Risks and Benefits of Puberty Suppression

The goal of this form is to provide the most up to date information about the expected effects of puberty suppression, including both the desired effects as well as possible unwanted side effects. You should have the information you need to make decisions about your care. Please do not hesitate to ask questions and talk about any concerns you have at any time.

There are advantages, disadvantages, and possible risks with treatment to block or pause puberty. The main way that the physical changes of puberty can be put on hold is by blocking the signal from the brain to the organs that make the sex hormones estrogen or testosterone. Estrogen is made by the ovaries. Testosterone is made by the testicles.

Gonadotropin releasing hormone agonists, or GnRH agonists, are the medications used for this purpose, and are more commonly called puberty blockers. They may be prescribed for use monthly, every three months, or yearly depending on the specific medication prescribed. In most young people, puberty blockers may be started just after the onset of noticeable physical changes of puberty. You and your medical provider can talk about how to recognize these early changes if you are unsure what to look for.

Your medical provider will help decide which medication(s) and dose(s) may be best for you based on gender affirmation goals, personal and family needs, and any medical or mental health conditions. As part of this treatment, you agree to take medications only as prescribed and to talk with your medical provider before making any changes. You and your medical provider can work together to best support your goals for care as safely as possible. GnRH agonists are not the only medications used to block the effects of estrogen and/or testosterone. Talk with your medical provider to go over all treatment options.

Fenway has worked with gender diverse people for many years. Our approach to gender affirming care is based on scientific evidence whenever possible, national and international guidelines, and the feedback and experience we get from our own gender diverse community. Research on gender affirming hormone therapy provides us with information on the safety and effectiveness of these medications in helping you to achieve your goals. Despite the available research, the long-term effects of puberty blockers and hormone therapy across the lifespan are not yet fully understood. This document outlines what we currently know about these medications. We will pass along any new information or research we learn, especially as it affects your health and wellbeing.

Puberty blockers (specifically GnRH agonists) have been used to help treat gender diverse youth for many years. Treatment follows the recommendations of medical specialists who work with hormones and puberty (endocrinologists). Guidelines for using these medications for gender diverse youth when the physical changes of puberty need to be delayed are published by the Endocrine Society and the American Association of Clinical Endocrinologists, however gender affirming care is still considered an "off label" use of these medications.

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Expected Physical and Emotional Effects of Lupron

The effects of this medication may take several months to become noticeable. No one can predict how quickly or slowly someone's body will respond.

The effect of GnRH agonists is NOT PERMANENT and if this medication is stopped, the body will restart making its own hormones and the changes of puberty will continue from where they were paused. This may take a few weeks to months or longer.

- Puberty blockers are used to help temporarily suspend or block the physical changes of puberty.
- While taking this medication, your body will not be making the hormones of puberty, testosterone or estrogen. This will "put on hold" some of your physical development.
- Lupron may not not stop all development, such as growing taller.
- These medicines may help you avoid the need for future gender affirming surgeries and other treatments (i.e. chest reconstruction or augmentation, facial surgeries, electrolysis) that may have otherwise been needed to reverse some effects of puberty.
- Stress that is present due to being gender diverse, social rejection and judgments, and needing to take any medications may cause increases in your level of distress, anxiety, depression, or other mental health issues.
- Many people who take this medication are also experiencing other social stressors in their lives associated with their gender identity and expression, such as social rejection and judgement from others. Additionally, sometimes the need to take any medication can cause increases in levels of distress, anxiety, or depression. Many patients and families benefit from mental health support to reduce stress and improve or maintain the ability to cope with everyday life and medical treatments. You are encouraged to talk with the medical provider about benefits from and recommendations for individual and family therapy.

Possible Fertility Effects of GnRH Agonists

- Blocking puberty development means you may not develop mature sperm or eggs which are needed for fertility.
- If interested in having children later in life with your own eggs or sperm, you would need to stop puberty blockers (and hormones if you are on them) and allow the ovaries or testicles in your body to develop and mature. The process of stopping puberty blockers and/or affirming hormones may also cause other secondary sex characteristics to develop that may not feel affirming.
- Data is limited as to the long-term effects of puberty blockers and GAHT on future fertility. If the decision is made to stop puberty blockers, there is good evidence to suggest that the development of mature eggs and sperm will occur, but the timeline and future fertility cannot necessarily be assured.
- With current technology, only mature/fully developed eggs and sperm can be banked for future use. Therefore, some degree of puberty will have to be achieved with one's own hormones if banking is desired. The degree to which pubertal development has to occur is variable for each individual. If you are interested in learning more about this process, let your medical provider know. Some find it helpful to speak with a reproductive endocrinologist to best understand the available options.

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Possible Side Effects and Risks of GnRH Agonists

- GnRH agonists (Lupron, Supprelin) have been given safely for other diagnoses for many years. However, the long-term side effects and safety of these medications are not completely understood.
- In the first few weeks of being on these medications, GnRH agonists may stimulate your own sex hormones before it blocks their production. This sometimes leads to uncomfortable symptoms that may last a few weeks before puberty is then suppressed. Please speak with your medical provider about expectations for your body.
- You may or may not get significantly taller. GnRH agonists may prevent growth spurts. Most youth continue to grow in height while on these medications, but not as fast as during puberty.
- Research shows that delays in bone density are common in young people on GnRH agonists, but generally bone growth and density catch up after puberty is resumed (either by stopping the medication, or starting hormone therapy). While on these medications, it is especially helpful to eat high calcium foods and exercise regularly. Your medical provider may recommend taking a Vitamin D supplement to help with this as well.
- GnRH agonists will stop your pubertal development. Other people may notice this, especially
 as you become older and are not developing at the same time as your peers.
- If you are already well into puberty when starting on a GnRH agonist, you may experience a withdrawal effect from your own hormones. For some, this can feel uncomfortable and cause symptoms such as hot flashes, mood changes and irritability, headaches, among other symptoms. These may last a few weeks and should resolve with time.

Expectations, Rights, and Responsibilities

- Tell your medical provider if you have any problems or side effects or are unhappy with the medication.
- You can choose to stop taking these medications at any time. If you decide to stop this medication, please speak with your medical provider to make a safe plan. Some forms cannot be stopped right away, such as implants or large injections that absorb slowly over time. These medicines will naturally slow down and stop on their own.
- Keep appointments for follow-up monitoring and other preventative health care needs, as recommended by your medical provider. Your medical provider will discuss which tests are necessary and any recommendations for ongoing care.
- Tell your provider about any other medications, vitamins, supplements, or other substances that you take or use.
- Inform your medical provider of any new symptoms or medical conditions that develop before or while you are on puberty suppression treatment.
- Let your provider know if you think you are having concerning side effects.
- Discuss any questions and concerns about puberty suppression treatment or adjustment concerns related to your environment and gender affirmation process, including changes in your family, school, or social systems of support.
- Puberty suppression is not the only way to affirm your gender. Your medical provider and/or
 a mental health provider can talk with you about other options if you are interested.