



If donor-conceived children have a constitutional right to know their genetic origins, what protection is there for donors in terms of their constitutional right to privacy?

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ABSTRACT

Increasingly, couples and individuals are turning to donor-conception as a means to conceive children. In South Africa, gamete donation is regulated by the National Health Act 61 of 2003, together with the Regulations relating to the Artificial Fertilization of Persons, 2012 and the Children's Act 38 of 2005 together with its regulations. In terms of these, the disclosure of the identity of a gamete donor is prohibited unless the law or the courts deem it permissible. This leaves a donor-conceived child without means of ascertaining his or her biological parent who is the donor. The lack of a right of a donor-conceived child to know his or her biological parents is seemingly inconsistent when compared with adopted and naturally conceived children. The position may be tenuous in our law therefore, as it may go against the spirit and objectives of the Bill of Rights, where both the Right to Equality is guaranteed, as well as the Right of Access to Information.

The position is further complicated by advancements in medical technology since the advent of direct-to-consumer genetic testing, as this makes it possible to track down biological relatives using online genealogical databases. This may make the position of donor-anonymity increasingly unfeasible as increasing numbers of people use direct-to-consumer genetic testing, and the online genealogical databases increase in size.

This dissertation will discuss the law as it stands pertaining to whether the position of donor-anonymity is in fact legal under the Bill of Rights. It will then discuss the challenges posed to donor-anonymity by direct-to-consumer genetic testing, and then draw conclusions and recommend that principle of donor-anonymity be abolished, by allowing donor-conceived children access to the identity of their gamete donors, while introducing other measures to protect the donors interests by introducing a framework as to how much interaction a donor-conceived individual is permitted with a donor. These may include laws pertaining to nuisance, trespass or anti-stalking.

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ABBREVIATIONS

ACRWC	African Charter on the Rights and Welfare of the Child
AI	Artificial insemination
ARTs	Assisted reproductive technologies
BDRA	Births and Deaths Registration Act 51 of 1992
CRC	Convention on the Rights of the Child
CROC	United Nations Committee on the Rights of the Child
GDPR	General Data Protection Regulation (EU) 2016/679
HFEA	Human Fertilisation and Embryo Authority (United Kingdom)
IVF	In vitro fertilization
PAIA	Promotion of Access to Information Act 2 of 2000
POPIA	Protection of Personal Information Act 4 of 2013
SALC	South African Law Commission
SALRC	South African Law Reform Commission
UNCRC	United Nations Convention on the Rights of the Child

CHAPTER I

INTRODUCTION

Donor insemination has been a practice since as early as 1884, when Professor William Pancoast used donor sperm to inseminate a woman whose husband was infertile, resulting in the birth of a child.¹ In 1953 a child was born for the first time using previously frozen donor sperm,² and in 1983 the first oocyte³ donation took place. Since then, many thousands of children have been born, and continue to be born each year using donated gametes. During the 1980s, the estimated number of children born via sperm donation in Finland alone was estimated to be between 100 and 150 annually.⁴ While the exact number of children born annually as a result of donor conception is impossible to quantify, in the United Kingdom (UK), the Human Fertilisation and Embryology Authority (HFEA)⁵ is a body holding statistics and data relating to assisted reproductive treatment performed each year. According to their published information, 31 000 children were born as a result of donor conception between 1992 and 2009,⁶ and, according to its latest figures, up to and including the year 2017 there has been a steady increase year on year in assisted reproduction treatment across all types of gamete donation from 1991 until 2017.⁷

The growing demand for donor conception has been attributed to several factors, including increasing infertility rates and the increasing number of sperm and oocyte banks,

¹ E Blyth & L Frith 'Access to genetic and biographical history in donor conception: An analysis of recent trends and future possibilities' in K Horsey *Revisiting the Regulation of Human Fertilisation and Embryology* (2015) 136-152..

² M Sälevaara *Transition to parenthood after fertility treatment with oocyte and sperm donation* (academic dissertation Department of Gynecology and Obstetrics University of Helsinki (2019) 18.

³ An oocyte is an immature egg cell which, through the process of ovulation, becomes an ovum, or egg. See David Diaz, MD 'What is an Oocyte', 2015, West Coast Fertility Clinic. Available at <https://www.eggfreezing.com/what-is-an-oocyte/>. This was therefore the first instance of assisted reproduction using a donated female gamete.

⁴ Sälevaara, M., op cit at 18.

⁵ The Human Fertilization and Embryology Authority (HFEA) is a UK government regulator which is responsible for ensuring compliance by fertility clinics with the law. In addition to this, it provides information relating to fertility clinics, treatment and donation, and also provides data and statistics regarding assisted reproduction treatment performed each year in the UK. See the website at <https://www.hfea.gov.uk/>. It may thus have the most useful data regarding the trends regarding donor conception available.

⁶ JC Harper, D Kennett & D Riesel 'The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business' (2016) 31(6) *Human Reproduction* 1135.

⁷ See HFEA, 2019. Fertility Treatment in 2017: Trends and Figures, p15. Available for download at <https://www.hfea.gov.uk/about-us/publications/research-and-data/>. This report breaks assisted reproduction treatments using gamete donation into three categories, namely own eggs and donor sperm (OEDS), donor eggs and partner sperm (DEPS), and donor eggs and donor sperm (DEDS).

increasing the ease with which it is possible to access donor gametes, as well as an increase in the number of homosexual couples who wish to have children.⁸

Since the first instance of donor insemination performed by Professor Pancoast, who advised the husband of the woman on whom the procedure was performed to never disclose what transpired, secrecy has been a standard characteristic of donor conception.⁹ Until the 1970s, doctors performing insemination procedures would often use more than one donor, so as to deliberately make it impossible to correctly ascertain paternity, and further destroy the records linking parents to donors. The first nationwide programme for gamete donation was founded in France in 1973, and it formally institutionalised the practice of anonymity,¹⁰ which practice was subsequently institutionalised by most Western countries.¹¹

South Africa followed this approach, and in the 1980s the Human Tissues Act¹² came into effect. This Act created donor anonymity as a legal principle in South Africa by providing that ‘no person shall publish to any other person any fact whereby the identity of . . . a living person from whose body any tissue, blood or gamete has been withdrawn or removed for the purpose of [the artificial fertilization of another person] may possibly be established’.¹³

In 1985 however, Sweden became the first country to prohibit donor anonymity. Other countries, including Austria, Finland, Germany, Iceland, the Netherlands, Norway, Switzerland, the UK, New Zealand and the Australian states of Victoria and Western Australia subsequently followed this approach and removed donor anonymity as well.¹⁴ Another approach, which was recommended by the European Society for Human Reproduction, and has been adopted by countries such as Denmark, is to allow both anonymous and non-anonymous donation.¹⁵

⁸ G Tamanza et al “‘Doubly Mother’: Heterologous Artificial Insemination between Biological and Social Parenthood: A Single Case Study’ (2019) 75(7) *World Futures* 480.

⁹ E Blyth, & Frith op cit at 136.

¹⁰ I Turkmendag, R Dingwall, & T Murphy ‘The removal of donor anonymity in the UK: the silencing of claims by would-be parents’ (2008) 22(3), *International Journal of Law, Policy and the Family* 283

¹¹ DR Beeson, PK Jennings, & W Kramer ‘Offspring searching for their sperm donors: how family type shapes the process’ (2011) 26(9) *Human reproduction*, 2415-2424.

¹² Act 65 of 1983.

¹³ S 33(1)(c).

¹⁴ G Cohen, et al 2 ‘Sperm donor anonymity and compensation: an experiment with American sperm donors’ (2011) 3(3) *Journal of Law and the Biosciences* 469.

¹⁵ Harper, Kennett & Reisel op cit note 6 at 1136.

Perhaps in recognition of this trend towards openness, and in response to the writings of various authors, both South Africa and other nations argued that the principle of donor anonymity contravened a fundamental right of donor-conceived children to have access to information concerning their genetic parents; the 2002 South African Law Reform Commission (SALRC) Discussion Paper on the Child Care Act included a discussion as to whether donor-conceived children should be allowed access to their donor's identity.¹⁶ The paper recommended that donor anonymity remain, but that the provisions in the Human Tissue Act¹⁷ be amended to allow donor-conceived children access to biological and medical information regarding their biological parents.¹⁸

The Human Tissue Act was subsequently repealed, and replaced by the National Health Act¹⁹ which came into effect in 2005, and regulations to this Act, Regulations Relating to the Artificial Fertilisations of Persons, were published in 2012,²⁰ which contained the anonymity provision recommended by the law commission. Regulation 19 prohibits any person disclosing the identity of a gamete donor, or a person who received a gamete. The Children's Act²¹ which came into effect in April 2010 also contains a provision prohibiting the disclosure of the identity of a gamete donor. In terms this Act,²² a donor-conceived child may be granted access to medical and any other information relating to the child's genetic parents, but such information may not reveal the identity of the gamete donor. Thus, the clear legal position in South Africa is that the identity of a gamete donor may not be released.

Significantly, in a study of South African egg donors, more than half of donors said that if they were given the option whether or not to remain anonymous, they would choose identity release; and 79% suggested that they would donate even where identity release was required by law.²³ This suggests that a trend towards openness might not only be reflected by the legal systems, but in South Africa could be reflected by gamete donors themselves, who seem to be open to identity release.²⁴

¹⁶ South African Law Reform Commission Discussion Paper 103, Project 110, *Review of the Child Care Act* (2002) 153-154.

¹⁷ Act 65 of 1983.

¹⁸ South African Law Reform Commission Discussion Paper 154.

¹⁹ Act 61 of 2003.

²⁰ National Health Act 61 of 2003, Regulations Relating to the Artificial Fertilisation of Persons(2012).

²¹ Act 38 of 2005.

²² S 41(1) and S 41(2).

²³ D Thaldar, D 'Egg donors' motivations, experiences, and opinions: A survey of egg donors in South Africa' (2020) *PloS One*, 15(1), p.e0226603, 8.

²⁴ See also p10.

In the recent case of *AB v Minister of Social Development*,²⁵ where section 294 of the Children's Act²⁶ came under scrutiny, the Constitutional Court held that clarity was needed regarding the origins of a donor-conceived child as it was important to the self-identity and self-respect of the child.²⁷ Partly because of this Constitutional Court judgment, the South African Law Reform Commission embarked on an investigation to reconsider donor anonymity in surrogacy as well as other types of assisted reproduction, including gamete donation,²⁸ thus bringing the principle of donor-anonymity into question in South African law once again.

I STATEMENT OF PURPOSE

The purpose of this paper is to consider the question: Should donor-conceived children have a right to know their genetic origins?

While a range of policy and other issues are often raised in discussing this topic,²⁹ this dissertation will focus on two specific fields which have not yet been adequately addressed in relation to South African law, namely:

- (a) a donor-conceived child's right to equality and;
- (b) the impact of direct-to-consumer genetic testing on donor-anonymity.

Thus, in responding to the main question, the following sub-questions will be considered:

- What is the legal position in South Africa regarding adopted, abandoned, and naturally conceived children with respect to a right to know the identity of their biological parents?
- Is a donor-conceived child's right to equality infringed when compared with other groups of children?

²⁵ *AB v Minister of Social Development* 2017 (3) SA 570 (CC).

²⁶ Act 38 of 2005.

²⁷ See paras 290 and 294.

²⁸ South African Law Reform Commission (SALRC), issue paper 32, project 140, *The Right to Know One's Own Biological Origins*, (2016) i-v (*Right to Know*). See also Chapter 1.

²⁹ These include arguments for health needs and medical information, the possibility of psychological harm, an interest in forging an identity, a comparison with adopted children, and arguments that the UN Convention on the Rights of the Child prohibits donor anonymity. Many of these arguments are discussed by various authors in foreign jurisdictions, as well as in the SALRC issue paper 32, project 140, *The Right to Know* supra.

- In an age of direct-to-consumer genetic testing, is donor anonymity even possible?
- Does the right to privacy extend to genetic information?
- Can a person's right to privacy regarding genetic information be infringed by a relative publishing his or her genetic information?

The questions listed above are not the only relevant issues relating to the principle of donor-anonymity. The most prevalent of other arguments frequently raised is perhaps the principle of the best interests of a child³⁰ reflected in international law, namely the United Nations Convention on the Rights of the Child (CRC), to which South Africa is a signatory.³¹ However, due to space limitations in my dissertation however, I focus only on the two topics (a) and (b) mentioned above.

II RATIONALE

With the SALRC currently reviewing the legal position in South Africa, it is appropriate to consider the principle of donor-anonymity in South Africa, especially as there is a dearth of literature on this topic with specific relevance to the South African legal framework.³² There are important considerations on the principle of donor-anonymity that have not been fully discussed with specific reference to the South African legal framework.

Whilst the SALRC paper discusses the position of 'other' groups of children, these being naturally conceived, adopted and abandoned children, in knowing their biological origins, it does not do so with donor-conceived children in order to ascertain whether there is consistency of the legal principle pertaining to all of these groups of children.³³ In this regard, and especially in light of South African law, it would be instructive to invoke the

³⁰ See s 7 and s 9 of the Children's Act 38 of 2005 and s 28(2) of the Constitution.

³¹ United Nations Convention on the Rights of the Child (1989) (CRC). S 7 gives a child a right to 'know and be cared for by his or her parents'. This section often interpreted as giving a donor-conceived child a right to know his or her biological parents.

³² A search conducted across Google Scholar, Sabinet, HeinOnline and Google using the terms 'donor anonymity South Africa', 's 41 of the Children's Act', 'regulation 19 of the Regulations Relating to the Artificial Fertilisation of Persons' as well as variations on these search terms only brought up one article of relevance: T Skosana 'A donor-conceived child's right to know their genetic origin: a South African perspective' (2017) 38(2), *Obiter*, 261-274. Using the 'related articles' function did not produce any further written articles of relevance either.

³³ Donor-conceived children are discussed in chapter 2 of the paper, adopted children in chapter 4 and naturally conceived children in chapter 5; in cases where there is a question or dispute over paternity, and abandoned children in chapter 6. However, each case is considered on its own, in isolation of the others as to whether there exists, or should be a right to know the biological origins of the child.

constitutional right to equality;³⁴ if a donor-conceived child's right to equality is infringed, the principle of donor-anonymity may be unconstitutional. The right to equality of donor-conceived children was touched on by another author, although only in comparison with adopted children.³⁵

The right to equality must be explored by applying the test for a violation of the equality clause in the Constitution, comparing donor-conceived children with all other applicable groups of children. These groups of children being adopted, abandoned, and naturally conceived children; including those naturally conceived children who know the identities of both parents and those who may not know the identity of one or both parents.

The second major issue which needs to be addressed is the impact emerging technologies, especially direct-to-consumer genetic testing, may have on the viability of donor-anonymity. This is because direct-to-consumer genetic testing may make it possible to locate the identity of a gamete donor, even where the identity is withheld.³⁶ It is necessary to confront the challenges which direct-to-consumer genetic testing poses to donor-anonymity in the South African legal framework.

In this regard, it is necessary to examine whether the right to privacy embraces a right to privacy over genetic information. A right to privacy would prevent the possibility of his or her genetic information being uploaded to any existing databases, and thereby preventing the possibility of being traced by a donor-conceived child via direct-to-consumer genetic testing. Since genetic information is shared with relatives, the question arises whether this right, if it exists, may be enforceable against a genetic relative by preventing a relative from undergoing direct-to-consumer genetic testing and uploading the results to a database, enabling a gamete donor to be traced thereby.

III CONCEPTUAL FRAMEWORK

The conceptual framework in this dissertation will be an analysis of the application of legal principles as well as policy to the existing principle of donor anonymity. This will entail not only applying existing legal principles, but also engaging with policy considerations of how development of medical technologies may impact donor-anonymity.

³⁴ S 9 of the Constitution of the Republic of South Africa Act 108 of 1996 (1996 Constitution).

³⁵ T Skosana, 'A donor-conceived child's right to know their genetic origin: a South African perspective. (2017) 38(2) *Obiter* 270.
Harper Kennett & Reisel op cit at 1135-1140.

IV LITERATURE REVIEW

(a) South African Law and the Constitution

(i) *The law relating to adopted, naturally conceived and donor-conceived children*

One author, Themba Skosana, has argued that ‘adopted children and donor-conceived children arguably share attributes and therefore should be treated alike’. This is due to both categories of children having ‘a parent-child relationship based on a social rather than a genetic link, or a mixture of one genetic parent and a social parent’.³⁷ Skosana further argues that developments in the field of adoption, where there is a move towards openness, permits adopted children to have access to the identity of their biological parents, should by analogy apply to donor-conceived children.³⁸

Any analogy would be incomplete however, without considering the law relating to the right of all groups of children to know the identities of their biological parents, as this would reveal whether the law relating to donor-conceived children is inconsistent with that for other groups of children, and whether donor-conceived children’s right to equality has been infringed by being denied access to the identity of their biological parents.

As stated above, in terms of both regulation 19 of the regulations relating to the artificial fertilisation of persons,³⁹ and sections 41(1) and 41(2) of the Children’s Act,⁴⁰ no person may disclose the identity of a gamete donor. A donor-conceived child may not know the identity of his or her biological parents. Section 248 of the Children’s Act⁴¹ permits an adopted child, adoptive parent, or biological parent of the adopted⁴² child access to the adoption register upon the adopted child reaching 18 years of age. The adoption register contains the identity of both the biological and adoptive parents.⁴³ Thus adopted children are entitled to know the identity of their biological parents, subject to the 18-year age limit, unless a court allows access to the adoption register earlier.⁴⁴

³⁷ Skosana op cit at 271.

³⁸ Skosana op cit at 269.

³⁹ National Health Act 61 of 2003, Regulations Relating to the Artificial Fertilisation of Persons, 2012.

⁴⁰ 38 of 2005.

⁴¹ 38 of 2005.

⁴² Provided there is written consent from both the adopted child and adopted parent.

⁴³ S 247(1)(b) of the Children’s Act 38 of 2005.

⁴⁴ S 248(1)(e) allows the court to allow earlier access to the adoption register if it finds that this is in the best interests of the child.

In the case of naturally conceived children, the Births and Deaths Registration Act,⁴⁵ provides that a birth certificate be issued on birth, which is evidence of the particulars of the child,⁴⁶ and the parents of the child (full names and identity numbers).⁴⁷ Thus, the birth certificate is the mechanism by which a naturally conceived child is able to identify his or her biological parents.

The right of naturally conceived children to know the identity of a biological parent becomes relevant in cases where there is only one parent on the birth certificate, and/or in cases of disputed paternity. In the unreported Western Cape High Court case of *South African Human Rights Commission v Minister of Home Affairs*,⁴⁸ the court held that a child had a constitutional right to have the name of a parent registered on his or her birth certificate, even without consent of such parent.⁴⁹ Since the birth certificate is the mechanism by which naturally conceived children are able to identify their biological parents, the registration of their names on the birth certificate translates into a right to know their identity. However, the court in this instance required evidence to prove paternity, and thus, the exercise of the child's right is dependent on whether the alleged parent may be compelled to undergo scientific paternity tests.

Pillay and Zaal suggest that in instances of disputed paternity, the known parent can request the court to order paternity testing.⁵⁰ The only case in which a person was compelled to undergo DNA testing to establish paternity was in the SCA case of *YM v LB*,⁵¹ on appeal from the reported High Court case *LB v YD*.⁵² In the High Court, the applicant applied for an order compelling the respondent and her minor daughter to undergo DNA testing to establish whether he was the biological father of the child. The court balanced the need to protect privacy and bodily integrity with the need to discover the truth through scientific methods whenever possible,⁵³ holding that the discovery of truth should prevail over the rights of privacy and bodily integrity, as it would 'most often be in the best interests of a child to have any doubts about true paternity resolved and put beyond doubt by the best

⁴⁵ Act 51 of 1992.

⁴⁶ Ss 9(7) and 9(8).

⁴⁷ See *Home Affairs to only Issue Unabridged Birth Certificates*, South African Government News Agency, available at <http://www.sanews.gov.za/south-africa/home-affairs-only-issue-unabridged-birth-certificates>.

⁴⁸ Case no. 17283/2014 available at <http://www.centreforchildlaw.co.za/cases/our-cases>.

⁴⁹ Para 32, 37.

⁵⁰ R Pillay & FN Zaal 'Misattributed Paternity: Should there be a Right to Reimbursement of Maintenance Erroneously Paid' (2012) 23(3) *Stellenbosch Law Review* 586.

⁵¹ *YM v LB* 2010 (6) SA 338 (SCA).

⁵² *LB v YD* 2009 (5) SA 463 (T).

⁵³ Para 18.

available evidence’.⁵⁴ On appeal, the SCA held that paternity was not in dispute as it was determinable on a balance of probabilities, and the respondent was seeking scientific evidence to which he was not entitled. The court did confirm that there might be instances where a DNA test of a child should be ordered where paternity was in issue, and the court had the inherent power to do so where it was in the best interests of the child.⁵⁵ However, the court noted that instances where the discovery of truth should prevail over rights to privacy and bodily integrity should not be generalised, and that a request for DNA tests, should be decided on the merits of the best interest of the child in the particular case.⁵⁶

Albertus argues that the SCA clarified that a minor child could be compelled to undergo DNA tests, even where the guardian refuses, ‘The Court did not, however, directly address the question of whether it may compel an adult to undergo a blood/DNA test’. Albertus states:

‘However, later in the judgment, the Court mentions that in ‘actual paternity’ disputes, an individual’s rights to privacy and physical integrity may be limited if that would be in the best interests of the child involved. It would then appear that the Court answered the question in the affirmative.’⁵⁷

The same author further considers whether this case bestows a right on a child to know his or her biological parent:

‘Unfortunately, the SCA did not consider a child’s right to know his or her genetic origin, other than providing that it is not always in the best interests of a person to know the truth. The High Court on the other hand would appear to have delved into this question by stating the following: “Where we come from and who we are, for most people, are questions within the realm of the sacred”.’⁵⁸

Thus, while the SCA did not bestow the right of a child to know the identity of his or her biological parents, the High Court appeared to have been leaning in this direction. However, the decision of the SCA did allow for a person to be compelled to undergo DNA testing to establish proof of paternity in certain circumstances. And this, read with *South African Human Rights Commission v Minister of Home Affairs* discussed above may bestow a right of a child to determine the identity of a biological parent, albeit with constraints and limitations.

⁵⁴ *LB v YD* supra para 23.

⁵⁵ *YM v LB* supra paras 1 -13.

⁵⁶ *YM v LB* supra para 16.

⁵⁷ L. Albertus . ‘Some unresolved complexities in matters involving paternity: a South African Perspective’ (2014) 3 *Adam Mickiewicz University Law Review* 238.

⁵⁸ P243. See also *LB v YD* 2009 (5) SA 463 (T) para 21.

If this is the case, then donor-conceived children would seem to be the odd group out of all other groups of children, who, under the right circumstances and limitations have a right to know their biological parents, whilst donor-conceived children are the only group denied this right. This creates a need to assess the reasons for such differentiation in treatment, as donor-conceived children may be being treated unfairly or unequally when compared with the other groups of children. This then also opens the way for a discussion as to whether or not their right to equality is being infringed, which will be discussed further in this dissertation.

(ii) *The Constitutional Right of Access to Information*

Section 32 of the Constitution⁵⁹ provides that:

- ‘(1) Everyone has the right of access to—
 - (a) Any information held by the state; and
 - (b) Any information that is held by another person and that is required for the exercise or protection of any rights.
- (2) National legislation must be enacted to give effect to this right, and may provide for reasonable measures to alleviate the administrative and financial burden on the state.’

The legislation contemplated in section 32(2) is the Promotion of Access to Information Act (PAIA).⁶⁰ This Act applies to the exclusion of any provision of other legislation that prohibits or restricts the disclosure of a record of a public body’.⁶¹ Section 19 of the Regulations Relating to the Artificial Fertilisation of Persons⁶² prohibits the disclosure of the identity of a gamete donor, and so the provisions of the Promotion of Access to Information Act may not be used directly to compel disclosure of the identity of a gamete donor.

However, in *President of the Republic of South Africa v M&G Media*,⁶³ which was a case brought under PAIA, therefore offered interpretation of the section 32 constitutional

⁵⁹ 1996 Constitution.

⁶⁰ Act 2 of 2000 (PAIA). See L Chamberlain ‘Assessing enabling rights: Striking similarities in troubling implementation of the rights to protest and access to information in South Africa’ (2016) 16(2) *African Human Rights Law Journal* 370.

⁶¹ S 5(a) PAIA.

⁶² National Health Act 61 of 2003, Regulations Relating to the Artificial Fertilisation of Persons, 2012.

⁶³ 2012 (2) SA 50 (CC).

right of access to information. The court held that ‘disclosure of information is the rule and exemption from disclosure is the exception’.⁶⁴ Section 39(2) of the Constitution states: ‘when interpreting any legislation, and when developing the common or customary law, every court, tribunal or forum must promote the spirit, purport and objects of the Bill of Rights’. Davel and Skelton suggest that the move towards greater openness is what prompted a change in existing legislation to allow adopted children access to the identities of their biological parents:

‘[I]n recent decades, both in South Africa and internationally, there has been an ongoing movement towards greater openness with regard to adoption . . . South African adoption practice has followed the international trend towards promoting a climate in which there would be an optimum level of sharing of information with adoptees about their origins’⁶⁵

The SALRC in the ‘Right to Know One’s Own Biological Origins’ links this change in legislation and openness towards adopted children with donor-conceived children:

‘A significant reason for the growing legislative support for non-anonymous gamete donations is the belief that donor-conceived children have a fundamental moral right to know their genetic origins and that the right should be legally protected by policies that prohibit anonymous donations. Often, however, this right is assumed rather than explicitly justified. Of course, the presumed right to know one’s genetic origin is not new. It has been used as grounds to promote openness in adoption records’⁶⁶

This move towards greater openness may be reflected in gamete donors as well. In a recent study by Thalдар, a large majority of egg donors indicated that they would be willing to donate even in the event of identity release being required. Even if given the choice whether to remain anonymous, more than half of egg donors indicated that they would choose identity release.⁶⁷ The right to access information and its applicability to donor-conceived children, as noted above, is ‘assumed rather than specifically justified’. This right has not been specifically considered in the existing literature in the context of the right of access to information as contained in section 32 of the Constitution. The chapter in this dissertation on the section 32 right of access to information seeks to assess the weight that the right should have in the development of the law with regards to donor-conceived children being given a right access identifying information pertaining to their biological parents.

⁶⁴ Para 9.

⁶⁵ CJ Davel, & A Skelton (eds) *Commentary on the Children’s Act* (2007) 28-29.

⁶⁶ SALRC, issue paper 32, *The Right to Know* (2016) 18.

⁶⁷ D Thalдар ‘Egg donors’ motivations, experiences, and opinions: A survey of egg donors in South Africa’ (2020) 15(1), *PloS one*, p.e0226603 8 & 10..

(iii) The Constitutional Right to Equality

Skosana suggests that ‘donor-conceived children and adopted children arguably share similar attributes and therefore should be treated alike’, and argues that:

‘The differentiation between adopted and donor-conceived children as regards access to information that identifies their biological parents may be challenged on constitutional grounds in terms of the equality clause in the Constitution.’⁶⁸

Section 9 of the Constitution provides that ‘everyone is equal before the law and has the right to equal protection and benefit of the law’. Section (3) prohibits the state from unfairly discriminating ‘directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth’. The Constitutional Court in *Harksen v Lane NO*⁶⁹ laid out a test to be applied in determining whether a person’s right to equality has been violated, as follows:

(a) Does the provision differentiate between people or categories of people? If so, does the differentiation bear a rational connection to a legitimate government purpose? If it does not then there is a violation of section 9(1) of the Constitution. Even if it does bear a rational connection, it might nevertheless amount to discrimination.

(b) Does the differentiation amount to unfair discrimination? This requires a two-stage analysis:

(i) Firstly, does the differentiation amount to ‘discrimination’? If it is on a specified ground, then discrimination will have been established. If it is not on a specified ground, then whether or not there is discrimination, will depend upon whether, objectively, the ground is based on attributes and characteristics which have the potential to impair the fundamental human dignity of persons as human beings or to affect them adversely in a comparably serious manner.

(ii) If the differentiation amounts to ‘discrimination’, does it amount to ‘unfair discrimination’? If it has been found to have been on a specified ground, then unfairness will be presumed. If on an unspecified ground, unfairness will have to be established by the complainant. The test of

⁶⁸ T Skosana, ‘A donor-conceived child’s right to know their genetic origin: a South African perspective’ (2017) 38(2) *Obiter*, 270-271.

⁶⁹ *Harksen v Lane NO* 1998 (1) SA 300 (CC), para 54.

unfairness focuses primarily on the impact of the discrimination on the complainant and others in his or her situation.

(c) If, at the end of this stage of the enquiry, the differentiation is found not to be unfair, then there will be no violation of section 9(2).’

Skosana argues that in terms of the test for unfair discrimination, donor-conceived children are unfairly discriminated against on a listed ground, in this case birth, when compared with adopted children. In such a case discrimination is unfair until proved otherwise in terms of section 36 limitation clause of the Constitution.⁷⁰ Skosana goes on to inquire as to whether such limitation is justified in terms of the section 36 but ultimately finds that the law in relation to donor-conceived children is discriminatory, and should follow the model used for adopted children.⁷¹

I suggest that bracketing donor-conceived children with adopted children with regard to the right to equality may be too narrow, as there are groups of ‘other-than-adopted’ children. Thus, comparing the rights of donor-conceived with adopted children is not conclusive in deciding whether a donor-conceived child’s right to equality has been infringed. There is still scope for the test of unfair discrimination to be applied to donor-conceived children compared to the other groups of children. The Skosana article, merely quotes the test set out in *Harksen v Lane*⁷² without discussing or applying the stages of the test, which is required to prove unfair discrimination and thus an infringement of the right to equality. The article immediately moves on to an inquiry as to whether a limitation of the right to equality is justifiable in terms of section 36 of the Constitution, apparently on the premise that donor-conceived children’s right to equality has automatically been infringed.

As such, the Skosana article is incomplete, as the question whether donor-conceived children’s right to equality has been infringed needs to be proved rather than assumed. Since this is the only academic analysis on this subject, there remains much space both for applying the test for unfair discrimination and doing so in comparison with all the relevant groups of children, which this dissertation will seek to do.

⁷⁰ Skosana op cit 271. See also section 36 of the Constitution.

⁷¹ Skosana op cit 272-273.

⁷² *Harksen v Lane* NO 1998 (1) SA 300 (CC).

(a) Direct-to-consumer genetic testing and its impact on donor-anonymity

(i) *What is direct-to-consumer genetic testing?*

In order to understand the impact of direct-to-consumer genetic testing and its effect on donor-anonymity, one must first have an understanding of what it is. Thus, a brief overview will be given before a discussion of any issues it raises or resolves.

Phillips gives a brief and concise definition of direct-to-consumer genetic testing as purchasing a kit online, receiving same by mail and collecting a DNA sample at home. The results may also be received at home without guidance from a medical practitioner or genetic counsellor.⁷³ The same author has listed the types of tests available, as well as the number of companies offering such tests. These tests include various forms of health testing, including carrier and nutrigenetic testing, ancestry, genetic relatedness, athletic ability, child talent, surreptitious testing, which is the testing of another person's DNA without their consent, and matchmaking. The test most relevant to the current discussion is the ancestry test, as 'it allows customers to compile family trees and search for related family members'. Phillips also explains that 'it is also common for companies to offer a 'family finder' function which allows people to connect with others to whom they may be related. This sometimes leads to unexpected discoveries including 'false' paternity and unknown siblings'.⁷⁴ However, ancestry and family finder tests are not the only tests which may be relevant and have an impact on the issues surrounding donor-anonymity.

(ii) *Access to medical and health information*

Kelly notes that 'perhaps the single most consistent concern raised by donor offspring who are unable to identify their donor is that they do not have access to half of their medical family history'.⁷⁵ In one study, Ravelingen, Provoost and Pennings carried out a qualitative analysis of reasons donor-conceived offspring gave for wanting to know the identities of their donors,⁷⁶ and one prominent reason found in the study was to understand their own predisposition to inheritable diseases.⁷⁷ Kelly further argues that 'offspring who may miss

⁷³ AM Phillips 'Only a click away—DTC genetics for ancestry, health, love... and more: A view of the business and regulatory landscape (2016) 8 *Applied & Translational Genomics* 17-20.

⁷⁴ Phillips op cit 18.

⁷⁵ F Kelly 'Is It Time to Tell: Abolishing Donor Anonymity in Canada' (2017) 30 *Canadian Journal of Family Law* 188.

⁷⁶ A Ravelingen, V Provoost, and G Pennings, G., Donor-conceived children looking for their sperm donor: what do they want to know?' (2013) 5(4), *Facts, Views & Vision in Obstetrics and Gynaecology* 58.

⁷⁷ A Ravelingen V Provoost & G Pennings op cit at 259.

the opportunity to participate in early screening, are at higher risk of misdiagnosis, or receive delayed diagnosis or treatment when compared with a person who has access to the medical history of their genetic parents', and that while the number of such situations was relatively low, there had been several such cases.⁷⁸

Dennison, in response to this argument suggests that recipients already have access to detailed family health histories. As early as 2007, Dennison suggested that with the increase of genetic testing, gametes were screened 'more than ever before for an even greater variety of inheritable diseases and characteristics', and that this screening was a more effective method of screening for genetic predisposition to diseases than donor identification, as donors may not even know as much information about their family health history as a genetic test could provide.⁷⁹ In the light of direct-to-consumer genetic testing, and in response to the arguments about the need for donor identification due to the need for access to possible medical and health concerns, De Melo-Martin argues that a person can have their genome sequenced and analysed. This would provide 'information about relevant genetic risks without the need to access genetic information about their progenitors'.⁸⁰ The need to access medical and health information is used widely as an argument in favour of donor-identity release and is one of the considerations in the SALRC *Right to Know* paper.⁸¹ This dissertation will include a discussion of how direct-to-consumer genetic testing affects this argument; specifically whether this argument is still relevant in lights of direct-to-consumer genetic testing, or whether donor-conceived children are able to access sufficient health and medical information about themselves by analysing their own DNA.

(iii) *Tracking relatives using direct-to-consumer genetic testing*

Erlich et al noted that law enforcement agencies have begun using databases in which consumers of direct-to-consumer genetic testing upload their genetic profiles to trace suspects. This type of tracing using genealogical databases has been dubbed long-range familial searches. The authors note that finding genetic relatives on these databases can link

⁷⁸ F Kelly 'Is It Time to Tell: Abolishing Donor Anonymity in Canada' (2017) 30 *Canadian Journal of Family Law* 188.

⁷⁹ M Dennison 'Revealing your sources: the case for non-anonymous gamete donation' (2008) 21 *Journal of Law & Health* 14-15.

⁸⁰ ID Melo-Martín 'The ethics of anonymous gamete donation: Is there a right to know one's genetic origins?' (2014) 44(2) *Hastings Center Report* 31.

⁸¹ SALRC *The Right to Know* supra 35.

individuals who are related as distantly as second or third cousins.⁸² They took an empirical study to find the probability that a long-range familial search could identify an individual, and suggest that with a database the size of just 2 per cent of the population within a specific ethnic group, more than 99% of the people ‘would have at least a single third-cousin match and more than 65% are expected to have at least one second cousin match’.⁸³ The same authors, in another article note that consumer genomics is growing at an exponential rate, and suggest that in the near future, most adults in the United States with European descent will be able to be traced using genealogical databases.⁸⁴ As the use of direct-to-consumer genetic testing becomes more popular, it is foreseeable that this will make it increasingly easier to trace relatives using these genealogical databases.

The question that may arise is whether the right to privacy extends to a person’s genetic data or results of a direct-to-consumer genetic test. May he or she invoke the right to privacy to prevent his or her genetic profile being uploaded to a genealogical database, and thus prevent the possibility of being traced by a relative finder tool. The constitutional right to privacy embraces the individual’s right not to have his or her person, home or property searched, possessions seized, or private communications accessed.⁸⁵ In *National Media Ltd v Jooste*,⁸⁶ the court held that ‘the right to privacy encompasses the competency to determine the destiny of private facts’, and that ‘a person is entitled to decide when and under what conditions private facts may be made public’.⁸⁷ In *Investigating Directorate: Serious Economic Offences v Hyundai Motor Distributors (Pty) Ltd*,⁸⁸ the court similarly held that ‘wherever person has the ability to decide what he or she wishes to disclose to the public and the expectation that such a decision will be respected is reasonable, the right to privacy will come into play’.⁸⁹

The Protection of Personal Information Act,⁹⁰ which was enacted to give effect to the constitutional right to privacy,⁹¹ defines personal information to include biometric

⁸² Erlich, et al ‘Identity inference of genomic data using long-range familial searches’ (2018) 362(6415) *Science* 690-694.

⁸³ Erlich et al op cit at 690.

⁸⁴ Erlich et al op cit.

⁸⁵ S 14 of the 1996 Constitution.

⁸⁶ 1996 (3) SA 262 (A).

⁸⁷ Supra at 271.

⁸⁸ *Investigating Directorate: Serious Economic Offences v Hyundai Motor Distributors (Pty) Ltd: In re Hyundai Motor Distributors (Pty) Ltd v Smit NO 2001 (1) SA 545 (CC)*.

⁸⁹ Supra at para 16.

⁹⁰ Act 4 of 2013.

⁹¹ S 2.

information of a person.⁹² Townsend and Thaldar⁹³ suggest that ‘genetic data is a species of biometric information, and therefore qualifies as “personal information” and “special personal information”.’ I suggest therefore that genetic data comprises those facts referred to in both of the cases above. The Act further prohibits the processing of this personal information⁹⁴ which includes ‘dissemination by means of transmission, distribution or making available in any other form’.⁹⁵

Thus, according to Slabbert, ‘[t]he taking of a genetic sample of an individual, the genetic testing itself, the collection of and acquaintance with, as well as disclosure or publication of the results without the person’s consent would . . . constitute an infringement of . . . the right to privacy’.⁹⁶

Chapter 3 of this dissertation will consider in-depth whether a donor may be able to invoke the right to privacy to prevent his or genetic data being made available on any ancestry databases to prevent the possibility of being traced by relatives. However, since genetic data is shared amongst relatives, the question also arises whether a donor may invoke the right to privacy over his or her own genetic data to prevent a relative from uploading his or her genetic data to a genealogical database.

As direct-to-consumer genetic testing develops and becomes increasingly popular, Woodage notes:

‘[There is an] absence of case law on point and that federal and state genetic privacy legislation was not designed to deal with the challenges of shared genetic information, it may be helpful to look to other bodies of law for guidance about how to deal with these issues. Looking to parallels with situations in which one party disclosed shared, non-genetic information in a manner that was adverse to the interests of another party provides useful analogies’.⁹⁷

According to Brown, case law on autobiographies provides such useful analogies, since ‘[j]ust as the memoirist reveals information that is mostly “her story”, she is also telling

⁹² S1 ‘Personal Information’ (d).

⁹³ BA Townsend & DW Thaldar ‘Navigating uncharted waters: biobanks and informational privacy in South Africa (2019) 35(4), *South African Journal on Human Rights* 13.

⁹⁴ S 26.

⁹⁵ S 1 ‘Processing’ (b).

⁹⁶ MN Slabbert ‘Genetic Privacy in South Africa and Europe: A Comparative Perspective’ (2008) 71 *THRHR* 86.

⁹⁷ T Woodage ‘Relative futility: Limits to genetic privacy protection because of the inability to prevent disclosure of genetic information by relatives’ (2010) 95 *Minnesota. Law Review* 705-713.

part of the private stories of others, who never consented to this story being told’⁹⁸. Brown goes on further to note that:

‘[E]ven in these cases where the shared content is deeply sensitive and potentially embarrassing, the courts have almost always sided with the authors. The individual’s First Amendment right to “tell her story” usually trumps the family member’s expectation of privacy’.⁹⁹

There is a dearth of case law in South Africa relating to shared genetic information, or even instances where one party disclosed information that was shared with another party, and which may have infringed such other party’s privacy rights. However, the experience of other countries is instructive, and this dissertation will consider international case law, and apply relevant principles from such cases to assist in interpreting the right to privacy in South Africa, and answer the question about the right to privacy regarding shared genetic information.

(b) International Law and the Child’s Best Interests

(i) *The best interests of the child*

Section 28(2) of the Constitution¹⁰⁰ states that ‘a child’s best interests are of paramount importance in every matter concerning the child’. This principle of the best interests of the child is also contained in international law, in article 3(1) of the United Nations Convention on the Rights of the Child¹⁰¹ which states that ‘[i]n all actions concerning children, whether undertaken by . . . courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration’. The African Charter on the Rights and Welfare of the Child¹⁰² goes further by stating in article 4 that the best interests of the child shall be *the* primary consideration, rather than *a* primary consideration as contained in other sources of law (emphasis added). This principle was incorporated in section 9 of the Children’s Act,¹⁰³ which reads: ‘In all matters concerning the care, protection and well-being of a child the standard that the child’s best interest is of paramount importance, must be applied’. However, the determination of what is in the best interests of the child has been

⁹⁸ TR Brown ‘Why We Fear Genetic Informants: Using Genetic Genealogy to Catch Serial Killers’ (2020) 21(1). *Columbia Science and Technology Law Review* 51.

⁹⁹ Brown op cit 52-53.

¹⁰⁰ 1996 Constitution.

¹⁰¹ United Nations Convention on the Rights of the Child (1989) (CRC).

¹⁰² African Charter on the Rights and Welfare of the Child (1990) (ACRWC)

¹⁰³ Children’s Act 38 of 2005.

contentious, as noted by the court in *S v M*:¹⁰⁴ '[T]he very expansiveness of the paramountcy principle creates the risk of appearing to promise everything in general while actually delivering little in particular'.¹⁰⁵ In the same paragraph, the court acknowledged that the best interests of the child principle has been attacked for being indeterminate, with various professions having different perspectives on the concept, and it being influenced by the value system of the decision-maker. The court held that 'a close and individualised examination of the precise real-life situation of the particular child involved' would be required in determining what is in the best interests of the child, and that 'a predetermined formula for the sake of certainty, irrespective of the circumstances, would in fact be contrary to the best interests of the child concerned'.¹⁰⁶ This would seemingly indicate that the best interests of the child should be decided on a case-by-case basis, avoiding any fixed rules in deciding the best interests of the child. However, in interpreting the best interests of the child, section 7 of the Children's Act¹⁰⁷ is instructive, as it provides factors to consider when determining the best interests of the child. The factors are first contained in subsections 1(h), which lists 'the child's physical and emotional security and his or her intellectual, emotional, social and cultural development' as being factors to consider in determining the best interests of a child. This echoes SALRC paper's finding that 'the interest in being free from psychological harm seems to present the most convincing argument that an individual has a right . . . to information about who their donor actually is'.¹⁰⁸ The other relevant subsection is 1(k): '[T]he need for a child to be brought up within a stable family environment – echoing the note in the SALRC *Right to Know* paper that 'rights proponents contend that withholding the truth about donor-conceived children's mode of conception is likely to have negative consequences on family relationships'.¹⁰⁹

In considering whether a child suffers psychological harm, or negative consequences to their family relationships because of donor-anonymity, there exists empirical evidence reported in a longitudinal study by Ilioi et al of these impacts on donor-conceived children:

'[T]he findings showed that adolescents who were unaware of their biological origins did not differ from adolescents who had been told about the circumstances

¹⁰⁴ *S v M* 2008 (3) SA 232 (CC).

¹⁰⁵ *S v M* supra para 23.

¹⁰⁶ *S v M* supra para 24.

¹⁰⁷ 38 of 2005.

¹⁰⁸ SALRC *The Right to Know* supra at 38.

¹⁰⁹ SALRC *The Right to Know* supra at 20.

of their birth (at any age), or from naturally conceived adolescents, in terms of psychological wellbeing or the quality of family relationships.’¹¹⁰

Thus, it would seem that the principle of the best interests of the child would not be a compelling argument in allowing donor-conceived children a right to know their biological parents, as empirical evidence suggests that they may not suffer harm as a result of not knowing. However, despite much having been written on this topic this topic is relevant in any discussion in law concerning children. As such, I will include a discussion on this principle for the sake of being comprehensive in this dissertation.

(ii) *International law*

The SALRC paper notes that ‘South Africa signed the United Nations Convention on the Rights of the Child on 29 January 1993 and ratified same on 16 June 1995’, making South Africa a state party to it.¹¹¹ It further states that ‘[w]hen interpreting and developing South African law, regard must be had to the CRC’.¹¹² Article 7 of the CRC reads as follows:

- ‘1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.
2. States Parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless’¹¹³

According to Clark,¹¹⁴ the ‘United Nations established the Committee on the Rights of the Child to monitor the rights granted by the CRC’. The author notes that ‘the committee has interpreted article 7 as granting a child the right to knowledge of his or her origins’, interpreting the definition of ‘parents’ broadly enough to not include biological parents alongside socio or legal parents.¹¹⁵

Article 8 of the CRC requires state parties to ‘undertake to respect the right of the child to his or her identity, including nationality, name and family relations’¹¹⁶, and according to

¹¹⁰ E Ilioi et al ‘The role of age of disclosure of biological origins in the psychological wellbeing of adolescents conceived by reproductive donation: a longitudinal study from age 1 to age 14’ (2017) 58(3), *Journal of Child Psychology and Psychiatry* 321.

¹¹¹ SALRC *The Right to Know* supra at 4.

¹¹² Para 1.14.

¹¹³ Art 7 United Nations Convention on the Rights of the Child (1989) (CRC).

¹¹⁴ B Clark ‘A Balancing Act: The Rights of Donor-Conceived Children to Know their Biological Origins’ (2011) 40 *Georgia Journal of International and Comparative Law* 625.

¹¹⁵ Clark op cit at 626.

¹¹⁶ Art 8 CRC supra.

Clark, ‘family relations is usually interpreted as going beyond knowing one’s legal parents and extending to biological and birth parents’.¹¹⁷ However, the United Nations Committee on the Rights of the Child does not have enforcement powers, and as such, this interpretation is not binding.¹¹⁸

After analysing these articles of the CRC, the SALRC paper concludes that ‘despite the interpretation of the CROC (United Nations Committee of the Rights of the Child), the formulation of the CRC is in fact open-ended and can accommodate interpretations’.¹¹⁹ Thus, it seems that states can interpret these articles as they see fit in incorporating them into their legal systems. Where the definitions of ‘parent’ in article 7 and ‘family relations’ in article 8 are subject to debate, reference must be made to South African legislation in providing their definitions. The Children’s Act¹²⁰ specifically excludes gamete donors in the definition of a parent;¹²¹ the definition of a family member includes a parent, ‘grandparent, brother, sister, uncle, aunt or cousin of the child’.¹²² Thus, a gamete donor is specifically excluded as both parent or family member of the child. This being the case, it is highly unlikely that any other person who might be considered part of the extended family by being biologically related to the child by virtue of the gamete donation having taken place would be included in the definition of family. Thus, it is unlikely that the law will be interpreted to extend the right of donor-conceived children to know the identity of their biological parents.

The international laws and their effects on donor-anonymity have been discussed in detail in existing publications, as well as in great detail in the SALRC paper. However, I have chosen to include discussion of the effects of international law, and specifically the CRC, in the main body of my dissertation for the sake of giving a complete and comprehensive discussion of the topic without leaving out any discussion of potentially relevant topics.

¹¹⁷ Clark op cit 627.

¹¹⁸ Clark op cit 625. See SALRC *The Right to Know* supra at 3, stating that states are not legally bound by a treaty, but are ‘obliged to refrain from acts that would defeat the object and purpose of such a treaty’.

¹¹⁹ Para 1.49, CRC supra at 13

¹²⁰ Children’s Act 38 of 2005.

¹²¹ S 1, Children’s Act supra; Interpretation, ‘parent’ (b), which excludes ‘any person who is biologically related to a child by reason only of being a gamete donor for purposes of artificial fertilisation’ from the definition of parent.

¹²² S1 Children’s Act supra; Interpretation, ‘parent’ (b), which excludes ‘any person who is biologically related to a child by reason Interpretation, ‘family member’ (a) and (c).

V CHAPTER BREAKDOWN

(a) Introduction

Chapter one will serve as an introduction to the principle of donor-anonymity. It introduces the legal questions and issues surrounding the principle of donor-anonymity in South Africa. It also introduces the effect that the development of direct-to-consumer genetic testing may have on donor-anonymity.

(b) South African Law and children's right to equal treatment in the Constitution

Chapter two will begin with the subheading: 'The law relating to adopted, naturally conceived and donor-conceived children. This will set out the legal position on whether or of these groups of children have a right to know the identities of their biological parents. This will be followed by the next subheading: 'section 32 and the right of access to information'. It will assess the constitutional right of access to information, and the extent to which this right should have a bearing on the principle of donor-anonymity in South Africa. The final subheading in this chapter will be 'section 9 and the right to equality', which will seek to determine whether donor-conceived children's right to equality is infringed by the principle of donor-anonymity. This will be done by applying the test for unfair discrimination to donor-conceived children in comparison with adopted and naturally conceived children.

(c) Direct-to-consumer genetic testing and its impact on donor-anonymity

Chapter three considers the effect of direct-to-consumer genetic testing on donor-anonymity. The first subheading 'What is direct-to-consumer genetic testing' introduces direct-to-consumer genetic testing. The second subheading in this chapter 'Access to medical and health information' addresses the familiar argument on the necessity of donor-conceived children to have access to medical information. It assesses this argument, and the effect of direct-to-consumer genetic testing on it. The third subheading, 'The ability to track relatives using direct-to-consumer genetic testing' sets out the likelihood of being able to track a donor using direct-to-consumer genetic testing. The fourth subheading in this chapter is 'The right to privacy in light of the advent of direct-to-consumer genetic testing' – whether the right of privacy extends to genetic data, and whether donors can use this to prevent their genetic data being available on databases where a donor might track them. It will also

consider whether this right can be enforced against relatives to prevent them publishing their genetic data, thus creating the possibility for donors to be traced thereby.

(d) International Law and the Child's Best interests

Chapter four will discuss the principles of international law and the best interests of the child, which are relevant to a fuller understanding of the issues surrounding the principle of donor-anonymity. The first of these will be under the subheading 'International law' and will discuss the United Nations Convention of the Rights of the Child (CRC). It will consider arguments of some authors that the rights of the child contained in CRC to 'know his or her parents', as well as 'preserve his or her identity, including . . . family relations'. It will consider the applicability of the CRC to South African law in order to determine whether it can be interpreted and applied in South African law so as to create a right of donor-conceived children to know their biological parents. CRC also contains a provision for the best interests of the child, (an important principle of South African law), and will be discussed in light of South African law under its own subheading in chapter four. The section 'the best interests of the child' will consider the constitutional principle of the best interests of the child in light of section 9 of the Children's Act, and its jurisprudential interpretation. It will consider how this principle is to be applied in weighing the best interests of the child with competing interests of the donors, as well as considering studies conducted and empirical evidence in deciding whether it is in fact in the best interests of the child to know his or her biological parents.

(e) Conclusion

Chapter five will conclude the dissertation by outlining the main conclusions reached and suggesting possible legal principles to be developed.

CHAPTER II

SOUTH AFRICAN LAW AND THE RIGHT TO EQUALITY UNDER THE CONSTITUTION

The law treats naturally conceived children, adopted children and donor-conceived children differently in the accessing of information about their biological parents. Does such differential treatment infringe on the donor-conceived child's right to equality? It is important to understand what the law states concerning an adopted and naturally conceived child's rights to know their genetic origins, and how this compares with the legal position concerning a donor-conceived child. Next, the right of access to information will be discussed. Finally, the right to equality will be considered in light of donor-conceived children compared with adopted and naturally conceived children.

(a) The law relating to adopted, naturally conceived, and donor-conceived children

Since this chapter considers whether the law concerning donor-conceived children is discriminatory *apropos* other children, the legal right of other children to know their biological origins will be discussed. There are several different groups of children. The first is children who are naturally conceived, are raised by their biological parents, and know the identity of their parents. This group will be referred to as naturally conceived children group A. A second group is children who know the identity of one of their biological parents, but the identity of the second parent is withheld for whatever reason.¹²³ This group will be referred to as naturally conceived children group B. A third group is adopted children, who may access the adoption register, and discover the identity of their biological parents, upon reaching 18 years of age, or younger if deemed appropriate by a court. The fourth group is donor-conceived children, for whom the identity of their biological parents is recorded, but they and any other person are not permitted to access the information. The final group is abandoned children, who many never find out the identity of the parents.¹²⁴

¹²³ A mother of a child may often withhold the identity of the biological father of the child for various reasons. These may include an acrimonious relationship with the father, and a decision by the mother that she does not want any further involvement with him. It may be to cover up marital infidelity, and an attempt to protect her marriage. She may have had several sexual partners during the time of conception, and genuinely not know the identity of the father. It may also be to protect herself or the child in cases of an abusive partner, or where the child was conceived as a result of rape or incest. See TM Young 'Removing the Veil, Uncovering the Truth: A Child's Right to Compel Disclosure of His Biological Father's Identity' (2009) *Howard LJ* 229-231.

¹²⁴ Abandoned children may fall into the category of adopted children, as they may, in terms of s 56(1) of the Children's Act 38 of 2005, General Regulations Regarding Children, be made available for adoption. However,

The law pertaining to adopted children is contained in the Children's Act,¹²⁵ which states that the adoption registrar must record personal details of adoptive children, as well as the details of both their adoptive and biological parents¹²⁶. This information is confidential. However, an adopted child, or their adopted parent, may access the information on the child reaching 18 years of age. Furthermore, upon both the adoptive child and their adoptive parents giving written consent, their biological parents, or previous adoptive parents may be given access to this information. A child may gain access to this information at a younger age, but only if a court deems this in the best interests of the child, or 'for any official purposes subject to conditions determined by the Director-General'.¹²⁷

The Births and Deaths Registration Act,¹²⁸ outlines the law relating to naturally conceived children. Section 9 requires that a child must be registered within 30 days of birth in compliance with prescribed requirements.¹²⁹ Further the biometrics of such child, as well as that of their parents may be taken,¹³⁰ and a birth certificate must be issued, which stands as evidence of the particulars of the child.¹³¹ This includes particulars of the child's parents in full, including their full names and identity numbers.¹³²

For naturally conceived children group A there is no mention of the right being given, as there is no need. They are given the identity of their biological parents via their birth certificate from the time it is issued, and so the question of a right is purely academic.

Where a child is born out of wedlock, however, the details of the father are not always recorded. They may be recorded with the consent of the mother, if the father acknowledges in writing that he is the father of the child.¹³³ Where the mother's consent is absent, the father may apply to court for a declaratory order confirming his paternity.¹³⁴ The information of the father is therefore not always recorded, but when it is it is therefore made available to

for the purposes of this dissertation, a distinction will be made, where adopted children are given access under the right conditions to the adoption register, and their biological origins, whereas for abandoned children, there may be no information on the adoption register regarding their biological origins.

¹²⁵ Children's Act *supra*.

¹²⁶ S 247(1)(b) of the Children's Act.

¹²⁷ See Ss 247 and 248 of the Children's Act for comprehensive information pertaining to the adoption register, what information is to be recorded in it, who may access it, and for what reasons.

¹²⁸ Births and Deaths Registration Act 51 of 1992.

¹²⁹ S 9(1).

¹³⁰ S 9(2).

¹³¹ S 9(7) and 9(8).

¹³² See *Home Affairs to Only Issue Unabridged Birth Certificates*, South African Government News Agency, available at <http://www.sanews.gov.za/south-africa/home-affairs-only-issue-unabridged-birth-certificates>.

¹³³ S 10(2).

¹³⁴ S 11(5).

the child via the birth certificate. The information of the mother is always recorded and made available. It must be noted, however, that where a child is abandoned, the details of neither parent will be known, and the registration is then done by a social worker. While there must be an attempt made to track and record the particulars of the parents of such child, this may not be possible, and such children will then not have any information or knowledge about their biological parents.¹³⁵

The next group to be discussed will be naturally conceived children, group B, in respect of whom the unreported Western Cape High Court case of *The South African Human Rights Commission v The Minister of Home Affairs* is instructive.¹³⁶ The case involved a minor who had been born to unmarried parents who had become estranged. A DNA test had been carried out, which proved paternity of her father; however, he refused to consent to be registered as her father, and the director-general would not register him as such without his consent.¹³⁷ The court held that upon proof of paternity, a child has a constitutional right to have their father registered as such, even without such father's consent.¹³⁸ This would seem to be in keeping with section 11(5) of the Births and Deaths Registration Act,¹³⁹ where a mother's consent may be dispensed with, and section 11(4A) which requires conclusive proof of the person being the father of the child. It is important to note here that a child has the right to have his or her father's name registered on the birth certificate, with or without consent, but proof of paternity is required for this. While the court held that a child has a constitutional right to have his or her father's name recorded on the birth certificate, it made no mention of whether there is a right to know the identity of such parent, I suggest that since the birth certificate is the means by which a naturally conceived child knows the identity of his or her parents, this right translates into a right to know the identity of such parent.¹⁴⁰ Indeed, where a child does not know the identity of his or her father, but seeks an order requesting that the mother provide the identity of the father, and that proof is provided, so that he may be registered as the father on the birth certificate, the right to have the name of the father on the birth certificate is being exercised, but the practical effect is that the child is then provided with the identity of the father.

¹³⁵ S 12

¹³⁶ Case no. 17283/2014. Available at <http://www.centreforchildlaw.co.za/cases/our-cases>

¹³⁷ Para 8

¹³⁸ Para 32, 37

¹³⁹ Act 51 of 1992

¹⁴⁰ Supra.

This right could apply to naturally conceived children group B, as well as to abandoned children upon being able to obtain proof about the identity of their biological father, and in the case of abandoned children, their biological mother. While the case dealt with the identity of the father of the child involved, there is no reason why, where the mother's identity can be proved, but the mother is not recorded on the birth certificate, this right should not also apply to children in such a situation, such as abandoned children. It is submitted therefore, that this right extends to abandoned children, who may be able in some way to obtain proof of maternity.

It has been argued, based on the *South African Human Rights Commission* case, that a child has a right to know the identity of his or her father, which legally is recognised as more important than the consent of either parent. However, this right is dependent on proof of such person being the biological parent of the child. The question arises then as to whether a child may have legal recourse to *obtain* proof of parentage from a person suspected to be his or her biological parent, or from a person who is reasonably expected to know the identity of his or her parent (emphasis added). While it has been argued above that there is a legally recognised right for a child to find the identity of his or her biological parent, specifically for naturally conceived children group B, it is important to note that there are limitations to the right of a child to compel either parent to provide proof of who the father is. The law is silent on whether a mother can or cannot be compelled to provide the identity of the child's father. While it is argued that a child can request the information from the mother, without express legal provisions it cannot be said definitively that a mother can be compelled by the courts to provide the identity of the father; it must be assumed that a mother, for reasons of her own¹⁴¹ is permitted to withhold such information. In the case of abandoned children, it might not be possible to track down the identity of the biological parents. Thus, while the right may exist for abandoned children, it may be more difficult or impossible to exercise.

Even in cases where the mother identifies a particular person as the father, he may dispute such paternity. The Births and Deaths Registration Act, as well as the *South African Human Rights Commission* case require proof of paternity.¹⁴² Neither the Act nor the

¹⁴¹ See footnote 1 above. Her reasons, might concern her fraught relationship with the father or her need to protect her marriage in cases of infidelity; or she may genuinely not know the identity of the father. She might wish to protect the child in cases of rape or incest, where the father may be abusive or any other circumstance where it is undesirable for the child to know the identity of the father.

¹⁴² S 11(4A) of Act 51 of 1992; *The South African Human Rights Commission v The Minister of Home Affairs*, paras 32, 37.

decision makes it clear how paternity is to be proved.¹⁴³ The Children's Act¹⁴⁴ contains provisions relating to assignment of parental rights and responsibilities;¹⁴⁵ persons claiming paternity to allow for amendment of the registration of the child identifying him as the father,¹⁴⁶ and miscellaneous issues involving the parents and presumptions of paternity.¹⁴⁷ Therefore, this discussion would be incomplete without taking into account provisions of this Act. Section 36 provides for a presumption of paternity for such children as follows:

'If in any legal proceedings in which it is necessary to prove that a particular person is the father of a child born out of wedlock it is proved that that person had sexual intercourse with the mother of the child at any time when that child could have been conceived, that person is, in the absence of evidence to the contrary which raises a reasonable doubt, presumed to be the biological father of the child.'

The wording of this section is important, as it cites instances where it is required to prove that a particular person is the father of the child. If a person can be proved to have had sexual intercourse with the mother during the time the child could have been conceived, then the presumption of paternity may suffice. However, this argument may be inadequate, as it has its flaws, the first being the difficulty, in the absence of an acknowledgement of the person in the affirmative, of proving such person to have had sexual intercourse with the mother.¹⁴⁸ The other is the possibility of the mother having had more than one sexual partner at the time. Another possibility is where the mother had more than one sexual partner at the time without admitting to it. These flaws with this presumption mean that other more reliable means should be used to settle issues of disputed paternity.

¹⁴³ S 11(4A) of the Births and Deaths Registration Act only requires 'prescribed, conclusive proof', without reference to what form such prescribed proof must take.

¹⁴⁴ Act 38 of 2005.

¹⁴⁵ Ss 18 to 22

¹⁴⁶ S 26.

¹⁴⁷ Ss 36 to 41.

¹⁴⁸ There have been questions raised as to whether evidence given by the mother is sufficient to satisfy section 36 of the Children's Act. In *Mayer v Williams* 1981 (3) SA 348 (A), the judge considered that a mother's evidence should be carefully scrutinised, and referred to the cautionary rule in criminal proceedings involving sexual offences. This rule does not always require corroboration, although corroboration would be useful as a safeguard. However, s 60 of the Criminal Law (Sexual Offences and Related Matters) Amendment Act 32 of 2007 did away with the cautionary rule, and thus the mother's evidence is unlikely to need corroboration. See J Heaton *The South African Law of Persons* 4 ed LexisNexis (2012) 57 for a discussion of this principle. However, S 11 (4A) of the Births and Deaths Registration Act requires conclusive proof, and it is doubtful whether the testimony of the mother, creating a common law presumption would suffice as conclusive proof as required by the Act.

Uncertainty over paternity is not uncommon;¹⁴⁹ in such cases, the man may request the court to order paternity testing.¹⁵⁰ Such tests are performed by DNA tests using blood samples.¹⁵¹ However, there have been several conflicting cases on whether or not courts can compel a person to submit a blood sample for paternity testing.

The eSwatini case of *Dlamini v Dlamini*¹⁵² considered whether a person could compel his wife and daughter to undergo DNA testing to establish whether he was the biological father of the child, as he had doubt about the issue. The court held that it was permissible to compel the respondents to undergo DNA testing so as to remove uncertainty and disputes – for example if the applicant died intestate. The order was justified as a means to remove mistrust and speculation fuelled and maintained by lack of knowledge. Where scientific means were available to settle issue of unknown parentage, the court held that it is the interests of the judicial system and justice that the truth be ascertained.¹⁵³

The most recent, and to date only SCA case relating to this issue was *YM v LB*¹⁵⁴. The court did not directly address the question of whether a person could be compelled to undergo DNA testing to prove paternity by finding that paternity in that instance was not in issue.¹⁵⁵ What the court did note was that ordering a person to submit to a paternity test may be an infringement on his or her right to privacy and bodily integrity. Such infringements may be justifiable in certain circumstances, but whether this would be so would depend on the circumstances of the case.¹⁵⁶ This case left open the question whether an adult can be compelled to undergo paternity tests.¹⁵⁷ The court was of the view that this may be done when in the best interests of the child, without giving details as to what circumstances would render this so.¹⁵⁸ Thus, all that can be concluded is that the question whether a person can

¹⁴⁹ See for example, *Ranjith v Sheela* 1965 (3) SA 103 (D), where the presumed father of the child denied that he had had sexual intercourse with the mother at the time of the child's conception, resulting in blood tests being performed which determined that he was in fact not the father of the child.

¹⁵⁰ Pillay & Zaal 'Misattributed Paternity' op cit at 586.

¹⁵¹ LI Schäfer *Child law in South Africa: domestic and international perspectives* (2011) LexisNexis 234. See also M Buthelezi 'A missed opportunity to settle the law on DNA testing in paternity disputes-YD (now M) v LB 2010 6 SA 338 (SCA): case' (2011) 32(2), *Obiter* 480. See also s 37 Children's Act, See J Heaton *The South African Law of Persons* 4 ed (2012) LexisNexis 59.

¹⁵² *Dlamini v Dlamini* 2801/10 2012 SZHC 10.

¹⁵³ Para 11.

¹⁵⁴ *YM v LB* 2010 (6) SA 338 (SCA).

¹⁵⁵ *YM v LB* 2010 (6) SA 338 (SCA) para 12. See also R Pillay & FN Zaal 'Misattributed Paternity' op cit at 586.

¹⁵⁶ Paras 15-16.

¹⁵⁷ See J Heaton op cit at 61.

¹⁵⁸ See paras 15-16. The court's reason was that it could be in the best interests of a child to discover the truth of his or her paternity, when paternity test was justified, but in other cases the rights to privacy would prevail.

be compelled to undergo paternity testing is an open one.¹⁵⁹ It has been argued by one author that it is ‘unlikely that there will be many cases in which a court could legitimately conclude that a child is better off not knowing the truth of his paternity’.¹⁶⁰ It is sufficient to note here that courts may or may not order paternity testing, taking a child-centred, best interest, approach.¹⁶¹ While *YM v LB*¹⁶² involved paternity testing in cases of disputed or unknown paternity, the principles adopted may find application in the case of abandoned children. The court held that the importance of finding the truth regarding a child’s parentage had to be balanced against the rights of the person against whom the order is sought to privacy and bodily integrity. The position with abandoned children differs slightly from naturally conceived children group B, as there may be a lack of a mother to testify to the identity of the biological father.¹⁶³ This makes the question of whether a person who is believed to be a biological parent can be compelled to undergo DNA testing slightly more complex as such an order would infringe their rights. The issue involves a balancing of rights.¹⁶⁴

It is suggested that the question of whether a person who is believed to be a biological parent can be compelled to undergo DNA testing will depend on the strength of the evidence being presented.¹⁶⁵ The onus of proof or rebuttal in civil matters is on a balance of probabilities, and this applies to issues surrounding application of provisions in the Children’s Act.¹⁶⁶ Indeed, since section 36 permits evidence which creates reasonable doubt in rebutting a presumption of paternity, it is submitted that where an abandoned child wishes to compel a person to undergo DNA testing, he or she would need to provide evidence which may create a reasonable belief that such person may be the biological father.

¹⁵⁹ See M Buthelezi ‘A missed opportunity’ op cit at 480. See also s 37 of the Children’s Act.

¹⁶⁰ Schäfer *Child law in South Africa* op cit at 235.

¹⁶¹ *M v S* 2007 (12) BCLR 1312 (CC), para 24. The Constitutional Court affirmed a child-centered approach, undertaking a ‘close and individualised examination of the precise real-life situation of the particulars of the child involved’.

¹⁶² 2010 (6) SA 338 (SCA).

¹⁶³ The position of the mother tends to be central to determining paternity in South African law. In terms of s 20 of the Children’s Act, where a woman gives birth to a child and the child was born during, or conceived before but born during or after the dissolution of the marriage, the man is rebuttably presumed to be the father. In terms of s 36 of the same Act, a person will be presumed to be the biological father where it can be proved that he had sexual intercourse with the mother during the time of conception. Thus, the role of the mother tends to be central in determining paternity.

¹⁶⁴ *YM v LB* 2010 (6) SA 338 (SCA), paras 15-16.

¹⁶⁵ For example, a reliance on similarity in physical features may not be used in determining issues of paternity. See L Albertus ‘Some unresolved complexities in matters involving paternity: a South African Perspective’ (2014) 3 *Adam Mickiewicz University Law Review* 230. Thus, it is inconceivable that an abandoned child could seek a paternity order based on similarity of physical appearance, and seek to compel the person to undergo DNA testing.

¹⁶⁶ 38 of 2005. See CJ Davel, & A Skelton (eds). *Commentary on the Children’s Act* 2007 ch3-p44.

Thus, while it has been argued that naturally conceived children group B, and abandoned children have a right to find the identity of their biological parents, such a right is limited either by the mother refusing to provide the identity of the father, or in some instances, the father being permitted to refuse to submit to a paternity test. Or, in the case of abandoned children, there either being no evidence present as to the identity of the biological parent, or the evidence not being sufficient to persuade a court to compel an unwilling person to undergo DNA testing. So the right can only be exercised where the parents are willing to allow this right to be exercised. In comparison, the law governing gamete donation is contained in the National Health Act¹⁶⁷ Regulations Relating to the Artificial Fertilisation of Persons. Regulation 19 reads as follows:

‘No person shall 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.’

This regulation prohibits the disclosure of the identity of any gamete donor unless the law or the courts deem it permissible. In absence of reasons given for this exception by the legislature, policy reasons for this rule as proposed by academic writers will have to be assumed.¹⁶⁸ The exception contemplated in regulation 19 can only apply by order of court. There have been no recorded instances where the law or the courts have permitted this.¹⁶⁹

There raises an apparent inconsistency in the law. One group, naturally conceived children group A, know the identity of both parents. Another group, naturally conceived children group B, only know the identity of one parent, but the law is silent on whether they should have a right to know the identity of the other parent. Adopted children are, albeit under certain limited circumstances, permitted if they so choose, to discover the identity of their biological parents, while donor-conceived children do not have a choice – the identity is simply withheld. And in the case of abandoned children, an attempt must be made to trace their biological parents, and where such parents cannot be traced, the quest ends. Such

¹⁶⁷ National Health Act 61 of 2003.

¹⁶⁸ Certain policy reasons are given in academic writings for withholding donor identity. These are privacy of the donors, privacy of the recipients, wishing to prevent unwanted intrusion into their lives from the donor, the commissioning parents wanting to prevent adverse effects that such knowledge could have on their relationship with their child and preserving donor supply. See M Dennison ‘Revealing your sources: the case for non-anonymous gamete donation’(2007) 21(1) *Journal of Law and Health* from 18

¹⁶⁹ A search was conducted across the Jutastat, LexisNexis, HeinOnline and Sabinet websites as well as Google, using the following search entries, and variations of them; ‘Regulation 19 Artificial Fertilization of Persons’, ‘donor identity disclosure’ and ‘gamete donor identity’, and no relevant information was found. Further, in the Jutastat website under the section entitled South African Case Law, Legislation Judicially Considered, Act 61 of 2003 – National Health Act, there were relevant cases listed.

failure is due to practical impossibility only – legislation requires that a social worker take all possible steps to discover the identity of such child’s parent(s).¹⁷⁰

Before dealing with the constitutional right to equality, an analysis of the constitutional right of access to information will show whether or how much prejudice children may suffer in not being given access to the identity of their parents.

(b) Section 32 and the Right of Access to Information

Section 32 of the Constitution¹⁷¹ replaces section 23 of the Interim Constitution.¹⁷² Both sections make access to information a constitutional right in response to the secrecy and control of information of the apartheid government, which was authoritarian, and not representative of the people.¹⁷³ Thus a right of access to information was included in the Interim Constitution to prevent a repeat of such previous mistakes,¹⁷⁴ and in the belief that such a right would be fundamental in holding government accountable, discouraging corruption, arbitrariness, and improving legitimacy in government decisions.¹⁷⁵ Section 23 of the Interim Constitution reads as follows:

‘Access to Information

23. Every person shall have the right of access to information held by the state or any of its organs at any level of government in so far as such information is required for the exercise or protection of any of his or her rights.’

The wording here is important, as the right only became enforceable when access to information was required to enforce or protect another right. The right was dependant on other existing rights. With the enactment of the Final Constitution, the scope of this right was greatly widened.¹⁷⁶ Section 32 of the 1996 Constitution reads as follows:

‘32 Access to information

(1) Everyone has the right of access to—

(a) Any information held by the state; and

¹⁷⁰ Regulations on the Children’s Act. Published as the ‘General Regulations Regarding Children’, 2010. S 56(1) requires a social worker must cause at least one advertisement to be placed in a newspaper circulating in the area where the child was found. S 56(2)(d) requires that a presiding officer be furnished with an affidavit setting out steps that were taken to trace the child’s parent.

¹⁷¹ 1996 Constitution.

¹⁷² Interim Constitution of the Republic of South Africa Act 200 of 1993. Hereinafter referred to as the Interim Constitution.

¹⁷³ I Currie & J Klaaren 2002. *The Promotion of Access to Information Act, Commentary* (2002) Siber Ink 2 at 1.2 .

¹⁷⁴ I Currie & J De Waal J *The Bill of Rights Handbook* (2013) Juta 692.

¹⁷⁵ C Hoexter *Administrative Law in South Africa* (2012) Juta 94.

¹⁷⁶ Currie & De Waal, J *The Bill of Rights Handbook* op cit at 693.

(b) Any information that is held by another person and that is required for the exercise or protection of any rights.

(2) National legislation must be enacted to give effect to this right, and may provide for reasonable measures to alleviate the administrative and financial burden on the state.’

Significantly, section 32 of the Constitution no longer requires existing rights as a prerequisite for accessing information held by the state. Thus, access to such information from the state is now a free-standing right, referred to by some authors as a ‘right to know’ rather than a ‘need to know’.¹⁷⁷ Another significant inclusion was section 32(1)(b) that recognises the importance of a person’s need to have access to information concerning themselves, rather than only ensuring accountability from the state. Indeed, it has been suggested that such information is important for the protection of other rights such as privacy and equality, as well as being an aspect of self-actualisation.¹⁷⁸

As contemplated by section 32(2) of the Constitution, the Promotion of Access to Information Act (PAIA)¹⁷⁹ was enacted setting out the means and practicalities by which a person must assert their constitutional right.¹⁸⁰ Section 2 of PAIA contains the requirements for access to state-held information. Part 2 of PAIA¹⁸¹ specifically notes that access to information from public bodies¹⁸² includes ‘personal information about the requester’. In terms of both the Children’s Act,¹⁸³ and the Regulations Relating to the Artificial Fertilisation of Persons,¹⁸⁴ the director-general is directed to keep a register containing necessary information. The director-general is in charge of a national information office under the leadership of the minister,¹⁸⁵ and so the director-general’s office constitutes a public body, and the director-general acts under and in terms of legislation. Therefore, in the absence of the legislation permitting adopted children access to the adoption register under the Children’s Act, they would be able to use PAIA as a means to request such information.

¹⁷⁷ GE Devenish K Govender & DH Hulme *Administrative Law and Justice in South Africa* (2001) Butterworth-Heinemann 189.

¹⁷⁸ See C Hoexter *Administrative Law in South Africa* op cit at 96.

¹⁷⁹ Promotion of Access to Information Act 2 of 2000. Hereinafter referred to as PAIA.

¹⁸⁰ L Chamberlain ‘Assessing enabling rights: Striking similarities in troubling implementation of the rights to protest and access to information in South Africa’ (2016) 16(2), *African Human Rights Law Journal* 370.

¹⁸¹ S 11(2) PAIA.

¹⁸² See Part 1, s 1 of PAIA. This section defines a public body is any department of state within the national, provincial or local sphere of government. It includes any institution that performs a function in terms of any legislation.

¹⁸³ 38 of 2005.

¹⁸⁴ National Health Act 61 of 2003.

¹⁸⁵ See <http://www.health.gov.za/index.php/director-general> for the profile of the Director-General of the National Department of Health.

The position regarding donor-conceived children differs, since PAIA ‘applies to the exclusion of any provision of other legislation that prohibits or restricts the disclosure of a record of a public body’,¹⁸⁶ which the regulations, and the Act do.¹⁸⁷ Further, the right of access to information is not unfettered. As with any constitutional right, there may be limitations, in respect of which lies the constitutional right to privacy.¹⁸⁸ To give effect to this right, the Protection of Personal Information Act (POPI) was enacted,¹⁸⁹ the preamble to which states that the purpose of the Act is ‘to promote the protection of personal information processed by personal and private bodies’. Section 2 of the Act states the further purpose to:

- (i) ‘give effect to the constitutional right to privacy, by safeguarding personal information’, and
- (ii) ‘balancing the right to privacy against other rights, particularly the right to access information’.¹⁹⁰

The purpose of this discussion is not to discuss the merits of the application of PAIA, and whether it could be used to access progenitor information. Rather, it is to show the weight our law places on the importance of access to information. This was clearly stated in *President of the Republic of South Africa v M&G Media*,¹⁹¹ where the court held that ‘disclosure of information is the rule and exemption from disclosure is the exception’. Indeed, there is also precedent to support the importance of the right of children to access information about their genetic origins. In the case of *AB v Minister of Social Development*,¹⁹² the court held that that it was important for a child to have clarity regarding his/her origins, as it ‘is important to the self-identity and self-respect of the child’. Although this case was about surrogacy and may have been *obiter*,¹⁹³ it at least is a persuasive precedent for the importance of a child’s need to know about his/her genetic origins.

¹⁸⁶ S 5(a) PAIA.

¹⁸⁷ S 19 Regulations Relating to the Artificial Fertilisation of Persons.

¹⁸⁸ S 14 of 1996 Constitution.

¹⁸⁹ Protection of Personal Information Act 4 of 2013. Hereinafter referred to as POPI.

¹⁹⁰ An in-depth discussion of the right to privacy will be given in a subsequent chapter. The mention here of the right to privacy is to illustrate that it may be used as a counter-argument to the right of access to information.

¹⁹¹ *President of the Republic of South Africa v M&G Media Ltd* 2012 (2) SA 50 (CC) at para 9

¹⁹² *AB v Minister of Social Development* 2017 (3) SA 570 (CC) at para 294.

¹⁹³ See L Meintjies-Van der Walt et al. *Introduction to South African Law Fresh Perspectives*, (2008) 74-75. Court decisions may be either *ratio decidendi* or *obiter dictum*. A *ratio decidendi*, is binding on all lower courts in similar matters. An *obiter dictum* refers to comments extraneous to the issue before court. An *obiter dictum* creates a persuasive, rather than binding source of law.

In summary, the Constitution provides a general right to information. The legal importance of the right is reflected in the recognition that children, including donor-conceived children, have an interest in knowing their biological origins. However, this right must be balanced against the right to privacy, and also express legislation prohibiting the disclosure of the identity of a donor. Consequently, the right may not be directly applicable in allowing a donor-conceived child a right to find the identity of his or her biological parent. That does not mean that the right has no relevance in this study. The finding that ‘disclosure of information is the rule and exemption from disclosure is the exception’ in the case above may have an effect on the development of common law,¹⁹⁴ as well as existing legislation.¹⁹⁵ This serves as a backdrop to further discussions regarding constitutional rights, most particularly the right to equality, and whether the right of donor-conceived children to equality is infringed when compared with the other groups of children mentioned in this dissertation.

(c) Section 9 and the right to equality

The right to equality, like the right of access to information was also driven by the past practices and of systematic discrimination in South Africa, and is contained in the founding provisions of the Constitution,¹⁹⁶ as follows:

1. Republic of South Africa. -The Republic of South Africa is one, sovereign, democratic state founded on the following values:

(a) Human dignity, the achievement of equality and the advancement of human rights and freedoms.

This theme of a society based on dignity, equality, and human rights and freedoms ‘runs like a golden thread through the Constitution’.¹⁹⁷ Indeed, equality is at its centre, its focus and organising principle.¹⁹⁸ In consequence, the Bill of Rights contains a right to equality that both promotes freedom from unfair discrimination and requires positive

¹⁹⁴ S 39(2) of the Constitution states: ‘When interpreting any legislation, and when developing the common or customary law, every court, tribunal or forum must promote the spirit, purport and objects of the Bill of Rights’.

¹⁹⁵ The moved towards openness was the driving force behind adopted children, being afforded access to the identity of their biological parents. See Davel & Skelton (eds) *Commentary on the Children's Act* ch 15 at 28-29.

¹⁹⁶ S 1(a) of the 1996 Constitution.

¹⁹⁷ T Deane *Affirmative action: a comparative study* (Doctoral dissertation, University of South Africa, 2009) 284

¹⁹⁸ See *President of the Republic of South Africa v Hugo* 1997 (4) SA 1 (CC), para 74

measures to promote equality.¹⁹⁹ The rights to equality and dignity are closely related,²⁰⁰ with the right to dignity, along with the right to life, ‘the most important of all human rights’, and form the source of all other rights contained in the Constitution.²⁰¹ The right to dignity is recognition that human beings are entitled to be treated with respect and concern.²⁰² While dignity forms the basis of other human rights, the principle of subsidiarity may apply, meaning that norms of greater specificity should apply before norms of greater abstraction.²⁰³ Thus, singular rights should be invoked before the more general right to dignity.²⁰⁴ As the source of other rights,²⁰⁵ the right to dignity it is a value that ‘informs the interpretation of many, possibly all other rights’.²⁰⁶ It is especially important in interpreting the right to equality.²⁰⁷ The close relationship between the right to dignity and the right to equality, and its importance in interpreting the right to equality will be referenced in this analysis. In discussing the right to equality, the distinction between formal and substantive equality must be understood. Formal equality focuses on the treatment of an individual, where all are extended the same rights and treated the same before the law. Substantive equality focuses on the effect of the treatment, in which equality of opportunity is important.²⁰⁸ In this sense, groups of people are situated in different circumstances, and thus different treatment is permissible in order to allow every person equal opportunity.²⁰⁹ In *National Coalition for Gay and Lesbian Equality*,²¹⁰ the court noted that equality and uniformity are two different principles, and in many ways, uniformity can have an adverse effect on equality. This condones substantive equality, which allows different treatment to allow equality of opportunity. South African jurisprudence has developed to being

¹⁹⁹ S Woolman *Constitutional Law of South Africa* (2006) ch35 p1.

²⁰⁰ See *National Coalition for Gay and Lesbian Equality v Minister of Justice* (1999) 1 SA 6 (CC), 30. See also Currie & De Waal *The Bill of Rights Handbook* op cit 250-251, referring to human dignity, equality and freedom as a ‘triplet’ in several places in the constitution ie in s 7(1), s 39 and s 36.

²⁰¹ *S v Makwanyane*, 1995 (3) SA 391 (CC), 144. Chaskalson P held that the rights to life and dignity formed the source of all rights in chapter 3 of the Interim Constitution which contained ‘fundamental rights’, the precursor to Bill of Rights.

²⁰² *S v Makwanyane* supra at 328.

²⁰³ Currie & De Waal op cit 353.

²⁰⁴ *Nokotyana v Ekurhuleni Metropolitan Municipality* 2010 (4) BCLR 312 (CC), 50.

²⁰⁵ *S v Makwanyane*, supra at 328.

²⁰⁶ *Dawood v Minister of Home Affairs* 2000 (3) SA 936 (CC), 35.

²⁰⁷ Ibid.

²⁰⁸ Woolman *Constitutional Law of South Africa* op cit ch35 p7: ‘Substantive equality recognises that it is not the fact of difference that is the problem, but rather the harm that may flow from this . . . Equality can thus be advanced through similar or differential treatment, depending on the context’.

²⁰⁹ See Currie & De Waal, op cit at 213 and Woolman op cit at ch35 p5 for discussions of the difference between formal and substantive equality.

²¹⁰ *National Coalition for Gay and Lesbian Equality v Minister of Justice* (1999) 1 SA 6 (CC), para 132.

substantive and flexible in its approach towards individual questions of equality.²¹¹ The importance of this distinction will become apparent when analysing the test for unfair discrimination below.

Section 9 of the Constitution reads as follows:

9. Equality. - (1) everyone is equal before the law and has the right to equal protection and benefit of the law.

(2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.

(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.

(5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.'

Early constitutional jurisprudence interpreted the right to equality as prohibiting discrimination in order to preserve this right. Authoritative cases relevant to this study are *Prinsloo v Van der Linde*,²¹² and *President of the Republic of South Africa v Hugo*,²¹³ where the court began to develop the right to equality,²¹⁴ culminating in the test for whether there has been unfair discrimination, and thus a breach of the right to equality, in *Harksen v Lane NO*.²¹⁵ These cases were decided in terms of the equality clause in the Interim Constitution.²¹⁶ While the Interim Constitution is no longer in effect, the court in *National*

²¹¹ See C Albertyn & B Goldblatt, *Section 9 – The Right to Equality*. Paper for presentation at the Constitutional Law of South Africa Conference, 29 March 2006.

²¹² *Prinsloo v Van der Linde* 1997 (3) SA 1012 (CC), Hereinafter referred to as *Prinsloo*.

²¹³ *President of the Republic of South Africa v Hugo* 1997 (4) SA 1 (CC). Hereinafter referred to as *Hugo*.

²¹⁴ C Albertyn, & B Goldblatt 'Facing the challenge of transformation: difficulties in the development of an indigenous jurisprudence of equality' (1998) 14(2), *South African Journal on Human Rights* 255.

²¹⁵ *Harksen v Lane NO* 1998 (1) SA 300 (CC). Hereinafter referred to as *Harksen*.

²¹⁶ The equality clause was contained in s 8 of the Interim Constitution, and reads thus:

'8 Equality

(1) Every person shall have the right to equality before the law and to equal protection of the law.

(2) No person shall be unfairly discriminated against, directly or indirectly, and without derogating from the generality of this provision, on one or more of the following grounds in particular: race, gender, sex, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience or belief, culture or language.

Coalition for Gay and Lesbian Equality v Minister of Justice, referring to section 9 of the Constitution, held:

‘[O]n the assumption that the equality jurisprudence and analysis developed by this Court in relation to s 8 of the interim Constitution is applicable equally to s 9 of the 1996 Constitution, notwithstanding certain differences in the wording of these provisions’.²¹⁷

Therefore the previously mentioned cases decided in terms of section 8 of the Interim Constitution remain authoritative.²¹⁸

As discussed above, equality in South African law is substantive equality, which allows differential of treatment to ensure equality of outcome. In *Prinsloo*, the court noted that differentiation ‘is at the heart of equality jurisprudence in general . . . and the section 8 right or rights in particular’.²¹⁹ *Prinsloo* adopted a rationality analysis in deciding whether differentiation contravened the right to equality. This requires determining whether there is a rational connection between the differentiation and a legitimate government purpose to be sought in the differentiation.²²⁰ The court did note, however, that even where a rational connection exists, there may nevertheless be unfair discrimination in terms of the listed grounds in section 8(2) if there is differentiation on these grounds is presumed to be unfair. There are also unspecified grounds for which unfairness must be proved.²²¹

In *Hugo*, the court used section 8(2), the prohibition on unfair discrimination, as its point of departure in deciding whether discrimination was unfair,²²² the effect of the discrimination on the complainants in each specific context, and whether this ‘furthers the Constitutional goal of equality or not’ was decisive; this included the nature of the group

(3)(a) This section shall not preclude measures designed to achieve the adequate protection and advancement of persons or groups or categories of persons disadvantaged by unfair discrimination, in order to enable their full and equal enjoyment of all rights and freedoms. (b)...

(4) Prima facie proof of discrimination on any of the grounds specified in subsection (2) shall be presumed to be sufficient proof of unfair discrimination as contemplated in that subsection, until the contrary is established.’

²¹⁷ *National Coalition for Gay and Lesbian Equality v Minister of Justice* (1999) 1 SA 6 (CC), para 15

²¹⁸ There are only two significant differences between the right to equality as contained in the Interim Constitution as compared with the Final Constitution. These are first, the listed grounds upon which unfair discrimination is presumed were increased to include pregnancy, marital status and birth. Second, there is a horizontally applicable right in s 9(4). This means that the equality right and prohibition on unfair discrimination includes a right not to be discriminated against by other people. The prohibition on discrimination under the Interim Constitution only extended to conduct by the state. See Currie and De Waal *The Bill of Rights Handbook* (2013) 215.

²¹⁹ *Prinsloo v Van der Linde* 1997 (3) SA 2012 (CC) at para 23.

²²⁰ R Kruger ‘Equality and unfair discrimination: refining the *Harksen* test’ (2011) 128(3) *South African Law Journal* 484.

²²¹ *Prinsloo v Van der Linde* 1997 (3) SA 2012 (CC) at para 26-28

²²² *President of the Republic of South Africa v Hugo* 1997 (4) SA 1 (CC), at para 41

which received the treatment, the nature of the power in terms of which the discrimination was effected, and the interests which had been affected by it.²²³

(i) *The Harksen Test and its application*

The court in *Harksen* consolidated a number of cases, approaching the right towards the right to equality by setting out a test to determine whether there had been unfair discrimination.²²⁴

- (a) *Does the provision differentiate between groups of people? Does it bear a rational connection to a legitimate government purpose?*

The first part of this test involves a two-stage analysis: whether there is differential treatment, for if there is not, then there is no possibility of the right to equality being infringed. If there is differential treatment, then such treatment must be rationally connected to a legitimate government purpose. This is the rationality requirement, and in the absence of such rational connection, section 9(1) will be infringed without having to prove unfair discrimination.²²⁵

With donor-conceived, naturally conceived, adopted, and abandoned children, there is a difference in treatment, with adopted children being given a right to access information about their biological parents. Naturally conceived children group A have access to the identity of their biological parents from the time of registration of their births, and naturally conceived children group B are given a right to know the identity of their biological parents albeit with greater limitations than the previous two groups. In the case of abandoned children, the position may overlap with the other groups. For example, they may fall under

²²³ *President of the Republic of South Africa v Hugo* 1997 (4) SA 1 (CC), at para 24

²²⁴ *Harksen v Lane NO* 1998 (1) SA 300 (CC), para 54. The full test as set out by Goldstone J reads as follows: '(a) Does the provision differentiate between people or categories of people? If so, does the differentiation bear a rational connection to a legitimate government purpose? If it does bear a rational connection, it might nevertheless amount to discrimination.

(b) Does the differentiation amount to unfair discrimination? This requires a two stage analysis: (b)(i) Firstly, does the differentiation amount to discrimination? If it is on a specified ground, then discrimination will have been established. If it is not on a specified ground then whether or not there is discrimination will depend upon whether, objectively, the ground is based on attributes and characteristics which have the potential to impair the fundamental dignity of persons as human beings or to affect them adversely in a comparably serious manner. (b)(ii) If the differentiation amounts to discrimination, does it amount to unfair discrimination? If it has been found to have been on a specified ground, then unfairness will be presumed. If on an unspecified ground, unfairness will have to be established by the complainant. The test of unfairness focuses primarily on the impact of the discrimination on the complainant and others in his or her situation. If, at the end of this stage of the enquiry, the differentiation is found not to be unfair, then there will be no violation of s 8(2).

(c) If the discrimination is found to be unfair then a determination will have to be made as to whether the provision can be justified under the limitation clause.

²²⁵ See Currie & De Waal op cit at 216.

the category of adopted children.²²⁶ While steps must be taken to trace the child's parent, guardian or caregiver,²²⁷ this might not yield any results, in which instance, principles similar to those which apply to naturally conceived children group B could apply to abandoned children; for example where information might arise regarding their biological parents after the conclusion of the required investigation by the social worker.²²⁸ Donor-conceived children are denied a right to such process.

With such differential treatment, the threshold for rationality falls to be discussed for treating donor-conceived children, and naturally conceived children group B differently from the adopted children and naturally conceived children group A. In order for the treatment to be rational, it should not be arbitrary or manifest naked preferences.²²⁹ The purpose of this inquiry is not to discuss the merits of the government purpose, or whether there is any better way to achieve the purpose. The test is confined to whether there is a reason for the differentiation connected to a legitimate government purpose.²³⁰ Rationality is the converse of arbitrariness; in deciding whether there is a rational connection, a court must make a value judgement based on the circumstances of each case.²³¹ It has been described as the 'most minimal of Constitutional limitations'²³² and is thus easily satisfied.²³³

The question to be answered then, for the rationality part of the *Harksen* inquiry, is whether there is a rational connection for allowing this information to be withheld from naturally conceived children group B, when it is made available to naturally conceived children group A, and adopted children, while withheld from donor-conceived children.

With naturally conceived children group B, the reason for allowing mothers to withhold the information could be that she has an acrimonious relationship with the father,

²²⁶ Supra.

²²⁷ S 56(2)(d)Children's Act supra, General Regulations Regarding Children supra.

²²⁸ There are many possibilities ie where a person known to the abandoned child, or in the community may know the circumstances regarding the child and being willing at a later stage to divulge the information.

²²⁹ *Prinsloo* supra at para 25.

²³⁰ *East Zulu Motors (Pty) Limited v Empangeni/Ngwezelane Transitional Local Council* 1998 (2) SA 61 (CC) para 24. See also *Jooste v Score Supermarket* 1999 (2) SA 1 (CC), para 17.

²³¹ L Kohn 'The burgeoning constitutional requirement of rationality and the separation of powers: has rationality review gone too far?' (2013) 130(4) *South African Law Journal* at 825.

²³² Kohn op cit at 824.

²³³ The rationality test failed in *Van der Merve v Road Accident Fund* 2006 (4) SA 230 (CC), involving a claim by a spouse married in community of property for damages against her husband when he intentionally knocked her over with his motor vehicle. Under the Matrimonial Property Act 88 of 1984, claims for damages between spouses married in Community of Property were prohibited, while such was permitted for spouses married out of Community. It was held affording spouses in one form of marriage greater protection than spouses in another form of marriage was absurd, and that there was no rational basis for such (paras 54-56).

and does not want any further involvement with him. It may be to cover up marital infidelity and so attempt to protect her marriage. She may have had several sexual partners during the time of conception, and genuinely not know the identity of the father, or be able to remember who the father is, in cases of casual sex, or sexual assault by a stranger. It may also be to protect herself or the child in cases of an abusive partner, or where the child was conceived as a result of rape or incest.²³⁴ For the purposes of this part of the inquiry, the merits of the reasons do not need to be discussed; merely that there is a connection between allowing the mother to withhold the information, and the reasons for such.

Potential fathers may refuse to undergo a paternity test to protect their right to privacy and bodily integrity as held in *YM v LB*.²³⁵ This is not arbitrary, as these are recognised rights, and so allowing a person to refuse to provide submit to such a test bears a rational connection to protection of his rights. In the case of abandoned children, difficulty or impossibility of procuring evidence as to the identity of a biological parent would also be a rational reason for refusal in circumstances where evidence linking him to the child is not forthcoming. The arguments for and against the permissibility of compelling paternity testing, as well as a discussion of the relevant cases will be given under the reasonableness part of the inquiry. For this part of the inquiry, a rational connection will suffice.

The next group to be considered is donor-conceived children. The identity of their donors is recorded upon donation, but disclosure of the identity to any person is prohibited. Thus, if children seek the identity of their biological parents, it is not a matter of requesting the information from their mothers or requesting paternity testing from a man whom the mother has indicated. Thus, different reasons for donor-anonymity may apply and will be discussed below. In the absence of judicial or legislative elucidation on the reasons for donor-anonymity, possible or plausible reasons will have to be assumed. One of these would be to protect a donor's right to privacy in line with the secrecy attaching to the traditional law regarding adoption – changed in modern times to promote openness.²³⁶ It could be argued that since the biological parents of both adopted and donor-conceived children are in similar situations, where they have genetic children, but are not legally parents to such children, where the law protects the rights to privacy of one group, it should also protect the

²³⁴ See TM Young 'Removing the Veil, Uncovering the Truth: A Child's Right to Compel Disclosure of His Biological Father's Identity' (2009) *Howard LJ*, 229-231.

²³⁵ 2010 SA (6) SA 338 SCA, paras 15-16.

²³⁶ See Davel & Skelton op cit at ch 15 p28-29

rights to privacy of the other group.²³⁷ With naturally conceived children group B, however, privacy has been raised in allowing potential fathers to refuse paternity tests; thus protection of privacy is inconsistent in that it protects the privacy of donors, but not biological parents of adopted children, but does at least in part protect the privacy of fathers, as well as the mothers in naturally conceived children group B.

Another reason suggested for reluctance to disclose the identity of a donor is the impact it might have on the child's existing relationship with the non-genetic parent.²³⁸ However, once again since families with adopted children and those with donor-conceived children are in similar positions, and it could be argued that disclosing such information would be a similar concern for both types of families and could not be a rational reason for the differential treatment. This reason has not been raised with any of the other groups of children either. A more plausible reason would be to protect donor supply on the ground that if donor-anonymity were to be done away with, potential donors would be reluctant to donate.²³⁹ This reason is more plausible as it constitutes a major difference between adoption and donor-conception. Parents give their children up for adoption for many different reasons,²⁴⁰ but seldom if ever do donors conceive children with the intention of giving such child up for adoption, and so protecting the supply of adoptive children does not arise. In donor-conception, the purpose is only for conception, and the protection of donor-supply could conceivably be a rational reason for donor anonymity and the differential treatment. Therefore, the rationality requirement is satisfied. The rationality analysis has a very low threshold and is easily satisfied. After rationality has been established, the test for unfair

²³⁷ S 247 (1) (b) of the Children's Act requires that the personal details of biological parents who are giving their children up for adoption be registered. If such parents choose to remain anonymous, such children no longer fall into the category of adopted children, but abandoned children, amounting to desertion of such child. S 1 of the Children's Act defines 'abandoned' as a child who has been 'deserted by the parent, guardian or care-giver'.

²³⁸ See EA Rauscher & MA Fine 'The role of privacy in families created through assisted reproductive technology: Examining existing literature using communication privacy management theory (2012) 4(3) *Journal of Family Theory & Review* 223.

²³⁹ I Turkmendag R Dingwall & T Murphy 'The removal of donor anonymity in the UK: the silencing of claims by would-be parents' (2008) 22(3) *International Journal of Law, Policy and the Family* 294.

²⁴⁰ See JG Dwyer 'First Parents: Reconceptualizing Newborn Adoption' (2008) 37(2) *Capital University Law Review* 293-320. Reasons for a parent giving a child up for adoption may be that the parent is unwilling or unfit to raise them. In none of these situations is the child conceived specifically with the purpose of someone else adopting the child and being given parental rights.

discrimination as set out in *Harksen* follows.²⁴¹ This test for unfair discrimination is the next part of the *Harksen* test, which is prohibited in terms of section 9(3) of the Constitution.²⁴²

(b) Does the differentiation amount to unfair discrimination?

This part of the test involves two stages: first, whether the differentiation amounts to discrimination, and secondly, whether such discrimination is unfair. The Constitution lists grounds²⁴³ which will constitute discrimination if the differential treatment is based on them. If the treatment is based on some other ground, discrimination will have to be established. This is done by considering the impact of the differential treatment on the person.²⁴⁴ It would need to have the potential to impair their human dignity, or ‘affect them adversely in a comparably serious manner’.²⁴⁵ The court has made reference to dignity as the principle in deciding whether there has been discrimination. While the courts have not explicitly defined dignity, but it has been invoked in a range of cases, including corporal punishment, privacy, defamation and socio-economic rights.²⁴⁶ It means the need to recognise the equal worth of every citizen,²⁴⁷ a principle with both physical and psychological dimensions²⁴⁸ and to give each person basic respect.²⁴⁹ Thus, for the differentiation to be discriminatory, it must cause prejudice to a person in some way.²⁵⁰ This stage of the test looks at the impact on the individual.

While many rights are built upon the right to dignity,²⁵¹ where there is an infringement of a person’s dignity, there is discrimination present.²⁵² However, while this could give a

²⁴¹ R Kruger ‘Equality and unfair discrimination: refining the Harksen test’ (2011) *South African Law Journal* 128(3) 486.

²⁴² See IM Rautenbach. ‘Means-end rationality in Constitutional Court judgments’ (2010) 4 *Tydskrif vir die Suid-Afrikaanse Reg* 771. The rationality requirement is related to equality in terms of s 9(1) of the Constitution, whereas unfair discrimination is prohibited in terms of s 9(3).

²⁴³ S 9(3) of the Constitution. They are race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

²⁴⁴ Kruger op cit at 488.

²⁴⁵ *Harksen v Lane* NO 1998 (1) SA 300 (CC), para 53.

²⁴⁶ E Grant ‘Dignity and Equality’ (2007) 7 *Human Rights Law Review* 311.

²⁴⁷ *S v Makwanyane* supra at para 329

²⁴⁸ Grant op cit at 312.

²⁴⁹ Grant op cit at 311.

²⁵⁰ S Woolman *Constitutional Law of South Africa* supra ch.35 p49. Discrimination is described here as ‘a demonstration of immediate harm that flows from the differentiation’. See also Kruger op cit 488, describing discrimination as making prejudicial distinctions between people.

²⁵¹ *S v Makwanyane* supra: ‘The rights to life and dignity are the most important of all human rights and the source of all other personal rights . . . see also para 328.

²⁵² *Harksen* supra. It was not the only case in which dignity was considered to be a deciding factor in determining whether or not there is discrimination. See *Prinsloo* supra: ‘Unfair discrimination . . . principally means treating persons differently in a way which impairs their fundamental dignity’. See also Woolman op cit at 26, where the author states that dignity informs the test for equality at two stages, namely distinguishing differentiation from discrimination, and deciding whether discrimination is unfair or not.

fairly straightforward definition of discrimination as it will always be present if there is an infringement of a person's right to dignity, the definition of dignity is less certain.²⁵³

The right of access to information is legally recognised, and in the specific context of donor-conceived children, has been recognised by the Constitutional Court in the *AB* case to the extent that that the need [for children] to know their genetic origins is important for their 'self-identity and self-respect'.²⁵⁴ The wording chosen by the Constitutional Court is of critical importance. While the right to dignity can be a somewhat abstract concept,²⁵⁵ reference to existing cases is instructive. In *Makwanyane*,²⁵⁶ the court held that the right to dignity entailed people being treated as worthy of respect and concern. In *Khumalo v Holomisa*²⁵⁷ the court held that dignity includes an individual's sense of self-worth.²⁵⁸ In *Le Roux v Dey*²⁵⁹ the court held that dignity relates to an individual's self-respect.²⁶⁰

As stated, the wording of the court in *AB* is of critical importance, as it indicates that where children may not know their biological origins, they are being denied, in the court's words, self-respect. As shown, where a person is being denied self-respect, their right to dignity is being infringed. Therefore, where children are denied a right to know their biological origins, they are being denied their right to dignity.

While a fair amount has already been written above on the interest a child may have in knowing their biological parents, reference will again be made to the case of *YM v LB*.²⁶¹ While the judgment is very brief, it upheld many of the earlier conclusions of the High Court,²⁶² which examined in detail the merits of ascertaining the truth about a child's biological origins. The following extracts from the from the High Court judgment were

²⁵³ Currie & De Waal op cit ch10 251. See also Woolman op cit ch36.2, identifying five definitions of dignity from existing jurisprudence: (a) Individual as an end-in-herself, (b) Equal concern and equal respect, (c) Self-actualisation, (d) Self-governance, (e) Collective responsibility for the material conditions for agency. See the text for an in-depth discussion of these definitions.

²⁵⁴ *AB v Minister of Social Development* supra at para 294.

²⁵⁵ Currie & De Waal op cit ch10, 251.

²⁵⁶ 1995 (3) SA 391 (CC), 328.

²⁵⁷ 2002 (5) SA 401 (CC), 27.

²⁵⁸ Self-worth is defined by the Merriam Webster dictionary as 'a feeling that you are a good person who deserves to be treated with respect'. Dictionary, M.W., 2002 *Merriam-Webster* available at <https://www.merriam-webster.com/dictionary/self-worth>. It is defined in the Collins dictionary as 'respect or a favourable opinion of oneself'. O'Neill, M. and Summers, E (eds) *Collins English Dictionary & Thesaurus*. (2016) Collins. Available at <https://www.collinsdictionary.com/dictionary/english/self-worth>. Thus self-worth synonymous with self-respect.

²⁵⁹ 2011 (3) SA 274 (CC), 138.

²⁶⁰ See also *Hugo* supra at 41 in which the court speaks of the need to treat people with equal dignity and respect.

²⁶¹ 2010 (6) SA 338 (SCA)

²⁶² *LB v YD* 2009 (5) SA 463 (T). LI Schäfer *Child law in South Africa: Domestic and international perspectives* (2011 LexisNexis, 235.

quoted with apparent approval by the SCA, namely that ‘where we come from and who we are, for most people, are within the realm of the sacred’.²⁶³ Furthermore, ‘that it will most often be in the best interests of a child to have any doubts about true paternity resolved and put beyond doubt’.²⁶⁴ Whilst the case related to a dispute over paternity, there is no reason why the same cannot be said for resolving questions of maternity.

This recognises a legal interest a child may have in ascertaining the truth in all aspects pertaining to their biological origins, and that a child may suffer prejudice from being denied an opportunity to enter the ‘sacred’ realm of knowing where he/she ‘comes from’. For any children, including naturally conceived children group B, as well as donor-conceived children and abandoned children, being denied such a legally recognised interest in ascertaining questions about their biological parentage, denies them respect and infringes upon their dignity. Therefore, they suffer prejudice, and the differentiation amounts to discrimination.

The second stage (part (b)) of the test seeks to decide whether such discrimination is unfair. Here again, if the discrimination is on one of the listed grounds, it is presumed to be unfair. If it is on some other ground, unfairness must be shown, by considering ‘the impact on the complainant and others in his or her situation’.²⁶⁵ This seems to be a repetition of the first stage of part (b).²⁶⁶ There is an important distinction, however: a careful reading suggests that in deciding if the discrimination is unfair, in evaluating the impact of not only the complainant, but also others in the same situation, the entire category of people being discriminated against must be considered.

The courts have also stated that patterns of disadvantage must be kept in mind when deciding this.²⁶⁷ The difference seems to be that whereas the first stage of the inquiry involved ‘decontextualized, abstract and mechanical’ formal equality,²⁶⁸ the second stage involves substantive equality.²⁶⁹ It is a contextual inquiry considering the impact on a group, taking into account their history, group disadvantage, socio-economic factors and other

²⁶³ *LB v YD*, para 21.

²⁶⁴ *LB v YD*, para 21. Quoted in *YM v LB 2010* (6) SA 338 (SCA), para 14.

²⁶⁵ *Harksen v Lane NO* 1998 (1) SA 300 (CC), para 54

²⁶⁶ R Kruger ‘Equality and unfair discrimination: refining the Harksen test’ (2011) *South African Law Journal*, 128(3), 489.

²⁶⁷ *Pretoria City Council v Walker* 1998 (2) SA 363 (CC), para 35

²⁶⁸ S Jagwanth ‘What is the Difference-Group Categorisation in *Pretoria City Council v Walker* 1998 (2) SA 363 (CC)’ (1999) 15 *South African Journal on Human Rights* 204

²⁶⁹ Kruger op cit at 489

relevant considerations.²⁷⁰ The second stage means that where applying the first stage of the test could benefit a privileged group then it might worsen existing inequality. Thus, this stage allows for certain forms of discrimination, in order to promote equality in the country by remedying the effects of past discriminatory practices.²⁷¹ Such discrimination is deemed fair discrimination. In deciding whether the discrimination is unfair or not, the court in *Harksen* gave the following non-exhaustive list of factors to be considered.²⁷²

- (i) The position of the complainants in society, and patterns of past discrimination;
- (ii) The nature of the discriminatory provision, and whether the goal sought to be achieved by it is a worthy societal goal;
- (iii) To the extent to which the complainant's rights have been impaired, the impact on his or her fundamental dignity.

In 2013, the United States, Assisted Reproductive Technology (ART) accounted for 1.6% of all donor-conceived children in born that year.²⁷³ While the percentage of births as a result of donor gametes is not given, there are different types of ART treatment, and so it can only be said that the number of births resulting from donor gametes is less than 1.6% of total births.²⁷⁴ South Africa's rate of poverty is markedly higher than that of the United States suggesting less affordability for such procedures. Therefore the figure might be even lower – if not they are still very much a minority group.²⁷⁵ However, since the Regulations Relating to the Artificial Fertilisation of Persons were only gazetted in 2012, those persons cannot be said to be from a group that has been either previously privileged or a victim of past discriminatory practices.

The reasons for denying children a right to know their biological parents discussed under the rationality section of the inquiry will be discussed again, with reference to the

²⁷⁰ Woolman op cit at ch 35 76

²⁷¹ *Brink v Kitshoff NO* (1996) 4 SA 197 (CC), from para 40. See also T Deane . *Affirmative action: a comparative study* (Doctoral dissertation, University of South Africa, 2009) 288-289

²⁷² *Harksen* supra at para 52.

²⁷³ S Sunderam et al *Assisted Reproductive Technology Surveillance – United States 2013*. Available at <https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6411a1.htm>

²⁷⁴ 'Types of ART Cycles – United States 2013', available at https://www.cdc.gov/art/pdf/2013-national-summary-slides/art_2013_graphs_and_charts_final_figure2.pdf.

²⁷⁵ In deciding vulnerability, membership of a minority group is a factor which is considered. See *National Coalition for Gay and Lesbian Equality v Minister of Justice* supra at para 35.

second factor listed in *Harksen* in deciding whether discrimination is unfair, namely whether the goal sought to be achieved is a worthy societal goal.

The first argument against allowing donor-conceived children a right to know their biological parents is that it constitutes an invasion of the donor's privacy. Since this chapter compares donor-conceived children with the other groups of children, it is necessary to discuss the application of the doctrine of privacy for the other groups of children, and decide whether these reasons are applicable to donor-conceived children. For naturally conceived children group A, there is no question of privacy concerns, as the identities of both parents are known to the children. For abandoned children, where the parents' identity cannot be discovered, privacy does not arise as a practical issue, despite legislation requiring attempts being made to locate such parents.²⁷⁶ However, where there is evidence pointing to the possibility of a person being the biological parent of an abandoned child, the same principles discussed below for naturally conceived children group B may be applicable.²⁷⁷ For adopted children, the issue of privacy has not been raised. This is perhaps because the children are allowed access to the adoption register under prescribed conditions, and privacy therefore cannot be considered as more important than the rights of the child to know the identity of the parents.

The issue where privacy has mostly been raised is in respect of naturally conceived children group B, both by the mother, as well by the father.

Therefore, the purpose of the law in protecting the privacy of such individuals, and whether such purpose is applicable to donor-conceived children arises when considering competing interests. The right to privacy has been raised as a factor militating against compulsory paternity tests.²⁷⁸ In the *YM* case however,²⁷⁹ the SCA endorsed the views of the High Court²⁸⁰ that the right to privacy of the potential father should yield to the importance of finding the truth, and that it was in the best interests of the child to resolve any doubts about paternity.²⁸¹ However, that is not to completely negate right to privacy.

²⁷⁶ Children's Act, General Regulations Regarding Children, sections 56(1) and 56(2).

²⁷⁷ The discussion refers repeatedly to fathers refusing paternity testing, as the cases so far only deal with disputed paternity. However, in the cases of abandoned children, the same issues in attempting to compel such fathers to undergo DNA testing may also apply to potential mothers who may object to being compelled to take DNA testing. Wherever 'father' is mentioned in the discussion, the word 'mother' and 'determining maternity' can also therefore be read in.

²⁷⁸ *YM v LB* 2010 (6) SA 338 (SCA), para 15.

²⁷⁹ 2010 (6) SA 338 (SCA), paras 14-15

²⁸⁰ LI Schäfer *Child law in South Africa: Domestic and international perspectives* (2011) LexisNexis, 235. The preceding high court case was *LB v YD* 2009 (5) SA 463 (T).

²⁸¹ *LB v YD* supra at para 23, *YM v LB* supra at para 14.

The court merely held that in instances where it was in the best interests of the child to know, the rights to privacy and bodily integrity might be infringed.²⁸² However, by the failure to elucidate on the best interests of the child, this judgment has created confusion and uncertainty,²⁸³ making it difficult to ascertain the extent to which the right to privacy applies in such a case. It is submitted, that the Children's Act standards of best interests of the child must be applied.²⁸⁴ The earlier High Court case of *LB*²⁸⁵ held that it was generally in the best interests of the child to know the identity of his or her father, and this would undoubtedly also apply to the identity of the mother, and this view has been endorsed by certain authors.²⁸⁶

The question then arises as to when it is not in the best interests of the child to find the truth. Section 7(1) (l) of the Children's Act²⁸⁷ notes the need to protect a child from physical or psychological harm, including maltreatment, abuse, neglect, exploitation, or degradation, or perhaps not listed in the Act, where the child was conceived as a result of sexual assault. Thus, it is submitted that only where it is undesirable to make the father's identity known, as this would cause some sort of harm or suffering to the child, would it be permissible to withhold the identity of the father. This is done to protect the child, rather than the father's right to privacy, and it is submitted that the father's right to privacy is not in practice a real consideration in this context.

However, privacy rights have also been used as an argument to allow mothers to withhold the identity of the father. It is unclear how privacy rights of the mother may apply, although some authors have suggested that this would be to save herself from having to divulge potentially embarrassing information.²⁸⁸ However, it cannot reasonably be said that a child should be denied such a right merely to save the mother embarrassment.²⁸⁹ It could also be argued that the mother prefers to care for the child without the father, with whom she has either an acrimonious relationship or only a casual sexual relationship.²⁹⁰ These factors could fall within her right to privacy; however, in both instances the mother is

²⁸² *YM v LB* supra at paras 15, 16.

²⁸³ M Buthelezi 'A missed opportunity to settle the law on DNA testing in paternity disputes – *YD* (now M) v *LB* 2010 6 SA 338 (SCA): case' (2011) 32(2) *Obiter* 480-488.

²⁸⁴ 38 of 2005.

²⁸⁵ *LB v YD* supra.

²⁸⁶ Schäfer op cit at 235.

²⁸⁷ 38 of 2005.

²⁸⁸ See TM Young 'Removing the Veil, Uncovering the Truth: A Child's Right to Compel Disclosure of His Biological Father's Identity' (2009) 53 *Howard Law Journal* 217.

²⁸⁹ See Young, op cit at 233.

²⁹⁰ Young op cit at 229.

denying her child a recognised right, simply because of her own desires. It is doubtful whether this could be a reasonable limitation on the child's right to determine his or her biological father.

To summarise then, with adopted children, the right to privacy is not mentioned at all regarding the biological parents. With abandoned children, and naturally conceived children group B, while the father's or mother's right to privacy has been judicially recognised, it is given less weight than the child's interest in determining the identity of the father or mother. For naturally conceived children group B, the arguments for the mother's privacy only extends to saving her from divulging embarrassing information, or to save her from having to associate with a person against her wishes. I suggest that saving a mother from having to divulge embarrassing information does not outweigh the right of a child to know his or her biological parents, and that her own personal desires are not be sufficient to deny a child the right. However, the issue is not settled and calls for a judicial imprimatur –even if only to serve as a limitation on the child's right.

The reasons argued for allowing a mother to withhold such information, even if they carry the day, are not applicable to abandoned children, as they do not know the identity of either parent, and so are not attempting to procure information from one parent as to the identity of the other.

These reasons are not applicable to donor-conceived children either, as such children are not conceived as a result of a sexual relationship, and so there would be no such embarrassing information regarding sexual history to save the mother, or biological mother from embarrassment. However, infertility may be a potentially embarrassing fact, albeit of a different nature, which the parents wish to keep private, and which may cause them to withhold the fact that a child is donor-conceived.²⁹¹ Neither is there usually an existing relationship between the commissioning parents and the donors.²⁹² It is not clear from the regulations relating to the artificial fertilisation of persons whether a couple may approach a fertility clinic with a known donor. However, if this is so, such donor would probably be carefully selected by the commissioning parents. Further, many commissioning parents would not know the donors personally, and so the likelihood of an acrimonious relationship

²⁹¹ VL Pi 'Regulating sperm donation: why requiring exposed donation is not the answer' (2009) 16 *Duke Journal of Gender Law and Policy* 397.

²⁹² According to regulation 19 of the National Health Act 61 of 2003, Regulations Relating to the Artificial Fertilization of Persons, 'no person shall 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'.

with the donor is very slim or would only be present in a select few cases of gamete donation. Where there is the possibility of such a relationship, it is doubtful whether this is sufficient to deprive the child a right to know the identity of his or her biological parents. Indeed, there is no mention of this regarding adopted children, where the possibility of an acrimonious relationship between the biological parents and adoptive parents is equally present. Thus, the law relating to adopted children presents an instance where there has not been a legal barrier to deny a child a right to find the identity of his or her biological parents.

A mother may withhold the identity of the father to protect the child in instances where it is not in the best interests of the child to know the identity of the biological father.²⁹³ However, with gamete donors, according to section 8 of the regulations relating to the artificial fertilisation of persons,²⁹⁴ the family history of a donor must be recorded.²⁹⁵ A donor must also undergo an evaluation of his or her psychological suitability to donate.²⁹⁶ Thus, there is a very low likelihood that a donor could be a person who would cause harm to a child, and if a donor is such a person, it would probably be known beforehand.

While some of these reasons for limiting the rights of children to know their biological origins may not be applicable to donor-conceived children, there are some reasons which could be applicable. There may be an existing relationship between a known donor and the commissioning parents which has turned acrimonious, or an instance where the parents wish to save themselves from having to divulge their infertility. Whether these reasons would be sufficient to limit this right would have to be tested in court. Where they may be held to be justifiable limitations, they would serve as limitations on the right of the children to know their biological origins, rather than reason to deny the right in all circumstances.²⁹⁷ Thus, they should serve as limitations to the right of donor-conceived children to know their biological origins, rather than as a reason not to extend the right.

²⁹³ The discussion above, considered a child's right to know his or her biological origins in light of the court's judgment in *YM v LB* that it is generally in the best interests of a child to know his or her biological parents. The question as to when it is not in the best interests of the child to know his or her biological parents was addressed in light of section 7(1)(l) of the Children's Act requiring a child to be protected from physical or psychological harm. It is suggested that where the child was conceived as a result of rape or sexual assault, this may also have the potential to cause psychological harm to the child. See also Young op cit 231.

²⁹⁴ National Health Act 61 of 2003, Regulations Relating to the Artificial Fertilisation of Persons.

²⁹⁵ S 8(1)(a)(iii).

²⁹⁶ S 8(d).

²⁹⁷ S 36 of the 1996 Constitution permits the limitation of rights in defined situations.

Therefore, since donor conceived children are the only group of children who are denied the right to know who their biological parents are, the possible reasons for denying this right, which is unique to this group, must be questioned.

On the issue of discrimination, the goal sought from the rationality requirement above, most plausibly would be to preserve gamete donor supply. The goal then would seem to be to protect the parents' rights to commission egg or sperm for the purposes of reproduction at the expense of the child's right to know their origins. The arrangement made by the parents and fertility clinics seek to deny the child the right. Some commentators have argued that this should not be permissible without allowing the child a voice in the matter.²⁹⁸ However, as no child ever has a say about the circumstances in which they were born, this argument may be academic.

In jurisdictions where there is donor anonymity, there is a larger supply than jurisdictions where anonymity has been abolished. Supply decreased in jurisdictions where anonymity was abolished;²⁹⁹ however, after a short period of time, the levels of donation usually increased again.³⁰⁰ It has been argued that new methods of commissioning donors, and a new type of donor may be willing to donate if anonymity were done away with,³⁰¹ and as such the impact on supply would not be detrimental.³⁰²

The third factor listed in *Harksen* in deciding whether or not discrimination is unfair is 'whether [the discrimination] has led to the impairment of their fundamental human dignity or constitutes an impairment of a comparably serious nature'.³⁰³ As argued above the discrimination has infringed the fundamental dignity of a donor-conceived child, and they have been prejudiced in a significant way by not being allowed to enjoy the right of access to information concerning their genetic origins. What will be considered now is the extent to which their dignity has been infringed.

²⁹⁸ N Cahn 'Do Tell! The Rights of Donor-Conceived Offspring' (2013) 42 *Hofstra Law Review* 1078. See also M Dennison 'Revealing your sources: the case for non-anonymous gamete donation' (2007) 21 *JL & health* 17.

²⁹⁹ See Liza Mundy, 'Shortage? What Shortage? How the sperm donor debate missed its mark' *The Guardian*. Available at <https://www.theguardian.com/commentisfree/2010/sep/19/sperm-donors-shortage-market-forces> discussing the accuracy of the reported drop in donors in the UK.

³⁰⁰ M Malone 'Gamete Donor Anonymity in Canada: An Overview of Potential Policy Solutions' (2017) 38 *Windsor Review of Legal & Social Issues* 84.

³⁰¹ N Cahn 'Necessary subjects: the need for a mandatory national donor gamete databank' (2009) 12, *DePaul Journal of Health Care Law* 216.

³⁰² An in-depth discussion on the impact on donor supply and the potential types of donors will be given in a later chapter.

³⁰³ *Harksen* supra at para 52.

In *YM v LB*,³⁰⁴ the court, in considering the pursuit of a child to discover the identity of his or her biological parents, quoted with approval the following line from the preceding High Court case,³⁰⁵ ‘where we come from and who we are, for most people, are questions within the realm of the sacred’.³⁰⁶ While the word sacred is often associated with religion,³⁰⁷ it also has a secular meaning. Something sacred is too valuable to be interfered with, is sacrosanct³⁰⁸ and entitled to reverence and respect³⁰⁹ or secured by a sense of justice against any defamation, violation or intrusion,³¹⁰ or considered too important to be changed.³¹¹ In a legal sense, the Constitution has been described as a sacred text.³¹²

Applying these meanings to the court’s interpretation regarding a child’s attempt to find out the identity of his or her parent and knowing where the person comes from falls within the realm of the sacred; being afforded the ability to find this information is too valuable to be interfered with, entitled to reverence and respect and secured against violation or intrusion. A right is something which must be respected, promoted or fulfilled. If being able to find out where one comes from is something which has been judicially recognised as something which is too valuable to be interfered with and entitled to reverence, this would suggest elevation to a right, the denial of which would surely indicate a fundamental infringement of such a child’s right to dignity.

Thus, it is submitted that the goal of preserving donor supply would, when balanced against this right, be outweighed, especially because may still be a sufficient supply anyway. The unfairness of the discrimination must be decided with reference to the extent to which a person’s dignity has been infringed. The court’s pronouncement cited above indicates that denying this right constitutes a fundamental infringement of their dignity, constituting unfair discrimination. Therefore, it is submitted that not allowing donor-conceived children this right, when some other children, such as adopted children, are allowed such access to the information, is unfair, and this then constitutes unfair discrimination.

³⁰⁴ 2010 (6) SA 338 (SCA).

³⁰⁵ *LB v YD* supra at 463.

³⁰⁶ Para 14.

³⁰⁷ A search conducted on both Jutastat and HeinOnline using the term ‘sacred’ brought up articles which were about religion or mentioned it. Dictionary definitions brought up variations like ‘considered to be holy and deserving of respect, especially because of a connection with God’, or ‘connected with religion’, Dictionary, C., (2008) *Cambridge Advanced Learner’s Dictionary*.

³⁰⁸ Dictionary, Oxford English (2015) OED Online.

³⁰⁹ Dictionary, Merriam-Webster (2008) ‘sacred’. *Cambridge Advanced Learner’s Dictionary*.

³¹⁰ M O’Neill M & E Summers eds, 2016. *Collins English Dictionary & Thesaurus*.

³¹¹ *Cambridge Advanced Learner’s Dictionary*.

³¹² PG Danchin ‘From parliamentary to judicial supremacy: reflections in honour of the constitutionalism of Justice Moseneke’ (2017) 1 *Acta Juridica* 39.

(c) *Can the unfair discrimination be justified under the limitation clause?*³¹³

This inquiry involves a two-stage approach: first to determine whether there is an existing right, which has been infringed; and second to determine if the limitation is justifiable.³¹⁴ This involves a proportionality exercise, weighing the purpose of the limitation or provision against the extent of the infringement on equality.³¹⁵ This has been criticised as being a near repetition of the second stage of the *Harksen* test in determining unfair discrimination.³¹⁶ In *Satchel v President of the Republic of South Africa*,³¹⁷ the court declined to engage in an analysis of this stage of the inquiry, and decided the case on the basis of unfair discrimination being present, so that the provisions were then not justifiable in terms of section 36 of the Constitution.³¹⁸

Indeed, from the discussion on unfair discrimination, it was argued that donor-conceived children had a right to know their genetic origins when compared with the other groups of children, and that such right was infringed by the provisions in the regulations.³¹⁹ The reason of diminished donor supply was argued to be insufficient to outweigh the children's right to know their biological parents. It was also argued that reasons for protecting the right to privacy of other groups were not necessarily applicable to donor-conceived children, and that such reasoning was inconsistent. It was also argued that reasons for withholding identity to protect the child from a harmful parent was covered by provisions in the regulations relating to the artificial fertilisation of persons³²⁰ preventing the type of person who would cause harm to a child from donating.

Even where these reasons are applicable to the other groups of children, they serve as limitations on their rights rather than reason to deny the right completely. Thus, in the case

³¹³ S 36 of the 1996 Constitution:

Limitation of rights.

(1) The rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including— (a) the nature of the right; (b) the importance of the purpose of the limitation; (c) the nature and extent of the limitation; (d) the relation between the limitation and its purpose; and (e) less restrictive means to achieve the purpose.

(2) Except as provided in subsection (1) or in any other provision of the Constitution, no law may limit any right entrenched in the Bill of Rights.

³¹⁴ Currie & De Waal op cit at 153-154.

³¹⁵ *Harksen* supra at para 52.

³¹⁶ R Kruger 'Equality and unfair discrimination: refining the Harksen test' (2011) 128(3) *South African Law Journal*, 503-505. See also Woolman op cit ch 35 p81-82.

³¹⁷ *Satchwell v President of the Republic of South Africa*, 2002 (6) SA 1 (CC), para 26-27

³¹⁸ Woolman op cit at ch34 p34-35, where the author argues that the considerations for unfair discrimination under s 9 are identical to those in deciding limitations under s36.

³¹⁹ National Health Care Act 61 of 2003, Regulations Relating to the Artificial Fertilisation of Persons.

³²⁰ Ss 8(1)(a)(iii) and 8(c) National Health Act, Regulations Relating to the Artificial Fertilisation of Persons.

of donor-conceived children, any limitations on their right to know their biological parents should not be sufficient reason to deny them the right in all circumstances.

It was argued then that such provision was not justifiable. An examination of jurisprudence indicates what additional considerations must be considered. Unfair discrimination was held to be justified under the section 36 limitation inquiry only in a case involving the reasons were for rates and service charges.³²¹ However the regulations already have a register of donors and commissioning parents, eliminating any extra administrative burden on the state. For the donor-conceived offspring to realise their right, they would need only to be given access to the register.

Therefore, in considering the right of access to information, the right to equality and applying the *Harksen* test, it is submitted that the law is unfairly discriminates against donor-conceived children and thus infringes their right to equality and of access to information, compared to the other groups of children.

³²¹ *Lotus River, Ottery, Grassy Park Association v South Peninsula Municipality* 1999 (2) SA 817 (C).

CHAPTER III

DIRECT-TO-CONSUMER GENETIC TESTING AND ITS IMPACT ON DONOR-ANONYMITY

(a) What is Direct-to-Consumer Genetic Testing?

In its most basic form, where traits are passed from one generations to another, these are called genes,³²² and are what give us our inherited characteristics from parents, such as height, eye colour, or shape of body parts.³²³ Genes consist of DNA (deoxyribonucleic acid)³²⁴ and form part of the chromosomes which are located in the nucleus of any human cell.³²⁵ Thus, DNA is described as the fundamental building blocks of life, by directing cellular function,³²⁶ giving instructions for biological functioning.³²⁷ Knowing the complete sequence of a person's DNA will tell them everything that there is to know about them.³²⁸ In 1990, the Human Genome Project commenced by the U.S. Department of Energy and the National Institutes of Health, which had as its purpose, amongst other things, to 'identify the approximately 20 500 genes in human DNA', and which completed its work in 2003.³²⁹ Humans share 99.9% of their genetic information; however, the 0.01% difference in their

³²² United States. Congress. Office of Technology Assessment, 1988. *Mapping our genes: the genome projects: how big, how fast?* Congress of the US, Office of Technology Assessment: For sale by the Supt. of Docs., USGPO, 1, 3.

³²³ J Beckwith 'Foreword: the human genome initiative: genetics' lightning rod' (1991) 17, *American Journal of Law & Medicine* 2.

³²⁴ United States. Congress. Office of Technology Assessment, 1988. *Mapping our genes: the genome projects: how big, how fast?* Congress of the US, Office of Technology Assessment: For sale by the Supt. of Docs., USGPO ('Mapping our genes'), 1, 3

³²⁵ CM Howles 'Genetic engineering of human FSH (Gonal-F®)' (1996) 2(2), *Human Reproduction Update*, 173.

³²⁶ ('Mapping our genes') 1, 3.

³²⁷ K Spector-Bagdady & Pike Consuming genomics: regulating direct-to-consumer genetic and genomic information. 2013 92 *Nebraska Law Review* 684.

³²⁸ Beckwith op cit at 1.

³²⁹ Other purposes of this project were to:

- *determine* the sequences of the 3 billion chemical base pairs that make up human DNA;
- *store* this information in databases;
- *improve* tools for data analysis;
- *transfer* related technologies to the private sector; and
- *address* the ethical, legal, and social issues (ELSI) that may arise from the project (original emphasis).

This project was also carried out with assistance from the Wellcome Trust in the UK, with contributions from Japan, France, Germany, China and others.

Human Genome Project Information Archive. Available at

https://web.ornl.gov/sci/techresources/Human_Genome/index.shtml

genetic information gives significant variation, which explains the differences and diversities between individuals or populations.³³⁰

Since a person's DNA contains coding for all aspects of their biological structure, it can be used to test for physical traits and health risks.³³¹ Genetic analysis began in 1956, when scientists were able to identify that a normal human cell contains 46 chromosomes, and shortly thereafter began identifying chromosomal abnormalities such as trisomy 21 in Down syndrome.³³² The next several decades saw the development of genetic testing to diagnose several well-known syndromes.³³³ At the beginning of the Human Genome Project, genetic testing was only able to identify 100 specific disease-causing genes, although this number has continued to grow rapidly since its completion.³³⁴ The first genetic testing was only accessible to patients through their healthcare providers, by which genetic material was collected, tested, and the result provided to the patient.³³⁵ Genetic testing has evolved significantly in the last decade or more, with direct-to-consumer genetic testing now available. These tests may be ordered over the internet or purchased at a pharmacy, and involve a sample collection kit for collecting a biological sample of the person to be tested,³³⁶ which is returned to the test provider who then delivers the results to the customer. Direct-

³³⁰ Presidential Commission for the Study of Bioethical Issues, *Privacy and Progress in the Whole Genome Sequencing* (2012), available at

https://bioethicsarchive.georgetown.edu/pcsbi/sites/default/files/PrivacyProgress508_1.pdf

³³¹ J Cacchio 'What You Don't Know Can Hurt You: The Legal Risk of Peering into the Gene Pool with Direct-to-Consumer Genetic Testing' (2018) *University of Missouri School of Law Review* 87 222

³³² Trisomy 21 is a disorder where a child is born with an extra copy of chromosome 21 and causes birth defects which include learning problems, distorted facial features, and possibility of heart defects as well as problems with vision and hearing. See 'Down Syndrome (Trisomy 21) in Children' *Stanford Children's Health*, available at <https://www.stanfordchildrens.org/en/topic/default?id=down-syndrome-trisomy-21-90-P02356>

See also A Durmazet al 'Evolution of genetic techniques: past, present, and beyond' (2015) *BioMed Research International*.

³³³ MR Dohn 'Personal Genomics and Genetic Discrimination: Is Increased Access a Good Thing' (2017) 45 *Western State University Law Review* 110.

³³⁴ K Spector-Bagdady & E Pike 'Consuming genomics: regulating direct-to-consumer genetic and genomic information' (2013) 92 *Nebraska Law Review* 686.

³³⁵ S Slokenberga . 'Direct-to-consumer Genetic Testing: changes in the EU Regulatory Landscape' (2015) 22(5) *European Journal of Health Law* 465.

³³⁶ Collecting this sample is as simple as providing the direct-to-consumer testing company with saliva in a tube provided, and then collecting results on their website three to five weeks later via an online account. See 'How it Works, 23andMe'. Available at <https://www.23andme.com/en-int/howitworks/>

to-consumer genetic testing offers, *inter alia*, health testing,³³⁷ ancestry,³³⁸ genetic relatedness,³³⁹ athletic ability,³⁴⁰ child talent,³⁴¹ surreptitious testing³⁴² and matchmaking.³⁴³

Since direct-to-consumer genetic testing has the potential to impact on policy arguments involving donor-anonymity, the impact of direct-to-consumer genetic testing will now be discussed. Direct-to-consumer genetic testing in South Africa remains under-regulated,³⁴⁴ with a much smaller market than in countries such as the United States. However, since many of the tests in the U.S. can be purchased online,³⁴⁵ and the tests are carried out there, much of the U.S. regulation will apply. Therefore, much of the discussion will focus on foreign research and regulations. Indeed, any information uploaded on to a database, would be uploaded on to the databases of those companies.

(b) The Right to Have Access to Medical and Health Information

Debate often centres on whether gamete donors should remain anonymous against the interest of donor-conceived children knowing family medical and health issues. One author has argued that since donor-conceived children only know one half of their genetic family, they may only have access to that part of their medical history. The same author has

³³⁷ This includes carrier testing, which allows individuals to know whether they have a heightened risk of a future child being affected by an illness or disability, as well as nutrigenetic testing, which provide personalised programs for diet, exercise and overall wellness, and genetic predisposition to certain diseases and probability of developing certain diseases in the future. See Spector-Bagdady & Pike *op cit* at 689

³³⁸ Ancestry testing involves giving individuals information about their ancient origins and ethnicity in both their paternal and maternal lines. It also includes finding others to whom an individual may be related, known as the ‘family finder’ function, and can lead to discoveries including unknown siblings or false paternity.

³³⁹ This for paternity and maternity testing, including pre-natal paternity testing.

³⁴⁰ Including claims about ideal training to fit a person’s individual genetics. However, there has been doubt raised as to the predictive value of these tests.

³⁴¹ This is to determine talent outside athletics. Here again, there is doubt as to the predictive value of such tests, as well as concerns as to allowing a child to consent to genetic testing.

³⁴² Also known as ‘infidelity testing’. It is doubtful as to whether these tests would be legal as consent is a relevant and serious concern in carrying out any DNA testing.

³⁴³ In order to find compatibility between an individual’s personality traits and a potential partner’s personality traits, as determined by their genetics. For an in depth discussion of these types of testing, see generally AM Phillips ‘Only a click away—DTC genetics for ancestry, health, love... and more: A view of the business and regulatory landscape’ (2016) 8 *Applied & translational genomics* 16-22.

³⁴⁴ There remain no regulations in South Africa on direct-to-consumer genetic testing, only research recommending that direct-to-consumer genetic testing be regulated. See generally MS Pepper et al ‘ASSAf consensus study on the ethical, legal and social implications of genetics and genomics in South Africa’ (2018) 114(11-12) *South African Journal of Science* 1-3. See also Greenberg et al ‘Direct-to-consumer genetic testing: to test or not to test, that is the question: forum-clinical practice’ (2013) 103(8), *African Journal of Health Professions Education* 510-512 for more specific recommendations as to what form the regulations should take.

³⁴⁵ A simple search on *Amazon.com* brings results from various companies offering these tests, with shipping being available to South Africa. There are not many direct-to-consumer genetic tests available in South Africa, and they tend to be rather limited in what they offer, focusing mainly on paternity testing, ancestry or health, and many cost more than ordering the tests from the U.S., including their shipping costs. Thus, South Africans can get a broader range of tests at a lower price from U.S. companies.

described it as not knowing what may be hidden in their genes, or not knowing what they may pass to their children.³⁴⁶ In general healthcare patients are required to provide details of the health history of their families, something which a donor-conceived child, or person is unable to do.³⁴⁷

A more pressing concern is the risk of inheriting a significant genetic condition, which can be detected and treated by early screening, preventing misdiagnosis or late diagnosis. Genetics plays an increasing role in the diagnosis and treatment of disease.³⁴⁸ Indeed, in most chronic diseases, including cardiovascular disease, diabetes, certain cancers asthma and osteoporosis, family history has been shown to be a significant risk factor; heart disease, hypertension, strokes or diabetes often happen within families where there is a history of cardiovascular disease.³⁴⁹ Family history is an important factor in enabling early diagnosis and treatment of even chronic diseases.³⁵⁰ It can be even be used to determine health risk and impact on lifestyle choices such as weight management and smoking status.³⁵¹

However, there are several arguments suggesting that family history may not be essential ie it make not be an accurate predictor of ill health. Studies conducted on accuracy of family history in healthcare have varied across disease types, and even within the same type of diseases. Generally the limited number of studies on the accuracy of a family history of healthcare does not admit a proper conclusion.³⁵² Further, there is evidence to suggest access to family history may not affect risk prediction and prevention. Where people have knowledge of increased risk of disease based on their family history, evidence points to resistance to change with no beneficial effect on their health-related behaviours.³⁵³

Another factor is the extent to which individuals know their family health histories. In order for it to be useful, individuals must have and provide accurate family health history

³⁴⁶ A Ravelingien V Provoost & G Pennings. Donor-conceived children looking for their sperm donor: what do they want to know?' 2013 5(4), *Facts, views & vision in Obstetrics, Gynaecology and Reproductive Health* 259.

³⁴⁷ F Kelly 'Is It Time to Tell: Abolishing Donor Anonymity in Canada' (2017) 30 *Canadian Journal of Family Law* 188.

³⁴⁸ Dennison op cit at 14.

³⁴⁹ Yoon et al 'Can family history be used as a tool for public health and preventive medicine?' (2002) 4(4) *Genetics in Medicine* 304.

³⁵⁰ Yoon et al op cit at 305.

³⁵¹ See generally L Claassen et al 'Using family history information to promote healthy lifestyles and prevent diseases; a discussion of the evidence' (2010) 10(1) *BMC Public Health* 248.

³⁵² AO Berg et al 'National Institutes of Health State-of-the-Science Conference Statement: family history and improving health' (2009) 151(12) *Annals of Internal Medicine* 875.

³⁵³ I De Melo-Martín 'Lack of Access to Genetic-Relative Family Health History: A Health Disparity for Adoptees?' (2016) *Bioethics* 16 (12) *The American Journal of Bioethics* 44.

information. However, active collection of this information is usually infrequent or incomplete,³⁵⁴ and as such, medical practitioners have difficulty with the reliability of such information.³⁵⁵ Individuals may simply not tell relatives about all of their health issues, as it is conceivable that where there are chronic issues such as hypertension or high cholesterol, or even diabetes, an individual could deem it unnecessary to divulge details of these to family members. Often parents simply lack or fail to disclose relevant information, or in the case of more serious diseases where there may be stigmatising consequences, parents may actively choose not to divulge information about it to their children.³⁵⁶ With more serious illnesses, individuals may not understand what exactly what a family health history entails, or the type of information required to make an adequate family health history.³⁵⁷ Even where an individual may have this information, he or she may simply not share it.³⁵⁸

By comparison, where a person wishes to become a gamete-donor, section 7(i) of the regulations relating to the artificial fertilisation of persons³⁵⁹ requires that such person be questioned as to his or her family history. Such family history specifically includes any possible genetic condition or carrier status and mental illness – including that of close family members including a child, brother or sister and parent or grandparent. In terms of section 8(a)(iii), such information is stored in the gamete donor's file, and in terms of section 8(2)(b), is made known to the recipient of the gamete. It can be argued that, this places the donor-conceived child in a more desirable position than a naturally conceived child, as there is an active duty on the donor, who is a biological parent, to provide comprehensive family history health information, whereas with naturally conceived children there is not.

In this regard, a search has been conducted across several sperm and egg donor banks, foreign South African, with health and genetic profiles annexed, in order to ascertain from a practical standpoint what information could be available to donor-conceived children.³⁶⁰

³⁵⁴ AF Goergen et al 'What you don't know: improving family health history knowledge among multigenerational families of Mexican origin' (2016) 19(2) *Public Health Genomics* 94.

³⁵⁵ S Daelemans et al 'The use of family history in primary health care: a qualitative study' (2013) *Advances in preventive medicine* 6.

³⁵⁶ ID Melo-Martín op cit at 31.

³⁵⁷ JN Lim & J Hewison 'Do people really know what makes a family history of cancer?' (2014) 17(6) *Health Expectations* 822.

³⁵⁸ M Fuller et al 'Primary Care Providers' Responses to Patient-Generated Family History' (2010) 19(1) *Journal of Genetic Counseling* 91.

³⁵⁹ National Health Act 61 of 2003, Regulations Relating to the Artificial Fertilisation of Persons.

³⁶⁰ Profiles from Aevitas sperm bank (SA), and two foreign sperm banks, the California Cryobank and Cryos International have been annexed to show what information may be available to a donor-conceived child. While this is not intended as an exhaustive or definitive list, it shows that a wealth of genetic and health information may be available to a donor-conceived child's parents.

Donor-conceived children can potentially have comprehensive family medical histories available from not only their donor, but family members of their donors, who in turn are extended family of the donor-conceived children.

Donor profiles obtained from the California Cryobank appears to have the most comprehensive information available of the donor profiles obtained from select cryobanks. Comprehensive genetic tests screen for 261 diseases in addition to a family medical history chart including the donor, the donor's parents, siblings, grandparents, aunts, uncles and cousins, and lists numerous cardio-vascular, blood, respiratory, skin, gastro-intestinal, renal, genital/reproductive, metabolic/endocrine, neurological, mental health, muscles/bones/joints, sight/sound/smell and several other conditions.

The least comprehensive information available from donor profiles obtained was from Aevitas sperm bank, based in South Africa. Nevertheless, information included an indication of whether or not the donor, or the donor's parents, grandparents or siblings had suffered from a list of 41 conditions, together with details of the condition if present.

Cryos International makes available a summary of results of blood tests, and indicates the presence of infectious diseases as well hereditary diseases.³⁶¹

In many instances, donor-conceived children may have a far more comprehensive knowledge of their family health history, as there is an active duty to be provided with information from the biological donor parent and also family members, going back to grandparents. Donor-conceived children may be provided with comprehensive medical histories from their donors, as well as the extended family, and even results of genetic DNA tests of their donors indicating the possible existence of many hereditary diseases.

As shown above, family health history even among naturally conceived children can be vague and information is often withheld. As such, naturally conceived children may be worse off than donor-conceived children, and donor-conceived children do not seem to be more significantly prejudiced than naturally-conceived children in any way when it comes to family health history.

Indeed, donor-conceived children are likely to have fewer genetically carried diseases, as potential donors are often screened by fertility clinics, and people carrying genetic

³⁶¹ See also 'Screening of Sperm Donors', *Cryosinternational.com* available at <https://www.cryosinternational.com/en-gb/dk-shop/private/about-sperm/screening-of-sperm-donors/>

mutations associated with disease are then disqualified from donating. Thus, there is very little chance they will inherit serious genetically hereditary diseases from their donors.³⁶²

To obtain early diagnosis, treatment or screening, what is really required is knowledge of potential diseases which such person may carry in his or her genes. As such, in obtaining knowledge of family health history, a person is in effect trying to ascertain knowledge about what may be in his or her genes. Thus, since the introduction of direct-to-consumer genetic testing, the whole argument as to whether family health history is required for adequate medical care becomes redundant. A person may simply purchase a kit, and send in a DNA sample for analysis, thereby having his or her genome decoded.³⁶³ This will then enable him or her to have a comprehensive and concrete knowledge of what his or her genes contain, including what potential diseases, or elevated risk factors may be contained in his or her genes.³⁶⁴ I suggest that this is more desirable than possessing a family health history as it removes an element of doubt as to what genes may or may not have been inherited by such person, thereby allowing a specific plan as to lifestyle, and what diseases to watch out for. It further allows early detection and proper diagnosis more easily than knowledge of a person's family health history.

³⁶² I De Melo-Martín 'How best to protect the vital interests of donor-conceived individuals: prohibiting or mandating anonymity in gamete donations?' (2016) 3 *Reproductive Biomedicine & Society Online* 104.

³⁶³ I De Melo-Martín 'The ethics of anonymous gamete donation: is there a right to know one's genetic origins?' (2014) 44(2), *Hastings Center Report* 31.

³⁶⁴ Direct-to-consumer testing does not give an exhaustive list of every risk a person carries in his or her genes. In the early 2000s, companies undertook to map hundreds of thousands of genetic variants across an individual's genome, and would then estimate their disease risk for dozens of diseases. However, in 2013 the US Food and Drug Administration prohibited this particular service as customers believed they were at risk for certain diseases and sought inappropriate treatment. For a period of time, direct-to-consumer genetic testing was only available to provide ancestry and genetic relative information. Then in 2017, the Food and Drug Administration authorised direct-to-consumer tests to provide information on an individual's genetic predisposition to certain conditions to facilitate proper lifestyle choices or a medical check. It only permitted information on 10 conditions, Parkinson's disease, late-onset Alzheimer's, celiac disease, alpha-1 antitrypsin deficiency, early-onset dystonia, factor XI deficiency, Gaucher disease type 1, glucose-6-Phosphate dehydrogenase deficiency, hereditary hemochromatosis and hereditary thrombophilia. Then in 2018, the body permitted information on 3 BRCA1/BRCA2 gene mutations for breast or prostate cancer in men, and breast or ovarian cancer in women. The market is sure to continue to develop, allowing regulation to allow more health information to be released. See A Hoglund-Shen 'Direct-to-Consumer Genetic Testing, Gamete Donation, and the Law' (2017) 55(3) *Family Court Review* 475; see also generally MA Allyse, et al 'Direct-to-consumer testing 2.0: emerging models of direct-to-consumer genetic testing' (2018) 93(1) *Mayo Clinic proceedings* 113-120). Elsevier; US Food and Drug Administration. 'FDA allows marketing of first direct-to-consumer tests that provide genetic risk information for certain conditions'(2017) available at <https://www.fda.gov/news-events/press-announcements/fda-allows-marketing-first-direct-consumer-tests-provide-genetic-risk-information-certain-conditions>

(c) The ability to track relatives using direct-to-consumer genetic testing

The most popular uses for direct-to-consumer genetic testing are for ancestry and genetic relatedness. These include the ability to test for paternity, maternity, identification of grandparents and siblings, as well as allowing individuals to compile family trees and search for related family members.³⁶⁵ In simple terms, because family members share DNA, an individual will share 50 per cent of the DNA of each parent, as well as 50 per cent of the DNA of each sibling. Such individual will also share 25 per cent of DNA with half siblings, each grandparent and uncle/aunt, roughly 12 per cent with cousins, six per cent with first cousins once removed, three percent with second cousins and so forth. A direct-to-consumer genetic test has the ability to show relatedness with another person, as well as the degree of relatedness.³⁶⁶ While there are different type of DNA testing, tests are available to assist in determining a male line of ancestors, and others to assist in following the maternal line.³⁶⁷

An individual using direct-to-consumer genetic testing to locate relatives will upload the results of a test on to a database website owned by one of several companies.³⁶⁸ These websites then have a feature, sometimes called DNA relative matching, which allows the individual to know whether there is another person on the same database who is a genetic relative to them. A person who enters their DNA profile on one of these databases is able to locate a genetic relative who is related within six generations, or up to a fourth cousin.³⁶⁹ In one study, it was estimated that about 60 per cent of individuals in the United States of European descent would be able to be identified through finding a relative on one of these databases.³⁷⁰ Although it took considerable work in the study to map a family tree in order to locate specific individuals,³⁷¹ it was estimated that where there is a database which covers only two percent of a specific population group, any individual within that group would be

³⁶⁵ Phillips op cit at 18.

³⁶⁶ D Adams. & S Allan 'Building a Family Tree: Donor-Conceived People, DNA Tracing and Donor Anonymity' (2013) 7(2). *Australian Journal of Adoption* 8.

³⁶⁷ See generally Adams & Allan op cit.

³⁶⁸ 23andme, GEDmatch, Ancestry.com, AncestryDNA offer the service, among a myriad of smaller companies. See Phillips op cit at 16-22. GEDmatch, which has one of the largest direct-to-consumer genetic testing databases has over one million profiles in its database. See EW Clayton et al 'The law of genetic privacy: applications, implications, and limitations'. (2019) *Journal of Law and the Biosciences*.

³⁶⁹ BE Kirkpatrick & MD Rashkin 'Ancestry testing and the practice of genetic counselling' (2017) 26(1) *Journal of Genetic Counseling* 9-10.

³⁷⁰ Y Erlich et al 'Identity inference of genomic data using long-range familial searches' (2018) 362(6415), *Science* 690-694.

³⁷¹ This involved compiling a 'suspect list' using matches from the databases. They would then cut down on this suspect list by estimating the age of the person within a 10-year interval and the location of the person within a radius of 100 miles. This list could further be reduced if the sex of a person was known. However, the amount of work would probably be too intensive for a casual hobbyist or somebody who is willing to compile a family tree out of interest. See Erlich et al op cit at 350231.

within reach.³⁷² Notably, with the increasing popularity of direct-to-consumer genetic testing,³⁷³ the number of individuals who can be traced through these databases is expected to increase significantly within a short space of time. The number of individuals in the United States of European descent who are able to be traced is expected to rise to 90 per cent within the next two to three years.³⁷⁴

(d) The right to privacy in light of the advent of direct-to-consumer genetic testing

Where there exists a threat to the principle of donor-anonymity due to direct-to-genetic testing, it falls to consider effect of privacy laws of South Africa. If privacy laws extend to genetic data, or the results of a person's direct-to-consumer genetic test, he or she may assert this right to privacy, to prevent the possibility of his or her DNA profile being uploaded to a database, and thus prevent any possibility of being traced by a donor offspring on a genealogical database.

(i) *An overview of the privacy laws in South Africa*

A person's right to privacy in South Africa is protected by the common law and legislation, as well as being a constitutionally recognised and protected right.³⁷⁵ The first recognition of a common law right to privacy was the case of *O'Keeffe v Argus Printing and Publishing Co Ltd*.³⁷⁶ Privacy has been defined by a legal scholar as:

‘An individual condition of life characterised by seclusion from the public and publicity. This condition embraces all those personal facts which the person concerned has himself determined to be excluded from the knowledge of outsiders and in respect of which he has the will that they be kept private.’³⁷⁷

³⁷² Erlich et al at 690-694.

³⁷³ Figures reported show that by the start of 2019 more than 26 million people had been tested by direct-to-consumer genetic tests, with the number of people taking the tests increasing exponentially year-on-year, with more than 100 million profiles expected to exist on the databases within two more years. See A Regalado ‘More than 26 million people have taken an at-home ancestry test’ (2019) *MIT Technology Review*, available at <https://www.technologyreview.com/s/612880/more-than-26-million-people-have-taken-an-at-home-ancestry-test/>

³⁷⁴ A Rasheed ‘Personal Genetic Testing and the Fourth Amendment’ (2019) *University of Illinois Law Review* 4.

³⁷⁵ See A Naude. & S Papadopoulos . Data protection in South Africa: The Protection of Personal Information Act 4 of 2013 in light of recent international developments’ (2016) 79 (1). *THRHR* 51

³⁷⁶ *O'Keeffe v Argus Printing and Publishing Co Ltd* 1954 (3) SA 244 (C). It was decided that the Roman Law concept of *dignitas* should include a right to privacy. This was in response to a photograph of a woman being published in an advertisement without her consent.

³⁷⁷ J Neethling JM Potgieter, & PJ Visser *Law of Personality* (2005) 32

In the case of *National Media Ltd v Jooste*³⁷⁸ the court held that privacy allows a person to determine the destiny of private facts. It also held that the person involved is entitled to decide the ambit of disclosure – whether such disclosure be to private friends, a professional adviser or the public. The person involved was entitled to prescribe the purpose and method of disclosure ie when, and under what conditions private facts may be made public.³⁷⁹ Thus, the right to privacy entails the right of a person to control his or her personal information free from unwanted intrusions, and can be infringed by either unlawfully processing information about an individual, which is true and correct, or by processing data, which is false and misleading.³⁸⁰

More recently the case of *Greef v Protection 4U h/a Protect International*³⁸¹ held that a person's right to privacy had been factually violated only when an outsider becomes acquainted with a person's personal affairs or personal life, either by direct intrusion, or unauthorised disclosure of private facts or personal affairs. Such private facts include:

- the contents of private correspondence;
- physical deformities and health;
- lifestyle;
- childhood and background;
- family life;
- past activities;
- confidential information;
- information stored in databanks.³⁸²

Other practical examples of infringements of the common law right to privacy are:

- entry into a private residence;
- reading of private documents;
- listening to private conversations;

³⁷⁸ *National Media Ltd v Jooste* 1996 (3) SA 262 (A)

³⁷⁹ *National Media* supra 271 paraG to 272 para B.

³⁸⁰ A Naude & S Papadopoulos . Data protection in South Africa: The Protection of Personal Information Act 4 of 2013 in light of recent international developments' (part 1) (2016) 79(1) *THRHR* 53

³⁸¹ *Greef v Protection 4U h/a Protect International* 2012 (6) SA 392 (GNP), 406-407.

³⁸² R Midgley (ed) *The Law of Delict in South Africa* (2012) 391.

- shadowing of a person;
- disclosure of private facts acquired by a wrongful act of intrusion;
- disclosure of private facts in breach of a relationship of confidentiality.³⁸³

The common law right to privacy falls under the law of delict, in which the normal elements must be present..³⁸⁴ Delictual remedies for a violation of a person's right to privacy include:

- (1) An interdict preventing further infringement of the person's right to privacy, by preventing further wrongful processing of the person's personal data; or
- (2) A claim under the *actio iniuriarum* for compensation for the harm suffered or injury caused to such person as a result of the wrongful processing of his or her personal data; or
- (3) A claim under the *Lex Aquilia* for patrimonial loss suffered by a person as a result of the wrongful processing of his or her personal data.³⁸⁵

The right to privacy is also afforded by the Bill of Rights contained in chapter 2 of the Constitution,³⁸⁶ which is binding on the executive, legislature, organs of state, and any other natural or juristic person.³⁸⁷ The Bill of Rights is applicable to all laws in the country, including the common law right to privacy.³⁸⁸ The Constitutional Court itself, in the case of *Bernstein v Bester*³⁸⁹ emphasised the interdependence between the common law and constitutional rights to privacy. In this case, the Constitutional Court held that the right to privacy applied to a person's inner sanctum, protecting his or her family life, sexual preference and home environment, but as a person moves from this inner space to more communal relations including business and social interaction and activities, this personal

³⁸³ Currie and De Waal. *The Bill of Rights Handbook*. (2013) 296.

³⁸⁴ See R Midgley (ed) *The Law of Delict in South Africa* (2012) 390. The elements, which must be present, are harm, conduct, factual and legal causation, fault and wrongfulness. A discussion of these elements are beyond the scope of the present discussion, however, *The Law of Delict in South Africa* (supra) may be perused for an in-depth discussion of each of these elements if required.

³⁸⁵ Naude & Papadopoulos, S., 2016. Data protection in South Africa: The Protection of Personal Information Act 4 of 2013 in light of recent international developments' (part 1) 79 *THRHR* 54. The differences between the *actio iniuriarum* and the *actio legis Aquiliae*, and thus remedies 2 and 3 listed, are the basis of the claim. *Actio iniuriarum* in where there is harm caused to a person's personality, but no patrimonial loss has taken place. *Actio legis Aquiliae* is based only on patrimonial loss. The remedies for both actions are the same, however, and take the form of monetary compensation.

³⁸⁶ 1996 Constitution.

³⁸⁷ S 8(1) and 8(4)

³⁸⁸ S 2.

³⁸⁹ 1996 (2) SA 751 (CC) para 63.

space shrinks accordingly.³⁹⁰ The right to privacy ‘becomes more intense the closer it moves to the intimate personal sphere of the life of human beings, and less intense as it moves away from that core’³⁹¹ At the very least, it includes, as explicitly stated in the Constitution, the right not to have:

- their person or home searched;
- their property searched;
- their possessions seized; or
- the privacy of communications infringed.³⁹²

However, the right to privacy includes not only an informational aspect, restricting what information another person may have access to, but also what has been termed personal autonomy privacy rights. This involves enabling individuals to make decisions of a personal nature, which would then include the ability to make decisions on matters involving family relationships, sexual orientation and so on, uninhibited by unwanted intrusion from others.³⁹³ The right to privacy has been divided into three groups for convenience and ease of understanding:³⁹⁴

- Privacy against intrusions and unwanted interferences with private life;
- Privacy against disclosure of private facts; and
- Privacy against infringement of autonomy.

There have been practical examples of where the courts have recognised infringements of the right to privacy against intrusions and unwanted interferences with private life. These include where a person’s room has been bugged,³⁹⁵ private telephonic conversations have

³⁹⁰ Para 67.

³⁹¹ *Investigating Directorate: Serious Economic Offences v Hyundai Motor Distributors (Pty) Ltd: In re Hyundai Motor Distributors (Pty) Ltd v Smit NO* 2001 (1) SA 545 (CC), para 35.

³⁹² S 14.

³⁹³ See for example *Curtis v Minister of Safety and Security* 1996 3 SA 617 (CC) where the Constitutional Court held that a prohibition on the possession of erotic material was a violation of an individual’s right to privacy. In *National Coalition for Gay and Lesbian Equality v Minister of Justice* (1999) 1 SA 6 (CC), the offence of sodomy, which criminalized private conduct of individuals, which was between consenting adults and did not harm anyone else, intruded on the innermost intimate sphere of a person. As such, this was a violation of the constitutional right to privacy.

³⁹⁴ South African Law Reform Commission, Project 124, *Privacy and Data Protection*, Report 2009 para 2.2.11.

³⁹⁵ *S v A* 1971 (2) SA 293 (T).

been listened to,³⁹⁶ spying on a person while he or she is undressing,³⁹⁷ reading private documents,³⁹⁸ unauthorised blood tests,³⁹⁹ and harassing or shadowing.⁴⁰⁰ Existing legislation also may affect the handling of a person's data extracted by carrying out a direct-to-consumer genetic test. However, in *South African National Defence Union v Minister of Defence*,⁴⁰¹ the Constitutional Court held that 'where legislation is enacted to give effect to a constitutional Right' such legislation must be relied on, rather than the constitutional right, when asserting such right. With respect to the common law, the court in *Bato Star Fishing (Pty) Ltd v Minister of Environmental Affairs and Tourism*⁴⁰² held that where a right exists in the common law as well as in legislation, such legislation must be relied on, with the common law serving to inform the provisions of the existing legislation. This is the principle of subsidiarity, which governs the relationship between the common law, legislation and constitutional law to prevent parallel systems of remedies being available by relying separately on the Constitution, legislation and/or common law. The principle of subsidiarity means that 'courts should avoid a constitutional decision if a matter can be decided on a non-constitutional basis', and 'seeks to prioritise legislation over common law'.⁴⁰³ As such, existing legislation in South Africa will be discussed in light of the right to privacy, together with its application to direct-to-consumer genetic testing.

(ii) Existing Legislation and its Impact on a Person's Right to Privacy

*National Health Act*⁴⁰⁴

The National Health Act applies to any public and private providers of health services,⁴⁰⁵ and section 14 of the Act protects the confidentiality of information held by such providers,

³⁹⁶ *Financial Mail Pty Ltd v Sage Holdings (Pty) Ltd* 1993 (2) SA 451 (A)

³⁹⁷ *R v Holliday* 1927 CPD 395. See also *MEC for Health, Mpumalanga v M Net 2002* (6) SA 714 (T), paras 718-9, 721

³⁹⁸ *Reid-Daly v Hickman* 1981 (2) SA 315 (ZA), see p323

³⁹⁹ There have been numerous cases considering the issue of whether blood and DNA tests may be ordered by court, or whether this constitutes an infringement of a person's right to privacy and bodily integrity. See for example, *Seetal v Pravitha* 1983 (3) SA 827 (D) at 861-2; *M v R* 1989 (1) SA at 416 (O) at 426-7; *Nell v Nell* 1990 (3) SA 889 (T) at 895-6; *C v Minister of Correctional Services* 1996 (4) SA 292 (T); and *S v Orrie* 2004 (3) SA 584 (T) at 589-1. The matter was seemingly settled in the case of *YM v LB* 2010 (6) SA 338 (SCA), discussed in this paper under Chapter 2, where the court held that ordering a DNA was a violation of a person's right to privacy and bodily integrity. In that instance, in the case of establishing paternity or maternity, this was a justifiable infringement as it was in the best interest of a child to establish the truth of his or her parentage.

⁴⁰⁰ *Huey Extreme Club v Mc Donald t/a Sport Helicopters* 2005 (1) SA 485 (C) at 498-9

⁴⁰¹ *South African National Defence Union v Minister of Defence* 2007 (5) SA 400 (CC), para 51

⁴⁰² *Bato Star Fishing (Pty) Ltd v Minister of Environmental Affairs and Tourism* 2004 (4) SA 490 (cc), para 22.

⁴⁰³ K Klare 'Legal Subsidiarity & Constitutional Rights: A Reply to AJ van der Walt (2008) 1 *Constitutional Court Review* 134.

⁴⁰⁴ National Health Act 61 of 2003.

⁴⁰⁵ S 2(a)(i).

by providing that no person may divulge information held by the provider regarding a person. Exceptions to this are

- a) where there is consent by the relative person in writing;
- b) where there is an order of court, or any other existing law requiring disclosure, or
- c) where non-disclosure would pose a serious threat to public health.

A further exception to the confidentiality rule exists where a health worker or healthcare provider has access to an individual's records. Such worker or provider may disclose the personal information of such individual 'to any other person, health care provider, or health establishment as is necessary for any legitimate purpose within the ordinary course and scope of his or her duties', where disclosing such personal information is in the interests of the individual.⁴⁰⁶ However, defining what is in the best interests of an individual in these cases is not always clear.⁴⁰⁷ The Act also has detailed provisions for the circumstances where a health worker or healthcare provider may access a person's health records,⁴⁰⁸ and very detailed provisions for the protection of a person's health records in their care.⁴⁰⁹

Health information and personal information are confidential.⁴¹⁰ The Act contains a definition of personal information, being 'information relating to the race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth of the individual'.⁴¹¹ Thus, the results of a person's direct-to-consumer genetic tests would be confidential in terms of the Act, since, as argued above, they contain information pertaining to a person's race, gender, ethnic or social origin, colour and disability, which are all aspects of personal information protected and confidential under the Act. This strengthens the argument that under the constitutional and common law rights to privacy, personal facts which a person would be entitled to keep private and personal include facts relating to race, gender, sex, pregnancy, marital status, ethnic or social origin, colour,

⁴⁰⁶ S 15(1).

⁴⁰⁷ See PA Carstens & D Pearmain *Foundational Principles of South African Medical Law* (2007) 955 for examples of where it may not be clear as to what is in the best interests of an individual.

⁴⁰⁸ S 16.

⁴⁰⁹ S 17.

⁴¹⁰ S 15.

⁴¹¹ S 1.

sexual orientation, age, disability, religion, conscience, belief, language and birth. These serve as not only prohibited grounds to protect an individual from discrimination, but are listed as personal information which is confidential under the Act.

*Promotion of Access to Information Act (PAIA)*⁴¹²

This Act gives effect to section 32(2) of the Constitution which provides that legislation must be enacted to give effect to the constitutional right of access to information held by the state or any other person, where this is required for the exercise or protection of any rights.⁴¹³ The Act applies to information held by both public and private bodies.⁴¹⁴ A public body in terms of the Act means any department of state or administration in any sphere of government, or any other functionary or institution exercising any power or performing a function or duty in terms of the Constitution or any legislation. A private body is a natural person, or partnership carrying out a trade, business or profession, or a juristic person that is not a public body.⁴¹⁵ The Act protects the privacy of third parties by requiring that a request for access to a record, or information, must be refused if disclosure of the record ‘would involve unreasonable disclosure of personal information about a third party, including a deceased individual’.⁴¹⁶ The Act further gives a non-exhaustive definition of what ‘personal information’ includes, listing ‘race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth of the individual’,⁴¹⁷ and ‘information relating to the education or medical, criminal or employment history of the individual’,⁴¹⁸ ‘identifying number, symbol or other particular assigned to the individual’,⁴¹⁹ and ‘the address, fingerprints or blood type of the individual’.⁴²⁰

Information about an individual which is protected by the National Health Act⁴²¹ and the grounds of protection from discrimination in the Bill of Rights⁴²² are also protected by

⁴¹² Act 2 of 2000 (PAIA).

⁴¹³ S9. See also s 32(1) of the Constitution

⁴¹⁴ Ss 11 and 50 of PAIA.

⁴¹⁵ S 1.

⁴¹⁶ S 34 for public bodies and s 63 for private bodies,

⁴¹⁷ S 1 ‘personal information’ (a).

⁴¹⁸ S 1 ‘personal information’ (b).

⁴¹⁹ S 1 ‘personal information’ (c).

⁴²⁰ S 1 ‘personal information’ (d).

⁴²¹ National Health Act supra 3

⁴²² S 9(3) of the 1996 Constitution.

PAIA.⁴²³ Personal information, which is protected by this Act, may be contained in the results of an individual's direct-to-consumer genetic test ie the person's race, gender, ethnic or social origin, colour and disability. The Act further lists blood type as personal information, which undoubtedly would be revealed in the genetic test results, and is thus also protected by the Act. While the purpose of the Act is primarily to provide freedom of access to information, rather than protection of data, it does give protection to the privacy of an individual.⁴²⁴ The wording of the Act specifically mentions privacy when protecting third parties, and lists privacy as covering personal information and gives a clear definition of personal information as listed above. A person's genetic information gives information regarding race, gender, ethnic or social origin, colour and disability. Thus, the Act provides a clear link between a person's genetic information and the right to privacy. From this, the inference can be made that a person's common law and constitutional rights to privacy extend to the results of a direct-to-consumer genetic test. As well as being protected under the National Health Act,⁴²⁵ a person's genetic information would be protected under this Act PAIA).

*Protection of Personal Information Act (POPIA)*⁴²⁶

The Protection of Personal Information Act, which came into effect on 1 July 2020, was enacted to provide and overhaul and remedy of the existing statutory framework in South Africa.⁴²⁷ This was to ensure that an adequate level of data protection would be provided by existing legislation, and for this such Act was enacted.⁴²⁸

This Act specifically was enacted to give effect to the constitutional right to privacy.⁴²⁹ Relevant to this study is whether the Act has application to genetic data, and whether it protects a person's results of direct-to-consumer genetic test and DNA profile. If the Act has application, and so extends the right to privacy to a person's genetic information, a donor

⁴²³ Race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth.

⁴²⁴ MN Slabbert 'Genetic Privacy in South Africa and Europe: A Comparative Perspective (2)' (2008) 71 *THRHR* 90.

⁴²⁵ National Health Act *supra*.

⁴²⁶ 4 of 2013 (POPIA).

⁴²⁷ For example, s 50 the Electronic Communications and Transactions Act 25 of 2002, applies to personal data obtained through electronic transactions. However, the person controlling such information may voluntarily subscribe to the data privacy principles contained in this Act by agreement with the data subject. While the person must subscribe to all nine principles contained in this Act rather than just parts of it, breach of these voluntary data principles is to be regulated by agreement between the parties. Thus, in terms of section 50(1) to 50(4), a glaring deficiency in this Act is the fact that the data privacy principles are voluntary

⁴²⁸ A Naude & S Papadopoulos 'Data protection in South Africa: The Protection of Personal Information Act 4 of 2013 in light of recent international developments (1)' (2016) 79 *THRHR* 59.

⁴²⁹ S 2(a).

can assert this right, in order to prevent any part of his or her genetic profile from being uploaded to a genetic or genealogical database, and thus prevent the possibility of thereby being traced by a donor-conceived child.

The stated purpose of this Act (POPIA) is to ‘give effect to the constitutional right to privacy by safeguarding personal information when processed by a responsible party’.⁴³⁰ It does this by ‘prescrib[ing] minimum threshold requirements for lawful processing of personal information’.⁴³¹ In other words, where personal information is collected, receipted, recorded, organised, collated, stored, updated or modified, retrieved, altered, used, disseminated or made available in any other form,⁴³² such must comply with the conditions set out in section 4 of the Act. The main guiding principles of the Act must first be discussed and understood, so that they may thereafter be applied to genetic information. As such, a brief overview of the eight conditions will be given below, whereafter the Act will be discussed in light of direct-to-consumer genetic testing, and the Act’s applicability to genetic information, so that the conditions can be applied as needed to the principles of genetic information, and whether a person may have a right to privacy in terms of the Act, over his or her genetic information. These are the eight conditions listed in the Act.⁴³³

Condition 1 – Accountability: In terms of section 8, this principle of accountability means that the responsible party, which is the party who ‘determines the purpose of, and means for processing personal information’,⁴³⁴ must ensure that the conditions, as set out in the Act, are complied with, meaning that the responsible party is the one who is responsible for compliance, regardless of who may have been processing the information for such party.

Condition 2 – Processing limitation: This principle is expanded on in detail in sections 9 to 12 of the Act, but in summary means that the processing must be done ‘lawfully and in a reasonable manner so as not to infringe of the privacy of the data subject’ and limit the processing to the adequate purpose for which it was given. It must also be done with the consent of the data subject, and the data which is processed must be collected directly from the data subject, although there are exceptions, which may apply.

Condition 3 – Purpose specification: In terms of sections 13 and 14, the data, or personal information which has been or is to be collected, must be done ‘for a specific,

⁴³⁰ S 2(a).

⁴³¹ S 2(b).

⁴³² S 1 “processing” (a)-(b).

⁴³³ S 4(1) (a)-(h).

⁴³⁴ S 1 ‘responsible party’.

explicitly defined and lawful purpose’, and ‘steps must be taken . . . to ensure that the data subject is aware of the purpose of the collection’. Such personal information should not be kept longer than necessary to achieve the purpose for which it was collected or processed, subject to certain exceptions listed in section 14, subsections (1)(a)-(d).⁴³⁵ Once the information or data has been used for its purpose, the responsible party must destroy, delete or de-identify a record of personal information as soon as practicably possible, in a manner so as to prevent its reconstruction in an intelligible form’.⁴³⁶

Condition 4 – Further processing limitation: Section 15 states that for further processing of information to be lawful, it must be compatible with the purpose for which it was collected, in keeping with the purpose specification principle. In order to assess this, the Act states that the responsible party must take account of certain listed factors, these being ‘the relationship between the purpose of the intended further processing, and the purpose for which the information has been collected, the nature of the information, the consequences of the intended further processing for the data subject, the manner in which the information has been collected, and any contractual rights or obligations between the parties’.⁴³⁷

Condition 5 – Information quality: In terms of section 16, a responsible party is required to have regard to the purpose for which the personal information was collected or processed, and take reasonable steps to ensure that such information is ‘complete, accurate, not misleading, and updated where necessary’.⁴³⁸

Condition 6 – Openness: The principle, contained in sections 17 and 18, require that a responsible party, where personal information is required, takes reasonable steps to ensure that a data subject is aware of what information is collected, and where it is collected from somewhere other than directly from the data subject, that the data subject is made aware of the source from which it is collected. The data subject should also be made aware of ‘the name and address of the responsible party’, the purpose for which the information is collected, whether the supply of the information by the data subject is voluntary or mandatory, the consequences of failure to supply the information, any particular law authorising or requiring the collection of the information, and the fact that, where applicable,

⁴³⁵ These are ‘where the retention is authorised by law, the responsible party reasonably requires the record for lawful purposes related to its functions or activities, retention of the record is required by a contract between the parties thereto, or the data subject or a competent person where the data subject is a child has consented to the retention of the record’.

⁴³⁶ See S 14(3)-(4).

⁴³⁷ See S 15(1)-(2).

⁴³⁸ S 16.

the responsible party intends to transfer the information to a third country or internal organisation and the level of protection afforded by that third country or internal organisation'.⁴³⁹

Condition 7 – Security safeguards: In terms of section 19, a responsible party is required to 'secure the integrity and confidentiality of personal information in its possession or under its control by taking appropriate, reasonable technical and organisational measures to prevent . . . loss of, damage to or unauthorised destruction of personal information, and unlawful access to or processing of personal information'. As such, the responsible party must take reasonable measures to 'identify all reasonably foreseeable internal and external risks to personal information in its possession or under its control, establish and maintain appropriate safeguards against the risks being identified, regularly verify that the safeguards are effectively implemented, and ensure that these safeguards are continually updated in response to new risks or deficiencies in previously implemented safeguards'.⁴⁴⁰

Condition 8 – Data subject participation: This condition, contained in section 23, gives a data subject who has provided adequate proof of identity, the right to request, at no charge to the data subject, confirmation by a responsible party whether or not such responsible party holds personal information relating to the data subject, as well as the description of such information, and information regarding any third parties who have had access to the information. Where the responsible party does hold such information, section 24 gives the data subject the right to access, view, as well as correct, destroy or delete the information held by the responsible party, where such information is 'inaccurate, irrelevant, excessive, out of date, incomplete, misleading, obtained unlawfully', or where the 'responsible party is no longer authorised to retain' the information'.⁴⁴¹

It must now be considered whether genetic information can fall within the ambit of any of the definitions listed in the Act, so as to assess whether the Act is applicable to genetic information, and if so, which sections of the Act are applicable. The Act protects a person's private information, and gives a non-exhaustive definition of personal information as information relating to race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth.⁴⁴² It also lists information which

⁴³⁹ See S 18(1)(a)-(h). See also exceptions listed in S 14(4)(a)-(f).

⁴⁴⁰ See S 19-22.

⁴⁴¹ S 23-25.

⁴⁴² S 1 'personal information' (a).

would allow the person to be contacted, including identifying number, symbol, e-mail address, physical address, telephone number, location information, online identifier, or other particular assignment.⁴⁴³ Importantly, personal information, including health information, in the Act also includes ‘biometric information’.

While this Act does not specifically define biometric data, it can be defined as biological information about a person which can be used to create a detailed record of his or her personal characteristics.⁴⁴⁴ Such data includes fingerprints, facial recognition, palm print, hand geometry, iris recognition, odour or scent, and most importantly for this discussion, a person’s DNA.⁴⁴⁵

The Act has two layers of protection, depending on what type of information is in the possession of the data controller, or is being processed. The first layer of protection relates to private information as discussed in the above paragraph, and is subject to the eight conditions already discussed, in order for the processing of this information to be lawful. However, the Act lists another type of information, which is ‘special personal information’, which is defined as information concerning ‘religious or philosophical beliefs, race or ethnic origin, trade union membership, political persuasion, health or sex life or biometric information’ or ‘criminal behaviour of the data subject’.⁴⁴⁶ This type of information is afforded a higher level of protection, as it is not subject to the eight conditions as listed; rather there is a general prohibition on processing this type of information. It has further been argued that genetic data is a species of biometric information, and therefore qualifies as ‘personal information’, and ‘special personal information’ in terms of the Act.⁴⁴⁷

Thus in terms of the Protection of Personal Information Act, the right to privacy and personal information includes genetic information, as this covers not only race, gender, ethnic or social origin, colour and disability, but also biometric information, which includes a person’s DNA. It must now be decided whether it would be considered as special personal information so as to be afforded a higher level of protection in terms of the Act.

It is instructive here to consider foreign legislation, in particular the General Data Protection Regulation 2016/679 (GDPR), which was adopted by the European Parliament

⁴⁴³ S1 ‘personal information’ (c).

⁴⁴⁴ M O’Neill & E Summers (eds) *Collins English Dictionary & Thesaurus* 2016. Available at <https://www.collinsdictionary.com/dictionary/english/biometric>

⁴⁴⁵ See A Babich *Biometric Authentication. Types of biometric identifiers* (2012).

⁴⁴⁶ S26(a).

⁴⁴⁷ TA Townsend & DW Thaldar 2019 ‘Navigating uncharted waters: biobanks and informational privacy in South Africa’ *South African Journal on Human Rights*, 35(4), p13.

in 2016, and came into effect in May 2018. The GDPR and POPIA are very similar pieces of legislation, with common foundational principles of data protection and privacy.⁴⁴⁸ While a discussion of all of the similarities between the GDPR and POPIA is beyond the scope of this dissertation, it is noteworthy that the GDPR also provides guidelines relating to the lawful processing of the personal data⁴⁴⁹ of a data subject, and, similarly to POPIA, two categories of information: one being personal data, with principles, or guidelines to be followed in determining whether processing such information is lawful;⁴⁵⁰ and the other being special personal data, carrying a general prohibition, subject to certain exceptions.⁴⁵¹ The GDPR is therefore useful in interpreting POPIA, especially because questions are being raised as to certain definitions in POPIA, specifically whether genetic information is personal information or special personal information.

The GDPR defines special categories of personal data as

‘data revealing racial or ethnic origins, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation’.⁴⁵²

The above definition is very similar to the definition in POPIA, the only addition being genetic information. While the reasons for this are not clear, nor are they given, it is instructive to consider the times during which the respective pieces of legislation were being drafted. Part of the reason for the inclusion of genetic information in the GDPR was the 2008 case of *S and Marper v United Kingdom*,⁴⁵³ which related to the retention of DNA samples. The court affirmed the sensitivity of cellular samples due to the DNA they contain, and as such, the genetic data, and the possibility that the DNA information could reveal other protected data, such as ethical origin, family genetic makeup or health information.⁴⁵⁴ This decision set a precedent for the fact that genetic information contains information relating

⁴⁴⁸ Yav, C., 2018. Perspectives on the GDPR from South Africa. *Int'l J. Data Protection Officer, Privacy Officer & Privacy Couns.*, 2, p.19.

⁴⁴⁹ Article 4(1), “‘personal data’ means any information relating to an identified or identifiable natural person (‘data subject’); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person”.

⁴⁵⁰ Chapter II, Article 5 of the GDPR.

⁴⁵¹ Art 9

⁴⁵² Art 9 (1).

⁴⁵³ *S and Marper v United Kingdom* App no 30562/04 and 30566/04 (ECtHR, 4 December 2008) 120

⁴⁵⁴ C Jasserand ‘Legal Nature of Biometric Data: From Generic Personal Data to Sensitive Data’ (2016) 2 *European Data Protection Law Review* 310.

to ethnic origin as well as health information. At the time, POPIA was already being drafted and presented as a Bill,⁴⁵⁵ later to be assented to in November 2013. At the time the numbers of people taking direct-to-consumer genetic tests was still quite small, whereas when the GDPR was adopted in 2016,⁴⁵⁶ direct-to-consumer genetic testing was significantly increasing in popularity.⁴⁵⁷ This gives two possible explanations for the inclusion of genetic data as special personal information in the GDPR, while excluding it from POPIA, the first being that the jurisprudence which influenced the inclusion of genetic data in the GDPR was more influential than that which influenced the drafting POPIA. The second explanation is that direct-to-consumer genetic testing was in its infancy in South Africa and, compared with the social context around the GDPR, much less relevant at the time of drafting POPIA. This suggests that the exclusion of genetic information under the category of special personal information in POPIA was not intentional, but rather due to the timing of the drafting of the legislation.

Statutory provisions should be interpreted purposively, meaning that an interpreter should ‘ascertain the purpose that [a] provision is intended to serve, and then interpret the provision in light of such purpose’.⁴⁵⁸ Accordingly, and in light of the above discussion, it is likely that the inclusion of genetic information in the GDPR, and its exclusion in POPIA suggests that the intention of the legislature in drafting POPIA would have been to include genetic information under the category of special personal information, rather than excluding it.

Judicial precedent, albeit only persuasive in the case of *S and Marper v United Kingdom*,⁴⁵⁹ that genetic information constitutes both health information, as well as information relating to ethnic origins, which are both included in special personal information, suggests that genetic information constitutes special personal information as contained in section 26 of POPIA. I therefore submit that a person’s genetic information as

⁴⁵⁵ See MN Slabbert ‘Genetic Privacy in South Africa and Europe: A Comparative Perspective’ 2008 (2) *THRHR* 71 at 81, giving an in-depth discussion of the provisions of the Protection of Personal Information Bill, at the same time that the case of *S and Marper v United Kingdom* supra was being decided.

⁴⁵⁶ C Yav ‘Perspectives on the GDPR from South Africa’ (2018) 2 *International Journal for the Data Protection Officer, Privacy Officer & Privacy Counsel* 19. .

⁴⁵⁷ BE Kirkpatrick, & MD Rashkin ‘Ancestry testing and the practice of genetic counseling’ (2017) 26(1) *Journal of Genetic Counseling* 8.

⁴⁵⁸ DW Thaldar & B Townsend ‘Genomic research and privacy: A response to Staunton et al’ (2020) 110(3) *South African Medical Journal* 172.

⁴⁵⁹ *S and Marper v United Kingdom* supra.

revealed in the results of a direct-to-consumer genetic test is protected both under POPIA and the right to privacy.

POPIA gives effect to the constitutional right to privacy, and so applies to the exclusion of other legislation which regulates the processing⁴⁶⁰ of personal information and which may be inconsistent with the Act, unless such other legislation is more extensive than the Act, in which case the more extensive conditions prevail.⁴⁶¹ As such, POPIA, as the standard for the right to privacy, contains provisions for the practical application of a person's right to privacy. The application of the Act will be discussed to provide an understanding of the practical effect of the right to privacy with regard to a person's genetic information. This Act applies to any personal information, including special personal information, which has been entered into a record by or for a responsible party (defined as a 'public or private body or any other person which, alone or in conjunction with others, determines the purpose of and means for processing personal information'),⁴⁶² using automated or non-automated means.⁴⁶³ Exclusions listed in the Act include personal information for a personal or household activity, where the identifying particulars or details of the information have been sufficiently removed ie any information which 'can either directly identify the data subject', or 'can be linked by a reasonably foreseeable method to other information that identifies the data subject',⁴⁶⁴ where the information has been 'processed by or on behalf of a public body in the interests of national security for the prevention, detection and identification of the proceeds of unlawful activities and combating money laundering, investigation of proof of offences, prosecution and execution of sentences or security measures, as long as safeguards have been established for the protection of such information'.⁴⁶⁵ There are also exclusions for journalistic, literary or artistic work, where a code of ethics provides safeguards.⁴⁶⁶ The regulator may grant exemptions in the public interest, where there is clear benefit for the data subject or a third

⁴⁶⁰ 'Processing' in terms of s1 of the Act means 'collection, receipt, recording, organisation, collation, storage, updating or modification, retrieval, alteration, consultation or use' and, 'disseminating by means of transmission, distribution, or making available in any other form' or 'merging, linking, as well as restriction, degradation, erasure or destruction of information'.

⁴⁶¹ S3 (2)(a)-(b).

⁴⁶² In terms of S 1, 'responsible party' means a public or private body or any other person which, alone or in conjunction with others, determines the purpose of and means of processing the personal information'.

⁴⁶³ S3 POPIA (1) (a). See also S1 'responsible party'.

⁴⁶⁴ S 1, 'de-identify'.

⁴⁶⁵ S 6.

⁴⁶⁶ S 7.

party,⁴⁶⁷ and where information is processed to discharge a relevant function.⁴⁶⁸ It is difficult to envision a situation where any of these exclusions would apply to genetic information obtained as a result of a person's direct-to-consumer genetic test. However, since it has been argued above that genetic information constitutes special personal information, which has a higher standard of protection than personal information, and has its own set of exceptions where processing such information is permitted in terms of the Act, these exceptions must therefore be considered.

The Act contains a general prohibition on the processing of special personal information. Exceptions to this are where such processing has been carried out with the consent of the person whose information is being processed; where it is necessary for the establishment, exercise or defence of a legal right or obligation; where it is necessary to comply with an obligation of international public law; it is for historical, statistical or research purposes, provided that there are guarantees that this will not disproportionately adversely affect the person's right to privacy, or the person involved has purposely made his or her personal information private.⁴⁶⁹ In addition to these exceptions, the Act provides further specific circumstances where the prohibition on processing personal information does not apply. In given circumstances, a responsible party is permitted to process personal information relating to religious or philosophical beliefs, race or ethnic origin, trade union membership, political persuasion, health or sex life, criminal behaviour or biometric information.⁴⁷⁰

Thus, where a person undergoes a direct-to-consumer genetic test, and his or her genetic information is then held, and/or processed by a company offering such tests, this information may only be processed with consent of the person undergoing such test, which is one of the exceptions as listed in the Act, permitting the processing of special personal information.⁴⁷¹ However, in terms of condition 3, purpose specification, the personal information must only be collected for a specific, explicitly defined and lawful purpose.⁴⁷² In this case, it would be for the company providing the tests to provide information regarding his or her DNA profile to the person undergoing the test. In terms of condition 4, further processing must be in accordance with or compatible with the purpose for which it was

⁴⁶⁷ S 37.

⁴⁶⁸ S 38.

⁴⁶⁹ S 27 POPIA.

⁴⁷⁰ S 28-33.

⁴⁷¹ S 27(1)(a).

⁴⁷² S 13.

collected.⁴⁷³ In the absence of consent, it is unlikely that to the company would be entitled to process the information beyond providing the DNA profile information to the person who has undergone the test. Further, in terms of condition 7 (security safeguards), the responsible party must secure the integrity and confidentiality of the personal information.⁴⁷⁴ The person's genetic information is protected under the Act, and in the absence of consent, a company carrying out such test is under a duty to protect the confidentiality of the genetic information, or any information relating to the DNA profile.

In case of breach of the provisions of the Act, the person whose information has been unlawfully processed has a claim for damages. The 'responsible party' against whom the action is being instituted may raise defences of *vis major*, the consent of the plaintiff, fault on the part of the plaintiff and that compliance was not reasonably practicable.⁴⁷⁵

It can be therefore be concluded that a person's right to privacy would probably extend to his or her genetic information, and this is probably protected in terms of the Protection of Personal Information Act. A person or company, known in the Act as a 'responsible party' would then not be authorised to release or disclose the results of a person's direct-to-consumer genetic test. As such, a donor would probably be afforded further processing limitation and security safeguards, protection from the possibility of being traced by a donor-conceived child via a genealogical database or website, as his or her genetic profile could not be uploaded without his or her express consent.

The exceptions are where a person consents to the disclosure, or publicly makes this information available. However, many of the companies offering direct-to-consumer genetic testing, as well as the genealogical databases, are not based within South Africa, and arguably not subject to its privacy laws; but in terms of section 3(b)(ii) of the Act, a 'responsible party' includes a party not domiciled within South Africa, but is nevertheless processing personal information as defined by the Act of South African origin. Section 40(1)(g) further gives the Regulator, as established by the Act, power to facilitate cross-border cooperation in the enforcement of privacy laws.

The provisions of the Act specifically aimed at the transfer of data abroad are sections 72 and 57; in terms of section 72(1)(a) and (b) data can only be transferred to a party in a receiving country if such country is subject to laws that provide adequate levels of protection

⁴⁷³ S 15.

⁴⁷⁴ S 19(1).

⁴⁷⁵ S 99.

when measured against the Act, or such party agrees to adhere to the provisions of the Act.⁴⁷⁶ Section 57(1)(d) relates to special personal information, and requires prior authorisation from the Regulator for transferring data to a party in a foreign country unless such party provides protection as envisioned in terms of section 72, namely the country is subject to laws which provide adequate levels of protections so as to be in keeping with the provisions of the Act, or agrees to adhere to the provisions of the Act.

Here again, it will be instructive to consider the effect of the GDPR on the transfer of data to parties in foreign countries. The GDPR applies to all foreign businesses that ‘offer goods or services in any of the 31 European Economic Area nations, or monitor the activities of data subjects within the EU’.⁴⁷⁷ The threat of penalties imposed on foreign companies not complying with the GDPR results in many companies needing ‘to align their data protection policies with the requirements of the GDPR’.⁴⁷⁸ Many of the direct-to-consumer genetic testing companies, including 23andMe,⁴⁷⁹ MyHeritage,⁴⁸⁰ and Ancestry.com⁴⁸¹ have undertaken to ensure compliance with all applicable privacy laws, specifically undertaking to comply with EU privacy laws and the GDPR. Where companies are in compliance with the GDPR, they are likely to comply with the Act.⁴⁸² This being the case, South African privacy laws are likely to bind such foreign companies as well. Thus, there is little likelihood of the test results or genetic information being published.⁴⁸³

There is little likelihood of donor-conceived offspring being able to track donors via ancestry sites as the genetic information is protected in terms of the Act. However, where such donor uploads the results to a site with a relative finder function, the protections would

⁴⁷⁶ C Staunton & E De Stadler ‘Protection of Personal Information Act No. 4 of 2013: implications for biobanks’ (2019) 109(4) *South African Medical Journal* 234.

⁴⁷⁷ ML Rustad. & TH Koenig ‘Towards a global data privacy standard’ (2019) 71 *Florida Law Review* 377.

⁴⁷⁸ Rustad, & Koenig op cit at 389.

⁴⁷⁹ <https://www.23andme.com/gdpr/>

⁴⁸⁰ <https://www.myheritage.com/privacy-policy>

⁴⁸¹ <https://www.ancestry.com/cs/legal/privacystatement?hideHeader=1#eu>

⁴⁸² C Yav ‘Perspectives on the GDPR from South Africa’ (2018) 2 *International Journal for the Data Protection Officer, Privacy Officer & Privacy Counsel* 20.

⁴⁸³ One of the largest direct-to-consumer genetic testing services, 23andMe has committed to comply with all existing privacy and protection laws, available at <https://www.23andme.com/privacy/?mkpc=true>. While this is not intended to be a definitive privacy guideline, 23andMe allows a person to decide whether or not his or her saliva sample may be stored by 23andMe, whether they wish their account to be visible to other 23andMe members, and whether or not they wish to participate in the DNA Relative tools finder, connecting a person with genetic relatives on the same database. Another of the largest direct-to-consumer genetic testing companies, MyHeritage similarly has a privacy section whereby a person can opt out of DNA matching and restrict access to his or her genetic information stored on their database.

not apply, as such person is voluntarily making the information publicly available – one of the exceptions listed in the Act.

The legal position can become rather confusing, however due to the fact that while each person's full genome is unique, and DNA which contains this genome has been conceptualised as a unique identifier, variants within a person's genome may be widely shared with biological relatives. Thus, while there may be strong privacy protections for genetic data, this data is not limited to an individual, but will reveal information about the persons close to the individual and even distant relatives.⁴⁸⁴

The most prevalent use for direct-to-consumer genetic tests is to provide insights into ancestry and family relationships, such as finding blood relatives who were previously unknown, birth parents of an adopted child, or the identity of a gamete donor, which could lead to unwanted contact, and pose a significant risk to donor-anonymity.⁴⁸⁵

So, there may be certain situations for example, where a relative of a person may elect to undergo a direct-to-consumer genetic test and upload the results to a database. In terms of the Act, such person is entitled to do so,⁴⁸⁶ depending on whether the website is South African or not. A person is entitled to consent to the disclosure of information, as well as making it publicly available by uploading it to genealogical databases. However, genetic information shared between relatives constitutes biometric information which is protected by the Act. The legal position may be murky, as a person is entitled to voluntarily disclose the information, while the information is also protected as it is information which is protected under the privacy rights of a relative.⁴⁸⁷ Thus, in terms of the right to privacy, and the Act, a person is entitled to disclose this information, while at the same time being prohibited from doing so.

⁴⁸⁴ EW Clayton et al 'The law of genetic privacy: applications, implications, and limitations' (2019) 6(1) *Journal of Law and the Biosciences* 2.

⁴⁸⁵ Clayton, et al op cit at 16.

⁴⁸⁶ Even though these websites may not be in South Africa, a person may still be permitted in terms of the Act to upload personal information to these websites, if they are compliant with the provisions of the Act by virtue of having to be compliant with the provisions of the GDPR.

⁴⁸⁷ Less than three per cent of shared DNA is sufficient between relatives in order for one to be able to be traced using a match to the other on a genealogical database where a person's DNA is uploaded. The relatives can be as distant as third cousins. Thus, even as little as three percent of a person's DNA may be protected as this information could be used to track them. This could create significant legal and practical difficulties, as a person may be unaware of this breach of his or her right to privacy and could conceivably not even know the relative. It has been hypothesised that as little as one percent of a population may be needed to upload their DNA to a database in order for any member of the population to be able to be traced. See C Moore 'The History of Genetic Genealogy and Unknown Parentage Research: An Insider's View' (2016) 8(1) *Journal of Genetic Genealogy* 35-37.

United States cases of joint occupancy assist in setting out the prevailing legal position. While these cases relate to the Fourth Amendment⁴⁸⁸ and the third party doctrine⁴⁸⁹ relating to police searches, they are being discussed in relation to the use of genealogical databases reflecting direct-to-consumer genetic tests, due to the fact that police have begun utilising these as tools to solve ‘cold’ cases by uploading DNA which they have from crime scenes, and tracking down perpetrators of crimes via relatives who come back as matches on these databases.⁴⁹⁰

(iii) *Can a person invoke his or her right to privacy to prevent a relative from sharing genetic information?*

The question of whether privacy rights that a person has over his or her own DNA can extend to family members has been gaining attention due to law enforcement in the United States using genealogical databases to track suspects by uploading DNA from crime scenes to genealogical databases, and tracking suspects through relatives who come up as matches on these databases.⁴⁹¹ Even in the United States, there is a dearth of case law dealing extensively with how expanding technology may apply to privacy rights regarding DNA.⁴⁹²

Consequently other sources of law will have to be considered, and parallels drawn insofar as they may apply to the issue of asserting individual privacy rights to prevent a relative from sharing his or her genetic information. However, much of the discussion in U.S. literature focuses on law enforcement, and as such the third party doctrine, or the fourth amendment rights, which might include principles that do not apply to private individuals asserting privacy rights against relatives. The Fourth Amendment relates to police searches,

⁴⁸⁸ The Fourth Amendment in the United States Constitution prohibits unreasonable searches and seizures of an individual’s person, house, papers and effects. see US Constitution Amendment IV. In the subsequent case of *Katz v United States*, 389, U.S. 347 (1967) para 361, a search was defined as a government intrusion upon a person’s reasonable expectation of privacy.

⁴⁸⁹ This principle is that police searches may be valid under the Fourth Amendment even if there is no warrant or probable cause, where information has been voluntarily shared. see G.M Dery III ‘Can a Distant Relative Allow the Government Access to Your DNA: The Fourth Amendment Implications of Law Enforcement’s Genealogical Search for the Golden State Killer and Other Genetic Genealogy Investigations (2019) 10 *Hastings Science & Technology. Law Journal* 122.

⁴⁹⁰ The first of these cases was the arrest of Joseph James DeAngelo, known as the Golden State Killer in April 2018, after a search of 42 years. Investigators eventually tracked him down using the genealogy and DNA database GEDMatch by uploading his DNA from the crime scenes. Since then, police have been utilising these databases in numerous other crime investigations. See Breeanna Hare and Christo Taouschiani ‘What We Know About the Golden State Killer Case, One Year After a Suspect Was Arrested’ *CNN*, April 24, 2019. Available at <https://edition.cnn.com/2019/04/24/us/golden-state-killer-one-year-later/index.html> . See also JJ Zabel . ‘Killer Genes: a Legal and Ethical Analysis of the Forensic Use of Direct-to-Consumer Genetics’ (2019) available at SSRN 3368705.

⁴⁹¹ For a discussion on this topic, see for example G.M Dery III op cit at 103-146.

⁴⁹² C Guest. ‘DNA and Law Enforcement: How the Use of Open Source DNA Databases Violates Privacy Rights’ (2018) 68 *American University Law Review* 1038.

and much of the discussion in literature on familial DNA searches focuses on whether there is a reasonable expectation of privacy, as this may affect the constitutionality of police carrying out searches. This is discussed in light of police officers carrying out searches on genealogical databases using DNA of suspects in their possession.⁴⁹³ These issues are not relevant to this current discussion however, since the principles under consideration do not relate to police searches, and as such, the legal principles such as the reasonable expectation of privacy are not applicable. However, while case law on privacy rights to prevent a relative from disclosing genetic information is scarce, there are some cases from which applicable principles may be gleaned, and these will be discussed below. The facts and relevant principles of the cases will be discussed, and thereafter, the applicability of these principles to the issue of privacy regarding shared DNA will be discussed.

*United States v. Matlock*⁴⁹⁴

In this case, police officers had arrested the defendant in front of the house in which he lived and detained him in a squad car. While the police officers were aware that the defendant resided in the house, they did not seek his permission to perform a search of the house, but gained permission from another person who appeared to also reside in the house. In the search evidence was found which was used against the defendant at his criminal trial. The court had to consider whether the co-occupant's consent made the search valid.⁴⁹⁵ The court held that 'voluntary consent of any joint occupant of a residence to search the premises jointly occupied is valid against the co-occupant'.⁴⁹⁶ Significantly the court further held that 'the consent of one who possesses common authority over premises or effects is valid against the absent, non-consenting person with whom that authority is shared'.⁴⁹⁷ This authority to consent is based on the mutual use of the property, with the occupants having joint access or control for most purposes.⁴⁹⁸

This case affirmed the principles of common authority, and assumption of risk. Common authority did not arise from mere property interests but on use and control of the property.⁴⁹⁹ The assumption of risk was based on the case of *Frazier v Cupp*,⁵⁰⁰ in which

⁴⁹³ See TR Brown 'Why We Fear Genetic Informants: Using Genetic Genealogy to Catch Serial Killers (2019) 21 *Columbia Science & Technology Law Review* 23.

⁴⁹⁴ 415 U.S. 164, 166 (1974).

⁴⁹⁵ Para 167.

⁴⁹⁶ Para 169.

⁴⁹⁷ Para 170.

⁴⁹⁸ *Supra*.

⁴⁹⁹ *Supra*.

⁵⁰⁰ 394 U.S. 731 (1969), see Para 740.

Frazier had permitted his cousin use of a duffel bag. His cousin subsequently consented to a search of the bag, and it was held that the cousin had authority to consent to the search because of joint use of the bag. Frazier had also assumed the risk that his cousin would allow someone else to look inside the bag.⁵⁰¹ Assumption of risk therefore means that where co-occupants share common space, each co-occupant accepts the possibility that another occupant may permit the common area to be searched.⁵⁰²

Regarding this, for the purposes of DNA and privacy, the principles of shared occupancy, common consent and assumption of risk must be considered. For these purposes, the sharing of DNA, or genetic information must be likened to a physical place, residence, or occupancy. Since DNA is shared, the principle of shared occupancy will apply, where if possession of shared DNA is to be likened to joint occupancy, as several people, who are relatives, are in possession of such DNA, then using this principle, a relative may be permitted to give consent to use of DNA information, where the relative is absent, and thus in the absence of their consent. The principle of common authority would likely also apply, since relatives are all have use and control of this shared DNA. However, the principle of assumed risk would likely not be applicable, as an owner of shared DNA has not voluntarily shared the same DNA or genetic information as a relative, and thus, there has not been any risk assumed, as a person has no choice in whether or not, and with whom they may share DNA. However, upon applying these principles, it is likely that a relative will be entitled to share DNA, or genetic information, as long as it is in the absence of a relative. Thus, a person would likely not need express consent from relatives. However, these cases do not deal with circumstances where a relative actively protests against use of this shared DNA or genetic information.

*Georgia v Randolph*⁵⁰³

This case involved the defendant, Scott Randolph and his wife Janet in a domestic dispute. The defendant refused to consent to a police search of his home, but his wife readily consented..⁵⁰⁴ The court affirmed that a warrantless entry and search of premises is permissible when consent is given by an occupant who shares authority over a common area with a co-occupant, even where the co-occupant later objects to the use of evidence obtained

⁵⁰¹ *United States v Matlock*, para 171.

⁵⁰² See RE Williams 'Third Party Consent Searches after *Georgia v. Randolph*: Dueling Approaches to the Dueling Roomates (2007) 87 *Boston University Law Review* 942.

⁵⁰³ 574 U.S. 103 (2006)

⁵⁰⁴ P 107.

during the search.⁵⁰⁵ The court, in referred to *Matlock*, drew a fine line in distinguishing the two cases. In *Matlock*, the defendant was not physically present, and therefore did not object to entry of the premises. In the current case, the court had to consider whether a co-occupant's consent should suffice where the co-occupant had an interest in objecting to the entry and search of the property. The court held that where an occupant is present and objects, while fellow co-occupant consents, the objection will be upheld, and police may not enter the property or perform a search. Where an occupant was not present but would have objected, the consent of a co-occupant would suffice.⁵⁰⁶

Principles gleaned from these cases may be applicable to cases involving relatives with shared DNA:

- First, the principles are based on the right to privacy; and
- Secondly, whilst relatives with shared DNA are not technically co-occupants, they are nevertheless co-holders of portions of the same DNA, over which they each hold authority, as required in *Matlock*. The principle of shared authority suggests that a relative is entitled to consent to the release of genetic information, as he or she has authority over this information. A difference between this and the joint occupancy in *Matlock*, however, is that there is no assumed risk. Where there is shared occupancy, an occupant assumes risk that a co-occupant may waive the right to privacy, and thus it could be argued that there is a voluntary aspect, whereas with shared genetic information, sharing segments of DNA and genetics is involuntary, and thus there is no assumption of risk.

Whether or not this is material is unclear, as the cases simply recognise the fact of shared authority, even though in *Matlock* it was at least partly based on the principle of assumed risk.⁵⁰⁷ *Randolph*, suggests that a person may prevent a relative from divulging genetic information such as uploading results of a test to a genealogical database to search for relatives. However, this mainly is academic, as a person may have untold numbers of relatives, who could access such genealogical databases at any time and any place. As such, a person would inevitably be an absent occupant at most places and times.⁵⁰⁸

⁵⁰⁵ P 106.

⁵⁰⁶ P 121 and 122.

⁵⁰⁷ See *Georgia v Randolph* 574 U.S. 103 (2006), p106, as well as *Illinois v Rodriguez* 497 U.S. 177 (1990) 179

⁵⁰⁸ Dery III, op cit at 133

More relevant is the case law relating to authors publishing autobiographies. This may have parallels to shared genetic information, in that the author may be sharing information which relates to himself or herself, but also forms the private stories of other individuals. This is the same as a person sharing genetic information, as he is sharing information relating to himself or herself, but which also forms private information regarding a relative. In these cases, ‘the courts have almost always sided with the authors’, since a person has the right to tell his or her own story, or reveal his or her own identity, even if doing so reveals private information about another person close to such author. In such instances, the authors rights trump the family member’s privacy.⁵⁰⁹ The leading case regarding this will be discussed below.

*Bonome v Kaysen*⁵¹⁰

This case involved a defendant named Susana Kaysen, who published a book which described factual, but intimate details about her relationship with Joseph Bonome. Even though she had altered details about his life such as his profession and where he was from, and did not identify him in the book, referring to him only as her boyfriend, many of his acquaintances, including friends and clientele were able to infer that he was the person referred to. Kaysen had not told Bonome of the content of the book, nor sought his permission for its publication.⁵¹¹ The court had to weigh Bonome’s right to privacy against Kaysen’s right to freedom of speech.⁵¹² The court gave a lengthy discussion as to whether these details related to matters of ‘legitimate public concern’,⁵¹³ suggesting that publication of facts which are of genuine interest to the public would outweigh a person’s right to privacy. Importantly, the court noted an additional interest, that of Kaysen’s

‘right to disclose her own intimate affairs. In this case, it is critical that Kaysen was not a disinterested third party telling Bonome’s personal story in order to develop themes in her book. Rather, she is telling *her own* personal story – which inextricably involves Bonome in an intimate way’. (original emphasis).⁵¹⁴

⁵⁰⁹ TR Brown ‘Why We Fear Genetic Informants: Using Genetic Genealogy to Catch Serial Killers’(2019) 21 *Columbia. Science. & Technology Law Review*, 53.

⁵¹⁰ *Bonome v. Kaysen*, 2004 W.L. 1194731 (2004)

⁵¹¹ Para 1

⁵¹² In the United States, the right to freedom of speech is contained in the First Amendment to the Constitution. In South Africa, the right to Freedom of Expression is contained in section 16 of the Constitution, and includes the freedom of press and other media, to receive or impart information or ideas, artistic creativity and academic freedom and freedom of scientific research.

⁵¹³ *Bonome v Kaysen* supra 3.

⁵¹⁴ *Bonome* 3.

It has been argued by one author that when deciding what parts of a person's life story are of interest, that power to decide should reside with that person alone, and where its content and intentions are biographical, its constitutional protection should not be affected by its perceived importance by others.⁵¹⁵ In so concluding, the court took into account that Kaysen had not used Bonome's name, nor subjected him to unnecessary publicity or attention. Kaysen's personal story was 'hers to contribute to the public discourse' and her rights were protected.⁵¹⁶ Kaysen's right to freedom of speech was not limited by Bonome's right to privacy. In this instance, the intimate facts and personal affairs, as referred to in *Bonome v Kaysen* will be likened to DNA, since in a physical way at least, knowledge of the complete sequence of a person's DNA reveals everything that there is to know about them.⁵¹⁷ This being the case, where Kaysen was permitted to reveal these intimate details of her life, even though it involved Bonome in a very personal way since it was details about her own life which she was choosing to reveal, a person would likely be permitted to reveal his or her DNA information, even where a relative objects, as it is personal information regarding themselves, even though it may reveal information regarding relatives.

Thus, the inference can be drawn that a person may be permitted to publish information which involves personal or private facts about themselves, including DNA and genetic information, even if it contains personal or private facts about other individuals and relatives as well; and this may be a permissible limit on their right to privacy. The manner of publication (name and obvious clues to identity) may also be important.

⁵¹⁵ SR West 'The Story of Me: The Underprotection of Autobiographical Speech' (2006) 84 *Washington University Law Review* 966.

⁵¹⁶ *Bonome* 4.

⁵¹⁷ Beckwith *op cit* at 1.

CHAPTER IV

INTERNATIONAL LAW AND THE CHILD'S BEST INTERESTS

(a) International Law

The United Nations Convention on the Rights of the Child (CRC) was signed in November 1989 and came into effect in September of the following year. It was the first legally binding international instrument to protect the human rights, including civil, cultural, economic, political and social rights of children.⁵¹⁸ South Africa ratified the CRC on 16 June 1995. As such, South Africa is bound by the CRC and the Constitution bound to enact and consider the principles of the CRC when interpreting and developing its own laws affecting children.⁵¹⁹ Article 7 of the CRC reads as follows:

‘1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.

2. States Parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless’⁵²⁰

Article 8 of the CRC further reads:

‘States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference’⁵²¹

Article 3 states that ‘in all actions concerning children . . . the best interests of the child shall be a primary consideration’.⁵²² Thus the CRC, and specifically the above-mentioned articles, have been invoked to justify an argument for the removal of donor-anonymity based on an interpretation of the word ‘parents’ and ‘family relations’ to include biological parents;⁵²³ and whether the right of the child to preserve his or her identity can

⁵¹⁸ M Ballantyne ‘My Daddy’s Name is Donor: Evaluating Sperm Donation Anonymity and Regulation (2012) 15 *Richmond Journal Of Law And The Public Interest* 578.

⁵¹⁹ SALRC *The Right to Know* supra 4.

⁵²⁰ Art 7 United Nations Convention on the Rights of the Child (1989) (CRC).

⁵²¹ Art 8 CRC supra.

⁵²² Art 3 CRC supra.

⁵²³ B Clark ‘A Balancing Act: The Rights of Donor-Conceived Children to Know their Biological Origins’ (2011) 40 *Georgia Journal of International and Comparative Law* 625.

be used to justify disclosure of the identity of the biological parent.⁵²⁴ The best interests of the child is also a deeply entrenched principle in South African common law, repeated and affirmed in section 28(2) of the Constitution⁵²⁵ and section 9 of the Children's Act,⁵²⁶ supported by a wealth of jurisprudence'. In light of this an in-depth discussion of the best interests of the child will be afforded a sub-chapter of its own.

It is important to note, that in terms of section 231(4) of the Constitution,⁵²⁷ an international agreement becomes national law when enacted by Parliament as an Act of Parliament; however, any international agreement will not be of effect if it is inconsistent with the Constitution or a statute.⁵²⁸ The CRC is mentioned in the preamble of the Children's Act,⁵²⁹ which affords recognition and effect to the CRC. It is therefore pertinent and relevant turn to the Children's Act for the definition of 'parent' and 'family', which will be instructive in deciding whether or not articles 7 and 8 in the CRC may be invoked in deciding for or against donor-anonymity in South Africa.

Gamete donors are specifically excluded under the definition of a parent⁵³⁰ in the Children's Act,⁵³¹ while the definition of a family member includes a 'parent, grandparent, brother, sister, uncle, aunt or cousin of the child',⁵³² none of which could include a gamete donor. Thus, a gamete donor is specifically excluded as both a parent or family member of the child. This being the case, it is highly unlikely that any other person who might be considered part of the extended family by being biologically related to the child by virtue of the gamete donation having taken place would be included in the definition of family.

Since article 7.1 of the Children's Act is unlikely to be applicable therefore in arguing for a removal of donor-anonymity, article 8 will now be considered to support an argument for removing donor-anonymity, as some authors suggest that knowledge of a biological

⁵²⁴ M Giroux and M De Lorenzi, 'Putting the Child First: A Necessary Step in the Recognition of the Right to Identity' (2011) 27 *Canadian Journal of Family Law* 60.

⁵²⁵ 1996 Constitution.

⁵²⁶ Children's Act supra.

⁵²⁷ 1996 Constitution.

⁵²⁸ J Dugard 'International Law and the South African Constitution' (1997) 92 *European Journal of International Law* 80.

⁵²⁹ Preamble, Children's Act supra.

⁵³⁰ S 1, Children's Act excludes 'any person who is biologically related to a child by reason only of being a gamete donor for purposes of artificial fertilisation' from the definition of parent.

⁵³¹ Children's Act supra.

⁵³² S 1 Children's Act supra; excludes 'any person who is biologically related to a child by reason of 'Interpretation'.

parent is essential for the child to establish an identity.⁵³³ A problem with this line of argument is that the CRC does define the concept of identity as including, nationality, name and family relations. In this context, a donor-conceived child's knowledge of his or her biological parents has no impact on the child's nationality or name. With regard to the right to identity in terms of the Children's Act,⁵³⁴ family relations would not include the biological parents of the donor-conceived child, as gamete donors are specifically excluded.⁵³⁵

While it has been suggested that this concept of identity requires the capture and preservation of data,⁵³⁶ other authors interpret the right to identity in more abstract terms as a right to foster a sense of belonging and self-understanding.⁵³⁷ However, the protagonists are generally unable to offer arguments as to what constitutes a healthy identity, and what role the child's knowledge of his or her genetic origins plays forging this healthy identity. If it is not clear what it means to have a sense of a healthy identity, then it is difficult to ascertain whether donor-anonymity or its removal harms or protects this interest.⁵³⁸

Aside from the best interests of the child, which will be discussed below, it would appear that the provisions and interpretations of international instruments, and specifically the CRC, which are invoked by proponents of the right of donor-conceived children to know their biological parents, are in fact open-ended.⁵³⁹ In considering the CRC together with South African law, it does not seem likely that it can be interpreted in such a way as to suggest that it creates a right to know. Rather, the only way to interpret the CRC is together with the Children's Act, in which case, it is likely that the right of a child to know and be cared for by his or her parents, as well as a right to identity including family relations, will specifically exclude gamete donors. As such, these provisions of the CRC

⁵³³ M Giroux and M De Lorenzi, 'Putting the Child First: A Necessary Step in the Recognition of the Right to Identity' (2011) 27 *Canadian Journal of Family Law* 77.

⁵³⁴ Children's Act *supra*.

⁵³⁵ Children's Act *supra*; 'Family member' includes 'parent', thus again specifically excludes gamete donors as a 'family member'.

⁵³⁶ B Clark 'A Balancing Act: The Rights of Donor-Conceived Children to Know their Biological Origins' (2011) 40 *Georgia Journal of International and Comparative Law* 628.

⁵³⁷ I De Melo-Martín. 'The ethics of anonymous gamete donation: Is there a right to know one's genetic origins?' (2014) 44(2) *Hastings Center Report* 32.

⁵³⁸ I De Melo-Martín 'How best to protect the vital interests of donor-conceived individuals: prohibiting or mandating anonymity in gamete donations?' (2016) 3 *Reproductive Biomedicine & Society Online* 104.

⁵³⁹ B Clark 'A Balancing Act: The Rights of Donor-Conceived Children to Know their Biological Origins' (2011) 40 *Georgia Journal of International and Comparative Law* 629.

do not serve to advance a right of a child to know his or her biological parents in the case of gamete donation.

What will now be considered is article 3 of the CRC,⁵⁴⁰ which protects the best interests of the child.

(b) The best interests of the child

The best interests of the child principle is contained in section 28(2) of the Constitution,⁵⁴¹ which states that ‘a child’s best interests are of paramount importance in every matter concerning the child’. This principle is also contained in article 3(1) of the United Nations Convention on the Rights of the Child⁵⁴² (CRC) which states that ‘[i]n all actions concerning children, whether undertaken by . . . courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration’. The African Charter on the Rights and Welfare of the Child⁵⁴³ goes further by stating in article 4 that the best interests of the child shall be *the* primary consideration, rather than *a* primary consideration as contained in other sources of law (emphasis added). This principle was incorporated in section 9 of the Children’s Act,⁵⁴⁴ which reads: ‘In all matters concerning the care, protection and well-being of a child the standard that the child’s best interest is of paramount importance, must be applied’.

In *Minister of Welfare and Population Development v Fitzpatrick*⁵⁴⁵ the court noted that ‘[T]he plain meaning of the words clearly indicates that the reach of s 28(2) cannot be limited to the rights enumerated in s 28(1) and 28(2) [and] must be interpreted to extend beyond those provisions. It creates a right that is independent of those specified in s 28(1)’.⁵⁴⁶ Thus, section 28(2) is not a guiding principle in interpreting other rights, but is a freestanding right of its own accord, and serves to strengthen other rights.⁵⁴⁷

This principle has long been part of South African jurisprudence in many areas involving children, requiring not only parents, but also the state to ensure appropriate care by providing necessary legal administration to children.⁵⁴⁸ The best interests principle

⁵⁴⁰ Art 3 CRC supra.

⁵⁴¹ 1996 Constitution.

⁵⁴² CRC supra.

⁵⁴³ African Charter on the Rights and Welfare of the Child (1990) (ACRWC)

⁵⁴⁴ Children’s Act supra.

⁵⁴⁵ *Minister of Welfare and Population Development v Fitzpatrick* 2000 (3) SA 422 (CC).

⁵⁴⁶ *Minister of Welfare and Population Development v Fitzpatrick* supra para 17.

⁵⁴⁷ Currie and De Waal. *The Bill of Rights Handbook*. (2013) 620.

⁵⁴⁸ *Bannatyne v Bannatyne* 2003 (2) SA 363 (CC).

entitles the child the right to housing or shelter,⁵⁴⁹ to the best mechanisms for enforcement of maintenance orders,⁵⁵⁰ and to the extension of maintenance orders to the paternal grandparents in respect of children born to unmarried parents.⁵⁵¹ It also includes the ability of unmarried fathers, foreign couples and same sex couples to adopt children,⁵⁵² and⁵⁵³ the child's right to medical treatment despite the refusal of the parents to consent so such treatment,⁵⁵⁴ to claim for loss of support arising from the death of a foster parent,⁵⁵⁵ and even in relation to future rights and interests, involving an unborn child post fertilisation.⁵⁵⁶

However, there can be difficulty in deciding where and how the best interests of the child right can be applied. It has been contended in other jurisdictions that where there is a conflict between a child's interests and the interests of another person, the child's interests must be the paramount consideration.⁵⁵⁷ However, this does not mean that this right is not subject to limitation, as in the case of any other right. The High Court, in the case of *De Reuck v Director of Public Prosecutions*⁵⁵⁸ held that 'a child's best interests . . . is the single most important factor to be considered when balancing or weighing competing rights and interests concerning children. All competing rights must defer to the rights of children unless unjustifiable',⁵⁵⁹ thus affirming that in the case of competing rights or interests, the courts would side with the interests or rights of the child. However, on appeal to the Constitutional Court this decision was overturned.⁵⁶⁰ The court held that section 28(2) of the Constitution did not 'trump' the rights of others, as that would be 'alien to the approach adopted by this court that constitutional rights are mutually interrelated and interdependent and form a single constitutional value system'.⁵⁶¹ Section 28(2) of the Constitution was subject to the section 36 limitation clause similar to any other right enshrined in the Constitution.⁵⁶² Therefore, it can no longer be assumed that the best interests of the children automatically outweighs the

⁵⁴⁹ *Government of the Republic of South Africa v Grootboom* 2001 (1) SA 46 (CC).

⁵⁵⁰ *Bannatyne v Bannatyne* supra.

⁵⁵¹ *Petersen v Maintenance Officer, Simon's Town Maintenance Court* 2004 (2) SA 56 (C).

⁵⁵² *Fraser v Children's Court, Pretoria North* 1997 (2) SA 261 (CC).

⁵⁵³ *Du Toit v Minister of Welfare and Population Development* 2001 (12) BCLR 125 (T).

⁵⁵⁴ *Hay v B* 2003 (3) SA 492 (W).

⁵⁵⁵ *Fortuin v Road Accident Fund* 2015 (5) SA 532 (GP).

⁵⁵⁶ *Ex parte MS* 2014 (3) SA 415 (GP).

⁵⁵⁷ M Giroux and M De Lorenzi 'Putting the Child First: A Necessary Step in the Recognition of the Right to Identity' (2011) 27 *Canadian Journal of Family Law* 72.

⁵⁵⁸ *De Reuck v Director of Public Prosecutions, Witwatersrand Local Division* 2003 (3) SA 389 (W).

⁵⁵⁹ *De Reuck* supra para 10.

⁵⁶⁰ *De Reuck v Director of Public Prosecutions (Witwatersrand Local Division)* 2004 (1) SA 406 (CC).

⁵⁶¹ *De Reuck* supra para 55.

⁵⁶² *De Reuck* supra paras 27-30.

competing constitutional rights of others.⁵⁶³ It has been suggested that ‘while the best interests of the child are of vital importance, they are not the only consideration’, and caution should be used in the application of this principle.⁵⁶⁴ This being the case, the determination of what is in the best interests of the child is contentious, as noted by the court in *S v M*:⁵⁶⁵ ‘[T]he very expansiveness of the paramountcy principle creates the risk of appearing to promise everything in general while actually delivering little in particular’.⁵⁶⁶ In the same paragraph, the court acknowledged that the best interests of the child principle had been attacked for being indeterminate, with various professions having different perspectives on the concept, and it being influenced by the value system of the decision-maker. The court held that ‘a close and individualised examination of the precise real-life situation of the particular child involved’ would be required in determining what is in the best interests of the child, and that ‘a predetermined formula for the sake of certainty, irrespective of the circumstances, would in fact be contrary to the best interests of the child concerned’.⁵⁶⁷ This indicates that the best interests of the child should be decided on a case-by-case basis, avoiding any fixed rules in deciding the best interests of the child. However, section 7 of the Children’s Act⁵⁶⁸ is instructive for interpreting the best interests of the child, as it provides factors to consider. The factors are first contained in subsections 1(h), which lists ‘the child’s physical and emotional security and his or her intellectual, emotional, social and cultural development’ as being factors to consider in determining the best interests of a child. This echoes SALRC paper’s proposal that ‘the interest in being free from psychological harm seems to present the most convincing argument that an individual has a right . . . to information about who their donor actually is’.⁵⁶⁹ The other relevant subsection is 1(k): ‘[T]he need for a child to be brought up within a stable family environment’, echoing the note in the SALRC *Right to Know* paper that ‘rights proponents contend that withholding the truth about donor-conceived children’s mode of conception is likely to have negative consequences on family relationships’.⁵⁷⁰

⁵⁶³ CJ Davel, & A Skelton (eds). *Commentary on the Children's Act 2007* ch2-16.

⁵⁶⁴ C Van Niekerk ‘Section 294 of the Children's Act: Do roots really matter?’ (2015) 18(2) *Potchefstroom Electronic Law Journal/Potchefstroomse Elektroniese Regsblad* 417.

⁵⁶⁵ *S v M* 2008 (3) SA 232 (CC).

⁵⁶⁶ *SvM* supra para 23.

⁵⁶⁷ *SvM* supra para 24.

⁵⁶⁸ 38 of 2005.

⁵⁶⁹ SALRC *The Right to Know* supra at 38.

⁵⁷⁰ SALRC *The Right to Know* supra at 20.

There does exist empirical evidence that a child may not suffer psychological harm, or negative consequences in family relationships because of donor-anonymity.⁵⁷¹ Evidence suggests that a main reason for donor-conceived children wishing to know the identity of their biological parents, is curiosity about the physical appearance of their biological parents, in order to make sense of their own physical or personality traits, rather than wanting a relationship with such biological parent. However, curiosity about such things is not likely to be sufficient grounds for amending legislation.⁵⁷² While it has been noted by one author that ‘genetic relatedness, in one way or another, informs most people’s self-understanding and sense of identity’, and thus the process of self-understanding becomes more challenging without information about a person’s genetic parents. However, many people who lack access to such information are still able to form perfectly healthy identities. The same author notes that

‘several studies investigating donor-conceived children’s social and emotional development have shown no significant differences in socioemotional adjustment between donor-conceived children and those naturally conceived.’⁵⁷³

Evidence reported in a longitudinal study by Ilioi et al of impacts on donor-conceived children is instructive:

‘[T]he findings showed that adolescents who were unaware of their biological origins did not differ from adolescents who had been told about the circumstances of their birth (at any age), or from naturally conceived adolescents, in terms of psychological wellbeing or the quality of family relationships.’⁵⁷⁴

This indicates that it is not necessarily in the best interests of donor-conceived children to know their biological parents, as there is no clear benefit indicated in any studies or empirical evidence suggesting this. That is not to say that it is in their best interests for the principle of donor-anonymity to remain in place, but rather that it does not seem to make a large difference to their psychological well-being either way.

⁵⁷¹ see S Golombok F MacCallum E Goodman and M Rutter ‘Families with Children Conceived by Donor Insemination: a Follow up at Age Twelve’ (2002) 73 *Child Development* 952; Waldman E ‘What do We Tell the Children?’ (2006-7) 35 *Capital University Law Review* 517; S Golombok et al ‘The European Study of Assisted Reproduction Families: Family Functioning and Child Development’ (2002) 17 *Human Reproduction* 830.

⁵⁷² I De Melo-Martín ‘How best to protect the vital interests of donor-conceived individuals: prohibiting or mandating anonymity in gamete donations?’ (2016) 3 *Reproductive Biomedicine & Society Online* 105.

⁵⁷³ ID Melo-Martín . The ethics of anonymous gamete donation: Is there a right to know one’s genetic origins? (2014) 44(2) *Hastings Center Report* 32.

⁵⁷⁴ E Ilioi et al ‘The role of age of disclosure of biological origins in the psychological wellbeing of adolescents conceived by reproductive donation: a longitudinal study from age 1 to age 14’ (2017) 58(3), *Journal of Child Psychology and Psychiatry* 321.

Thus, it would seem that the principle of the best interests of the child would not be a compelling argument in allowing donor-conceived children a right to know their biological parents. In balancing the competing rights and interests of various role players, if the psychological well-being of the child is of importance in attempting to consider the competing rights of donor-conceived children with the rights of their biological parents as donors, it is unlikely that the best interests of the donor-conceived children would be a conclusive right, as the evidence suggests that they do not derive a clear psychological benefit from knowing the identities of their biological parents.

CHAPTER V

CONCLUSION

The right to privacy in our law probably extends to an individual's DNA or genetic information, as the provisions in POPIA are likely to be applicable to genetic information. As such, it will up to the individual to decide whether to protect or divulge his or her genetic information. Since a person may consent to having personal, or special personal information disclosed or divulged, he or she would be entitled to do so in terms of POPIA.

Where an individual wishes to disclose or publish his or her own DNA or genetic information, even though it may reveal information about a relative, he or she is choosing to divulge information which involves another. He or she is not using another person's name, nor specifically or intentionally subjecting another to publicity or attention. Any unwanted attention which a relative may receive would be incidental to an individual exercising his or her rights to publish information relating to his or her DNA or genetic data. Thus, applying the principles from *Kaysen*, as well as considering the principles of the joint occupancy cases, it is likely that a person's right to publish his or her genetic data would not be limited by the right of a relative to privacy.⁵⁷⁵

This poses a significant risk to donor anonymity, not by directly allowing a donor-conceived child access to the identity of his or her donor, but by allowing persons the right to publish the results of their direct-to-consumer genetic tests, or uploading them to genealogical databases, where they are putting relatives at risk of being located by other genetic relatives who may come up as matches on these databases. This puts donors at risk of being tracked by donor-conceived offspring, and could conceivably make the principle of, or attempts at, donor-anonymity futile.⁵⁷⁶

In addition to this, within the existing legal framework, the principle of donor-anonymity as it stands may not pass constitutional muster, while the principles contained in the CRC are not likely to be interpreted as extending a right to donor-conceived children to know their biological parents. Nor is the principle of the best interests of the child, enshrined

⁵⁷⁵ T Woodage 'Relative futility: Limits to genetic privacy protection because of the inability to prevent disclosure of genetic information by relatives' (2010) 95 *Minnesota Law Review* 707.

⁵⁷⁶ See 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* 1135-1140. See also Meghana Keshavan, 'There's no such thing as anonymity: With consumer DNA tests, sperm banks reconsidering long-held promises to donors' *Statnews*, September 11, 2019. Available at <https://www.statnews.com/2019/09/11/consumer-dna-tests-sperm-donor-anonymity/>

in international law, as well as our own Constitution, legislation and jurisprudence, likely to be able to be applicable to end donor-anonymity, as each instance must be decided on a case-by-case basis, and in the context of donor-conceived children, empirical evidence does not suggest that there is a clear benefit for donor-conceived children to know their biological parents. Nevertheless, South African law as it stands denies a clear benefit protected in our law to donor-conceived children, that of access to information, which is afforded to all other groups of children, namely adopted and naturally conceived children. It also infringes the rights of donor-conceived children to equality when considering a denial of this benefit as compared to the other groups of children. As such, after a consideration of the existing legal principles in South Africa, together with the impact of developing technologies, it is unlikely that donor-anonymity as a principle will endure in South African law.

This being the case, any amending law will have to allow donor-conceived children to know the identity of their biological parents, or donors, while still protecting the interests of such donors. Adopted children are sometimes used as an analogy for donor-conceived children, and one recommendation has been to amend the law relating to donor-conceived children in order to make it similar to that for adopted children, where donor-conceived child, like the adopted child, would be, given access to the identity of the biological parent upon reaching the age of 18 years.⁵⁷⁷

This position fails to take into account the challenges posed by direct-to-consumer genetic testing. While a discussion of the legal position relating to adopted children is beyond the scope of the current analysis, the principle of donor-anonymity is precarious due to the fact that adopted parents are increasingly likely to be able to be traced using increasingly popular genealogical databases. The present framework may become untenable if the law pertaining to donor-conceived children were to be altered to reflect the new reality.

However, there are other ways to protect the privacy of donors. Arguably, there is no more harm in donor-conceived individuals managing to locate donors than there is any other member of the public tracking relatives using genealogical databases. Where existing laws are invalid, either parliament may intervene to amend the relevant provisions, or courts may be called upon to pronounce upon the constitutionality of the provisions.⁵⁷⁸ Were the courts to declare the provisions prohibiting the disclosure of the identity of gamete donors

⁵⁷⁷ T Skosana, 'A donor-conceived child's right to know their genetic origin: a South African perspective.' (2017) 38(2) *Obiter* 274.

⁵⁷⁸ C Van Niekerk 'Section 294 of the Children's Act: Do roots really matter?' (2015) 18(2) *Potchefstroom Electronic Law Journal/Potchefstroomse Elektroniese Regsblad* 414.

unconstitutional, there are alternative remedies available in law to protect a person's privacy against unwanted intrusion, which are as equally applicable to donor-conceived individuals as any other ordinary person. These include laws against nuisance, trespass, anti-stalking or violence.⁵⁷⁹ There could also be contractual clauses when a person obtains gametes which would aid in regulating what he or she may or may not do in relation to the ability to track down the donor.⁵⁸⁰ However, relying on contractual clauses would leave the principle of donor anonymity completely up to the discretion of the individual gamete supplier, and thus there would not really be a principle of anonymity or disclosure at all.

If the laws against nuisance, trespass, anti-stalking or anti-violence as abovementioned are to be relied upon to protect the interests of gamete donors, or even donor-conceived children, who do not wish to be contacted by the biological relative, these laws in South Africa would be laws against trespassing, as contained in the Trespass Act⁵⁸¹ as well as the Protection from Harassment Act.⁵⁸² In terms of the Trespass Act, no person may enter the land, building or part of a building without the permission of the owner or lawful occupier of such land, building or part of the building.⁵⁸³ In terms of the Protection From Harassment Act, a person may not engage in conduct which causes harm to another person, by unreasonably :

‘(i) following, watching, pursuing or accosting of the complainant or a related person, or loitering outside of or near the building or place where the complainant or a related person resides, works, carries on business, studies or happens to be;

⁵⁷⁹ D Adams & S Allan ‘Building a Family Tree: Donor-Conceived People, DNA Tracing and Donor-Anonymity’ (2013) 7(2) *Australian Journal of Adoption* 12.

⁵⁸⁰ There is at present a court case under way in the United States involving a woman, Danielle Teuscher, who conceived using donor sperm, and subsequently uploaded her daughter's DNA to a genealogical database after using a direct-to-consumer genetic test. The mother of the donor, or the paternal grandmother of her daughter came up as a match. After contacting the woman who came back as a match, Danielle received a cease and desist letter from the sperm bank from which she had purchased her sperm. The sperm bank further notified Daniella that they were entitled to liquidated damages in the amount of \$20 000, as well as revoking further vials of sperm which she had purchased, for breach of an agreement which she had signed with them that she would not ‘seek or make any effort to obtain information not directly provided through NW Cryobank concerning the identity, background, or whereabouts of the donor at any time and from any source whether directly or indirectly and/or by any means’. The sperm bank claimed two breaches, one for taking the genetic test, and one for contacting the mother of the donor. Daniella Teuscher is in the process of suing the sperm bank. The outcome of this case will indicate whether or not a person can contract out of his or her right to taking a direct-to-consumer genetic test, although it has been suggested that this is unlikely to be the case. It will also indicate what the legal position may be where a donor is located using a direct-to-consumer genetic test and a genealogical database. see Ellen Trachman, ‘Beware Of The Home DNA Test! Mom Strikes Back Against Sperm Bank’ *Above the Law*, October 23, 2019. Available at <https://abovethelaw.com/2019/10/beware-of-the-home-dna-test-mom-strikes-back-against-sperm-bank/>

⁵⁸¹ Act 6 of 1959.

⁵⁸² Act 17 of 2011.

⁵⁸³ S 1.

(ii) engaging in verbal, electronic or any other communication aimed at the complainant or a related person, by any means, whether or not conversation ensues; or

(iii) sending, delivering or causing the delivery of letters, telegrams, packages, facsimiles, electronic mail or other objects to the complainant or a related person or leaving them where they will be found by, given to, or brought to the attention of, the complainant or a related person;⁵⁸⁴

The definition of ‘harm’ is given as ‘any mental, psychological, physical or economic harm’.⁵⁸⁵ While the definition of what constitutes harm may be somewhat broad, it seems that the Protection From Harassment Act would apply to prevent either a donor-conceived child, or perhaps even a donor, to contact the biological parent or child, by any means including entering their property or physical vicinity, or any other means of communication, where the other party does not consent to such means of communication or contact. However, this method of protecting the interests of the party is not ideal since, in terms of the Act, application must be made to court, the court must consider the application, and must make an interim protection order. A return date must then be given, and the order may be made final, but reasons can be given why it should not be made final.⁵⁸⁶ Thus, a party is not automatically given protection from contact or communication being made.

Under the Act then, if a donor-conceived child has made contact with a donor, or vice versa, and the donor, or donor-conceived child objects to this contact, he or she must make application to court, and specifically be given a protection order, so that this contact is prohibited. This requires the aggrieved party to prove that harm has been suffered, and the order may or may not be granted. As such, existing laws could be invoked to protect the interests of the donor, or donor-conceived child, although they may not be ideal.

Perhaps a more ideal framework would be for consent to be required by the parties, before contact is permitted between the donor and the child.⁵⁸⁷ This could be done by the donors preferences being recorded in a databank when he or she is to donate his or her gametes. However, a donor’s preferences regarding contact may change between the time

⁵⁸⁴ S 1 ‘harassment’ (a).

⁵⁸⁵ S 1 ‘harm’.

⁵⁸⁶ S 3.

⁵⁸⁷ N Cahn ‘Necessary subjects: the need for a mandatory national donor gamete databank’ (2009) 12, *DePaul Journal of Health Care Law* 223.

of donation, and the time that the child were to attempt contact with the donor.⁵⁸⁸ More ideal then would be for consent to be required at the time of first contact being made between the parties. Thus, legislation should be altered, specifically the clauses prohibiting identity release of gamete donors, regulation 19 of the regulations relating to the artificial fertilisation of persons,⁵⁸⁹ and sections 41(1) and 41(2) of the Children's Act,⁵⁹⁰ which would then allow identity release, but an extra clause in these sections should be added, requiring consent to be given either by a donor, or a donor-conceived offspring, before further contact may occur.

Thus, due to the advent of direct-to-consumer genetic testing, the principle of donor anonymity may become increasingly unfeasible, although as the law stands, other measures could be taken to protect the privacy rights of donors against unwanted intrusion or contact by donor offspring. It is submitted therefore, that the principle of donor-anonymity should be abolished, but that at present existing laws be invoked to protect the interests of donors (including their right to privacy) using the Trespass Act,⁵⁹¹ as well as the Protection from Harassment Act.⁵⁹² However, these existing laws may not be ideal, and more desirable would be for the legislature to alter the law, and existing statutes could also be altered, permitting identity release of gamete donors, specifically protecting the rights of both donors and donor-conceived children, including requiring a donor, or perhaps a donor-conceived child, to express his or her consent to be given before any contact is permitted to take place between the donor and the donor-conceived child.⁵⁹³ This consent should be either given or withheld upon first contact for further contact between the parties. Where consent is given, contact may continue, but where consent is not given, contact may not continue. Thus, while the principle of donor-anonymity should be removed, there are other mechanisms to protect the interests and privacy of a donor.

⁵⁸⁸ JE Scheib A Ruby & J Benward 'Who requests their sperm donor's identity? The first ten years of information releases to adults with open-identity donors' (2017) 107(2) *Fertility and sterility*, 491.

⁵⁸⁹ National Health Act 61 of 2003, Regulations Relating to the Artificial Fertilisation of Persons, 2012.

⁵⁹⁰ 38 of 2005.

⁵⁹¹ 6 of 1959.

⁵⁹² 17 of 2011.

⁵⁹³ N Cahn 'Necessary subjects: the need for a mandatory national donor gamete databank' (2009) 12, *DePaul Journal of Health Care Law* 223.

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APPENDICES

(a) California Cryobank

GENETIC TEST SUMMARY



Donor: 14897

ANCESTRY	JEWISH ANCESTRY?*
Irish, Italian, Sicilian	No

IT IS STRONGLY RECOMMENDED THAT YOU DISCUSS THE DONOR'S RESULTS WITH YOUR PHYSICIAN PRIOR TO SHIPMENT TO VERIFY THAT THIS DONOR IS SUITABLE FOR YOUR USE.

TEST RESULTS

GENETIC TEST	RESULT	DETAILS / ESTIMATED RESIDUAL RISK**
Chromosome (karyotype) analysis	Normal male karyotype	No evidence of a clinically significant chromosome abnormality
Hemoglobin evaluation	Normal hemoglobin fractionation and MCV/MCH results	Reduced risk to be a carrier for sickle cell anemia, thalassemias, and other hemoglobinopathies
Expanded Carrier Screening	See attached	Some donors may have positive carrier screening results for one or more of the conditions tested. Please see the following reports for details. Please note that this donor has more than one report attached.

ALL people carry genetic mutations for disorders inherited in an autosomal recessive (AR) manner, and some of these mutations can be detected by genetic carrier screening. A person's offspring are not expected to develop that condition unless they inherit mutations for the same AR condition from BOTH parents. Therefore, CCB strongly recommends that all recipients and their physicians discuss a donor's genetic test results PRIOR to shipment of a donor's specimens, to ensure that the results are suitable for the recipient's reproductive plans. CCB also recommends that the recipient meet with a genetic counselor who can help to explain the donor's results and testing options that may be appropriate for the recipient to consider.

Genetic testing can only reduce the chance for specific inherited conditions in a donor's offspring; it cannot eliminate the risks for those specific disorders or other untested conditions. There is always a 3 to 4% chance to have a child with a medical issue, regardless of the screening performed.

*Please see the Donor Profile for details on the type of Jewish ancestry (Ashkenazi, Sephardic, maternal, paternal, etc.).

Donor: 14897
This donor's GTS was originally created: 08/09/16 and last revised: 04/01/20.
Results are subject to change without notification.

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PATIENT INFORMATION	SPECIMEN INFORMATION	PROVIDER INFORMATION
14897, Donor ID#: Not Listed DOB: 1989 Sex: Male	Type: Semen Collected: September 23, 2016 Received: March 19, 2020 PG ID:	Jaime Shamonki, MD Samantha Melnick, MS, LCGC California Cryobank

MOLECULAR GENETICS REPORT:
Oculocutaneous Albinism Type 2 (OCAII) via the OCA2 Gene

SUMMARY OF RESULTS

NEGATIVE

RESULTS AND INTERPRETATIONS: In this patient, for the OCA2 gene, we found no sequence variants that are likely to be a primary cause of disease.

This patient is apparently negative for copy number variants (CNVs) within the genomic regions of this test.

These results should be interpreted in context of clinical findings, family history and other laboratory data. All genetic tests have limitations. See limitations and other information for this test on the following pages.

NOTES: Since this test is performed using exome capture probes, a reflex to any of our exome-based tests is available (PGxome, PGxome Custom Panels).

GENE ANALYZED: OCA2

SUMMARY STATISTICS:

Pipeline	Version	Average NGS Coverage	Fraction Bases Covered with NGS
Infinity Pipeline	1.0.0	179x	100.0%

Minimum NGS coverage is $\geq 20\times$ for all exons and $\pm 10\text{bp}$ of flanking DNA, and $\geq 10\times$ from 11-20bp of flanking DNA.

ENHANCED GENE LIST (Transcript Number - 100% coverage): OCA2 (NM_000275)

Electronically signed on March 30, 2020 by:
Madhulatha Pantrangi, PhD
Human Molecular Geneticist

Electronically signed and reported on March 30, 2020 by:
Luke Drury, PhD, HCLD(ABB)
Human Molecular Geneticist

Patient	Sample	Referring Doctor
Patient Name: Donor 14897 Date of Birth: [REDACTED]/1989 Reference #: [REDACTED] Indication: Carrier Testing Test Type: CCB Expanded Carrier Screen - Male Panel (261)	Specimen Type: Purified DNA Lab #: [REDACTED] Date Collected: 7/28/2016 Date Received: 6/7/2017 Final Report: 6/27/2017	Jamie M. Shamonki, M.D. California Cryobank-Genetics Department 11915 La Grange Ave Los Angeles, CA 90025 Fax: 888-317-4725

RESULT SUMMARY

THIS PATIENT WAS TESTED FOR 261 DISEASES

POSITIVE for primary hyperoxaluria, type 3

A heterozygous (one copy) pathogenic variant, c.700+5G>T, was detected in the *HOGA1* gene

NEGATIVE for the remaining diseases

Recommendations

Testing the partner for the above positive disorder(s) and genetic counseling are recommended.

CGG repeat analysis of *FMR1* for fragile X syndrome is not performed on males as repeat expansion of premutation alleles is not expected in the male germline.

Individuals of Asian, African, Hispanic and Mediterranean ancestry should also be screened for hemoglobinopathies by CBC and hemoglobin electrophoresis.

Consideration of residual risk by ethnicity after a negative carrier screen is recommended for the other diseases on the panel, especially in the case of a positive family history for a specific disorder.

Interpretation for primary hyperoxaluria, type 3

Next generation sequencing and targeted genotyping were performed for 3 pathogenic variants and 7 out of 7 exons of the *HOGA1* gene. Please note that additional variants not listed may be identified by sequencing. A heterozygous (one copy) intronic variant, c.700+5G>T, was detected in the *HOGA1* gene. This variant is considered to be pathogenic and when present *in trans* with a pathogenic variant causative for primary hyperoxaluria, type 3. Therefore, this individual is expected to be at least a carrier for primary hyperoxaluria, type 3. Heterozygous carriers are not expected to exhibit symptoms of this disease.

What is primary hyperoxaluria, type 3?

Primary hyperoxaluria, type 3 is an autosomal recessive disease caused by pathogenic variants in the *HOGA1* gene. While it has been diagnosed in patients of various ethnicities, it may be more prevalent in individuals of Ashkenazi Jewish descent due to the presence of a founder mutation. Age of onset is typically in childhood, and

Patient: Donor 14897	DOB: [REDACTED]/1989	Lab #: [REDACTED]
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the disease is characterized by the accumulation of calcium oxalate in the kidney and urinary tract, leading to kidney stone formation. Some patients have a milder phenotype where they do not develop kidney stones. Life expectancy is not thought to be affected, and no genotype-phenotype correlation has been reported.

This patient was tested for a panel of diseases using a combination of sequencing, targeted genotyping and copy number analysis. Please note that negative results reduce but do not eliminate the possibility that this individual is a carrier for one or more of the disorders tested. Please see *Table of Residual Risks Based on Ethnicity* for specific detection rates, exons sequenced, number of variants tested and residual risk estimates after a negative screening result. With individuals of mixed ethnicity, it is recommended to use the highest residual risk estimate. Detection rates were determined based on the exons and list of pathogenic variants that are guaranteed by this testing. Please note that additional variants not guaranteed by this test may be identified by sequencing. Only variants determined to be pathogenic or likely pathogenic are reported in this carrier screening test.

TEST SPECIFIC RESULTS

Alpha-thalassemia

NEGATIVE for alpha-thalassemia

HBA1 copy number: 2

HBA2 copy number: 2

No pathogenic variants detected (aa/aa)

Reduced risk of being an alpha-thalassemia carrier

Genes analyzed: *HBA1* (NM_000558.4) and *HBA2* (NM_000517.4)

Inheritance: Autosomal Recessive

Recommendations

Individuals of Asian, African, Hispanic and Mediterranean ancestry should also be screened for hemoglobinopathies by CBC and hemoglobin electrophoresis.

Interpretation

No pathogenic variants were detected in this patient, suggesting that four copies of the alpha-globin gene are present (aa/aa). Typically, individuals have four functional alpha-globin genes: 2 copies of *HBA1* and 2 copies of *HBA2*, whose expression is regulated by a cis-acting regulatory element HS-40. Alpha-thalassemia carriers have three (silent carrier) or two (carrier of the alpha-thalassemia trait) functional alpha-globin genes with or without a mild phenotype. Individuals with only one functional alpha-globin gene have HbH disease with microcytic, hypochromic hemolytic anemia and hepatosplenomegaly. Loss of all four alpha-globin genes results in Hb Barts syndrome with the accumulation of Hb Barts in red blood cells and hydrops fetalis, which is fatal in utero or shortly after birth.

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This individual was negative for all *HBA* deletions, duplications and variants that were tested. These negative results reduce but do not eliminate the possibility that this individual is a carrier. See *Table of Residual Risks Based on Ethnicity*. With individuals of mixed ethnicity, it is recommended to use the highest residual risk estimate.

Table of Residual Risks Based on Ethnicity

Ethnicity	Carrier Frequency	Detection Rate	Residual Risk
Caucasian	1 in 500	90%	1 in 4991
African American	1 in 30	90%	1 in 291
Asian	1 in 20	90%	1 in 191
Worldwide	1 in 25	90%	1 in 241

Spinal Muscular Atrophy

NEGATIVE for spinal muscular atrophy

SMN1 Copy Number: 2

SMN2 Copy Number: 1

g.27134T>G: g.27134T>G negative

Negative copy number result

Decreased risk of being an *SMN1* silent (2+0) carrier (see *SMA Table*)

Genes analyzed: *SMN1* (NM_000344.3) and *SMN2* (NM_017411.3)

Inheritance: Autosomal Recessive

Recommendations

Consideration of residual risk by ethnicity after a negative carrier screen is recommended, especially in the case of a positive family history for spinal muscular atrophy.

Interpretation

This patient is negative for loss of *SMN1* copy number. Complete loss of *SMN1* is causative in spinal muscular atrophy (SMA). Two copies of *SMN1* were detected in this individual, which significantly reduces the risk of being an SMA carrier. Parallel testing to assess the presence of an *SMN1* duplication allele was also performed to detect a single nucleotide polymorphism (SNP), g.27134T>G, in intron 7 of the *SMN1* gene. This individual was found to be negative for this change and is therefore, at a decreased risk of being a silent (2+0) carrier, see *SMA Table* for residual risk estimates based on ethnicity.

SMA Table: Carrier detection and residual risk estimates before and after testing for g.27134T>G

Ethnicity	Carrier Frequency	Detection rate	Residual risk after negative result*	Detection rate with <i>SMN1</i> g.27134T>G	Residual risk g.27134T>G* negative	Residual risk g.27134T>G* positive
Ashkenazi Jewish	1 in 41	90%	1 in 345	94%	1 in 580	^likely carrier
Asian	1 in 53	92.6%	1 in 628	93.3%	1 in 702	^likely carrier
African American	1 in 66	71.1%	1 in 121	N/A	1 in 396	1 in 34
Hispanic	1 in 117	90.6%	1 in 1061	N/A	1 in 1762	1 in 140
Caucasian	1 in 35	94.9%	1 in 632	N/A	1 in 769	1 in 29

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DOB: [REDACTED]/1989

Lab #: [REDACTED]

*Residual risk with two copies *SMN1* detected using dosage sensitive methods. The presence of three or more copies of *SMN1* reduces the risk of being an *SMN1* carrier between 5 - 10 fold, depending on ethnicity.
FOR INDIVIDUALS WITH MIXED ETHNICITY, USE HIGHEST RESIDUAL RISK ESTIMATE

^ Parental follow-up will be requested for confirmation

Fragile X syndrome

Fragile X CGG triplet repeat expansion testing was not performed at this time, as the patient has either been previously tested or is a male. Sequencing of the *FMR1* gene by next generation sequencing did not identify any clinically significant variants.

This case has been reviewed and electronically signed by Ruth Kornreich, Ph.D., Co-Laboratory Director

Laboratory Medical Consultant: George A. Diaz, M.D., Ph.D.

Donor #: 14897Date Completed: 05/11/2016**FAMILY MEDICAL HISTORY**

Please indicate the number of each type of family member. Include half-siblings and individuals who are deceased. Do not include persons who are not biologically related to you.

Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins	
		F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M
1	1	0	1	1	1	1	1	1	2	3	0	1	1	0	1

BLOOD TYPE: AB positive

Please use a checkmark to indicate which of the following medical problems you or one of your family members have had:

Medical Problem	You	Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins		No one	Comments	
				F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M			
1. Cardiovascular																				
A. congenital heart defect																		✓		
B. aneurysm																		✓		
C. angina																		✓		
D. atherosclerosis																		✓		
E. cardiomyopathy																		✓		
F. circulatory disorder																		✓		
G. congestive heart failure																		✓		
H. heart arrhythmia																		✓		
I. heart attack									✓										fatal at age 65; smoker	
J. high blood pressure																		✓		
K. stroke																		✓		
L. other																		✓		

If neither you nor any family members are affected by the medical problem listed, please place a check mark in the box in the far right column labeled "No One".

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Donor #: 14897Date Completed: 05/11/2016**FAMILY MEDICAL HISTORY**

Please use a checkmark to indicate which of the following medical problems you or one of your family members have had:

Medical Problem	You	Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins		No one	Comments	
				F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M			
2. Blood																				
A. anemia																			✓	
B. Fanconi anemia																			✓	
C. hemochromatosis																			✓	
D. hemophilia or other bleeding problem																			✓	
E. immune deficiency																			✓	
F. leukemia																			✓	
G. sickle cell anemia																			✓	
H. thalassemia																			✓	
I. other hereditary anemia																			✓	
J. other																			✓	
3. Respiratory																				
A. birth defect of respiratory system																			✓	
B. asthma																			✓	
C. chronic obstructive pulmonary disease [COPD]																			✓	
D. cystic fibrosis																			✓	
E. emphysema																			✓	
F. hay fever																			✓	
G. lung cancer																			✓	
H. other																			✓	

If neither you nor any family members are affected by the medical problem listed, please place a check mark in the box in the far right column labeled "No One".

Donor #: 14897Date Completed: 05/11/2016**FAMILY MEDICAL HISTORY**

Please use a checkmark to indicate which of the following medical problems you or one of your family members have had:

Medical Problem	You	Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins		No one	Comments	
				F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M			
4. Skin																				
A. acne																			✓	
B. eczema																			✓	
C. melanoma																			✓	
D. pigmentation disorders																			✓	
E. psoriasis																			✓	
F. skin cancer																			✓	
F. other																			✓	
5. Gastro-intestinal																				
A. birth defect of gastro-intestinal system																			✓	
B. celiac disease																			✓	
C. cirrhosis of the liver																			✓	
D. Crohn's disease																			✓	
E. colon/rectal/intestinal cancer																			✓	
F. gall stones			✓																	diagnosed at age 55
G. hernia																			✓	
H. irritable bowel syndrome																			✓	
I. liver cancer																			✓	
J. other liver disease			✓																	impaired liver function attributed to hepatitis C; diag. at age 60
K. pancreatic cancer																			✓	
L. pancreatitis																			✓	
M. stomach cancer							✓													diagnosed and died at age 60; smoker
N. ulcerative colitis																			✓	
O. other																			✓	

If neither you nor any family members are affected by the medical problem listed, please place a check mark in the box in the far right column labeled "No One".

Donor #: 14897Date Completed: 05/11/2016**FAMILY MEDICAL HISTORY**

Please use a checkmark to indicate which of the following medical problems you or one of your family members have had:

Medical Problem	You	Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins		No one	Comments	
				F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M			
6. Renal																				
A. birth defect of the renal system																			✓	
B. cancer of the urinary tract																			✓	
C. other disease of urinary tract																			✓	
D. polycystic kidney disease																			✓	
E. kidney stones																			✓	
F. other kidney disease																			✓	
7. Genital/Reproductive																				
A. birth defect of the reproductive system																			✓	
B. breast cancer																			✓	
C. cervical cancer																			✓	
D. hypospadias																			✓	
E. infertility																			✓	
F. ovarian cancer																			✓	
G. prostate cancer																			✓	
H. testicular cancer																			✓	
I. undescended testicle(s)																			✓	
J. uterine cancer																			✓	
K. other																			✓	

If neither you nor any family members are affected by the medical problem listed, please place a check mark in the box in the far right column labeled "No One".

Donor #: 14897

Date Completed: 05/11/2016

FAMILY MEDICAL HISTORY

Please use a checkmark to indicate which of the following medical problems you or one of your family members have had:

Medical Problem	You	Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins		No one	Comments	
				F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M			
8. Metabolic/Endocrine																				
A. birth defect of the endocrine system																			✓	
B. adrenal disease																			✓	
C. diabetes mellitus			✓																	type II diabetes diagnosed at age 62
D. Gaucher disease																			✓	
E. metabolic disorder																			✓	
F. parathyroid disease																			✓	
G. pituitary disease																			✓	
H. thyroid cancer																			✓	
I. other thyroid disease																			✓	
J. other																			✓	
9. Neurological																				
A. birth defect of brain or spinal cord																			✓	
B. Alzheimer's disease																			✓	
C. attention deficit disorder																			✓	
D. autism																			✓	
E. brain or spinal cancer																			✓	
F. Canavan disease																			✓	
G. cerebral palsy																			✓	
H. developmental delay																			✓	
I. disorders of spinal cord																			✓	
i. anencephaly																			✓	
ii. spina bifida																			✓	

If neither you nor any family members are affected by the medical problem listed, please place a check mark in the box in the far right column labeled "No One".

Donor #: 14897

Date Completed: 05/11/2016

FAMILY MEDICAL HISTORY

Please use a checkmark to indicate which of the following medical problems you or one of your family members have had:

Medical Problem	You	Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins		No one	Comments	
				F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M			
9. Neurological (continued)																				
J. epilepsy or seizure disorder																			✓	
K. familial dysautonomia																			✓	
L. Huntington's disease																			✓	
M. hydrocephalus																			✓	
N. learning disorder																			✓	
O. migraine headaches																			✓	
P. mental retardation																			✓	
Q. movement disorder																			✓	
R. multiple sclerosis																			✓	
S. neurofibromatosis																			✓	
T. Niemann-Pick disease																			✓	
U. Parkinson's disease																			✓	
V. senility before age 50																			✓	
W. speech delay or disorder																			✓	
X. Tourette Syndrome																			✓	
X. other							✓													dementia diagnosed at age 83
10. Mental health																				
A. bipolar disorder																			✓	
B. obsessive compulsive disorder																			✓	
C. depression																			✓	
D. panic or anxiety disorder																			✓	
E. schizophrenia																			✓	
F. other																			✓	

If neither you nor any family members are affected by the medical problem listed, please place a check mark in the box in the far right column labeled "No One".

Donor #: 14897

Date Completed: 05/11/2016

FAMILY MEDICAL HISTORY

Please use a checkmark to indicate which of the following medical problems you or one of your family members have had:

Medical Problem	You	Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins		No one	Comments	
				F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M			
11. Muscles/bones/joints																				
A. birth defect of the skeletal system																			✓	
B. arthritis																			✓	
C. cleft lip and/or cleft palate																			✓	
D. club foot																			✓	
E. deformity of spine																			✓	
F. dwarfism																			✓	
G. gout																			✓	
H. growth delay																			✓	
I. lupus																			✓	
J. muscular dystrophy																			✓	
K. other chronic muscle disease																			✓	
L. osteoporosis																			✓	
M. other																			✓	
12. Sight/sound/smell																				
A. birth defect of sensory system(s)																			✓	
B. deafness before age 60																			✓	
C. deformity of the ear																			✓	
D. significant hearing loss																			✓	
E. blindness																			✓	
F. cataracts before age 50																			✓	
G. color vision deficiency																			✓	
H. glaucoma																			✓	
I. deviated septum																			✓	
J. any other sight/sound/smell disorder																			✓	

If neither you nor any family members are affected by the medical problem listed, please place a check mark in the box in the far right column labeled "No One".

Donor #: 14897

Date Completed: 05/11/2016

FAMILY MEDICAL HISTORY

Please use a checkmark to indicate which of the following medical problems you or one of your family members have had:

Medical Problem	You	Mother	Father	Siblings		Grandparents				Aunts		Uncles		Maternal Cousins		Paternal Cousins		No one	Comments	
				F	M	MGM	MGF	PGM	PGF	Mat	Pat	Mat	Pat	F	M	F	M			
13. Other																				
A. alcoholism																			✓	
B. drug abuse or addiction																			✓	
C. non-cancerous growths or tumors																			✓	
D. cancer not mentioned above																			✓	
E. birth defect not mentioned above																			✓	
F. genetic disorder not mentioned above																			✓	
G. other condition not mentioned above																			✓	

If neither you nor any family members are affected by the medical problem listed, please place a check mark in the box in the far right column labeled "No One".

Has anyone in your family, including yourself, experienced recurring and/or chronic symptoms that have not been evaluated by a physician?

☒ No

☐ Yes

If YES, please describe symptoms.

OTHER SIGNIFICANT MEDICAL HISTORY:

None

(b) Cryos International

Cryos International - Denmark ApS
Vesterbro Torv 3, 5. | 8000 Aarhus C | Denmark
Website: www.dk.cryosinternational.com
E-mail: dk@cryosinternational.com | Tel.: +45 86 76 06 99
Company registration no.: 35514252



Summary of Records

03JUL2020

Donor No.	DUSTIN		
Type:	Non-ID Release	Weight (kg):	105
Race:	Caucasian	Psychological profile:	Qualified
Ethnicity:	Danish, Polish	Education/occupation:	Student (Pedagogue)/Chef
Eye colour:	Brown/Green	Blood group:	O+
Hair colour:	Brown	Extended profile:	Yes
Height (cm):	189		

Infectious Diseases			
HIV 1/2	Negative	HBsAg	Negative
Chlamydia	Negative	Gonorrhea	Negative
Syphilis	Negative	CMV	Positive (IgG+/IgM-)
Anti-HBc	Negative	HTLV I/II	Negative
Anti HCV	Negative	HIV 1/2-NAT	Negative
HBV-NAT	Negative	HCV-NAT	Negative
Urine Culture	Negative	Semen Culture	Negative
Mycoplasma	Negative	Ureaplasma	Negative

Hereditary Diseases			
Karyotype	Normal	Tay-Sachs Disease (HEXA)	Negative
Cystic Fibrosis (CFTR)	Negative	Sickle Cell Disease (HBB)	Negative
Gaucher's Disease (GBA)	Negative	Alfa-thalassemia (HBA)	Negative
Beta-thalassemia (HBB)	Negative	Canavan's Disease (ASPA)	Negative
Familial dysautonomia (IKBKAP)	Negative	Carnitine Transporter Deficiency (SLC22A5)	Negative
Spinal Muscular Atrophy (SMN1)	Negative	Fanconi Anemia Type C (FANCC)	Negative
Mucopolidosis Type IV (MCOLN1)	Negative	Niemann-Pick Type A (SMPD1)	Negative
Bloom Syndrome (BLM)	Negative	Abetalipoproteinemia (MTTP)	Negative
Alport Syndrome (COL4A3)	Negative	Alport Syndrome (COL4A4)	Negative
Arthrogryposis (SLC35A3)	Negative	Bardet-Biedl Syndrome (BBS1)	Negative
Bardet-Biedl Syndrome (BBS2)	Negative	Bardet-Biedl Syndrome (BBS10)	Negative
Carnitine palmitoyltransferase II deficiency (CPT2)	Negative	Congenital Amegakaryocytic Thrombocytopenia (MPL)	Negative
Congenital Disorder of Glycosylation Type 1a (PMM2)	Negative	Dyskeratosis Congenita (RTEL1)	Negative
Ehlers-Danlos Type VIIC (ADAMTS2)	Negative	Familial Hyperinsulinism (ABCC8)	Negative
Galactosemia (GALT)	Negative	Glycogen Storage Disease Type Ia (G6PC)	Negative
Joubert Syndrome 2 (TMEM216)	Negative	Maple Syrup Urine Disease Type 1B (BCKDHB)	Negative
Maple Syrup Urine Disease Type 3 (DLD)	Negative	Multiple Sulfatase Deficiency (SUMF1)	Negative

DUSTIN

Page 1 of 2

Nemaline Myopathy (NEB)	Negative	Phosphoglycerate Dehydrogenase Deficiency (PHGDH)	Negative
Polycystic Kidney Disease (PKHD1)	Negative	Retinitis Pigmentosa (DHDDS)	Negative
Smith-Lemli-Opitz Syndrome (DHCR7)	Negative	Tyrosinemia Type 1 (FAH)	Negative
Usher Syndrome Type IF (PCDH15)	Negative	Usher Syndrome Type III (CLRN1)	Negative
Walker-Warburg Syndrome (FKN)	Negative	Wilson Disease (ATP7B)	Negative
Zellweger Syndrome (PEX1)	Negative	Zellweger Syndrome (PEX2)	Negative
Zellweger Syndrome (PEX6)	Negative		

Biochemistry			
Blood Glucose	Normal	Blood Count	Normal
Creatinine	Normal	Cholesterol	Normal
Triglycerides	Normal	Transaminase	Normal
G6PDH	Normal		

Quarantine released

Standard	Source	Number
DK	www.cryosinternational.com/standards/dk	1-101
EU	www.cryosinternational.com/standards/eu	1-101
ISR	www.cryosinternational.com/standards/isr	1-101
ITA	www.cryosinternational.com/standards/ita	67-101

Released to a Standard in effect at the time of donation.

(c) Aevitas Sperm Bank (SA)



AEVITAS FERTILITY CLINIC

p15

VPW097

Family Profile

Have you or any of your immediate family (parents, grandparents or siblings) ever had any of the following? (If yes, list the family member with the disorder):

Condition	No	Yes	Member	Details
Alcoholism	X			
Allergies	X			
Alzheimer's disease	X			
Anaemia	X			
Arthritis	X			
Asthma or other lung disorders	X			
Cancer (type and age of onset)	X			
Cardiovascular disease		X	Maternal Grandfather	Heart Surgery after Minor Heart Attack
Cerebralpalsy	X			
Cystic Fibrosis	X			
Deafness	X			
Depression	X			
Diabetes	X			
Disorder of eyes or eyesight	X			
Drug abuse/ addiction	X			
Emphysema	X			
Endometriosis	X			
Epilepsy	X			
Haemophilia (bleeding disorder)	X			
High Blood Pressure		X	Mother	Heart Valve Defect
High Cholesterol	X			
Hyperactivity	X			
Inherited Metabolic Disorders	X			
Kidney Disease	X			
Learning Disability	X			
Leukaemia	X			
Liver Disease		X	Me	Helaton Hepatitis (Anesthesia allergy)
Migraines	X			
Multiple Sclerosis	X			
Muscular Dystrophy	X			
Osteoporosis	X			
Ovarian Cysts	X			
Psychological Disorders	X			
Psychiatric Disorders	X			
Sickle Cell Anaemia	X			
Skin Disorders	X			
Tay-Sach's Disease	X			
Thalassemia	X			
Thyroid Disease	X			
Tuberculosis	X			
Ulcers	X			

Mr Justin Michael Basil D'Almaine (211541767)
School Of Law
Howard College

Dear Mr Justin Michael Basil D'Almaine,

Protocol reference number: 00011543

Project title:

Exemption from Ethics Review

In response to your application received on 17/03/2021, your school has indicated that the protocol has been granted **EXEMPTION FROM ETHICS REVIEW**.

Any alteration/s to the exempted research protocol, e.g., Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through an amendment/modification prior to its implementation. The original exemption number must be cited.

For any changes that could result in potential risk, an ethics application including the proposed amendments must be submitted to the relevant UKZN Research Ethics Committee. The original exemption number must be cited.

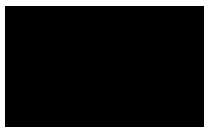
In case you have further queries, please quote the above reference number.

PLEASE NOTE:

Research data should be securely stored in the discipline/department for a period of 5 years.






I take this opportunity of wishing you everything of the best with your study.

Y



Mr Simphiwe Peaceful Phungula
obo Academic Leader Research
School Of Law

UKZN Research Ethics Office
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Website: <http://research.ukzn.ac.za/Research-Ethics/>

Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg  Westville