

**The Genetic Interest Group (GIG) is a national alliance of organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders.**

Response to **Genetic Predisposition** 8.23 – 8.31

***Do you agree that there is no current justification for legislating to prohibit genetic predisposition discrimination?***

Medical conditions with a genetic component are many and varied; predictions made from genetic tests vary in their predictive accuracy; the conditions themselves are often complex and multifactorial. The risk of discrimination against individuals with a potential genetic predisposition (from a family history) or a definite genetic predisposition (from a positive test result) is high because of a widespread lack of understanding as to the limited predictive power of most genetic information. Furthermore there is also a widespread fear in those at risk that they will experience unfair discrimination arising from misuse of personal genetic data.

**The Genetic Interest Group believes that measures should be taken, through legislation, education, codes of practice, properly enforced to prevent genetic predisposition discrimination following the Discrimination Law Review.**

Currently the most common issues on which people feel there is potential for discrimination on the basis of a genetic predisposition to a condition seems to be that of life insurance, health insurance, travel insurance and insurance against loss of earnings. However people at risk also have concerns about access to medical treatment, employment, social stigmatisation and access to financial services.

The Genetic Interest Group has surveyed its members to find their experiences of unfair discrimination. Some of their responses are detailed below. More can be found in the annex to this document.

*"[We feel] threatened, pressured, belittled, scared, worried, restless. [O]ur old neighbours' [...] eldest son still intimidates us, more so my Husband."*

Member of the Restricted Growth Association

*"[We feel] at a loss to support UK citizens who clinically meet the criteria for new therapeutic treatment because they were regarded as too expensive to treat. Death [is] ultimately cheaper for society at large. [We have seen] discrimination in access to the same level of clinical management and therapy between the four countries of the United Kingdom."*

Member of Society for Mucopolysaccharide Diseases

*"Local cutbacks mean less consultants/professionals running clinics at the Child Development Centre, therefore we have to attend the hospital, with long waits, inappropriate waiting areas, toys (if any), changing facilities, etc. [It] seems the vulnerable groups in society have the most cutbacks or worst service, such as elderly and disabled."*

Member of SWAN (Syndromes Without A Name)

*"We have a daughter who is now nearly 20. She has an undiagnosed disability. When she was small we had NO support from any quarter. We struggled with her for YEARS until she was 13. We then took our local [education authority] to a tribunal."*

Member of SWAN (Syndromes Without A Name)

The moratorium on requests for genetic test results by insurance companies has largely prevented this from occurring. Insurance companies can currently only ask about test results for Huntington's Disease (HD) for life, health and loss of earnings policies above a certain value; and may not discuss any other genetic test results. Indeed, insurance companies may use information about family history in determining insurability and in setting premiums for individuals whose parent has the condition (conferring a 50% risk upon their offspring), even if the individual has not had a test, citing family history. This situation creates a dilemma for the individual: there is a 50% likelihood that if they take the test they will not have the gene, and may obtain insurance at standard rates, but a 50% likelihood that they will discover that they do have the gene, leading to certain knowledge of reduced life expectancy and physical and mental disability. Many individuals who are aware that they may have the gene due to a family history would rather be free to choose whether or not to have a genetic test free from any feelings of external pressure arising from fears about their (potential) insurability.

The Genetic Interest Group has collected reports from patients and those caring for families affected by Huntington's disease, through the Huntington's Disease Association, and the Scottish Huntington's Association. After being refused insurance cover or employment on the grounds of a family history of HD, they explain how this made them feel. A report from a patient with Motor Neurone Disease is included also; this shows an insurance company's inability to differentiate between inheritable conditions and those that occur sporadically.

*"I was declined as my mother suffers from the illness and at the time I had not been tested. [...] Therefore the insurance company was allowed to discriminate against this as HD has a 50/50 risk of being passed from parent to child. Yet illnesses such as Parkinson's, cancer etc are not allowed to be discriminated against as their hereditary stats were lower. [...] Only choices were to not take life insurance or go through the testing process to hope for a positive resulting to demonstrate the exact risk."*

Scottish Huntington's Association Member

*"Facing life with 50:50 risk of this condition is bad enough without being told you're too big a risk to allow you to do the things you want. [I felt] frustrated, [I had] low self esteem, [I felt] useless, [a] 2nd class citizen [and] alone. [...] The] Police Force insist on genetic test, but this is before they interview for job, so you can end up with no career in police force (won't take you if positive) and knowing 100% you have faulty HD gene."*

Huntington's Disease Association Member

*"A gentleman contacted the MND Association after he was denied critical illness insurance cover with respect to Motor Neurone Disease because his mother had*

*the disease, over 15 years ago. This was despite the fact that in 90% of cases, including his mother's, MND is sporadic rather than familial. The insurance company did not make any effort to establish whether [in his case there is] a family history of MND."*

MND Association Report

One of the intentions behind the insurance moratorium was to prevent individuals from being pressured into, or being discouraged from, taking a predictive genetic test. The choice to take a genetic test should be made on personal grounds, not by balancing the potential insurance or employment consequences of a diagnosis.

**Following this consultation, any measures taken by the Government with regard to genetic predisposition testing should seek to prevent individuals from being deterred from, or compelled into, taking a genetic test.** Specific proposals for preventing unfair genetic discrimination should be based on the predictive power of medical information, not focussed on the route (e.g. DNA based analysis) by which the information is obtained.

Though our evidence of discrimination on grounds of a genetic predisposition to a condition is limited, the Genetic Interest Group believes that these are examples of the potential for discrimination that could become more widespread as genetic tests become more available and more accurate.

The genetic test for HD is different from other genetic tests. HD is fully penetrant; i.e. carriers of the HD gene will get the condition. The number of conditions with onset that can be accurately predicted through genetics is currently very small, while the number of conditions that we know have some genetic component, but for which accurate predictions cannot be made, is large. The Genetic Interest Group believes that the predictive value of genetics should not be overvalued, and that individuals with a positive test should be protected from misinterpretation of the power and/or accuracy of these tests.

The progressive nature of many inherited conditions has led to patients and family members feeling discriminated against, as employers and other institutions make assumptions about their future health, and link all poor health with their condition.

*"It has always been a problem for me getting jobs. Then when I do get a job any time I have been off sick has been put down to me having PXE which is ridiculous when it's been a chest infection. [...] This attitude is very common in the workplace, it is a fear of the unknown as no one understands what the disease is. Therefore don't employ someone with PXE as they will probably be off sick a lot of the time. Just because a condition may have 5 or 6 symptoms doesn't mean you will have all of them etc. Nor does it mean that the symptoms you do have will stop you from being able to work!!"*

Pseudo Xanthoma Elasticum (PXE) Support Group: PiXiE Member

## Annex

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The Genetic Interest Group sent a questionnaire entitled “Unfair Discrimination Questionnaire” to 130 patient organisations supporting patients with inheritable conditions. These were the questions:

- **I feel that I / a member of my family / someone I know have been unfairly treated. YES / NO**
- **Which condition / support group do you belong to?**
- **How did you feel because of this?**
- **Were you able to do anything to change what had happened?**
- **If you have any specific examples within the categories below please do let us know.**
  - **Healthcare**
  - **Employment**
  - **Education / Social Life**
- **Any other comments.**

Further Comments:

*“X(child’s name) doesn’t understand safety with roads or strangers [or] dogs. It’s scary as he is hyper all day long, tiring and he runs [...] in the house. When we go shopping we try to involve X (child’s name) but [he’s] gone and people don’t understand, he can’t help it and they look at us as if we have no control.[...]Sometimes [my husband and I have] been in tears. We all love X (child’s name) but sometimes feel out of our depth. “*

Parent of a child with undiagnosed developmental delay, member of SWAN Syndromes  
Without A Name

*“Due to doctors and consultants not being trained or familiar with Huntington’s Disease (HD) we can’t get a specialist in Ayrshire interested in our cause”*

Scottish Huntington’s Disease Association

*“Two of my children (aged 40 and 45) were both placed in inappropriate units for almost one year. A resource was eventually found at a facility which is a 120 mile round trip from my home. I am 65 years old and do not drive. I have to travel most of the day in order to see them.”*

Scottish Huntington’s Disease Association

*“Extremely disappointed in the [insurance] system. Despite being in good health, I was declined life insurance due to the fact that my mother suffers from HD and I was at risk [although] had not been tested. [...] The insurance company were allowed to openly discriminate against this, as DH has a 50/50 chance of being passed from parent to child. Yet illnesses such as Parkinsons and cancer are not allowed to be discriminated against as there hereditary statistics are lower.”*

Scottish Huntington’s Disease Association

*"[I] was refused access onto a bus at night as they thought I was drunk. I tried to explain but my speech is slurred and poor so they did not understand. Because I refused to get off the bus the police were called and I was arrested and kept in the cells overnight"*

Scottish Huntington's Disease Association

*"[There is] such a lack of awareness regarding Huntington's and rather than have to explain about my husband's condition all the time, we just don't go out anymore"*

Scottish Huntington's Disease Association

*"Travelling is always a problem as my husband always gets singled out at airports. Also in hospitals or at appointments, people wonder why I have to be with my husband as they do not realise that I am his carer"*

Scottish Huntington's Disease Association