

**QueenslandFertilityGroup**

Leading minds dedicated to your success

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Committee Secretary
Legal Affairs and Safety Committee
Parliament House
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Re: Submissions to the Queensland parliamentary inquiry into matters relating to donor conception information from the Queensland Fertility Group

Thank you for accepting the submission of the Queensland Fertility Group (QFG) to the Queensland parliamentary inquiry into matters relating to donor conception information.

QFG, a member of Virtus Health, was founded in 1983 by Brisbane-based pioneers in fertility to become the largest single provider of fertility services in Queensland, with clinics in Brisbane, Cairns, Townsville, Mackay, Sunshine Coast, Toowoomba and Gold Coast. QFG fertility specialists were responsible for the birth of Queensland's first IVF baby in 1984, the state's first baby conceived using a frozen embryo in 1986 and the first Australian baby born to a mother who was conceived through IVF in 2010.

QFG has championed public access to reproductive services, pioneering the expansion of fertility services into regional areas without which many Queenslanders would not have the chance to start a family; establishing Australia's first affordable and accessible IVF model through the introduction of the Fertility Centre and advocating for gamete and embryo donation, including Queensland's first surrogacy pregnancy in 2010.

QFG supports the parliamentary inquiry into matters relating to donor conception and the continued equitable access to donor gametes and embryos in a responsible, safe, and accessible framework. As such, QFG, as an organisation, operates a modern, socio-culturally responsible, person-centred donor program that supports the disclosure of identifying donor information to donor-conceived individuals in line with the requirements of the National Health and Medical Research Council (NHMRC)¹ and the

¹ NHMRC has a unique role in the Australian health system, set out in the National Health and Medical Research Council Act 1992 (NHMRC Act) as the national lead agency for funding health and medical research and the promotion of health and wellbeing. Through clinical, public health and environmental health guidelines, NHMRC supports the translation of research into health practice and policy, and through guidance on responsible research practices and ethical issues, fosters the highest standards of ethics and integrity in the conduct of research and the delivery of health care. (<https://www.nhmrc.gov.au/art>)

Reproductive Technology Accreditation Committee (RTAC)² of the Fertility Society of Australia and New Zealand (FSANZ)³.

In the absence of specific Commonwealth legislation, donor conception practices are regulated autonomously by the states and territories of Australia. Only Victoria, South Australia, Western Australia and New South Wales have enacted legislation governing donor conception. In Queensland, the NHMRC (2017) *Ethical Guidelines on the Use of Reproductive Technology in Clinical Practice and Research*, RTAC (2021) *Code of Practice for Assisted Reproductive Technology Units* and the *Prohibition of Human Cloning for Reproduction Act 2002*⁴ dictate clinical practice. All Queensland clinics providing donor services are accredited by RTAC of the Fertility Society of Australia (Fertility Society). This accreditation, by an independent, third-party regulator, occurs on an annual basis and covers all aspects of the selection and utilisation of donor material.

QFG has been providing donor services since 1983. In the last five years alone, QFG has managed approximately six thousand sperm, egg and embryo donor cycles. The outcome of each cycle has been reported to the Australian and New Zealand Assisted Reproduction Database (ANZARD)⁵, published annually in the Assisted Reproductive Technology in Australia and New Zealand and benchmarked nationally on the YourIVFSuccess⁶ website, both readily accessible public resources. This framework provides an unprecedented degree of regulation, transparency, and accountability unparalleled in any health service in Australia. As such, QFG highlights the risk that state-based legislation of reproductive health care and medical services may jeopardise the access to such services by Queenslanders, as clearly illustrated by the discriminatory draconian legislation mandating police checks for couples accessing fertility services in Victoria until 2020⁷.

At QFG, prospective and existing donors are managed by a clinical and administrative nursing team to verify donor identity in a validated checkpoint system, collate physical and personality descriptions, and collect a medical and family history. Each verified donor then proceeds to full medical and genetic screening. QFG has led the genetic screening of donors through a comprehensive reproductive carrier screening that predates and surpasses the recommendations of the Royal Australian and New Zealand College of Obstetricians and Gynecologists (RANZCOG). Any positive results in donors are managed through the pre-existing medical infrastructure of the clinic without further expense to the donor.

² RTAC is charged with the responsibility of setting standards for the performance of ART through an audited Code of Practice and the granting of licences to practice ART within Australia. RTAC reports to the Board of FSANZ. (<https://www.fertilitysociety.com.au/code-of-practice/#copanz>)

³ FSANZ is the not-for-profit peak body representing scientists, doctors, researchers, nurses, consumers and counsellors in reproductive medicine in Australia & New Zealand. (<https://www.fertilitysociety.com.au/>)

⁴ The object of this Act is to address concerns, including ethical concerns, about scientific developments in relation to human reproduction and the utilisation of human embryos by prohibiting certain practices. This Act specifically prohibits commercial trading in human eggs, sperm or embryos. (<https://www.legislation.gov.au/Details/C2017C00306>)

⁵ ANZARD is a Clinical Quality Registry administered by the National Perinatal Epidemiology and Statistics Unit (NPESU) that collates information and outcomes on all assisted reproductive technology (ART) treatment cycles undertaken in Australian and New Zealand fertility clinics. Over 90 fertility clinics submit data each year as part of their licencing requirements under the RTAC Code of Practice. This report is published annually. (<https://npesu.unsw.edu.au/surveillance-reports>)

⁶ The Australian Government sponsored the development of this website to provide independent and impartial information about all fertility clinics in Australia. In addition to being able to search for Australian IVF clinics, the website also has an IVF Success Estimator so that those thinking about starting, or continuing IVF can make informed decisions. This website was set up by an expert working party established by the Minister for Health, the Honorable Greg Hunt MP, and chaired by Dr Des Soares on behalf of Senator Griff. The working party included representation from IVF patients, Minister Hunt, Senator Griff, FSANZ, ART units, and the NPESU. (yourivfsuccess.com.au)

⁷ Victoria serves as the prima facie exemplar of how state-based legislation can disrupt health care services until the implementation of the recommendations of the *Final Report of the Independent Review of Assisted Reproductive Treatment*. (<https://www.health.vic.gov.au/publications/final-report-of-the-independent-review-of-assisted-reproductive-treatment>)

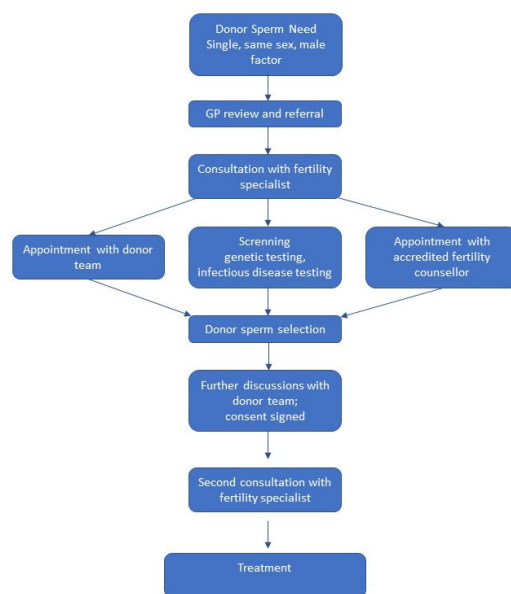
The medical information of each donor is collated, reviewed and actioned by medical specialists, including subspecialists in reproductive endocrinology and genetics. Donor counselling is performed by appropriately qualified, experienced counsellors under RTAC guidelines, including specific emphasis on identity disclosure, continuity of care and the release of identifying information to donor-conceived individuals on request. There is no anonymous donation at QFG.

Document security and medical record management are integral components of modern fertility management. At QFG, donor and recipient data are maintained in a secure, encrypted database with national backup and file recovery, compliant with Australian Standard (2828.1:2019) for digitised and paper health records. Record retention is governed by the Department of Health Standard (QH-IMP-280-1:2014) for the retention and disposal of clinical records, as mandated by Queensland Health. There has been no loss, alteration, or destruction of donor records in possession of QFG.

Health information is managed in the framework outlined in the *Privacy Act 1988* (the Privacy Act), which outlines the privacy responsibilities of healthcare providers, encapsulated in the *Australian Privacy Principles* (APPs). Access to the donor database is by authorised staff through dedicated access points, protected by a secure physical entrance requiring identity verification and logged, password-protected network access in a fully compliant health informatics infrastructure. Given the regulation in place that already governs the management of Health information by healthcare providers, QFG questions the rationale for the collection, retention and administration of health care records by a non-clinical government agency or registry.

QFG has a dedicated professional donor team that links into a national framework under the Virtus Health umbrella. This donor team manages and coordinates all donor, recipient, and donor-conceived person information, as illustrated in Figure 1. Since 2004, all donors have been contacted biannually by the dedicated QFG donor team to maintain the integrity of donor information. As such, critical information such as changes in health status, exemplified by the discovery of a genetic or potentially heritable disorder, can be immediately actioned by clinical personnel within the clinic. The immediacy of this information management pathway is critical to the maintenance of a safe donor program. QFG is concerned that the establishment of a third party register may compromise the integrity of donor information or clinical safety inherent to the current donor, recipient and donor-conceived person management structure.

Figure 1. Person Centred Donor Journey



QFG follows the *Prohibition of Human Cloning for Reproduction Act 2002*, which prohibits the payment of 'valuable consideration' for a donated oocyte, sperm or embryo. However, it permits the payment of 'reasonable expenses' incurred by the donor in connection with the supply of the oocyte, sperm or embryo. 'Reasonable expenses' are defined as including, but not limited to, expenses relating to the collection, storage or transportation of gametes or embryos. consultations, parking or other expenses. Such expenses are reimbursed on the basis of receipts presented to the clinic. There is no non-altruistic donation at QFG.

QFG donor teams are dedicated to the minimisation of the considerable medical and administrative load on donors, which already limits donor acceptability of the donation process. There is a material risk that additional Queensland legislative requirements will increase the complexity and cost basis of donor selection, reducing access for an already vulnerable population.

The linkage of donors, recipients and donor-conceived individuals must occur within a timely, accurate and appropriate framework that protects health information of all individuals. Fertility clinics, as health care providers, have the appropriate infrastructure, knowledge base and skill set to administer this complex information exchange. At the time of this submission, QFG had received, managed and resolved under one hundred patient linkage requests.

Thus QFG is concerned that the establishment of further legislative constraints, would limit the acceptability of the process to donors, increase complexity and cost for recipients and increase health risks to donor-conceived individuals. Australian fertility clinics have already established robust, contemporary processes to manage donors in a safe, transparent and publicly accountable framework.

QFG recognises the importance of and supports the disclosure of identifying donor information to donor-conceived individuals. Undoubtedly, the Queensland parliamentary inquiry into matters relating to donor conception information will receive submissions in relation to the access to identifying donor information where donations occurred anonymously prior to 2004. QFG recognises the importance of this information to donor conceived persons, as well as donors, and has implemented mechanisms for linkage of donors and donor conceived individuals wherever possible.

Medicine, like any other profession, has evolved over time and some practices have historically occurred that, by the current standard, may now not be considered appropriate. Such actions must be seen in their historical socio-cultural context and were taken in the best interest of the donor, the recipient, the donor offspring and their families at the time. Nonetheless, QFG does not support the legislated release of identifying information on donors prior to 2004, as donors provided and recipients accepted gametes on the understanding that their identities would remain confidential. If this commitment of patient confidentiality was to be overridden by any new legislation, without evidence that the presumptions of benefit are shown to be erroneous, there could be widespread consequences to the health care community by undermining the trust implicit in the confidentiality of any patient-doctor or other therapeutic relationship.

In the context of historical donor anonymity, fertility clinics are optimally positioned to facilitate linkage between donors and donor-conceived persons through voluntary linkage programs and support networks. However, not all donor-conceived persons will be able to be linked and QFG acknowledges the challenges and difficulties experienced by some donor-conceived persons in such circumstance. However, QFG recognises that the changes implemented almost two decades ago will protect the current generation of donor-conceived individuals. Fertility clinics have and will continue to support affected donor-conceived individuals, donors and recipients through linkage programs, counselling and support networks.

QFG does not participate in private donor arrangements and cannot provide information on the management of private donor agreements from an organisational point of view. However, QFG recognises the potential medical and legal risks private donor arrangements pose for donors, recipients and donor-conceived individuals. These risks include, but are not limited to, transmission of medical or heritable disorders, uncertainty in the absence of a legal agreement and the unknown number of families created by a single donor. Private donor arrangements are driven by the limited accessibility and cost of donor processes in accredited medical units, and any additional legislative requirements are likely to propagate clandestine donor arrangements by increasing cost and complexity.

In summary, QFG supports the release of identifying donor information to donor-conceived individuals in line with NHMRC and RTAC requirements. Importantly, health care administration cannot be separated from service delivery and therefore, donor services need to continue to rest with fertility clinics who have an established infrastructure and track record of delivering services and managing sensitive health care information. QFG has managed donor services in Queensland in a responsible, safe, transparent and publicly accountable framework without the imposition of state-based legislation or registration. On the contrary, state-based legislation and registration are likely to limit

the acceptability of the process to donors, increase complexity and cost for recipients and increase health risks to donor-conceived individuals by imposing a bureaucratic third party.

QFG is committed to engaging in a collaborative framework with all stakeholders to optimise the outcomes for donors, recipients and donor-conceived individuals.

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