

[THE PATH]

Year one of the three-year project will focus on genetic technologies for pre-birth testing, with emphasis on pre-implantation genetic diagnosis (PGD). This will involve a description, analysis and critique of the issues surrounding PGD, taking into account scientific, clinical, cultural and ethical perspectives.

The report will examine the overall readiness of the New Zealand legal system, institutions and government agencies to respond to the issues, and will also recommend any necessary law changes or other initiatives.

Current collaborators include:

- ~ Stanford University
- ~ Glasgow University
- ~ Canterbury Polytechnic Institute of Technology

Learning Opportunities, Collaborations and Support

The Human Genome Research Project is initiated by the New Zealand Law Foundation and will be moving on to the next phase of its development.

The project is based at the University of Otago which provides teaching by eminent scholars, a rich learning environment, and well-established tradition of study, research and reflection.

Postgraduate candidates are encouraged to contact the project or the relevant department or school.

www.otago.ac.nz/departments/index.html

Opportunities are being created for New Zealand and international scholars and policy-makers to visit and work with the project and the relevant department. Expressions of interest should be directed to genome.lawpolicy@otago.ac.nz.

The project welcomes New Zealand and international collaborations, NGO support and community partnerships.

The project accepts bequests and gifts for the advancement of its research and policy development programme.

CONTACT DETAILS

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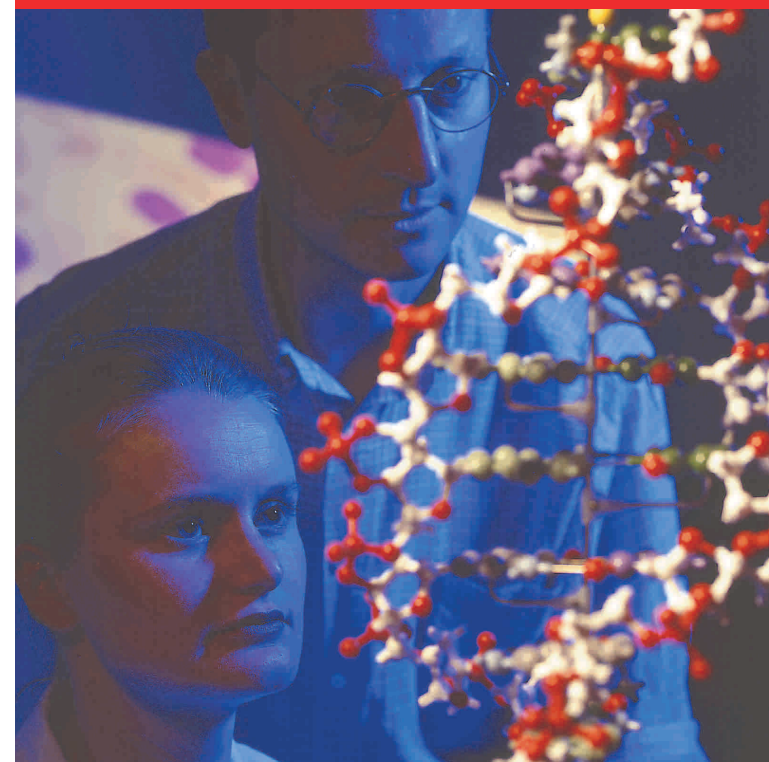
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HUMAN GENOME RESEARCH PROJECT

Te Kaupapa Rangahau Ira Tāngata

Law, Ethics and Policy for the Future



www.otago.ac.nz/law/genome

HUMANGENOME RESEARCH PROJECT

Te Kaupapa Rangahau Ira Tāngata

Law, Ethics and Policy for the Future

The Human Genome Research Project is a multidisciplinary three-year project looking at how New Zealand should respond to emerging human genetic technologies.

Led by the University of Otago's Law Faculty, with funding from the New Zealand Law Foundation, the three-year project will analyse whether, how, and to what extent, human genome-based technologies should be regulated.

The New Zealand Law Foundation initiated the project because it recognised that the rapid development of genetics research has outpaced the much-needed medical, ethical, legal and cultural debates.

Complex issues need to be dealt with, such as biotechnology and patents, genetic engineering, population screening, eugenics, ownership, data protection, human rights and indigenous populations.

New Zealand needs to have a clear direction as to where it stands on these issues so that it is in a position to be able to enjoy the benefits of the advances in gene technologies while still being able to respond to risks of harm, public concerns, perceptions and beliefs.

"As a country and as a society we need to have a clear direction as to where we stand and where we are going with these issues. We need to be in a position where we can enjoy the benefits of the advances in gene technologies, while still being able to respond to public concerns, perceptions and beliefs about its place in medicine and in our lives."

PROJECT LEADER

Professor Mark Henaghan

[THE PEOPLE]

A global, interdisciplinary approach that crosses legal, scientific, economic and philosophic boundaries is needed to understand the range of implications from emerging genetic technologies on New Zealand society and the law.

To do this, the Human Genome Research Project will tap into the expertise of the University of Otago Bioethics Centre and is supported by a team of New Zealand and international researchers in Law, Bioethics, Science, Māori and Paediatrics.

Key members of the Human Genome Research project team include:

Professor Mark Henaghan

Dean of the University of Otago Law Faculty

Internationally recognised for his legal research and writing on family law, with a particular emphasis on 'children's voices' in legal proceedings, Professor Henaghan is a pioneer of the application of interdisciplinary research (child development, psychology, paediatrics) to family law in New Zealand.

For this project, Prof Henaghan will be focusing on the relationship between families and genetic technologies, for example how the development of genetic testing affects and is used by family members for health care and reproductive purposes. He will also examine broader questions of public policy relating to accessibility and the regulation of new technologies.

Professor Donald Evans

Director of the University of Otago Bioethics Centre

A highly respected member of the international bioethics community, Professor Evans has played a key role in developing the teaching of bioethics as part of health curricula. His expertise is in demand and he has been commissioned to head up a range of research projects for public bodies, government departments and international groups.

Professor Evans is a member of the International Bioethics Committee of UNESCO and has also been invited to join a new United Nations' Ethics Commission.

Professor Stephen Robertson

Clinical Geneticist, University of Otago Dunedin School of Medicine

Chair in Child Health research at the University of Otago, Professor Stephen Robertson is a clinically active geneticist and paediatrician. He heads up the Clinical Genetics Group, Women's and Children's Health, at the Dunedin School of Medicine and works with the Central and Southern Regional Genetics Service.

Professor Robertson has a special interest in the genetic determinants of congenital malformations in humans and the ethical questions raised by the clinical use of genetics, particularly the way being able to identify genetic susceptibility to common diseases may impact on medical practice in the future.

Professor Grant Gillett

University of Otago Bioethics Centre

Dunedin School of Medicine Department of Neurosurgery

A neurosurgeon, a Professor of Medical Ethics, and a member of the Philosophy Department, Professor Gillett brings a wide ranging and particularly applicable background to the work of the Human Genome Research Project.

His interests include the philosophy of mind and the philosophy of medical ethics, while his main area of research is in bioethics where he has published on issues to do with clinical practice and the care of patients, particularly at the end of life. In his work he has emphasised the need for empowerment of patients – a concept particularly relevant to psychiatric practice.

Dr Ian Morison

Cancer Genetics Laboratory

Combining a busy research schedule with his work as a clinical haematologist, Dr Ian Morison is particularly involved with childhood disease such as childhood acute lymphoblastic leukaemia (ALL).

Although it is the most common of all childhood malignancy little is known about the role of genetics and there is emerging evidence that it usually arises before birth. Dr Morison and his research team are investigating the possible role of parent-of-origin effects in ALL.

Dr Tony Merriman

Department of Biochemistry Senior Research Fellow

By unravelling the genetics behind autoimmune disease, Dr Tony Merriman hopes there will eventually be a reasonably clear genetic signature for people who are at risk of developing conditions like rheumatoid arthritis.

He is particularly interested in using this sort of knowledge to more accurately predict things like the severity of the disease, as well as identify genes that could be potential clinical targets.

Project Manager – Richman Wee

Faculty of Law

Richman, LL.M GDART (Moral Philosophy), was the Policy Advisor at the Health Research Council of NZ and before that, taught at Waikato Law School. Over this time he has advised on health law, research ethics and public policy.

His main focus will be on the evolution of the research programme and supporting project team members in their work. Richman also has a research role, examining a systematic policy approach for genetic technologies in NZ.