Rachel Stephen-Smith MLA
Minister for Health
Minister for Children, Youth and Family Services
Minister for Disability
Minister for Aboriginal and Torres Strait Islander Affairs

Member for Kurrajong

RESPONSE TO QUESTION ON NOTICE
Questions on Notice Paper No 44
28 June 2024
Question No. 2044

Asked by MS KIKKERT MLA – To Minister for Health:

1) Which drugs does the ACT public health system administer as "puberty blockers".

2) What was the cost to the ACT public health system of administering these drugs as puberty blockers over the past three financial years, including 2023-2024 (to date).

3) What is the age of the youngest patient to whom any of these drugs has been administered by the ACT public health systems as a puberty blocker.

4) For each drug that is administered as puberty blocker, what are the known side effects.

5) How are these side effects communicated to children/young people who are seeking puberty blocking drugs and their parents.

6) What other information about these drugs is shared with children/young people and their parents, apart from known side effects,

7) What support is offered to these young people experiencing side effects from the puberty blockers.

8) What support is offered to parents.

MS STEPHEN-SMITH MLA - The answer to the Member's question is as follows:

1) Which drugs does the ACT public health system administer as "puberty blockers".

Gonadotropin Releasing Hormone (GnRH) Analogues suppress the secretion of gonadotropin-releasing hormones and are commonly used to pause puberty in young transgender people. In the

ACT Legislative Assembly London Circuit, GPO Box 1020, Canberra ACT 2601
+61 2 6205 2661 stephen-smith@act.gov.au
@RachelSS_MLA rachelSSMLA rachelss_mla

ACT the current puberty blocker used is Diphereline® (Triptorelin embonate) which is given six monthly as a single intramuscular injection.

2) What was the cost to the ACT public health system of administering these drugs as puberty blockers over the past three financial years, including 2023-2024 (to date).

CHS is unable to provide costs related to gender affirming care only as these drugs are also used for medical reasons other than gender affirming care, such as treating precocious puberty, endometriosis and prostate cancer.

3) What is the age of the youngest patient to whom any of these drugs has been administered by the ACT public health systems as a puberty blocker.

This historical data cannot be provided. Given the very small numbers involved in this care the public disclosure of age risks these young people being identifiable.

However, with the establishment of the Paediatric Gender Service (PGS), this data will be able to be provided in future.

It should be noted that, given the importance of sex hormones in normal development during adolescence, initiation of treatments is not recommended until puberty is underway. As the medical component of the PGS has not yet started, no patient has been initiated on this treatment for the last 18 months.

4) For each drug that is administered as puberty blocker, what are the known side effects.

The known side effects of Diphereline include:

- Hot flashes
- Weight gain
- Abdominal pain
- Vaginal bleeding
- Pain and inflammation at the injection site
- Acne
- Headaches
- Hypersensitivity
- Mood changes

These side effects are generally well tolerated by adolescents. Puberty Blockers are considered reversable in that once you stop taking them, puberty will restart from the point it was paused. There are, however, potential long-term effects:

- Decreased bone mineral density. Typically, there is an improvement in bone density once the person stops taking the blockers (or hormone affirming treatment starts), however long-term impact on bone mineralisation is currently unknown.
- The final height of the young person may be different than otherwise expected. Puberty hormones cause growth plates to close; blockers therefore keep them open. This may result in slightly taller height.

There is insufficient evidence to know if there are long term impacts on cognitive- or neurodevelopment.

There are currently long-term studies being conducted that will further inform the evidence base and treatment will evolve accordingly. As such, it is recommended that clinicians follow an individualised approach to gender affirming care, where the risks and benefits for each adolescent is carefully considered. The options for intervention for one young person might not be helpful for another and not every young person accessing care with CHS will be eligible for or choose to access puberty blockers.

5) How are these side effects communicated to children/young people who are seeking puberty blocking drugs and their parents.

The process to access puberty blockers is very involved with specific legal requirements, where there must be agreement among the parents (or those with parental responsibility), the adolescent and the medical practitioner regarding the adolescent's capacity to consent, the diagnosis of gender dysphoria and the proposed treatment. Where there is any dispute over these points, including between the parents, treatment cannot commence without approval from the Family Court.[1]

This process involves multiple assessment sessions with various health professionals including a psychologist or psychiatrist, social worker, nursing, and medical specialists such as a Paediatric Endocrinologist and/or a Paediatrician. Discussion around the risks and benefits of puberty suppression are part of those sessions. As part of the consent process, the adolescent and their parents are given written information on the risks and benefits of puberty blockers. The parents are required to review and sign a consent form that also outlines the risks and benefits before treatment can commence.

6) What other information about these drugs is shared with children/young people and their parents, apart from known side effects.

The treating team will discuss the potential benefits of puberty suppression, including:

- Puberty suppression typically relieves the distress that a trans adolescent experiences with puberty by halting the progression of physical changes;
- It provides a pause to let adolescents develop cognitively and emotionally prior to making a decision regarding gender affirming hormone therapy, as some of those effects are irreversible; and
- Provision of supportive gender affirming care (which may or may not include medical treatment) in adolescence is thought to improve mental health and wellbeing outcomes for trans young people.

The treating team will also provide information on fertility preservation. Puberty suppression will also stop ongoing production of sperm or maturation of eggs, but this is reversible once the medication is stopped. If, however, the young person continues puberty blockers, followed by commencement of gender affirming hormone therapy, future chances of fertility may be adversely affected. As such, this is explicitly discussed, and all adolescents receive fertility counselling and information on fertility preservation prior to starting puberty suppression.

The treating team will also discuss other considerations in relation to when to start puberty suppression. For example, for transgender feminine adolescents there is the consideration of the benefits of allowing sufficient genital growth to support the success of future surgical options.

7) What support is offered to these young people experiencing side effects from the puberty blockers.

Care for all patients, whether or not they are experiencing side effects, includes:

- Regular medical reviews and, depending on side effects being experienced, referral on to other specialists such as a nutrition services, mental health services or gynaecology.
- Assessment of bone density prior to starting blockers and regular monitoring during treatment.
- Calcium and vitamin D supplementation.
- Ongoing support with their psychologist.
- Young people are referred to peer support and other support agencies.

8) What support is offered to parents.

- Parents are supported throughout the decision-making process. This may be ensuring they receive the appropriate information but could also include support from the psychosocial team.
- Referral to community supports in Canberra, such as A Gender Agenda, as well as being informed about web-based supports.
- Ongoing support with the psychosocial allied health team members, i.e. Social Work or Psychology.

It should be noted that this information relates to complex and individualised decisions that adolescents and their parents make with the support of their treating team. Continued questioning of the rights of transgender young people to access medical care is very distressing to young people and their families. CHS is committed to providing care in accordance with Australian guidelines: Australian Standards of Care and Treatment Guidelines for Trans and Gender Diverse Children and Adolescents – AusPATH Main Website.

Approved for circulation to the Member and incorporation into Hansard.

Rachel Stephen-Smith MLA
Minister for Health

Date: 17/8/24

This response required 6 hours 66 mins to complete, at an approximate cost of $855.56