A Gender Agenda

Submission on the General Treatment Plan Application for *Testosterone Replacement for Testosterone Deficiency due to Testicular Failure/Insufficiency in Infancy*, under the ACT *Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023*.

18 November 2025

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Acknowledgements

This Submission

A Gender Agenda, henceforth referred to as 'AGA', thanks the ACT Government for the opportunity to make a submission under the public consultation provision of the *Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023* legislation.

We welcome the opportunity to provide our feedback and input into the consultation process concerning the proposed general treatment plan for the use of testosterone replacement for testosterone deficiency due to testicular failure/insufficiency in infancy.

For brevity, ease of communication, and clarity, *testosterone deficiency due to testicular failure/insufficiency in infancy* will additionally referred to as *"this condition"* throughout the submission. We would like to state that our intent behind, and use of the term "condition" is not pathologised nor referential of language such as *"medical conditions"*. We use this term solely to describe a particular state of being, arising from multiple aetiologies.

A Gender Agenda maintains our intentioned commitment to the depathologisation of our language, and our position that innate variations in sex characteristics represent natural human bodily diversity. To this end, we wish to acknowledge that depathologising and destigmatising language presented a challenge in responding to, and considering this application. The descriptive terms for the described condition such as *"deficiency", "failure",* and *"insufficiency"* are inherently stigmatising and value-laden. We note that this language can contribute to an individual's sense of feeling "incorrect", "less-than" or personally "deficient/insufficient" in their gender, identity or sense of self. Such understandings are unavoidable given the constructions of sex, sex characteristics and the normative ranges of these, such as hormone levels in Western biomedicine.

Our submission has been drafted by our Intersex Projects Coordinator, Gabriel Filpi, and has been reviewed and approved by our Executive Director, Dr. Vik Fraser.

Our Organisation:

A Gender Agenda is a Canberra-based, community-led and community-controlled charity, whose origins stem from grassroots community activism and self-advocacy. For the past 20 years we have, and continue to, provide a wide range of peer and psychosocial support services, personal and community advocacy, systems navigation, education and training. Our work centers around supporting the needs and interests of intersex, transgender and gender diverse communities, and their families in the ACT and surrounds. We work closely with individuals, families, community organisations, professional bodies, and government to advocate for the needs and rights of the communities we serve.

AGA acknowledges the Ngunnawal and Ngambri peoples as the traditional custodians of the land on which we work. We pay our respects to the Elders of the Ngunnawal and Ngambri Nations, both past and present. We acknowledge and respect their continuing connections to land, water, and community.

As an organisation, AGA fundamentally operates from a human rights-based framework, respecting and celebrating the uniqueness and diversity of human experiences. We believe that there is no 'right' way to be male or female, masculine or feminine, and that all people are entitled to autonomy over their bodies, gender identity, and gender expression.

Our Submission

Overview

We would also like to thank A. Quigley for the preparation of this application and the time, research and justification put forward.

While we do not foresee any major issues with the proposed General Treatment Plan, it is our position that this application not be approved, on the basis that Individual Treatment Plans constitute a more appropriate, and superior approach to the management of testosterone deficiency, due to primary testicular failure/insufficiency.

We maintain that an Individual Treatment Plan approach is most suited to the management of this condition, owing to the self-referential rarity, heterogeneity and idiosyncratic presentation of the condition, as evidenced in the application.

We wish to present additional justification, and expand on these points in our submission below.

Additional note:

Prior to the justification of our position, we wish to acknowledge that the desire to provide treatment for the described condition, is proposed here with the intention of the diagnosed individual developing within normative constructions of sex, sex characteristics in Western biomedicine, as closely as possible. Such justification pervades this application, particularly in relation to genital size, linear growth/height and body composition, without acknowledgment of the diversity and ranges of these features in the general population.

Additionally, this treatment is rationalised in no insignificant part, on psychosocial justifications such as the avoidance of potential psychological distress due to physical differences (Part 3.4). Such justification is also invoked by the potential need for future counseling in relation to *"severe teasing"* drawn from a study conducted well over two decades ago (Part 5.3). Conversations, education, and social perceptions of bodily differences, self-esteem and body image have progressed significantly in this time, and we do not feel that this is an appropriate justification for treatment.

Instead, an individualized, case-by-case approach that considers the individual in the context of their family and community is warranted, particularly where such psychosocial factors are to be considered.

Justification for the use of Individual Treatment Plans over a General Treatment Plan:

1. **Documented due process**

The proposed early nature of intervention, difficulties with delaying treatment, and young age of the individual will in most cases preclude their direct involvement in decision making about their body. Where this must occur, a well-documented, evidenced and considered individual treatment plan is appropriate. This allows the individual to request and access this information when they are older and are informed of the early intervention they underwent. An individualized process outlines the specific justification for the treatment in their circumstances, the steps that were undertaken to provide information and support to their caregivers around making their decision regarding treatment and the process of consideration and approval from the Assessment Board. This can be extremely beneficial to caregivers, families and professionals when having disclosure conversations, in any required or chosen subsequent therapy and counselling, and for the individual when learning about their medical history and processing resultant emotions.

For individuals for whom treatment is not approved by the Board, is selectively delayed or deferred at the discretion of families, or for those who clinically present with testosterone deficiency, due to primary testicular failure/insufficiency at an age where they can be involved in decision-making, an individual treatment plan and regulated approach through the Assessment Board similarly allows clear documentation of due process and rationales behind decision making.

As specified in the application, some individuals may clinically present with testosterone deficiency, due to primary testicular failure/insufficiency at an age where they can be involved in decision-making such as childhood or teen years:

> *"The variability of clinical features and age at presentation detailed below indicate that degeneration and failure of the testes may occur during the latter prenatal period (after the first trimester), during infancy, or in childhood"*
>
> *"Although testicular failure/insufficiency is believed to occur most often during the latter prenatal or early perinatal period, clinical presentation can be substantially delayed, in some cases as late as the teen years … The reasons for presentation include absence of testes from the scrotum (empty or flat scrotum), small penis, or failure to enter puberty"*

For such individuals, an individual treatment plan allows and protects their direct and personal involvement in decision making about their body.

2. **Maintained access to appropriate and considered treatment.**

Rejection of a General Treatment Plan for the specified condition will neither deny, nor functionally remove access to medical management of the specified condition. Such nuance is absent from this General Treatment Plan application. This application incorrectly positions a General Treatment Plan as the only way to provide fair and accessible care to individuals, and any opposition of such as denial of care.

For example:

- *"Failure to treat a known hormone deficiency would be contrary to standard of care for endocrine disorders and would deprive an affected child of the right to safe and effective treatment to provide the best opportunity for health and wellbeing."*
- *"the alternative of delaying or denying treatment for a child with a clearly demonstrated endocrine deficiency could be considered experimental and cannot be supported"*
- *"The choice to withhold testosterone replacement during infancy represents a decision not to restore an affected child's endocrine system to its physiologic balance – deliberately prolonging a state of testosterone deficiency in such infants would represent an illogical and experimental approach to management, out of alignment with the principles of treatment of other endocrine disorders"*
- *"Although postponing testosterone replacement for children with testicular failure/insufficiency until adolescence would allow them to participate in decision-making, this approach has no physiological basis and would represent an untested experimental approach of leaving an endocrine deficiency untreated for an extended period of time, and therefore cannot be medically justified"*
- *"… In contrast, by failing to treat a diagnosed endocrine deficiency, denial of testosterone replacement for an affected infant/young child…"*

We wish to address this misconstruction in the justified need for a General Treatment Plan. The use of Individual Treatment Plans does not preclude or inhibit medical intervention. Instead, this creates the best opportunity to document and consider individualised person-centered care that best meets the needs of the individual and their decisionmaker/s. Further this process ensures decisionmakers have the appropriate information and support to make appropriate treatment decisions.

3. Rarity of the described condition and systemic burden

As outlined in the General Treatment Plan application testosterone deficiency, due to primary testicular failure/insufficiency, despite its multiple aetiologies is demonstrably rare.

> *"Bilateral testicular failure/insufficiency is rare, with estimated prevalence of 1:20,000 to 1:40,000 male births"*

Given this rarity and the size of the ACT population, the use of Individual Treatment Plans is unlikely to become onerous or so high in volume so as to overwhelm the system and Assessment Board. Should cases of the described condition arise in the ACT population, individual consideration by the Assessment Board is likely to be straightforward and have the additional benefit of capturing the prevalence cases and treatment decisions, contributing to better data and documentation for the Territory.

Further to this point, the multiple aetiologies of testosterone deficiency, due to primary testicular failure/insufficiency would not always inherently meet the legislative definition of an innate variation in sex characteristics. The General Treatment Plan application states that the aetiology of the condition can include:

> *"Primary testicular failure/insufficiency occurring early in life can result from a variety of causes, including:*
>
> - *genetic variation*
> - *vascular accident/thrombosis*
> - *prenatal torsion or twisting of the testes during their descent from the intraabdominal position in which they originate during fetal life, to the scrotum*
> - *torsion or trauma during the perinatal period*
> - *unknown or hypothetical prenatal or perinatal factors, such as environmental insult or pregnancy complications"*

Where the origin of the condition is demonstrably traumagenic in nature, and not innate, or potentially so, (such as testicular injury, torsion, accidents etc.) these cases are unlikely to require an Individual Treatment Plan or consideration under the *ACT Variation in Sex Characteristics (Restricted Medical Treatment) Act, 2023*.

An individualised approach allows cases of testosterone deficiency, due to primary testicular failure/insufficiency to be understood and responded to in context.

4. Heterogeneity and idiosyncratic clinical presentation

The General Treatment Plan describes not only a wide range of aetiologies, but also a wide variance of clinical presentation, age of clinical presentation/onset and variable clinical features of the described condition.

For example, developmental genital differences are only present in approximately 50% of cases, however, forms a significant focus of proposed treatment:

- *"a typical feature of late-prenatal and early postnatal-onset testosterone deficiency in about half of cases (Zenaty 2006). This readily identifiable clinical sign has historically been the focus of treatment efforts and outcome studies, irrespective of the underlying cause of reduced penile growth"*
- *"low-dose testosterone enanthate treatment increases penile growth in children with small penis, a clinical feature of testicular failure in about half of cases"*
- *"a long-term follow-up study showed a trend toward greater penile length in men who had small penis (a feature of testicular failure in about half of affected infants, Zenaty 2006) and were treated during infancy, compared with those whose treatment was delayed (Wisniewski 2001)."*
- *"a short course of intramuscular testosterone injections during infancy has been standard of care for over half a century for treatment of reduced penile size, which is associated with testosterone deficiency due to testicular failure/insufficiency in about 50% of cases"*
- *"delayed testosterone replacement was less effective than treatment during infancy for increasing the growth of a small penis – a feature of testicular failure in about half of affected infants"*

Additionally, other clinical features and age of presentation are similarly variable as outlined throughout the application:

- *"The variability of clinical features and age at presentation detailed below indicate that degeneration and failure of the testes may occur during the latter prenatal period (after the first trimester), during infancy, or in childhood"*
- *the fact that testes are palpable at birth in some cases provides evidence for a postnatal insult in a subset of patients. Despite variability in the underlying pathological process and age of presentation, affected individuals share a common diagnosis of primary testicular failure/insufficiency resulting in testosterone deficiency"*
- *"As with all endocrine conditions, children who suffer testicular failure/insufficiency have clinical features of varying severity, largely dependent on the timing of the testicular damage and resultant testosterone deficiency"*
- *"However, at some point late in pregnancy, during delivery, or after birth, an acute event causes irreparable damage to the testes, leading to degenerative changes and dysfunction affecting all components of testicular tissue"*
- *"Although testicular failure/insufficiency is believed to occur most often during the latter prenatal or early perinatal period, clinical presentation can be substantially delayed, in some cases as late as the teen years … The reasons for presentation include absence of testes from the scrotum (empty or flat scrotum), small penis, or failure to enter puberty"*
- *The pattern of genital growth primarily reflects the timing of onset of testosterone deficiency, as detailed below.*
  a. Prenatal onset: When testicular failure/insufficiency occurs during the 2nd or 3rd trimester of gestation, the resulting testosterone deficiency leads to reduced growth in

> *length and girth of the penis … In addition to reduced growth of the penis, the other typical feature of prenatal onset testicular failure is shrinkage or atrophy of the testes, leaving a testicular remnant or an empty scrotum*
> *b. Postnatal onset: When testicular failure/insufficiency occurs after birth, the penis is again fully formed, … the size of the penis at birth is likely to be within the normal range for typical male infants of similar gestational age, and testes or testicular remnants may be palpable at birth. However, due to testosterone deficiency during the first 6 or so months of life, the penis may fail to undergo the usual postnatal growth that occurs in male infants with normally functioning testes during the period of mini-puberty, when testosterone production by the infant's testes increases markedly. When testicular failure occurs postnatally, the testes "regress" and become impalpable over time, testosterone production ceases, and penile growth is impaired, such that size may be reduced compared with that of male infants of similar age and ethnicity.'*

Given that clinical features, age of clinical presentation and severity of the described condition are highly variable, it is our position that an individualised approach best meets the needs of individuals and a General Treatment Plan is an inappropriate means by which to approach clinical care and management of testosterone deficiency, due to primary testicular failure/insufficiency.

5. **Psychosocial considerations.**

Due to the young age of most prescribed individuals, verbal and other childhood development factors such as the age of identity formation, gendered considerations are sparse throughout this application. With that said, questions around gender and identity are one of the points that warrant psychosocial support, particularly from the Canberra Health Services' Variations in Sex Characteristics Psychosocial Service (VSCPSS). The application, does however correctly adopt a universal referral approach to the VSCPSS for all diagnosed individuals and their families, irrespective of gendered considerations or concerns/ Individual Treatment Plans, however, would likely offer a more-consistent and documented referral to the service and other psychosocial support that may be missed or less constantly offered under a General Treatment Plan.

The application does not shy away from the importance of this stating that

> *"such support may be effective in helping families to understand the condition and their own responses to it. Support from these sources may help to build resilience for families coping with diagnosis and decisions regarding the benefits and risks of testosterone replacement, thereby fostering overall positive therapeutic outcomes."*

This support is critical in coming to an informed decision and should be documented through an Individual Treatment Plan, rather than offered as a compliment to treatment offered under a General Treatment Plan.

Thank you again for the opportunity to provide commentary on the application for this General Treatment Plan. A Gender Agenda is grateful for your time and consideration of our submission and we encourage the ACT Government to deny this application for a General Treatment Plan in favour of the utilisation of Individual Treatment Plans as the primary function of the ACT Variation in Sex Characteristics (Restricted Medical Treatment) Act, 2023.

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