



**A LEGAL ANALYSIS OF TRADE IN
PERSONAL INFORMATION REGARDING
HUMAN GAMETE DONORS**

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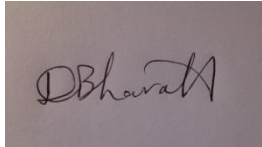
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DECLARATION

I, Deepthi Bharath, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

Signature:

A rectangular box containing a handwritten signature in black ink. The signature appears to be 'DBharath' written in a cursive style.

ACKNOWLEDGEMENTS

To my supervisor, Dr Donrich W Jordaan, thank you for invaluable knowledge and contribution to this leg of my LLM journey. Apart from periodically ‘cracking the whip’ to push me to write each chapter to the best of my ability, thank you for lending an ear and encouraging me when I felt lost and overwhelmed.

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ABSTRACT

The aim of this dissertation is to legally analyse whether personal information concerning gamete donors can be traded in South Africa, particularly by South African gamete banks and agencies. As business enterprises, gamete banks and agencies may view such trade as a profitable business model which provides them with a competitive edge in the fertility industry. However, absence of regulation in this regard has caused legal uncertainty for those banks and agencies who wish to engage such a business model. In this desktop-based research, it was found that:

- Autonomy is a key bioethical factor in the consideration of whether personal information should be offered to prospective parents by gamete banks and agencies. In particular, a significant amount of donor information acts as an autonomy-enhancing tool for prospective parents during the donor selection process, and thus South African gamete banks and agencies should be allowed to offer such information as an optional extra.
- Comparator countries such as the United States of America, United Kingdom and Canada deal with the provision of gamete donor information differently to South Africa. Many gamete banks and agencies in these countries provide prospective parents with detailed donor information without compromising donor anonymity. Furthermore, many of these gamete banks and agencies provide a basic donor profile free of charge, while charging a fee for access to extra detailed donor information.
- South Africa can, in principle, allow the trade of personal gamete donor information.

As it is established that trade in personal gamete donor information is permissible, this must be made clear to eradicate any uncertainty experienced by South African gamete banks and agencies. Furthermore, there should be safeguard mechanisms in place to guard against undue enticement of donors with regard to profit-making in the sale of donor information. Therefore, the following recommendations are advised:

- A minor amendment in section 60(3) of the National Health Act.
- Promoting donor autonomy by strengthening the informed consent mechanism. This can be done via state regulations concerning donor-counselling or guidelines issued by SASREG.

- Offer donors modest compensation for the provision of their personal information; such compensation may be determined through guidelines issued by SASREG.

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CHAPTER 1 – INTRODUCTION

1.1 Introduction

Meet Margaret, a 35 year old South African doctor who owns a small family practice. She and her husband Michael have been trying to have a child for the past three years, but after countless unsuccessful attempts, Margaret decided that it was time for them to visit a fertility specialist. Michael has been diagnosed with azoospermia, a male medical condition characterised by the semen being devoid of sperm cells. After deliberating over all their options going forward, Margaret and Michael decided to try conceiving through donor sperm. Unfortunately, none of the South African sperm banks they have researched offer an amount of donor information that they deem as adequate to make an informed choice. As a result, Margaret and Michael had to purchase and import sperm from an international sperm bank that offered a significant amount of non-identifying donor information – a rather costly affair. Now, with a healthy baby girl who recently celebrated her first birthday, it is Margaret's dream to eventually open either a sperm or egg bank to help other infertile South Africans realise their dreams of becoming parents. While she is aware that donor anonymity is protected in South Africa, Margaret wishes to follow a certain business model (similar to that of some international gamete banks and agencies) where basic biographical information concerning the donor is provided free of charge, and extra non-identifying information (such as handwriting samples, audio clips etc) is provided at a fee. She wants to prevent other prospective parents from having to incur great expense in importing gametes from abroad, simply because those international gamete banks offer the option of purchasing extra donor information such as handwriting samples, audio clips etc, whereas none of the South African gamete banks do. She feels, however, that she requires legal certainty regarding this aspect before proceeding with her business endeavour.

1.2 Definitions

1.2.1 Gametes

Gametes are sex cells that possess 50 per cent of the genetic material necessary to form a complete being.¹ In terms of National Health Act 61 of 2003 ('the NHA'), the term 'gamete'

¹ 'Gamete' available at <https://www.britannica.com/science/gamete>, accessed on 24 September 2017.

is defined as ‘either of the two regenerative cells essential for human reproduction’. Therefore, a sperm cell is a male gamete and an egg cell is a female gamete.

1.2.2 Gamete donor v gamete recipient

The Regulations Relating to Artificial Fertilisation of Persons² (‘the Regulations’) in terms of the NHA, define a gamete donor as a ‘living person from whose body a gamete or gametes are removed or withdrawn, for the purpose of artificial fertilisation’.³ The Regulations also define a gamete recipient as a woman who will be artificially fertilised, or whose womb will house an embryo.⁴

1.2.3 Gamete bank v gamete agency

When prospective parents decide to use a gamete from a donor, the gamete has to be sourced from a third part supplier ie a gamete agency or gamete bank.⁵ Although both gamete agencies and banks recruit potential gamete donors, the essential difference between agencies and banks is that agencies merely match prospective parents to the donors, while banks go on to collect and store gametes which are then available for immediate use.⁶

1.2.4 Required Information v Additional Information

This definition has been extracted from the founding affidavit in the *Nurture* case. Required Information is a reference to the exhaustive list of gamete donor information that is legally required to be disclosed to recipients, as per Regulation 9(2)(b) of the Regulations.⁷ Conversely, Additional Information is a reference to any other personal yet non-identifying gamete donor information falling outside the ambit of Regulation 9(2)(b) ie information that is *not* legally required.⁸

1.3 The discussion

Androcryos; Gift ov life; Nurture Egg Donors CC (‘Nurture’); Aevitas Sperm Bank; Medfem; and Vitalab Egg Donation Agency. These names represent a random selection of some South African gamete banks and agencies. A cursory view of each of these institutions’ websites reveals two common themes – none of these banks and agencies sells donor

² GN R1165 GG 40312, 30 September 2016.

³ The Regulations, 33.

⁴ Ibid.

⁵ Founding affidavit para 17 p15.

⁶ Founding affidavit para 18 p15.

⁷ Founding affidavit para 51 p32.

⁸ Founding affidavit para 63 p37.

information to prospective parents, and not many of these institutions even offer an extensive amount of donor information as compared to some international gamete banks and agencies. Of course, each institution offers prospective parents a limited amount of basic biographical information (with slight variations) about potential donors, such as age, height, mass, eye colour etc as this is in direct compliance with the primary legislation pertaining to gamete donation in South Africa – the NHA and the Regulations. Regulation 9(2)(b) requires that this exhaustive list of basic biographical donor information be disclosed to gamete recipients. Furthermore, Regulation 9(2)(b) works in accordance with Regulation 19 which ensures the legal protection of gamete donor anonymity. However, what should be made of non-identifying donor information that falls outside the ambit of Regulation 9(2)(b)? Furthermore, what should gamete banks and agencies do if they wish to provide extra non-identifying donor information at a fee to gamete recipients?

Consider, for example, the Fairfax Cryobank in the United States of America (‘USA’) which is a sperm bank.⁹ With regard to their anonymous donors, the Fairfax Cryobank allows prospective parents to browse through summary donor profiles, medical history (including that of the donor’s family), childhood photographs, staff impressions, donor essays, audio clips etc, free of charge.¹⁰ If, however, prospective parents wish to access further detailed non-identifying information about the donor (such as a personal profile, full audio interview, personality test results etc), they would have to purchase a package option to gain such access (the cost depends on the package option the prospective parents want to purchase).¹¹

Currently, the NHA outlaws the trade in gametes, as per section 60(4)(b). However, both the NHA and its Regulations are silent with regard to the trade in gamete donor *information*. The Southern African Society of Reproductive Medicine and Gynaecological Endoscopy (‘SASREG’) offers the most influential (though not legally binding) guidelines and recommendations pertaining to reproduction and surrounding issues. However, even SASREG does not address this lacuna in the law. At most, SASREG’s Guidelines for Egg Donation Agencies stipulate that no identifying information about the donor can be revealed to prospective parents, but it does allow photographs of egg donors up until the age 10 years to be provided to prospective parents.¹² Thus, nothing in SASREG’s Guidelines precludes

⁹ See <https://fairfaxcryobank.com/>, accessed 10 October 2017.

¹⁰ Ibid.

¹¹ Ibid.

¹² https://ifaasa.co.za/fertility-treatment/newsletter_02_2015_egg_donation_guidelines/, accessed on 10 October 2017.

other non-identifying information from being disclosed to prospective parents, let alone being sold to them. As such, the overall lack of regulation with regard to the trade in gamete donor information paints a grey area for gamete agencies and banks wishing to engage with such a business model.

The issue of trade in gamete donor information, however, was recently the subject of a South African High Court application: *Nurture Egg Donors CC v Minister of Health*¹³ ('the *Nurture* case'). Regrettably, the application was withdrawn after *litis contestatio*, therefore, there will not be any judgment in this matter. Nevertheless, the extensive papers¹⁴ filed in this matter are in the public domain. In the fourth chapter of this dissertation, I analyse the papers filed in the *Nurture* case. For now, the following synopsis of the *Nurture* case will suffice:

The applicant (*Nurture*), a South African egg donation agency, applied to Court concerning the issue of whether gamete banks could provide Additional Information¹⁵ to prospective parents at a profit. *Nurture* stated that it intended to establish an egg bank in South Africa – independent of any fertility clinic and hence, a first of its kind in South Africa. However, it stated that as it is a good corporate citizen, it was prudent to first seek legal certainty as to whether it could follow the international business model of offering Additional Information to prospective parents at a profit. In support of its position that Additional Information can be freely traded, *Nurture* first highlighted the conceptual difference between donor *gametes* and donor *information*, and argued that while trade in gametes is prohibited, no similar prohibition is applicable to donor information. Secondly, it differentiated between Required Information and Additional Information, and conceded that the provision of Required Information is integral to the gamete provision transaction and consequently subject to the same trade ban; the provision of Additional Information, on the other hand, is an optional extra relative to the gamete provision transaction, and therefore sufficiently *removed* from the latter *not* to be affected by its trade ban.

The respondents (Minister of Health, Director-General of the National Department of Health, and the National Director of Public Prosecutions) opposed the application on four grounds. Their core argument was that although the provision of Additional Information is an optional

¹³ (82891/15) [2016] ZAGPPHC 185.

¹⁴ This is a reference to the Notice of Motion, Founding Affidavit, Interim Judgment, Answering Affidavit and Replying Affidavit.

¹⁵ Examples of Additional Information include childhood photographs, audio clips, handwriting samples, donor essays etc.

extra, it is *dependent* on the provision of gametes and therefore sufficiently *proximate* to the latter to be affected by its trade ban.

To this argument, the applicant replied that if the respondents' argument is accepted, it would render unlawful all commercial acts that are factually connected with, but do not amount to gamete donation. Examples of such commercial activities that were used by the applicant include '(a) the laboratory consumables supplier that provides the plastic straws in which the gametes are kept, and (b) the courier service that handles the transport of gametes.'¹⁶ The applicant argued that this consequence – rendering unlawful all commercial acts that are factually connected with, but do not amount to gamete donation – was clearly not the intention of the legislature.

1.4 Statement of purpose

The analysis concerns whether Additional Information can, as averred by Nurture, be legally traded in South Africa. The fact that Nurture had instituted a High Court application shows that there *is* an interest in trading in Additional Information, and is hence a proper and topical subject for legal investigation.

1.5 Research questions

- What is the psychological underpinning of prospective parents wanting personal gamete donor information?
- How do countries such as the USA, United Kingdom ('UK') and Canada deal with the provision of donor information?
- Should South Africa legally allow trade in personal information regarding human gamete donors?

1.6 Research methodology

The research methodology is desk-top based. Sources that will be consulted include primary sources (cases and legislation) and secondary sources (journal articles, text books, text books chapters and internet articles).

¹⁶ Replying affidavit para 42 p12.

Initially, the dissertation will analyse the motivations and experiences of prospective parents wanting personal donor information. This sets the tone for the remainder of the dissertation, as this will illustrate that there is a general *need* by prospective parents for the option of accessing Additional Information. Thereafter, a comparative study will be undertaken with the USA, UK and Canada with regard to the provision of personal donor information. This will include the analysis of the laws and practices of the aforementioned countries and their gamete agencies/banks respectively, as they all protect donor anonymity (albeit in varying degrees). This chapter will also serve as a contrasting background for Chapter 4, which will discuss the status quo in South Africa with regard to trade in personal gamete donor information. Here, South African law will be discussed and analysed, in addition to the main source for this chapter – the *Nurture* case. The concluding chapter in the dissertation will provide a recapitulation of the dissertation, recommendations concerning methods in which to create legal certainty regarding trade in personal gamete donor information and a recommendation concerning areas for further research.

1.7 Structure of dissertation

- Chapter 2: Gamete Donor Selection: an overview of parental motivations and experiences

This chapter will discuss the various studies that were undertaken to illustrate the importance of having access to gamete donor information in general. It will also focus on how this aspect enhances the prospective parents' autonomy in decision-making.

- Chapter 3: A comparative legal study concerning the provision of donor information
The USA, UK and Canada will be used in a comparative study as these countries' legal systems share the same basic values with South Africa's legal system.
- Chapter 4: An analysis of South African law: can South Africa permit the trade in personal gamete donor information?

This chapter will focus primarily on the various papers filed in the *Nurture* case – the leading source in the chapter – and existing legislation. The arguments in the *Nurture* case and the unpacking thereof are essential to the legal analysis of the topic at hand.

- Chapter 5: Conclusion

This chapter will provide a summary of the dissertation, recommendations of methods that create legal certainty regarding trade in personal gamete donor information in South Africa and a recommendation concerning areas for further research.

CHAPTER 2 – GAMETE DONOR SELECTION: AN OVERVIEW OF PARENTAL MOTIVATIONS AND EXPERIENCES

2.1 Introduction

What if she's really ugly! You know it's the things that you think about. Ridiculous really, but (. . .) you do worry.¹⁷

the donor might look strange, the donor might have a beaked nose or, something odd (. . .) I didn't imagine the donor could be pretty or nice. (. . .) When I heard she was short, she had to be dwarf and I just magnified anxiety about it; the fact that I didn't know.¹⁸

These are just a couple of the many thoughts that plague some prospective parents during the donor-selection process. These thoughts, however, reflect the anxiety that some people experience as a result of not having adequate donor information. In this chapter, I discuss the following questions: What are the psychological effects of infertility? How important (or not) is the process of gamete donor selection to prospective parents? What are prospective parents' donor preferences? Why do prospective parents choose gametes the way they do? Is access to Additional Information important? If so, should South African gamete banks make the option of accessing Additional Information available to prospective parents?

2.2 Infertility and its psychological effects

Human reproduction is a social and biological drive.¹⁹ People have a general expectation of parenthood which is often encouraged by social institutions²⁰ such as culture.²¹ While couples generally have a deep desire to have children, a 2002 study of 729 participants in Sweden found that females especially regard biological motherhood (either genetic or gestational) as extremely important.²² The same study found that 78 per cent of female participants and 67 per cent male participants agreed with the statement that 'having children is the most important thing in life'.²³ Seeing that having a child is a key developmental stage in many

¹⁷ SJ Stuart-Smith, JA Smith & EJ Scott 'To know or not to know? Dilemmas for women receiving unknown oocyte donation' (2012) 27(7) *Human Reproduction* 2071.

¹⁸ Ibid.

¹⁹ AS Svanberg et al 'Public opinion regarding oocyte donation in Sweden' (2003) 18(5) *Human Reproduction* 1112.

²⁰ Ibid.

²¹ Rodrigues expert opinion 1, 9 May 2013, filed in *AB v Minister of Social Development* 2017 (3) SA 570 (CC), Constitutional Court record pp 852 – 869 para 7.

²² Svanberg (note 19 above) 1107.

²³ Svanberg (note 19 above) 1107.

people's lives,²⁴ it is no wonder then that receiving news of infertility can take people unawares, causing them to suffer a range of negative emotions such as depression, stress and worthlessness.²⁵ In fact, the ill-effects of infertility tend to infiltrate *all* aspects of a woman's life, whereas men tend to compartmentalise their infertility.²⁶ Furthermore, infertile persons often experience 'painful social and psychological consequences',²⁷ such as feelings of isolation and marginalisation.²⁸ This may stem from the fact that those near and dear to them often cannot completely comprehend the reality and impact of their infertility.²⁹ Thus, with the use of in-vitro fertilisation (IVF), 'the transition to parenthood takes place in the context of complex losses that derive from their infertility'.³⁰

2.3 The importance of the process of gamete donor selection to prospective parents

The decision to have a child amounts to an 'intensely personal decision, at the core of most people's life plans'.³¹ Equally, people attach great personal importance to the selection of a gamete donor³² because it is a process that is so emotionally charged.³³ Clinical experience indicates that the selection of gamete donors overlaps greatly with the selection of a life partner.³⁴ Furthermore, this great personal importance is reflected in the significant time, thought and mental effort that prospective parents expend when selecting a gamete donor.³⁵ This can be observed in the careful consideration, study and comparison of their options when browsing through online databases containing donor profiles.³⁶ By playing an active role in the process of screening and selecting their donors, prospective parents are able to

²⁴ IS Rodino, PJ Burton and KA Sanders 'Mating by proxy: a novel perspective to donor conception' (2011) 96(4) *Fertility Sterility* 998.

²⁵ Svanberg (note 19 above) 1110.

²⁶ Rodrigues expert opinion 1 (note 21 above) para 9.

²⁷ LF Mabasa 'The psychological impact of infertility on African women and their families' (D. Phil. thesis, University of South Africa, 2009) 2.

²⁸ Rodrigues expert opinion 1 (note 21 above) para 10.

²⁹ Rodrigues expert opinion 1 (note 21 above) para 10.

³⁰ L Cudmore 'Becoming parents in the context of loss' (2005) 20(3) *Sexual and Relationship Therapy* 300.

³¹ Rodrigues expert opinion 1 (note 21 above) para 14.

³² Rodrigues expert opinion 1 (note 21 above) para 14.

³³ S Brown 'Genetic Aspects of Donor Selection' in MV Sauer (ed) *Principles of Oocyte and Embryo Donation* (2013) 73, 74.

³⁴ Rodrigues expert opinion 1 (note 21 above) para 14; DM Zeifman & JE Ma 'Experimental examination of women's selection criteria for sperm donors versus life partners' (2013) 20(2) *Personal Relationships* 13.

³⁵ Rodrigues expert opinion 1 (note 21 above) para 16; L Frith, N Sawyer & W Kramer 'Forming a family with sperm donation: a survey of 244 non-biological parents' (2012) 24(7) *Reproductive BioMedicine Online* 716.

³⁶ Rodrigues expert opinion 1 (note 21 above) para 16.

somewhat alleviate their stress.³⁷ Donor egg recipients in particular view the donor screening and selection process as a means to take control over their destinies and ‘experience some sort of maternal sovereignty’.³⁸

2.4 Gamete recipient preferences and search criteria

A wealthy merchant and his wife sought treatment for infertility with Dr. William Pancoast. When azoospermia was diagnosed, Dr. Pancoast asked the most attractive medical student in his class to serve as a sperm donor and later inseminated the wife. The donor was selected by the medical team with no input from the couple, and the wife was inseminated with donor sperm without the knowledge or consent of either her or her husband. The husband was later informed of the insemination, but neither the wife nor the resulting child was told of the use of donor gametes.³⁹

Over a century later, assisted reproduction hardly bears any resemblance to this scenario.⁴⁰ However, within a formal context, sperm donation banks *preselect* candidates on the basis that such candidates will eventually be successful donors.⁴¹ Furthermore, such agencies and banks *advise* and *guide* donors as to the type of content that should be put into their profiles, so as to make them more ‘saleable’.⁴² As such, prospective parents are often aware of the fact that donors, gamete banks and agencies have a vested interest in donor profiles.⁴³ In a 2012 study involving 22 egg recipients in the United States of America (USA), participants felt that profiles were sometimes ‘unreliable’ as they were deliberately made to simply ‘look good’ and get selected by the respective clinic and recipients.⁴⁴ It is argued that the process of gamete banks and agencies preselecting donors reflects bias in the possibility set of prospective parents.⁴⁵ It is also argued that for the sake of prospective parents, donor profiles

³⁷ H Flores et al. ‘Beauty, Brains or Health: Trends in Ovum Recipient Preferences’ (2014) 23(10) *J of Women’s Health* p831.

³⁸ Ibid.

³⁹ JT Woodward ‘Third-party reproduction in the Internet Age: the new patient-centered landscape’ (2015) 104(3) *Fertility and Sterility* 525.

⁴⁰ Ibid.

⁴¹ S Whyte & B Torgler ‘Determinants of online sperm donor success: how women choose’ (2016) 23(8) *Applied Economics Letters* 592.

⁴² Ibid.

⁴³ LR Rubin et al. ‘Once you’re choosing, nobody’s perfect: is more information necessarily better in oocyte donor selection?’ (2015) 30(3) *Reproductive BioMedicine Online* 315.

⁴⁴ Ibid.

⁴⁵ Whyte & Torgler (note 41 above) 593.

should provide ‘a fairly accurate image of the donor so that they are reassured about the origin of the material and are able to handle the transaction more easily’.⁴⁶

In contrast, the informal and unregulated online market – born from a global shortage of gamete donors⁴⁷ – allows more recipient-donor communication.⁴⁸ Therefore, this allows for a true reflection of what characteristics prospective parents find most appealing.⁴⁹ Seeing that the internet has served as a conduit for gamete donation,⁵⁰ prospective parents have access to a wide spectrum of information which even allows them to find their own donors without consulting a gamete bank or agency.⁵¹ However, *how* exactly do prospective parents choose their donors?

Evidence suggests that people often choose their mates in terms of assortative mating and homogamy, that is, they often select mates who share common characteristics as them with regard to physical characteristics, psychological characteristics, socio-economic status and so forth.⁵² Despite the advent of the internet, which offers a greater variety of mates by superseding geographical and social proximity barriers, the feature of choosing mates in terms of homogamy is as common as when picking a mate in the same geographical and social proximity.⁵³ Surprisingly, within the context of selecting a sperm donor, women generally display homogamy with regard to their own characteristics as well as that of their partners.⁵⁴

Although there is great diversity in what prospective parents prioritise as important donor characteristics,⁵⁵ there are grounds of similarity as well.⁵⁶ While past trends indicate that more than half of the couples chose donors with an emphasis placed on physical resemblance, ethnicity and common genetic heritage,⁵⁷ prospective parents’ donor choices are increasingly motivated by characteristics that would be of benefit to the donor-conceived child’s mental

⁴⁶ G Pennings ‘The right to choose your donor: a step towards commercialization or a step towards empowering the patient?’ (2000) 15(3) *Human Reproduction* 514.

⁴⁷ Whyte & Torgler (note 41 above) 592.

⁴⁸ Whyte & Torgler (note 41 above) 593.

⁴⁹ Whyte & Torgler (note 41 above) 593.

⁵⁰ Whyte & Torgler (note 41 above) 592.

⁵¹ Woodward (note 39 above) 525.

⁵² S Whyte & B Torgler ‘Assortative mating in the online market for sperm donation’ (2016) 18(3) *J of Bioeconomics* 170.

⁵³ Ibid 172.

⁵⁴ Ibid 184. These characteristics especially relate to ethnicity, personality traits and agreeableness (such as being older or a lesbian).

⁵⁵ Pennings (note 46 above) 509; CT Drewes *Anonymous Sperm Donor Preferences of Non-Genetic Mothers* (Master of Social Work, Smith College School for Social Work; Northampton, MA, 2009) p72.

⁵⁶ Rodrigues expert opinion 1 (note 21 above) para 18.

⁵⁷ Flores et al. (note 37 above) 832; Zeifman & Ma (note 34 above) 3.

and physical health ('good genes'), such as athleticism and intellect.⁵⁸ In fact, in a 2009 survey of 244 non-biological parents in the USA, 91,8 per cent of participants revealed that they would not have chosen a sperm donor if no health record was available on the particular donor.⁵⁹ Additionally, in a 2012 online survey that used 56 potential sperm donors, personality characteristics (such as being systematic, introverted and so forth) outweighed physical characteristics (such as height, weight and so forth) in donors.⁶⁰ Therefore, it can be said that prospective parents tend to choose donor characteristics that follow 'general societal norms and perceptions of success'.⁶¹ Where, then, does this leave the importance of physical similarity, ethnicity and common genetic heritage?

The aforesaid studies do not imply that physical similarity, ethnicity and common genetic heritage have decreased in importance. It simply means that many prospective parents are now *also* placing importance on donor personality traits and characteristics that would be of 'benefit' to the donor-conceived child (health being the most favoured characteristic).⁶² In a 2012 study involving 22 egg recipients in the USA, most participants in the survey shared two main goals: first, to have a healthy child, and secondly, to have their donor-conceived child 'pass' as genetically linked to them.⁶³ Matching the donor's physical features to the non-genetic parent allows for the constructive genetic link between the non-genetic parent and the donor-conceived child, thereby masking the obviousness of the donation⁶⁴ and ensuring some sort 'genetic continuity'.⁶⁵ Consequently, medical information and specific physical donor characteristics are still of particular importance to prospective parents.⁶⁶

When evaluating donor characteristics, prospective parents are also curious about donors' reasons for donating their gametes.⁶⁷ Many prospective parents often bring up the question of donor motivation in the hope that it stems from altruism (financial motivation is viewed as emotive).⁶⁸ Consequently, altruistic motives are appreciated, while financial incentive

⁵⁸ Flores et al. (note 37 above) 832; Zeifman & Ma (note 34 above) 3.

⁵⁹ Frith, Sawyer & Kramer (note 35 above) 713.

⁶⁰ Whyte & Torgler (note 41 above) 595.

⁶¹ Drewes (note 55 above) 78.

⁶² Flores et al. (note 37 above) 832; Rodino, Burton & Sanders (note 24 above) 308; Drewes (note 55 above) 77.

⁶³ Rubin et al. (note 43 above) 313.

⁶⁴ Zeifman & Ma (note 34 above) 13.

⁶⁵ Frith, Sawyer & Kramer (note 35 above) 716.

⁶⁶ Drewes (note 55 above) 75.

⁶⁷ Rodrigues expert opinion 1 (note 21 above) para 20.1; Stuart-Smith, Smith & Scott (note 17 above) 2073; Rodino, Burton & Sanders (note 24 above) 309.

⁶⁸ Rodino, Burton & Sanders (note 24 above) 309.

removes the donor as an option.⁶⁹ Furthermore, ‘...recipients regard this information as particularly important for their offspring’s view of self and that a donor who has been altruistic enables the recipient to make the narrative of the birth story more sensitive to the perceived needs of their donor-conceived child’.⁷⁰

Ultimately, it can be seen that irrespective of whether it is a formal or informal context, many prospective parents display homogamy in their choices of gamete donors. In addition to a donor’s physical characteristics, genes that would be of benefit to the donor-conceived child as well as reasons for the donation are of importance to prospective parents.

2.5 Is access to additional information important?

Not enough attention has been given to the type and quantity of donor information that is provided to prospective parents.⁷¹ Within the South African context, this aspect has been thoroughly neglected up until recently. Over the last two decades, there have been on-going global demands for more donor information, as well as for further choice during donor selection.⁷² In fact, the global demand for donor information has grown to the point where identity-release⁷³ gamete donors have become increasingly popular.⁷⁴ Consequently, this has led numerous international gamete banks and agencies to provide extensive personal donor information such as photographs, audio recordings and video recordings.⁷⁵ In the USA, there are many models of donor information that are made available to prospective parents (which have been available for over two decades already).⁷⁶ It ranges from the most basic information (such as medical history and a description of physical appearance) to substantively detailed (such as adult photographs and audio clips).⁷⁷

⁶⁹ Rodrigues expert opinion 1 (note 21 above) para 20.1.

⁷⁰ Rodino, Burton & Sanders (note 24 above) 309.

⁷¹ Rubin et al. (note 43 above) 312.

⁷² J Benward, AM Braverman & B Galen ‘Maximizing Autonomy and the Changing View of Donor Conception: the Creation of a National Donor Registry’ (2009) 12 *DePaul J Health Care L* 227.

⁷³ This refers to donor-conceived children having access to identifying donor information, and the possibility of contacting their donors. Generally, this only occurs upon the request of the donor-conceived child, provided that they have reached 18 years of age. See <https://www.thespermbankofca.org/content/identity-release-program> and A Ravelingien, V Provoost & G Pennings ‘Open-Identity Sperm Donation: How Does Offering Donor-Identifying Information Relate to Donor-Conceived Offspring’s Wishes and Needs?’ (2015) 12(3) *J of Bioethical Inquiry* 503.

⁷⁴ Woodward (note 39 above) 528.

⁷⁵ Benward, Braverman & Galen (note 72 above) 228.

⁷⁶ Rubin et al. (note 43 above) 312.

⁷⁷ Rubin et al. (note 43 above) 312; Stuart-Smith, Smith & Scott (note 17 above) 2068.

A 2009 online survey involving 244 lesbian sperm recipients in the USA demonstrates that the most vital criterion in the selection of a sperm bank was the *amount* of donor information the bank provided.⁷⁸ This suggests that during the selection process, prospective parents want detailed donor information so as to make an informed decision.⁷⁹ In this way, prospective parents may experience greater autonomy.⁸⁰ In the 2012 study involving 22 egg recipients in the USA, some participants felt that access to substantively detailed donor information allowed them to be informed and have the process under control: ‘No one likes to buy things without seeing what something looks like. So this is like a huge purchase [laughs]. . .’⁸¹

Some participants found ‘signs’ within the information which they interpreted to be indicators that they were choosing the correct donor. Others built narratives and fantasies about donors, by ‘reading in between the lines’ of the information provided:

and of course [we wanted to know] if she had kids herself. Like that almost like made us feel better if she had a kid. . . She’s like a young girl, like why she’s doing it? What’s her motive? But if she could have kids herself and just wants to give some of her own eggs we felt like, oh, *this is like a really good person*. And I wanted somebody who had *good traits* also. You know, *a good person*.⁸² [Own emphasis]

In a 2011 study using 11 egg recipients in the UK, some recipients experienced a fear of the unknown due to a lack of adequate donor information.⁸³ These recipients then sought IVF treatment in the USA, where it is possible to access more comprehensive donor information.⁸⁴ Some recipients simply sought enough information for them to feel that they trust their donors: ‘I always remember someone saying that they felt their babies were going to come out with blue flashing lights saying, ‘I’m different, I’m from donated eggs’. (. . .). I never had any of those worries (. . .), because I had the security of knowing what their donor is like’.⁸⁵

While a great amount of information allowed for increased trust in the donor and a decrease in anxiety, others without such access simply imagined the donor in a polarised fashion.⁸⁶ This did not necessarily bring relief, as once again, there was a fear of the unknown and some

⁷⁸ Frith, Sawyer & Kramer (note 35 above) 713; Rodrigues expert opinion 1 (note 21 above) para 17.

⁷⁹ Rodrigues expert opinion 1 (note 21 above) para 17.

⁸⁰ Woodward (note 39 above) 527.

⁸¹ Rubin et al. (note 43 above) 314.

⁸² Rubin et al. (note 43 above) 314.

⁸³ Stuart-Smith, Smith & Scott (note 17 above) 2071.

⁸⁴ Stuart-Smith, Smith & Scott (note 17 above) 2071.

⁸⁵ Stuart-Smith, Smith & Scott (note 17 above) 2071.

⁸⁶ Stuart-Smith, Smith & Scott (note 17 above) 2071.

recipients imagined the worst possible outcomes for their donor-conceived child.⁸⁷ Interestingly, the 2011 study using 11 egg recipients in the UK refers to clinical experience that points to many recipient couples experiencing negative fantasies about the donor (especially in the earlier stage of the pregnancy) when they were provided with little to no donor information.⁸⁸

All this being said, gamete recipients may also view access to a great amount of donor information in a negative light. Despite there being a generally positive attitude towards the great amount of information available, more than half of the participants in the 2012 study involving 22 egg recipients in the USA expressed at least one instance where such information undermined the process of choosing a donor.⁸⁹ Many participants were in search of the ‘perfect’ donor, but after having had access to the donor information, many soon realised that there was in fact no ‘perfect’ donor.⁹⁰ This meant that participants had to choose from a range of ‘imperfect’ donors, leaving some with a feeling of dissatisfaction or having settled for less.⁹¹ Overall, some participants felt overwhelmed by all the donor information that was provided to them, and surprisingly wished that they had less information.⁹²

Providing prospective parents with sufficient information to make an autonomous decision is difficult without causing the aforesaid problems.⁹³ In fact, the question of how much donor information should be provided to prospective parents is a highly contested debate within the field of reproduction.⁹⁴ The debate is fuelled by the fact that there is little empirical research in this area to provide adequate guidance.⁹⁵ Consequently, many recipients find the decision-making process burdensome.⁹⁶ Initially, some felt that it was rational to make use of all the information they were provided in order to make an informed decision.⁹⁷ Yet, in a sense, they felt *obliged* to make use of all the donor information since it was available to them.⁹⁸

⁸⁷ Stuart-Smith, Smith & Scott (note 17 above) 2071.

⁸⁸ Stuart-Smith, Smith & Scott (note 17 above) 2073.

⁸⁹ Rubin et al. (note 43 above) 314.

⁹⁰ Rubin et al. (note 43 above) 314.

⁹¹ Rubin et al. (note 43 above) 314.

⁹² Rubin et al. (note 43 above) 314.

⁹³ Rubin et al. (note 43 above) 314.

⁹⁴ JB Appleby & S Franklin ‘Oocyte donor information – how much is enough?’ (2015) 30(3) *Reproductive BioMedicine Online* 209.

⁹⁵ *Ibid.*

⁹⁶ Rubin et al. (note 43 above) 314.

⁹⁷ Rubin et al. (note 43 above) 315.

⁹⁸ Rubin et al. (note 43 above) 315.

While many international fertility centres provide detailed donor profiles such as adult photographs (sometimes including those of the donor's own children and other family members), some fertility centres aim to keep donor anonymity through the sole provision of childhood photographs. The danger is that, the more presumably non-identifying information a donor provides, the more the donor's anonymity is compromised.⁹⁹ A motivated prospective parent willing to invest the time and effort¹⁰⁰ may be able to use age progression software to develop an adult image using the childhood photograph.¹⁰¹ In fact, there are websites which provide guidance as to which search tools should be used to identify the donor, depending on what information is available.¹⁰² Ultimately, a 'for-and-against extra donor information' argument can be made. The argument for extra information is that it allows prospective parents to make a truly informed (autonomous) decision about the donor they want.¹⁰³ On the other hand, the argument against extra donor information is that it is unlikely that any amount or type of donor information would lead to any understanding of the donor as a person, and so such information may not hold much significance.¹⁰⁴

2.6 *To have or not to have additional donor information, that is the question*

Should South African gamete banks provide prospective parents the option to access Additional Information? As it can be observed in the previous subsection, there are various *subjective* pros and cons to having Additional Information. The only two objective factors that can be extracted from the various pros and cons are the possible use of age progression software to determine a donor's possible adult face (and hence identity), and the other is a core biomedical¹⁰⁵ principle related to decision-making – autonomy. How do these two arguments measure against each other?

First, the use of age progression software is not an exact science.¹⁰⁶ While some software produces better results than others, thus far, there has not been a single technology that can

⁹⁹ Pennings (note 46 above) 512.

¹⁰⁰ Pennings (note 46 above) 512.

¹⁰¹ Woodward (note 39 above) 528.

¹⁰² Woodward (note 39 above) 528.

¹⁰³ Appleby & Franklin (note 94 above) 210.

¹⁰⁴ Appleby & Franklin (note 94 above) 210.

¹⁰⁵ Bioethics refers to 'the study of ethical, social, and legal issues that arise in biomedicine and biomedical research' (see https://www.niehs.nih.gov/research/resources/bioethics/what_is_bioethics/index.cfm)

¹⁰⁶ 'Predicting Age Progression: A Science or Not?' available at <http://www.askdrmannny.com/2017/07/10/predicting-age-progression-science-not/>, accessed on 7 September 2017.

determine a future image of a person with complete accuracy. Additionally, it becomes increasingly difficult to generate an accurate image with the use of childhood photographs: “Aging photos of very young children from a single photo is considered the most difficult of all scenarios...,”...Part of that challenge is using candid photographs, not posed portraits, to generate a future likeness.¹⁰⁷ Depending upon the effectiveness of the software used, there would be myriad of factors that one would have to consider before a fairly accurate image is generated (assuming the donor does not have any changes to his/her physical features,¹⁰⁸ either intentionally through plastic surgery or by accident) as aging is influenced by various factors.¹⁰⁹ The risk of donor anonymity being compromised in this manner does exist, however, it is negligible.

Interestingly enough, donor anonymity is becoming increasingly compromised in any event, particularly with the use of genetic testing.¹¹⁰ Genetic testing, unlike age progression technology, is clearly an exact science: ‘In 2005, a 15-year-old boy tracked down his father after taking a Y chromosome test with a commercial ancestry company. His father was not in the database but was identified through a match with another man sharing the same rare surname’.¹¹¹ The argument, therefore, that age progression technology compromises donor anonymity is irrelevant in the face of an exact science such as genetic testing, which requires absolutely no donor information to determine donor identity. How does this ‘risk’ compare with autonomy?

Autonomy refers to the concept of ‘self-rule’, where a person – after being given *all* the relevant information about a particular situation – can make a truly informed decision.¹¹² Respecting a person’s autonomy includes obtaining *informed consent* before any medical examination, treatment or surgery.¹¹³ Informed consent is not only an ethical requirement, but is also a legal requirement.¹¹⁴ It refers to eliciting a person’s permission to proceed with a certain medical procedure, after such person has deliberated over all the risks and benefits of

¹⁰⁷ ‘Age Progression Software Is So Good People Can’t Tell The Difference Between Real Photos And Mock-Ups’ available at <http://www.medicaldaily.com/age-progression-software-so-good-people-cant-tell-difference-between-real-photos-and-mock-ups-276084>, accessed on 7 September 2017.

¹⁰⁸ Ibid.

¹⁰⁹ P Rashmi, B Shifana & BR Kishore ‘Review on Face Recognition across Age Progression’ (2017) 3(5) *International Journal of Recent Trends in Engineering and Research* 208.

¹¹⁰ JC Harper, D Kennett & D Reisel ‘The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business’ (2016) 31(6) *Human Reproduction* 1136.

¹¹¹ Ibid.

¹¹² K Moodley *Medical Ethics, Law and Human Rights: a South African Perspective* (2011) 42.

¹¹³ Ibid 43.

¹¹⁴ Section 6(1) of the NHA.

each and every option available to him/her.¹¹⁵ Such deliberation is derived from one of informed consent's threshold elements - disclosure.¹¹⁶

Applied to the question at hand, I submit that counter-arguments to the provision of Additional Information, particularly the argument of causing undue stress and imposing burdens (both concepts being subjective perceptions) upon prospective parents, does not hold water. Considering that stress is a normal occurrence in life, it is not a legally or ethically relevant consideration. In fact, being stressed about such a situation can actually be seen in a *positive* light. Prospective parents *should* feel stressed, albeit not debilitated, by a decision that has a presumably life-long consequence. Surely the value of autonomy triumphs over the possible harm of being ignorant in matters of such a serious nature. Furthermore, the negligible risk of having an extremely keen gamete recipient trying to conjure up an adult image of his/her child's donor through age progression, cannot compare to a gamete recipient's need to make a fully informed choice with regard to their future child. Therefore, in order to promote autonomy, South African gamete banks and agencies should ideally go beyond their legal duty of providing Required Information by providing prospective parents the option of accessing Additional Information. While there is a possibility that some prospective parents may not want Additional Information, the option of accessing such information should necessarily exist for those who do wish to have such information.

2.7 Conclusion

Procreating is a primal drive in most – if not all – species, with humans as no exception. As having children constitutes a core part of most people's lives, news of infertility can cause devastating psychological effects in people. Since many infertile people choose gamete donation as a means to fulfilling their parenthood, the process of carefully selecting a gamete donor is extremely important in somewhat alleviating the negative psychological effects of infertility, as well as helping infertile persons feel that they have retained some control in an area of life that would have otherwise felt like a hopeless loss.

Although there is great diversity in what prospective parents prioritise as important donor characteristics, there are grounds of similarity as well. While past trends indicated that more than half of infertile couples chose donors mainly based on physical similarity, ethnicity and

¹¹⁵ Moodley (note 112 above) 45.

¹¹⁶ Moodley (note 112 above) 43.

common genetic heritage, recent studies have shown that prospective parents are increasingly choosing donors based on ‘good genes’ and the benefits it will confer to the donor-conceived child. Additionally, donors are looked upon favourably when they choose to donate for altruistic reasons as opposed to financial reasons.

For some prospective parents, donor selection and Additional Information may be inextricably linked as it enhances their autonomy and alleviates fear of the unknown. For others, Additional Information may have an adverse effect and hamper the selection process by causing undue stress and burdens upon them. Furthermore, there is a slight risk that Additional Information may compromise donor anonymity in cases where revealing the donor’s identity is prohibited either by the donor’s personal choice or law. Ultimately, satisfying all stakeholders may prove to be difficult, if not impossible. The best possible solution, therefore, is focusing on the only viable and objective argument – autonomy.

CHAPTER 3 – A COMPARATIVE LEGAL STUDY CONCERNING THE PROVISION OF DONOR INFORMATION

3.1 Introduction

In the previous chapter, the importance of Additional Information to prospective parents was highlighted and argued for. This chapter focuses on the analysis of practices concerning the provision in gamete donor information in three jurisdictions: the USA, UK and Canada. These three jurisdictions were chosen because, (1) their legal systems share the same basic values with South Africa's legal system; (2) their law is easily accessible online; (3) their law is in English; and (4) there are relatively high numbers of academic publications analysing the regulation of the fertility industries in these countries. It is worth noting that these three countries, like *every* other country, do not legally regulate the trade in gamete donor information per se. Had the *Nurture* case been adjudicated upon, South Africa would have been the first country in the world to have judicially addressed this matter. In any event, it is worth studying how developed countries such as the USA, UK and Canada deal with the issue of provision and trade in donor information, and how gamete agencies and banks in these countries also function in relation to this particular lack of regulation. Furthermore, it must be noted that unlike South Africa, the USA, UK and Canada do not have legislation mandating specific information to be recorded and disclosed to prospective parents. In Chapter 1, this type of specific information within a South African context was referred to as Required Information (as per the *Nurture* case). This South African legal requirement allowed Nurture to distinguish between Required Information and Additional Information. However, with regard to the USA, UK and Canada, no such legal distinction can be made because the laws of these jurisdictions do not create a *numerus clausus* of information that is required as South Africa does. Lastly, as the term 'Additional Information' has a South African-specific meaning (discussed in Chapter 1), the term 'detailed/extended donor information/profile' will be used to describe donor information/profiles in the comparator countries that have a roughly equivalent content to Additional Information.

Before commencing the comparative study, it must be noted that gamete agencies and banks often use the terms 'identity-release', 'open-identity', 'identity-disclosure' and 'non-anonymous' in order to refer to donors that are anonymous but agree to have their identifying/contact information (such as their full name, last known address, telephone number etc) released to donor-conceived offspring, on condition that these offspring are 18 years and above (ie adults) and have specifically *requested* such information. In other words,

these donors are anonymous *until* their identities are revealed upon their adult donor-conceived children's requests. For the purpose of this dissertation, such donors will consistently be referred to as 'identity-release' donors.

3.2 UK

The UK is the first country to have passed legislation that extensively regulates reproductive technology,¹¹⁷ viz the Human Fertilisation and Embryology Act 1990 ('the HFE Act of 1990').¹¹⁸ Prior to the HFE Act of 1990, it was common practice for donor anonymity to be enforced.¹¹⁹ It came as no wonder then that the HFE Act of 1990 barred prospective parents from receiving identifying information about gamete donors, albeit allowing donor-conceived offspring the right to access *non-identifying* donor information, once they were 18 years of age.¹²⁰ Donor anonymity, however, had caused much dissatisfaction in the ensuing years which led to debates, a court case¹²¹ and lobbying from non-governmental organisations.¹²² Consequently, in early 2000 after public consultation, the HFE Act of 1990 underwent review which resulted in new legislation: the Human Fertilisation and Embryology Act 2008 ('the HFE Act').¹²³ Like South Africa, the UK has two types of gamete donors: anonymous and known (known donors are clearly known to the recipient or prospective parents eg family members or friends). The HFE Act provides that donor-conceived offspring, who were conceived from gametes that were donated after 1 April 2005, can request non-identifying donor information¹²⁴ from the Human Fertilisation and Embryology Authority ('HFEA') after the age of 16.¹²⁵ Furthermore, the HFEA allows donor-conceived offspring access to identifying information pertaining to their donors from the HFEA after the age of 18.¹²⁶ Essentially, this means that as of 1 April 2005, *all* donors are identity-release donors, as their identities can be legally accessed by their adult donor-conceived offspring.

¹¹⁷ J Speirs 'Anonymous Semen Donation: Medical Treatment or Medical Kinship?' (2013) 9(1-2) *Cargo* 76.

¹¹⁸ Ibid 77.

¹¹⁹ E Blyth 'Access to genetic and birth origins information for people conceived following third party assisted conception in the United Kingdom' (2012) 20(2) *International Journal of Children's Rights* 301.

¹²⁰ J Speirs (note 117 above) 77.

¹²¹ See *Rose and Another versus Secretary of State for Health and Human Fertilisation and Embryology Authority*, 2002, where it was argued that donor anonymity violated the claimants' 'right to respect for private and family life' in terms of Article 8 of the European Convention on Human Rights; the Court held that people had a right, in terms of the aforesaid article, to access information regarding their biological parenthood.

¹²² J Speirs (note 117 above) 78.

¹²³ E Blyth (note 119 above) 304.

¹²⁴ This may include a pen portrait and goodwill message from the donor, if this is available.

¹²⁵ I de Melo-Martin 'How best to protect the vital interests of donor-conceived individuals: prohibiting or mandating anonymity in gamete donations?' (2016) 3 *Reproductive BioMedicine and Society Online* 101-102.

¹²⁶ Ibid 102.

With regard to prospective parents, nothing much has changed. While prospective parents may request non-identifying donor information from the HFEA *after* their donor-conceived child is born (note that this is *not* even a statutory right), they are not legally *entitled* to access non-identifying donor information for the purpose of choosing gametes. In terms of the HFE Act, it is my understanding and interpretation of section 33A(2)(h)¹²⁷ read together with section 33B,¹²⁸ that if a gamete donor has consented, his/her non-identifying information *can* be disclosed. Provision of detailed donor information, therefore, is left to the discretion of gamete agencies and banks as they are not legally prohibited from doing so.¹²⁹ In a 2016 UK journal article that analysed whether prohibiting or mandating donor anonymity protects the interests of donor-conceived offspring, it was claimed that many gamete agencies and banks in the UK collect a significant amount of non-identifying donor information, though not legally obliged, to help prospective parents in their choice of gamete donors.¹³⁰

In order to determine the amount of donor information UK gamete agencies and banks choose to provide prospective parents, I randomly selected and searched the following seven UK gamete donor websites: New Life Egg Donation Agency, Atrui Egg Donation, Nurture UK, London Sperm Bank Donors, London Egg Bank Donors, Fairfax Cryobank (UK branch) and Complete Fertility. A quick browse of the websites reveals the following:

- New Life Egg Donation Agency: claims to offer ‘personalized one-on-one matching’ in addition to offering detailed donor profiles containing non-identifying information (there is no ‘basic profile’ with the option of purchasing extra information).¹³¹ All donors are identity-release donors (donor-conceived children can request identifying donor information as per the HFEA). While the agency states that donors have detailed profiles, these profiles are *not* provided on an online database for parents to browse through and select. Prospective parents must *advertise* the requirements they want their donors to possess with regard to ‘physical characteristics as well as any extra requirements you may have regarding the donor’s blood group, education, interests, talents and abilities’¹³² ie the agency best matches the prospective parents to

¹²⁷ Section 33A(2)(h) of the HFE Act states that: ‘Subsection (1) does not apply where the disclosure is of information other than identifying donor information and is made with the consent required by section 33B’.

¹²⁸ Section 33B states that: ‘Subject to subsection (5), the consent required by this section is the consent of each individual who can be identified from the information.’

¹²⁹ I de Melo-Martin (note 125 above) 104.

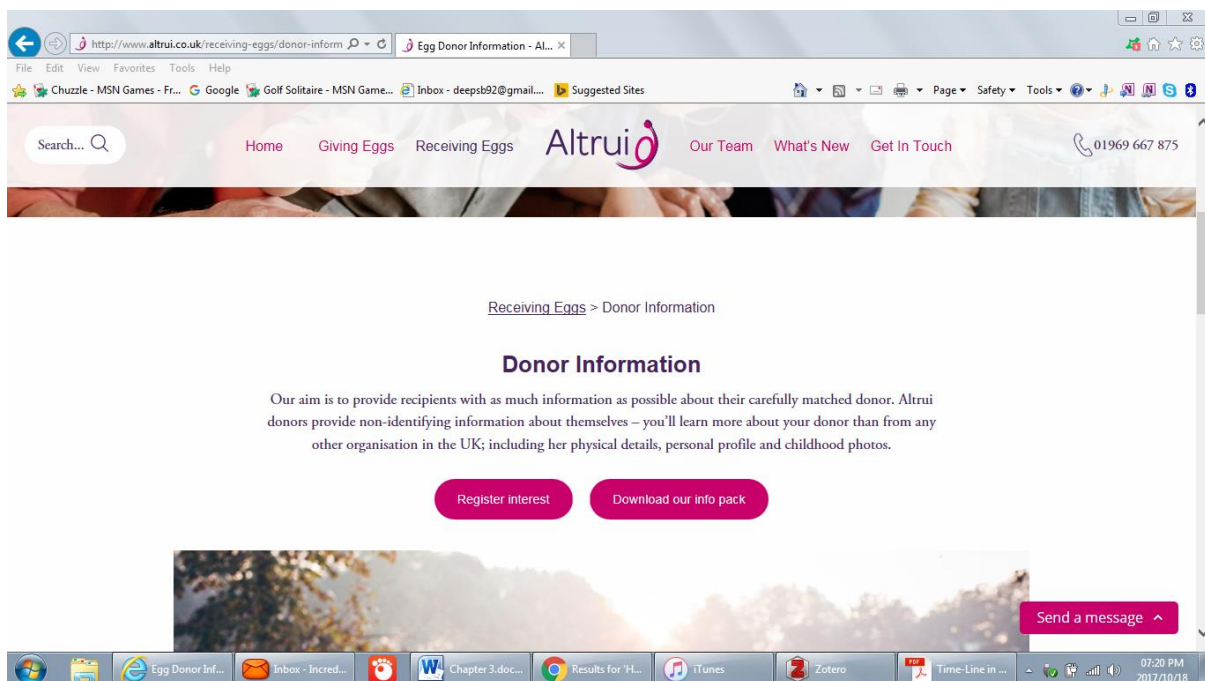
¹³⁰ I de Melo-Martin (note 125 above) 104.

¹³¹ http://eggdonation-uk.com/uk_recipients.html accessed 18 October 2017.

¹³² http://eggdonation-uk.com/how_it_works.html accessed 30 October 2017.

the donors in accordance to the requirements the prospective parents have *asked for*. Thus, these detailed profiles are essentially for the *agency's use* for the purpose of matching prospective parents to donors. Prospective parents do not pay for extra information as it is not applicable in this scenario.

- Atrui Egg Donation: unlike the New Life Egg Donation Agency, this agency claims to offer prospective parents the most amount of non-identifying donor information than any other gamete agency or bank in the UK.¹³³ It appears that this agency's business is hinged on providing the most amount of non-identifying donor information ie it does not provide a basic donor profile first, and then ask for additional payment for access to the extra information. This, it claims, sets it apart from its competitors which the agency is clearly proud of. [See screenshots below]



¹³³ <http://www.altrui.co.uk/receiving-eggs/donor-information/info-about-your-egg-donor/>, accessed on 18 October 2017.

http://www.altrui.co.uk/receiving-eggs/donor-inform Information About Your Egg... x

File Edit View Favorites Tools Help

Chuzzle - MSN Games - Fr... Google Golf Solitaire - MSN Game... Inbox - deepsb92@gmail... Suggested Sites

Page Safety Tools

Search... Q Home Giving Eggs Receiving Eggs Altrui Our Team What's New Get In Touch 01969 667 875

Receiving Eggs > Donor Information > Information about your egg donor

Information about your egg donor

We aim to give you as much information as we can about your egg donor, providing that it is non-identifying. Almost certainly it will be much more than you will get from any other organisation in the UK and will generally include:

- **Full Individual Characteristics.** We will send you the same set of information about the donor that we use for matching, except for her adult photograph.
- **Child Photograph.** If possible, we will give you a photograph of the donor as a baby or child (up to the age of 6), but she is under no obligation to provide one if she prefers not to. If it identifies her as an adult we will not be able to pass this on.
- **Personal Profile.** Each donor is asked to complete a more extensive personal profile, written in her own words, giving a greater insight into her character and personality.

Register interest Download our info pack

Send a message ^

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5 / 8 100% ? Sign In

How we match you with a donor

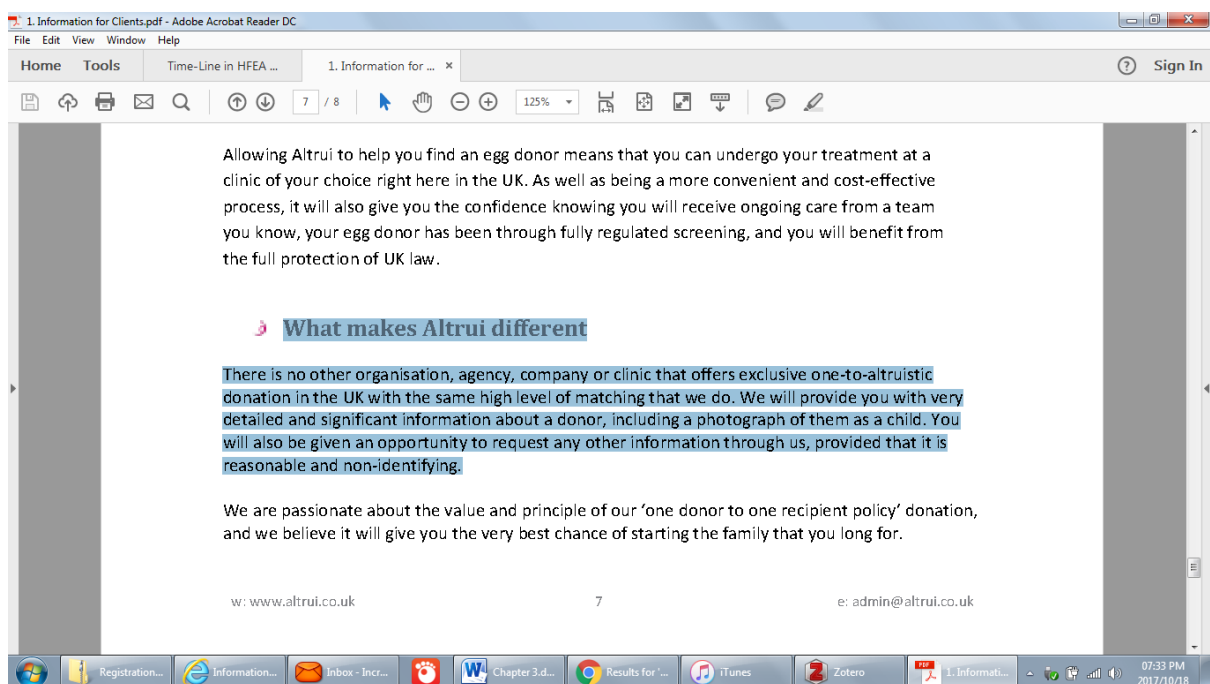
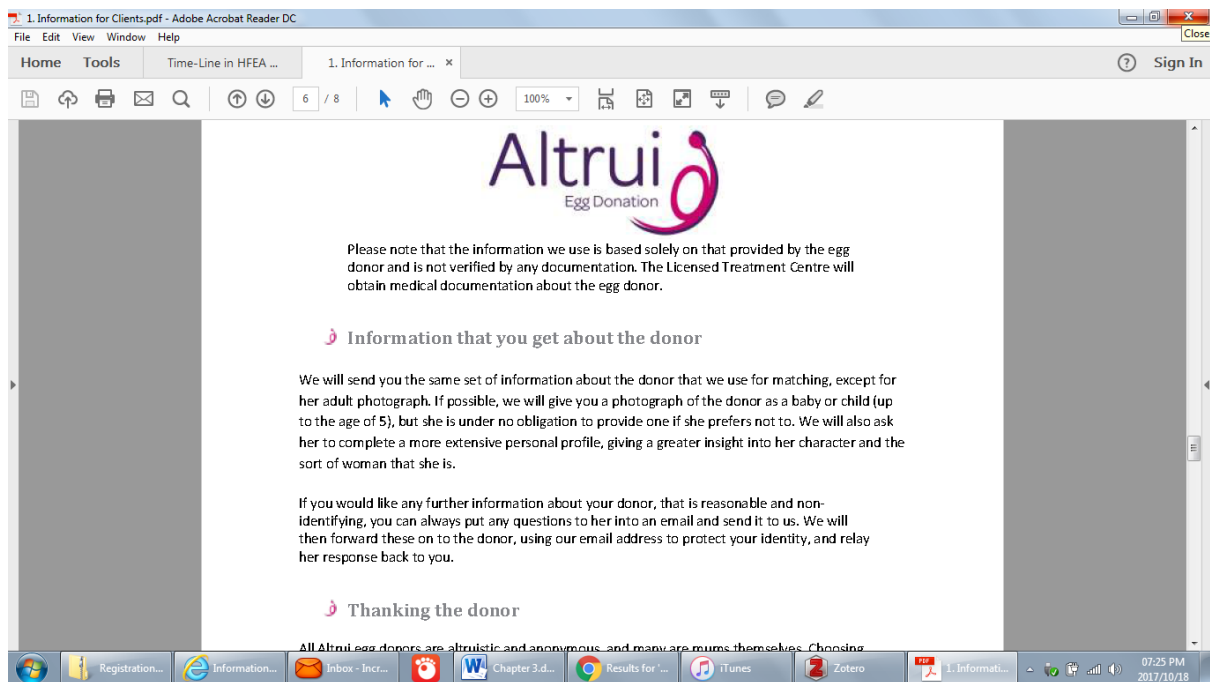
We understand that an important part of coming to terms with egg donation is feeling that care has been taken to match you with a suitable egg donor - one with whom you would feel comfortable. The fact that the donor will almost always be anonymous to you makes it even more important for us to get this right.

To help us do this, we will ask you for a photograph of yourself on your own and one as a couple. We will do the same with those women who are prepared to become an egg donor, and this is the starting point for the matching process.

We try and match the females through:

- General build
- Height
- BMI
- Eye Colour
- Hair colour
- Skin tone
- Ethnicity & Heritage
- Your backgrounds, including:
Education, Qualifications and Occupation. We ask egg donors their level of education, including further training, degree or professional registration. We also find out similar information about her siblings and parents. Some of our egg donors are young mums who chose to have children early instead of professional training or degree. We take all this into account when matching, once we understand them in their wider family context.
- A subjective assessment. This will be based on the commonalities of personality and character. This includes attributes such as sense of humour, love of animals, life experiences etc.

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- Nurture UK: this is the UK branch of Nurture. As is the case with the South African branch, the UK branch offers 'full information about prospective donors, including personality and character information, family history going back two generations,

education history, medical information, etc'.¹³⁴ There is no indication that a basic donor profile is first given with the option of accessing extra information at a fee – the extra information is merely provided without extra payment.

- London Sperm Bank Donors: this bank provides a basic biographical description of its donors (such as ethnicity, ethnicity of parents, highest qualification attained, staff impression, a scant personality description etc) but does *not* offer the option of purchasing detailed donor information.¹³⁵ At most, it offers a category of donors that have a pen sketch and an extended profile available, but this information must be requested from the HFEA and not the bank itself.
- London Egg Bank Donors: this is the partner bank of the London Sperm Bank Donors. Like the aforementioned bank, a basic biographical description of its donors exists.¹³⁶ If a pen sketch of the donor exists, it must be requested from the HFEA.
- Fairfax Cryobank (UK branch): this USA-based bank freely offers prospective parents information such as a summary profile, medical profile, staff impression, donor essay and an audio clip of the donor.¹³⁷ If prospective parents want extra donor information, they would have to purchase an information package option. [see screenshot below]

The screenshot shows the Fairfax Cryobank website with a comparison table for donor information packages. The table lists various features and their availability across different price points.

90 Day Unlimited Access Plans	Free	Childhood Photos \$54.95	Childhood Photos PLUS \$124.95	FULL Access \$194.95	FULL Access with Club Fairfax \$294.95
Summary Profile	✓	✓	✓	✓	✓
Medical Profile	✓	✓	✓	✓	✓
Staff Impression	✓	✓	✓	✓	✓
Donor Essay	✓	✓	✓	✓	✓
Audio Clip- Hear the Donor	✓	✓	✓	✓	✓
Audio Clip- Staff Comments	✓	✓	✓	✓	✓
Childhood Photo		✓	✓	✓	✓
Personal Profile			✓	✓	✓
Silhouette			✓	✓	✓
Full Audio Interview with Donor			✓	✓	✓
Lifetime Photos				✓	✓
Keirsey Donor Report				✓	✓
Take the Keirsey Test				✓	✓
\$100 off your First Order					✓
Buy 5 vials and receive 6th free anytime over the next 12 months					✓
Preview new donors before others over the next 12 months					✓

Buttons: Free, Buy, Buy, Buy, Buy

Donor Information Packages: Unlimited Access 90 Day Plans. Options: Childhood Photos, Childhood Photos Plus, Full Access, Full Access with Club Fairfax. Order Today.

DONOR SEARCH

Fairfax FaceMatch (TM)

Match your partner, yourself or even someone famous to our

¹³⁴ <https://www.nurturedonors.com/intended-parents-faqs/#faq14>, accessed on 18 October 2017.

¹³⁵ <https://london.spermbankdonors.com/donor?specs=649>, accessed on 18 October 2017.

¹³⁶ <http://www.londoneggbankdonors.com/Donor>, accessed on 18 October 2017.

¹³⁷ <http://www.fairfaxcryobank.co.uk/donorpackages.shtml>, accessed on 18 October 2017.

- Complete Fertility: prospective parents ‘can select donors based on their physical characteristics and their employment, education and hobbies’.¹³⁸ There is no option of purchasing any information in addition to the aforesaid information.

As can be seen above, gamete donor agencies and banks in the UK do not behave uniformly with regard to the provision of detailed information. While there are some gamete agencies and banks that choose to exclusively provide basic biographical information, there are more agencies and banks that *do* choose to provide detailed information, albeit at varying amounts of information. In fact, as was already discussed, Altrui Egg Donation’s core business is focussed on matching prospective parents with donors based on an extensive amount of non-identifying donor information. Of these agencies and banks that do provide detailed information, most provide it at no extra cost (Fairfax Cryobank being the exception). While Fairfax Cryobank seems to be the only bank trading detailed information (from the other gamete agencies and banks that were selected), it is still indicative of the fact that detailed information *can* be traded in a system where donor anonymity is protected. The UK and South Africa are in a similar position with regard to the prohibition of the trade in gametes¹³⁹ and the protection of donor anonymity (apart from the instance where UK donors have their identities released to adult donor-conceived offspring). Yet many gamete agencies and banks in the UK still *choose* to provide detailed non-identifying donor information to prospective parents. This contrasts with South African gamete agencies and banks, where thus far, the vast majority of gamete agencies and banks provide a scant amount of Additional Information.

3.3 Canada

As is the case in South Africa, gamete donation in Canada can either be anonymous or known.¹⁴⁰ In Canada, assisted human reproduction is regulated by the Assisted Human Reproduction Act S.C. 2004, c. 2 (‘the AHRA’). The AHRA was a comprehensive piece of legislation that was enacted by the federal government in 2004.¹⁴¹ The AHRA, inter alia, had

¹³⁸ <http://www.completefertility.co.uk/index.php>, accessed on 18 October 2017.

¹³⁹ V Gruben & A Cameron ‘Donor Anonymity in Canada: Assessing the Obstacles to Openness and Considering a Way Forward’ (2017) 54(3) *Alta L Rev* 674.

¹⁴⁰ M Malone ‘Gamete Donor Anonymity in Canada: An Overview of Potential Policy Solutions’ (2017) 38 *Windsor Rev Legal & Soc Issues* 71.

¹⁴¹ V Gruben & A Cameron (note 139 above) 669.

created a complex system for the processing¹⁴² of both identifying and non-identifying information of stakeholders such as donors, prospective parents using artificial reproductive technologies ('ARTs') and donor-conceived offspring.¹⁴³ It had protected donor anonymity by stipulating that donor-conceived offspring could only be provided certain non-identifying information about their donors, and identifying donor information was to only be disclosed upon the consent of the donor.¹⁴⁴ Many of the details concerning the processing of stakeholders' information (both identifying and non-identifying) were to be encapsulated within regulations. Of particular importance is the fact that the regulations were meant to, *inter alia*, stipulate that physicians had to collect identifying and non-identifying donor information, but only disclose non-identifying donor information to prospective parents for the purpose of choosing a donor. Although it is not certain, it is *likely* that this information would have almost mirrored Required Information ie height, weight, eye colour, medical history etc.¹⁴⁵ These regulations, however, never had the chance to be drafted.¹⁴⁶

Shortly following its enactment, the AHRA found itself challenged by the Attorney General of Quebec ('AGQ').¹⁴⁷ The AGQ argued that many of the health-related provisions in the AHRA were *ultra vires* Parliament's legislative authority,¹⁴⁸ and rather belonged in the realm of provincial legislative authority.¹⁴⁹ The AGQ succeeded, and though the case was appealed at the Supreme Court of Canada, the Court held that the majority of the provisions in the AHRA belonged to the legislative authority of the provinces as they were health-related provisions.¹⁵⁰ However, the sections that did survive in their entirety include the: short title (section 1), principles (section 2), prohibited activities (sections 5-9),¹⁵¹ and offences (sections 60-64).¹⁵² Consequently, many of these provisions were soon repealed,¹⁵³ which

¹⁴² The term 'processing' in this instance specifically refers to the collection, usage and provision of information.

¹⁴³ V Gruben & D Gilbert 'Donor Unknown: Assessing the Section 15 Rights of Donor-Conceived Offspring' (2011) 27(2) *Can J Fam L* 252.

¹⁴⁴ *Ibid.*

¹⁴⁵ *Ibid* 253.

¹⁴⁶ *Ibid* 252.

¹⁴⁷ V Gruben & A Cameron (note 139 above) 670.

¹⁴⁸ B Seaman 'Assisted Human Reproduction: Should Sperm Donor Anonymity Be Maintained?' (2011) 35(4) *LawNow* 10.

¹⁴⁹ V Gruben & A Cameron (note 139 above) 670.

¹⁵⁰ V Gruben & A Cameron (note 139 above) 670.

¹⁵¹ 'Prohibited procedures' (section 5), 'payment for surrogacy' (section 6), 'purchase of gametes' (section 7), 'use of reproductive material without consent' (section 8), 'gametes obtained from minors' (section 9).

¹⁵² 'Offence and punishment' (section 60-61), 'court orders' (section 62), 'consent of Attorney General' (section 63), 'and notice to interested authorities' (section 64).

¹⁵³ B Seaman (note 148 above) 10.

‘effectively removed the federal law mandating donor anonymity, leaving only the provincial and territorial privacy statutes to fulfil this function’.¹⁵⁴

To date, however, most of the provincial legislatures have neglected to regulate this area, particularly with regard to donor anonymity and information.¹⁵⁵ Of the few provincial legislatures that have passed legislation, the focus of the legislation relates to the funding of IVF.¹⁵⁶ As such, there is now regulatory uncertainty within the area of assisted human reproduction.¹⁵⁷ Despite this regulatory uncertainty, however, it seems that many Canadian gamete agencies and banks have not veered away from the previous system of donor anonymity. As Canadian gamete donation currently operates in an environment of great legal uncertainty, the Canadian fertility industry has largely created its own certainty by simply operating in a system that would help it avoid judicial scrutiny – anonymity.¹⁵⁸ In other words, for there to be commercial certainty, the industry had to create its own ‘system’ in the absence of substantial legal regulation.¹⁵⁹ “Buyers want to buy, donors want to sell, banks want to market,” and doctors want to make money, help vulnerable patients, and/or advance science’.¹⁶⁰ Donor anonymity, then, serves multiple interests in this regard (apart, perhaps, from donor-conceived offspring):

Donors have a vested interest in avoiding claims of parentage or support that exceed their contractual intention to donate. Intending parents suffering from infertility may want to conceal the circumstances of their children's birth and avoid claims of parentage by third party donors. As for banks, agencies, and medical professionals, their main consideration vis-a-vis the law may be simply to avoid entanglements in unpredictable lawsuits.¹⁶¹

For the purpose of using Canada as a comparator, however, it can be accepted that despite the lack of a comprehensive regulatory system, Canada – like South Africa – practices donor anonymity. In light of this statement, an observation of how Canadian gamete agencies and banks operate with regard to the provision of donor information must be made. A quick Google search allowed me to randomly pick four websites of Canadian gamete agencies/banks: Xytex, ReproMed, Donor Egg Bank USA, and Little Miracles.

¹⁵⁴ V Gruben & A Cameron (note 139 above) 670.

¹⁵⁵ V Gruben & A Cameron (note 139 above) 670; V Gruben & D Gilbert (note 143 above) 254.

¹⁵⁶ V Gruben & A Cameron (note 139 above) 670.

¹⁵⁷ B Seaman (note 32 above) 10.

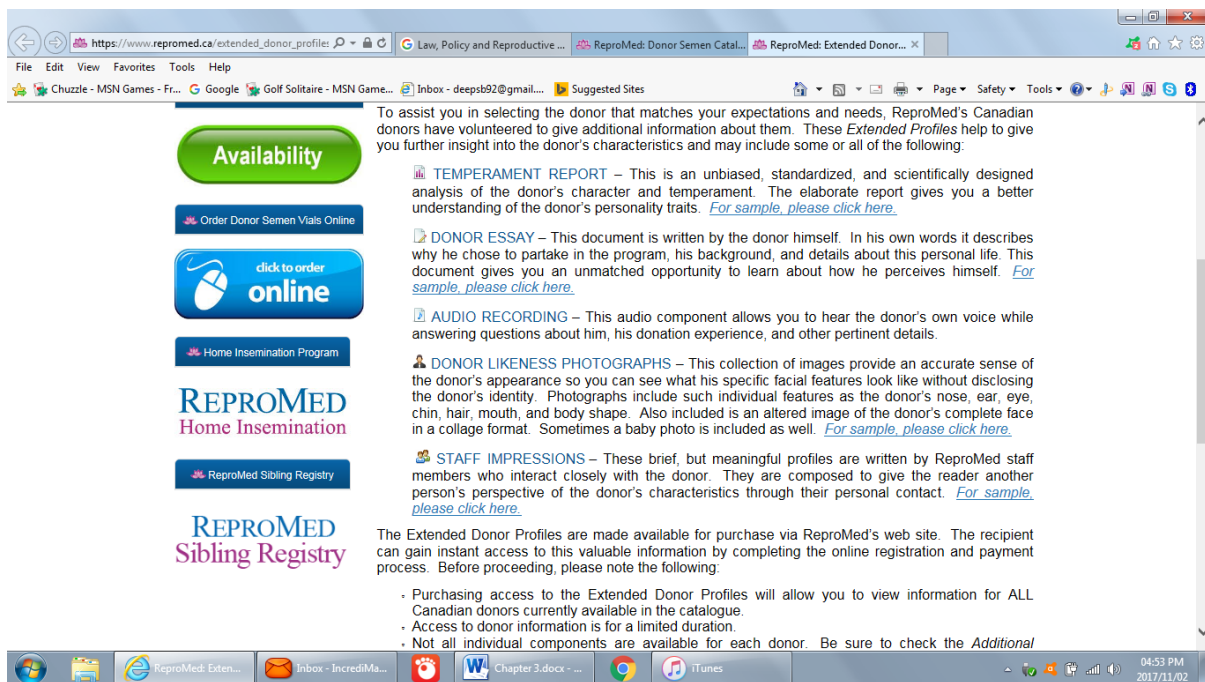
¹⁵⁸ M Malone (note 140 above) 77.

¹⁵⁹ M Malone (note 140 above) 77.

¹⁶⁰ M Malone (note 140 above) 77.

¹⁶¹ M Malone (note 140 above) 77.

- Xytex: offers both anonymous and identity-release sperm donors.¹⁶² It freely offers basic information and a very limited amount of detailed information. For extensive detailed information, prospective parents can purchase what Xytex calls ‘enhanced donor profiles’, either at \$75 for a 90-day access to a single profile, or \$225 for a 90-day access to all ‘enhanced’ donor profiles. Enhanced donor profiles include more information such as child and adult photographs, donor essay, personality test etc. Photographs can be viewed online, but there is an option of purchasing hardcopy photographs.
- ReproMed (The Toronto Institute for Reproductive Medicine): offers both anonymous and identity-release sperm donors. Basic donor information (similar to Required Information) can be accessed free of charge, but access to all extended donor profiles (for a limited period of time) is offered at a fee.¹⁶³ Extended donor profiles may contain some or all of the following donor information: temperament report, essays, audio clips, donor likeness photographs, and staff impression. [See screenshot below]



¹⁶² <https://www.xytext.com/patient-information/donor-options/>, accessed 2 November 2017.

¹⁶³ https://www.repromed.ca/extended_donor_profiles/, accessed 2 November 2017.

- Donor Egg Bank USA: although this bank is essentially a network of egg donation programs in the USA,¹⁶⁴ some fertility clinics in Canada, such as Olive Fertility Centre,¹⁶⁵ import eggs from it for their Canadian clients. Donor Egg Bank USA offers both anonymous donors (yet adult photographs of these donors are provided) and identity-release donors. They do not charge a fee for registering for an account on their website, or for viewing donor profiles.¹⁶⁶ Donor profiles seem to contain varying amounts of donor information. Prospective parents may only seek treatment in California, New York or Canada.
- Little Miracles: claims to be the only egg donation agency in Canada.¹⁶⁷ It offers ‘comprehensive’ donor information, although this information is not available for browsing on the website. Although it does not charge an additional fee for these detailed profiles, access to the profiles can only be gained if a prospective parent first registers and fills out a questionnaire.¹⁶⁸ This questionnaire is then reviewed by a co-ordinator, who then contacts the prospective parent to learn more about the prospective parent and his/her specific requirements.

It must be noted that there are many more USA gamete banks, like Donor Egg Bank USA, that export their gametes to Canada (the reason for this will be explained at the end of the USA section below). Furthermore, there are not as many gamete agencies and banks in Canada as there are in the USA. As such, there was an overlap in the Google search results, with a narrow range of Canadian agencies/banks to choose from. Therefore, I refrained from discussing more USA gamete banks in this section.

At this juncture, it is also worth mentioning that, like South Africa, Canada’s ban on the trade in gametes is still in place.¹⁶⁹ Trade in gametes is strictly prohibited by section 7(1) of the AHRA, which states that: ‘No person shall purchase, offer to purchase or advertise for the purchase of sperm or ova from a donor or a person acting on behalf of a donor’. In any event, it can be seen that despite operating in a system of anonymity, Canadian agencies and banks often provide detailed donor information to prospective parents, often at an additional charge.

¹⁶⁴ <https://donoreggbankusa.com/our-program>, accessed 27 October 2017.

¹⁶⁵ <https://www.olivefertility.com/our-services/donor-eggs>, accessed 2 November 2017.

¹⁶⁶ <https://donoreggbankusa.com/faqs>, accessed 27 October 2017.

¹⁶⁷ https://www.little-miracles.ca/donors_faq.html, accessed 2 November 2017.

¹⁶⁸ https://www.little-miracles.ca/recipients_application.html, accessed 2 November 2017.

¹⁶⁹ M Malone (note 140 above) 82.

Once again, this contrasts greatly with most South African gamete agencies and banks that fail to provide such an option to prospective parents.

3.4 USA

For thousands of couples in the USA, reproductive technology realises their dream of becoming parents.¹⁷⁰ It is estimated that 62 million women alone in the country suffer from infertility, and approximately 7,4 million of these women will utilise reproductive technology at some point in their lives.¹⁷¹ It is no wonder then that ARTs have turned into a lucrative multi-billion dollar industry in the USA,¹⁷² albeit being a private industry.¹⁷³ In fact, sperm donation alone generates annual revenue of 3.3 billion dollars.¹⁷⁴ For an industry that clearly contributes to and impacts the USA economy,¹⁷⁵ it would naturally be expected that such an industry would be heavily regulated. The irony, however, is that the USA fertility industry severely lacks comprehensive federal- and state-level regulation:

Unlike the United Kingdom and Canada, oversight of ART in the United States is not led by a dedicated regulatory body. Rather, the industry relies primarily on *self-regulation* in the form of *voluntary* guidelines issued by two professional associations—the American Society for Reproductive Medicine (ASRM) and the Society for Assisted Technology (SART)... Fertility clinics in the United States are also subject to state regulation, but few states have chosen specifically to regulate this industry and none has created a central oversight body similar to the HFEA or ARHC.¹⁷⁶ [*Own emphasis*]

"[w]e have more rules that go into place when you buy a used car than when you buy sperm."¹⁷⁷

At most, the ASRM recommends that donor information should be recorded and kept indefinitely.¹⁷⁸ Also, with so few states exercising their discretion to regulate gamete agencies

¹⁷⁰ J Gregorio 'Hatching a Plan towards Comprehensive Regulations in Egg Donation' (2017) 65(4) *DePaul L Rev* 1283.

¹⁷¹ Ibid 1285.

¹⁷² M Sabatello 'Disclosure of Gamete Donation in the United States' (2014) 11(1) *Ind Health L Rev* 54-55; *ibid* 1285.

¹⁷³ J Gregorio (note 170 above) 1283.

¹⁷⁴ M Ballantyne 'My Daddy's Name is Donor: Evaluating Sperm Donation and Regulation' (2012) 15(3) *Rich J L & Pub Int* 569.

¹⁷⁵ J Gregorio (note 170 above) 1297.

¹⁷⁶ AD Levine 'The Oversight and Practice of Oocyte Donation in the United States, United Kingdom and Canada' (2011) 23(1) *HEC Forum* 20.

¹⁷⁷ R Johns 'Abolishing Anonymity: A Rights-based Approach to Evaluating Anonymous Sperm Donation' (2013) 20(2) *UCLA Women's LJ* 111.

and banks,¹⁷⁹ there is no uniformity ‘as to how, whether, and under what conditions, donors’ information is obtained, is checked, and can be released’.¹⁸⁰ With regard to gamete regulation, there clearly is a stark contrast between the USA and many other Western countries (such as the UK, Netherlands, Norway etc)¹⁸¹ and arguably even South Africa with the NHA and its Regulations. Hence, with little external authority to govern it, the USA fertility industry has total control over donor information and how to deal with it.

It comes with little surprise, therefore, that the USA has not prohibited the practice of donor anonymity;¹⁸² a practice that has endured for over a century.¹⁸³ While the majority of gamete donations occur anonymously, like Canada and South Africa, known donations do occur in the USA and some gamete agencies and banks also choose to have identity-release donors, without being legally mandated to do so.¹⁸⁴ Washington is the only exception in this regard; Washington is the only state whose law, as of 2011, requires gamete donors to be identity-release donors ie allow their identifying information to be made available to donor-conceived offspring who request it after the age of 18.¹⁸⁵ The proviso, however, is that a gamete donor can instruct the fertility clinic to *not* make their identifying information available to the donor-conceived offspring.¹⁸⁶ It is submitted that this proviso makes the law redundant in instances where donors in Washington opt to not have their identifying information released. With most of the states operating in a system of donor anonymity, what then makes the USA fertility industry such a success?

The USA proves to be a key player in reproductive tourism – a phenomenon that sees many people from across the globe seeking fertility treatment in the USA, rather than in their own countries.¹⁸⁷ While the fact that the industry being unregulated at a national and state level may make it easier for the industry to function as it pleases, I suggest that another reason that

¹⁷⁸ M Sabatello (note 172 above) 40-41.

¹⁷⁹ J Gregorio (note 170 above) 1299.

¹⁸⁰ M Sabatello (note 172 above) 41; M Ballantyne (note 174 above) 581.

¹⁸¹ I de Melo-Martin (note 125 above) 101; M Sabatello (note 172 above) 40.

¹⁸² IG Cohen & TG Coan ‘Can You Buy Sperm Donor Identification? An Experiment’ (2013) 10(4) *J Empirical Legal Stud* 11.

¹⁸³ R Johns (note 177 above) 111.

¹⁸⁴ S Allan *Donor Conception and the Search for Information: From Secrecy and Anonymity to Openness* (2016) 144, available at <https://books.google.co.za/books?id=EislDwAAQBAJ&pg=PA144&lpg=PA144&dq=gamete+banks+and+donor+information&source=bl&ots=xwhXl3casB&sig=G3ohpMQC8XS00291LbvRqGMZ01Y&hl=en&sa=X&ved=0ahUKEwjIleqDw4TXAhXMaRQKHRnpByAQ6AEISjAG#v=onepage&q=gamete%20banks%20and%20donor%20information&f=false>, accessed 27 October 2017; IG Cohen & TG Coan (note 182 above) 2.

¹⁸⁵ M Ballantyne (note 174 above) 585; M Sabatello (note 172 above) 41.

¹⁸⁶ M Sabatello (note 172 above) 41.

¹⁸⁷ J Gregorio (note 170 above) 1296; M Sabatello (note 172 above) 54-55.

makes USA gamete agencies and banks a preferential choice for many prospective parents is the availability of detailed donor information. In the previous chapter, it was mentioned that many prospective parents – from the USA and other countries as well – would prefer having detailed donor information. Much of the evidence for this statement was based on studies conducted in the USA. Clearly, there seems to be a link between the USA’s gamete agencies’ and banks’ popularity and the manner in which they operate as businesses, especially with regard to the amount of donor information they generally provide despite practicing donor anonymity in most instances. While basic donor information is always provided, detailed donor information is provided only as a matter of choice for the gamete agency or bank.¹⁸⁸ With freedom for USA gamete agencies and banks to trade in donor information as they please, many of these agencies and banks choose to provide *detailed* donor information, as consumer demand has warranted it.¹⁸⁹

Upon my Google search, I randomly selected and searched six USA gamete agencies’ and banks’ websites for information regarding the provision and trade of donor information. The six agencies/banks were: Cryos International, Fairfax Cryobank, Fairfax Egg Bank, Donor Egg Bank USA, Seattle Sperm Bank, and The Sperm Bank of California.

- Cryos International: this bank offers both sperm and eggs.¹⁹⁰ Sperm and egg donors are either anonymous or identity-release. Egg donors – irrespective of whether they are anonymous or identity-release – have detailed profiles with varying amounts of donor information. Sperm donors, on the other hand, are available with either a basic profile or detailed profile eg prospective parents can choose a non-anonymous donor with a basic profile if they wish etc. There is no extra fee for accessing detailed profiles. [see screenshots below]

¹⁸⁸ AM Braverman ‘How the Internet is Reshaping Assisted Reproduction: From Donor Offspring Registries to Direct-to-Consumer Genetic Testing’ (2010) 11(2) *Minn JL Sci & Tech* 493.

¹⁸⁹ J Benward, AM Braverman & B Galen ‘Maximizing Autonomy and the Changing View of Donor Conception: the Creation of a National Donor Registry’ (2009) 12 *DePaul J Health Care L* 227.

¹⁹⁰ <https://usa.cryosinternational.com/resources>, accessed 27 October 2017.

https://usa.cryosinternational.com/resources/donors Donor Sperm FAQ

File Edit View Favorites Tools Help

Chuzzle - MSN Games - Fr... Google Golf Solitaire - MSN Game... Inbox - deepsb92@gmail... Suggested Sites

Cryos International continues to proactively prevent the spread of Zika in sperm and egg donations. Read about how we screen every donor for the virus [at our FAQ](#).

Cryos USA Donor Search Donor Sperm Donor Eggs Become a Donor Fertility Preservation About

The Donors

Which information about the donors is available?

We have two types of donors: Anonymous and Non-Anonymous donors. In both groups you can find Basic and Extended profiles. In all groups there are [Exclusive Donors](#).

The donors are either Anonymous or Non-anonymous. These definitions do not mean that the donors are not identifiable. As donor sperm carry DNA, there is always a risk that donors, recipients and children can be traced via DNA-analysis and maybe otherwise making the privacy questionable in the future.

Anonymous: If the donor is Anonymous Cryos will never release the identity of the donor, and the client agrees not to try to contact the donor.

Non-Anonymous: Non-Anonymous donors identity can be revealed to a donor child when he/she has reached the age of 18. The donor child must contact Cryos.

Basic profile:
These profiles are registered with a number e.g. 3456. Only a few characteristics (race, ethnicity, eye colour, hair colour, height, weight, blood type and in most cases education/occupation) are available. We do not check education/occupation.

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https://usa.cryosinternational.com/resources/donors Donor Sperm FAQ

File Edit View Favorites Tools Help

Chuzzle - MSN Games - Fr... Google Golf Solitaire - MSN Game... Inbox - deepsb92@gmail... Suggested Sites

Cryos International continues to proactively prevent the spread of Zika in sperm and egg donations. Read about how we screen every donor for the virus [at our FAQ](#).

Cryos USA Donor Search Donor Sperm Donor Eggs Become a Donor Fertility Preservation About

eye colour, hair colour, height, weight, blood type and in most cases education/occupation are available. We do not check education/occupation.

Extended profile:
These profiles are registered with a fictitious name, e.g. CLIFF. Extended Profiles have comprehensive information about the donors e.g. background, favorite pet, and family relations.

On most of the profiles you can see the Staff impression - a short, subjective description of the donor by our staff. In most cases you are able to see a childhood photo of the donor as well as hear a voice message recorded by the donor. In 2011 we started to register Emotional Intelligence (EQ). We check the race, ethnicity, eye colour, hair colour, height, weight, and blood type.

What type of donor should I choose? ▾

Do you have open ID donors? ▾

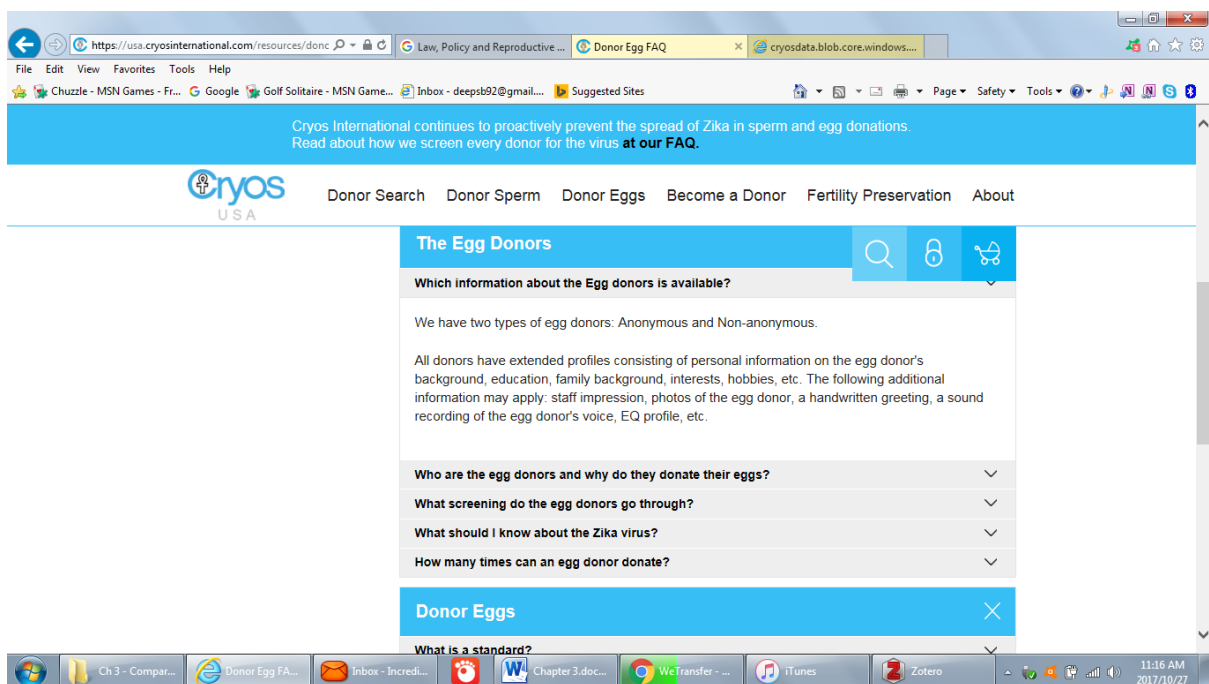
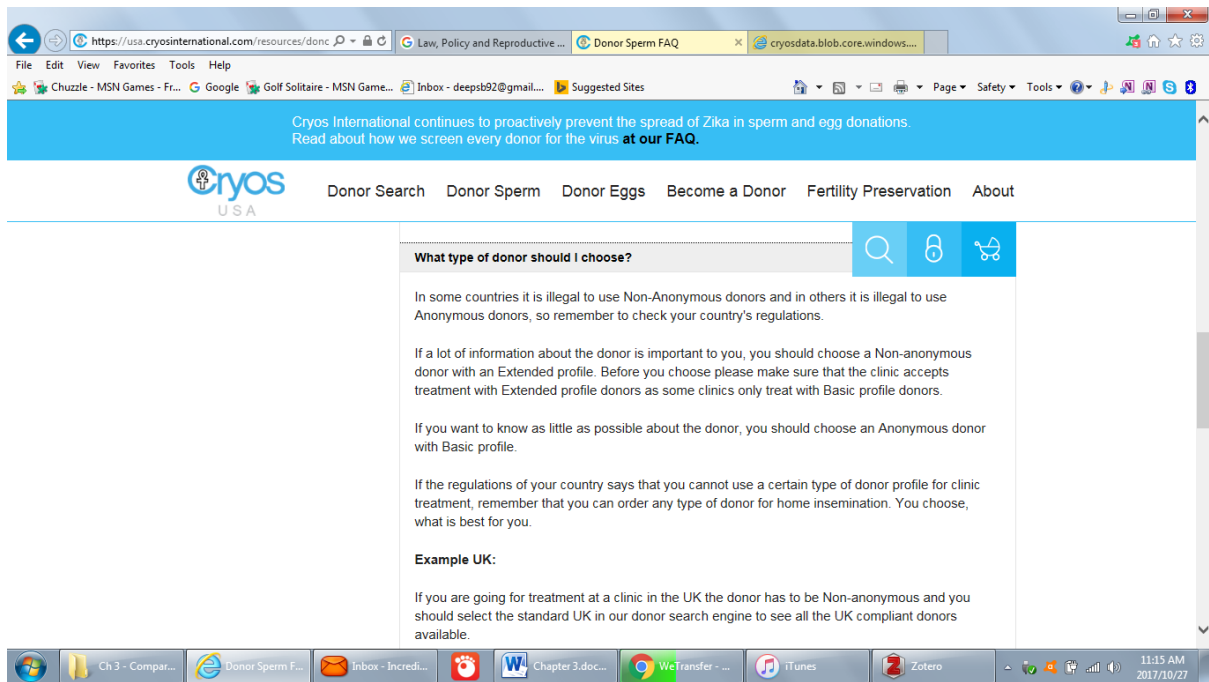
Can I get in touch with donors in the future? ▾

What is an exclusive donor? ▾

What should I know about the Zika virus? ▾

Show more

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- Fairfax Cryobank: this bank offers both anonymous and identity-release donors. The Fairfax Cryobank allows prospective parents to browse through summary donor profiles, medical history (including that of the donor's family), childhood photographs, donor essays, audio clips etc free of charge.¹⁹¹ If prospective parents wish to access further detailed non-identifying donor information (such as a personal

¹⁹¹ <https://fairfaxcryobank.com/donor-unlimited-access-packages>, accessed 27 October 2017.

profile, full audio interview, personality test results etc), they would have to purchase a package option to gain such access (the cost depends on the package option the prospective parents want to purchase).

- Fairfax Egg Bank: this bank is a ‘sister’ company to the Fairfax Cryobank. It does not require prospective parents to register or pay a fee for viewing donor profiles (effectively, *anyone* can freely browse through the profiles).¹⁹² Unlike its ‘brother’ company, the egg bank does not offer donor information packages for purchase. All donors are anonymous – no identity-release donors are offered. It states that it offers:

...a significant amount of detailed information about each egg donor. In fact, our program is one of the few to offer such a vast amount of information on each donor. Profiles can be found on the website, including medical and personal history, donor essays, audio interviews, and childhood photos. Adulthood photos for all donors are also available as a patient of any affiliate clinic once the confidentiality agreement has been signed and returned, as a reasonable precaution to preserve their anonymity. Many recipients say that this additional information and extensive screening are incredibly helpful in selecting just the right donor.¹⁹³

- Donor Egg Bank USA: this bank is essentially a network of egg donation programs in the USA.¹⁹⁴ They offer both anonymous donors (yet adult photographs of these donors are provided) and identity-release donors. They do not charge a fee for registering for an account on their website, or for viewing donor profiles.¹⁹⁵ Donor profiles seem to contain varying amounts of donor information. It is not, however, as comprehensive as what is provided at the Fairfax banks. Prospective parents may only seek treatment in California, New York or Canada.
- Seattle Sperm Bank: this bank predominantly offers identity-release donors;¹⁹⁶ there are only four anonymous donors available at the time of writing this section.¹⁹⁷ It offers basic donor information freely, however, prospective parents wishing for detailed information must purchase such information. Audio interviews, baby photographs, extended profiles etc, individually cost \$10 each. Alternatively,

¹⁹² <https://www.fairfaxeggbank.com/advantage/>, accessed 27 October 2017.

¹⁹³ <https://www.fairfaxeggbank.com/faqs/#411>, accessed 27 October 2017.

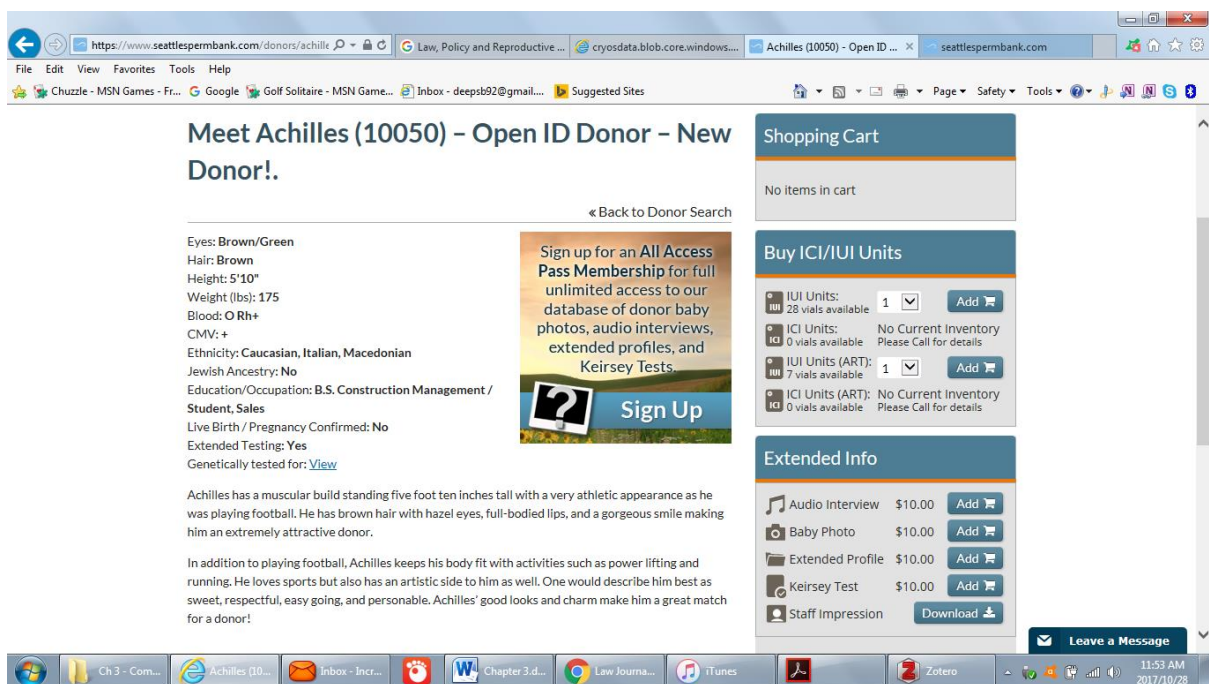
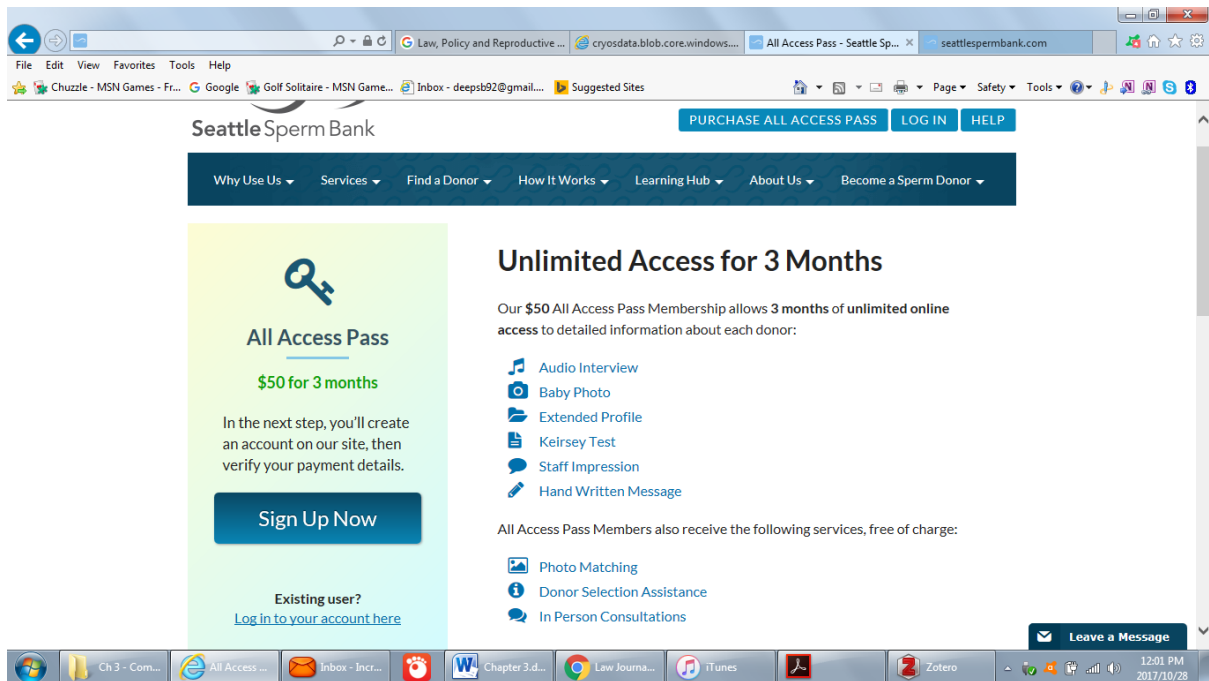
¹⁹⁴ <https://donoreggbankusa.com/our-program>, accessed 27 October 2017.

¹⁹⁵ <https://donoreggbankusa.com/faqs>, accessed 27 October 2017.

¹⁹⁶ <https://www.seattlespermbank.com/>, accessed 28 October 2017.

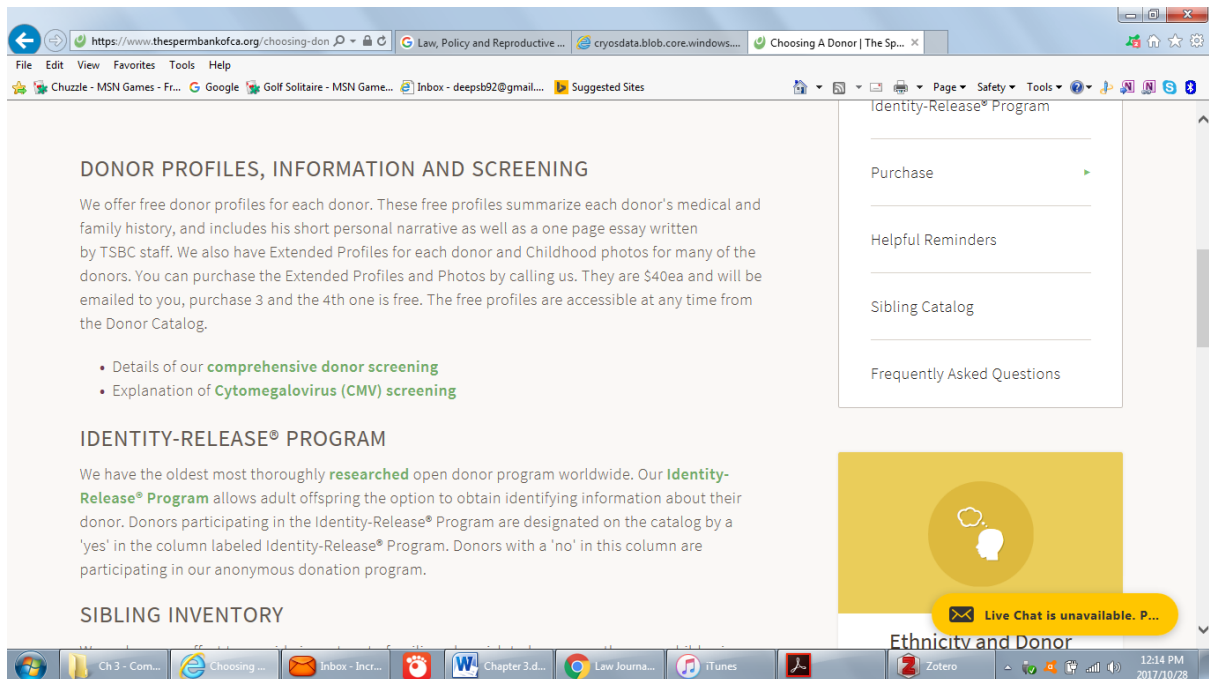
¹⁹⁷ <https://www.seattlespermbank.com/anonymous/>, accessed 28 October 2017.

prospective parents can pay \$50 for an ‘All Access Pass Membership’, which includes three months of unlimited access to all information available about the donor.¹⁹⁸ [see screenshots below]



¹⁹⁸ <https://www.seattlespermbank.com/all-access-pass/>, accessed 28 October 2017.

- The Sperm Bank of California: this bank offers both anonymous and identity-release donors. It provides basic donor profiles (with relatively scant information compared to the previous USA agencies/banks that were searched), however, detailed information (found in ‘extended profiles’) and baby pictures have to be purchased at \$40 each.¹⁹⁹ [See screenshot below]



Apart from the Fairfax Egg Bank, the rest of the aforementioned USA gamete agencies/banks offer both anonymous and identity-release donors (barring the fact that some of these agencies/banks offer adult photographs for their ‘anonymous’ donors). For the purpose of this dissertation, it must be noted that while identity-release donors are meant to provide identifying information to the agency/bank so that donor-conceived children may request it upon reaching the age of 18, identity-release donors are effectively *anonymous* until such time. Therefore, all the donors offered at these agencies/banks can be considered as anonymous. Bearing this in mind, it can be seen that these agencies/banks still offer detailed donor information to prospective parents, often at an additional fee. This observation is proof that even when maintaining an anonymous donor program, it is still possible for a gamete agency/bank to offer prospective parents detailed donor information, either freely or at a fee.

¹⁹⁹ <https://www.thespermbankofca.org/choosing-donor-0>, accessed 28 October 2017.

Nota bene: Due to the fact that there is a severe shortage of gametes in Canada,²⁰⁰ Canadian agencies often import gametes from the USA. Fairfax Cryobank, Fairfax Egg Bank, Donor Egg Bank USA and Seattle Sperm Bank are examples of gamete banks that export their gametes to Canada. The USA is a convenient choice in this instance, mainly because it has effectively commercialised gamete donation and also provides a greater selection of donors.²⁰¹

3.5 Conclusion

As can be observed from the analysis above, the UK, Canada and USA – countries that share the same basic values with South Africa’s legal system – deal with the provision of donor information rather differently to South Africa. Many gamete banks and agencies in these three countries, which operate within the context of donor anonymity (albeit at varying degrees) as South Africa does, choose to provide prospective parents with relatively detailed donor information on their own accord. The provision of detailed information can either be freely provided or at a fee. Nonetheless, these countries are prime examples for proving that gamete banks and agencies can provide detailed donor information without significantly compromising donor anonymity. Thus, it would seem *prima facie* that South African gamete banks and agencies can also do the same.

²⁰⁰ M Malone (note 140 above) 81-82: more than 95 per cent of Canadian couples import gametes from the USA.

²⁰¹ M Malone (note 140 above) 81.

CHAPTER 4 – AN ANALYSIS OF SOUTH AFRICAN LAW: CAN SOUTH AFRICA PERMIT THE TRADE IN PERSONAL GAMETE DONOR INFORMATION?

4.1 Introduction

In the previous chapter, a legal analysis of the provision of gamete donor information was undertaken to gauge how the comparator countries, who share the same basic values with South Africa's legal system, dealt with this phenomenon. While the *Nurture* case focusses on Additional Information, this dissertation explores the question of whether *personal* donor information can be traded in South Africa. In light of the *Nurture* case, personal information would include both Required Information and Additional Information. The chapter will start with providing the relevant law, followed by a summary of each of the papers filed in the *Nurture* case. Thereafter, the question of whether gamete banks and egg agencies (there are no sperm donation agencies as sperm can be easily donated and cryopreserved immediately in a sperm bank)²⁰² can legally operate in South Africa. This question must necessarily be dealt with before determining whether a new business model (of selling personal gamete donor information) can be engaged. Lastly, the analysis will end with determining what impact the POPI Act will have on such a business model, once it fully comes into force.

4.2 Relevant law

The following laws and regulations, which are stated verbatim, are provided for ease of reference:

4.2.1 The NHA

Payment in connection with the importation, acquisition or supply of tissue, blood, blood products or gametes

60. (1) No person, except-

- (a) a hospital or an institution contemplated in section 58(1)(a), a person or an institution contemplated in section 63 and an authorised institution or, in the case of tissue or gametes imported or exported in the manner provided for in the regulations, the importer or exporter concerned, may receive payment in respect of the acquisition, supply, importation or export of any tissue or gamete for or to another person for any of the purposes contemplated in section 56 or 64;

²⁰² Founding affidavit para 20 p16.

(b) a person or an institution contemplated in section 63 or an authorised institution, may receive any payment in respect of the importation, export or acquisition for the supply to another person of blood or a blood product.

(2) The amount of payment contemplated in subsection (1) may not exceed an amount which is reasonably required to cover the costs involved in the importation, export, acquisition or supply of the tissue, gamete, blood or blood product in question.

(3) This section does not prevent a health care provider registered with a statutory health professional council from receiving remuneration for any professional service rendered by him or her.

(4) It is an offence for a person-

(a) who has donated tissue, a gamete, blood or a blood product to receive any form of financial or other reward for such donation, except for the reimbursement of reasonable costs incurred by him or her to provide such donation; and

(b) to sell or trade in tissue, gametes, blood or blood products, except as provided for in this Chapter

(5) Any person convicted of an offence in terms of subsection (4) is liable on conviction to a fine or to imprisonment for a period not exceeding five years or to both a fine and such imprisonment.

4.2.2 The Regulations

Compensation in respect of the withdrawal or removal of gametes

5. A person from whose body a gamete has been removed or withdrawn may be reimbursed for any reasonable expenses incurred by him or her in order to donate a gamete as contemplated in section 60(4)(a) of the Act.²⁰³

...

Gamete donor files, availability of information and destruction of gametes

9. (1) The competent person must immediately record the following information and documents in the gamete donor's file before a gamete is removed or withdrawn-

(a) the gamete donor's -

²⁰³ Please note that 'the Act' is a reference to the NHA.

- (i) full name, surname, date of birth and identity number;
- (ii) age, height, mass, eye colour, hair colour, complexion, population group, nationality, sex, religion, occupation, highest educational qualification and fields of interest;
- (iii) family history referred to in regulation 8(i); and
- (iv) subject to regulation 7(a), wishes in respect of the number of artificial fertilisations for which her or his gametes may be used;
- (b) the particulars of medical tests for genetically transmissible disorders or for infectious diseases, or genetic evaluation of the gamete donor;
- (c) particulars of any evaluation of the psychological suitability of the gamete donor to donate a gamete;
- (d) particulars of each donation of gametes made by the gamete donor, including the date on which the donation of gametes was made;
- (e) the informed consent and documents contemplated in regulation 8(e);
- (f) results of the tests and the analysis or examination contemplated in regulation 8(e) to (g); and
- (g) any other relevant document or information that the competent person may request.

(2) The competent person-

- (a) must retain the gamete donor file in safe-keeping and may not destroy the file, except with the written permission of the Director-General;
- (b) must make the particulars set out in sub-regulation (1)(a)(ii), (iii) and (iv), (b),(c) and (f), together with the identification number referred to in regulation 8(a), available to the recipient and the competent person who is to effect the artificial fertilisation of the recipient;
- (c) must furnish the central data bank before 31 January of each year with the following particulars regarding the preceding year in respect of the gamete donor:
 - (i) the identification number of the gamete donor file;
 - (ii) the number of donations of gametes, with the dates on which the donations were made; and
 - (iii) the number of live births reached through the artificial fertilisation from the gametes of the specific gamete donor;
- (d) must not make the gamete donor file, or information there from, available to any person other than a person acting under her or his supervision, except in terms of legislation or a court order;

....

Prohibition of Disclosure of certain facts

19. No person may disclose the identity of any person who donated a gamete or received a gamete, or any matter related to the artificial fertilisation of such gametes, or reproduction resulting from such artificial fertilisation except where a law provides otherwise or a court so orders.

4.3 The Nurture case

The papers filed in the *Nurture* case will be individually summarised. Kindly note that the case makes reference to the Regulations (GN R175/2012) before it was amended in 2016. While the current amended Regulations (GN R1165 GG 40312) do not significantly alter the arguments in this case, it is still worth noting that the regulations applicable to the case have merely changed regulation numbers. For instance, regulation 8 in the case is in fact the current regulation 9. For the purposes of this dissertation, any regulations referred to in the case will be referred to as per the *current* Regulations.

4.3.1 Notice of motion

Nurture gave notice to the respondents that it intended to apply to Court to have it declared that Additional Information falls outside the ambit of section 60 of the NHA and regulation 5 of the Regulations.²⁰⁴

4.3.2 Founding affidavit

The application concerned the question of whether gamete banks could provide Additional Information at a profit in South Africa.²⁰⁵ Nurture claimed that there is a development amongst international gamete banks in response to market demand – the provision of Additional Information to prospective parents.²⁰⁶ South African sperm banks, however, do not offer Additional Information, causing some South African prospective parents to incur great costs in order to import sperm from international sperm banks that offer Additional

²⁰⁴ Notice of motion para 1 p2.

²⁰⁵ Founding affidavit para 8 p11.

²⁰⁶ Founding affidavit para 23 p17.

Information.²⁰⁷ Nurture averred that in jurisdictions that ban the trade in gametes, like South Africa, there exists a business model whereby prospective parents can freely access basic donor profiles on a given donor database, but must pay for access to extra (optional) donor information.²⁰⁸ Nurture is an egg donation agency, however, it had plans of establishing an egg bank that would be independent of any fertility clinic.²⁰⁹ This plan included implementing the international business model of providing Required Information (either freely or on a cost-recovery (non-profit) basis), but providing prospective parents access to Additional Information at a cost that would allow the bank to gain a profit from such a sale.²¹⁰ As the concept of trading in Additional Information raised a *res nova*, Nurture felt that it was prudent to first seek legal certainty on the matter before expending significant time and financial resources on its intended business plan.²¹¹

In terms of the bank-customer relationship, Nurture argued that the implication of section 60 of the NHA was that a gamete bank (which is recognised as an authorised institution) could only receive payment to cover its reasonable costs in return for the provision of gametes.²¹² Similarly, with regard to the bank-donor relationship, donors are only entitled to be reimbursed for the reasonable costs they incurred in donating.²¹³ From both these instances, it can be seen that the transaction is subject to a cost-recovery regime ie no profit can be derived from the transaction.²¹⁴ It was argued that this, however, is only the case where the object of the transaction happens to be gametes, and not *information* about the gamete donor.²¹⁵

Furthermore, with regard to regulations 9(2)(b)-(c) of the Regulations and any sub-regulations they cross-reference, Nurture stated that there was a range of specific information that was legally required from the gamete donor ie Required Information.²¹⁶ This Required Information is, therefore, vital in any transaction where gametes are the object of the transaction.²¹⁷ Also, Nurture acknowledged that donor anonymity is protected by regulation

²⁰⁷ Founding affidavit para 24 p17-18.

²⁰⁸ Founding affidavit para 26 p18.

²⁰⁹ Founding affidavit para 35 p22.

²¹⁰ Founding affidavit para 38 p23.

²¹¹ Founding affidavit para 37 p22-23.

²¹² Founding affidavit para 41a p25.

²¹³ Founding affidavit para 41b p26.

²¹⁴ Founding affidavit para 42 p26.

²¹⁵ Founding affidavit para 42 p26.

²¹⁶ Founding affidavit para 51 p33.

²¹⁷ Founding affidavit para 68 p39.

19 of the Regulations.²¹⁸ However, Nurture argued that Additional Information clearly falls outside the ambit of regulation 9(2)(b)-(c) and does not generally disclose the donor's identity.²¹⁹ As such, Additional Information can be legally disclosed to prospective parents.²²⁰

Nurture referred to regulation 5 of the Regulations, and argued that the phrase 'in order to donate a gamete' pointed to acts that a donor was *legally required* to perform apart from the actual donation itself ie undergo specific medical tests and provide Required Information.²²¹ Therefore, in order for a donor to donate, the aforesaid acts must necessarily be performed and consequently, a donor must be reimbursed for any costs incurred in performing these acts. In contrast, however, the donor's provision of Additional Information is not legally required in order to donate a gamete, and therefore, is not subject to regulation 5 of the Regulations.²²² As such, it was argued that a donor may be compensated for *any* amount agreed upon (between the donor and the bank) for the provision of Additional Information, even if this amount surpasses a reasonable expense.²²³ Likewise, the bank may sell this information to prospective parents for any amount agreed upon.²²⁴

In conclusion, Nurture stated that Additional Information falls outside the scope of the NHA and the Regulations, and hence, a gamete bank is allowed to trade in Additional Information.

4.3.3 Answering affidavit

The respondents opposed Nurture's application on five grounds: First, the respondents opposed the application on the ground that the distinction between 'hard-type' and 'soft-type' information²²⁵ is cosmetic and, therefore, legally non-existent.²²⁶ This argument was simply

²¹⁸ Founding affidavit para 55 p34.

²¹⁹ Founding affidavit para 61 p37: Nurture admits that it *may* be possible to have the donor's identity revealed if there are unique combinations of information, however, this risk *also* exists with only having Required Information as well. Nurture uses the following example (para 58 p35): '...if only a few elements of the Required Information of a donor are relatively unique, a well-resourced investigator may be able to identify the donor. Say for instance the donor is female, has red hair, her highest qualification is a doctorate, her occupation is university lecturer, and her field of interest is Criminal Procedure, I state that it would be relatively easy to discover the identity of this hypothetical person through an internet search...'

²²⁰ Founding affidavit para 62 p37.

²²¹ Founding affidavit para 65 p38.

²²² Founding affidavit para 67 p38.

²²³ Founding affidavit para 127c p59.

²²⁴ Founding affidavit para 127e p59.

²²⁵ 'Hard-type' information is a term used by Nurture in its founding affidavit, and is a general reference to the legally Required Information defined in 1.2.4 of the Definitions section in Chapter 1. Similarly, 'soft-type' information is a term used by Nurture in its founding affidavit, and is a general reference to the Additional Information defined in 1.2.4 of the Definitions section in Chapter 1.

²²⁶ Answering affidavit para 6.3.1 p3.

put forward without much elaboration, therefore, nothing further will be mentioned about it for now.

Secondly, the respondents alleged that the legally *non-required* information contained in the donor file is prohibited from disclosure to anyone apart from a person supervised by a competent person.²²⁷ The respondents argued that, as per regulation 9(1)(g) of the Regulations, a competent person can record ‘any other relevant document or information that the competent person may request’;²²⁸ this information supposedly may include Additional Information.²²⁹ In addition to this argument, the respondents claimed that regulation 9(1)(g) read in conjunction with regulation 9(2)(d) prohibits the competent person from making the donor file, or information contained within the file, available to any other person (including the gamete recipient).²³⁰ The exception to the prohibition of disclosure is applicable only when the disclosure is made to a person acting under the competent person’s supervision, or as per legislation, or if a court order requires such disclosure.²³¹

Thirdly, the respondents urged the Court to exercise its discretion against the applicant because granting in the applicant’s favour may unduly cause vulnerable and poor women to donate their eggs by foregoing informed consent in response to the temptation of financial reward.²³² The respondents claimed that certain South African egg donation agencies, who were not working with South African fertility clinics, recruited donors for the sole purpose of having them travel abroad to donate their gametes; large sums of money were provided to donors as an incentive.²³³ Some of these donors returned to South Africa in poor health as a result of receiving sub-standard medical treatment abroad.²³⁴ It was argued that if egg donation became a profit-driven business, bearing in mind that South Africa is subject to high levels of poverty and unemployment, poor women would easily be enticed to become donors

²²⁷ Answering affidavit para 6.3.2 p3. Please note that as per the Regulations, a competent person is defined as ‘a medical practitioner registered with the Health Professions of South Africa (HPCSA) with expertise in specialist gynaecologist and sub-specialist in Reproductive Medicine, or a trainee in Reproductive Medicine in a training unit under the supervision of a registered HPCSA sub – specialist’.

²²⁸ Regulation 9(1)(g) of the Regulations.

²²⁹ Answering affidavit 26.3 p31.

²³⁰ Answering affidavit para 9.10 p14.

²³¹ Answering affidavit para 9.10 p14.

²³² Answering affidavit para 6.3.4 p4.

²³³ Answering affidavit para 9.13 p15.

²³⁴ Answering affidavit para 9.16 p15.

while having less regard for the medical risks associated with donation.²³⁵ For these further reasons, the respondents urged the Court to exercise its discretion against Nurture.²³⁶

Fourthly – and perhaps the most important argument rendered by the respondents – it was argued that gametes and gamete donor information are inextricably linked, therefore, trading information contained in the donor file is tantamount to trading in gametes.²³⁷ This subjects the trade in information to the same sanctions as the trade in gametes.²³⁸

Fifthly, the respondents argued that gamete banks are not supposed to be profit-driven business enterprises, but rather part of medical practice in general.²³⁹

The respondents did, however, state that trade in Additional Information should be allowed *before* the harvesting of the eggs from the donor.²⁴⁰ However, it was argued that trade in Additional Information is prohibited *after* the eggs have been harvested from the donor.²⁴¹ The reason for this argument was that prior to harvesting the eggs, the information is about the gamete donor; after harvesting the eggs, the information ceases to be about the donor and is rather about the gamete itself.²⁴² The respondents argued that Additional Information only retains its value in relation to the supply or acquisition of a gamete.²⁴³ In other words, information pertaining to harvested gametes is inextricably linked to the gametes themselves, and consequently has no value in the absence of the gametes.²⁴⁴ Therefore, an authorised institution and donor cannot derive profit from such a transaction.²⁴⁵ The implication then is that actual gamete donation and the profit derived from the trade in Additional Information are tantamount to the same transaction; this means that if trading in gametes is banned, then so is the trading of any information relating to the gametes.²⁴⁶

The respondents' expert, Prof John Anthony, the Head of Maternal and Fetal Medicine Unit in Groote Schuur Hospital and Associate Professor in the Department of Obstetrics and Gynaecology at the University of Cape Town, reiterated the arguments based on the five

²³⁵ Answering affidavit para 9.19 p17.

²³⁶ Answering affidavit para 9.20 p17.

²³⁷ Answering affidavit para 6.3.3 p4.

²³⁸ Ibid.

²³⁹ Answering affidavit para 22.3 p28-29.

²⁴⁰ Answering affidavit para 27.4 p33.

²⁴¹ Answering affidavit para 27.5 p34.

²⁴² Answering affidavit para 27.6 p34.

²⁴³ Answering affidavit para 9.6 p13.

²⁴⁴ Answering affidavit para 25.7 p31.

²⁴⁵ Answering affidavit para 9.7 p13.

²⁴⁶ Answering affidavit para 31.2 p36.

grounds put forward in the answering affidavit. However, he elaborated further on the argument that gametes and gamete donor information are inextricably linked, therefore, trading information contained in the donor file is tantamount to trading in gametes.

For one, he argued that the medical field is based upon principles that differ from the business field and even general society.²⁴⁷ With regard to determining the legality and morality of human transactions, he stated that the circumstances of the transactions are crucial because what may be acceptable in general society may not be acceptable as a medical transaction.²⁴⁸ As such, trading in Additional Information can only be acceptable so long as it remains within the ambit of civil transaction; the moment it enters the arena of medical practice, it is no longer permissible to trade in Additional Information with a profit-oriented agenda.²⁴⁹ He argued that, ultimately, what determines whether trading in donor information should be permissible is whether it falls within scope of a civil or medical transaction.²⁵⁰

Prof Anthony stated that the application can actually be regarded as two separate applications: one, trading in donor information prior to medical procedure of harvesting the eggs, and two, trading in donor information after the medical procedure has begun.²⁵¹ In other words, the first scenario does not entail any medical intervention because it is simply a transaction between the donor and recipient;²⁵² the second scenario, however, entails the trading of information concerning harvested eggs which are stored in an egg bank as a direct result of medical practice.²⁵³ Furthermore, after harvesting, the information ceases to be about the donor but is rather about the gamete.²⁵⁴ This is because the information regarding the gametes only retains its value in conjunction with the gametes themselves. Therefore, trading in gamete information is prohibited by the same trade ban applicable to gametes themselves; they are one and the same transaction.²⁵⁵

²⁴⁷ Anthony expert opinion, 22 June 2016, para 13.11 p7.

²⁴⁸ Ibid para 13.11 p7.

²⁴⁹ Ibid para 13.13 p8.

²⁵⁰ Ibid para 13.21 p10.

²⁵¹ Ibid para 13.15 p8.

²⁵² Ibid para 13.16 p9.

²⁵³ Ibid para 13.17 p9.

²⁵⁴ Ibid para 13.26 p10.

²⁵⁵ Ibid para 13.26 p10.

4.3.4 Replying affidavit

With regard to the four grounds the respondents argued to oppose the relief sought by the applicant, the applicant answered as follows:

- a) The distinction between hard-type and soft-type information was used in an explanatory fashion and is *not* the basis for the application – the application is hinged on the difference between Required Information and Additional Information.²⁵⁶
- b) The Regulations²⁵⁷ restrict the *competent person* (who keeps the donor file) from disclosing any information contained within the file; in no way do the Regulations – or any other legislation for that matter – prohibit the *donor* from sharing his/her personal information contained in the donor file,²⁵⁸ or place a restriction on the content of donor information that should be disclosed.²⁵⁹ Nor does the competent person's restriction have anything to do with a gamete bank's provision of donor information.²⁶⁰ This is because the gamete bank does not obtain such information from the competent person, but *directly* from the donor herself.²⁶¹ Information, being intangible in nature, can exist in various places at any one time.²⁶² While no one may access the donor file, this does not mean that no one can have access to the donor information outside the donor file.²⁶³ It would seem illogical to prohibit a donor from ever using the information commercially that s/he provided to the competent person.²⁶⁴ So long as the donor's anonymity is maintained, there is no reason as to why a donor cannot enter into an agreement with the egg bank to provide her personal information for commercial use (without, of course, compromising donor anonymity).²⁶⁵
- c) Essentially, the respondents averred that providing poor female donors with remuneration for the provision of Additional Information, arguably at a profit, would compromise their autonomy when deciding to donate their eggs because they would disregard the risks associated with egg donation in response to the temptation of

²⁵⁶ Replying affidavit para 34-35 p10-11.

²⁵⁷ Specifically regulations 14(2)(b) and 8(e)(iii).

²⁵⁸ Replying affidavit para 49 p13.

²⁵⁹ Replying affidavit para 275.3 p57.

²⁶⁰ Replying affidavit para 275.4 p58.

²⁶¹ Replying affidavit para 275.4 p58.

²⁶² Replying affidavit para 46 p13.

²⁶³ Replying affidavit para 258 p54.

²⁶⁴ Replying affidavit para 50 p14.

²⁶⁵ Replying affidavit para 88.3 p22.

money.²⁶⁶ Apart from the fact that medical complications occurring as a consequence of egg donation are a rarity,²⁶⁷ the reality in South Africa concerning the remuneration amount would constitute a compromise in autonomy as well.²⁶⁸ As per SASREG's Guidelines, an egg donor's reasonable costs are considered to be R7000.²⁶⁹ With egg donors being paid R7000, as a general rule, this could be regarded as a considerable amount of money for a poor person.²⁷⁰ Therefore, providing some profit for the provision of Additional Information would hardly be of consequence.²⁷¹ In any event, there are two ways in which undue enticement can be prevented, instead of using the paternalistic approach of simply prohibiting the trade in Additional Information.²⁷² The first solution is to strengthen and enhance the informed consent mechanism to promote donor autonomy.²⁷³ Donors must be made aware of possible risks (medical and emotional) concerning donation, even if the possibility of these risks materialising being low.²⁷⁴ This can be done by the state creating regulations concerning the issue of donor-counselling.²⁷⁵ Alternatively, the state (or SASREG) could issue guidelines concerning informed consent procedures. The second solution would simply be to offer donors a modest compensation for their provision of Additional Information.²⁷⁶

- d) The prohibition of trade in gametes does not include the prohibition of trade in donor information.²⁷⁷ Conceptually, gametes and gamete donor information are factually related, however, they are undoubtedly distinguishable.²⁷⁸ Prospective parents may access donor information about a specific donor, but may choose not to purchase that specific donor's gametes.²⁷⁹ What is important to note at this juncture, is that both Required Information and Additional Information constitute personal information of the donor – not the gamete.²⁸⁰ For instance, as was argued by the applicant, 'a gamete does not have education, family history, personal and physical characteristics, et

²⁶⁶ Replying affidavit para 57 p15.

²⁶⁷ Replying affidavit para 54 p14.

²⁶⁸ Replying affidavit para 60 p15.

²⁶⁹ Replying affidavit para 59 p15.

²⁷⁰ Replying affidavit para 59 p15.

²⁷¹ Replying affidavit para 241 p50.

²⁷² Replying affidavit para 248 p52.

²⁷³ Replying affidavit para 247 p52.

²⁷⁴ Metz expert opinion, 6 August 2016, para 17 p7.

²⁷⁵ Ibid para 19 p8.

²⁷⁶ Ibid para 20 p8.

²⁷⁷ Replying affidavit para 39 p11.

²⁷⁸ Replying affidavit para 40 p11.

²⁷⁹ Replying affidavit para 40 p11.

²⁸⁰ Replying affidavit para 104 p25.

cetera’.²⁸¹ Any transaction relating to donor information cannot be the same as a transaction (acquisition, supply, importation or export) concerning gametes.²⁸² Consequently, it was argued that it is rather illogical to state that the same donor information can be traded before harvesting, but not after.²⁸³ Furthermore, the applicant stated that donor information does not change simply because a medical process has commenced.²⁸⁴ The applicant used the following analogy: ‘A photo of an actress is intrinsically linked to the actress, but the photo is not the actress. Accordingly, although the actress’s body is extra commercium, the photo is intra commercium. The same applies to gametes and donor information: While gametes are extra commercium, donor information is intra commercium.’²⁸⁵

A second argument is that reading the statutory ban on the trade in gametes to include donor information is far too broad.²⁸⁶ This overly-broad interpretation would imply that all commercial acts that have a factual relationship with, but do not amount to, any transaction concerning gamete donation is illegal.²⁸⁷ Examples of such commercial activities that were used by the applicant include ‘(a) the laboratory consumables supplier that provides the plastic straws in which the gametes are kept, and (b) the courier service that handles the transport of gametes.’²⁸⁸ This, clearly, was not the intention of the legislature.²⁸⁹ The intention of the legislature is to simply ban the trade in gametes.²⁹⁰

- e) Lastly, the applicant denied that an egg bank is a species of medical practice; while it admitted that certain aspects of medical practice are necessarily part of an egg bank’s function, an egg bank is *not* a medical practice itself.²⁹¹ A gamete agency or bank is a facility that provides donor information which prospective parents use to select a donor (a non-medical aspect), recruits donors (also a non-medical aspect) and coordinates an assortment of medical services pertaining to gamete donation.²⁹²

Wanting to provide Additional Information as a *competitive advantage* is a *business*

²⁸¹ Replying affidavit para 275.2 p57.

²⁸² Replying affidavit para 41 p12.

²⁸³ Replying affidavit para 153 p34.

²⁸⁴ Replying affidavit para 156 p35.

²⁸⁵ Replying affidavit para 214 p45.

²⁸⁶ Replying affidavit para 42 p12.

²⁸⁷ Replying affidavit para 42 p12.

²⁸⁸ Replying affidavit para 42 p12.

²⁸⁹ Replying affidavit para 42 p12.

²⁹⁰ Replying affidavit para 79 p19.

²⁹¹ Replying affidavit para 21 p7.

²⁹² Replying affidavit para 29 p9.

decision.²⁹³ Not only would Additional Information be an advantage for a gamete bank, but it also allows prospective parents to optimally exercise their autonomy by making an informed decision for, with all the information that is available to them.²⁹⁴ While there are clearly some aspects of the egg donation process that are clearly of a non-medical nature, not all aspects are as they do not require a doctor-patient relationship.²⁹⁵ Cryopreserved eggs may be stored in an egg bank as a direct consequence of medical practice, but this does not imply that the egg bank (or egg agency for that matter) itself is a medical practice.²⁹⁶ As such, it does not follow that the permissibility of the practice is determined by whether it falls within the ambit of a civil or medical transaction.²⁹⁷

4.4 Is it, in principle, legal to operate an egg donation agency and/or gamete bank in South Africa?

As per section 60(1)(a) of the NHA, a gamete bank would only be allowed to function legally if it is first deemed to be an ‘authorised institution’. According to this section, only an authorised institution may receive payment for any transaction (acquisition, supply, importation or export) concerning gametes. As such, a gamete bank – if it is an authorised institution – falls squarely into this section as it acquires and supplies gametes. Furthermore, the terms ‘freezing or cryopreservation’ are defined in the Regulations as ‘freezing or cryopreserving genetic material including ova, sperm, embryos, ovarian tissue or stem cells by an *authorised institution*’²⁹⁸ [*own emphasis*]. As freezing or cryopreservation is generally executed by a gamete bank, this would imply that a gamete bank must first be an authorised institution before operating as such.²⁹⁹ Egg donation agencies, on the other hand, are not covered by section 60(1)(a) of the NHA (or any other legislation for that matter) because agencies do not engage in any transactions with eggs – an agency’s role is simply to match prospective parents with potential donors. That being said, all egg agencies in South Africa are SASREG-accredited.³⁰⁰ The risk for an egg agency not being SASREG-accredited,

²⁹³ Replying affidavit para 161 p36.

²⁹⁴ Replying affidavit para 161 p36.

²⁹⁵ Replying affidavit para 292.2 p62.

²⁹⁶ Replying affidavit para 292.2 p62.

²⁹⁷ Replying affidavit para 298 p63.

²⁹⁸ Regulation 1 of the Regulations.

²⁹⁹ Founding affidavit para 71 p40.

³⁰⁰ ‘South African Organ Donor Agencies – regulatory issues’ available at <http://hsf.org.za/resource-centre/hsf-briefs/south-african-organ-donor-agencies-2013-regulatory-issues>, accessed 14 December 2017.

however, is that an accredited fertility clinic may boycott it. Nonetheless, it is not legally mandatory for agencies to be SASREG-accredited.

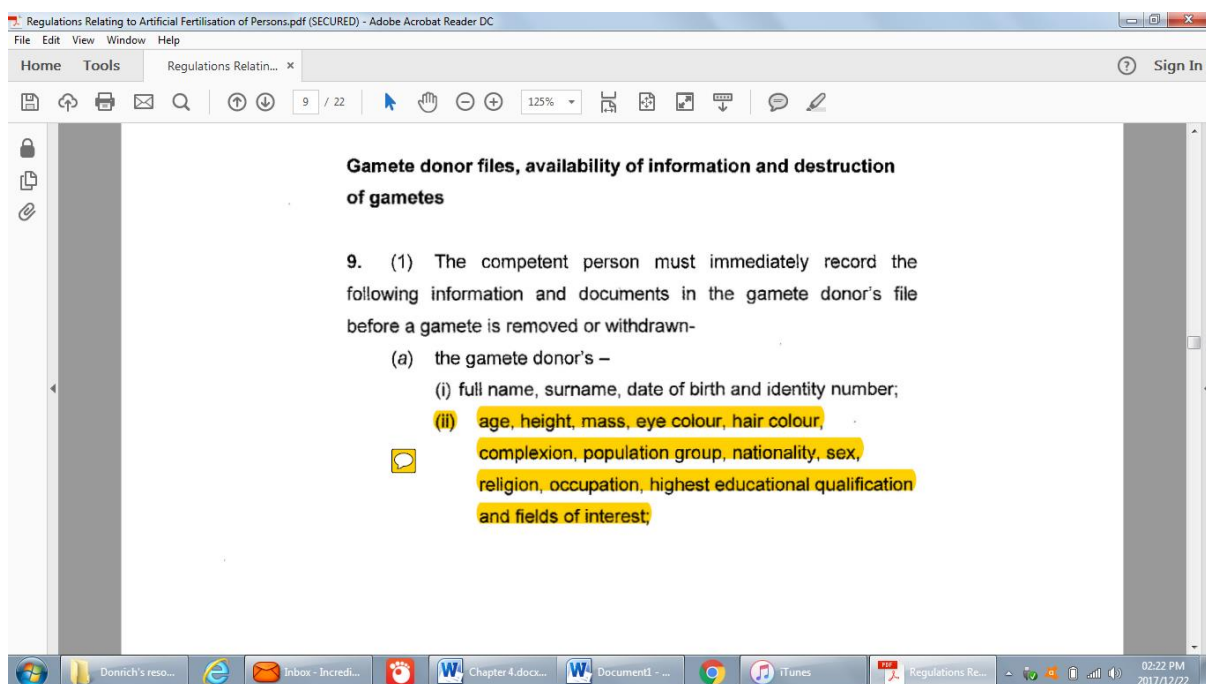
4.5 A critique on the respondents' arguments and a conclusion concerning the issue of whether selling personal gamete donor information is legal in South Africa

With regard to the respondents' first argument – the distinction between 'hard-type' and 'soft-type' information is cosmetic and, therefore, legally non-existent – this argument was swiftly nullified by the applicant simply because this allegation stood without much elaboration and was a feeble attempt to distract the Court from what was actually being argued by the applicant – the difference between Required Information and Additional Information. Essentially, the respondents' first argument was a non-argument and already gave the indication that the respondents' were opposing the matter for the sake of opposing it.

The second argument – legally *non-required* information contained in the donor file is prohibited from disclosure to anyone apart from a person supervised by a competent person – was yet again a misinterpretation of the applicant's argument. It should have been obvious to the respondents that the information would be retrieved by the bank from the donor herself and placed on a donor database where recipients can access it directly; this aspect clearly has nothing to do with the competent person (doctor) at all. The applicant had already argued extensively in its founding affidavit as to why a gamete *bank* and a *donor* should be free to contract as they wished regarding Additional Information, and consequently why the *bank* and the *recipient* could similarly contract (of course without compromising donor anonymity).³⁰¹ The applicant, in other words, was referring to the *bank-donor* and *bank-customer* relationship, which is based upon a contractual agreement – there is no need for the doctor's intervention in such an instance. Even if some Additional Information which the donor provides does overlap with the information contained in the donor file, the applicant rightly argued that there is only a restriction upon the competent person, and *not* the donor herself – from revealing such information. Yet even so, it seems that this possible overlap of information is still far-fetched. For argument's sake, let us consider the respondents' argument in this instance. The respondents argued that, as per regulation 9(1)(g) of the Regulations, a competent person can record 'any other *relevant* document or information that

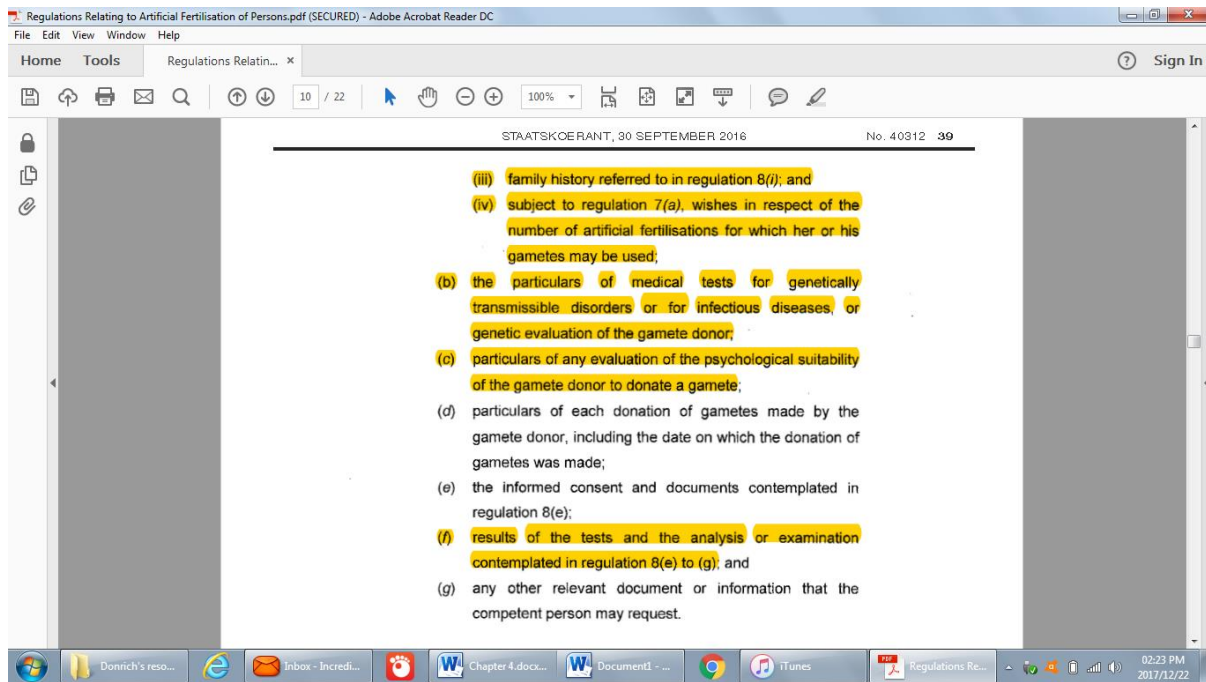
³⁰¹ This argument was based on the cost-recovery regime that governs transactions where the object of the transaction is gametes, and not gamete donor *information*.

the competent person may request' [*own emphasis*], which supposedly could include information that could be considered as Additional Information. I submit that the risk of this overlap occurring is highly unlikely for the following reason. Regulation 9(1) provides a list of information that a competent person must immediately record in the donor file. Of this list, some of the information recorded must necessarily be disclosed to a recipient because it is cross-referenced by regulation 9(2)(b).³⁰² The remaining items on the regulation 9(1) list can, therefore, *not* be revealed to anyone, including a recipient.³⁰³ These remaining items, however, must be analysed in order to gauge the *nature* of the information that must be kept in the donor file without ideally being revealed. Consider the two screenshots below depicting regulation 9(1). The sub-regulations that are highlighted refers to information that must be revealed to a recipient, and the sub-regulations that are *not* highlighted refers to information that must be held in the donor file without ideally being revealed viz regulations 9(1)(a)(i), 9(1)(d), 9(1)(e) and 9(1)(g).



³⁰² Note that regulation 9(2)(b) refers to information that the competent person must reveal to a recipient.

³⁰³ Such information can only be revealed to a person acting under the competent person's supervision, or in terms of legislation or a court order.



Sub-regulation 9(1)(a)(i) refers to *identifying* donor information, which obviously cannot be revealed as it would contravene regulation 19 which protects donor anonymity; sub-regulation 9(1)(d) refers to information regarding the actual donation of gametes and is a matter of fact; sub-regulation 9(1)(e) refers to informed consent and cross-references regulation 8(e)³⁰⁴ which refers to various instances where the donor's informed consent is required before gamete donation can occur. Thus, a certain theme seems to be running through the information in the donor file that cannot be revealed – all this information is logically required for actual gamete donation to occur. In other words, gamete donation cannot occur if the donor's identifying particulars, history of previous donations, and informed consent are not recorded. Furthermore, sub-regulation 9(1)(g) directs attention to other 'relevant' documents or information. Thus, the word 'relevant' must necessarily be read to refer to information that is necessarily required for actual gamete donation to occur. Therefore, there seems to be no logical reason as to why a competent person may request Additional Information, as such information is not required or 'relevant' for actual gamete

³⁰⁴ Regulation 8(e) states that 'A competent person who intends to remove or withdraw a gamete, or cause a gamete to be removed or withdrawn from the body of a gamete donor, must, before such removal or withdrawal obtain informed consent from the gamete donor relating to-

- (i) physical examination and questioning by a competent person;
- (ii) the removal or withdrawal a gamete for testing, analysing or other processing as the competent person may deem necessary;
- (iii) particulars contemplated in regulation 9(1)(a)(ii),
- (iii) and (iv), (b), (c) and (f) being made available to the recipient and the competent person who is to perform the artificial fertilisation; and
- (iv) to particulars contemplated in regulation 9(2)(c) being submitted to the central bank'.

donation to occur. In other words, the reason behind the competent person requesting Additional Information would serve no real purpose.

The respondents' third argument – vulnerable and poor women may be unduly enticed by financial reward into donating their eggs, causing them to disregard the potential risks of egg donation – is *prima facie* a noble one. However, as the applicant rightly pointed, the current suggested remuneration for donors by SASREG is R7000, which is arguably a significant amount of money for a poor person in any event, thereby causing the profit for the provision of Additional Information to be of little consequence. What is noteworthy, however, is the applicant's attempt to provide *viable* solutions to guard against undue enticement resulting from any profit that may be derived from the provision of Additional Information. The truth of the matter is, irrespective of what business endeavour one may pursue, challenges will always present themselves. The key, as illustrated by the applicant, is to first look for solutions that can satisfy as many stakeholders as possible as opposed to simply discarding the endeavour. If viable solutions are not utilised, it may adversely affect the competitiveness of a business.

With regard to the respondents' fourth argument – gametes and gamete donor information are inextricably linked, therefore, trading in such information is tantamount to trading in gametes which subjects the trade in information to the same sanctions as the trade in gametes – it can be acknowledged that this was a good argument *prima facie* and perhaps the best one proffered by the respondents. However, this argument was nullified by the applicant whose main counter-argument in this instance was shockingly simple and precisely on point that one wonders how the respondents did not see it in the first place – gametes do 'not have education, family history, personal and physical characteristics, et cetera',³⁰⁵ therefore, the information is necessarily and clearly about the *donor*. While initially being deceptively appealing, the respondents' argument was destroyed by this one simple counter-argument, let alone all the other counter-arguments offered by the applicant in this instance. I further submit that the respondents' assumption that donor information retains little significant value in the absence of the gametes themselves appears to be a reference to *heritable* donor characteristics. The only logical reason that can be assumed for the respondents' stance that the information is actually about the gametes as opposed to the donor (after egg-harvesting), is because the gametes contain the potential of manifesting donor characteristics that are

³⁰⁵ Replying affidavit para 275.2 p57.

described in a donor's personal information; genetic heritability can be the only reason why the 'inextricably linked' argument can be offered. While this logic seems valid *prima facie*, donor information cannot actually be about the gametes for the following two additional reasons: first, no one knows exactly which 23 chromosomes are contained in a gamete, therefore, there is no guarantee that a potential offspring will inherit specific characteristics; secondly, characteristics that are potentially heritable are already described in the Required Information which is made available to recipients in any event. If a donor characteristic can never be heritable, then it has no direct link to the gamete as that gamete will never carry the potentiality of manifesting such a characteristic. Additional Information describes such uninheritable donor characteristics. As such, Additional Information cannot be inextricably linked to the gamete.

With regard to the respondents' argument that donor information can be traded before egg harvesting (the equivalent argument being that gametes must still be within the body of the donor when it is traded) but not after egg harvesting (the equivalent argument being that donor information cannot be traded once the gametes are out of the donor's body), in conjunction with the argument that poor females would be enticed into donating their eggs in the name of profit-making, it appears that the respondents imply and concede that egg agencies (and sperm agencies, had there been any) are free to trade in Additional Information. This is because egg agencies must first match recipients to potential donors before the donors can donate. Gamete banks, on the other hand, are already in possession of donated cryopreserved gametes. However, being able to trade donor information before donation, rather than after donation, makes no sense in light of the respondents' own argument – if donor information is inextricably linked to the gamete, then surely this supposed inextricable link exists whether the gamete is in the donor's body or out of the donor's body ie irrespective of whether donation has occurred or not. In any event, the applicant correctly argued that information cannot miraculously cease to be about the donor once medical procedures have begun. Donor information *remains* as donor information, irrespective of when it is traded, and cannot logically be about the gamete. However, one positive development from the respondents' argument has emerged and can be seen as a point of consensus between the parties – although there is currently no consensus as to whether *gamete banks* can trade in Additional Information, it can at least be said that *agencies* are seemingly free to trade in Additional Information.

Lastly, the respondents' fifth argument - gamete banks are not supposed to be profit-driven business enterprises, but rather part of medical practice in general – seems to be misguided. Before delving into this argument, it must be noted that gamete *agencies* can be and are clearly profit-driven enterprises; as recipient-donor 'match-makers', they are neither part of medical practice, nor are they governed by the any legislation discussed thus far. Gamete banks, however, do share some elements of medical practice but essentially they are businesses. Once again, the applicant pointed out a simple but undeniable fact – wanting to provide Additional Information as a *competitive advantage* is a *business* decision. Aside from this fact, it cannot be ignored that for-profit businesses do exist within the field of medicine. Furthermore, not every transaction by the recipient in the setting of an egg bank requires a doctor-patient relation, therefore, it cannot be said that an egg bank is a medical practice.

In light of the above analysis, it can clearly be seen that trading in personal donor information is, in principle, legal in South Africa (both by agencies and banks) despite whether there is consensus or not. Furthermore, if it is legal to operate an egg agency and gamete bank in South Africa, then surely it is legally acceptable for such businesses to engage a business model that provides them with a competitive edge (as trading in personal donor information would). I am confident that, had judgment been passed in the *Nurture* case, the Court would have ruled in *Nurture*'s favour.

4.6 How will the potential trade in gamete donor information be affected when the POPI Act comes into force?

One of the main purposes of the POPI Act is to balance the right to privacy against the right to access information.³⁰⁶ While the protection of personal information, as the title of the POPI Act suggests, is the ultimate aim of this piece of legislation, nothing contained in it precludes the processing³⁰⁷ of personal information (particularly the collection, use and dissemination thereof) for the purpose of trade by gamete banks or agencies. In fact, with regard to some of the instances where personal information may be processed, section 11(1)(f) of the POPI Act states that personal information can be processed if it 'is necessary

³⁰⁶ Section 2(a)(i) of the POPI Act.

³⁰⁷ According to section 1 of the POPI Act, the term 'processing' denotes 'any operation or activity or any set of operations, whether or not by automatic means, concerning personal information, including—

- (a) the collection, receipt, recording, organisation, collation, storage, updating or modification, retrieval, alteration, consultation or use;
- (b) dissemination by means of transmission, distribution or making available in any other form; or
- (c) merging, linking, as well as restriction, degradation, erasure or destruction of information'.

for pursuing the legitimate interests of the responsible party or of a third party to whom the information is supplied'. Thus, when the POPI Act comes into force, this Act will not prevent a gamete bank and agency from pursuing the business model of trading personal gamete donor information. This, of course, is subject to the conditions that must be satisfied for the processing of personal information as per the POPI Act.³⁰⁸ As long as a gamete donor provides informed consent³⁰⁹ for the trade in his/her personal information and knows exactly why his/her information is being collected³¹⁰ (which should necessarily be done irrespective of whether the POPI Act is in force or not) the POPI Act does not prevent a gamete bank or agency from contracting with donors and recipients for the purchase and sale of personal donor information respectively.

³⁰⁸ These conditions are found in section 4(1) of the POPI Act. Some conditions include accountability, purpose specification, openness, security safeguards etc.

³⁰⁹ Section 27(1)(a) of the POPI Act.

³¹⁰ Section 13(2) and 18(1)(c) of the POPI Act.

CHAPTER 5 – CONCLUSION

At the beginning of this dissertation, the research problem put forward concerned the uncertainty surrounding trade in personal gamete donor information. This issue was placed in the context of the NHA expressly outlawing the trade in gametes (but not the trade in gamete donor information) as per section 60(4)(b), and the Regulations protecting donor anonymity as per regulation 19. The importance of addressing this issue lays in the fact that South African gamete banks and agencies will experience legal uncertainty if they wish to engage the business model of trading personal donor information similar to that of their overseas counterparts. Thus far, there has been no literature concerning trade in donor information, save for the *Nurture* case whose application was withdrawn after *litis contestatio*. As such, the dissertation sought to explore whether personal donor information could, in principle, be traded in South Africa.

Of course, before considering if donor information could be traded, it was vital to establish why there is a need for Additional Information. In chapter two, it was noted that since having children formed an integral part of many people's lives, news of infertility could serve as a devastating blow to such people. In the context of such complex losses, many people seek to fulfil their dreams of parenthood via IVF. It was seen that the importance of choosing a gamete donor overlaps greatly with the importance of choosing a life partner. Consequently, the role of extensive donor information in donor selection was examined. Ultimately, while various pros and cons to having Additional Information were found, it was argued that the overriding factor that should be considered is the bioethical principle of autonomy. Given that many prospective parents attach great significance to choosing their gamete donors, having access to extensive donor information to make a truly informed choice is vital. Admittedly, not all prospective parents may want Additional Information, however, the option of accessing such information should necessarily exist for those who do wish to have such information.

For an international perspective, a comparative study was undertaken with the UK, USA and Canada in order to gauge how these countries dealt with the provision of donor information. While it was established that there is currently no country which regulates the trade in donor information, it was worth determining if there were any differences and/or similarities in the way donor information was provided in these countries, as compared to South Africa. Seeing that all the comparator countries protected donor anonymity (albeit at varying degrees) as South Africa does, many gamete banks and agencies in these countries still chose to provide

prospective parents extensive donor information on their own accord without compromising donor anonymity. Furthermore, some of these gamete banks and agencies provided a basic donor profile free of charge, while charging a fee for access to extensive donor information. This is in direct contrast to South Africa, where Nurture is the only agency to provide Additional Information.

Chapter four, the crux of this dissertation, dealt with the analysis of the *Nurture* case and the relevant legislation. From this analysis, the conclusion drawn was that in principle, personal gamete donor information can be traded in South Africa. Furthermore, trade in personal gamete donor information will not be affected by the POPI Act.

5.2 Recommendations

5.2.1 Legislation – the NHA

In order to create legal certainty as to whether South African gamete banks and agencies can engage in trade in personal gamete donor information, there needs to be a minor amendment in the NHA, particularly section 60(3):

(3) This section does not prevent a health care provider registered with a statutory health professional council from receiving remuneration for any professional service rendered by him or her nor does this section prevent an authorised institution and gamete donor from receiving remuneration beyond reasonable costs incurred for the trade in non-identifying gamete donor information.

5.2.2 Informed consent

To guard against undue enticement of donors that may occur as a result of payment for Additional Information beyond reasonable expenses, there are two safeguard mechanisms that can be employed (as was suggested by the Nurture's expert).

Firstly, the informed consent mechanism must be strengthened and promoted. In other words, donors must necessarily be made aware of material risks that may materialise in the course of donation, irrespective of the nature (physical, psychological, emotional etc) or likelihood of occurrence of the risk. Such awareness can be ensured by the State issuing regulations

concerning donor-counselling. In fact, donor-counselling ought to be compulsory, whether or not a gamete bank or agency chooses to trade in Additional Information. The reason for this, once again, stems from the bioethical principle of autonomy. In chapter two of this dissertation, autonomy was hailed as the overriding factor in deciding whether Additional Information should be offered to prospective parents. The rationale behind this argument was that such information could be of assistance in helping prospective parents make a truly informed decision concerning their choice of donor. In a similar vein, gamete donors must also be given the opportunity to make a truly informed decision as to whether they would like to donate their gametes, notwithstanding any material risks involved in the donation. Thus, donors should be able to decipher if taking such risks are worth the profit they could make from selling their Additional Information. Standard counselling sessions need not exceed a single session to educate a donor about the material risks involved. This session should be provided at the gamete bank's or agency's cost, which can then be recouped from the fees charged to the relevant prospective parents. If the donor feels s/he needs additional counselling, this must be done at his/her own cost. Although prospective parents would ultimately bear the cost of the single counselling session, it should be seen as a matter of fairness to the donor. Donors must be educated about possible consequences of their donation, irrespective of whether there is trade in Additional Information. If the State is unable to issue regulations, the alternative would be to have the State (or SASREG) issue guidelines concerning informed consent procedures. The issue with guidelines, however, is that they lack legal force. Therefore, guidelines should be seen as a secondary resort.

An additional solution is to simply offer donors a modest compensation for their provision of Additional Information. This can be done by SASREG recommending an agreed amount for Additional Information, as it has done for the reimbursement of reasonable expenses incurred.

5.3 Areas for further research

The topic of this dissertation is arguably a novel one; apart from the *Nurture* case, there has not been any literature concerning this area. Furthermore, the majority of the sources referred to in this dissertation are not of South African origin. Thus, there seems to be a paucity of research in the field of IVF from a South African legal perspective. It is suggested that more research regarding donor reimbursement be done, particularly in light of SASREG's R7000

recommendation. Moreover, the question of what exactly constitutes ‘reasonable expenses incurred’ should be investigated. Currently, it is unknown as to how the figure of R7000 was decided upon by SASREG. Additionally, competition law must be considered in order to decide if SASREG is behaving anti-competitively. Have SASREG and other fertility clinics formed a cartel by deciding upon a random figure (R7000) for donor reimbursement? Of course, it is necessary to engage in empirical research. Thus, there should be an investigation into what South African donors’ actual reasonable costs are on average, in order to suggest a relatively more accurate figure for donor reimbursement for reasonable costs incurred as contemplated by section 60(4)(a) of the NHA.

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