# THE HISTORY OF DONOR CONCEPTION RECORDS IN VICTORIA

A report prepared for the Victorian Assisted Reproductive Treatment Authority (VARTA)

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# CHAPTER 1 A BRIEF SOCIO-LEGAL HISTORY OF DONOR CONCEPTION IN VICTORIA

#### Introduction

There have been significant changes in the way donor conception is practiced in Victoria over the past sixty years. This report provides a history of Victoria's donor conception programs and records from the mid-1970s to July 1988 when the *Infertility (Medical Procedures) Act 1984* (Vic) commenced and mandatory record keeping practices were introduced.

Victorian doctors have provided donor conception treatment services since at least the 1940s.<sup>1</sup> In the early days, individual doctors performed inseminations in their private rooms using fresh semen. Donors were told they would remain anonymous and few, if any, records were kept. Prior to regulation, doctors were not legally obliged to keep a record of the donor's identity or to provide the parents or resulting children with any information about the donor. Just as donors were told their identities would never be disclosed, recipient parents were instructed to keep their child's conception story a secret. It was not recognised by those providing the services, or those receiving them, that donor information may be important to the child who was born.

By the mid-to-late 1970s, three hospital-based donor insemination programs had begun operating in Victoria at the Royal Women's, Prince Henry's and Queen Victoria hospitals.<sup>2</sup> Record keeping practices developed as the services grew. It was not until 1988 that there was any legal regulation of the practice in Victoria. By then, it is estimated that several thousand donor-conceived children had been born.<sup>3</sup>

In 1984, Victoria passed the first legislation in the world regulating assisted reproduction.<sup>4</sup> Commencing in 1988, the *Infertility (Medical Procedures) Act 1984* (Vic) mandated certain record keeping practices and the granted donor-conceived people and their parents the right to apply for information about their donor, which could be provided if the donor consented. The donor was also able to apply for information about donor-conceived offspring which could be provided if adult donor-conceived people or parents of younger children consented. Additional reforms have followed which have all expanded information rights. In 2016, the *Assisted Reproductive Treatment Amendment Act 2016* (Vic) was passed, which provided every donor-conceived Victorian, no matter when they were conceived, with the right to know the identity of their donor. The whereabouts and quality of those early donor records has thus become vitally important to the success of the legislation.

<sup>&</sup>lt;sup>1</sup> Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilisation, *Issues Paper on Donor Gametes in IVF* (Victoria, Standing Review and Advisory Committee on Infertility) August 1983, 4.

<sup>&</sup>lt;sup>2</sup> Only the Royal Women's Hospital continues to exist.

<sup>&</sup>lt;sup>3</sup> Law Reform Committee, Parliament of Victoria, *Inquiry into Access by Donor-Conceived People to Information about Donors* (2012) 11.

<sup>&</sup>lt;sup>4</sup> Victoria's 1984 legislation was followed quickly by Sweden, which enacted the *Swedish Law of Artificial Insemination* (no.1140/1984), which was the first legislation in the world to come into force that governed the practice of artificial insemination. The legislation required that clinic records be kept for 70 years and enabled donor offspring to apply for their donor's identifying information from the treating clinic when they reached adulthood.

In this report, we begin with a brief socio-legal history of donor conception in the State of Victoria. Then, in subsequent chapters based on case studies of the three hospital sites, we trace what information was collected about donors pre-1988, how it was recorded and managed, where the records were stored, and where those records are currently located. We also provide a brief history of the sites, noting name and location changes, amalgamations and closures.

#### The early years: private practice

During the 1960s and early 1970s, inseminations were performed in the private rooms of individual doctors using fresh sperm. Donors were not necessarily tested for infectious diseases or genetic abnormalities, and there was no legal requirement that information about them be collected or stored. The identity of the donor was rarely recorded and parents were advised to keep the nature of the children's conception a secret. Little is known about which doctors conducted private inseminations, as their services were not advertised and those who received them did not speak openly about undergoing treatment. In the absence of legal regulation or medical guidelines, these doctors were able to operate without oversight. In preparing this report, it has not been possible to unearth any additional information about these early private practices or their records.

By the mid-1970s, demand for donor conception services was growing, caused in part by a reduction in the availability of infants for adoption. For instance, according to their Annual Report 1976, at the Royal Women's Hospital in Melbourne, the number of babies available for adoption had decreased from 390 in 1970-71 to 142 in 1974-75. This change is consistent with the decreasing stigma attached to ex-nuptial births, as indicated by the creation of a Supporting Mother's Pension in Australia in 1973 for single mothers who were not widows.<sup>5</sup> The increasing availability of safer and affordable abortions was also a factor in the reduced number of infants available for adoption. At the same time, interest in the science of donor conception had increased, as scientists raced to develop sperm freezing techniques and, eventually, to successfully perform *in vitro* fertilisation (IVF). Victorian scientists were at the forefront of IVF in particular.<sup>6</sup> Victoria's role as a leader in the field meant that there was growing public awareness of the opportunities assisted reproduction offered couples struggling with infertility. However, with that additional attention came increased scrutiny of the field and the social and ethical dilemmas it raised.

#### The emergence of clinic-based donor insemination services

In the 1970s, Prince Henry's, Queen Victoria and the Royal Women's hospitals founded what were then called AID (artificial insemination by donor) programs.<sup>7</sup> Each of the programs relied on a steady stream of men willing to donate their sperm regularly. Initially, fresh semen was used at Prince Henry's

<sup>&</sup>lt;sup>5</sup> Deborah Dempsey and Jo Lindsay, *Families Relationships and Intimate Life* (Oxford University Press, 2nd ed, 2014) 125.

<sup>&</sup>lt;sup>6</sup> Jean Cohen et al, 'The early days of IVF outside the UK' (2005) 11(5) Human Reproduction 439, 445.

<sup>&</sup>lt;sup>7</sup> AID later became known as donor insemination (DI) to avoid confusion with acquired immune deficiency syndrome or AIDS, once the HIV/AIDS pandemic reached Australia in the early 1980s.

and Queen Victoria, which meant that donors needed to be on site. For this reason, many of the early donors were medical students. By the late 1970s, sperm freezing techniques had been perfected, enabling clinics to build a larger supply of sperm with a greater variety of donors.

Prior to July 1988, there was no regulation of assisted reproduction, and thus no requirement that doctors and clinics keep records of their donors or treatment procedures. However, each of the programs did keep basic records that linked donors to inseminations and pregnancies, though the principle underlying their protocols was anonymity. Donors were assigned codes and all records that related to inseminations referred only to this code. Parents were still advised not to tell their child's conception story.

In 1977, the first Australian Workshop on AID was held, with the Fertility Society of Australia forming five years later. At that first workshop, Australia's fertility medicine pioneers gathered to discuss the science of assisted reproduction, but also to debate some of the ethical issues the industry faced. Discussions about whether donors should be limited to a certain number of offspring took place, with there being general agreement that limits should be imposed. While the workshop did not produce a national rule, it appears that the three Victorian clinics agreed to keep offspring numbers to below 20 families per donor, with further reductions in the 1980s. This decision was prescient given the legislative reform that has happened since. Victoria, NSW and WA now impose statutory limits on how many women or families can produce children from a particular donor, with limits ranging from five to 10. The remaining states and territories operate under a system of self-regulation in accordance with the National Health and Medical Research Council *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (NHMRC Ethical Guidelines), and the Reproductive Technology Accreditation Committee (RTAC),<sup>8</sup> both of which recommend family limits. While some overseas jurisdictions also impose legislative limits,<sup>9</sup> many others have chosen not to, resulting in large donor offspring cohorts.

#### **Regulating the industry: the first legislation**

Despite contemporaneous debates about the rights of adopted people to have access to information about their birth parents, it appears that many clinicians performing donor inseminations prior to and during the 1970s were unaware of the potential implications of donor anonymity for donor-conceived people, their parents, and donors. The view at the time was that infertility was a great source of anguish and the emphasis was on fulfilling infertile couples' desire to have children while at the same time attempting to reduce the embarrassment and sense of failure attached to being infertile. Infertility for men could raise questions about virility and was a strong affront to predominant views about masculinity. There was a great deal of shame associated with having to use the sperm of an unknown man to conceive.<sup>10</sup> Insemination was also equated with adultery (being unfaithful to one's husband) according to some sources that document the prevailing views of the time.<sup>11</sup> Secrecy was thus necessary to

<sup>&</sup>lt;sup>8</sup> The Reproductive Technology Accreditation Committee (Fertility Society of Australia) has advised that 'a maximum of ten donor families per sperm donor' is acceptable. See Reproductive Technology Accreditation Committee, Advice to Units, Technical Bulletin 3 (5 May 2011), available at: https://www.fertilitysociety.com.au/rtac/technical-bulletins/.

<sup>&</sup>lt;sup>o</sup> For an overview of laws, guidelines and recommendations from professional bodies on offspring limits see: <a href="http://www.health-lawcentral.com/donorconception/family-limits/#note-11240-7">http://www.health-lawcentral.com/donorconception/family-limits/#note-11240-7</a>>.

<sup>&</sup>lt;sup>10</sup> Louise Johnson, Kate Bourne and Karin Hammarberg, 'Donor Conception Legislation in Victoria, Australia: The 'Time to Tell' campaign, donor-linking and implications for clinical practice" (2012) 19(4) *Journal of Law and Medicine* 803.

<sup>&</sup>lt;sup>11</sup> Erica Haimes and Ken Daniels, 'Introduction' in Erica Haimes and Ken Daniels (eds), *Donor insemination: international social science perspectives* (Cambridge University Press, 1998).

maintain the integrity of the marriage, masculine pride and the nuclear family unit. Couples were advised not to disclose information about their treatment to anyone, especially their donor-conceived child.<sup>12</sup> Once the family left the program, they were encouraged to go home and forget about it or continue on as if "nothing had happened".

It was also believed that donors would not want information about their donor offspring or want to have contact with them or their parents.<sup>13</sup> Donors were required to sign consent forms that stipulated that the clinic would not release their information to recipients, and that the donor would not seek contact with their donor children. Donor anonymity was also thought to be necessary because of the lack of clarity around the legal status of donors.<sup>14</sup> There were concerns that a donor may be considered the legal parent of a child for the purpose of inheritance law. Anonymity was therefore understood to provide a layer of legal protection for donors who were concerned about claims on their estate, and parents who were worried that donors might intrude on their family life.

Over time, attitudes towards donor conception began to change. As society began to accept the view that children had a right to know their biological origins, the need to regulate donor conception became apparent. In 1982, in response to growing concerns about the interests of children conceived using donor sperm or via *in vitro* fertilisation (IVF), the Victorian Government established the Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, chaired by Professor Louis Waller (the "Waller Committee").

The Waller Committee released two reports in 1983, the second of which addressed the use of donor gametes. The Committee concluded that use of donated sperm and eggs should continue in Victoria, but that assisted reproduction should be regulated. The most significant recommendation was that, "Whether or not a person pursues his or her origins, it should be possible for everyone to discover them".<sup>15</sup> It was thus recommended that assisted reproduction services maintain registers that would record and preserve information about donors and pregnancies, so that it would be possible in the future for a donor-conceived person to identify their donor.

A draft bill was prepared based on the recommendations of the Waller Committee. It became the *Infertility (Medical Procedures) Act 1984* (Vic). Coming into effect on 1 July 1988, it was the first legislation in the world to comprehensively regulate assisted reproduction.

### The Infertility (Medical Procedures) Act 1984 (Vic)

*The Infertility (Medical Procedures) Act* established a licensing system for assisted reproductive services, requiring providers to receive ministerial approval. The Act also required approved facilities to maintain a register that recorded the details of each sperm or egg donor, the recipient parents, and whether any children had been born from the use of donated gametes. This information was to be forwarded to the Health Commission which would add it to a central register. The Act also introduced

15 Ibid.

<sup>&</sup>lt;sup>12</sup> Law Reform Committee, Parliament of Victoria above n 3, 26.

<sup>13</sup> Ibid.

<sup>&</sup>lt;sup>14</sup> Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilisation, above n 1, 26.

compulsory counselling with an approved counsellor for couples receiving treatment, as well as for donors and their wives, where relevant. Finally, the Act established a Standing Review and Advisory Committee on Infertility (SRACI), whose functions included advising and reporting to the Minister on matters and procedures relating to infertility.

The Act was passed in 1984, but because it did not come into effect until July 1988, donor programs had four years to prepare for the changes. As the accounts in later chapters indicate, the three donor programs in Victoria began implementing changes much earlier, particularly with regard to the type of donor they recruited. For example, Prince Henry's began only recruiting donors who were willing to be known to offspring, while Queen Victoria asked donors on their intake forms whether they were willing to have their identity released to offspring when the child turned 18. Counsellors at the Royal Women's began interviewing and screening donors in the mid-80s to ensure they were aware of the implications of the impending legislative changes. It was also reported that the clinical directors at Prince Henry's instructed those who maintained the records to ensure that they were in good order.

#### Further reform: 1988-2008

While the *Infertility (Medical Procedures) Act* introduced significant changes to practice, further reform was to come. From May 1990 to October 1991, SRACI completed a three volume review of the Act. It was recommended that the Act be amended, with a particular focus on information rights. Most notable was the recommendation that:

[A]ny person born as a result of the use of donated gametes may, upon reaching the age of 18, obtain identifying information about the gamete donor from the central register. This recommendation is based on the clear belief that the interests of such a person in discovering his or genetic parent or parents should be accorded primacy.<sup>16</sup>

SRACI's draft legislation formed the basis for the *Infertility Treatment Act 1995* (Vic), which came into effect on 1 January 1998.

The *Infertility Treatment Act 1995* brought an end to anonymous gamete donation in Victoria. Under the Act, all donors were required to consent to having their identity released to offspring. A donor-conceived person could obtain identifying details about his or her donor at the age of 18, or younger with the consent of his or her parents or guardian. However, the new legislation did not provide people conceived prior to 1998 with the same access rights which remained dependent on the date of donation and when an individual was conceived.

The *Infertility Treatment Act 1995* also established the Infertility Treatment Authority (ITA), which was given the task of compiling and storing the donor conception records, managing access to those records, and licensing and overseeing the regulation of infertility treatment providers. Licensed treatment providers were required to provide the ITA with information every six months about donor treatment procedures, including details of children born, donors, and women who underwent donor treatment.

<sup>&</sup>lt;sup>16</sup> Standing Review and Advisory Committee on Infertility, *Report on Matters Related to the Review of Post-syngamy Embryo Experimentation – Part III: Recommendations for Amendment of the Infertility (Medical Procedures) Act 1984,* SRACI, Melbourne 1991, 6.

The ITA recorded this information in the central register.

The Act also established a voluntary register which allowed donors, donor-conceived people, parents and descendants of donor-conceived people to voluntarily provide identifying information, or other information not included in the central register, such as photographs or medical updates. Information on the voluntary register was released in accordance with the wishes of the individual who provided it. It enabled donors and donor-conceived people who were conceived prior to 1998, but after 1988, to share information where there was mutual consent. In 2001, the Act was amended so that those conceived prior to 1988 could also use the voluntary register.

In 2002, the Victorian Law Reform Commission (VLRC) conducted an inquiry into the laws governing assisted reproductive technology and adoption. The inquiry was, at least in part, prompted by debates about access to assisted reproduction for same-sex couples and single women. The *Assisted Reproductive Treatment Act 2008* (Vic) incorporated almost all of the VLRC's 130 recommendations. The Act made few changes to the rights of donor-conceived people. However, the Act changed the name of the Infertility Treatment Authority to the Victorian Assisted Reproductive Treatment Authority (VARTA) and transferred management of the voluntary and central registers from ITA/VARTA to the Registry of Births, Deaths and Marriages (BDM). The provision of counselling and donor linking services were also removed from ITA/VARTA. These reforms took effect in 2010.

#### A radical rethinking of donor laws: retrospective access to donor records

The legislative reform of the 1980s and 1990s created an environment of openness in donor conception that was unprecedented. Victoria was one of the few jurisdictions in the world that had abolished donor anonymity. However, the practical effect of these incremental legal changes was that the rights of individual donor-conceived Victorians depended on when they were conceived. Those conceived after 1998 had access to their donor's identity, while those conceived before did not. Furthermore, individuals conceived between 1988 and 1998 had the details of their conception held on the Central Register, while people conceived prior to 1988 were left with uncertainty about whether any record of their conception even existed.

Frustrations with the unevenness of access rights were increasingly voiced by donor-conceived adults who argued that equality demanded all donor-conceived people should have access to their donor's identity. This issue, amongst others, was addressed in 2012 by the Victorian Parliamentary Law Reform Committee's *Inquiry into Access by Donor-Conceived People to Information about Donors* report. The Committee concluded that the inequity of the existing legal framework should cease.

In response to the recommendations of the Law Reform Committee, the *Assisted Reproductive Treatment Act 2008* was amended in 2015 to permit those who were donor-conceived prior to 1988 to access their donor's identity if the donor provides consent. To facilitate this change, assisted reproductive treatment providers were required to provide details of any pre-1988 records they held to BDM, which managed the Central Register at the time. Individuals who had possession of pre-1988 records were also required to provide their records to BDM. These amendments came into effect in June 2015. However, just months later the legislation was further amended to remove the consent requirement, creating one rule for all donor-conceived Victorians. Every adult donor-conceived person can now apply to the Central Register for identifying information about their donor, without requiring donor consent. Donors can, however, lodge contact preferences in which they indicate whether they are open to contact or their preferred type of contact, including 'no contact'. These most recent reforms came into effect in March 2017.

Now that Victorians who were donor-conceived prior to July 1988 have a legal entitlement to their donor's identity, the existence, maintenance and integrity of the pre-1988 donor records has become a matter of significant importance. In the next section of the report, we provide detailed histories of the Royal Women's, Prince Henry's and Queen Victoria hospitals donor conception programs pre-1988, including a discussion of the integrity of the records and where they are now. First, we describe how we obtained information about the three hospital sites, followed by detailed discussion of the history and practices at each site.

#### Approach to information gathering about the three pre-1988 hospital sites

The three major sites where donor programs operated prior to July 1988 were the Royal Women's Hospital, Prince Henry's Hospital and Queen Victoria Hospital. A chapter is devoted to each site. Unlike the Royal Women's, Prince Henry's and Queen Victoria underwent a number of amalgamations, name changes, and relocations. These changes are traced to ensure the integrity of the information.

Information was obtained from a variety of sources, including qualitative interviews, government and law reform commission reports, books and academic articles, media, and ITA/VARTA archival information. Interview participants were recruited via various VARTA newsletters, advertisements in Victorian newspapers, and through a list held by VARTA of current and former clinicians who provided consent to be contacted.

Qualitative interviews were conducted with medical and scientific staff, as well as with donors and recipients of donor treatment. Interviews were also conducted with staff from the relevant government department at the time, members of the Waller Committee, employees of the Infertility Treatment Authority, and interstate clinic staff who participated in an informal semen exchange program with Victorian clinics. A total of 32 interviews were conducted between October and December 2017. Information about record keeping practices was also gathered from scientific articles and books written by clinicians at Victoria's pre-1988 donor programs, newspaper articles, the reports of the Standing Review and Advisory Committee on Infertility, archival information held by VARTA, and various government and law reform commission inquiries.

It is not possible to know conclusively whether the experiences, motivations and recollections of the medical professionals, donors and parents we interviewed are accurate or representative. Thus, wherever possible, we have attempted to corroborate our interview findings with information from published sources including peer reviewed and 'grey' (other non-peer reviewed) literature.

Interview participants are referred to using pseudonyms, except where a participant expressly consented to being identified by name.

#### **Royal Women's**

Nine people associated with the Royal Women's Hospital donor program 1976-1988 were interviewed. These were as follows: two doctors who worked in the program, one from its inception in 1976; a nurse who ran the Artificial Insemination Donor (AID) section in the early 1980s; a medical scientist who was in charge of the laboratory and record keeping from the commencement of the program, two social workers who worked in donor screening and with recipients of treatment from the early 1980s, two recipient parents whose children were donor-conceived prior to 1988, and a sperm donor who donated to the program in 1978. In addition to the interviews, the research team also had access to archival material from the Royal Women's including an annual report, a Masters' thesis written by one of the social workers circa 1980, and some early published and unpublished research studies produced by members of the medical and counselling team.

#### **Prince Henry's**

Twelve interviews were conducted with individuals connected to the Prince Henry's AID program prior to July 1988. Six Prince Henry's medical and scientific staff were interviewed. Their roles included two scientists in charge of the andrology laboratory, two endocrinologists, a director of the AID program, and a founder of the program. The time period covered by the interviews with medical and scientific staff is 1976-2000. Four donors from Prince Henry's were interviewed, covering the time period 1978-1988. Two recipient parents from Prince Henry's were interviewed. They were patients in the program between 1986 and 1990.

#### **Queen Victoria**

Ten interviews were conducted with individuals who had some connection to the Queen Victoria donor program prior to July 1988. Four Queen Victoria medical and scientific staff were interviewed. Their roles included one scientist involved in the andrology laboratory, two research scientists, one of whom was also a gynaecologist and the clinical director of the donor program in the 1970s, and an obstetrician who became director of the program in the 1980s. A clinician in South Australia who was part of a semen exchange program with Queen Victoria was also interviewed. The time period covered by the interviews with medical and scientific staff was 1971-2000.

Three donors from Queen Victoria were interviewed, covering the time period 1977 to 1988. Two recipient parents from Queen Victoria were interviewed. They were patients in the program between 1979 and 1983.

# CHAPTER 2 ROYAL WOMEN'S HOSPITAL

#### Early history of the program

The Royal Women's Hospital Artificial Insemination Donor (AID) Program began in May 1976. According to Churches (unpublished MA thesis, c. 1980), from its inception it provided services to public and private patients and was attached to the Sterility Clinic which later became the Reproductive Biology Unit at the hospital. Doctors from the Reproductive Biology Unit went on to form Melbourne IVF in 1989, which continues to operate at the Royal Women's. Melbourne IVF is now owned by Virtus Health, which listed on the Australian Stock Exchange in 2013.

Dr Ian Johnston, at that time a senior gynaecologist at the hospital, instigated the AID program. Dr Andrew Speirs and Dr John McBain were two other prominent fertility specialists involved in this program pre-1988.

From its early days, only frozen sperm was used at the Royal Women's by contrast with Prince Henry's and Queen Victoria where both fresh and frozen sperm were used. A medical scientist was employed by Ian Johnston in February 1976 to set up the andrology laboratory and organise a system for the storage, testing and quarantine of semen samples.

By 1979, staff included three medical doctors, a senior nurse to do testing and inseminations, two scientists in the Biochemistry Department, a medical scientist in charge of the Andrology Department (sperm bank and associated record keeping); and two counsellors with social work training whose responsibilities included interviewing couples considered medically suitable for AID.<sup>17</sup>

From its inception, the inclusion of counsellors was a distinctive feature of the donor insemination program at the Royal Women's. According to the 1976 Royal Women's Annual Report, the perceived need for social workers initially arose as a response to the increasing number of infertile couples who were unable to obtain a child through adoption. AID was considered a viable alternative to the dwindling number of babies available for adoption and the role of the social worker was to assist couples to understand the implications of using AID to form a family. Up until the mid to late 1980s, counsellors at the Royal Women's Hospital worked with recipient couples only, and the medical doctors were responsible for interviewing and testing donors. The service for recipient couples included not only counselling prior to inseminations but follow up support in the event of conception and birth.<sup>18</sup>

In 1979, a social worker connected with the program, Barbara Churches, wrote an MA thesis entitled "A follow up study of patients from the Royal Women's Hospital Artificial Insemination Donor Program who produced children 1976-1979". By this time, forty-five couples had had children through the Royal Women's Hospital program and twenty-seven of these couples agreed to take part in the study.

<sup>&</sup>lt;sup>17</sup> Barbara Churches, A Follow-up Study of Patients from the Royal Women's Hospital Artificial Insemination Donor Programme who Produced Children, May 1976-December 1979 (unpublished masters thesis, Stanford University, 1980).

<sup>&</sup>lt;sup>18</sup> Kath Lancaster, 'Medical Social Work', Royal Women's Hospital Annual Report (1976).

Churches found that participants were completely satisfied with all aspects of the Royal Women's Hospital AID program, experienced "an enrichment of their lives by parenthood, and complete acceptance of their children".<sup>19</sup> Additionally, Churches found that:

The most frequently made comment was that once pregnancy had been achieved, they felt no different to other couples expecting a child, in contrast to their feeling of isolation prior to conception and during the period of attempting to determine the cause of their infertility.<sup>20</sup>

Most of the couples in the study planned to have more children through AI, and the study also concluded that there appeared to be no marital problems as a result of the AI. It was also clear that most of the couples (87 per cent of 31) did not intend to disclose the donor conception to the children. The study's conclusions were also that longitudinal follow up of these families was unlikely to be successful given study participants did not want the ongoing intrusion into their lives or the possibility that the study could alert their children to the circumstances of their conception.

In 1998, Jenny Blood, also a social worker in the Royal Women's Hospital program, conducted another study into whether recipient parents had disclosed the donor origin of their pregnancy to their children. Her research included some parents who received donor gametes prior to 1988. It was apparent at that time, that despite some shift towards disclosure, non-disclosure was still considered favourable by the parents who had had children through the Royal Women's program. Of the 134 couples who had had donor inseminations between 1976 and 1997, 84 (62 per cent) had not yet told their children that they were donor-conceived. Of the 84 couples who had not yet told their children, 30 (22 per cent of the total number of couples surveyed) had decided that they did not ever intend to tell.<sup>21</sup>

#### How were donors recruited?

In the early days of the Royal Women's Hospital program, sperm donors were recruited through lectures given to medical students at the University of Melbourne. Other men were recruited through word of mouth. One recipient parent interviewed recalled that she was told her donor would be 'a worker at the hospital', suggesting there had been a recruitment drive among hospital staff. A man who donated in 1978 recalled seeing a poster or advertisement at RMIT where he had been studying at the time. A nurse and two social workers involved remembered more concerted efforts to recruit donors in the 1980s, and that potential donors also heard about the program through the publicity it was receiving in the media. Founding director Ian Johnston wrote that early donors were the husbands of patients as well as medical students. Later, they were men aged between 18 and 40 who came from all walks of life and recruitment actively took place in a range of community languages:

Since AID has become better known and more widely adopted throughout the country it has become necessary to extend our recruiting activities to the community at large...Personal representation to small groups and meetings, appeals placed in undergraduate newspapers of institutes of tertiary

<sup>&</sup>lt;sup>19</sup> Churches, above n 17, 25.

<sup>20</sup> Ibid.

<sup>&</sup>lt;sup>21</sup> Jenny Blood and Hugh William Gordon Baker, 'Parents of donor-conceived children: the experience of telling', unpublished paper, 1998, cited in Victorian Law Reform Commission, *Assisted Reproductive Technology and Adoption Final Report* (2007) 211.

#### Sperm Doners Wanted

Royal Women's Hospital Within our community, 10% of all marriages are infertile; that is, a pregnancy does not occur within twelve months of pregnancy. Of these couples, 25% are unable to have children because the husband is the infertile member. The option for them is to either adopt or seek help with A.I.D. As there is a five to seven year waiting list for adoption, A.I.D. is the more commonly preferred treatment requested by these patients.

Consequently a continuing supply of donors is necessary.

These vitally necessary donations can be collected over a relatively short period of time say 6 weeks - so that any one donor is not required to continue his contact with the hospital for more than two months and donors are paid \$10 per specimen twoards the cost of travelling and it is paid in cash, after approximately five donations to the Sperm Bank.

Donations are always a matter of absolute privacy.

Prospective donors are required to have a physical examination, semen analysis and certain blood tests. Please phone 347 1233, Ext.

2371, 9.00a.m. to 4.30p.m. Monday to Friday.

Catalyst, RMIT Student Newspaper, July 12 1977, p. 7 education, the distribution of pamphlets, and the enthusiastic co-operation of the media in all its forms has made the public aware of the need for this service. In the clinic at the Royal Women's Hospital, Melbourne, donors came initially in response to whatever had been the latest media appeal but many are now coming as a recommendation from a past or current donor...Information is also distributed in the languages of the major migrant groups within the community.<sup>22</sup>

As the program grew, there was a lot of work involved in recruiting donors yet this often yielded very few usable donations. One nurse recalled going on radio in the mid-1980s in an attempt to attract donors. A medical doctor who joined the program in 1987 explained:

We recruited by advertising and later on we tried to get more sophisticated and we would leave pamphlets in doctor's waiting rooms. I think we even had something on a tram at one point around Melbourne University and the fire brigade maybe or police stations... We used to say that every time we had a campaign we'd end up with one donor for every 10 phone calls. For every 10 enquiries, only one would make it.

#### **Donor screening, testing and incentives**

From the early days of the Royal Women's Hospital program, potential sperm donors underwent a medical examination, a psycho-social interview and a test for semen quality.

The semen would be assessed for freeze/thaw potential and semen quality (including motility and shape of sperm), chromosomal abnormalities and sexually transmitted infections such as Hepatitis B, syphilis and gonorrhoea. Dr Ian Johnston, who at the time was in

charge of the AID program at the Royal Women's wrote that up to 70% of donors could be rejected on semen quality alone in programs using cryopreserved semen due to an 'abnormal seminal profile'.<sup>23</sup> According to Johnston, an unsuitable family medical history was another reason for rejecting donors:

Donors with a family history of any genetically determined condition or with a recurrent family history of illness or any birth defects are not considered suitable.<sup>24</sup>

23 Ibid 15.

<sup>24</sup> Ibid 14.

<sup>&</sup>lt;sup>22</sup> Ian Johnston, 'The Donor' in Carl Wood, John Leeton and Gabor Kovacs (eds), *Artificial Insemination by Dono*r (Monash University Press, 1980) 13.

In the same book chapter, Johnston also explained that a small number of donors (less than five percent) were rejected because they were believed to be overly interested in the outcome of their donation. This was considered a threat to the principles of anonymity that underpinned the program:

Apart from the obvious medical grounds for rejection an occasional person will not be considered if he seems unusually interested in the progeny that may be produced from his semen. The absolute anonymity of the donor is considered essential in this country and all donors must be prepared to donate semen without any follow up on its use or results.<sup>25</sup>

The first case of acquired immune deficiency syndrome (AIDS) was diagnosed in Australia in November 1982 and the first death from AIDS occurred in July 1984.<sup>26</sup> In 1984, the donor insemination program at the Royal Women's Hospital closed down for a year due to concerns the sperm supply could be infected and in order to quarantine the sperm. From 1985 when the program reopened, HIV testing was part of the testing regime for sperm donors, and donors required two tests six months apart to ensure the 'window period' during which HIV could manifest was covered.

From the early days of the Royal Women's Hospital donor program, a small payment of \$10.00 was made to donors for, as one doctor explained, 'expenses and inconvenience'. The payment may have later been increased to \$20 per donation. Johnston (1980) indicates that the small payment was carefully designed to provide sufficient motivation among donors without creating too great an incentive to give false health information. This idea is consistent with the views of Richard Titmuss who compared US and UK blood and organ donor programs. Titmuss found that the voluntary UK system was less exploitative of donors than a compensation-based system, and produced more accurate health information for recipients of blood products and organs.<sup>27</sup>

A social worker attached to the counselling program recalled that in the mid-1980s, the counselling team began screening the donors whereas previously they had exclusively been involved with recipient parents. The impetus for this was the knowledge that changes to the law would no longer preserve donor anonymity and wanting to ensure that donors understood the implications of this. The social work team at the Royal Women's were very experienced in supporting adoptive parents, and believed there were potentially parallels with donor conception with regard to the shift in attitudes towards openness:

Because we were coming out of an adoption model, and we had seen the significant changes happening there...We explored with them [potential donors] motivation, implications for them in the future, the issues around children being informed or finding out in the future and possibly that the laws would change.

As such, it would seem that Royal Women's Hospital donors from at least the mid-1980s would have known about the possibility of legislative change regarding identity release. The sole donor we interviewed had donated at the Royal Women's Hospital in 1978 and had had contact with several of his donor offspring through the VARTA voluntary register.

<sup>&</sup>lt;sup>25</sup> Ibid 15.

<sup>&</sup>lt;sup>26</sup> See William Bowtell, "Australia's Response to HIV/AIDS 1982-2005", Lowy Institute for International Policy, Sydney, Australia, 2005, 5.

<sup>&</sup>lt;sup>27</sup> See Richard M. Titmuss, The Gift Relationship: From Human Blood to Social Policy (George Allen & Unwin Ltd, 1970).

#### What were donors told about the objectives of the donor program?

Only one donor from the Royal Women's Hospital program volunteered to be interviewed. He recalled donating in 1978 and being asked to sign an agreement that the donation would be totally anonymous. It is clear he knew his sperm was being used to help infertile couples have children and had known there was an upper limit of 10 donations.

#### What were the donors' experiences of donating?

This donor had become interested over time in knowing about whether any children had been conceived from his donation. He had contacted the Royal Women's Hospital in the late 1980s and been told there had been births, and the number and gender of the children but was unable to obtain identifying information. He also recalled being notified that some of his sperm had been sent interstate to South Australia. This had later been denied by the andrology staff when he contacted them, and we found no other evidence or mention of donations to the Royal Women's Hospital being sent interstate.

This donor had since found out his donor code (although he had been unaware of it at the time) and has linked with his donor offspring through the Voluntary Register.

#### Information collected from donors and matching

According to the medical scientist in charge of the sperm bank, in the early days of the Royal Women's Hospital program, there were at least two sources of information kept about the donors: medical histories with identifying information in the Andrology Department and possibly the files of doctors with private patients, and anonymised punched cards for the purposes of phenotypic matching that enabled the donor's physical characteristics to be compared with those of the recipient parents.

Family medical histories taken included history of mental and physical illnesses, surgical procedures, birth defects, and known genetic conditions. Other information collected was that considered useful for phenotypic matching, e.g. height, weight and blood group, hair colour, eye colour, complexion and ethnic origin. Johnston contends that the donor's educational background and achievements were also recorded, although participant interviews indicate these characteristics were not used for matching throughout the 1970s.

Prior to the mid-1980s, recipient parents at the Royal Women's Hospital were not given a choice of sperm donor. One recipient parent who had received inseminations in 1981 explained she was told by the doctor that he would 'pick somebody who was the same height and appearance as my husband'. Donors were selected with the intention that any children born could comfortably 'pass' as the biological offspring of the couple, and care was taken to ensure that matching would safeguard against the revelation that the social father was not biologically related to the child. As one doctor commented:

We tried to match on blood group because that seemed in those naïve days to be the way that people might be caught out if the child was the wrong blood group... to safeguard against the child finding out in their high school science experiment that their father couldn't possibly be their father.

This practice reflects the strength of the emphasis at the time on confidentiality and ensuring that the couple's use of donor sperm could not be inadvertently detected. In the days before DNA paternity

testing was invented, blood group was the only available paternity test because some combinations serve to exclude the possibility that a parent and child are related. For example, a man who has type AB blood could not father a child with type O blood, because he would pass on either the A or the B allele to offspring.

Punched phenotype cards were kept in the sperm bank that could be compared with similar cards kept by nurses containing characteristics of the recipient parents. These cards were created with information from the medical history files.

From the early to mid-1980s at the Royal Women's Hospital, once the counselling staff became involved in donor recruitment, the information obtained from donors became more comprehensive. As it became clearer that laws would change to require release of the donor's identity, the concept of matching evolved from the emphasis on blood group and physical characteristics that would preserve anonymity to getting information from donors that would enable the recipient couple to make a meaningful choice. The logic behind this appeared to be that if couples were being encouraged to disclose the donor conception to offspring, it made more sense for them to have input into donor selection. The donor came to be conceptualised as a person who may become meaningful to the child or family in the future rather than the previous emphasis on impersonal matched traits, as one of the counselling staff we interviewed implied:

In the early days, it was all about the secrecy...the sister in charge of the clinic did the matching on physical characteristics only but the significant thing would be the blood group...because it was all about maintaining secrecy...I remember asking to do it [when the counsellors became involved] because I thought there's much more to this than meets the eye...We devised a much more comprehensive questionnaire which andrology got them to complete. It had physical characteristics still but also occupation, interests, hobbies...why they were doing it. There weren't many donors but I would just make the information available to them [recipient parents] so they could have a choice.

#### What records were kept about donors and recipients and where were they stored?

According to the health professionals involved, at the Royal Women's, scrupulous records were kept about donors, recipients and births. Records about donors were kept in locked filing cabinets in the Andrology Department. Records about recipient parents were kept separately in another part of the Reproductive Biology Unit, and were accessible to the nurses and counsellors in the relevant case files. There was some disagreement among the doctors we interviewed as to whether identifying information linking parents and donors could be found in doctors' private medical files. However, it does appear that there have been cases over the years where doctor's private medical files have been used to track down which donor's sperm was used for a particular recipient couple.

The main linking mechanism was the unique two letter code assigned to each donor. This began with AA in 1976 and continued through the alphabet chronologically. It had no specific meaning and was purely for the purposes of matching semen samples to particular donors and recipient parents, keeping track of who had received the donation and whether any births had resulted. According to one medical doctor involved with the program, only the consulting fertility specialist and the medical scientist had access to identifying information about the donor. The nursing staff and counsellors only knew the

HUSBAND'S CHARACTERISTICS				THE	ROYAI	. WOMEN'S	HOSP	ITAL -	– A.I.D.	— RECIPI	i <b>ent</b> 's ri	ECORD
A B C D	Jewish Caucasian Mongolian Negroid	RAG	CE	COMMENTS	5:	Item MR. 11E						
E F G	Fair Dark Olive	COMPL	EXION									
H I J	Slight Medium Heavy	BUILD					MEN		L RECOR	*****		
K L M	160-175 cms. 176-190 cms. 191-205 cms.	HEIGHT		Spontane	eous	Modified	ECORD	Contro OF INS	SEMINAT	Usual Int	terval	Variation
N O P	Blond Dark Red	HAIR COLOUR		Cycle		LMP		ate		of Cycle	Туре	Monitor
Q R S	Blue Green Brown	EYE COLOUR		2								
T U	O A	ABO GROUP		3								
v w	B AB			4								
X Y	Positive Negative	Rh GR		5								
U.R. Rea	IOR RECORD No. ction come	1	2	3	4	5	6		7	8	9	10

**ROYAL WOMEN'S HOSPITAL RECIPIENT RECORD** 

donors by their donor code, until the point in time in the 1980s when the counsellors began screening the donors. The information linking the donor code to the donor's identity was kept in andrology. According to those responsible for setting up and maintaining the system, it has been possible since the beginning of the program, by virtue of this code, to match donors to the recipient parents who received their sperm and to know how many children were conceived with their sperm. It is not known to what degree recipient parents were aware of the donor code, but indications are that it was not hidden and is likely to have appeared on the paperwork they were given.

The medical scientist in charge of andrology kept records indicating which women received which sperm and how many pregnancies and births had resulted from a particular donor's sperm. Keeping track of how many children were conceived and born was the responsibility of the senior nurses in the Reproductive Biology Unit, who would notify andrology when there were pregnancies and births. At least for a time in the mid-1970s, an upper limit of 20 offspring per donor was set. In the early to mid-1980s, this changed to an upper limit of 10 recipient families, in keeping with newly developed Fertility Society of Australia guidelines.

#### Where are the Royal Women's Hospital records now?

The original records from the pre-1988 days of the donor conception program remain in the Andrology Department of the Royal Women's Hospital, which is now part of Melbourne IVF. Pre-1988 donor treatment record data was provided by Melbourne IVF to Births, Deaths and Marriages in April 2015.

Due to minimal moves or organisational restructures, and continuity of staffing, organisational memory was strong. Several long-term staff members, one of whom is still employed at the hospital, had been responsible for setting up and maintaining the system over time. When the Royal Women's Hospital relocated in 2008, this staff member was able to oversee the move of the records. There were no doubts expressed about the location of the records or their accuracy.

One donor raised the prospect that some of the sperm donated at the Royal Women's may have resulted in unrecorded births because the sperm was sent to South Australia for use in clinics there. However, this claim was not supported by any of the health care professionals we interviewed.

#### Conclusion

Record keeping throughout the pre-1988 years at the Royal Women's Hospital, according to a variety of the health care professionals involved, was consistent and scrupulous, and the donor records appear to be intact.

The early inclusion of counsellors was a defining feature of the AID program at the Royal Women's Hospital and indicates the interest among the health care professionals involved in the welfare of families and children created.

Attitudes towards matching and the kind of information collected about donors appear to have shifted quite considerably at the Royal Women's Hospital between 1976 and 1988. Whereas in the 1970s, there was a strong emphasis on donor anonymity and the senior nurse's role in matching the physical attributes of the donor to the prospective father, a substantial shift appears to have occurred in practices in the mid-1980s when counsellors became involved in donor screening. From that time, the choice, albeit between a small number of donors, was given to the recipient parents, who now had more holistic information about the donor available to them.

## CHAPTER 3 PRINCE HENRY'S

#### The history of the Prince Henry's donor program

The Prince Henry's Medical Research Centre was established in 1969 at the Prince Henry's Hospital on St Kilda Road in South Melbourne. The Reproductive Medicine Clinic, which conducted what was then referred to as 'artificial insemination with donor semen (AID)', commenced in 1976 and operated from within the Medical Research Centre. The program was established by Drs David de Kretser and Doug Lording, with Dr Henry Burger serving as its first director. The Centre initially had ties to the Medical School at the University of Melbourne and then to Monash Medical School.

In 1987, the Centre moved from its St Kilda Road premises to Monash Medical Centre, Clayton during the amalgamation of Prince Henry's Hospital with the Queen Victoria Medical Centre and Moorabbin Hospital. Responsibility for patient and medical records was transferred to the Monash Medical Centre. The donor program continued to operate. In 1990, the Prince Henry's Institute of Medical Research relocated to Monash Medical Centre and the donor program was incorporated into the Institute.<sup>28</sup>

The donor program at Prince Henry's Institute of Medical Research ceased operation in 1998. Existing patients and donors, along with their records, were transferred to Monash IVF. Closed records were relocated to a storeroom of the Prince Henry's Block ('E Block') of Monash Medical Centre. In 2006, the records were transferred to the Public Records Office of Victoria.

The Prince Henry's Institute of Medical Research and the Monash Institute of Medical Research merged in 2014 to form the Hudson Institute of Medical Research, which continues to operate today.

### How were donors recruited and what made them suitable for the program?

Clinicians who ran the donor program at Prince Henry's reported that recruitment of donors evolved considerably over the life of the program. In the mid to late 1970s, fresh semen was used, making it necessary to have donors available on site. Clinicians reported that the majority of the donors in the early years of the program were therefore medical students attending Prince Henry's for training, as well as students from the nearby Victorian College of the Arts. A small number of donors came from the general community, typically from businesses located near the hospital. A survey conducted with 25 Prince Henry's donors in 1983 found that five were between 18 and 20 years of age, 11 were between 20 and 25, and nine were between 25 and 40. Four were married and two had previously fathered children.<sup>29</sup>

During the early years of the program, clinicians recruited donors by attending the lectures of fourth year medical students to talk about the program.<sup>30</sup> Two of the donors we spoke to reported that they were recruited in this way. Clinicians also participated in interviews with journalists and radio presenters in which they discussed the need for donors.

<sup>&</sup>lt;sup>28</sup> Prince Henry's Hospital was closed, the buildings demolished, and the site sold in 1994.

<sup>&</sup>lt;sup>29</sup> Gabor Kovacs, Christine Clayton and Patricia McGowan, 'The attitudes of semen donors' (1983) 2 *Clinical Reproduction and Fertility* 7, 78.

<sup>&</sup>lt;sup>30</sup> Committee to consider the social, ethical and legal issues arising from in vitro fertilisation, above n 1, 5.

Advertisements were placed in Melbourne newspapers, such as *The Age* and *The Herald*.<sup>31</sup> Efforts were made to recruit donors from diverse ethnic backgrounds, particularly following increased immigration from countries such as Vietnam and India. This was done by placing advertisements in, and doing interviews with, foreign language newspapers. At one point, the Clinical Director at Prince Henry's wrote to the teams of the Victorian Football League, asking their players to donate. On another occasion, airline pilots were approached. Neither proposal yielded many donors.

In the 1970s, Prince Henry's donors were paid \$10 per donation, which was described by clinicians as "covering the cost of attendance" at the clinic or "paying for the tram fare". A clinician involved in screening potential donors in the early 1980s described the donors as "altruistic people by and large, because \$10 wasn't much, and because you had to be pretty committed too, to come in and give more than one [sample]." The survey of Prince Henry's donors in 1983 reinforces the conclusion that most donors came from a place of altruism. The survey found that the most common reason for donating was "to help infertile couples", and that while financial reasons were also high on the list, 64% of donors said that they would donate without payment.<sup>32</sup> A second survey of Australian donors conducted in 1982 reached a similar conclusion, with the majority reporting they would continue to donate even if the financial reward was withdrawn.<sup>33</sup> However, several of the Prince Henry's donors interviewed indicated they were at least partially motivated to donate because of the payment. A former medical student who donated in 1981 described donating as a "fun and...altruistic thing to do", as well as a "great way to get a little bit of beer money". A second Prince Henry's donor, who donated in 1978 as a struggling university student, stated that a newspaper advertisement for donors had attracted his attention because it presented an opportunity to earn some extra money. It is thus fair to conclude that while many donors were driven exclusively by altruism, payment was significant to at least some donors, particularly in the early years of the program when the majority of donors were students.

Research with Prince Henry's donors from the early 1980s suggests that a small, but significant number of them were open to identity disclosure. In the survey of donors conducted in 1983, they were asked if they would still donate if the program no longer offered anonymity.<sup>34</sup> Eight of the 25 donors surveyed said that they would continue to donate, 13 said they definitely would not, and four were not sure. Twelve of the donors reported that they may donate even if there was a possibility of their donor offspring contacting them when the child became an adult. Thirteen felt it was important for identifying information to be kept on file somewhere, while 10 felt that only non-identifying information should be maintained. Donors were also surveyed to determine the amount of feedback they would like to have about their offspring. Fourteen indicated that they would like to know if there were any births, nine wanted to know the number of children born, and eight the sex of the offspring. Eleven donors indicated that they would like the "opportunity to discuss in greater detail the implications of their involvement" in the donor program.<sup>35</sup> These survey findings indicate that while only a third of donors were comfortable

<sup>31</sup> Ibid.

<sup>&</sup>lt;sup>32</sup> Kovacs, Clayton and McGowan, above n 29, 74.

<sup>&</sup>lt;sup>33</sup> M Nicholas and J Tyler, 'Characteristics, attitudes and personalities of AI donors' (1983) 2(7) Clinical Reproductive Fertility 47.

<sup>&</sup>lt;sup>34</sup> Kovacs, Clayton and McGowan, above n 29, 74.

<sup>35</sup> Ibid.

with ending anonymity – still a remarkable finding for 1983 – most were open to some degree of information disclosure. It is also evident that many donors had considerable interest in the offspring born as a result of their donations.

By 1986, donor numbers at Prince Henry's were dwindling. A small number of couples, estimated at less than five per cent, provided their own donor. The rest needed to be recruited by the AID program. In December 1986, a young scientist, Rose, was hired to oversee the andrology laboratory, but also to revamp the donor program. While the initial driving force was to increase donor numbers, the doctors were also concerned that many of the donors they had recruited in the past were no longer suited to the era of openness signalled by the new *Infertility (Medical Procedures) Act 1984* (Vic). The Act, which was to come into force in July 1988, created a Central Register in which the names of all participants in donor conception procedures were to be recorded. The doctors who led the program understood that it was no longer possible to assume that donors would remain anonymous. Rose reported that the director of the program told her "it was going to be a lot more open in the future" and so only donors who were willing to be known to offspring should be recruited. Rose explained what this meant in practice:

[They] wanted me to completely redo the way we attracted donors, treated donors, and educated our donors so that we would be prepared for the future. So they wanted me to increase the number and they wanted me to change the type of person that we accepted. So these [were] not hard and fast rules, but we came together with the agreement that our donors should be married, they should have children of their own [because] they have proven fertility, but they also had a better understanding of what it is to be a father. We were trying to get donors who were either educated or educable; donors who were prepared to understand that things can change in the future...[T]hat was my goal, that I would try to discuss with them and just see what their attitude might be to the idea of their identity one day actually being given out to people. And then the other thing that we felt that they needed to have [was] a bit of a more altruistic kind of attitude, in other words, not just doing it for the money. So that was my job, to make that happen.

Rose screened the new donors by discussing with them the possibility of identity disclosure, explaining that the doctors at the program "really believe this is going to be the way of the future". Men who reacted negatively were not chosen. However, many "were extremely open to it" and those were the men who moved to the next stage of screening. As she explained, "[W]e recruited a whole lot of fantastic donors, all of whom I surveyed and then interviewed, and we were so happy with our response that we were really able to sort of pick and choose the donors that fitted our brand new criteria without compromising the range of characteristics and genetic diversity we wanted to have in our program."<sup>36</sup>

It was also important that Rose "moved on" existing donors who no longer met the new criteria. She contacted all the donors already in the program and explained its new direction. Some of the men who had been donating for a few years were not comfortable with the possibility of disclosure and chose to withdraw from the program. Those who were comfortable were retained. Rose noted that there were also men who wanted to continue donating, but who Rose did not think had "really considered the consequence of their actions." She decided to "eliminate them from the program". She usually notified them that the program "won't be accepting any more donations". However, some would still come in to

<sup>&</sup>lt;sup>36</sup> Rose's account of the new recruitment policies is reflected in advertisements from *The Age* in 1986 and 1987 that specifically requested married men.



Now without hurting their feelings, occasionally they would still come in and donate, and sometimes I would just discard it. I didn't want to upset them and I still gave their little stipend, but I didn't want our program to go in that direction because I felt like that was not consistent with what we thought was going to happen in the future...So I built up this group of married men with families who were very altruistic and very open to being contacted in the future.

Rose also introduced a new approach to payment, which was offered from late 1987. Rather than the donor receiving the \$10, Rose offered them the opportunity to give the money to a charity of their choice. As she explained:

I said, "Look we can give you the money for coming in", but what a lot of donors did is they nominated a charity that's close to their heart, and then I would send them a little card and say, you know, "This quarter I donated this much to the Blind Institute or something on your behalf. Thank you very much"...So we had this wall covered in cards and I'd show the donors when they came in, "Look at all our donations. It's fantastic".

Rose did not know whether the charity donations continued after she left Prince Henry's at the end of 1989.

#### What were donors told about the objectives of the donor program?

Men who donated in the early years of the program may not have been aware that their semen was being used for artificial insemination. A man who donated in 1978 reported that he was told his donations were for "research". After donating for about five or six months, he was told that his services were no longer needed. Believing that his contribution was solely to research, he did not think about it again until 2007 when he saw an advertisement in a newspaper asking men who had donated to get in contact with the Infertility Treatment Authority (ITA). Upon contacting the ITA, the precursor to VARTA, he was told that he had eight offspring. He described his reaction:

- *Q:* It sounds like from what you've described, when you started as a donor and what you were told at the time, it was very much research based.
- A: Absolutely, yeah.
- **Q:** And not necessarily about conception?

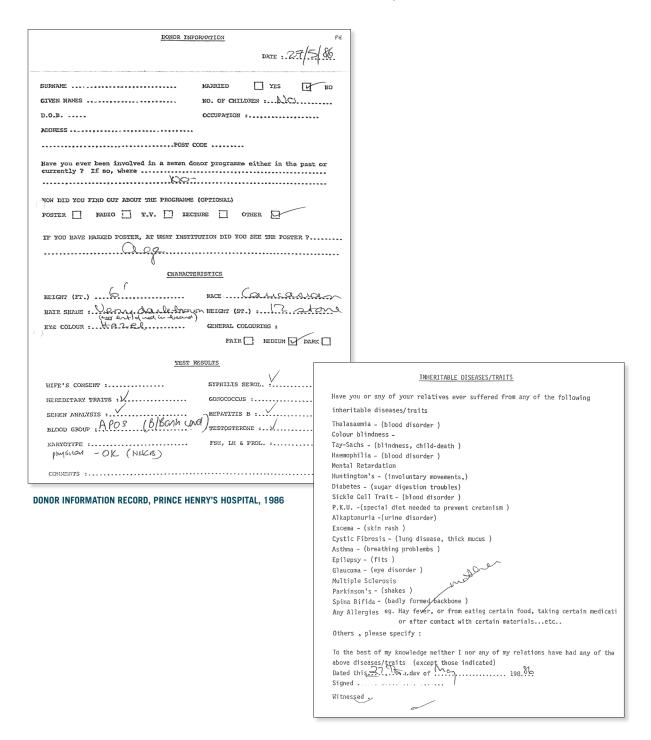
**A:** It was never put like that. Ever. And, as I said, neither my wife nor I had ever really considered that there was going to be a child conceived out of it. It was an absolute stunner when we got that letter. We'd never thought about that...It took a great bit of getting used to that because it came right out of the blue.

It is possible that some of the semen collected in the late 1970s was actually used for research. However, this particular donor believes that he was not provided with an accurate explanation of the program.

By the 1980s, the information provided to donors made it clear that infertile couples would use their semen. John, who was recruited through an announcement at the end of a university lecture and who donated in 1981, reported that donors were encouraged to participate because they could help an infertile couple "achieve a pregnancy".

#### What information was collected about donors?

Intake and screening forms obtained from Prince Henry's provide evidence of the information collected from each donor. Forms from the 1970s indicate that a number of physical characteristics were recorded for each donor: height, weight, hair colour, eye colour, race, and general colouring (with the options of fair, medium or dark). A semen analysis was conducted, in addition to medical screening for syphilis and gonococcus. The donor's blood group was recorded and karyotyping was undertaken to ensure there were no chromosomal abnormalities. A basic family medical history was taken, though at least one donor, who donated in 1978, indicated that this was very limited.



By late 1986, additional information was being collected, including the donor's occupation, religion, highest level of education, interests, the nationality of his parents and grandparents, his marital status, and whether he had any children. By 1988 this information was provided in a notification form for the Central Register.

/	РН	
INFERTILITY (MEDICAL PROCEDURES ) ACT & REGULATIONS - CENTRAL REGISTER As required by the Infertility (Medical Procedures) Act 1984 & Regulations 1988 Name of Approved Hospital <u>Prince Herry's Institute of Medical Research at Marash Medical Contre</u> Hospital Record Number of Donor	FORM A	INFERTILITY (MEDICAL PROCEDURES) ACT & REGULATIONS - CENTRAL REGISTER As required by the Infertility (Medical Procedures) Act. 1984 & Regulations 1988. Name of Approved Hospital Prince Henry's Institute.of Medical, Research.at, Marash, Medical, Copter Hospital Record Number of Donor
PERSON PROVIDING GAMETES       Sex Marital Status Scheduler       Occupation     Scheduler       Religion (if any)     MA       Country of Birth     MACCELER       Highest Educational level reached     TEREMARKS       Interests (Personal & professional)     MACELLINACIONAL CONTA       Blood group     Attached       ANCESTRY (ie: Nationality of the following at birth)       Market     Market	ATES GAMETES	PERSON PROVINING GAMETES     SILIN       Full Names.     Maiden & Previous Married Name(s).       Residential Address
PERSONAL HEALTH PROBLEMS &/OR FAMILY HISTORY OF GENETIC DISORDERS,BIRTH DEFECTS & / OR MAJOR REALTH PROBLEMS	DF A PERSON WHO DONATE	Maiden & previous married name(s)
TEST RESULTS   DATES OF SCREENING IN EACH CASE     (Results of tests conducted to determine the above conditions)   1110     1110   241637,101066, 24173,152     11500   141006, 24173,152     11500   14100,152  <	PRESCRIBED PARTICULARS O	Date person provided gamete(s) <u>1(1)</u>

#### CENTRAL REGISTER NOTIFICATION FORM

The donor was also required to provide information about his health, as well as that of his family, including any history of genetic disorders or birth defects. If the donor was married, his wife's consent was also required. Medical testing was extended to include HIV and Hepatitis B. The donor's health status was not updated while he was in the program. If a donor experienced a medical issue, he would have to disclose it to the program for his record to be updated. Most donors were involved in the program for less than six months making it unlikely that many updated their health records.

By late 1986, Prince Henry's donors were required to complete an additional form. It was titled "Non-identifying Information about Donors" and consisted of a series of questions, including ones related to the donor's temperament, family history, how he settled disputes, hobbies, interests and whether he suntanned easily. The form had been adapted from one created by adopted children and consisted of non-identifying questions they would like to ask of their biological parents. The final question was "Would you be interested in meeting children produced from your donor semen?" Rose, the scientist at the Prince Henry's andrology laboratory who screened new donors from 1986 to 1989, indicated that the program was more likely to accept donors who answered 'yes'. Donors who donated after 1986 have confirmed the existence of this question. Observations about the donors by those undertaking the screening were sometimes also added to the form. They were typically positive comments about what type of person the donor was perceived to be (eg, thoughtful, sensitive, particularly open to contact). Donors who donated post-1986 reported that they were also given the option of being kept informed of the outcome of their donations.

#### What were the donors' experiences of donating?

A number of the donors described feelings of awkwardness and discomfort while donating at Prince Henry's. The Andrology Department was located at the back of Prince Henry's, not in the hospital itself. Roger described it as an out-dated "terrible little building". In a similar vein, John referred to the donation room as a "very non-clinical environment" that was not "purpose built in any way", almost like "going into a public school or university type toilet". Several donors noted that there was no physical separation between the spaces used by donors and those for prospective parents, creating an awkward environment for the men who came in to donate. As Roger explained:

It was a weird sort of place. It was a place that...there was a very awkward moment in as much as, they had this terrible waiting room, and you had to walk through [it]. And there were always women in there, for obvious reasons. I said to the [head of the andrology lab] one day "I'm not comfortable with this at all." There's this bloke wandering in and he walks straight through – he doesn't wait to go to the receptionist, or anything. Anyway they showed me the back door.

lan described a similar experience:

The one sort of awkward thing about it was, particularly at the old clinic at Prince Henry's, which was this funny little building at the back of the hospital – you toddle in there, and I used to go on the way to work...so I'd turn up in a suit and a brief case and wander in up to the counter and go, "Give me a bottle and the key". And there's all these women sitting there in the clinic. And I can remember I was thinking, I wonder if they know why I'm here. And I'd disappear for ten minutes and then I'd come back and put a bottle...and still to do this day I wonder, gee, I wonder what they were thinking. I wonder if they knew the connection.

The primary reason for donating cited by the Prince Henry's donors who were interviewed was altruism. As noted above, this finding is supported by the survey of donors conducted by Professor Gab Kovacs in 1983.<sup>37</sup> The donors understood that by donating they could help infertile couples have a child. As lan explained:

## The clear intent that I had was to help people. And it was driven by an awareness of this as an issue, of people who were infertile. So this notion of wanting to help was really key.

However, while donors were motivated by altruism, several reported that they did not think about, or perhaps fully understand, the gravity of their actions. John, for example, noted that while he understood that children would be created through his donations, he had not put "any great thought into the enormity of what [he was] doing". Ian had a similar view: "When I look back on it now, I didn't understand...I didn't really realise the implications of what I was doing." Two donors also noted that at no point in the process were they given the opportunity to discuss the potential complexities of what

<sup>&</sup>lt;sup>37</sup> Kovacs, Clayton and McGowan, above n 29.

they were doing. John for example, reported that the recruitment process did not include a discussion of "the real implications" of donating. Ian went so far as to describe the process as lacking "informed consent". As he explained:

*Ian:* When I looked back at it I thought no...there was no sense of informed consent there. There wasn't the kind of conversation – there were certainly no forms [that explained to us] what we're doing here.

**Interviewer:** Like, this is what will happen and this is what the potential risks and benefits are? **Ian:** This is what will happen. Do you understand this? There was none of that at all. It was just quite a low key kind of conversation and "are you happy to do this?" We need to do some blood tests. We need to gather some information about you. There was not, I'm strongly of the view that there was not proper informed consent.

It is important to note that society's understanding of the ramifications of donor conception for offspring was fairly limited in the late 1970s and early 1980s. It is evident, however, that Prince Henry's staff did not provide donors with the opportunity to discuss the wider implications of what they were doing. The potential absence of informed consent by donors has also been raised by Helen Kane, the former manager of the Donor Registers Service at the Infertility Treatment Authority, who provided a written submission to Victoria's *Inquiry into Access by Donor-Conceived People to Information about Donors* in 2010 in which she stated, "Donors did not see counsellors in this state until the 1984 legislation required this. There are questions, prior to that, about the "informed consent" of any donor."<sup>38</sup> Kane further states, "It would be fair to say that no consent prior to 1984 would meet the criteria of informed consent in law." <sup>39</sup>

#### What records were kept about donors and recipients and where were they stored?

Each donor had a manila folder that contained his name, contact details, and medical and non-identifying information. That folder, which sometimes also included correspondence between the donor and program staff, was kept in a locked cabinet in the andrology laboratory. This file was only accessible to the head of the andrology laboratory. Each donor was also allocated a donor code. The donor code was made up of a letter and number. The letter was the first letter of the donor's surname and the number was based on how many donors already in the program had a surname beginning with that letter. For example, if the donor was the first donor with a surname beginning with A, he was A5. The donors reported that they were not told their donor code, though some had since obtained it via application under the *Assisted Reproductive Treatment Act 2008* (Vic).

Each donor also had a small card, kept in a separate card file, on which he was identified only by his donor code. The card system, which was kept in a locked filing cabinet in the andrology laboratory, was used to record who had received the donor's semen and the date of inseminations. Pregnancies were recorded on the card with a 'P' and births with a 'B'. Recipients were identified by number, with each woman allocated a number when she entered the program. As one clinician explained:

<sup>&</sup>lt;sup>38</sup> Helen Kane, Submission No. DCP16 to Law Reform Committee of the Parliament of Victoria, *Inquiry into Access by Donor-Conceived People to Information about Donors*, 5 August 2010, 2.

<sup>39</sup> Ibid 3.

What would happen is, let's say that one nurse knew that Mary Smith, number 1457, got pregnant. Then they would tell the [andrology] lab that 1457 got pregnant with B6. So they could keep a tally. They also looked at the efficacy of the various donors.

Clinicians indicated that the donor's code was also included on the recipient's file, which was kept in the 'infertility rooms'. For example, if a woman was inseminated with sperm from A3, her file included the insemination dates and A3 was recorded next to each date. It was common for multiple inseminations to occur each month. Prince Henry's always used the same donor for each insemination in a particular cycle. If, after two to three months, a pregnancy had not been achieved, a new donor might be selected.

Donors who have accessed their records from Prince Henry's have reported that they are in good condition and appear to be thorough. Ian, for example, who acquired his Prince Henry's file noted that:

My impression from my own experience and from other people's experience is that they seem to me to be the best kept set of records. And it seems as though they have made a very diligent attempt... their approach was very through. That is my impression from talking to with a number of people who've been involved at various times with Prince Henry's.

Roger, who was able to review some of his donor file after it was provided to him by one of his adult offspring, made similar comments about the thoroughness and integrity of the Prince Henry's records.

#### How were donors and recipients matched?

In the early days of the Prince Henry's program, attempts were made to allocate a donor to a couple whose physical characteristics matched those of the woman's husband. Attempts were also made to match blood groups so that parents who intended to keep the issue of donor insemination secret could do so more easily. As time went on, couples began to make requests that focused more on a donor's non-physical attributes. For example, they might request a donor who was kind, thoughtful or artistic. Attempts were made to respond to these requests, though physical characteristics were still taken into account.

#### What were recipients told about donors?

In the late 1970s, recipients of donor sperm at Prince Henry's were provided with little information about their donor and received no counselling prior to entering the program. However, by the mid-1980s, recipient couples were counselled prior to entering the program. They were told that they had the option of providing a known donor, such as a family member, or using anonymous donor sperm. From the outset, they were instructed of the procedures that would ensure confidentiality.

Recipients were informed that donors had undergone medical screening and that those who did not meet the highest standards "would be excluded". The couples were told that the matching of donors to recipients was done primarily on the basis of physical characteristics. In the early years, couples did not see donor profiles or any paperwork related to the donor, but were provided with an oral description of him. Couples were told about the cultural background, skin tone and basic physical characteristics of the donor, such as his height, weight and hair and eye colour. By 1986, couples were provided with one to two pages of non-identifying information about their donor, including information about his hobbies and interests.

There is evidence that if recipients from the pre-1988 period contacted Prince Henry's staff requesting further information about their donor, non-identifying information was sometimes provided. For example, in 1992 a recipient couple requested information about their son's pre-1988 donor. They received a letter from Professor Gab Kovacs, the director of the program at the time, which provided considerable non-identifying information. It is reproduced below.

	VE MIEDICINE CLINIC Institute of Medical Research
Postal Address; P.O. Boy 152 Clayton 3168. Ph: \$50 3553 Fan: 550 6125 17th December 1992	Dr. H.W.G. Baker 16658 Prof. H.C. Burger 16669 Prof. D.M. De Kreiser 17333 Dr. P. J. Fulter 47056 Prof. D.J. Healy 18617 Prof. G.T. Korkes 2040(J) Dr. R.I. McLachdan 4768/5 Mr. W.C.F. Straffon 267176
He had two children, both of them girls his hair is brown, his eyes are blue, his o he is medium build. He has natural or himself as a tough exterior but soft on company of a family and close friends. make close friends easily. When he has a he is ready he will discuss it and act rat completed secondary schooling and his f He was not good at maths, but loved a occupation is as a writer and producer of worked with travel agents and advertisi	of age at the time and has been married twice. by his first marriage. He is born in Australia, complexion was medium, he was 180cm tail and ints in his hair and tans easily. He describes the inside. He enjoys the home-life and the He gets on very well with people, but doesn't a problem he stews on it for a while, then when ionally. Very slow to lose his temper, he has avourite subjects were drawing, art and history. prot. He enjoyed school very much and his video and TV programmes. In the past he has ing. His ambitions are to be happy and to
music, television and bushwalking. His sk drawing. He regrets not being able to p rides a bicycle every day and is very fit. operations and he has no relevant medica drinker. Both his parents are Australian	His other hobbies are water-colour painting, tills are in cross-country skiing, bushwalking amd lay a musical instrument, he is in good health, His only operations have been ear and tonsil a history. He doesn't smoke and he is a social is and all his four grandparents also were. He sister and he would be prepared to meet any
PROFESSOR GABOR T. KOVACS	

LETTER TO RECIPIENT PARENTS FROM PRINCE HENRY'S REPRODUCTIVE MEDICINE CLINIC, 1986

### Were limits put on the number of offspring per donor?

The efficacy of having a limit on the number of offspring a donor could produce was a topic discussed by Prince Henry's clinicians from the outset. It was also discussed at the annual national workshop for donor insemination clinicians that began in 1977. The decision to limit offspring numbers was based on a desire to reduce the risk of consanguinity and ensure genetic diversity. Information obtained in the interviews indicates that limits were put on the number of offspring each Prince Henry's donor could produce, but the numbers provided were not consistent across the interviews, suggesting that the rule was not definitive or evolved as the demand for services increased. Interviews conducted with clinicians who were at Prince Henry's in the late 1970s consistently reported that donors were limited to three successful pregnancies. However, clinicians who were at Prince Henry's in the 1980s referred to a 20, 12 and then 10 child limit. A Prince Henry's donor recruitment flyer from 1987 stated "we limit most donors to a total of 20 children, the rest are limited to fewer." By this time, the program had grown substantially and it is likely that the demand for sperm was much greater than in the 1970s. Two Prince Henry's donors interviewed were able to obtain information from their records. The first donated in 1986 and had five recorded offspring; the second donated in 1987 and had seven recorded offspring.

A number of Prince Henry's clinicians stated that sperm was sometimes sent to South Australia when a donor had reached the offspring limit for the state in which they originally donated. Donors from minority racial groups that were difficult to recruit were particularly sought after through this arrangement. The inter-state exchange of semen occurred at Prince Henry's from the late 1970s until at least 1988. It was reported that donors would not have been informed that their semen had been sent interstate.

As a Prince Henry's clinician explained:

We had an arrangement with Queen Elizabeth Hospital (Adelaide) for years that when we got to our – look, again, my memory's not exact – I think we got to 10 families in those days or 10 children. No, it was 10 children I think. When we got to 10 children per donor then we wouldn't use the semen any more for Victorian women and we'd sent it over to Adelaide and they would send us some of their donors who has exceeded their limit too. So, we had that sort of informal arrangement.

No one was able to clarify whether these donors were given new donor codes when their semen was sent interstate, or if or how their identities were connected to the other state's records.

#### What were donors told about their offspring?

Both donors and clinicians confirmed that in the early years of the program most donors were not told whether their donations had produced children, though a number of them discovered this information over time. However, a Prince Henry's donor recruitment brochure from 1987 states that donors can choose to receive feedback on the number of offspring produced and their sex. Ian, who donated for approximately 11 months in 1986-87, was not informed of any donor offspring at the time of donating and so presumed he had none. However, he received a letter from Monash IVF in 1999 informing him that his sperm had resulted in several pregnancies, with the last recorded pregnancy in 1992. Ian described the letter as "confronting" and a "bolt out of the blue". He was shocked to discover that his frozen sperm may still be in circulation and that it had been used as recently as 1992. Upon learning this information, he contacted Monash IVF to withdraw his consent. He was informed that the straws had been destroyed. Ian does not know why he received the letter in 1999. None of the other donors interviewed had received such a letter.

Upon reflection, Ian decided to pursue further information about his offspring, contacting Monash IVF to ask how many children had been conceived and when, and if they were in good health. He received a letter from the Director of Clinical Research in 2000, which indicated the sex, age and birth date of each of his offspring.

Roger, who donated from 1986-88, was the only donor to be informed of offspring as they were born. Roger got to know the head of the andrology laboratory, Rose, quite well as he volunteered his services to promote the AID program. One day he asked her about the recipients of his donations. He explained:

**Roger:** [I asked her if] I had any offspring. And she was very quick out of the blocks to provide that information. I've still got the letters. And she lists the couples who were recipients of my sperm.

Interviewer: With their actual names?

**Roger:** No. She lists their occupations, and their attitudes, and what they were looking for, and all that sort of stuff. And then, when the children started to appear, she just sent little handwritten notes, and I've still got some of those.

Roger received five notes in total. In 2008, when he applied for the same information from VARTA it was confirmed that he had five donor offspring. The months and years of birth matched those provided by Rose.

#### What happened to the donor records when Prince Henry's moved to Monash Medical Centre?

In 1987, the Prince Henry's Medical Centre moved to Monash Medical Centre in Clayton. The donor program took its records to Clayton. Clinicians continued their existing record keeping practices and maintained their own records. In 1990, the donor program became part of the newly incorporated Prince Henry's Institute of Medical Research. It remained physically located at Monash Medical Centre.

The donor program at Prince Henry's Institute of Medical Research ceased operation in 1998. Existing patients and donors, along with their records, were transferred to Monash IVF. Closed records were moved to filing cabinets in a storeroom at the Monash Medical Centre.

#### Where are the Prince Henry's records now?

In 2006, it was decided by the Board of Prince Henry's Institute of Medical Research to transfer the donor program records to the Public Records Office of Victoria, which has designated them 'permanent records'. The transfer of records was completed in November 2006. The records contain information from 1976-1998. They include infertility patient records, sperm donor files including both identifying and non-identifying information, a donor insemination register which lists pregnancies from 1976-1998, and known donor files (1985-1997).

#### How do donors view their participation in the program now?

The donors were asked to offer their thoughts on the social and historical factors that made donor anonymity the accepted norm at the time they donated. They all acknowledged that they went into the process of sperm donation with a degree of naivety. They participated on the basis that they were helping people, and none of them were initially inclined to question the status quo. However, they also emphasised that donor conception in the 1970s and 1980s needs to be understood in its historical context. In the 1970s, conceiving with donor sperm was often compared to adultery, and religious groups who opposed the practice targeted fertility services.<sup>40</sup> The donors noted that this social environment made it very difficult for them, and parents, to talk about participating in the Prince Henry's program.

Being a sperm donor and using infertility services were also topics about which people did not speak candidly and the Prince Henry's program operated within that context. As Roger explained:

At the time I was a donor...it was a complete taboo subject. I never mentioned it to my friends, my family. Only...my wife. The rest of the family really didn't know...And if there are offspring out there who have got a percent of anger about anonymity, or if there's anxiety, I would say to them that that was the way it was. It was a bit like talking about death, about funerals. It was the way that society was. And the taboos on donor conception, and assisted reproductive treatments, were all hush-hush.

However, Roger felt that Australia was currently "on the brink of change" and that he had played a role in that transformation. From very early on, he decided he would "put [himself] forward" to do interviews with the media and to write newspaper and magazine stories about donor conception, "to try to get this thing out in the open".<sup>41</sup> His goal was to "try and break down, not necessarily the anonymity, but the business about donor conception. And that it was normal and acceptable. And to be a donor was something that you could do and be altruistic about it".

Ian also felt it was important to highlight the role societal attitudes towards male infertility played in creating an environment of secrecy and shame. As he explained:

I think in that era it was generally considered to be a detrimental thing for parents to tell their children that they were donor offspring and...I think with regards to the male, I think infertility and virility or manhood were very much connected issues so therefore it was something that they wanted to keep secret as well. I think it was [understood as] a bit of a reflection on their manhood in that particular era and I think the general message that was being portrayed at that time was that it was all very secretive and should be kept that way. I don't think there was any research or information to suggest that it could be harmful to those offspring not knowing and I think also there was almost a thought that if it was a secret then it would remain a secret.

Though the donors understood that their donations were anonymous, this did not stop them from thinking about their donor offspring. For example, once he became aware that his donation had resulted in children, Ian indicated that he often wondered about them: "Are they in good health? How many are there? Just concerned for them, essentially". In 2014, he drafted a letter to them that could be provided if they applied to the Voluntary Register. He stated:

I think about you often – in something like the way I imagine a relinquishing parent of adopted children must do. I wonder how your life has been. Are you happy, healthy and well loved? I dearly hope that you are.

<sup>&</sup>lt;sup>40</sup> John Leeton, *Test Tube Revolution: The Early Years of IVF* (Monash University Publishing, 2013) 58.

<sup>&</sup>lt;sup>41</sup> See, eg, "The gift of life: a sperm donor's own story", *Portfolio*, September 1988.

The other Prince Henry's donors shared lan's perspective. All of them had made themselves available to offspring through the Voluntary Register. John explained how he came to join the Register:

It was something I had always thought about in the back of my mind, but I had been working [overseas] for quite a few years and I remember getting – it must have been 10 or so years ago – and I remember getting a newspaper on the flight and the lead story was about a girl...who was trying to trace her donor father. It was just interesting because I think it was something that I had always had in the back of my mind and then there was this story that actually really hit home. And I thought this was quite an important thing for a donor child if they know and they are desperate to have this information, to be able to find it out. So that's when I thought it would be important to go onto the Voluntary Register in case I was one of those people who was being desperately searched for.

Through his register application John was informed that he had six donor children, though none had joined the register themselves. John indicated his support for the recent legislative changes that retrospectively opened pre-1988 donor records and had begun the process of seeking more information through VARTA.

The views expressed by the donors interviewed appear to be representative of the donors who have sought assistance over the years from the ITA and, later, VARTA. For example, as Helen Kane, the former manager of Donor Register Services at the Infertility Treatment Authority, noted in her submission to the Victorian *Inquiry into Access by Donor-Conceived People to Information about Donors*, in her experience "it has not been unusual…to find that donors have wondered if there were children, and if there were, what were their lives like, and was there anything that they needed of them."<sup>42</sup>

#### Conclusion

The donor insemination program at Prince Henry's went through remarkable evolution between 1978 and 1988. Attitudes towards donor recruitment, screening and anonymity changed considerably, reflecting the shifting legal and social context in which the program operated. Most notable is the shift in the type of donor recruited from late 1986 onwards. Considerable effort was made to recruit men who were open to having their identity released to offspring. It can thus be speculated that this particular group of donors might be quite open to applications from offspring. It is also evident from the survey conducted with Prince Henry's donors in 1983 that a significant number of pre-1986 donors may also welcome contact.

The process of recording donor information and pregnancies at Prince Henry's appears to have been comprehensive and rigorous. The records have been well maintained and, following the decision of the Prince Henry's Board to relocate them to the Public Records Office in 2006, have been well preserved. They may, at times, be difficult to decipher due to the record keeper's handwriting, as well as the use of pencil in some cases. Overall, however, the records remain in good condition and are fully accessible to VARTA.

<sup>42</sup> Kane, above n 38, 4.

# CHAPTER 4 QUEEN VICTORIA HOSPITAL

### The history of the Queen Victoria Hospital donor program

The Queen Victoria donor program had many incarnations over the years, with numerous name and location changes. It proved difficult to build an accurate timeline, with different interview participants and other sources providing conflicting accounts, particularly in relation to the chronology of events. While the name changes do not appear to have had much impact on the way in which record keeping was conducted or managed, the movement of the donor program across several sites has made tracing records challenging. While the donor program was relocated from Queen Victoria to the Epworth Hospital in 1982 and ceased all connections with Queen Victoria at this time, for ease of identification it is referred to in this chapter as the 'Queen Victoria program'.

The earliest origins of the Queen Victoria donor program can be traced to the agreement in 1965 between Queen Victoria Hospital and Monash University that Queen Victoria become the teaching hospital for the university's Department of Obstetrics and Gynaeocology (the Department). Though the Department was located within Queen Victoria Hospital, it operated separately from it. It quickly became a focal point for research on infertility and, eventually, IVF treatment. Donor insemination treatment was provided on an ad hoc basis as early as 1971, though the formal program commenced in 1974 under the leadership of Dr John Leeton.

In 1973, the Monash University doctors and scientists working on IVF and donor insemination treatment established the Melbourne Family Medical Centre within Queen Victoria Hospital. The focus of the Centre's work was infertility treatment and IVF research. Dr Leeton managed the program, while Dr June Backwell conducted the inseminations using fresh semen and managed the donor records. The program attracted a number of research scientists interested in developing sperm freezing techniques and IVF treatment, including Dr Carl Wood and Dr Alan Trounson. The program did not always have the full support of the Queen Victoria Hospital, and so at various times in the mid-1970s it operated out of Dr Leeton's private rooms in Richmond.

In 1977, the Queen Victoria Hospital amalgamated with McCulloch House and the Jessie McPherson Hospital and was renamed Queen Victoria Medical Centre. The donor insemination program continued to operate out of Monash University's Department of Obstetrics and Gynaecology, located at Queen Victoria. It became known as the Melbourne Family Medical Centre and while it was located at Queen Victoria, it was an independent entity. At the same time, the AID Trust was established by Dr Carl Wood on behalf of Monash University and began trading at Queen Victoria. It charged and paid expenses related to donor insemination treatment, and was financially independent of Queen Victoria. Two additional trusts – the Monash Family Medical Centre and the Infertility Medical Clinic – were also established in 1977 to pay for the donor insemination program and IVF program respectively. In the early 1980s they were combined to create the Infertility Medical Centre, a private company controlled by Monash University but still located at Queen Victoria.

By 1978, advances in research meant that semen could be frozen. Fresh sperm was no longer used within the Queen Victoria program. By this time, Sister Gillian Wood, a nurse working in the program, managed the donor records. They were maintained separately from the general hospital records and were not subject to Queen Victoria record keeping practices.

In 1981, the IVF program moved to St Andrew's Hospital in Richmond. However, the donor insemination program and IVF program re-formed in 1982 to become the Infertility Medical Centre, which relocated to the Epworth Hospital in Richmond under the directorship of Dr John McBain. The Queen Victoria donor program ceased operation. During its time at the Epworth Hospital, the program was not affiliated with Monash University. Dr Backwell participated in the move to the Epworth, but was only loosely affiliated with the Infertility Medical Centre. She continued to perform inseminations in her private rooms at the Epworth using fresh sperm in the early 1980s. While the Queen Victoria donor program operated out of a number of different physical locations in the 1970s and early 1980s, it was the clinicians, rather than the host institution, who managed the records.

In 1984, the relationship between the Infertility Medical Centre and Monash University was re-established. The Centre became Monash IVF Pty Ltd, a private company owned by Monash University and under the directorship of Professor Gab Kovacs. It continued to operate at the Epworth Hospital. However, in 1987 Monash IVF relocated to the newly created Monash Medical Centre at Clayton, though it operated as a private company within the university. Responsibility for patient records was also transferred to the Monash Medical Centre.

Monash IVF continues to operate today. It was publicly listed on the Australian Stock Exchange in 2014.

#### How were donors recruited and what made them suitable for the program?

In the early years of the donor program, when fresh sperm was used, donors were largely recruited from the Monash University Medical School. Monash University medical students spent six weeks doing obstetrics and gynaecology at Queen Victoria, providing a steady stream of donors.<sup>43</sup> One of the doctors explained how they were recruited to the program:

I would give this talk [to the students] at the beginning and virtually no takers at all, but by the end of their six or eight weeks when they had exposure to the problems of what we were dealing with, such as infertility, and realising the problems, it was interesting that that's when I got a few recruits to do it. When they could actually see the problems. I think that's important, because just telling them straight off to their face, first, they didn't understand what the problem was.

Recruitment was also conducted through advertisements in Melbourne and university newspapers, radio interviews, and flyers and pamphlets that were handed out on the city streets. Mary, a scientist in the semen analysis lab from 1979 to 1982, recalled distributing donor recruitment flyers at Flinders Street train station. One of the scientists also reported that networks of donors were created via word



of mouth. For example, a man might donate and then tell his friends or colleagues about it, such that "a big network was created".

Donors at Queen Victoria received \$10 per donation, which was described as "travel money" in the interviews. Those involved in the program described the donors as

Farrago, Melbourne University Student Newspaper, March 23, 1978, p. 27.

<sup>43</sup> John Leeton and June Blackwell, 'Artificial Donor Insemination' (1976) 16(2) *Australian and New Zealand Journal of Obstetrics and Gynaecology* 45.

largely altruistic. Mary recalled the story of one donor who joined the program because he felt so fortunate to have been able to have four children with his wife and wanted to offer the same joy to infertile couples. Ray, who donated from 1980-1987, expressed a similar sentiment. He and his wife had several children and decided together that Ray should donate sperm so others could experience parenthood. Ray received \$10 per donation, which he used to pay for petrol and parking as he lived in country Victoria. Michael, who donated as an 18 year old in 1982, also reported that he donated because of a "desire to help people". He noted that "the money was lovely, but I don't think it was the main reason." Michael was also a regular blood donor, a service for which he was not paid. Patrick, however, who donated between 1977 and 1979 while living on a meagre student stipend, acknowledged that the \$10 payment was a motivating factor.

Beyond medical fitness and semen quality, which are discussed below, there were no restrictions on who could become a donor at Queen Victoria.

A.I.D.

Semen Donors are required by Melbourne Family Medical Centre for research and A.I.D, (Artificial Insemination by Donor). There is a reimbursement of \$10 per specimen. For further information ph. 663 3894.

Catalyst, RMIT Student Newspaper, May 9, 1979.

#### What were donors told about the objectives of the donor program?

Mary, a scientist in the semen analysis lab who conducted donor intake interviews from 1979 to 1982, reported that donors were told that their semen would be used for artificial insemination of women whose husbands were infertile. Similarly, one of the scientists working in the IVF program reported that recruitment in newspapers and in medical school lecture theatres included clear statements of the purpose of the program. Two of the donors interviewed confirmed that they understood that their donations would be used for donor insemination. Patrick, however, who started donating in 1977, reported being told that his donations would be used for both fertility treatment and research.

#### What information was collected about donors?

Information about the Queen Victoria donors was recorded on the "Semen Donor Application Form". See page 36. The donor underwent a medical examination, including screening for infectious diseases. A donor's blood group was also recorded, and chromosomal karyotyping was undertaken to ensure donors did not carry any genetic abnormalities. The donor also completed a medical questionnaire, which included questions about his family medical history. The donor's physical characteristics, including height, build, ethnic background, complexion, and hair and eye colour were recorded, as well as his occupation, marital status, and whether he had fathered any children. The physical characteristics of the donor's parents were also recorded. If the donor had produced children, the health and physical characteristics of his children were reported. Finally, the donor was asked whether he wanted to be informed of any pregnancies resulting from his donations. It was reported by two of the clinicians that the donors were mostly single men.

#### DONOR STATEMENT AND CONSENT

- I offer my services as a donor of semen with the understanding that it is your intention to use my semen for purposes of artificial insemination.
- II. For the purposes of determining whether I am acceptable as a donor of semen, I consent to a physical examination including the taking of blood and other body fluids, by you or any other doctor or medical worker whom you may designate.
- III. There are some people in the community who MUST NOT donate semen because their semen may infect patients who receive it. The following statement must be completed and signed by any person who wishes to donate semen. Please read it carefully as it is an offence to make a false statement or to give false information in relation to any statement, and any person who does so is liable to a heavy penalty. If in doubt, please consult the Artificial Insemination Service staff.

#### STATEMENT

I hereby certify that to the best of  $\ensuremath{\mathsf{my}}$  knowledge all of the following statements are true:

- 1. I have not engaged in male to male sexual activity during the past five years.
- I have not injected myself, or been injected with, any drug not prescribed by a qualified medical practitioner within the past five years.
- I am not suffering from night sweats, weight loss, persistent fever, diarrhoea or swollen glands.
- I have no reason to believe that I am suffering from AIDS (Acquired Immune Deficiency Syndrome) or any disease related to it.
- I have not received a blood transfusion or recurring treatment with human blood products within the past five years.
- 6. My spouse or any sexual partner does not come within the categories described in items 1, 2, 3, 4 and 5.
- I have not been treated by acupuncture, had my ears pierced or been tattooed within the past five years.
- I have not been in a tropical area where malaria occurs within the past twelve months or had an attack of malaria or taken anti-malarial drugs within the past two years.

	QV
MELBOURNE FAMILY MEDICAL CENTRE	1985
SEMEN_DONOR_APPLICATION_FORM	
NAME	
TELEPHONE HOME	·
DATE OF BIRTH	·
ETHNIC HISTORYAUSTBALLAN	
OCCUPATION	
CONTACT: NONE	
MEMC STAFF ONLY.	
OTHERS	
WARITAL STATUS	
	·
HAVE YOU FATHERED A CHILD?	
had a partner become pregnant?	
NUMBER OF CHILDREN	
NUMBER OF CHILDREN	
HAIR, EYE COLOUR OF CHILDREN. FOW., T. DULL. LUCS:	
MAR, BIE CODOR OF CHILDREN. ACTU, ALL CONCOLLED THE THE	
PHYSICAL CHARACTERISTICS	
DONOR FATHER MOTHER WIFE	
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COMPLEXION. TENY - Alver Aire Bir.	
HAIR COLOUR. L.J. brown St. brown. Lt brown. Lt.b	
HAIR COLOUR	700000
EYE COLOUR. blue blue blue blue	, I
/2	

	DONOR HISTORY
	Optional, non-identifying information which prospective AID patients/children may wish to know. You need only answer questions you wish to.
Date:	10/12/85 Donor Code:
	PERSONAL INFORMATION Age 18 - 24 Years 25 - 29 Years 30 - 34 Years 35 - 40 Years
	Nationality: AUSTRIALIAN
	Country of Birth: AUSTRALIA
	Married: (YES)/ NO
	No. of Children: Girls:
	Boys: No. of:
	PHYSICAL CHARACTERISTICS
	Height:5'6"
	Build:Slight-med
	Hair Colour: 14. brown
	Eye Colour:bule
	complexion:
	Blood Group:A, RS
	/3

Grandfather's	Nationality: AUST	RALIAN.
	Country Birth: AUSTR	
	Age:	
	still Living: YES / NO	
OTHER INFORMAT	ION	
Occupation:		
If Student, Co	urse being studied:	
	-	
Level of Educa	tion Reached: leaving	(5th form)
Interests and	Hobbies:	
	/	
	/	
Do you have an	y Special Talente? (e.g. music	
Do you have an		al, sporting, artist
Do you have an		al, sporting, artist
		al, sporting, artist
		al, sporting, artist
Are you allerg		al, sporting, artist
Are you allerg If any childre you, when they	ic to anything? <u>NO</u> m result form AID treatment wi reached 18 years:	al, sporting, artist
Are you allerg If any childre you, when they Definit	ic to anything? <u>NO</u> n result form AID treatment wi reached 18 years: ely never wish to meet them?	al, sporting, artist
Are you allerg If any ohildre you, when they Definit Like to	ic to anything? <u>NO</u> m result form AID treatment wi reached 18 years:	al, sporting, artist th your eemen, would YES / NO YES / NO

DONOR INFORMATION RECORD, QUEEN VICTORIA HOSPITAL (MELBOURNE FAMILY MEDICAL CENTRE), 1985 From at least 1979 onwards, donors were also provided with a second, optional, form titled "Donor History", which asked them to provide non-identifying information that could be given to "prospective AID patients/children". This form repeated many of the questions in the Semen Donor Application Form, but also included additional information about the donor's extended family, level of education, interests and hobbies, and special talents. The final question asked whether the donor was interested in meeting his donor offspring. Donors were provided with three options:

If any children result from AID treatment with your semen, would you, when they reached 18 years:

Definitely never wish to meet them?	Yes/No
Like to meet them?	Yes/No
Be prepared to meet them if they wished	
to, but not solicit a meeting?	Yes/No

Mary, who conducted the donor intake interviews from 1979-1982, reported that, "it wasn't uncommon that [a donor] would say yes, they didn't mind". However, it was "more common amongst the students that they weren't interested at all". The donor's answer to the question had no bearing on whether he was accepted into the program.

#### What records were kept about donors and recipients and where were they stored?

Throughout various incarnations of the Queen Victoria program, each donor had a file that was kept in a location separate from the semen laboratory. This file contained his Semen Donor Application Form, which included his name and contact details. In the semen laboratory, each donor had a card on which he was identified via two codes. The first was a four-digit code that referred to his physical characteristics (height, build, hair colour and eye colour) and was used for matching donors with recipient couples. The second was the donor's code, which consisted of a number and a letter. The letter was the first letter of the donor's surname and the number was based on how many donors already in the program had a surname beginning with that letter. For example, if the donor was the first donor with a surname beginning with J, he was 1J.

Each semen sample was also coded, so a sample might be 1J5, meaning the fifth semen sample from donor 1J. When an insemination was conducted it would be recorded on the recipient's file that the semen sample used was 1J5. Similarly, on the donor's card it would be recorded that 1J5 had been used to inseminate a particular (coded) recipient. Mary, who managed the donor records from 1979-82, confirmed that the codes were successfully used to match donors and recipients in the event that couples returned to the program for a second child. Of the donors interviewed, all confirmed that they were not given their donor code, though two of the three have since obtained it.

Recipients had a patient file that was stored in filing cabinets in the nurses' office. It was nurses who conducted the inseminations. The patient file recorded the donor's code only. When a pregnancy occurred, the nurse would notify the semen lab that the insemination had been successful using a particular sample. The pregnancy would be recorded on the donor's card, which enabled the laboratory to monitor how many offspring each donor had produced.

#### What were recipients told about donors?

Recipients reported that they were told very little about donors and were given virtually no choice in the donor assigned to them. Each of the recipients reported that they were told they would never be able to obtain the identity of the donor. One couple was also told that the records would be destroyed after ten years.

In all cases, recipients were reassured by nurses and doctors that efforts had been made to physically match the donor to the husband. In one case, the couple was able to request a donor who shared their religious faith. One of the couples who conceived via IVF in 1980 was given non-identifying information about the donor once the pregnancy was confirmed. However, this was not the case with the other two couples, suggesting there was an inconsistent approach to information provision. A second parent, who received treatment in 1982 and again in 1986, contacted her treating doctor in 1997 to request non-identifying information about her children's donors. She was promptly provided with several pages of health and physical information about each donor and his parents, as well as the donor codes.

One of the recipients, Nicholas, had adopted a child a year before his wife received treatment and reflected on the differences between the two experiences. Victoria had recently amended its adoption legislation, creating the possibility of open adoption. He and his wife were encouraged to tell their child early on that she was adopted, whereas they were advised the opposite with regard to their donor-conceived children. As he explained:

### **Recipient parent:** [With the donor conception] you were very much, you just get on with your life as if...it was all natural.

#### Interviewer: As if nothing happened?

**Recipient parent:** Yeah. That's the way it was presented and the way we carried things through – if that makes sense. Given our background with the adoption, it is a contradiction, when you think about...It's interesting because I think for quite a while there was this clash between the two systems. And I think what people presumed was that you could just hide donor conception in a way that you couldn't hide adoption.

Nicholas also noted that when he and his wife adopted their daughter they received information about the child's mother from the Royal Women's Hospital. The information included a physical description of the mother, as well as a letter she had written to her daughter. As he noted, they "got nothing like the equivalent" for their donor-conceived children, despite them being born just 18 months after the adoption.

#### Were limits put on the number of offspring per donor?

Queen Victoria clinicians participated in the annual national workshops on donor insemination that began in 1977, and subsequently became the Fertility Society of Australia in 1982. They were therefore

<sup>&</sup>lt;sup>44</sup> David Danks, 'Genetic Considerations' in Carl Wood, John Leeton and Gabor Kovacs (eds), *Artificial Insemination by Donor* (Brown Prior Associates, 1979) 94.

part of discussions around the appropriateness of limiting offspring numbers. These discussions focused on the risk of consanguinity and relied on evidence provided by geneticists.<sup>44</sup>

It was reported by the Queen Victoria clinicians who worked in the program in the mid-1970s that there was an initial limit of 20 offspring per donor. That was decreased to "15 or even 10" by the late 1970s. Mary, who worked directly with the donors and their records, reported that by the early 1980s, donors were limited to six offspring. Ray, who donated from 1980 to 1987, confirmed that he was told that he was only able to father six offspring. Additional offspring were permitted only if the couple already had a child using that donor.

Queen Victoria clinicians, as well as a clinician from South Australia, confirmed that semen was sometimes sent interstate when a donor had reached the offspring limit for the state in which they originally donated.<sup>45</sup> The inter-state exchange of semen occurred at Queen Victoria from the late 1970s until at least 1988. It was reported that exchanges occurred between Queen Victoria and Queen Elizabeth Hospital in South Australia, as well as with hospitals in Queensland. Donors would not have been informed that their semen had been sent interstate. When semen was transported interstate, the donor's medical information was also sent, but it could not be confirmed if donors were given a new donor code in each state. Donors from minority ethnic groups were in particularly high demand.

#### What were donors told about their offspring?

Queen Victoria donors were given the option of having any pregnancies resulting from their donations reported back to them. Michael, who donated in 1982, reported that he had been informed of two pregnancies from his donations. He was also told that his semen would be stored in case those families came back for a second child. When he made contact with the Infertility Treatment Authority in 2000, he discovered that two additional children had been born.

Ray was informed of one successful pregnancy while he was donating. When he contacted Births, Deaths and Marriages (BDM) in 2011, he was told he had three additional offspring. BDM staff also provided him with his donor code, which they obtained from Monash IVF. Ray has since joined the Voluntary Register.

#### Where are the Queen Victoria records now?

The clinicians uniformly reported that most of the pre-1988 Queen Victoria records no longer exist. A small number were transferred to Monash IVF because patients were continuing with treatment that had begun at the Epworth Hospital. It is understood that these records were provided to Births, Deaths and Marriages. However, it was the position of the clinicians interviewed that the remainder of the records were "inadvertently lost" in the move from the Epworth Hospital to Monash Medical Centre at Clayton in 1987. As one of the clinicians explained:

There would have been records kept for tracing. We kept the records. I would like to say here that no records of ours were deliberately destroyed...We kept them. I think the records, later on, years later, were inadvertently lost, but they were never destroyed.

<sup>&</sup>lt;sup>45</sup> Colin Matthews and John Peek, 'Artificial Insemination- donor and husband' in Roger Pepperell, Bryan Hudson and Carl Wood, *The Infertile Couple* (Longman Group, 1980) 233, 243.

Statements of this type have been made in a variety of contexts over the years, including letters to parents from clinicians and interviews and other communications with staff at ITA and VARTA. The only Queen Victoria records that are said to exist from the pre-1988 period are those of patients who were receiving treatment at the time of the move to the Monash Medical Centre.

One of the clinicians stated that the fresh semen records from the early days of the program were held by Dr June Backwell. The clinician was under the impression that those records were not part of the move to Monash Medical Centre. It was presumed that Dr Backwell took those records with her when she left the practice. The researchers have been unable to locate Dr Backwell.

The donors speculated that some records must still exist given how much information had been provided to them at different times. For example, VARTA was able to obtain Ray's donor code and offspring numbers from Monash IVF, suggesting that significant information was available to Monash IVF staff. As Ray noted, "Because of the anonymity thing I was a little – I was perhaps surprised that they were actually able to tell me as much as they did." Similarly, Michael was able to obtain his donor code and VARTA had located two of his donor offspring. One of the recipient parents was also able to access significant information. In 2009 she was informed that Monash IVF had been able to confirm the donor's code, as well as the sex and month and year of birth of each of her child's donor offspring. The provision of this information suggests that some Queen Victoria records still exist, though they may not have been made available to VARTA.

Evidence was obtained about the existence of a Queen Victoria 'pregnancy book' that was completed by nurses and dates from 1978 onwards. During the course of this research, it was confirmed by current staff at Monash IVF that the pregnancy book still exists and is accessible to them. Monash IVF has provided VARTA with information on pre-1988 records held, including the pregnancy book, in accordance with the *Assisted Reproductive Treatment Act 2008* (Vic).

#### How do donors view their participation in the program now?

The three donors reported that they had thought about their donor offspring over the years and that their interest in them grew over time. They each conceded that they did not fully grasp the gravity of what they were doing at the time of donating. Michael, who was only 18 when he donated in 1982, explained:

You didn't consider what it was going to be like in 20 or 30 years' time, especially when you then have your own children later. You suddenly realise, "Oh wow. There's other children out there that are mine and now that I've been through that, not being able to connect with them would be very disturbing"...I also talked to my psychologist and other people in that area all said the same thing. That even though they might not want to know, every child has the right to know where they've come from.

Through VARTA, Michael had made contact with two of his offspring, a set of twins, one of whom "embraced it 100 per cent" and the other who had been in touch only to thank him and "wish him well in the future".

Ray also found that as he aged and became more aware of the challenges donor-conceived adults sometimes experienced, he began to rethink the implications of what he had done. As he explained:

[I]t would be nice to meet them and have a coffee, but I don't see any long-term relationship with them. That wasn't why I registered [on the voluntary register]. It was more for if they were in that position and they really wanted to know. [If] a sperm donor was holding out on them then I think that would be very traumatic or could be traumatic. [I read about offspring] who found it very difficult not to know their biological heritage.

At the same time, Ray felt that he, and the clinicians of the time, could not have anticipated how matters would unfold. He felt that he was "doing a service for people" and, at the time, "didn't realise that some kid that I may have fathered would have been desperate to find out who their biological father was. It's just how society has changed and we realise we can't do things like we used to."

#### Conclusion

The Queen Victoria donor program was located at five different sites from 1974 to 1988 period. It also underwent numerous name changes as it broadened its scope and moved between different institutions. Throughout this period, however, it operated as an independent entity, with its records never being subject to the rules of the hospital or medical facility within which it was located. As a result, the records were maintained by, and moved with, the clinicians with little oversight.

It is the evidence of the clinicians who worked in the donor program that the Queen Victoria records were inadvertently lost when the program moved from the Epworth Hospital to Monash Medical Centre in Clayton in 1987. Each of the clinicians interviewed wished to make it clear that the records were not deliberately destroyed. It became apparent during the course of our research, however, that Monash IVF continued to hold some relevant documentation from the requisite time period, including a "pregnancy book". This material has now been made available to VARTA.

## CONCLUSION

Given that all donor-conceived Victorians now have a legal entitlement to their donor's identity, the existence, maintenance and integrity of the pre-1988 donor records has become a matter of significant importance. In this report, we began with a brief socio-legal history of donor conception in the State of Victoria. We have also traced what information was collected about donors pre-1988, how it was recorded and managed, where the records were stored and, where possible, where those records are currently located. We have also provided a brief history of the three, main hospital-based sites, noting name and location changes, amalgamations and closures. In preparing this report, we were not able to add to the slim information that exists about how doctors in the 1940s-60s practised donor insemination in private clinics or the records that may have been kept from that time. However, we have been able to obtain substantial information about practices and processes from the mid 1970s to 1988 in the three hospital-based programs.

Attitudes towards matching and the kind of information collected about donors appears to have shifted quite considerably at all three sites between 1976 and 1988. Whereas in the 1970s, there was a strong emphasis on donor anonymity and matching the physical attributes of the donor to the prospective father, a substantial change appears to have occurred in practices from the early to mid-1980s. Although this was slightly different at each of the three sites, we can conclude with confidence that from the mid-1980s, more donors and recipient parents were given information that prepared them for the possibility that donors' identities would be released to offspring in the future. Rather than viewing the donor as a collection of traits to be matched to recipient parents, the donor was increasingly understood as a person who may become known to recipient parents and their children in the future.

Our findings also indicate that donors from the pre-1988 period could well be open to some degree of information disclosure. It is also evident that some donors from that time subsequently had considerable interest in the offspring born as a result of their donations.

The process of recording donor information and pregnancies at the Royal Women's and Prince Henry's appears to have been comprehensive and rigorous, and the records are known to be in good condition. The records have been well maintained and their current location is known. The records at these sites remain in good condition and are believed to be fully accessible to VARTA.

At the same time, there are likely to be issues in coming years with regard to the condition of the Royal Women's and some Prince Henry's records. At the Royal Women's, there is potentially an issue with the quality of some of the original paper files which may have faded or become fragile over time. Transferring these original files to an archive such as the Public Records Office of Victoria, where temperature and pest control protocols are in place, is therefore recommended. It was also unclear from our research exactly where the recipient parent files are located in relation to the Andrology Department-based sperm donor files, although there appears to have been no problem to date in linking them when this has been required. Following the decision of the Prince Henry's Board to relocate their records to the Public Records Office in 2006, they have been well preserved. However, some may be difficult to decipher due to the record keeper's handwriting, as well as the use of pencil in some cases.

By contrast, despite what appear to have been rigorous record keeping processes in the pre-1988 period, many of the records from the Queen Victoria program have been reported as lost or destroyed, with the exception of those from patients who continued treatment with Monash Medical Centre at the time of the hospital's closure. The clinicians associated with this program maintain that records were never deliberately destroyed. Evidence emerged during the course of our research that Monash IVF continued to hold some pre-1988 Queen Victoria donor program records, including a pregnancy book. Monash IVF has now provided VARTA with access to the material in accordance with the *Assisted Reproductive Treatment Act 2008* (Vic).

Where possible, in this report, we have endeavoured to capture the attitudes and reflections of those involved in the early days of the Victorian fertility industry in an effort to understand the social and legal context in which decisions were made. We hope this report contributes to a sense of closure for those whose family lives have been affected by past practices.



The **Victorian Assisted Reproductive Treatment Authority** independent statutory authority funded by the Victorian Department of Health and Human Services.

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