

# Genetic Discrimination Project Update



July 2003, Issue 1

## Our First Issue

Welcome to the first newsletter providing interested professionals and members of the community with an update on the progress of the Genetic Discrimination Project.

This national research project is a cross-institutional and interdisciplinary study funded for 2002-2004 by the Australian Research Council (ARC) Discovery Project Scheme. The full title of the project is:

*Genetic discrimination in Australia: an exploration of the nature and extent of the phenomenon within the legal and social context.*

## About The Project

The project is an empirical investigation of the experiences and perspectives of all key stakeholders. Specifically, data will be gathered from **consumers** (those considered to be at risk as a result of a genetic test result or because of their family history), **third parties**, comprising insurers and employers (recognised as being in a position to discriminate – either positively or negatively – on the basis of a person's genetic status) and also the various organizations within the **legal system** through which complaints of genetic discrimination may be pursued. There is also a **verification** component to the research, where attempts will be made to follow up consumer allegations of genetic discrimination. The aim of the verification sub-project is to gain greater insights into the issues involved for all parties.

The research has been approved in accordance with the National Health and Medical Research guidelines by the Human Research Ethics Committees associated with the researchers' institutions.

## Summary of Sub-projects

- Project A** The Consumer Study
- Project B** The Third Party Study
- Project C** The Legal System Study
- Project D** The Verification Study

The Genetic Discrimination Project team is well underway with these sub-projects, and a summary of our achievements to date will be outlined in this newsletter. Progress reports from the teams involved with each project will also be provided.

## Team Information

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### Expert Reference Group

An important feature of the project is the support of an expert reference group. Members of the group have made themselves available to provide input into the development of the project generally, and to discuss specific aspects of the study where they have expertise. The efforts of the expert reference group in providing support and guidance on numerous matters so far are greatly appreciated, and the team looks forward to further collaboration with them.

### The Consumer Study

Sandy Taylor, based at The University of Queensland, leads the Consumer Study team of Kristine Barlow-Stewart, based at The Centre for Genetics Education, and Susan Treloar and Kellie Chenoweth both at UQ.

Numerous support groups for people with a genetic illness in Queensland, Tasmania and New South Wales have been approached and informed of the GD project. Details of the project have appeared in the newsletters of some support groups and we thank them for their assistance in distributing information to their members.

Interviews and focus groups have been conducted with consumers and professionals across three states in an effort to gain an understanding of the

meaning of the phrase "genetic discrimination". As a result of this initial exploratory phase of the research, we have already uncovered a small number of cases of alleged genetic discrimination.

A detailed survey is currently being finalised for nationwide distribution. We are confident of receiving assistance from some support groups and clinical genetics services with the questionnaire's distribution. If you are interested in receiving information on how you can support this process please contact the team, toll free, on 1800 554 000.

In other news, Dr Kristine Barlow-Stewart is currently organising the inclusion of questions on attitudes towards genetics in the **Australian Survey of Social Attitudes**, a nationwide survey of community attitudes conducted by the Australian National University.

### The Third Party Study

Margaret Otlowski and Mark Stranger are both based at the University of Tasmania's Centre for Law and Genetics. They are responsible for conducting the Third Party Study into the use of genetic information by employers and insurers.

### Employers

The team is currently in the process of collecting samples of guidelines, policies and other documentation on the use of genetic information from the peak national, state and territory employer organizations.

After considerable consultation and deliberation, the Business Review Weekly's Top 1000 list was chosen as the main sample frame for an employer survey. It was decided that the organizations on this list, which include government and private sector organizations, were the most likely to have the resources available to undertake the kind of background health checks the project is interested in. Other samples are being considered in order to bring the total sample of employer organizations up to between 1500 and 2000.

Fifty pilot surveys have recently been distributed to a random sample of organizations on the BRW list. The survey asks questions about the organization, and its use of genetic information in pre employment health screening and programs for monitoring the health status of its current employees. Respondents are given the opportunity to volunteer for follow-up interviews. These interviews will be conducted in the next stage of the research.

### **Insurers**

Samples of guidelines, policies and other documentation on the use of genetic information in insurance underwriting are currently being collected from the insurance sector's peak representative organizations (IFSA, ICA, AFA IAAust, FPA, NIBA) as well as from individual insurers.

The peak representative body for life insurance organizations, the Investment and Financial Services Association (IFSA), has been conducting research of its own into the use of genetic information through the Institute of Actuaries of Australia (IAAust). Consultation with these two organizations is being undertaken in order to benefit from their ongoing research and to ensure that the GD Project adds to the data they have already collected rather than duplicate it.

It is expected that a survey will be distributed to insurance sector companies later in 2003.

### **The Legal System Study**

This study is being conducted by Margaret Otlowski. It aims to explore what use, if any, is being made of legal avenues by individuals who feel they have been discriminated against on the basis of their genetic status.

Contact has been made with all tribunals and other legal and quasi-legal bodies that may deal with complaints of this nature, in particular Federal, State and Territory Anti Discrimination Tribunals as well as Commissioners, ombudsmen, and industrial tribunals where issues relating to employment may be raised.

Inquiries to date suggest that very few such formal complaints have been brought. The few possible cases of genetic discrimination that have been uncovered are being followed up. We have requested that these organizations advise us of any new cases of possible genetic discrimination that arise during the life of the project.

### **The Verification Study**

This study builds on the consumer and third party research and will be jointly conducted by the Queensland (Sandy Taylor and Sue Treloar) and Tasmanian (Margaret Otlowski and Mark Stranger) based research teams. This will be the last study undertaken for the project and involves following up individual cases of alleged genetic discrimination with the parties involved. Cases that are suitable for more in-depth examination will be identified through the consumer study and, subject to the consent of all parties, these cases will then be discussed separately with the third parties and consumers involved.

The aim of the verification study is to gain a greater depth of understanding of the issues involved in these cases than previous studies have been able to achieve.

### **Recent and forthcoming publications**

The GD Project team has been successful in publishing papers detailing the project.

Otlowski, M.F., Taylor, S.D. and Barlow-Stewart, K.K. (2003) Genetic discrimination: too few data. *European Journal of Human Genetics*, 11(1), 1-2.

Otlowski, M.F., Taylor, S.D. and Barlow-Stewart, K.K. (2002) Major study commencing into Genetic Discrimination in Australia. *Journal of Law and Medicine*, 10(1), 41-48.

Otlowski, M.F., Taylor, S.D. and Barlow-Stewart, K.K. (2002) Australian empirical

study into genetic discrimination. *Genetics in Medicine*, 4(5), 392-395.

Otlowski, M.F., Taylor, S.D. and Barlow-Stewart, K.K. (2002) Australian empirical study into genetic discrimination. *Eubios Journal of Asian and International Bioethics*, 12(5), 164-167.

Numerous other papers are currently being developed and we will of course keep you updated regarding future publications via the website and newsletter.

### GD Project website

We have been busy developing a comprehensive project website over the past few months. The aim of the website is to provide information about the project and its individual phases and stages, the team members, the expert reference group, research updates and newsletter links. In the future, the questionnaire for consumers will also be available online. The website address is: [www.gdproject.org](http://www.gdproject.org)

### ALRC/AHEC update

A two-volume document entitled **Essentially Yours: The Protection of Human Genetic Information in Australia** has recently been released. The document is the culmination of a comprehensive inquiry by the ALRC and AHEC and canvasses a broad range of areas. The potential use of genetic information by insurers and employers has received in-depth coverage in the recently released document, with numerous recommendations highlighted. For more details about the document and recommendations, visit the website: <http://www.alrc.gov.au>

### Happy 50<sup>th</sup> anniversary DNA!

This year is an exciting one in genetics as 2003 is the 50<sup>th</sup> anniversary of a huge leap forward for biology – the discovery of the double-stranded helix structure of DNA. On April 25<sup>th</sup> 1953, Francis Crick and Dr James D. Watson published their paper detailing the structure of DNA in the highly respected journal *Nature*. Celebrations are

planned across Australia and the world this year to mark the anniversary of this major scientific development.

The Genetics Congress, to be held in Melbourne from 6-11 July 2003, will also celebrate the 50th anniversary of the discovery of the structure of DNA. An impressive lineup of special guests are presenting at the Congress, including 8 Nobel laureates. For further details about the Genetics Congress, visit the website: <http://www.geneticscongress2003.com/index.php>

The GD project team will be displaying a poster at the Genetics Congress outlining the research and the issues, challenges and opportunities arising from it. If you are attending the Genetics Congress, we look forward to the opportunity of meeting you and discussing the research further.

### Tell us what you think

If you have any suggestions for future editions or want to give us your views, please contact us.

### The Consumer study

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### The Third Party, The Legal System and The Verification Study

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