Information on Suppression of Puberty

Puberty in General . . .

Let’s start by describing what happens naturally during puberty.

When the brain determines that it is time to start puberty, usually around age 11 in assigned males at birth and 10 in assigned females at birth, the pituitary gland releases 2 hormones called LH (luteinizing hormone) and FSH (follicle stimulating hormone). With a rise in these two hormones, they both effect the sex gland (either the testes or ovary) by stimulating production of sex hormones: testes produce testosterone, and ovaries produce estrogen. It is these sex hormones that cause the typical changes we see with puberty:

In assigned males at birth: First, the LH and FSH cause increase in testicular size, which then results in an increase in testosterone production. Testosterone causes increase in pubic hair and phallic size. There is more acne. Axillary hair and facial hair grow. Eventually a growth spurt occurs, and voice deepens. At around 17-18 years of age, puberty is complete, and growth stops.

In assigned females at birth: estrogen causes breast development first. This progresses, and fat deposits in the typical adult female places, resulting in a curvy body type. About 2 years after the start of breast development, menstrual cycles typically start. A female bodied person does get pubic hair, axillary hair and acne, but not from estrogen. These changes come from hormones that are produced from the adrenal glands, and happen independently of LH, FSH and estrogen.
1. **What are puberty suppressors and how do they work?**

These are medications that *suppress* the release of LH and FSH from the pituitary gland. This then stops testosterone from being released from the testes, and estrogen from being released from the ovaries. Thus, they **SUPPRESS PUBERTY**. Without exposure to sex hormones (testosterone or estrogen), the body does not undergo the changes associated with them. **Puberty suppression is reversible. Once discontinued, the person will re-enter their puberty of assigned sex at birth after a period of time (approximately 6 months).**

These medications come in 2 forms:

1. **Leuprolide or Depot Lupron**: This form of the medicine is an *injectable* form that is given every 12 weeks. It is injected into the muscle. Most often patients come to a doctor’s office to receive their shot.

2. **Supprelin or Histrelin or Vantus**: This form is an *implant*. A very small device is implanted under the skin of one’s upper arm, and it slowly releases the agent over a period of one to two years. The unit must be replaced every other year by a surgeon. This can be performed with sedation or general anesthesia.

2. **Why are they used and when are they prescribed?**

These agents are used for a variety of reasons. In children, they are used to treat precocious puberty, when puberty happens too early. They are given to a child until the child is old and mature enough to enter puberty, and once these agents are stopped, the child will go through puberty on their own.

In adults, they are used for treatment of certain sex hormone sensitive cancers, like prostate cancer, to prevent the patient from being exposed to hormones that can increase cancer growth.

In transgender youth, puberty suppressors are used to suppress the pubertal changes of their assigned sex at birth that quite often worsen the individual’s gender dysphoria. In addition, by not being exposed to one’s biological sex hormones, cross hormone therapy is even more effective at achieving the desired physical appearance in gender transition.

3. **What about their safety?**

We can safely and legally recommend puberty suppressors based on our medical expertise and judgement. The Endocrine Society
and World Professional Association for Transgender Health (WPATH) support the use of these medications in youth. The Food and Drug Administration approves puberty suppressors for children who start puberty at a very early age. We have been doing this practice for over 40 years, and the safety of these agents has been demonstrated. However, the FDA has not approved puberty suppressors for use in transgender children yet as this is a new indication for the use of these medications.

4. **What do they cost and are they covered by insurance?**

   These agents are expensive. Typically, depot-Lupron costs approximately 8,000 to 9,000 dollars for the 12 week preparation. The histrelin implant is approximately 32,000 for the device, plus the cost of implanting it.

   Also, labs need to be monitored while on these agents. A pre-treatment LH, FSH and Testosterone or Estradiol level is checked, as well as a post treatment level to assess level of suppression.

   As of January 2015, Oregon Health Plan covers puberty suppression, and now most major health care plans will. If denied, we will appeal.

   • **Some insurances cover one form of puberty suppression and not another, for example some may cover the shots but not the implant. We will inform you of your insurance benefits in order to help make the best decision for you and your family.**

5. **What if the child has already begun puberty?**

   Even better. :)  

   Actually, one **must** have started puberty to demonstrate that there is puberty to suppress. LH and FSH need to be elevated to prescribe these agents. Then the levels are checked again after treatment to make sure they have decreased.

   Being on these medications will cause some breast reduction in birth assigned females. They will not reduce or stop the growth of pubic hair, axillary hair or acne. In birth assigned males, testicular size will decrease and phallic growth will stop, but not regress. The frequency of spontaneous erections and wet dreams goes down significantly. Still, the person will have pubic hair, axillary hair and acne from the adrenal glands.

   In adolescents further along in puberty, the decision to start pubertal suppression is individual. People with ovaries who menstruate may experience menopausal symptoms with an abrupt
decrease in estrogen levels. Breast development, if advanced, will not regress. In people with testes, the size of the testicle does not decrease if it is further along in puberty. However, if there is not a lot of other effects of testosterone such as facial hair or voice change, it may be beneficial for that person not to be exposed to more testosterone. Your doctor will discuss these aspects and how they pertain to you or your child in order to make the best decision for you.

6. How does the Doctor know I am in Puberty?
First the doctor will perform a physical exam looking for the first signs of puberty (testicular enlargement or breast development). If these signs are present, labs will be obtained (yes, a blood draw) for levels of LH, FSH, and Testosterone or Estrogen. We may obtain a bone age X Ray to determine how old your bones are to help guide our decision making. The labs can take up to 14 days to return as we send them to an outside lab in California.

If the labs do not show that you are in puberty, but the doctor thinks you are in puberty by physical exam, we may elect to perform what is called a stimulation test. This procedure takes place in our day treatment unit where a nurse will place an IV. Baseline labs will be drawn and then a medication will be given. This medication will stimulate the pituitary to release LH and FSH, but only if a person is in puberty. Labs are then obtained at 1 hour and at 24 hours to look for pubertal rises in these hormones, as well as with either testosterone or estrogen.

7. What are the Risks of Puberty Suppressors?
A. Short Term
   a. Pain at the injection or insertion site. We will work with you to find ways to minimize the experience of pain at these sites. With injections, you can take ibuprofen, use heat or ice, and most importantly keep using the muscle that the injection went in! If an implant is inserted, the surgeons use local anesthesia to numb the site, and may recommend Tylenol or Ibuprofen for post-operative soreness.
   b. Sterile abscesses rarely occur with Lupron injections. Occasionally we can see a painful abscess at the site of the injection that is not bacterial. This presents with intense pain, heat, and swelling up to two weeks after the shot is administered. To evaluate, an ultrasound would be ordered. The abscess may need to be drained by a surgeon. If this happens, shots can not be continued, and
an implant would be recommended. This is a rare occurrence.

B. Long Term
   a. Bone Health: Blocking puberty can make bones weaker (lower bone density). This may get better when you stop the puberty blockers or start cross hormones. While on suppressors, we recommend you take Vitamin D and get ample amounts of calcium, as well as engage in weight bearing exercise.
   b. Fertility: Infertility is a concern for people who stay on puberty suppressors and then take cross hormones as their reproductive organs do not mature. We recommend talking about this with your doctor to understand the potential impact on your fertility before starting any medications. We can also arrange a consult with a fertility specialist.

8. Are Puberty Suppressors Right for Me?
   We will work hard to answer all of your questions about the benefits and risks of puberty suppressors. We want you to have a good understanding of what to expect before you start. These medications can prevent some of the male or female specific changes to the body that puberty causes. It can be distressing for transgender people to go through puberty. In some, the use of these medications may decrease the need for future surgeries, such as top surgery or hair removal.

   How long before they start working?
   It can take several months for puberty suppressors to start working. Everyone is different and people respond at different rates. Typically by 3-6 months, all puberty hormones are suppressed. You may see an increase in the signs of puberty in the first month after starting, and possibly a one time menstrual bleed in assigned females at birth, but these will lessen as the suppressors are continued.

9. How Long to Continue Puberty Suppressors?
   This is also an individualized plan. Typically one can stay on puberty suppressors until one is on adult doses of cross hormones. This means one will be on a suppressor as cross hormones are started and increased incrementally over time. If one has started suppressors before cross hormones, the body needs exposure to a sex hormone (either cross hormones or own’s biological hormone) by the age of 16 years at the latest. This is important for bone strength and building peak bone mass.
RCH T-Clinic Locations
Cornell Medical Plaza
1960 N.W. 167th Place, Suite 103
Beaverton OR 97006

Randall Children’s Hospital at
Legacy Emanuel Medical Center
Medical Office Building 2
501 N Graham St
Suite 375
Portland OR 97227

Phone:
503-413-1600
Fax:
503-413-1915

www.legacyhealth.org/tclinic
childrenendocrineneurser@lhs.org

RCH T-Clinic
Providers
Karin A. Selva, MD
Maya K Hunter, MD

Behavioral Health Clinician
Clancy Roberts, LCSW

Nurse
Connie Earnest-Ritchey, RN BSN

Psychologist
Laura Edwards-Leeper PhD

Legacy Specialty Pharmacy
Puberty Suppressors are
Considered Specialty Drugs.
Specialty drugs typically have
special handling requirements,
require prior authorizations
or are only available via a limited
drug distribution network.
Specialty drugs demand intensive
(financial, social, clinical)
support to successfully complete
the therapy. Legacy Specialty Pharmacy
helps in all these areas when puberty
suppressors are prescribed.

Unsure how to ask your insurance
cOMPANY about coverage?
We can help!
See our Insurance Questions Info Page at
Specific questions about puberty suppressors?
Please call
Connie, T-Clinic Nurse
503-413-1596

Or
Clancy Roberts, T Clinic Behavioral Health Clinician
503-413-5443