

## ENSURING GENETIC TRANSPARENCY: LEGAL RIGHTS FOR DONOR- CONCEIVED CHILDREN IN INDIA

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### ABSTRACT

*This study looks deeply into the realm of existing technologies in artificial reproduction. It gives a brief overlook and interpretation of the subsisting legal framework that exists in India, finds the flaws and loopholes present, and suggests necessary amendments that can be brought about to meet the rights and interests of the donor-conceived children soon. In this study, we will also explore and understand why an individual must know their genetic origins as it is inherently linked to many aspects of their life. The introduction of such rights is imperative at this point as the genetic origin is not merely a right but the study shows us its connectedness with one's personal identity, psychological well-being, and emotional stability along with the medical history. Executing a robust judicial and legislative intercession will corroborate efficiently with the perception of a just and equitable society and a decorous life.*

**Keywords:** Donor-Conceived Children, Genetic Origin, Assisted Reproductive Technology (ART), Equality.

### INTRODUCTION

From the dawn of civilization, one thing that has been significantly consistent and vital for societal growth is the adherence to the basic law of procreation. The desire to carry forward the generations and uphold the family's name is one thing that has been a fundamental norm. As society has evolved and technology has advanced, numerous challenges have emerged, one of which is infertility – the inability of parents to naturally conceive a child. However, with the growing trend and advent in advancement, Assisted Reproductive Technology (ART)<sup>1</sup> has evolved and has proved to be an effective solution for couples facing infertility. With the increase in the donation of sperm and eggs, new lives are artificially brought into this world very easily, but with these developments, many loopholes have come to the forefront. One such ethical and pressing issue that has come to light is the legal rights of such donor-conceived

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<sup>1</sup> Assisted Reproductive Technology (Regulation) Act 2021

children to know their genetic origins. In a progressive country like India where people are so highly conscious about their rights, it is imperative to incorporate and ensure the rights of such donor-conceived children whose basic genetic identities often remain obscured. Knowing one's genetic origins is more than just a source of interest; it is an essential component of human identity and sovereignty. The present regulations prioritize donor anonymity over the rights of children conceived using ART technologies. This approach ignores the rising global acceptance of the right to know one's genetic heritage, which many nations have already codified in their legal systems.

### **INTERPRETATION OF ASSISTED REPRODUCTIVE TECHNOLOGIES IN INDIA(ART)**

Driven by the numerous advancements in availing medical facilities, skilled healthcare professions, and cost-effective treatments, India has become a hub for ART. We can skim through this growth by seeing around us, how multiple clinics are offering services like in-vitro fertilization (IVF), gamete donation, and gestational surrogacy. As per private estimates shared with the Standing Committee on Health and Family Welfare (2017), around 2.8 crore couples in the reproductive age group in India are infertile and about 1% of these seek infertility evaluation.<sup>2</sup>

One of the crucial reasons surrounding the surge of people availing of ART and IVF technologies in India is the perceived convenience, affordability, and promising results it has shown over the years. People from both overseas as well as in the country are attracted to this method due to the cost-effectiveness of these treatments making India an appealing destination for fertility tourism. The country's medical facilities have been proven to be substantial as the clinics are well-equipped, with developed infrastructure meeting the international standards of healthcare aligning with the satisfactory needs of the people. The Indian Council of Medical Research (ICMR) has given guidelines that provide for the registration of clinics offering ART services, permit single women and couples to access ART services, and allow ART banks to compensate donors.<sup>3</sup>

Despite the fast rise of ART in India, the regulatory framework has struggled to keep up with the times. The lack of comprehensive and enforceable rules creates several ethical and legal

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<sup>2</sup> Surrogacy (Regulation) Bill 2016, Report 102

<sup>3</sup> National Guidelines for Accreditation Supervision and Regulation of ART Clinics in India, 2005

concerns, notably over the rights of children born through this technological means. There is an urgent need for strong laws that cover the various difficulties related to ART, such as the well-being and rights of donor-conceived children, the welfare of surrogate mothers, and the protection of the intended parents. Children born through the use of donor gametes shall not have any right whatsoever to know the identity (such as name, address, parentage, etc.) of their genetic parent(s).<sup>4</sup> This hour requires an amicable guarantee that donor-conceived children have access to information about their genetic origins protecting their right to privacy and medical records. Additionally, such regulations should promote transparency, ethical practices, and accountability within various clinics, fostering a system that upholds the dignity and rights of all stakeholders involved. Implementing such measures will pave the way for equality for children born artificially, like naturally born children, thereby ensuring the ethical and legal integrity of the practices involved.

Assisted Reproductive Technology (ART) in India has grown dramatically, appearing as a beacon of hope for couples struggling with infertility. With cutting-edge facilities and trained medical personnel, India has become a popular destination for ART treatments such as in vitro fertilization (IVF), sperm donation, and egg donation. The country's low cost compared to Western countries, along with excellent medical infrastructure, draws a diversified clientele looking for successful and affordable reproductive treatments. Despite these developments, the regulatory environment around ART in India remains challenging, particularly in terms of donor-conceived children's rights to know their genetic origins. As the profession evolves, having comprehensive law that protects ethical practices and respects individual rights is important to the future of ART in India.

To remedy circumscribing inadequacies in India's Assisted Reproductive Technologies (ART) legislation must take a comprehensive step in mending and enforcing the rights and interests of all the stakeholders involved in this system. The government of India should prioritize developing strong legislative structures to safeguard the safety and well-being of donor-conceived persons, surrogate mothers, and also intending parents. This arena involves providing the necessary knowledge to donor-conceived persons to access their genetic origins, providing adequate health care and legal recognition and rights to all such individuals so that they can cope and live up to the equality sphere availed to all the other citizens. Furthermore, the legislation should impose robust stringent ethical standards and accountability requirements

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<sup>4</sup> Ibid

for ART clinics, cultivating openness and combating abuse. India can continue its collaborative efforts in ART by introducing measures that ensure ethical procedures and protect the rights and interests of all the parties involved thereby endorsing their nobleness.

### **GRAVITY OF COMPREHENDING GENETIC ORIGINS**

Transparency and openness in family structures are vital ethical ethos. Recognizing the right of donor-conceived children to know their genetic origins respects their individuality and builds a sense of trust and affection within the family circle. It also undermines the importance of ethical practices in the field of reproductive medicine, which further ensures that the rights and dignity of all the individuals involved are highly preserved.

Additionally, understanding one's genetic lines has a tremendous influence on an individual's sense of identity and psychological well-being. A lot of donor-conceived children often highlight that grappling with their biological origins would help them build a complete sense of self. It can alleviate feelings of confusion or grief about their lineage while also contributing to emotional stability. Access to genetic information is essential for knowing the medical history of the persons conceived via donation. Awareness of genetic origins can show predispositions to specific hereditary conditions, allowing for anticipatory treatments. This knowledge is critical for medical practitioners to make prompt decisions about treatment and prevention.

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From the legal lens, the right to know one's genetic origins is fundamentally linked to the protection of personal rights. This includes the right to identity<sup>5</sup>, which is a recognized human right under several international frameworks, including the United Nations Convention on the Rights of Child, 1989 ('CRC'). Legal acknowledgment of this right assures that donor-conceived children have access to information about their genetic parents, confirming their identity and personal history. Inheritance rights are knotted to biological connections. Donor-conceived children require access to their genetic information to claim legal rights to inheritance, which would otherwise be turned down if such origins were unidentified.<sup>6</sup>

Legal exposure to genetic origins can help enforce anti-discrimination legislation. Individuals who are well aware and conscious of their genetic origin can better comprehend and exercise

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<sup>5</sup> United Nations Convention on the Rights of Child 1989

<sup>6</sup> Aditya Kumar, 'Issues for consideration: Assisted Reproductive Technology (Regulation) Bill' (2021) PRS <<https://prsindia.org/billtrack/prs-products/issues-for-consideration>> accessed 07 July 2024

their rights in situations where genetic discrimination happens to appear. Like, in instances where a person faces discrimination because of inherited health defects, having documented and valid access to their genetic origins might help them build a legal case against such unjust treatment. Many nations have existing laws regarding adoption and donor conception which generally include provisions for the right to know the genetic origins. These laws are intended to balance the interests of the donor-conceived children, donors, and parents thereof. Legal frameworks that acknowledge the right to genetic data assist in guaranteeing that donor-conceived persons are not merely disadvantaged when compared to those who are adopted or conceived by natural means, thus fostering a natural sense of justice and equality in society.

Globally, there is rising consensus on the right to know one's lineage. Several nations have introduced laws allowing donor-conceived individuals to obtain donor information once they reach a particular age. These statistics indicate a growing recognition of the relevance of genetics in defining human identity and health consequences. Nations such as the United Kingdom, Sweden, and Australia have legislative frameworks already existing in a place that allow donor-conceived persons to acquire identifying information about their donors, such as names, addresses, and medical histories when they reach the age of 18.<sup>7</sup> The worldwide initiative that recognizes the right to know one's genetic origins indicates a change towards more transparency and reverence for individual rights in the realm of assisted reproductive technology (ART). As most of these countries are enacting comparable legislation, the emphasis of the Indian legislation should have a sharp shift towards balancing the rights and interests of the people involved while encouraging the well-being and autonomy of the donor-conceived persons.

### **POSITION OF DONOR-CONCEIVED CHILDREN IN INDIAN LAW**

Under Indian law, the closest thing to defining such conceptions is 'guardianship', which solely confers 'parental duty' on the guardian. S. 24 of the Guardians and Wards Act of 1890<sup>8</sup> specifies the obligations of a guardian, which include providing for the ward's health, education, and other auxiliary needs. There is no provision in Indian law to acknowledge social parenting. With the increased use of Assisted Reproductive Technology (ART) and a wider range of reproductive options, the law must provide adequate recognition of social parenting while

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<sup>7</sup> Riju Mehta, 'Inheritance rights: How self-acquired, ancestral property will go to different categories of children' *The Economic Times* (India, 28 November 2023) 2

<sup>8</sup> Guardians and Wards Act 1890, s 24

shifting its focus away from biological and genetic parentage.<sup>9</sup> This transition is adequately necessary to ensure that children conceived via ART receive proper legal recognition and protection within family patterns and structures that may differ from traditional conceptions of paternity based exclusively on genetic relationships. Recognizing social parenting in Indian law is critical for encouraging inclusion, protecting all children's rights, and reflecting the intricacies of contemporary family dynamics.

In India, biological parents are not automatically granted legal parenting status in circumstances of adoption, surrogacy, or Assisted Reproductive Technology (ART). This legal framework is critical in addressing the rights of donor-conceived children who may be born through these procedures.

In adoption instances, biological parents give up their parental rights through a legal process that grants complete legal parentage to the adoptive parents. For donor-conceived children who may be adopted, the priority is to integrate them into their adoptive homes while honoring their right to a secure and supportive environment. The Surrogacy (Regulation) Act, 2021<sup>10</sup> governs surrogacy agreements in India.

A considerable range of arguments exist that state that children born out of the wedlock of marriages who are naturally conceived children have due right to know their genetic lineage and history. But when it comes to those born out of ART or other artificial means such rights seem to disappear from the picturesque. Is it a right that can be claimed only when asked for? Like the assurance of other basic fundamental rights that are ensured, comprehensible steps are to be taken to ensure that such facts are disclosed to the children irrespective of their urge to know or not know such facts. There are many corners in India where people are not so well versed with such day-to-day technological developments, for such a crew of people who aren't aware of these rights and may be subject to alienation or discrimination based on their lineage it is quite unjust to keep such people astray from knowing their genetic origins.

S.112 of the Indian Evidence Act (IEA),<sup>11</sup> establishes a presumption that the husband of a pregnant woman is the biological father of the child who is born during the subsistence of such marriage. In India, paternity tests are normally conducted only when there is indisputable proof

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<sup>9</sup> Shreya Jaipuria, 'Parenthood and a child's right to knowledge of genetic origins' (2021) JILS <<https://jils.blog/2021/04/11/parenthood-and-a-childs-right-to-knowledge-of-genetic-origins/>> accessed 10 July 2024

<sup>10</sup> Surrogacy (Regulation) Act 2021

<sup>11</sup> Indian Evidence Act 1872, s 112



that the spouse is not the biological father of the child.<sup>12</sup> This vigilant approach strikes a sense of compromise between the importance of genetic origins, as recognized by the Supreme Court, and other conflicting decisions. Despite the judicial standpoint that has been placed before as to how important it is to understand one's genetic origins for identification and medical perspectives, the legal system is quite skeptical about standardizing court-ordered paternity testing. This reluctance is driven by several factors including the preservation of family unity. Privacy rights of those indulged in this and other possible emotional and social consequences of such disclosures. The Supreme Court of India has underlined the importance of genetic information, stating that understanding one's genetic origins can be crucial for identification purposes, emotional development, and analyzing medical backgrounds. This is particularly pertinent for donor-conceived children, who may have a strong desire to know about their genetic parents to complete gaps in their medical history. Comprehend potential inherited problems and develop a sense of identity. But somewhere the court's decisions are tempered by the base for considering the wide implications of court-ordered paternity tests. If such routine tests were held frequently there would soon appear a sense of distress in the peaceful going of a family. Disrupt the emotional stability of the individuals involved and infringe on privacy rights thereby leading to potential stigma for everyone. The legal arena must keep these factors in mind while deciding upon the rights of donor-conceived children and do something that best suits the rights and interests of all.

Donor-conceived children often confront particular difficulties due to their genetic background. While the right to know one's genealogy is vital for personal and clinical fulfillment, current statutes do not automatically provide such individuals access to such information. Donor confidentiality is frequently safeguarded to maintain their privacy and willingness to engage in Assisted Reproductive Technologies (ART) programs. However, Donor-conceived children may be left in utter darkness about their genetic order due to such secrecy of the donors.

## **SUGGESTIONS**

After analyzing the status of donor-conceived children in India and seeing why the disclosure of such genetic information is of utmost necessity, adequate steps can be taken by the legislative bodies to ensure the guarantee of such rights. The current position in Indian law doesn't recognize any such law that benefits the interests of such children, this part often remains neglected, and a comprehensive and staunch judicial intervention is required to meet the

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<sup>12</sup> Supra note 9

interests and needs of these children so that we all can live up to the true meaning of equality as enshrined in Article 14 of the Indian Constitution.<sup>13</sup>

Necessary modifications and amendments can be made to the Assisted Reproductive Technology (Regulation) Act, 2021 and the Surrogacy (Regulation) Act, 2021 to explicitly include provisions for disclosing the genetic lineage and information of the donor-conceived children. Establishing clear and detailed guidelines as to how such children can request and receive information about the donors, their medical backgrounds as well and their family history can be brought into light once they reach the basic age of understanding so that there is mutual respect and openness between the parties involved.

Implementation of a regulated system of donor anonymity and right to privacy as enshrined in Article 21 of the Indian Constitution<sup>14</sup>, along with the specific rights of the donor-conceived children could be a beneficial step. Non-identifying data can be disclosed at any time and identifying data can be given access to after a particular age when the individual reaches the age of understanding and maturity. An age limit of 18 years and above can be fixed for the same alike other countries having such legislative provisions. Legislating the recognition of social parenting as well as intending parenting as the legal guardian of such donor-conceived children will ensure a sense of clarity, feasibility, and stability in the bubble of the family.

Voluntary disclosure registries along with informed consent can be obtained from the donors. Registries can be mutually beneficial for both parties, where the donors can choose to provide their information so that it can be accessible to their genetic offspring. Implied consent in such matters is highly appreciated as the donor-conceived children will have a superseding interest with the consent of the donor's willingness to access such information about their genetic origins.

Counseling services and support systems can be established as a necessary step to meet this challenge. Providing quality counseling can help people understand the need for the disclosure of such events and also create a friendly atmosphere for them to safely address their concerns and emotional thoughts about identity-related issues. The support systems can help the donors to share their valuable experiences and alongside receive guidance and help to overcome their questionable choices if any and come out with a clear and free mind. Awareness programs

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<sup>13</sup> The Constitution of India 1950, Art.14

<sup>14</sup> The Constitution of India 1950, Art.21



along with proper education and training must be made mandatory to make people aware of these things and bring about a wave of normalization. Everything starts from the brain and educating and feeding the brain with the right information is very crucial. Professionals of healthcare must be made more equipped and trained accordingly to treat the donors carefully by explaining to them the importance of disclosing such genetic origins to future kids.

Data protection must also be ensured to make sure that the information and personal details of the donors are not easily accessible to anyone and everyone. The data is to be protected and disclosed only at the right place when necessary circumstances appear. Regulatory bodies can also be set up to ensure that such functions are carried on smoothly by the ART bodies and clinics so that these practices don't become corrupt shortly and necessary grievances must be addressed from time to time related to all donor conceptions. Lastly, collaborative efforts, proper research, and needful guidance from international standards can be adhered to before drafting and making amendments to such laws so that eventually when a law comes to use it suits the best interests of all and none of the sections of the society is to be a victim of any sort of discrimination.

## CONCLUSION

As the people of India keep advancing with steady steps towards a progressive and developed future, these necessary amendments in the existing laws will not only uphold the sense of an equitable society but also meet the criteria of a dignified virtuous life fully empowered and well informed. India can preserve the ideals of justice and equality inherent in its Constitution by establishing comprehensive legislation that provides access to genetic information, providing strong support networks, and balancing donor privacy with children's rights.

In the times to come, ensuring the rights of donor-conceived children to know their genetic origins will be a major step in the pages of the history written and such equality, candor, pellucidity, and justice will be looked up in society.