselled or medically advised in connection with AIDS or sexually-transmitted diseases?

(2) Have you ever had an HIV/AIDS test? If so, please give details, dates and results.

3.3 The word “personally” has been included at the request of the Terrence Higgins Trust. They argued that everyone in the UK had been counselled for HIV by having leaflets through their letterboxes and so would have to answer ‘Yes’. In terms of semantics, they were right but the criticism smacked of their desperation for more wholesale changes.

3.4 The question itself identified those who knew they were HIV positive, if they told the truth, and it also helped to identify those who were at high risk. In essence, if someone was having regular HIV tests, he or she might be following a lifestyle which could lead to AIDS. An office might request a medical examination and its own HIV test in such cases. There was a difference of emphasis here as the Terrence Higgins Trust thought that regular HIV testing was more a sign of social responsibility than promiscuity.

3.5 It is hard to avoid emotive language, but someone might have an HIV test for incidental or ‘innocent’ reasons. To cover this, life offices added the words: “To enable us to process your application as quickly as possible, please indicate if the test was for routine screening (eg blood donation, ante-natal, employment) or for any other reason and give details including the date and the result.” If, for example, a female said she had an AIDS test during pregnancy and the result was negative, the underwriter would disregard the information.

3.6 In the early days of AIDS, one office declined two proposers who had had HIV tests, solely on the grounds of having a test. This was a mistake that cost the industry dear as the view was formed that life offices were declining cover to all those who had had HIV tests. This led to the ABI stating quite unequivocally that an individual would not be declined cover or charged more solely on the basis of a negative HIV test.
3.7 I am certain this is true. Apart from the two cases above, I don’t know of any office which has declined anyone life insurance *solely* as a result of previous HIV tests. Why should they? It doesn’t make sense as an office wants to accept as much business as practicable. However, the question may indicate someone who was at high risk from AIDS. As a spokesman for one large UK office bravely told the press, although he may have been misquoted, “The vast majority of people who go for a test do so because they feel they had put themselves at risk in some way. If they are liable to engage in high risk activities, then we believe that it should be taken into consideration.”

3.8 The question about the AIDS risk was sensible and business-like, but the public stigma about the practice increased. Some doctors, AIDS lobby groups, led by the Terrence Higgins Trust, and the Consumers Association argued for a change to the question. The curious view was formed that some people who were at risk might decide against an HIV test because they may want life assurance in the future and would thus have to declare it on a proposal. I think this view was mistaken and I have never come across anyone to whom this applied. And why might someone not want to declare a negative HIV test? Is it simply embarrassment?

3.9 In any event, it is possible to have an HIV test anonymously or with a false name, and at the time of a claim, a life office would have difficulty establishing that the deceased knew at the time of proposing that he was HIV positive.

3.10 The unlikeliness of their complaint can be seen when it is taken out of the AIDS arena. You couldn’t imagine anyone saying, “I’ve got chest pains, but I won’t have an ECG because I might have to declare it on a life assurance proposal in the future.” The general public, as we all know, thinks very little about insurance.

3.11 Nevertheless, it was considered that the attitude of insurance companies to those who had undergone an HIV test had been a deterrent to people taking tests in the first place. The ABI disputed this and in 1991 they jointly sponsored a survey with the Department of Health. The report, ‘AIDS and Life Insurance’, was published by HMSO and it concluded that “it is definitely the case that there are some people who are put off taking an HIV test because of the questions on insurance proposal forms.” I wouldn’t disagree with that - there must be *some* people, however misguided and maybe only a few, who would be put off having an HIV test for this reason.

3.12 The report commented on the size of the problem, “We are confident that in percentage terms it will be very small, probably considerably less than 1%.” This was good news for the industry - effectively, the proposal questions made no difference to the decisions of over 99% of the population. In the survey, it was simply 3 in 1,400. However, in gross numbers, “it would certainly be in the thousands, possibly in the tens of thousands.”

3.13 That final remark undid the good work of the survey. Virginia Bottomley, then Minister for Health, described the results as ‘worrying’ and said that such questions could be hindering the Government’s attempts to halt the spread of AIDS. The newspapers, with a disregard for numeracy, ran headlines like “AIDS question puts off thousands”. The trade press, which should, I think, be supportive, ran negative stories. We were shooting ourselves in the foot, and an onslaught on the AIDS question was inevitable. The Terrence Higgins Trust referred to our ‘disgraceful practice’ and ‘The Times’ (13.11.93) said, “Many people have been discouraged from taking an HIV test for fear that, irrespective of the result, it will disqualify them from obtaining life insurance.” We had lost the publicity war. We were the big bad insurance companies making unreasonable requests of our clients.
3.14 In 1994 Lord Jellicoe introduced a Private Member’s Bill in the House of Lords which would compel insurance companies to change their ways. The question would simply ask a proposer if he or she was HIV positive. If this bill were debated in parliament, the situation could be grim for the industry. Private Member's Bills tend to be loose cannons and all kinds of amendments might be tabled during the debates. How many MPs know the principles of insurance? Who could say what amendments would be tabled and, in view of various insurance scandals, the industry was short of political friends. Any MP who said “The industry is doing a good job and no legislation is necessary”, would be howled down.

3.15 Parliamentary time is also at a premium and ministers are always wanting to reduce the agenda. Therefore, the Department of Health discussed Lord Jellicoe’s bill with the ABI to see whether some quasi-legislation could be agreed. In 1994 the ABI told offices that, with effect from January 1995, proposals should not request details of HIV/AIDS tests unless the result was positive. The revised question was to be:

Have you ever been tested positive for HIV/AIDS or Hepatitis B or C, or have you been tested/treated for other sexually-transmitted diseases, or are you awaiting the result of such a test?

3.16 All members accepted the position. Personally, I felt the question was a bit convoluted and I didn’t see the purpose of adding Hepatitis B or C. For what it’s worth, I changed it to two separate questions:

Are you HIV/AIDS positive, or are you awaiting the result of a test?

Have you been tested or treated for any other sexually-transmitted disease?

3.17 ‘The Times’ (15.12.94) was delighted. In an editorial, it stated, “In many beneficial respects, the deterrents to testing for HIV are at last being reduced. Primary amongst them used to be the insurance companies’ attitudes to those who had undergone a test, whatever the result. To discriminate against the socially responsible was as insulting as it was counter-productive. Now, after years of pressure, the insurers have agreed to ask only whether an applicant has been tested positive.”

3.18 In terms of submitted medical information, we lost the fight and a little of our Freedom to Underwrite. Following the ABI guidelines, we no longer find out if someone has had regular HIV tests. On the other hand, we have received nothing but media praise for our change.

3.19 During the course of the debate, I heard two highly individualistic ways of determining a suitable question, neither of which, I am sure, would have been acceptable. One was, “Are there any factors in your life which put you at risk of HIV infection?” This is too subjective, someone could be having the time of his life every night and yet believe, quite erroneously, that he was not putting himself at risk - eg. thinking that AIDS happens to older men. Hence, the question could be answered honestly as “No”.

3.20 Similarly, I have heard it suggested that an office should ask, “Are you prepared to take an HIV test?” This was a gloriously Catch-22 question. Anyone who answers “No” should be asked to go for one.
3.21 If you score a point, you try again and so the change on proposal forms will not be the end of the matter. Ivan Massow, an IFA whose company specialises in gay clients, wrote in ‘Financial Adviser’ (9.2.95): “When I opened an office in Edinburgh, the city seemed a monument to pompous self-righteous propriety that housed some of the most vindictive life assurance underwriters. They sat in their emerald castles and passed judgment on the promiscuous behaviour of homosexual men.”

3.22 One of Ivan Massow’s arguments is that the industry doesn’t know what it’s doing. When the Government Actuary told offices that the recommended projection of AIDS deaths contained some safety margin, Ivan Massow said in ‘Money Marketing’: “It would seem that everything that its smug underwriters have predicted has turned out to be totally incorrect.”

3.23 Going by my own experience, only a handful of proposers have ever complained about the AIDS question on proposals, but several have objected to the Lifestyle Questionnaire. This forms part of the standard medical examination but otherwise it is given to single males who propose for over, say, £40,000. This is a series of questions relating to the sexual orientation of a proposer and his or her partners, and it could be that those who complain have most to gain by not completing it.

3.24 The limits for HIV testing have not changed for some years and the limits in most offices are of the order:

<table>
<thead>
<tr>
<th>Category</th>
<th>Limit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single males</td>
<td>Sum assured over £150,000</td>
</tr>
<tr>
<td>Married males</td>
<td>Sum assured over £250,000</td>
</tr>
<tr>
<td>Females</td>
<td>Sum assured over £250,000</td>
</tr>
</tbody>
</table>

Some offices apply the tests at higher levels for females.

3.25 There are very few criticisms of the HIV test, particularly as it can now be done by either blood or saliva. In the past, a few have objected to giving blood but no-one can object to chewing on a cotton swab, unless they are wholly against taking the test for other reasons.

3.26 In the past, several offices have declined proposals from homosexuals, but most now offer terms, provided he does not indulge in promiscuous behaviour. Today a homosexual in a stable relationship with a negative HIV test is likely to be charged an extra premium of around £3 per annum for each £1,000 sum assured. At least one office, however, is allowing standard rates for ten year policies.

3.27 Surprisingly, there has not been wholesale criticism of the HIV test itself, providing that there has been proper counselling. Admittedly, some AIDS spokespersons have considered the counselling should last an hour. This would push up the industry’s costs and also worry many proposers unnecessarily.
3.28 The AIDS debate has occasionally gone outside its boundaries and shown the direction that industry criticism is going. Baroness Gardner of Parkes in the House of Lords (1.12.94) said, “On health grounds, I think it wrong that anyone should ask whether a patient has had any negative test of any type, whether it is a test for breast screening, or a chest X-ray or any other sort of test. Surely it must be good that a person should be screened for a condition rather than have that held against him when applying for insurance.” This is a simplistic view because the underlying reason for the test is surely important, and the negative test may not guarantee there is no disease. Taking this to the limit, we might end up with just one question, “Are you healthy?” If you answer “Yes”, you can have cover at standard rates.
4. AIDS (INTERNATIONAL)

"Everybody knows that the plague is coming, 
Everybody knows that it's moving fast."  
('Everybody Knows', Leonard Cohen)

4.1 AUSTRALIA - Following a Government inquiry, insurers adopted a Code of Practice in 1988. The code ensures that no-one will be declined for insurance on the basis of their sexual orientation alone, although its application has been questioned by AIDS pressure groups. The Commonwealth Disability Discrimination Act, introduced in 1993, makes it illegal to exclude someone from insurance or superannuation benefits where the act of discrimination is not based on actuarial evidence. It has been suggested that, if the AIDS exclusion clauses imposed on superannuation benefits are tested in court, they may be deemed illegal.

4.2 CANADA - According to the country's law on human rights, proposers for life assurance cannot be discriminated against because they are gay or because they have been tested for HIV infection. A spokesman for the Canadian AIDS Society, an umbrella organisation of more than 70 community AIDS groups across Canada, has said, "It's not a problem here. I don't know of any instance where insurance companies have turned people away or discriminated in any way against them because they have taken a test previously. Nor do I know of anyone being turned down or discriminated against on the basis of being in a high risk group."

4.3 DENMARK - There are no questions about lifestyle on the proposal form and the Danish Medical Association has instructed doctors to "only disclose information that is relevant, and this should not include a HIV negative test." However, a proposer can obtain cheaper premiums by answering a questionnaire which asks about HIV tests taken in the previous 10 years.

4.4 FRANCE - The Ministry of Health forbids questions about lifestyle and it obliges offices to issue acceptance terms for policies covering mortgages to applicants who are HIV positive. The resulting business is pooled amongst direct offices and reassurers, but as the extra premium charged is large (around £60 per £1,000 sum assured per annum) there have not been many takers.

4.5 ITALY - Following an agreement with the trade body, HIV testing takes place when the sum assured is over £135,000 or when it is merited by the medical evidence. Otherwise, there is an exclusion clause for death as a result of AIDS during the first five years of a contract. If a proposer refuses to take a test, the exclusion clause is extended to seven years. Neither the authorities nor pressure groups have opposed this.

4.6 THE NETHERLANDS - Until 1993, proposers were asked, "Have you ever undergone a blood test for sexually-transmitted diseases such as syphilis or AIDS? If yes, why, when, for what and with what result?" Many objections to this question were raised and, after discussion in parliament, the Dutch Association of Life Insurers modified the questions to "Have you got AIDS? Have HIV antibodies been found in your blood?" The Government has accepted life offices requesting an HIV test automatically for larger sums assured, the equivalent of £80,000. Haemophiliacs who are HIV positive have to be accepted for endowment assurances.
4.7 NORWAY - No questions about lifestyle are permitted but individuals can be asked the results of an HIV test.

4.8 UNITED STATES OF AMERICA - The USA position is complex because legislation varies from State to State. Some States, for example, insist that HIV tests are taken before someone is given a driving licence or gets married. It is against public policy to penalise people who have taken an HIV test because the USA wants to encourage testing. Life offices can request HIV tests but they cannot ask questions to determine if a proposer is a member of a high risk group. Some States have stricter legislation than others and, as a result, some offices have decided not to write business in them.
5. GENETICS - THE BACKGROUND

"They tell you that you're most likely to die of the same things that your grandparents did. So provided I steer clear of marauding Cossacks, I'll be fine." (Alexei Sayle)

5.1 Although there is much public debate about genetics, there is no official definition of what genetic disease and genetic testing mean. This in itself leads to confusion and for the sake of argument, I will take genetic disease as one which may cause a significant reduction in life expectancy and is detectable through laboratory testing before any symptoms are apparent. In view of the ethical and legal questions that are bound to emerge over genetic matters, it is important for a definition to be determined.

5.2 In years to come, genetic testing will predict many elements of a person's future health. Genes pass characteristics from parents to their children, and the information is stored in the molecule DNA (deoxyribonucleic acid). A complete set of genes is in most of the body's cells, irrespective of their particular purpose. As there are between 50,000 and 100,000 different genes in each cell in our bodies, and only 5,000 have been identified in terms of an inherited characteristic or disease, an enormous amount of development remains to be done. Having said that, developments are proceeding fast, particularly in the US, and any timetable is likely to be brought forward. It is possible that most of our genes will have been identified by the year 2000. The human genome map is expected to be completed by 2015.

5.3 Genes are generally unaltered throughout life, although mutations in normal genes is possible via environmental factors such as smoking, pollution and sunlight. Ultimately, all cancers can be said to be genetic, but most will be through mutations acquired after birth. For example, 1 in 12 females in the UK develop breast cancer but of these only 8% are familial.

5.4 Everybody carries some genes which are associated with disease: nobody has a perfect set of genes. Our genetic profiles can be likened to a game of cards. Some of us will have been dealt a fine hand and play it well: others will make elementary mistakes. Some will have poor hands and yet manage to pull through. Genetic testing enables us to see what our cards are, although we may be able to guess from the experience of our immediate families.

5.5 Genetic testing on children is controversial because a child is not old enough to give his consent and, in later years, might not have wanted this knowledge. Conversely, the parents' authority is surely valid if some preventative measures can be taken straightway. Even more contentious is pre-natal testing, which may lead to questions of abortion.

5.6 Some abnormalities are so significant that the disease is certain to manifest itself in everyone affected. These monogenic disorders such as Huntington's chorea, cystic fibrosis and muscular dystrophy are caused by a single defect, but fortunately they are rare. However, there are many, more common diseases for which several genes acting together determine susceptibility. These polygenic disorders include cancer and heart disease.
5.7 Huntington's chorea is a slow, wasting disease in which the patient's progressive mental and physical disability leads to involuntary movements, dementia and then premature death. Huntington's chorea is still incurable and if someone is carrying the gene, he will get the disease, although he may not have symptoms until he is 50 or older. It is a rare disease - even the quoted figure of 1 in 10,000 seems excessive - and the most noted sufferer was the American folk singer Woody Guthrie, composer of 'This Land Is Your Land' and, ironically, 'So Long, It's Been Good To Know You'.

5.8 In the past, a proposer with a family history of Huntington's chorea would be refused life assurance or given a high, additional premium, even though no symptoms were present. This is because the life office could not know if a proposer would succumb to the disease - and there was a 50% chance of it happening. Now it is possible for someone to be tested for the disorder and these tests are almost 100% accurate, and becoming more so as the months go by.

5.9 Genetic tests are also available for other inherited, fatal diseases such as muscular dystrophy, cystic fibrosis, polycystic kidneys and Marfan's syndrome. Some disorders will have manifest themselves during childhood and so they present no challenge to insurers. However, with these tests, many people who previously have been denied insurance should be able to obtain it - providing there is evidence of a negative test.

5.10 These diseases are rare and are not regularly encountered by life underwriters although, taken together, the number is significant. However, life offices have long been interested in inherited diseases. Why else are questions about family history asked on proposals? A history of heart disease in both parents may give rise to a medical examination and, perhaps, an additional premium. As has been said, the surest way to a long life is to choose your parents carefully!

5.11 Genetic testing will soon be significant for the most common disorders because it can determine a predisposition towards heart disease, certain types of cancer, and many other complaints. Here the situation is very different from Huntington's chorea. If you have a positive genetic test for Huntington's chorea, you will develop the disease. If you have a positive genetic test for heart disease, you may develop the disease but the genes are just one of several factors, including smoking, eating habits, lack of exercise and other environmental factors.

5.12 Genetic testing can only indicate that someone has a predisposition to heart disease; it cannot say when it is likely to occur. If someone has a positive genetic test for heart disease, he or she may still die at an advanced age.

5.13 Indeed, that person may take measures to reduce the risk by changing his lifestyle. Again, someone with a positive test for cancer may receive regular screenings so that an early diagnosis can be made and treatment given. Many diseases which had not been regarded as genetic have now been linked to certain genes. Hence, tests may also be developed for predispositions to other genetic disorders such as Alzheimer's disease, asthma, diabetes, epilepsy, high blood pressure, mental illness and even alcoholism.

5.14 Who knows where it will end? To take a very simple example, a common cold may be going round an office. 25 of the workers get it: why those 25? Is there a genetic component that makes them more likely to catch colds?
5.15 Quite possibly though, the tests will be developed long before treatment is available. The Science and Technology Committee of the House of Commons said in its report in 1994:

"71. While genetics is likely to transform medicine, it may take some while before treatments based on genetic knowledge become available. Identifying a disease gene permits diagnosis. The ability to conduct such a diagnosis may precede discovery of the gene's functions. While a knowledge of how the gene works, when established, should, in time, lead to new drug development, through rational drug design, at present it can take fifteen years to develop and gain approval for a new pharmaceutical product."

5.16 Eventually, I think it is inevitable that the results of genetic testing will become a way of life. Initially, those with significant family histories may be tested, but, in 20 years perhaps, the tests may be available to everyone. It wouldn't surprise me if Westerners carried round a Smartcard containing their current genetic profile. From a life assurance viewpoint, this could lead to a no-win situation - people with perfect genes will only want insurance against accidents and infectious diseases, and the rest won't be prepared to pay the extra premiums.

5.17 Even more mind-boggling is genetic engineering, which can correct genetic disorders. Some gene transplants have already taken place in the US and the process may be no more disagreeable than a blood transfusion. This is all very well for treating disease but ethical and religious problems arise if a change is requested for non-medical reasons: for example, someone might want to become a better athlete or change the colour of his skin. The common good of allowing people to be as they want to be has to be measured against potential abuses, and some would argue that it is best for people to stick with the genes they got at birth. But, then again, who's to say that the genes of embryos won't also be changed?

5.18 All this is in the future, but that future is not far away. The first genetically-related insurance policy has already been developed by a Lloyd's syndicate. A policy, which can be effected by a pregnant mother, provides a payment if a child is born with one of five genetic disorders.

5.19 One reputable organisation is offering genetic tests for cystic fibrosis by post. The Select Committee has warned that there is "a very real danger that unscrupulous companies may prey on the public's fear of disease and genetic disorders and offer inappropriate tests, without adequate counselling. At present it appears impossible to prevent this." Taking this a stage further, the possibility of individuals undertaking genetic testing with home-kits is a future possibility.

5.20 Should this be allowed to happen? My own feeling is that the Government should outlaw all forms of home and postal testing. Such legislation is in force for HIV testing as the user could misuse the equipment and counselling is needed before acquiring such knowledge. The social consequences of someone receiving damning information without counselling are alarming, irrespective of the hole it makes in our business if individuals can find out the result of tests privately and apply for life or sickness insurance on the strength of it. The industry will have terrible problems if legislation does not take place.

5.21 What does a life office do now about genetic testing? A proposal asks the client in general terms about medical tests and, all things being equal, these should include genetic tests.
5.22 A proposer who withholds this information is withholding material facts. In years to come when the tests are more common, they may be specifically referred to on the proposal. A typical question might be,

Have you ever had a test to see whether you have the gene for any disease? If so, please give the reason and the result.

There is no point in putting such a question on today's forms as it would confuse most clients.

5.23 Questions concerning the possible mishandling of confidential information by life offices have been raised by various geneticists. This creates a problem where none exists. Life offices have a very good record on confidentiality of medical information and have given Codes of Practice to their staff. It seems highly unlikely that genetic information would go astray. Of course, it may happen on the odd occasion, but then it happens in hospitals as well. As I write, some confidential medical records have turned up on a rubbish tip, and an American teenager rang up her father's patients and told them they were HIV-positive.

5.24 Even with the consent of the proposer, it may be difficult for a third party such as a life office to obtain written confirmation of the results. A life office that is not able to obtain confirmation will have to decide each case on its merits.

5.25 It has been suggested that life offices should show an enlightened view and specifically state that proposers need not give details of genetic testing. In other words, for whatever good reason, they are allowed to withhold pertinent information. To date, few people have had genetic tests, but a life office naturally wants to know the results. The underlying concept of insurance is that proposers pay for the risks they bring to the fund, and, if a life office does not seek this information, it may be selected against by clients who are privy to certain information about themselves. A client with a positive genetic test for heart disease might be tempted to propose for critical illness policies with several offices.

5.26 Recently, some preserved samples from the body of the US politician, Hubert Humphrey, have been tested. It has been discovered that his bladder cancer could have been diagnosed with genetic testing over ten years before he had any symptoms. Think of the damage individuals could inflict on the industry with such knowledge.

5.27 In short, if the proposer knows the results of genetic testing, then the life office wants to know them too. Problems obviously arise if tests can be taken anonymously as no-one may be able to establish what is known at the time of proposing, just as with HIV testing.

5.28 Another parallel with HIV testing is the widely-circulated but erroneous belief that people will be refused insurance simply for having had a test, whatever the result. We have to ensure that the public does not think that having a genetic test means no insurance.

5.29 Think too of the intellectual anguish a proposer could go through if he were asked to go for a genetic test. Many of our proposers get upset at the thought of medical examinations and HIV tests at present, and, in the future, the request for genetic tests could be even more unsettling. This is where good counselling comes into play.
5.30 Consider too the recent speculation over the introduction of haemophilia into the Royal family. The book, 'Queen Victoria's Gene' by D.M.Potts and W.T.W.Potts (Alan Sutton Publishing, 1995) is an exhaustive study of haemophilia in the royal families of Europe, and much can be learnt about the disorder because their family histories are so well-documented. The gene might have been introduced into the Royal Family by Victoria's mother having an affair or by a mutant gene developing from Victoria's elderly father. Either way, the haemophilia began with a rogue gene somewhere along the line and, had there been genetic testing in Victoria's time, she might have learnt that her father was not her father after all. Today this is another concern of genetic testing as possibly 3% of the UK are not the products of their so-called parents.

5.31 Are life offices going to ask proposers to undertake genetic testing? In the short term, this is unlikely, and no movement is likely until such time that the tests have been fully accepted and endorsed by the medical fraternity. Even then life offices are unlikely to recommend testing until the principle has been accepted by the general public: for example, will most people with a family history of Huntington's chorea want to have the test, or not? Life offices are loath to initiate social change but they have to respond to it.

5.32 Research laboratories may be unwilling to undertake testing for insurance companies, but, once the testing can be done commercially, the laboratories will be actively encouraging offices to use them. It is inevitable because there will be commercial ventures who will be anxious to test as many people as possible, thereby ensuring a reduction in unit costs. Life offices are unlikely to request tests for all individuals but it may become obligatory for the larger proposals (say, £1m and more), and for smaller proposals with a significant family history.

5.33 The test itself will present few problems and should be no more difficult to arrange than those for blood sugar or cholesterol, and there are no risks to the proposer. The cost may be high, but one national newspaper has reported tests will become available for a mere £2. Such economies of scale are only likely if the whole UK population is screened.

5.34 The main problem, as with HIV testing, will relate to counselling both before and after the test so that clients are fully aware of its nature. The counselling may need to be extensive and may involve the proposer's family. Therefore, it is bound to be expensive.

5.35 There have been patronising comments in the press that no individual can properly consent to these tests because he does not appreciate what he is authorising in the first place. Again, appropriate counselling should resolve this.

5.36 Another problem occurs with those who do not wish to know their genetic profile. Their way of life may be changed by such information and they may have preferred to remain ignorant. But this could apply to anyone who attends a medical examination for life assurance - and there is no counselling there. When a life office feels genetic information is necessary, a life office may have to say, "Sorry, but we can't give you the cover you require without this test."
5.37 Today, life offices accept 95% of all proposals on standard terms. However, about one in 10 of all genetic screening for heart disease may be positive. Should a life office increase the premium for this alone? We are in unchartered territory here, but we could be on the verge of a totally new concept in life assurance - there is less grouping via standard rates and instead each proposer is individually assessed and a process akin to motor or household insurance takes place. However, at this point in time, it is fair to say that life offices do not want a small healthy pool; they want to offer cover to as many clients as possible.

5.38 The whole question as to whether insurance companies should be allowed to use genetic information is controversial. In California, legislation was being introduced which would allow an individual to conceal information about genetic testing from a life office but the extensive lobbying by the industry was successful and the proposed legislation was vetoed by the Governor. However, legislation forbidding the rights of insurers in some way has been passed in seven States.

5.39 A ban on genetic screening as a condition for an insurance policy has been recommended to the European parliament. Their recommendation, made in 1992, said, “Insurers should not have the right to require genetic testing or to enquire about the results of previously performed tests as a precondition for the conclusion or modification of an insurance contract.”

5.40 Once again, it appears that insurance principles are not understood by its critics, although it is possible that the insurance companies decided that the financial risk was not too great and so withheld their lobbying. However, a ban on genetic screening could leave insurance companies and their funds unprotected. We have to protect ourselves and our existing policyholders from proposers who know the results of genetic or other tests which reveal a poor outlook. It is reasonable to ask proposers about all the tests they have previously undergone, including genetic ones.

5.41 If genetic tests can be taken privately, then I think the results will be wanted by insurance companies and they will want the right to test individuals. If genetic tests become a regular and acceptable routine that people regard as part of a regular health check, they could become part of the underwriting process. If not, then it is unlikely that underwriters will call for genetic testing except to clarify the position on a person with an already identified problem.

5.42 And think of the people who have favourable genetic tests. Would they not want to use this information to obtain standard terms, or even to request discounts? It is often overlooked that many proposers would benefit from genetic testing. They might object strongly to not being allowed to use this information to obtain more favourable rates.

5.43 Taking this a stage further, those with a good genetic profile may create a run on the annuity market as they know their life expectancy is above the norm. Therefore, should we be obtaining medical evidence for annuities, something that is not done at present? Again, those with an unfavourable genetic profile may want increased annuity rates because their life expectancy is shortened.

5.44 My gut reaction is that we should not shy away from the opportunities presented by using genetic testing to develop more cost-effective products, but I appreciate that this view is hardly likely to win the day.
Take the Health Council of the Netherlands which has stated with regards to life assurance, “We find it unacceptable that people affected from birth with a genetic predisposition should be faced with additional social obstacles, and that their relatives should also be at a disadvantage in this way.” That is a total misunderstanding of the principles of insurance.

The current trend is to argue that, if no fault is involved, then social pressures against discrimination outweigh normal scientifically-based judgments. This is a real concern and is very understandable. Consider the views of Professor Bob Williamson, a geneticist from St Mary’s Hospital Medical School in London. He draws a distinction between information over which people have no control (genes) and factors which are matters of choice (smoking, hazardous pursuits). He has called for legislation so that “the former is not used to discriminate against individuals”. In other words, we should only charge an extra premium when it is the proposer’s own fault.

Such arguments do not differentiate between unfair discrimination and fact. Unfair discrimination is an inappropriate, incorrect or unsubstantiated bias against an individual or group of individuals. Facts are different, and that information should be used by insurers.

Take car insurance. Someone who lives in a high risk area is going to pay more but he may have no option but to live there. He may not have the money to move. Should he pay less for car insurance because his address isn’t one of his choice? Charging him more for car insurance isn’t discrimination: the fact is, he lives in a high risk area.

It is not the insurance companies that are being unfair, it is life itself. In any event, for most purposes, differential rates are used for males and females and also for attained age, something over which a person has no control. Quite simply, if a proposer is more likely than the average person of the same sex and the same age to die prematurely, the premium should be higher. It is the increased probability of death that is important to the life office and not how it has arisen.

Recommendations regarding the life assurance industry have come from non-governmental bodies such as the Nuffield Foundation’s Council on Bioethics. It is in this climate that the Science and Technology Committee looked at the questions surrounding human genetics and life assurance. Initially, I was cautious about this. There was, and still is, a danger of premature and ill-conceived regulations through the Committee being persuaded by criticisms from the medics, the moralists and those who are “genetically unfit” and consider they are being victimised.

Baroness Warnock at the International Human Gene Mapping Conference said that legal safeguards must be established against compulsory genetic screening. She said, “Insurance companies will demand a genetic print-out as they now demand a medical examination, and the result will be that people and their families may be compelled to discover things that they would have preferred not to know. Similarly, when potential employers now demand a medical check, they too may demand a genetic screen.” The word, “compelled”, is wrong because no one is compelled to apply for life assurance.

Another angle for the industry relates to employment medicals. Some hapless individuals may find it difficult to gain employment because the results of their genetic tests suggest higher levels of sickness in the future. Similarly, with on-going medical checks, some of the existing workforce may be dismissed for the same reason. The tabloid will have a field day with “My genes got me the sack”.

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5.53 The question of employment is particularly pertinent in the USA. There is no equivalent to the National Health Service, and so employers may be liable to provide healthcare benefits to an employee and his family. Genetic tests may be requested on the family as a whole and decisions reached about the potential liability.

5.54 The issues facing the insurance industry over genetic testing are immense and, in some ways, they can be seen as a re-enactment of the issues surrounding HIV testing and AIDS. However, there are distinct differences - genetic testing may affect us all but, unlike AIDS, this cannot lead to any additional early deaths . . . except possible suicides. Indeed, the whole thrust of genetic testing is to improve mortality.

5.55 Back to Dr Pokorski, who told UK life underwriters in 1995, “If you thought AIDS was bad for the industry, genetics is much worse. Bad legislation has the opportunity to devastate the industry. There has to be a level playing-field between what the assured knows and what the assurer knows. We are going into unchartered territory if we change this.”

5.56 In the US, the medical director of Lincoln National Life has said, “From an underwriting point of view, insurers may wish that genetic tests had not been developed.” I don’t accept this. The benefits have to be considered alongside the drawbacks, and such a negative response is as one-sided as the life offices’ critics. It has never been possible to pinpoint individuals with such accuracy before and anything which enables an underwriter to make a more accurate assessment of a future risk can only be beneficial to society as a whole and to the industry.
6. GENETICS - THE SELECT COMMITTEE

"There's been a brand new breakthrough
Though they're not sure what it means,
We used to blame our parents
Now we can pin it on our genes."
('1994', Loudon Wainwright III)

6.1 The House of Commons appointed the Science and Technology Committee in 1992. Sir Giles Shaw was elected Chairman and the members in early 1995 were Spencer Batiste, Dr Jeremy Bray, Anne Campbell, Cheryl Gillan, Dr Lynne Jones, Andrew Miller, William Powell, Sir Trevor Skeet, Sir Gerard Vaughan and Dr Alan Williams. At that time, they were gathering evidence and forming opinions for their Third Report, 'Human Genetics: The Science And Its Consequences', which was published on 6th July 1995.

6.2 The issues relating to genetic tests and life insurance were of particular interest to the Committee. Concerns about the industry were raised by a leading geneticist, Professor Peter Harper, the British Diabetic Association and the Genetic Interest Group. Written evidence was submitted by the Association of British Insurers, and an ABI team of Roger Bowley, Dr Richard Croxson and Paul Smee appeared twice before the Committee. Dr Nicholas Barr from the London School of Economics looked at the issues independently and gave both verbal and written evidence. Whatever we may think of the conclusions, the issues were fully aired and, indeed, I must commend the Committee for their thoroughness. In particular, they grasped the problem of “adverse selection”.

6.3 The Report is of crucial importance to the future of the industry and so, with the kind permission of HMSO, I am quoting the section on insurance in full - the Committee chose to put some sentences in bold type, which is repeated here. I am appending my own comments to each paragraph and discussing the way forward at the end.

"234. Many witnesses pointed out that health insurance was of relatively little importance in the United Kingdom because the National Health Service provided high quality health care without direct charge. Life insurance, however, is much used by home buyers, and the government is encouraging people to take more responsibility for their futures through private pensions and mortgage protection. Most of our remarks below are related to life insurance. However, we consider that genetic information may also have implications for other forms of insurance although it will not affect all types of insurance in the same way or to the same extent."

6.4 There is a misstatement in the text as it assumes that life insurance is mainly for home buyers when, as we all know, there are many other purposes, in particular family protection and keyman assurance.

6.5 Genetic information has considerable implications for both PHI and critical illness. Indeed, life offices might be at their most exposed with concessions made on underwriting critical illness contracts as the benefit is paid if the life develops a specified disease such as a heart attack or cancer.
6.6 Initially, life offices would be happy if a portion of their business were untouched by regulations or legislation in this regard as they could request whatever information they thought necessary. However, inconsistencies in approach would soon be apparent and offices might be accused of acting outside the spirit of the rulings. Therefore, and this is a contentious view, I think it is best that the whole range of policies which an office writes at present should be considered when forming the rulings. This could work to our advantage as the problems of adverse selection are even clearer with critical illness.

"235. Many of our witnesses were very concerned that the availability of genetic information might have profound effects on the insurer as well as the insured. Knowledge of the results of a genetic test showing susceptibility to a serious illness gives an incentive to that person to take out a life insurance. To avoid adverse selection of risks, insurance companies now require the insured to give the results of any genetic test they may have had, but do not require that any further tests be made. An adverse result from a test may increase the premium required, or may make insurance unobtainable. This in turn gives an individual an incentive to avoid having a genetic test. Such avoidance may imperil the health and well being of the insured and of their families. In seeking a solution which resolves the problem, it is useful to consider who should bear which costs. At present the individual may bear the cost of higher premiums or the non-availability of insurance, or incur a risk to health. If insurance companies did not seek or use available information on the results of genetic tests, individuals knowing they were going to die early could take out large insurances, and the costs of the higher premiums would fall on the general body of the insured. There is some benefit to the insured generally in that they would know that in the future they would not be discouraged from taking otherwise desirable genetic tests by the cost of new insurances. But there is a cost in higher premiums. The problem is to seek arrangements that balance the costs and benefits."

6.7 It is interesting to re-read this section substituting the words "medical test" for "genetic test" in the appropriate places. Few would argue that a medical test for heart disease should be kept from an insurance company. Genetic tests are medical tests, and yet the thrust of the argument is that they are somehow different from other tests. Are they, and should someone who has had a genetic test as opposed to a medical test for some other reason be treated differently?

6.8 The logic is that a genetic test predicts a future event in a well person and an insurance company should make its decision on the current state of health. This is illogical and not what happens with other conditions. An ECG may indicate ischaemia, although the person may feel extremely well. A life office cannot ignore this information. All testing should be regarded as one continuum. Genetic tests give early warning of a disease, medical tests at a later date.
6.9 At present, proposal forms do not mention genetic tests. They do, however, require proposers to give details of any medical tests they have undergone. The wording, "insurance companies now require the insured to give the results of any genetic test they may have had", indicates that the Select Committee accepts that it would be non-disclosure if a proposer currently failed to give us this information.

"236. This is not solely a United Kingdom fear; in the Netherlands, there has been a moratorium which bans the use by insurance companies of the results of information from genetic tests for applicants for life and private disability insurance up to to D.FL. 200.000 (£81,300). This moratorium has recently been renewed and the Government has asked insurance companies to revise their policy of not covering those with a family history of muscular dystrophy or Huntington's disease. Discussions on the implications of genetics for health insurance have been held in the USA."

6.10 The word "moratorium" frequently arises in debates on genetic testing and life assurance. We live in an industry which promotes Plain English and, in an 'ad hoc' survey, I found that only 1 out of 20 people knew what a moratorium was. We should adopt the much simpler word "ban" for that is what it would be.

6.11 The effect of the ban in the Netherlands means that proposers are able to withhold relevant information from insurance companies - and the companies are obliged to meet claims as they arise. It is difficult to determine the overall cost of such concessions as individuals with a genetic disorder could be advised to effect life policies. In the long run, the additional claims would be paid by the policyholders themselves through increases in premium rates both for new policies and, where possible, for revision of existing ones. If the premiums increase, those at high risk from a genetic disorder may still apply for policies but those at low risk may decide not to, hence escalating the problems for offices.

6.12 Taking this a stage further, a salesman could legitimately visit hospices signing up many of the occupants. Notices might even be placed in doctors' waiting-rooms. Even our most vicious critics should realise that this is untenable. Also, some people may learn that they are high risk from cancer and some low risk. Those at high risk are far more likely to want insurance.

6.13 If genetic history is banned on proposals, adverse selection becomes a major issue. How can discrimination against life offices by those who know they are high risk be controlled? If the average sum assured is £50,000, those at higher risk may request £250,000, with effectively the remaining policyholders paying for that risk.

6.14 A ruling would be necessary and suppose it was "Every UK citizen between the ages of 18 and 60 is entitled to £50,000 insurance but only accidental cover is available during the first year of the policy." Should offices band together so that the first £50,000 of everyone's insurance is at a particular rate? It would be expensive to develop a register to show exactly who had proposed for what, and so those at greater risk could insure themselves with a range of offices. What, too, is to be done about existing cover at the introduction of such a ruling?
6.15 One way to avoid a register would be to have the proposer sign a declaration to say that this was the only concession he was applying for. At the time of a death claim from a genetic disease (whatever that might be), offices could be circulated by the ABI and the payment of benefits delayed for a week to see if other offices respond positively. Delaying the payment of death benefits and the potential cutback in the overall amount could have negative repercussions on the industry.

6.16 All concessions have their costs and, to quote the actuary, David Purchase, writing in ‘The Times’, “If society wishes certain adverse consequences to be avoided, society itself should pay the bill.” Yes, true, but it is unlikely that the British Government would give the industry financial support if such a ban were introduced.

“237. If a genetic test predicted the future with sufficient accuracy, genetic information could, in theory, undermine the whole concept of insurance; as Dr Nicholas Barr, of the London School of Economics, said “The insurance industry cannot cope with certainty.” In practice, this is unlikely to happen. At the moment, as the Association of British Insurers (ABI) pointed out, there are few genetic tests available, and those are for serious conditions. No test is entirely certain, but these tests show whether or not a particular condition will develop to a very high degree of probability. However some of our witnesses expected more extensive genetic tests for a far wider range of disorders to be introduced in the next decade. In fact, since screening or testing is likely to be introduced to identify those with a genetic predisposition to certain diseases, rather than those who will certainly develop them, all it is likely to do is to give more information about an individual’s risk. We must also remember that, however accurate genetic testing may be about disease, people are always at risk of accident. Nonetheless, Dr Barr told us:

“My experience as somebody who studies the economics of insurance is to say that if the effectiveness of genetic testing spreads as widely as we are told, then that will have very major implications for insurance very quickly.”

6.17 A textbook could be written on the first sentence alone. People are not only going to die of genetic disorders but also from accidents, infectious diseases and the consequences of their lifestyles. Furthermore, the ages of death of those with defective genes cannot be predicted. In any event, the insurance industry is able to cope with certainty. If someone has a 25 year mortgage, a policy can be effected to pay it off at the end of the term. Irrespective of social considerations, the industry should welcome genetic tests as they could bring more accuracy to the pricing of risks.

6.18 Being an actuary is jokingly described as a cross between a bookmaker and an undertaker, and there is truth in that. We might take 100 people for life insurance. We are handicapping them for their sex and age, and a few carry additional weight for their medical and family histories - and their weight! Some are scratched from the race. Suppose that genetic testing takes off and, considering a bunch of lives, we can say that one is more likely to reach the finishing post before another. This race may not appeal to Dr Barr but I still think that insurance companies would want to place their bets.

“238. In their evidence to the Committee, the ABI said that “...insurers do not require applicants for insurance policies to undergo genetic tests and they have no intention of doing so in the foreseeable future. However, insurance companies do expect their clients to reveal the results of any genetic tests they may have undergone and failure to do so could invalidate the policy.”
6.19 Quite so. It would be interesting to have Counsel's confirmation on *uberrima fides* and whether non-disclosure of a genetic test constituted non-disclosure.

"239. It is clear that some insurers have more experience in dealing with particular disorders than others, and that the industry does consider the opinions of professional geneticists when drawing up its assessment of risks. Individual medical officers of insurance companies also seem to have responded positively when geneticists have contacted them on behalf of particular patients. However, witnesses were concerned that, even at present, insurers were not able to interpret the relatively simple genetic information available to them. While there were no comprehensive studies to the extent to which genetic information was misinterpreted to a person's disadvantage, several cases in which this had clearly occurred were drawn to our attention."

6.20 I am sure I am not the only underwriter who finds this section patronising - and wrong. Life offices employ eminent consultant physicians as Chief Medical Officers and so they have access to the best possible medical advice. My own office's CMO has had no difficulty coping with the information he has seen to date but even if he had, he would recognise the difficulty and seek advice. He would not make a decision, particularly to the client's disadvantage, without adequate knowledge.

6.21 The Committee says that several cases of incorrect underwriting have been drawn to its attention and I would like to know where they came from. To be honest, I question their existence but if they do exist, perhaps I can put the shoe on the other foot. If it is argued that life offices are not able to interpret "relatively simple genetic information", is it not possible that some geneticists do not appreciate the long-term nature of life insurance, the guarantees of premiums and the particular policies we have to underwrite?

6.22 I must add a word of warning. The majority of offices employ CMOs, but some do not. It may be because they have cut back on expenses, it may be because they are a new office and do not see the need for one. This is false economy. Every office should take good, professional medical advice which, in turn, will improve the training of the underwriters. If an office does not have a CMO, then some of the criticisms above may be justified.

"240. If insurers are unable to deal with the simple tests available today, how will they react to the more complex tests which may soon be introduced? The insurers, in the main, were sanguine. They pointed out that genetic research had not yet produced any of the anticipated tests for the genes involved in common multifactorial disorders and that genetic testing would not change the rate at which particular disorders occurred in the population. The ABI claimed that such tests would have little effect as long as the extra mortality from any genetic conditions was likely to be under 100 per cent since it was industry policy to put 95 per cent of those insured into a standard rate band."

6.23 Following on from the last paragraphs, if these tests become so complex, just who will be able to understand them? It is not only CMOs who need educating but also every family doctor. However, if the tests are so complex that they would not be able to interpret them, what is the point of doing them at all? Why should the Government fund the provision of test facilities that can only be understood by a handful of geneticists? My guess is that the Committee has been heeding too many geneticists. If they are promoting their own specialty, does the Committee have a balanced view of the medical profession?
6.24 This is simplistic but surely the main issue is the interpretation of results rather than the understanding of the technicalities of the test itself, whether that test is ordered by an attending doctor or, perhaps in the distant future, an insurer. All that may be needed is the likelihood that an individual may succumb to a particular disease, rather than the ins and outs of the test itself.

6.25 I cannot grasp the final sentence. At present, between 92% and 97% of all proposals are accepted on standard terms. If the extra mortality of genetic condition were assessed at 100%, then the client could be accepted at twice the normal premium for a term assurance contract, which is roughly the same rating as for a well-controlled insulin-dependent diabetic. Also, if the extra mortality for a particular genetic condition were assessed at 50% or 75%, then an office would want to charge it accordingly.

"241. Opponents claimed that individual insurers might over-react to the mention of a genetic test on a proposal form, particularly in the early stages of genetic testing when such tests were associated with research programmes and their results were unclear. If this were to be the case disclosure of genetic tests to insurers could mean, as the Genetic Interest Group said:

"the advantages and risks of knowing one’s risk are balanced with the advantages and risks of not knowing. For example, people with hypercholesterolaemia suffer from early onset heart disease, resulting in permanent disability and early death. If they are not identified as having a genetic disorder they can get life insurance, or be employed despite the fact that their health prognosis is extremely poor. Yet if they are listed, and follow the appropriate diet and medical care, they should be able to live a normal lifestyle. However, they will be severely penalised by many insurance companies and often by employers too.”"

6.26 I would have said that it doesn’t take a genetic test to diagnose high cholesterol levels. However, if the Committee is widening the definition of genetic tests to include cholesterol tests, the industry has a problem.

6.27 Also, even with familial hypercholesterolaemia, it should be possible to accept an applicant for life assurance, maybe even at standard rates.

"242. Although the ABI said “there are a very great number of...considerations of a social and of a personal nature before you go into screening...Insurance must be way down the list, we understand that discussion of insurance is included in much genetic counselling. We accept that the insurance industry has collectively tried to deal with genetics in a responsible way; nonetheless we are concerned there is a real danger that people could decide to decline genetic testing, even when such testing would be advantageous to them, because of the possible insurance implications. Not only will this act to the detriment of those directly concerned, but such reluctance could also hinder the research which will be needed if genetic knowledge is fully to benefit society.”"

6.28 I would like to know what is said about insurance in genetic counselling. Is it balanced and accurate? Judging by the counsellors for AIDS that I have heard at insurance conferences, there is a misunderstanding of life insurance, despite the ABI’s explanatory leaflets. This time the ABI should produce leaflets and, in exchange for any concessions we make, obtain a commitment that they will be used by counsellors.
6.29 The argument is similar to HIV testing - someone may not present himself for testing because he may have to declare it on a proposal in the future. It would be good for the industry if people did think of insurance so often, but we all know that, despite the advent of direct line insurance, insurance is sold rather than bought, except in situations involving anti-selection. I don't believe this is an issue for individuals themselves, although pressure groups often maintain that it is.

"243. Although insurance companies do not require genetic tests at present, some witnesses suggested that if one firm attempted to "cherry-pick" by offering low rates to those with good genetic profiles others would be forced to do so. This would raise a number of ethical difficulties. Glasgow University Law Unit suggested that:

"the insurance companies will in effect force individuals to undergo testing which they may otherwise have chosen not to do. Insurance companies do not at present possess the necessary follow-up counselling procedures and care to educate people as to the relevance of this information."

When the Nuffield Council in Bioethics investigated Genetic Screening in 1993 it called for a moratorium on the use of genetic information in insurance policies below a certain threshold, and many geneticists and patients' interest groups have supported its proposal. Professor Harper told us that the insurance industry had been urged to hold discussions with the professions in genetics and the Department of Health. In May we were told that discussions between the ABI and geneticists were now being arranged and a meeting with genetic interest groups had already been held. We welcome this and hope it will mark the beginning of continuing contact between the insurers and those concerned with genetics research and treatment."

6.30 At present, underwriters prefer a pooled approach, where a wide number of people are covered at standard premiums and only those with conditions that affect longevity are charged special terms or refused insurance. We may want to keep this stance or we can change our approach.

6.31 In the last few years, we have seen the development of preferred lives insurance. Here proposers qualify for a discount of around 15% if they do not smoke, have a good family history, a good medical and no other specified risk factors. This is cherry-picking but the offices have stressed that this is not connected with genetic testing. Not at the moment, that is. It is possible that preferred life insurance will become the norm, and that different criteria will be used to assess preferred lives. Because of the sheeplike nature of our industry, it only takes one office to break rank and choose genetic testing. I suspect that most healthy people would be happy to submit themselves to tests as it would reduce their premiums, and it may be possible to develop special policies for families with good genes.
"244. The insurance industry's objections to a moratorium on the use of genetic information are based on the fear of adverse selection. Although genetic knowledge will not change the risk pool in the population as a whole, it will give people access to indications of their health prospects. If they do not have to reveal the results of genetic tests to insurers (and, one assumes, consequently pay a higher premium if appropriate), then those with bad prospects are more likely to insure themselves than those with good. The risk pool among the insured may be changed for the worse and insurance premia may rise. A vicious circle could be created if the risk pool deteriorated still further because those with good health prospects became increasingly reluctant to take out (expensive) insurance. We were told that this had indeed happened in the recent past:

"the insurance industry did a bold thing in the early 1980s. In terms of mortgage protection policies a number of companies at that stage decided that if a person was taking out a mortgage they could offer the cover without health evidence;...the evidence is that the mortality rate of those lives is broadly fifty per cent higher...than the normal insured life..." 

6.32 I know that Dr Pokorski in the USA has had difficulty in establishing that adverse selection exists. It is, after all, something that insurance companies go out of their way to avoid. Some good has come out of the mistaken assumptions surrounding the MIRAS campaign in the UK as it illustrates the follies of our ways. It shows, beyond doubt, that adverse selection exists.

"245. Adverse selection is a real problem. Dr Barr admitted:

"Any sensible individual knowing they have got an unfavourable genetic predisposition will insure, and will insure as much as they are allowed to, and it is a matter for public policy to decide to what level they should be, if you like, entitled to insure."

"246. We discussed possible solutions to the problem of adverse selection with Professor Kenneth Arrow, the Nobel Laureate economist of Stanford University, and Dr Barr. One suggestion put to the Committee was that

(i) Insurance companies should not ask for any information or genetic tests at the time the contract was made.

(ii) If the insured dies of a genetic disease on a list maintained by an appropriate authority as predictable by a genetic test, then the sum paid by the insurance company need not exceed a ceiling specified at the time of the contract.

(iii) Insurance companies would re-insure in an industry pool against the risks of deaths from genetically identifiable causes on the list.

The effect of this would be to spread the cost of payments from the genetically determined diseases on the list over the whole population of the insured. They would in turn gain from the knowledge that in a rapidly moving field, they would not be discouraged from taking otherwise desirable genetic tests by the cost of new insurances. Such a scheme would need detailed study and design. The evidence given to us by Professor Arrow and Dr Barr suggests that it would be possible to find ways to regulate the use of genetic information in insurance which would both protect the interests of society in enabling as many people as possible to obtain insurance and protect the insurance companies themselves." "

28
6.33 The fact that this potential solution is specifically mentioned suggests that it found favour with the Committee. If we fail to come up with a solution satisfactory to Parliament, this may be forced upon us. And yet is it in any way practicable?

6.34 Assume that a family man and breadwinner effects a policy to cover his mortgage for £250,000. Three years later he dies. If the disease is not on the list, the full £250,000 will be paid and the mortgage will be redeemed. If the disease is on the list, the sum assured may be reduced to £50,000, even though he will have paid premiums based on the higher sum assured. The lender may be forced to reclaim the property and the family is forced to move.

6.35 Is the total amount available on one policy, say, £50,000 on death from a genetic disorder, or is this spread over all life policies? And is it only policies with that company, or with all offices? If it is going to be spread across the industry, how will it be policed? Why should a person keep reviewing his insurance needs and effecting more cover if it is all going to be cut back?

6.36 There is also the unpredictability of this approach. How accurately can someone plan for the future? No one knows how they are going to die and the family will be able to claim the full amount if someone has a fatal accident just before the genetic disease goes into its final stages. Who's to say that all the deaths will really be accidents? Another example: Abraham Lincoln had Marfan's syndrome but it was an assassin's bullet which killed him.

6.37 If this approach becomes the norm, how accurately will deaths be recorded? At the present time, AIDS deaths are under-recorded and suicides are often classed as accidents. What pressure will a doctor be under to record a different cause of death such as heart failure and to omit the genetic component? £200,000 might be riding on it.

6.38 The definition of what is a genetic disease is increasing all the time and the list may become increasingly long. It would be unreasonable if someone who effected a policy in the year 2000 and dies in the year 2010 were to have his cause of death matched against the 2010 list.

6.39 The solution of a reassurance pool hardly helps the insurers. The funding for these pools has to come from somewhere - admittedly, the cost would be spread across several companies but the total loss to the industry would be the same. We might question the use of reassurance at all if the sum assured is being limited.

6.40 There is another flaw in the argument. What if we request a medical attendant's report at the outset and the GP tells us the result of a genetic test? Should we be telling a medical attendant, "Please give us the life's medical history but do not disclose the results of any genetic testing."

6.41 There are not enough details given for us to judge this suggestion properly, but even based on what is given, it is unlikely to work. It is far better to make an equitable assessment of the risk at the outset, charge the appropriate premium and stick with it.

6.42 I would find this suggestion ludicrous if it wasn't being propounded in such an eminent document. Taking it a stage further, maybe we could learn something from the way that motor engineers view insurance claims. They argue about the quality of a car, taking into account wear and tear, damage to the chassis and the amount of rust, and then come to a judgment. What if death claims were viewed in the same light: "He's not been looking after himself so we'll reduce the claim on the policy."
"247. We cannot see into the future; it may be that the ABI is correct, and that the use of genetic information in insurance is limited, and raises no new problems. However, the great majority of our witnesses, including those with expertise in genetics, think that such information could have major implications for the industry in a relatively short time. In our view the ABI has reacted to these predictions with undue complacency; it would, at least, be prudent to have contingency plans in place to ensure that changes were dealt with in an orderly manner."

6.43 This is a disappointing paragraph. If the ABI has acted “with undue complacency” (and I don’t believe it has), then it has a lot of explaining to do to Chief Executives. Still, it matters little what the true position is since the damage has been done - the media has picked up on this critical phrase.

"248. Such plans may now be being made. When we met the ABI we were told that the industry hoped to make its own proposals for dealing with genetic tests in 1995. The Committee recommends that the insurance industry be allowed one year in which to propose a solution acceptable to Parliament, and that if it fails to do so a solution should be sought, by legislation if necessary."

6.44 When speaking to the media, the ABI has been satisfied with the outcome, but it is still pretty swingeing. The industry has to have something in place within a year - and it will need to be fairly substantial. I am not clear when the year ends but the Report was published on 6th July 1995 and so it makes sense to have the regulations in place by 5th July 1996.

"249. Our proposal is limited to genetic information. Professor McLean pointed out that allowing use of family histories gave insurers access to a considerable amount of genetic information, and that there needed to be wholesale consideration of the use of medical information in insurance. She believed that we should accept that premia would increase in the interests of equity. This may happen in the long term; however, in the short term, like Dr Barr, we stand by “pure, grubby empiricism”: the extra premia currently charged affect only a relatively small number of people; the implications of genetic testing may however be much wider."

6.45 This paragraph relates to our current practices. Offices have asked about family history for years, and it is particularly relevant for critical illness policies. Some proposers will be charged extra premiums on the basis of a poor family history. I would hope that this section of the Report does not find much favour as I would be reluctant to give up such questioning without a strong fight.

"250. Our discussion has concentrated upon life insurance, since that is the most relevant in the UK. However, if the most optimistic forecasts are right, genetic knowledge could change the whole nature of health insurance by limiting the ability to spread risk. A recent study in the US suggested that “information about past, present or future health status, including genetic information, should not be used to deny health care coverage or services to anyone”, and indeed medical underwriting has already been forbidden in several states. Sir Walter Bodmer thought that any country that “does not have some form of health service that spreads the insurance risk not as a function of an individual’s constitution will not be able to benefit” from the advances of genetic medicine. Several witnesses commented, unprompted, that the existence of the National Health Service was likely to spare the United Kingdom some of the most acute of
the problems genetic science is likely to engender. We believe that one effect of genetic information may well be to limit the scope of medical insurance in the medium to long term. Certainly countries which wish to use genetic information in healthcare to the full will need some social health system such as the National Health Service."
7. GENETICS - THE WAY FORWARD

“You may see the meaning of within,  
It is speaking, it is speaking.”

(‘Tomorrow Never Knows’, John Lennon for the Beatles)

7.1 The last sentence of paragraph 248 said “The Committee recommends that the insurance industry be allowed one year in which to propose a solution acceptable to Parliament, and that if it fails to do so a solution should be sought, by legislation if necessary.” Section 7 considers the choices facing insurers and suggests a course of action.

7.2 It would be possible to ignore the Select Committee’s recommendation, to call their bluff as it were, and risk legislation. The ABI could argue that it represents profit-making organisations, and why should they be forced to make changes that will affect their profitability? That would be a brave argument and probably foolhardy. At the very least, we would lose goodwill and it is likely that the legislation would follow. That legislation could be more stringent than our recommended solution.

7.3 Without any embargoes and looking well into the future, genetic testing could be used by an office anxious to steal a lead over its rivals. Is there anything wrong with this? The ABI, in its response to the Select Committee, needs to consider whether it is right to stifle competition. Indeed, the Office of Fair Trading is keen on competition being used to reduce the cost to consumers.

7.4 Self-regulation is preferable to legislation. We would have no control over proposed legislation once it is discussed in the House, and the results could be damaging to the industry. When a subsequent change is necessary, it is easier and quicker to amend regulations.

7.5 Certain principles need to be addressed and hopefully incorporated in any solution to these issues:

7.5.1 The principle of *uberrima fides.*
An insurance company cannot know everything about an individual and so it relies on the concept of “utmost good faith” - it can challenge a claim on the grounds of non-disclosure. This is one of the legally accepted tenets of insurance and it is not something we should waive lightly.

7.5.2 Regulations need to be reviewable, perhaps every three years.
The Committee says in 247 “We cannot see into the future.” No-one knows how genetic testing is going to develop - and nor should we be expected to. For example, a commercial company is already advertising a test for cystic fibrosis. The Committee recommends legislation to stop testing by home collection or by post and without counselling. If this does not become law, the insurance industry has a major problem as clients can perform their own tests and can apply for life insurance without anyone being aware of the results. Des Le Grys, Managing Director of Munich Re in the UK, wrote in ‘The Times’, “The public’s attitude towards genetic tests, the frequency of genetic tests and their uses will vary with time, by country and by group: it is not sensible to draw up rigid regulations today on the grounds that it will always be appropriate.” Following on from what Des says, I anticipate that the attitude of the young (say, under 35s) will be very different from the views of older people. Young people are likely to accept genetic testing as a fact of life.
Furthermore, any regulations should be reviewed over time, perhaps through a forum with the medical profession, to reflect the changes in genetic testing itself.

7.5.3 Regulations should not involve life offices in needless expense.
There is a cost to every concession. If we gave in to our critics, we would be involved in considerable expense. However, from the Committee's Report, it is evident that our regulations need approval from other interested parties. A balance has to be drawn and costings made for any potential solution.

7.5.4 Regulations should endeavour to get it right first time.
We are unlikely to determine a solution that will be totally acceptable to all parties. The Genetic Interest Group, for example, has radical views because it is at pains to avoid a genetic underclass. This is very commendable but a private company like a life office might find their requirements hard to accept. Hopefully though, the solution would be such that pressure groups would agree not to continue with their criticism.

7.5.5 Regulations should be in Plain English and comprehensible to the general public.
If we tell proposers that the results of genetic testing do not have to be passed to us, we must make what we are saying precisely clear.

7.5.6 Regulations should cover all types of business transacted by a life office.

7.6 The concerns surrounding genetic testing and insurance that need to be addressed are:

7.6.1 Those who would benefit from genetic testing may decide otherwise because they would have to declare the test on a future proposal.
Life offices cannot afford to be seen as obstructing medical progress and perhaps getting in the way of screening programmes. It may not be too much of a concession, at present, to say that the results of genetic tests do not have to be declared, providing we retain our question about family history.

7.6.2 Those who do not want a genetic test may be asked to have one by a life office.
Again, this is very unlikely to be an issue for some years. Perhaps in five years' time, an office might want to introduce screening for proposals over £1m.

7.6.3 There may be unfair assessments of genetic information by life offices.
I hope I have demonstrated that our CMOs do have the ability to treat this information fairly. With concessions, it is more likely that those who are rated for something other than a genetic result may have cause for complaint.

7.6.4 Life offices cannot be trusted with genetic information.
This has already been addressed in the paper.

7.7 Proposed solution 1 - Ban genetic testing by life offices.

7.7.1 At present there is no danger of an insurance company requesting a genetic test on an applicant. A test for Huntington's chorea with appropriate counselling could cost £500 and no company would want to pay that. However, as the Committee acknowledged, the cost of genetic testing could come right down and the position could change dramatically.
7.7.2. The cost, however, is still likely to be substantial on account of the counselling. So many issues have to be taken into consideration, not least the possibilities that someone may learn that his parents are not his real parents or that other family members may be affected.

7.7.3 Dr Pokorski said that having a ban for a few years on requesting genetic tests was ill-conceived, even though life offices would not be giving much away. "It puts the boot on the wrong foot and it would be very hard to remove it when you wanted to. At this point though, it would be disastrous for offices to say that they were going to carry out their own tests - they can only follow this course when the tests become commonplace as, of course, they will. Remember too, that most people are going to have favourable genes and they will want insurance companies to take that into account. The US male believes in "every man for himself" so he wants the best terms possible - he isn't going to subsidise anyone else. You wouldn't find anyone in New York willing to subsidise earthquake insurance for householders in California."

7.8 Proposed solution 2 - Ban the questioning of clients about previous genetic tests.

7.8.1 We may concede the point, but if a test has been done, we should be allowed to know the result. If, for example, someone has had a screening for cervical cancer, we would expect to be told the result. Why should a genetic test be different?

7.8.2 No questions about genetic testing appear on life assurance proposals - and at the moment there is no point in including one. Most people would be confused by the question.

7.8.3 If an applicant completed a proposal which did not contain a family history question and subsequently died of Huntington's chorea, what would an office do? Would it repudiate the claim on the grounds that the applicant had not disclosed a material fact, namely, the family history of Huntington's chorea? Possibly too there had also been the non-disclosure of the result of a genetic test. There are good grounds for doing this but, at this delicate stage of negotiation, I do not think an office would be recommended to pursue the non-disclosure.

7.9 Suggested Code of Practice - Genetic Testing

What follows is purely a suggestion I devised after reading the Committee's Report. It has no official status whatsoever, but the outcome could be along these lines:

7.9.1 A genetic test can determine whether an individual is susceptible to a particular inherited disease.

7.9.2 At present life offices do not request genetic tests on proposers for life or sickness insurance.

7.9.3 Individuals are expected to answer questions on a proposal truthfully. They should give details of any medical tests undergone, including genetic tests, and of any information requested regarding family history.
7.9.4 Any adverse results of genetic tests must, therefore, be disclosed, but they will be ignored for the purposes of life assurance where the initial sum assured on death is £50,000 or below, the term 10 years or less, and the proposer can confirm that no other cover has been obtained through this concession. An office will, however, take both the family history and any past or current illnesses into account when assessing proposals.

7.9.5 No concessions are available for any form of sickness insurance.

7.9.6 The agreement expires on 31st July 1998, unless reinstated by the regulatory authorities.

7.10 The concession relates to life assurance but it is important that sickness insurance, which would include critical illness cover, is specifically mentioned.

7.11 At present there is confusion as to what a genetic test is - and there is a possibility that a cholesterol test could be regarded as genetic. Rather than enter that debate, the ABI could say, “These are the tests we rely on at present - ECG, X-ray, HIV, blood profile, gamma-GT, urinalysis. We do not regard any of them as genetic tests.”

7.12 We may not be using some of the genetic information mentioned above for underwriting purposes, but by requesting it the industry, with cooperation between offices, will be able to gauge the extent of the problem. This will give us concrete facts when the matter is reviewed.

7.13 Once a concessionary sum assured has been determined, the life offices can never go back and the only way is up. Whatever the amount is, others will argue that it should be twice or five times that amount. I don’t think that the ABI could realistically propose less than £10,000, but the £80,000 sum assured as advocated in Norway is too generous. We are, after all, giving proposers something for nothing. Hence, my chosen figure of £50,000, although I would prefer it to be lower. Nevertheless, this suggested concession is costlier than it appears.

7.14 The Committee’s Report gives the incidence for some inherited diseases. For Huntington’s chorea, the figure is 1 in 10,000. If there are 30m adults under the age of 65, then the disease affects 3,000 people. If half of them already have physical symptoms and are therefore uninsurable, then 1,500 people could make proposals for life assurance and be underwritten accordingly with the positive results of any genetic tests deliberately being ignored. Based on family history alone, they might be accepted by a generous office with an additional premium of £5 per £1,000 sum assured per annum instead of being declined. Therefore, the life offices are at risk for a sum assured of £75m for concessions for this disease alone.

7.15 The quoted figure is 1 in 4,000 for muscular dystrophy, which would lead to a sum assured of £180m. The total sum assured for the monogenic diseases might be as high as £500m. With 100 life offices, the additional exposure for each office is £5m on average.

7.16 We would need to fund for this additional liability, and, in effect, we become part of the Social Services. We would cease to be commercial companies solely making commercial decisions, and part of the Freedom to Underwrite would be lost.
8. DISABILITY - THE BACKGROUND

“One thing you can’t hide
Is when you’re crippled inside.”
(Crippled Inside, John Lennon)

8.1 According to the Royal Association for Disability and Rehabilitation, around 12% of the total population has some form of disability. This is 6.5 million people, and even though the majority are elderly, a considerable number are of working age. Many of the disabilities have no bearing upon insurance companies' terms, but, nevertheless, the issues relating to insurance in the forthcoming legislation could affect huge numbers of disabled people.

8.2 Although I personally believe that insurance companies are relatively blameless, many disabled people have suffered social injustice in recent years - sometimes it is through a lack of understanding, sometimes it is deliberate. It is only right that legislation should be introduced to protect their rights and to determine rules for providing services and employment. This is no easy matter as the costs can be very considerable.

8.3 Insurance is brought into the debate as disabled people may not be able to obtain insurance on the same terms as healthy lives. In 1982 the Committee on Restrictions Against Disabled Persons said:

"Many disabled people find that trying to obtain insurance reveals yet another area where they are at a disadvantage. For those who have struggled to overcome physical disability, it is particularly wounding to be told that their lives are uninsurable: and doubly so where this means that they are unable to provide the protection for their families that others not so disabled would consider normal. It can also mean that they are unable to obtain a mortgage or enter into any financial contract that requires life insurance. Even where insurance cover is granted, the premium may be loaded to such an extent that it seems disproportionate to the disability, and causes additional financial hardship to those whose finances are already stretched to the limit."

8.4 As an example of illogical decisions, the Report continued, “Deaf people have had to pay loaded motor car insurance premiums, although no additional premiums are required from drivers with radios, telephones or cassette players in cars.” This is a recurring theme. In October 1994, the Research Institute of Consumer Affairs - an offshoot of ‘Which?’ - found that 36 out of 48 companies did load premiums for certain categories of disabled drivers. The categories were arthritis, stroke, paraplegia and multiple sclerosis. Their director, David Yelding, said, “The report shows that firms discriminate without evidence to justify their actions.” Any legislation is bound to have wide implications for motor and travel insurance but this paper concentrates on the life issues.

8.5 The Americans with Disabilities Act is universally applauded in America. It mandated equal access to products, services and benefits for 50 million who qualify under the broad definitions of disabilities in the law. The financial burden imposed on the private sector was overcome because of the emotional arguments in support of the bill. Similar legislation has been enacted in Australia and Canada, but, generally, discrimination - or selection - is allowed when it is merited by the circumstances of the individual case.
8.6 A curious exception has arisen in New York State where a community-rating law has been introduced. Companies writing medical expenses insurance have to accept all applicants using flat premiums with adjustments only for geographic location, i.e. no adjustment for age or sex. Pre-existing conditions were covered after a 12-month waiting period. One company lost $100m in 1994 as it found that enrolment dropped and the average age rose, leading naturally to a higher proportion of claims. After only a few more months, they withdrew from the market.

8.7 In the UK, it is practically impossible for a Private Member's Bill, involving substantial legislation, to become law without the backing of the Government. The aim of a bill is to draw attention to an issue and hope that the Government will act upon it. That was the intention of the Civil Rights (Disabled Persons) Bill 1994.

8.8 There was no prospect of the Bill becoming law, simply because of the estimated £17bn cost to industry, commerce and Government. The proposed changes to school facilities, public transport and public buildings made the Bill prohibitive, and so the Government offered all help short of assistance.

8.9 In May 1995, the Bill was brought down by a large number of formalities - 80 amendments appeared in the names of five Conservative members who had taken little, if any, part in the debates. The Minister for the Disabled, Nick Scott, lost his job. The Government's mishandling of the Bill gave it and its cause much more publicity than its backers could have expected.

8.10 As part of the price for this, the Government agreed to make its own proposals in the form of legislation or codes of practice. This led to the Disability Discrimination Bill 1995, which will shortly be on the statute books.
9. DISABILITY - THE LIFE OFFICE ISSUES

"Many's the time I've been mistaken
And many times confused."
('American Tune', Paul Simon)

9.1 Premise 1 - Life offices should not be allowed to treat disabled lives differently from able-bodied ones.

9.1.1 The process of selection is one of the fundamental features of life assurance, and yet it is tempting for any government to say that life and disability insurance must be available to all without any classification of risks. The government could then make cuts in social security benefits because the public could buy life and sickness insurance without being rejected or being charged extra premiums. Actuarial theory advising against this and illustrating how insurance companies might go insolvent may go unheeded.

9.1.2 It could happen. The Civil Rights (Disabled Persons) Bill 1994, which was brought down for other reasons, effectively banned insurers from differentiating between risks.

9.1.3 As a guess, something of the order of an additional 50% in the current expenditure on death claims might be incurred if companies were not allowed to differentiate on medical grounds. £1.6bn was paid out in death claims in 1992 and although this would be a large increase, the total amount paid for all claims by life offices during the year was £33bn.

9.1.4 The effect of this would be to increase premium rates substantially. Is this really what a consumer would want?

9.1.5 Lord Inglewood showed an appreciation of insurance issues when he told the House of Lords in June 1995, “The Government will not require insurance companies to charge lower premiums than the risk insured requires simply because the risk is based on the customer's disability. I am aware of no legislation in the world which would require insurance companies to do that.”

9.1.6 Representatives of several disability groups have remarked that there is unfair discrimination by insurers against the disabled. At one extreme, there are militant disabled person's groups who want legislation to remove every vestige of what they see as discrimination. Such views are not going to disappear overnight.

9.2 Premise 2 - Life offices do not know how to underwrite the disabled.

9.2.1 In my view and I realise this is controversial, insurance companies do not discriminate unfairly against the disabled. In fairness to all policyholders, we assess the relative risks of all proposals presented to us and charge appropriate premiums. Fairness means equal treatment for equal risks.

9.2.2 However, life offices are more competitive than ever when it comes to charging additional premiums, and more favourable terms can be obtained now than at any other time in their history. Indeed, there are thousands of people who would be classified as disabled and yet they are still able to obtain life insurance on standard terms.
9.2.3 Lord Rix, speaking in the House of Lords on 15th June 1995 said, “My contacts in the insurance industry before and since the setting up of MENCAP City Insurance Services have given me the realisation that in some instances discrimination is based not on actuarial tables or painful commercial experience, but on what I can only describe as prejudice and ignorance. It really is quite extraordinary how usually well-informed people can blunder into ill-informed decisions - though I suppose that I should not be totally surprised when immigration rules of certain world powers have apparently been based on the assumption that Down's Syndrome is a contagious disease!”

9.2.4 I would disagree with Lord Rix and suspect that he is generalising from a few well-chosen examples. One example was discussed by a Standing Committee in the House of Commons in March 1994. A proposer had been asked to pay a higher life assurance premium because he had cerebral palsy. He walked with a limp, but apart from that, he did not consider that he had any disability. The office withdrew the extra premium after it had been asked to provide statistics to prove its case. An MP told the Committee, “He was being unfairly treated because the assumption being made about his life expectancy was unfair. It was not based on evidence, but on a broad assessment of the average condition of people with cerebral palsy.”

9.2.5 A single case like this can damage the industry. The details are repeated in the House and in the media and we are made to look foolish. We are accused of excessive caution, inexperience, and acting on inadequate information. Any problems would be over a lack of knowledge about different types of disabilities, rather than an intrinsic problem over discrimination.
10. DISABILITY DISCRIMINATION BILL

"No-one likes us, I don't know why.
We may not be perfect but heaven knows we try."
('Political Science', Randy Newman)

10.1 In November 1994, the Government announced that it would be introducing a Bill concerning the discrimination on grounds of disability. The Bill aims to end unfair discrimination against disabled people. In its White Paper, the Government said, “The Government accepts that measures to end discrimination must be comprehensive. The lives of disabled people cannot be compartmentalised into a series of separate activities. Like everyone else, disabled people want to be allowed to live life to the full. Improved access to goods and services is of little use to someone who cannot get on the bus to go to the shops. Access to a good education is essential when competing in the jobs market. For these reasons, government action must affect all areas of life, including work, travel, study and leisure. In some areas, such as getting work or going shopping, legislation is needed to secure equal status for disabled people. In other areas, such as education, it is better to build on existing provision with practical measures which improve access.”

10.2 The Minister for Disabled People, William Hague, said, “The consultation document made clear the Government's intention to exclude financial services from any right of equal access. But as a result of responses received, I propose to include financial services in the new statutory right. We shall be looking closely, in consultation with the insurance industry, at how legislation could be best framed to prevent discrimination while recognising the legitimate need for insurance companies to distinguish between any customers on the basis of likely costs entailed in meeting their insurance claims.”

10.3 Baroness Hollis of Heigham asked, “May we hope that there is as much toughness with regard to the provision of financial services as to other aspects of the Bill?”

10.4 The Bill was published in January 1995. Over 200 amendments were tabled and there was also a new Private Member's Bill, presumably because it was thought that the Government's Bill did not go far enough.

10.5 The Disability Discrimination Bill has completed its third reading in the House of Commons and is heading for the House of Lords. The Government's aim is for it to be on the Statute Book by Autumn 1995 and for its first provisions to have been implemented within a year.

Part I
1. (1) Subject to the provisions of Schedule 1, a person has a disability for the purposes of the Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

10.6 In this context, the word 'substantial' has yet to be defined, while 'long-term' is defined as a minimum of a year. 'Normal day-to-day activities' covers such areas as mobility, manual dexterity, physical co-ordination, continence, ability to lift, carry or otherwise move everyday objects, speech, hearing or eyesight, memory or ability to learn or understand and the perception of the risk of physical danger.
10.7 As it stands, there has to be a disability in place, that is, the disability has manifest itself. This seems eminently sensible, but there has been extensive lobbying for the inclusion of those who are HIV positive and those with a poor genetic profile. The inclusion of either category would cause problems for insurers.

10.8 Baroness Gardner of Parkes told the House of Lords, “The insurance industry’s record, although improving, is not good on dealing with those who are disabled, particularly through HIV or AIDS. Before my noble friend tells me that the Bill is not concerned with the rights of those with HIV but with the disabled, I hasten to remind him that HIV leads to AIDS.”

10.9 In a similar vein, Lord Ashley of Stoke has said, “It is absolutely undeniable that some, although not all, employers, and some insurance companies, will discriminate against people with a genetic predisposition. From their own extremely narrow self-interest some of them are bound to do that, and these are the people who we must prepare ourselves for and for whom we must legislate.”

10.10 In any event, I would have thought it could be mentally damaging to treat currently healthy people as disabled. Lord Ashley would disagree: “They are very vulnerable people; they are waiting for an illness. There is no excuse for the Government refusing them protection.”

10.11 Those with a poor genetic profile may decide against having a family, and this led to some brilliant logic from Earl Russell. “The Minster argued that a genetic defect is not a disability. Parenthood is a normal activity. How far it is exactly to be described as a day-to-day activity, I am not exactly clear. However, I should have thought that within the meaning of the Act, arguing that case in court, I might have had a sporting chance.”

Part II

3 - (1) It is unlawful for an employer to discriminate against a disabled person -
(a) in the arrangements which he makes for the purpose of determining to whom he should offer employment;
(b) in the terms on which he offers that person employment; or
(c) by refusing to offer, or deliberately not offering, him employment.

10.12 There are several sections on employment and most of it is good common sense. It is clear that every job cannot be open to every person. It would be unthinkable to employ a blind fireman or bus driver. Quite clearly though, the number of disabled persons in employment will increase, and, so there will be more disabled employees in group schemes.

10.13 As most of the benefits in group life assurance schemes will be under free cover limits, life offices will need to determine how the mix of employees may change for particular schemes and how it may affect the claims experience. In some extreme instances, the free cover limits may be reduced.

Part III

12 - (1) It is unlawful for a provider of services to discriminate against a disabled person -
(a) in refusing to provide, or deliberately not providing, to the disabled person any service he provides, or is prepared to provide, to members of the public;
(b) in failing to comply with any duty imposed on him by Section 15 in circumstances in which the effect of that failure is to make it impossible or unreasonably difficult for the disabled person to make any use of that service;
(c) in the standard of service which he provides to the disabled person or the manner in which he provides it to him; or
(d) in the terms on which he provides a service to the disabled person.

12 - (3) The following are examples of services to which (subject to any regulations) this Part applies -
(a) access to and use of any place which members of the public are permitted to enter;
(b) accommodation in a hotel, boarding house or other similar establishment;
(c) facilities by way of banking or insurance or for grants, loans, credit or finance;
(d) facilities for entertainment, recreation or refreshment;
(e) facilities provided by employment agencies or under Section 2 of the Employment and Training Act 1973;
(f) the services of any profession or trade, or any local or other public authority.

14 - (4) Regulations may make provision as to other circumstances in which, for the purposes of this Part, a provider of services of a prescribed description (for example, insurance services) is to be taken as justified in treating a disabled person less favourably than he treats, or would treat, other members of the public.

10.14 In the White Paper, the Government said, “Insurance services will be subject to a special rule which recognises the need to distinguish between individuals on the basis of the risks against which they seek to insure. Insurers will be allowed to charge higher premiums only to the extent that the extra charge is based on actuarial data or other good reasons.”

10.15 This exemption is similar to that in the Sex Discrimination Act 1975. The exemption for life offices can be seen as rather vague and the phrase, “other good reasons” would need to be tested in court. On the whole though, I do not see it making too much difference to day-to-day underwriting decisions. Hopefully, any underwriter who puts on a decision today will be able to justify his action. This is surely good practice. My concern is that we may become too hidebound by statistics, so that the underwriter’s experience and judgment has a lesser role.

10.16 Fortunately, there is an interchange between underwriters for different offices on industry issues. There are bound to be beneficial discussions on the application of any regulations.

10.17 The ABI’s response to the Government’s Consultative Document in October 1994 set out the main elements of a Statement of Practice:

10.17.1 The need for insurers to be aware of the main forms of disability and whether they have any relevance in assessing the size and probability of an insurance claim.

10.17.2 The need for insurers to be aware of the wide range of conditions which might amount to ‘disability’ as distinct from medical impairments.

10.17.3 The need for insurers being able still to reflect claims experience, mortality and morbidity or other relevant factors in their underwriting.
10.17.4 The need for insurers only to ask for medical information which is demonstrably related to the additional risk associated with insuring the disabled person.

10.17.5 The need for complaints from disabled people to be handled sensitively.

10.17.6 The need for insurance companies to have a clear mechanism for the investigation of a complaint by a disabled person.

10.18 The ABI is bound to have extensive discussions with the Department of Social Security and the Department of Trade and Industry with the aim that insurers should be able to differentiate premiums on the basis of reliable data concerning relative risks.

10.19 Decisions will need to be made on objective information and, to this end, it would be mutually beneficial to have a database of information. This needs to be two-sided as either side could otherwise just put forward the most favourable figures to their cause.

10.20 The ABI needs to contact disabled groups in order to encourage the emergence of any further information that may be of assistance to underwriters in assessing disabled lives. However, actuarial expertise will be needed to explain why a particular set of favourable statistics may not be appropriate, e.g. based on too small a sample.

10.21 Similar legislation in New Zealand states that the statistics have to be based on local information. With a small community, distortions could lead to inaccuracies.

10.22 In this regard, I feel that the CMI Bureau has a role to play, particularly with its investigations into impaired lives. Although funded by the industry, it is an independent body purely reporting on mortality and morbidity statistics. If these statistics were unfavourable to the offices, they would still be published. This being the case, all offices not currently contributing to the CMI should reconsider that decision.

10.23 I hope that not too much reliance is placed on statistics and that an underwriter's judgment still has some significance.

10.24 Although it may not be the Bill's intention, life offices may be reluctant to introduce new products. Innovation involves risk and assumes a step into the unknown. It might be hard to justify the "good reason" for applying additional premiums as appropriate data may not be available.

10.25 The Government will provide free advice to complainants in disputes, so disabled people will be able to take insurers to court for damages. Damages for hurt feelings can be sought, although there will be an upper limit to this.

10.26 Finally, it should be stressed that many disabilities are not life-threatening at all and are accepted on standard terms by life offices.
11. OTHER CHALLENGES

“If you keep your goal in sight
You can climb to any height.”
(‘Everybody's Got The Right’ from ‘Assassins’, Stephen Sondheim)

11.1 This paper has concentrated on the most pertinent challenges to the Freedom to
Underwrite - AIDS, genetics and disability. There have also been challenges to the way
life offices determine premiums, which in turn affects underwriting processes.

11.2 For example, the US insurers had to ward off a challenge that age should not be a factor
in determining premium rates.

11.3 After the most obvious factor of age, sex has most bearing on the risk most people
present to an insurance company. It is easy to show that a woman is likely to live seven
years longer than a man, but unisex rates are often suggested. Some countries now have
unisex rates for annuities, even though, actuarially, it makes no sense.

11.4 At the present time, the only group we can penalise wholeheartedly and without a word
of complaint, is smokers. Sooner or later, there is bound to be a backlash and offices
will be accused of victimising smokers.

11.5 On another front, there are regular attacks from the media and pressure groups on the
Association Registry, which is administered by the ABI. This was established in 1896
for offices to enter details, in coded form, of lives they rate heavily or decline. If a life
then proposes to another office, the Registry provides a check against possible non-
disclosure. Although the criticism is unjustified, I cannot see the Association Registry
surviving much beyond its centenary.

11.6 And, in this brave new world, I am surprised that no-one has advocated that a
polygraph should replace professional medical evidence. That would tell us whether the
client was lying or not and would eliminate the problems of non-disclosure.

11.7 Baroness Jay said in June 1995, “Genetic counselling, genetic testing and identifying
genetic markers is potentially one of the most exciting and liberating developments in
medical science at the end of the 20th century.” I would agree but it could herald the
end of life assurance as we know it. We need to ask whether we want to maintain the
status quo of accepting say, 95% of our proposers on standard terms or whether we
want something akin to motor or household insurance where the premiums are charged
according to a number of specific factors.

11.8 Sadly, I am forced to conclude that the Freedom to Underwrite is becoming a thing of
the past. With all these challenges, life offices might decide to withdraw from the
protection market. Now that could place a burden on the State.
ACKNOWLEDGMENTS

"Everybody needs a little help sometime,
No-one stands alone."
('My Forever Friend', Charlie Landsborough)

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My thanks also to Chris Hudson for arranging the publication of 'The Freedom To Underwrite' and a remarkable thank you to HMSO who allowed me to reproduce up to 10% of the Select Committee's Report without charge. I've still got 5% in hand, so maybe I'll do another paper sometime.

My only regret is that this paper has had to go print before the Disability Discrimination Act was published. If the changes are known before January 1996, I will brief members at the meeting.

Now, where did I put that bandana?

Spencer Leigh, October 1995