

# **MASTER OF LAWS**

**Law, Justice and  
New Genetic Technologies**

**Study Guide  
Semester 1, 2010  
LWN135**

# Academic Calendar

The [QUT academic calendar](#) includes the starting and finishing dates for the University's first and second semesters, and the Summer Program.

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# Introductory Guide

## PART A - UNIT OUTLINE

### LWN135 LAW, JUSTICE AND NEW GENETIC TECHNOLOGIES

<b>Credit Points:</b>	12
<b>Prerequisites:</b>	Nil
<b>Co-requisites:</b>	Nil
<b>Coordinator:</b>	Barbara Hocking
<b>Semester of Offer:</b>	Semester 1 2010 INTERNAL and EXTERNAL
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#### 1. Rationale

Our ability to test, screen and manipulate the human genome is made possible by recent technological breakthroughs in science. The science of genetics is not new, but its public profile has never been higher. Current initiatives in ~~biotechnology genetic knowledge have been~~ are often described as an international voyage of scientific discovery. The scientific findings are prompting major rethinking of concepts of law, ethics and justice ~~and. Th, the~~ the legal community faces a perpetual challenge in keeping apace ~~of the revolution in genetics.~~ This unit ~~examines the looks at some~~ legal implications ~~of this revolution~~ and charts the major responses of our legal system to modern genetics and biotechnology, with a particular focus on the patenting of biological materials once thought to be 'reserved exclusively to none'. The rationale for ~~the~~ this unit is that ~~it is clear that~~ lawyers of the ~~21<sup>st</sup>~~ 21<sup>st</sup> ~~next century will feel the impact of biotechnology in a broad sense and genetics in a narrower sense,~~ across the sweep of their practice, in areas as diverse as criminal justice, torts, human rights, medico-legal, and intellectual property. Correspondingly, scientists ~~of the next century~~ will also feel the impact of the law across in their ~~genetic discoveries and~~ endeavours. All lawyers who ~~interface will be dealing~~ with science, and justice ~~related~~ professionals will benefit from understanding advanced knowledge of the increasingly complex ~~relationship between dimensions to the interaction between~~ law and ~~modern~~ genetics.

~~genie.~~

#### 2. Aims

The aim of the unit is to achieve an overview of the major legal issues arising from new genetic technologies. The unit also aims to place those legal issues in an ethical context. At the completion of this unit, you should be able to demonstrate:

- (1) A knowledge and understanding, at post-graduate level, of the links between genetics and law, and of the key issues in criminal justice, human rights, medico-legal and intellectual property law raised by these links.
- (2) An understanding of the differences and commonalities relevant to law between human, plant and animal genetics
- (3) A knowledge of both legal and political policy ~~documents~~ dealing with the ways in which law interfaces with genetics particularly in Australia
- (4) A comprehension of the complexity of the challenges that the application of new genetics technologies poses to government and lawyers throughout the world
- (5) The capacity to analyse and apply both primary legal principles and current governmental policies in appropriate cases

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- (6) An appreciation of relevant principles of international law and the application of UNESCO's Universal Declaration on Bioethics and Human Rights (2005)
- (7) An understanding of the dynamics to the relationship between specific scientific areas such as human, plant and animal genetics, biotechnology, bio-ethics and law
- (8) An understanding of the major, and constantly unfolding, regulatory scheme in Australia and the legal issues that call upon the discipline of genetic science
- (9) Skills in legal research, particularly electronic research, time-management, and comprehension, including recognition of relevant materials, synthesis and analysis.

### **3-2. Learning outcomes**

At the completion of this unit, you should be able to demonstrate:

- (1) A knowledge and understanding of the links between law and genetics;
- (2) An understanding of the differences relevant to law between human, plant and animal genetics and of their global significance;
- (3) A knowledge of relevant national and international legal and political policy documents dealing with ways that law interfaces with genetics;
- (4) An appreciation of the human rights and ethical challenges that the applications of, and discoveries in, genetics pose for governments;
- (5) The capacity to analyse and apply both primary legal principles and current governmental policies in appropriate cases;
- (6) An understanding of the dynamics within the relationship between specific scientific areas such as human, plant and animal genetics, biotechnology, bio-ethics and law; and
- (7) Advanced written and critical analysis skills within the context of biotechnology and genetics law and high level research skills in this area.

### **4. Content**

Topics that may be covered in this unit may include issues such as:

- (1) an overview of the biotech century and the emerging biotechnical age;
- (2) differences between the disciplines of law, genetics, biotechnology and bioscience, and the extent to which they currently interact and communicate;
- (3) differences between human, plant and animal genetics relevant to law
- (4) the 'mighty gene', gene sovereignty, genome mapping and genocentrism;
- (5) legal dimensions of Human Genome Diversity Project, cultural diversity and pluralism;
- (6) ethical and legal implications of medical applications of genetic technology, pre-implantation genetic diagnosis and issues of discrimination, privacy and insurance;
- (7) genetic bases of behaviour;
- (8) the regulatory schemes in Australia and New Zealand, their recent reviews, overarching politics and policies in the Australian human, plant and animal genome context;
- (9) international law and human rights dimensions to the law and science of human, plant and animal genetics, UNESCO's Universal Declaration on Bioethics and Human Rights;
- (10) the breast and cancer gene litigation;
- (11) novel intellectual property issues raised by genetic technology, especially those relating to "ownership" of genes and genetic sequences and the arguments as to benefit-sharing.

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## 5. Approaches to Teaching and Learning

This unit will be taught in internal and external mode ~~and is - The unit will be~~ divided into select topics with prescribed reading and revision questions. It will be taught using a lecture and seminar format with student discussion and lecturer-led summaries of the main issues.

Lecture/seminar material will be available electronically, and interactive seminars will be supported through a class electronic discussion group. At the start of the course, a lab class will be arranged to demonstrate the science of genetics and obtain one's own DNA.

## 6. Assessment

### Assessment item 1:

#### Assessment name; Presentation and Film Critique (written)

**Description:** Presentation about a film that addresses genetic and law issues and a written critique on the film

**Relates to learning outcomes:** (1)-(2), (6)-(7)

**Weight: 40% (20% presentation, 20% critique (written))**

**Internal or external:** Internal

**Group or individual:** individual

**Due Date:** Presentation as decided in class: critique - by end of week 9

### Assessment item 2:

#### Assessment name: Film critique

**Description:** a short (2,000 words) critique a film of your choice dealing with a law and genetics issue

**Relates to learning outcomes:** (1) - (2), (6) - (7)

**Weight:** 20%

**Internal or external:** External students only

**Group or individual:** Individual

**Due date:** Before week 9

### Assessment item 3

#### Assessment name: Short Essay

**Description:** short (2000 words) essay appraising the *Queensland Code of Ethical Conduct for Biotechnology*.

**Relates to learning outcomes:** (1) - (2), (4) - (7)

**Weight:** (20%)

**Internal or external:** External students only

**Group or individual:** individual

**Due date:** week 9

### Assessment item 4

#### Assessment name: Major research paper

**Description:** A 4,000-5,000 word paper on topic of film critique.

**Relates to learning outcomes:** (1) - (7)

**Weight:** 60%

**Internal or external:** All students

**Group or individual:** Individual

**Due date:** end of week 13 of semester.

**Presentation and film critique (internal students)** You will be required to select one area of law and genetics where there is both at least one film and further related literary and scholarly material available to sustain a major research essay. In this first assessment item you will be required to discuss the film that relates to your topic in class in a half hour presentation for which you will include a written summary as a hand-out for the other members of class and the unit co-ordinator. Examples of such topics and films could be *saviour siblings* (*My Sister's Keeper*), *Destiny and Genes* (*Gattaca*), *Species Preservation and Genes* (*Jurassic Park*), *Personality and Genes* (*The Nutty Professor*), *Genetic Engineering and Cloning* (*The Boys from Brazil*), [Medicines for Rare Genetic Syndromes and Patents \(Lorenzo's Oil\)](#), etc. [eA creative search of the internet Movie Databank](#)

(iMDB.org) under "genes", "patents," "bioengineering," "cloning," will yield many options. The presentation should include both a film clip and critique of the chosen film, and the accompanying written summary must be no more than 2000 words. This must be completed by end of Week 9 and is an essential pre-requisite for Assessment No. 4.

**Film critique (external students):** You will be required to select one area of law and genetics where there is both at least one film and further related literary and scholarly material available to sustain a major research essay. In this first assessment item you will be required to write a scholarly critique of no more than 2,000 words. ~~Examples of suitable topics and films could be saviour siblings (My Sister's Keeper), Destiny and Genes (Gattaca), Species Preservation and Genes (Jurassic Park), Personality and Genes (The Nutty Professor), Genetic Engineering and Cloning (The Boys from Brazil), etc.~~ This must be completed before Week 9 and is an essential pre-requisite for Assessment No. 4.

**Comment [jvh1]:** Omitted because examples are listed immediately above.

**Short Essay (external students only):** You will be required to prepare a short essay (up to 2000 words) appraising the *Queensland Code of Ethical Conduct for Biotechnology*. The submission of the paper will take place during Week 9.

**Major Research Paper (all students)** You will be required to undertake a final research essay on the same topic as the presentation and critique (internal students) and the film critique (external students) that draws upon a much wider range of sources including literature, case law, statutes, policy documents, international instruments, etc. The length of the essay is to be between 4 and 5 thousand words. This final assessment is due at the end of week 13.

## 7. Resource Materials

### Prescribed Text

Luigi Palombi, *Gene Cartels (biotech patents in the age of free trade)* (Scribe Publications, Melbourne, 2009)

### Recommended Texts and Further Reading

Article I. David Koepsell, *Who Owns You: The Corporate Gold Rush to Patent Your Genes* (Blackwell Public Philosophy Series, Oxford, 2009)  
 Roger Brownsword, W R Cornish & M Llewelyn, (eds) *Law and Human Genetics - Regulating a Revolution*, Hart Publishing 1999,  
 David McKay, *Unravelling Genes*, Pearson Education, 2005, 2<sup>nd</sup> ed  
 Jeremy Rifkin, *The Biotech Century*, Jeremy P. Tarcher/Putnam, 1998  
 Moyra Bremner, *GE Genetic Engineering and You*, Harper Collins, 1999  
 Jodie Picoult, *My Sister's Keeper* (Allen & Unwin, 2005).  
 Brian Appleyard, *Brave New Worlds*, Harper Collins, 2000  
 John Avise, *The Genetic Gods*, Harvard University Press, 1998

Ian Freckelton and Kerry Petersen, *Disputes & Dilemmas in Health Law*, The Federation Press, Sydney, 2006

## 8. Risk Assessment

There are no out of the ordinary risks associated with this unit (laboratory procedures are followed for the laboratory instruction which includes the wearing of protective footwear).



## 9. Unit Coordinator

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*Dr Barbara Ann Hocking*



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## **PART B: FACULTY POLICIES**

For all relevant faculty policies consult the law school website – see:

<http://www.law.qut.edu.au/current/postgrad/>

Click on either “**School of Law Postgrad Handbook**” or “**Postgraduate School of Law Forms**” for the information you are seeking.

It is your responsibility to read and understand these policies and to ensure that you comply with them.

### **Academic Dishonesty**

Academic dishonesty, including plagiarism, is a serious breach of QUT Student Rules relating to assessment, and is of particular relevance to any unit which has a research assignment or similar assessment as an assessment item.

All instances of academic dishonesty in this unit will be dealt with in accordance with the University procedures as detailed in Chapter C of the Manual of Policies and Procedures (MOPP) and penalties may be imposed under these procedures in accordance with Student Rule 29. Student Rules are accessible from:

<http://www.qut.edu.au/admin/mopp/Appendix/append01cst.html>

Academic dishonesty procedures are accessible from:

<http://www.qut.edu.au/admin/mopp/chapC.html>

Academic dishonesty includes copying any part of another student’s work, providing copy to another student for the purposes of plagiarism, collaboration with other students which defeats the purpose of the assessment, copying information directly from books, articles or the internet without full and comprehensive acknowledgement of the source, obtaining material from a plagiarism website which provides complete papers on university topics, or similar activities.

# Study Guide

## TOPIC 1: Introductory & Contextual Issues in Law & Genetics

Date: 23 February

### Reading

- Class Handout with Online Access

### 1. Introduction

This class will outline key assessment requirements for this unit and introduce the many ways in which there are intersections between law and science, with a particular focus upon the science of genetics. It will also introduce the concept of bioethics. Many of the ever-expanding bioethical dilemmas confronting the law are now 'standard topics' in bioethics: notably abortion, euthanasia, genetics, cloning, stem cell research.<sup>1</sup> However, as bioethicist Michael Selgelid has observed, both interest and research funding tends to focus on the major first world pre-occupations precisely with abortion, euthanasia, genetics. Besides introducing the unit and outlining assessment details, in this introduction we also set genetics in context, in terms of research, in terms of science, in terms of its place vis a vis other medical and scientific disciplines, and in terms of the many contemporary bioethical dilemmas confronting the law worldwide.

### 2. Questions to consider

1. What is the background to the emergence of genetic science?
2. What is genetic science (as compared to social or physical science) all about?
3. What are the most significant contemporary bioethical dilemmas raised by genetics?
4. What does Richard Hindmarsh mean with the title of his book "*Edging Towards BioUtopia*"?
5. Why do genetic modifications and genetic engineering raise such strong responses, whether positive or negative?

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<sup>1</sup> See Michael J. Selgelid, Margaret P. Battin, and Charles B. Smith, *Ethics and Infectious Disease* (Blackwell Publishing, 2005), p. 111

## **TOPIC 2: Exploring Terminology: Genes, Genetic Engineering, Gene Therapy, Genetic Databases, Eugenics, Congenital, Genocide**

Date: 2 March

### **Reading**

- “Striving for National Fitness: Eugenics in Australia” see:  
<http://ses.library.usyd.edu.au/bitstream/2123/402/2/adt-NU2000.0015front.pdf>

### **1. Introduction**

The recent development of molecular genetics has created concern that society may experience a new eugenics. Notions about eugenics and what took place in the 1930s and 1940s are actively shaping questions about which uses of the new genetics should be considered illegitimate. This topic looks at the dominant view of eugenics and asks whether, in spite of a general condemnation of eugenics, health authorities today are trying to prevent individuals with deviant behavior from reproducing or at least from rearing children. It looks at issues arising from the risk of transmitting defective genes, synthesising that with the risk of producing undesirable social problems. The historical legacy of eugenics continues to haunt modern genetics. The debate continues whenever it is suggested that we ought as a society pursue “prevent unhappy people” policies. We ask whether past episodes of eugenics are historically specific, and whether or not modern genetics has forgotten or left behind its eugenic heritage and legacy.

### **2. Questions to consider**

1. What does the word “eugenics” connote?
2. Are there eugenic tendencies in modern genetics?
3. Why has the Nazi regime been condemned as the ultimate eugenicists?
4. Is eugenics a purely historical phenomenon and hence no longer relevant to modern debates about genetics?
5. What are our common understandings of words like gene, gene therapy, genetic engineering, genetic disability, genetic disease, genetic counselling, genoism, genetic identity, congenital, eugenics and genocide (and any others you may think relevant)?
6. What is the background to the so-called eugenics in Australia?

## TOPIC 3: Nature, Genetics, Religion, Being Human and Owning Humans

Date: 9 March

### Readings

- *Time Magazine*, November 13, 2006, 'Does God exist?' pages 35-41
- Luigi Palombi,
- <http://cgkd.anu.edu.au/menus/PDFs/Explanatory%20memorandum%2006.11.06.pdf>

### 1. Introduction

It has been said that the 'new genetics' is 'diametrically opposed to the mechanical conception of nature that has dominated the West for hundreds, if not thousands, of years.'<sup>2</sup> The many bioethical dilemmas outlined so far pose particular problems for their close relationship and overlap with strongly held moral and religious beliefs, even in predominantly secular societies – and particularly so where governments act to support them through funding and related support (Dayton, 2006, 40). Where religious beliefs are affronted by these new scientific capabilities, it is perhaps inevitable that the law will be called upon by way of challenge to individual reproductive choices, no matter how invasive of the privacy of the family or the individual seeking to reproduce. Biology long ago explained what it is to be human yet the links with religion persist to this day. Indeed, DNA has captured the imagination to the extent that Neame contends that in answer to the question, "what is man?":

'There is evidence that, at least in the media and perhaps even in public consciousness, anthropology is being increasingly outgunned by the science of human genetics, and those theories, such as behavioral genetics, evolutionary psychology and socio-biology, which claim to derive their legitimacy from the study of human genetics' (Neame, 2003, 53).

Where once we looked to the stars for explanations on the origins of human conduct, we now turn to gene sequencers. Enthusiasts in biotechnology believe that individual genomes are not only our 'linkage to life'<sup>3</sup> but can unlock 'the Mystery of Life.'<sup>4</sup>

<sup>2</sup> Ho, M.W., *Genetic Engineering: Dream or Nightmare? The Brave New World of Bad Science and Big Business* (Gateway Books, UK, 1998)

<sup>3</sup> Richard Hindmarsh and Geoffrey Lawrence, 'Recoding Nature Deciphering the Script' Chapter 1 of Richard Hindmarsh and Geoffrey Lawrence (eds) *Recoding Nature: critical perspectives on genetic engineering* (UNSW Press, Sydney, 2004), 23-40, at p. 24, citing the International Congress of Genetics Melbourne 2003 (Conference theme).

Mary Shelley's *Frankenstein* takes on new and alarming meaning. 'Dr Frankenstein's unnamed monster may well be merely a metaphor for humankind's dangerous flirtation with science (given new meaning through recent breakthroughs in genetic engineering).'<sup>5</sup> The popular representation of science in general becomes '...a form of theatre, a theatre of representation – a public performance with actors, narratives, plots and metaphors.'<sup>67</sup> For modern biology, we see that the 'central characters exemplify the script of the proponents,'<sup>8</sup> replete with an element of fear or, at least, foreboding. Nevertheless '... because of the problems of that script and its language, many have difficulty hearing, believing, understanding, or agreeing with it; it appears as a theatre of the absurd.'<sup>9</sup>

The scientific pursuit of 'genes for' certain diseases and disorders attracts powerful and romantic language. The sociologist Dorothy Nelkin describes the human genome project as offering us the 'essence of personal identity'—the 'molecular vision of life' and the 'set of instructions for making a human being.'<sup>10</sup> Our fascination with being decoded – an interesting theatrical representation in itself - has also gripped the creative visions of geneticists. Steve Olson states that: 'The story written in our DNA is one of great promise, not peril'. He explains this promise in euphoric language:

It's one of the best stories you'll ever hear. It has adventure, conflict, triumph, and sex – lots of sex. It ranges from jungles to deserts to icy plains, across generations and thousands of years. It's the story of us, from our humble origins on the savannas of Africa to a position of unprecedented mastery over our own future.<sup>11</sup>

Yet that future comes at a cost as these explanations are not undisputed. In recent years, creationism has taken on a new currency as the 'spiritual progenitor of "Intelligent Design" (I.D.), a "scientifically worded attempt to show that blanks in the evolutionary narrative are more meaningful than its very convincing totality."<sup>12</sup> In the United States, these matters have reached the courts, with the famous "Monkey case" (the trial of teacher John Scopes for teaching evolution) the best-known, and surprisingly recent, example. In 2005, "I.D" lost some of its force when a federal judge dismissed it as pseudoscience unsuitable for teaching in Pennsylvania schools.

## 2. Questions to consider

1. Why does Dawkins consider the question of whether there exists a supernatural creator, a God, one of the most important that we have to answer?
2. Why does Dawkins believe this to be a scientific question and what does Collins say as to that?

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<sup>4</sup> Ibid., citing *The (Brisbane) Sunday Mail*, 2000

<sup>5</sup> Gerry Turcotte *Border Crossings Words and Images* (Brandl and Schlesinger, Blackheath, NSW, 2004), p. 68

<sup>6</sup> Hindmarsh and Lawrence, op. cit., p. 40

<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

<sup>9</sup> Ibid.

<sup>10</sup> Nelkin, D. 2001. Molecular Metaphors: The Gene in Popular Discourse, *Nature Reviews* 2: 555-559, p. 555; citing B. Wallace, *The Search for the Gene*, Cornell University Press, Ithaca, New York.

<sup>11</sup> Steve Olson, *Mapping Human History*, p. 7

<sup>12</sup> God vs Science, *Time* November 13, 2006, p. 35

3. Why does Collins argue that humanity's moral sense is both a gift from God and a sign that God exists?
4. What were the key issues in and the outcome of the "Monkey trial"?



## TOPIC 4: DNA, Biotech Markers and the “Crime Gene”

Date: 16 March

### Readings

- Gregor Urbas, ‘DNA Evidence in Criminal Appeals and Post-Conviction Inquiries: are New Forms of Review Required?’ [2002] *Macquarie Law Journal* 6
- Kirsten Edwards, “Ten things about DNA contamination that lawyers should know” (2005) 29 *Crim LJ* 71
- *R v Butler* [2009] QCA 111 see: link on <http://www.austlii.edu.au>

### 1. Introduction

This topic will deal with the collection of DNA samples from crime scenes and suspects and the ways in which DNA can identify the guilty and exonerate the innocent. We will consider the controversies that have surrounded uses of DNA in criminal trials and some high profile cases. The issue of wrongful convictions will be canvassed, drawing upon some of the work of Griffith Law School’s “Innocence Project”. Issues of DNA contamination as well as the arguments that DNA provides us with the paradigm, epitome and exemplar of scientific expert evidence, will be discussed, using case examples, including:

1. Cases that demonstrate the increasing acceptance of DNA
2. Ways in which DNA is argued in courts in Australia, Canada, and UK
3. Issues arising with testing and sampling for crime purposes
4. Accreditation of laboratories and the purposes of accreditation

### 2. Questions to consider

1. What are the main questions that criminal defence counsel should ask with respect to DNA evidence?
2. What might be meant by a comment about “the nullifying effects of human biases and suggestibility”?
3. Why might scientists consider that the ‘concept of a random control group ... was one of science’s most important insights’?
4. Why are conclusions about correlation and causation especially prone to error in criminal trials involving complex scientific evidence?
5. What errors have occurred in Australian laboratories re DNA?
6. If DNA is 99.9% conclusive a match, can a criminal lawyer tell their client they may be found not guilty?

7. What is the relevance of identical twins to uses of DNA crime matching?
8. What does the Jama case tell us about juries, DNA and family alibis?

## TOPIC 5: Informational Issues of Privacy and Discrimination

Date: 23 March

### Readings

- Chapter in text to be advised
- Report and Papers of the Genetic Discrimination Project: see <http://www.gdproject.org/reports/index.php>
- NH&MRC Genetic Discrimination: See [http://www.nhmrc.gov.au/your\\_health/egenetics/ethics/discrimination.htm](http://www.nhmrc.gov.au/your_health/egenetics/ethics/discrimination.htm)
- Genetic Discrimination: 'Unfair or Natural?' Time Magazine, 8 May 2008: see

<http://www.time.com/time/magazine/article/0,9171,1738513,00.html>

- Anne Mainsbridge, 'Employers and Genetic Information: A New Frontier for Discrimination' *Macquarie Law Journal* (2002). Accessed at:

<http://www.austlii.edu.au/cgi-bin/disp.pl/au/journals/MqLJ/2002/3.html?query=genetic%20technology>

### 1. Introduction

Following on from uses of DNA in crime, is the related non-criminal use of genetic information in the workplace and insurance. Rapid advances in genetic technology have resulted in an increasing number of tests becoming available to detect genes associated with disease. However, in one view, genetic tests and the information they are able to reveal provide a classic example of 'technology's double edged sword'. An enhanced potential for diagnosing, treating and possibly even preventing many forms of disease has been accompanied by significant potential for abuse. By making it possible to differentiate between individuals on the basis of their genetic makeup, genetic testing has effectively opened up a new frontier for discrimination. There is increasing concern, and even growing evidence to suggest, that individuals who have undergone genetic testing may subsequently be discriminated against on the basis of

their genetic makeup by third parties, including insurers, employers and service providers.

This topic will focus on the threat of genetic discrimination in the area of insurance and the relatively unexplored issue of genetic discrimination in employment. It will be shown that the growing evidence of genetic discrimination by employers, along with the potentially serious consequences of such discrimination can no longer be ignored and that some form of legislative response is now imperative. It will look at these dilemmas in the context of recent changes to industrial relations, particularly Work Choices.

## **2. Questions to consider**

1. What are the major individual, family and societal dimensions of genetic discrimination?
2. Should insurers be entitled to access to genetic test Information?
3. What is the relevance of the limited predictive value of much genetic information in the formulation of appropriate responses to genetic discrimination and the limitations of the Disability Discrimination Act?
4. Should one be able to refuse a workplace-related genetic test, in the same circumstances as one can refuse the taking of a DNA sample?
5. What are the implications of the new Work Choices legislation in the context of employer and employee negotiations

## **TOPIC 12: Final Summary and Feedback on Research Papers**

Date: 25 May

This topic is dedicated to a focus upon the finalisation of the research essays.

## **TOPIC 6: The Gene Technology Act (Cth) and Related Australian State Legislation: Action, Implementation & Critique**

Date: 30 March

### **Readings**

- Website of the Office of the Gene Technology Regulator: see <http://www.ogtr.gov.au/>
- Charles Lawson and Richard Hindmarsh, 'Legitimising Regulatory Decision-Making about Genetically Modified Organisms under the Gene Technology Act 2000 (Cth)' (on OLT)

### **1. Introduction**

This topic contends that the Australian Gene Technology Act 2000 (Cth) (the GT Act) in its current structure and its current implementation is failing to provide the kinds of assurances necessary to address the asymmetric information in the markets for genetically modified (GM) organisms (GMOs) and GM products. Recent analyses of the liability regime in the GT Act suggests that 'gaps' in the existing liability arrangements create the potential for producers and marketers (including the supply chain handlers) of GMOs, who are best placed to know and be aware of the potential and scope of the possible risks of GMOs and their consequences, to escape liability. Those analyses of the rigor of decision making under the GT Act challenge the suitability of 'science' alone as a basis for regulatory decision-making to deliver a credible assurance (openness and transparency) about the safety of GMOs and GM products. Their solution is to acknowledge the subjective judgments and construct the regulatory scheme in a way that does not characterize community concerns about the risks of GMOs as a technical, scientific matter within the expertise of experts and free of political and other non-science concerns and impose a scheme of strict liability. By failing to address these sorts of concerns the GT Act and its implementation will fail to provide the kinds of assurances necessary to address the asymmetric information in the markets for GMOs (and GM products). The consequences will be ever decreasing market price, market quality and market size.

### **2. Questions to consider**

1. What is the basic structure of the regulatory regime in Australia?
2. What have been the key criticisms of this mode of regulation?
3. Are the criticisms of the Review Committee's findings justified?
4. What are Lawson and Hindmarsh's specific criticisms?
5. What do Lawson and Hindmarsh mean when they talk about subjective judgments and why do they consider assurances are necessary?
6. What is the optimal regulatory path for Australia in the future?

## TOPIC 7: The UNESCO Declaration and Search for International and Universal Values and Responses to Genetics

Date: 20 April

### Readings

- Luigi Palombi

<http://cgkd.anu.edu.au/menus/PDFs/Explanatory%20memorandum%2006.11.06.pdf>

- Chapters in text to be advised

### 1. Introduction

There are both real and perceived dangers in the science of human genetics. So it is that human rights scholar Conor Gearty has articulated what he considers the ‘real human rights dilemmas about genetic technology.’<sup>13</sup> And as Greely says, ‘Different cultures react differently to various human biological enhancements’,<sup>14</sup> just as they do to the many other biological and genetic developments currently proceeding apace, such as “designer babies”, etc. A question, typical of criminology, emerges which is also apt for the impact of modern genetics on law and justice:

‘What happens to the conceptual apparatus of criminology and how salient are its taken-for-granted terms – crime, law, justice, state, sovereignty – at a time when global change and conflict may be eroding some elements at least of the international framework of states it has taken for granted?’<sup>15</sup>

Then there are the problems of practicality in a global world. With the ban on stem cell cloning in Australia, there was increasing evidence of moves by scientists to procure their stem cells in Singapore, where it was not prohibited. With the ban on posthumous conception in England, some women travelled to Belgium, just as Irish women used to travel to England when abortion was illegal in Ireland. Our capacity to travel is putting more and more pressure on the need for international principles in the context of health. These situations all cause us to confront the limitations of sovereignty and national regulation in the globalized genetics environment. One solution to cultural variation is to seek universally acknowledged principles: bioethical incarnations of “natural” law. It became widely acknowledged that ultimately these dilemmas could only be resolved through the formulation of universal principles. Those can be found in UNESCO’s Declaration on Bioethics, and

<sup>13</sup> Conor Gearty, *Can Human Rights Survive?* (Cambridge University Press, 2006), P. 148

<sup>14</sup> Henry T. Greely, ‘Regulating Human Biological Enhancements: Questionable Justifications and International Complications’ in 87-110, at p. 106

<sup>15</sup> Russell Hogg, ‘Criminology beyond the nation state: global conflicts, human rights and the ‘new world disorder’, in Carrington, K., and Hogg, R. (eds) *Critical Criminology: Issues, debates, challenges* (Willan, Devon, 2002), p. 195

will continue to unfold as the biological revolution proceeds apace. Besides those mentioned here, there will be many more such dilemmas before the Anglo American courts over the next decades, fuelled by the rapid pace of medical and reproductive change, and all calling upon “one of the great civilizing achievements of the modern era”<sup>16</sup>: human rights law. By adopting in October 2005, the Universal Declaration on Bioethics and Human Rights, UNESCO has demonstrated its full capacity as a UN organisation to elaborate within 2 years a universal instrument which takes into account both cultural diversity and pluralism. This topic will provide a detailed and critical approach to the UNESCO declaration.

## 2. Questions to consider

1. What are some of the major human rights dilemmas arising from genetics?
2. What has been the international response to the claims of eugenics?
3. Are there clear and justifiable distinctions between those past uses and current uses?
4. What are the key principles behind and the significance of the UNESCO Declaration on Bioethics and Human Rights?

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<sup>16</sup> Gearty, *op. cit.*, p. 1

## **TOPIC 8: The Human Genome Diversity Project, Patenting, Intellectual Property and the Concept of Bio-Piracy**

Date: 27 April

### **Readings**

- Joseph Vogel: 'A Proposal Based on the "Tragedy of the Commons": A Museum of Bio-prospecting, Intellectual Property Rights and Public Domain' (on OLT)

### **1. Introduction**

Continuing the human rights theme, this topic turns to the views of Joseph Vogel, who believes that biopiracy of Indigenous resources has been widespread in the genetic resources context. Joseph Vogel argues that once one recognizes genetic resources as literally information, it does not matter that the resources exited the countries of origin before 1993, the date when the Convention on Biological Diversity entered in force as international law. Vogel builds upon the work of Paul Oldham who has tracked and documented millions of patents based on value added to genetic resources. The access to almost all such genomes was without prior informed consent. When recognised as information, the only part of a genome that would not require prior informed consent are those metabolites or stretches of DNA for which value was added and patented before the ratification of the CBD in 1993. This means that the rest of the genome for accessed species in *ex situ* collections can still be claimed by the countries (NB plural) of origin. The resounding implication according to Joseph Vogel is that bio-piracy is occurring on a vast and almost unimaginable scale throughout the world.

### **2. Questions to consider**

1. How does one define biopiracy? Is there an internal contradiction in the definition?
2. Genetic resources were first defined in the Convention on Biological Diversity (CBD) as hereditary units and then amplified to include metabolites. To what extent can one further amend the definition to include the phenotype?
3. Is sovereignty over genetic resources compatible with fair and equitable sharing of benefits as required by various articles of the CBD?
4. Will Certificates of Origins be the solution to Access and Benefit-Sharing (ABS)? Or will they aggravate the problem of insignificant royalties? What are the advantages of disclosure of species in a patent application without disclosure of country of origin?



## TOPICS 9 and 10: Patenting of Biological Materials – the Monopolization of Nature?

Date: 4 May AND 11 May

### Readings

- Chapters in Text to be advised

### 1. Introduction

This topic deals with one of the most problematic areas of law in the context of biotechnology and genetic science: patenting and intellectual property. This raises the issue of whether it is appropriate to patent the laws of nature, physical phenomena and abstract ideas. Prior to the 1970's few cases involved patenting non-human organisms as naturally occurring organisms were not considered patentable. Yet since that time the range of patentable material has spiralled. There are strongly put arguments that the human genome is not appropriate for this form of ownership and monopolization and that intellectual property is not a workable paradigm in this regard. Modern fears are also being raised in the security context, including uses of patents in economic warfare and the ways in which such property rights interact with national security. In this topic after an overview of the history of Anglo-American patent systems and analysis of patent monopolies versus free trade, attention can also be paid to the concerns uniting policy-makers in their concern for national and international security: infectious disease and bio-terrorism. In the midst of the 'war on terror,' people in the countries of "The Alliance of the Willing" were alerted to the possibility of biological warfare attacks which have 'often been dismissed as science fiction or as too immoral as to be beyond imagination'.<sup>17</sup> Given the exposés through the mass media since the onset of the "war on terror," people are less reluctant to dismiss biological warfare as the stuff of Hollywood fantasy, for in fact, 'biological weapons pose by far the greatest threat'<sup>18</sup> of the proliferation of nuclear, chemical and biological weapons of mass destruction. The fear is now that:

'... the revolution in biology could be misused in offensive biological weapons programs directed against human beings and their staple crops or livestock.'<sup>19</sup>

The dilemma of research that may generate knowledge with the potential for harmful as well as beneficial applications is at the heart of Eric Drexler's argument in *Engines of Creation*, where he supports the unrestrained development of nanotechnology purely on the basis of the conflict potential of (molecular) nanotechnology:

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<sup>17</sup> Claire M. Fraser and Malcolm R. Dando, 'Genomics and future biological weapons: the need for preventive action by the biomedical community' (2001) 29 *nature genetics* 253-256

<sup>18</sup> *Ibid.*, p. 253

<sup>19</sup> *Ibid.*

“The unilateral suppression of nanotechnology and AI, in contrast, would amount to unilateral disarmament in a situation where resistance cannot work. An aggressive state could use these technologies to seize and rule (or exterminate) even a nation of Gandhis, or of armed and dedicated freedom fighters.”<sup>20</sup>

## 2. Questions for consideration

1. What were the key findings of the *Chakrabarty* case?
2. Should laws of nature, physical phenomena and abstract ideas be patentable?
3. David Koepsell in *Who Owns You?* Asserts that the developing case law in the area of intellectual property rights in one’s genes is ‘a rather muddled area of jurisprudential philosophy’: why so; what does he mean by this?
4. If there was an urgent need for access to a particular vaccine that was subject to a patent, what measures are available to put the patent on hold in the interests of public health?
5. Koepsell also maintains that the law has attempted to deal with an object which it was ‘ill-prepared’ to come to grips with, either scientifically or philosophically, and argues further that lawyers and judges have shown that they do not consider the long-term effects of patenting genes: do you agree?
6. What does Palombi mean by ‘the monopolization of nature’?

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<sup>20</sup> Eric Drexler, *Engines of Creation* (1986), Chapter 12.

## TOPIC 11: Breast and Cancer Gene Litigation

Date: 18 May

### Readings

- Chapter in text to be advised
- Sally Sheldon, 'Gender Equality and Reproductive Decision-Making' (2004) *Feminist Legal Studies* 12: 303-316

### 1. Introduction

In both Australia and the USA there has been a recent re-activation of the abortion debate, and in Australia, there has recently been a debate as to the availability of the "abortion drug", RU486. Increasingly, the common law courts are being asked to determine disputes over biology where there can be no happy outcomes and where one gender appears as a "winner takes all". A recent example is the attempt to use The Human Fertilisation and Embryology Act 1990 (UK) in a woman's controversial quest for access to her stored embryos, a quest denied her by her former partner's withdrawal of consent. With the male's standpoint upheld – the refusal to allow this former partner to produce the child - the woman now faces an inevitably childless future, at least in terms of her own biological children. Similarly Diane Blood faced a biologically childless future but was able to move to Belgium to procure a baby using her dead husband's sperm. The deliberate creation of "saviour siblings" has awakened fears of "designer babies" which many fear will lead to allowing parents to use embryo testing to choose other characteristics of the baby, such as eye colour and sex. Related issues include genetic secrets and genetic privacy and whether genetic information ought receive protection as a form of personal health data. Given genes 'run' in families, to what extent ought the information, for example, during genetic counselling, be kept secret? Commercialisation issues again arise: many women donated tissue for the purpose of research into breast cancer yet with the discovery of the genetic links, a diagnostic test was developed that was not affordable to many of those women. Myriad patented a cause of human disease in the form of a defective gene. Two USA patents brought this about but litigation brought by the Marie Curie Institute over the patent over the gene, through the European Patent Office prompted reconsideration. There has been related litigation over the genetic-cancer links. This topic looks at the legal, philosophical, feminist and ethical dilemmas arising from the many multi-faceted ways in which genetics features particularly in women's lives.

### 2. Questions to consider

1. What are the major feminist dilemmas arising from genetic science?
2. How does the potential inherent in reproductive technology intensify the gender issues that are so prominent in medical ethics literature?
3. What are the major arguments pro and con about "saviour siblings"?

4. How do “saviour siblings differ morally and legally from “designer babies”?
5. Why does Sheldon suggest that the facts in Evans represented a ‘seemingly intractable dilemma’?
6. How might genetic information be used to discriminate in the workplace?
7. What was the effect of the patent granted to Myriad?
8. Why does Palombi refer to the “gene wars” and what are they?
9. What were the key issues and outcome in the breast cancer litigation?

## **TOPIC 12: Final Summary and Feedback on Research Papers**

Date: 25 May

This topic is dedicated to a focus upon the finalisation of the research essays.

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