

# Genome project team's "extraordinary" job

The ground-breaking New Zealand-based international research endeavour, the Human Genome Research Project (HGRP), released its final report on 4 March. Justice Minister Simon Power launched the project's third volume of *Genes, Society and the Future* – bringing to a climax nearly 3½ years of research funded by the New Zealand Law Foundation.

Those involved in the project, which traversed the many legal, ethical, medical and cultural issues surrounding the regulation of human genome-based technologies in New Zealand, had done "an extraordinary job," Justice Bruce Robertson said at the launch.

As well as praising everyone involved, Justice Robertson particularly congratulated Law Foundation Director Lynda Hagen, who had conceived the project and had ensured its continuation, and the project leader, Otago University Law Faculty Dean, Professor Mark Henaghan.

"We are all in your debt," Justice Robertson said.

He also noted that the work of the project would continue, with the Law Foundation's "wonderful" endowment of a chair in emerging technologies at Otago University.

With the release of volume three of *Genes, Society and the Future*, the project has drawn on New Zealand and overseas expertise from a range of disciplines to produce a series of reports totalling 1,800 pages.

This third part covers a range of topics, from pharmacogenetics, or so-called personalised medicine, to the implications surrounding the use of genetic testing for insurance purposes. Other topics include the impact of the patenting of genetic knowledge on research, accessing stored human tissue samples for genetic research, and issues surrounding intellectual property gained from studies of whole communities.

The report further examines preimplantation genetic diagnosis (PGD) and its implications, building on the recommendations of the project's first report, *Choosing Genes for Future Children*.

Genetic knowledge, Professor Henaghan said, was both inspiring and intimidating.

"It taps into our strongest hopes and our deepest fears. This knowledge can be used to choose the genes of future children, test for potential diseases in our genetic make-up, find the relationships between illness, genetic profile and environmental influences in a community, and design drugs which are better suited for our particular human genome," he said.

"It can also be misused to discriminate against those with certain conditions once we know their genetic code."

Professor Henaghan said the objective throughout the project had been to determine whether regulation was necessary or not.

"Our focus has been to analyse the benefits and harms from a range of perspectives and disciplines. We give each position

as fair a hearing as possible. We then take a position which is contestable and will not be accepted by everyone.

"In a democracy, this is the only way we can proceed on issues which have the potential to divide and unite us."



Key players in the Human Genome Research Project (from left) project manager Richman Wee, project director Mark Henaghan and NZ Law Foundation Director Lynda Hagen looking at the cover of the project's final report.

Professor Henaghan said the project team was hugely indebted to the New Zealand Law Foundation for enabling this research to be carried out. Like Justice Robertson, he thanked Lynda Hagen who had thought of the idea and put it out for tender, and thanked the project manager, Richman Wee, for his outstanding contribution.

"One of the strengths of the Human Genome Research Project is that it is independent of Government or any particular interested professional body," Professor Henaghan said.

"This research will give the people of New Zealand the ability to appreciate and discuss ethical

choices and will help inform policymakers in developing appropriate policy and regulatory frameworks," Lynda Hagen said.

"We recognised the need to take the initiative and explore significant areas where it appeared that the development of the law may well be lagging behind developments in biotechnological advancement."

Lynda Hagen said the Law Foundation's sponsorship had meant the HGRP had remained independent, lending significant weight to its findings and recommendations.

"It is pleasing to know that this valuable research will be able to continue with the establishment of the New Zealand Law Foundation Chair in Emerging Technologies and a new Centre for Law and Policy in Emerging Technologies within the Law Faculty at Otago."

The new centre would focus on projects relating to legal issues, regulations and policies affected by the increasingly rapid rate of technological advancements. ■



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