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GUEST EDITORIAL – *Sonia Allan*

Donor conception, secrecy and the search for information – *Sonia Allan*

Donor conception has historically been shrouded in secrecy. Such secrecy has been underpinned by social views and legal issues concerning the adults involved in the process – the donor, the recipient parent(s), and, at times, the doctor. However, there is increasing recognition of the need to focus upon donor-conceived people’s interests and rights to have identifying and non-identifying information about their donors. This editorial examines issues raised in relation to information release, while also introducing some of the arguments presented by other authors in this Special Issue of the JLM. It also considers recent Australian federal and State government inquiries that have favoured information release and the former Victorian Infertility Treatment Authority’s service model to support people in the process of information access and release. While there has been a clear shift to favouring openness and honesty, legislative action is still required to ensure the balancing and realisation of people’s interests. 631

LEGAL ISSUES – *Danuta Mendelson*

Decriminalisation of abortion performed by qualified health practitioners under the Abortion Law Reform Act 2008 (Vic) – *Danuta Mendelson*

In 2008, the Victorian Parliament enacted the *Abortion Law Reform Act 2008 (Vic)* and amended the *Crimes Act 1958 (Vic)* to decriminalise terminations of pregnancy while making it a criminal offence for unqualified persons to carry out such procedures. The reform legislation has imposed a civil regulatory regime on the management of abortions, and has stipulated particular statutory duties of care for registered qualified health care practitioners who have conscientious objections to terminations of pregnancy. The background to, and the structure of, this novel statutory regime is examined, with a focus on conscientious objection clauses and liability in the tort of negligence and the tort of breach of statutory duty. 651

MEDICAL ISSUES – *David Ranson*

Excited delirium syndrome: A political diagnosis? – *David Ranson*

“Excited delirium” has become increasingly recognised as a medical entity that is typically associated with individuals suffering from a mental illness and/or affected by a variety of stimulant-type drugs. Because the diagnostic label has been used in association with situations of violence on the part of the person affected, and this has included circumstances where chemical and electrical as well as physical restraint has been applied by law enforcement personnel, the diagnostic entity has come to be reviewed by a variety of courts and tribunals. There is considerable debate in medical circles as to the scientific validity of such a “diagnosis” but there appears to be some medical and therapeutic value in clustering the relevant signs and symptoms under such a label. At the same time, using such a term in relation to deaths associated with circumstances where individuals are restrained could be seen as a way of deflecting the investigation of such deaths away from the actions of law enforcement personnel. 667

BIOETHICAL ISSUES – *Grant Gillett*

The evolution of informed consent – *Grant Gillett and Simon Walker*

Informed consent and the changes in what is expected over the 21st century provide an instructive case study of the mutual influence on one another of medical law and medical ethics. Over the years we have moved from a doctor-centred standard to a patient-centred standard and from a one-size-fits-all patient-centred standard to a more individual requirement that engages with the needs of a particular patient. It is unreasonable to expect those changes to be reflected in anything less than an extended conversation in which the health care professional gives out some version of what a reasonable patient would expect to hear from an informed health care professional and then responds to the patient's questions as informatively and helpfully as he or she can. It is therefore convenient to refer to spontaneous and responsive disclosure as a very concrete implementation of the health care professional-patient partnership that is contemporary health care and at the heart of health care ethics.

673

NURSING ISSUES – *Kim Forrester*

Nurses, midwives and the requirement for “appropriate” professional indemnity insurance – *Kim Forrester*

The *Health Practitioner Regulation National Law Act 2009* (the National Law) imposes the obligation on nurses and midwives to have appropriate professional indemnity insurance coverage as a condition of applying for, or renewing, their registration to practise in Australia. The National Law also empowers the Nursing and Midwifery Board of Australia to develop a registration standard and guidelines in relation to professional indemnity insurance and to enforce compliance through the registration process. Though not previously a requirement for their registration, nurses and midwives must now understand the nature and extent of the professional indemnity insurance under which they practise and declare that they will not practise their profession unless they have appropriate professional indemnity insurance arrangements which cover the full scope of their practice. This column provides an overview of the obligations and responsibilities imposed on nurses and midwives under the National Law and the Nursing and Midwifery Board of Australia's registration standard and guidelines. It is imperative that nurses and midwives understand the National Law provisions and the standard and guidelines developed by the Board before making decisions about their professional indemnity insurance and self-declaring that they have “appropriate” professional indemnity arrangements in place.

678

MEDICAL LAW REPORTER – *Thomas Faunce*

A bad trip for health-related human rights: Implications of *Momcilovic v The Queen* (2011) 85 ALJR 957 – *Tim Vines and Thomas Faunce*

Momcilovic v The Queen (2011) 85 ALJR 957; [2011] HCA 34 arose from a prosecution for drug trafficking brought under the *Drugs, Poisons and Controlled Substances Act 1981* (Vic). The Australian High Court held that the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (the Charter) validly conferred a power on the Victorian Supreme Court and Court of Appeal to interpret legislation in a manner consistent with a defined list of human rights. By a slim majority it also held that the Charter validly created a judicial power to “declare” a law inconsistent with one or more enumerated human rights. In reaching its decision, however, the majority supported a narrow interpretation likely to undermine the intended capacity of the Charter to act as a remedial mechanism to reform laws, regulations and administrative practices which infringe human rights and

freedoms. Although *Momcilovic* involved interpretation of a specific State human rights law, the High Court judgments allude to significant problems should the Federal Government seek to introduce a similar Charter-based human rights system. *Momcilovic*, therefore, represents a risk to future efforts to develop nationally consistent Australian human rights jurisprudence. This has particular relevance to health and medically related areas such as the freedom from torture and degrading and inhuman treatment and, in future, enforceable constitutional health-related human rights such as that to emergency health care. 685

LETTER TO THE EDITOR AND THE EDITOR’S RESPONSE

Epistemology and the ethics of homœopathy: A response to Freckelton – *David Levy and Ben Gadd* 699

The editor’s response – *Ian Freckelton* 704

ARTICLES

Accessing donor conception information in Australia: A call for retrospective access – *Damian Adams and Caroline Lorbach*

Donor conception practices in Australia have left thousands of donor-conceived people, their families and gamete donors bereft of information. The lack of a nationally timeline-consistent approach to information access has driven these people to seek support and information from self-help groups, online communities and even their own DNA. This article examines the historical perspective of information access and how progress is being made through lobbying and public awareness. To determine the current status of information availability, fertility clinics around Australia were surveyed. It is argued that current practices continue to fail donor-conceived people, their families and gamete donors, and that until all donor offspring are afforded the right to know their genetic family history, they will continue to suffer discrimination, and potentially risk psychological and physical trauma. 707

Information rights and donor conception: Lessons from adoption? – *Richard Chisholm*

This article reviews the Australian experience in providing information rights for people separated through adoption, and considers its relevance in adjusting the competing interests of those involved in donor conception. The Australian laws, which differ from State to State, create information rights for adults who have been adopted, and also – with more qualifications – for other family members, such as birth parents and siblings. Some laws also seek to protect privacy, notably by use of the “contact veto”. The author argues that the review of the Australian laws provides strong support for the rights of donor offspring, when adult, to information about their genetic origins. It also raises important questions about the rights and interests of other family members involved in donor conception, and how they might be accommodated. 722

Donor-conceived individuals and access to information about their genetic origins: The relevance and role of rights – *John Tobin*

The discourse of rights has increasingly been used to frame debates about access to information for donor-conceived individuals. This article seeks to clarify the moral and legal basis upon which human rights are relevant to this issue. It outlines the elements of a substantive rights-based approach which is then used to resolve the competing rights of a donor and a donor-conceived individual. Three arguments are offered. First, donor anonymity must be prohibited prospectively and donor-conceived individuals must be entitled to information about their genetic parents. Secondly, a context-sensitive

application of a human rights-based approach allows retrospective access to non-identifying information but precludes retrospective access to identifying information where a donor wishes to remain anonymous in circumstances where anonymity was guaranteed at the time of donation. Finally, despite this finding, a rights-based approach requires states to actively encourage such donors to consent to the release of identifying information and to take reasonable steps to support donor-conceived individuals in circumstances where donors refuse to provide their consent. 742

Keeping mum about dad: “Contracts” to protect gamete donor anonymity – Anne Rees

This article considers the legal status of so-called contracts for anonymity between fertility clinics and donors of gametes that were made in the period before legislation authorising disclosure. It notes that while clinics frequently cite the existence of these “contracts” to argue against retrospective legislation authorising disclosure of the donor’s identity, they may be nothing more than one-sided statements of informed consent. However, the article notes that even if an agreement between a donor and a clinic is not contractual, it does not follow that a person conceived through assisted reproductive technology has any right of access to the identity of the donor. The writer has not been able to locate examples of written promises by the clinics promising anonymity. There are written promises by the donors not to seek the identity of the recipients. These promises do not bind the resulting offspring nor do they appear to be supported by consideration. The article suggests that the basis for any individual donor to restrain a clinic from revealing their identity may be found in promissory estoppel. Nevertheless, there is no real issue in Australia concerning clinics revealing these details absent legislative authority. The issue is whether parliaments will legislate to authorise the disclosure. The article notes that it would be rare for parliaments to legislate to overturn existing legal contracts but suggests that the contract argument may not be as strong as has been thought. 758

Donor-conceived people’s views and experiences of their genetic origins: A critical analysis of the research evidence – Eric Blyth, Marilyn Crawshaw, Lucy Frith and Caroline Jones

This article reports on a systematic review of English language, peer-reviewed publications from 13 empirical studies with donor-conceived children and adults regarding their experiences and perceptions of donor conception. A total of 19 articles that met the inclusion criteria were reviewed. These were identified by means of a bibliographic search of four electronic databases for the period 1990-2011 and supplemented by the authors’ personal knowledge of work in this field. No reports from such studies appeared prior to 2000, and more than half have been published since 2008, demonstrating the relative novelty of research in this field. Much of the reviewed research evidence concerns individuals conceived through sperm donation conducted under a regime promoting both anonymity and non-disclosure. Consequently, there is little research that pertains to individuals conceived through other forms of collaborative reproduction, nor to those conceived under arrangements and regimes in which early parental disclosure is both advocated and practised and the identity of the donor and of other genetic relatives may be accessible to donor-conceived individuals. The studies consistently report that most donor-conceived people have an interest in securing information about their genetic and biographical heritage – more information than most of them have been able to obtain. Although a number of methodological limitations in the research base are identified, the authors conclude that the evidence is sufficiently robust to promote the implementation of policies and practices that promote transparency and openness in collaborative reproduction, thus reflecting the importance of maximising future choices and opportunities for donor-conceived people. 769

Legal parent versus biological parent: The impact of disclosure – Naomi Cahn

This article addresses arguments regarding disclosure of information to donor-conceived individuals, showing that disclosure is entirely different from the recognition of parental rights and responsibilities for the gamete providers. It argues that disclosure of information is not equivalent to saying: “donors are parents”. Instead, information release simply provides a basis for donors, donor-conceived individuals and recipient parents to exchange information about themselves. When a jurisdiction enacts laws that provide for such information release, these statutes are distinct from any other legal rights and responsibilities for any members of the donor-conceived community. In its first section, the article briefly explains the means for determining legal parentage before reviewing research on how parents tell their children about their means of conception. Next, it explores studies of why members of the donor-conceived world search, providing an empirical basis for the claim that disclosure does not equal parenthood. The article explores concerns about information release, and, in the final section, suggests possible approaches for protecting the rights of donor-conceived people while reinforcing the legal separation between social and biological parents.

790

Donor conception legislation in Victoria, Australia: The “Time to Tell” campaign, donor-linking and implications for clinical practice – Louise Johnson, Kate Bourne and Karin Hammarberg

The State of Victoria in Australia was one of the first jurisdictions in the world to introduce legislation regulating donor conception. Under the *Infertility (Medical Procedures) Act 1984* (Vic), donor-conceived people, aged 18 years and over, parents of children under 18 years, and donors gained the right to apply for the release of identifying information about each other recorded in a Central Register. As a result, of this and subsequent legislation, services providing donor treatment were obliged to change clinical practice relating to recruitment of donors, counselling of donors and recipients and record-keeping. Since this legislation was introduced in 1988, over 5,000 donor-conceived children have been born and in 2006 the first 100 of these children reached the age of 18. The Victorian Infertility Treatment Authority (ITA) conducted a public education campaign to provide information and support to people affected by the legislation. This article describes clinical practice changes prompted by legislation, the “Time to Tell” campaign and the service model developed for linking parties on the donor registers. The Victorian experience demonstrates that laws allowing the parties involved in donor conception access to information about each other must be accompanied by changes to clinical practice, public education about the implications of the laws, and services to meet the needs of those seeking information relating to donor conception and those contacted as a result.

803

Regulating assisted reproductive technologies in Victoria: The impact of changing policy concerning the accessibility of in vitro fertilisation for preimplantation tissue-typing – Malcolm K Smith

On 1 January 2010, the *Assisted Reproductive Treatment Act 2008* (Vic) came into force. The legislation was the outcome of a detailed review and consultation process undertaken by the Victorian Law Reform Commission. Arguably, the change to the regulatory framework represents a significant shift in policy compared to previous regulatory approaches on this topic in Victoria. This article considers the impact of the new legislation on eligibility for reproductive treatments, focusing on the accessibility of such services for the purpose of creating a “saviour sibling”. It also highlights the impact of the Victorian regulatory body’s decision to abolish its regulatory policies on preimplantation genetic diagnosis and preimplantation tissue-typing, concluding that the regulatory

approach in relation to these latter issues is similar to other Australian jurisdictions where such practices are not addressed by a statutory framework. 820

Challenging Australia’s “closed” model of neonatal care: The need for reform following *Re Baby D (No 2)* – Michael Williams, John Chesterman and Philip Grano

The withdrawal or withholding of life-sustaining treatment to compromised newborns is a subject of controversy in countries where there is now highly advanced neonatal care to keep such newborns alive. The topic has generated comparatively less debate in Australia, where case law is sparse and parents and clinicians themselves make decisions regarding the cessation of care, largely free from external oversight. The recent case of *Re Baby D (No 2)* [2011] FamCA 176 endorses this “closed” approach to neonatal decision-making. This article critically discusses some of its implications and makes suggestions for reform to ensure meaningful oversight of decisions to withdraw or withhold treatment. The authors argue that the judgment fails to address some fundamental issues, such as ensuring that those with the responsibility to make decisions are doing so on a “best interests” basis. This is important because, in a society where disability remains stigmatised and poorly understood, there is no opportunity under the approach adopted in *Baby D* to guarantee adequate protection of the rights of individuals born with physical or intellectual impairments. 835

BOOK REVIEW
Charlatan by Pope Brock 854

VOLUME 19 – 2011-2012

Table of Authors	859
Table of Editorials	862
Table of Legal Issues	862
Table of Medical Issues	862
Table of Bioethical Issues	863
Table of Nursing Issues	863
Table of Complementary Health Issues	863
Table of Medical Law Reporter	863
Table of Letters to the Editor	864
Table of Book Reviews	864
Table of Cases	865
Table of Statutes	877
Index	899