

The Most Frequently Asked Questions when Beginning Growth Hormone Therapy

1) What is Growth Hormone?

Growth hormone is a protein hormone secreted by the pituitary (master gland), which promotes linear growth. There are currently seven brands of growth hormone available in the United States. The first recombinant human growth hormone became available in 1985. The one prescribed by your physician is largely decided by your insurance formulary and the medical diagnosis or indication for the growth hormone. Your provider will also consider which product would be most appropriate for your child based upon their experience with the different preparations and injection devices.

2) Is Growth Hormone a Steroid?

No. It is a natural protein made up of amino acids. The purpose of growth hormone treatment in children is to promote linear growth. Growth hormone also has beneficial effects on metabolism, bone density, and body composition (i.e. fat distribution and lean muscle mass).

3) Are there any side-effects when using Growth Hormone?

When growth hormone is prescribed to replace a deficiency, it is rarely associated with significant side effects. Children with hypopituitarism (multiple pituitary hormone deficiency) may sometimes experience fasting hypoglycemia (low blood sugar) that is improved with treatment. Children with growth hormone deficiency are also at risk of Slipped Capital Femoral Epiphyses (instability of the hip joint), which presents as knee or hip pain that is usually accompanied by limping. This is more common in children that are growing rapidly and overweight and is most common during puberty. Increased intracranial pressure (elevated pressure in the brain) presents as severe headache, nausea or visual changes. If your child experiences any of these symptoms contact your child's doctor for an evaluation right away since these symptoms may be associated with a rare side effect of Growth Hormone treatment. Growth hormone does not cause scoliosis (curvature of the spine) but children with scoliosis may find it is aggravated by rapid growth; this should be discussed with your physician.

4) Why is growth hormone necessary?

Growth hormone is a natural hormone of the body that is necessary for normal linear growth and several other metabolic functions including bone mineral density, exercise endurance, lean muscle mass, and healthy cholesterol profiles. Therefore, growth hormone is indicated for the long-term therapy of children with impaired growth due to inadequate or insufficient growth hormone secretion. Individuals that have multiple pituitary deficiencies may require growth hormone throughout their lives.

5) How do you determine the dosage and will the dosage remain the same throughout therapy?

Initial growth hormone doses are determined by your child's medical diagnosis and your child's weight. Research has determined that children with different medical conditions respond differently to growth hormone; there are established guidelines for dosing based on the medical condition requiring treatment. In general, a child being treated for isolated growth hormone deficiency is treated at a dose of approximately 0.3mg/kg/wk. Higher doses (up to 0.7mg/kg/wk) may benefit some teenagers during puberty, especially those who are the most growth retarded at the start of puberty.

6) What changes, if any, should I expect to see in my child during therapy? (moodiness/hyperactivity etc.)

There should be no specific changes in your child's mood or activity with Growth Hormone therapy. However, there will be a period of adjustment with starting daily Growth Hormone injections that will require minor alterations to your family's day-to-day routine. Also some children may feel anxious about the injections; your child's endocrinologist or endocrinology nurse can discuss techniques to help reduce anxiety associated with injections.

7) What often is growth hormone administered?

Growth hormone is usually administered 6 – 7 days per week. The total weekly dose would be the same – the weekly dose is divided into 6 or 7 equal injections. This decision is at the discretion of the prescriber and the family.

8) Should I worry when bubbles appear in the syringe that has been prepared for my child's injection?

A few small bubbles may be of no consequence. Practicing with a syringe and a vial of sterile water will help to improve your technique. If you are using the Genotropin Miniquick, you do not try to remove the air in the syringe prior to giving the injection.

9) How long will my child be on growth hormone?

Growth hormone is generally continued until your child has reached their full height potential. This is indicated by bone maturation (bone age) of 16 years or more in males and 14 years or more in females along with a growth rate of less than 2.5cm/yr. If your child has been diagnosed with panhypopituitarism (has more than one pituitary deficiency), they may have additional testing done to determine whether they meet criteria for treatment as an adult.

10) Should my child give his own injections?

Children can share in the administration of their injections with the supervision of their parent(s). Young children may want to help with gathering the supplies, choosing the injection site, cleansing the skin with alcohol, or applying the bandage. Often, children around the age of 10 years will be interested in preparing and administering their own injection. You will always need to provide some level of supervision to ensure your child continues to take their growth hormone therapy and to ensure your refills are ordered on time.

11) What kind of growth should I expect to see in my child?

Generally, growth rate prior to therapy is less than 1.5 to 2 inches per year. Growth rates generally double or triple the initial year of therapy to approximately 3 – 4 inches per year. The second and third year of therapy may be closer to 2.5 inches per year. Typically speaking, your child will have 'catch-up' growth and then begin to track along the same percentile on the standard growth curve.

12) I left the growth hormone out at room temperature for several hours. I accidentally dropped my growth hormone pen. What should I do?

Growth hormone is a protein hormone that can be destroyed by heat or extreme temperatures. The stability at room temperature varies greatly from one brand to another, discuss this with your endocrinology

nurse or contact the company directly. Your growth hormone should be clear and not cloudy – if cloudy it was definitely left out too long and should not be used. If you dropped your pen device, repeat the steps to prime your pen and make sure your growth hormone is still clear in appearance.

13) If my child prefers injections in the legs instead of the arms, is it okay in the legs only?

Rotation of the injection sites is recommended. Possible sites for injection administration include: the arms, legs, hips, and lower abdomen. Avoidance of the same spot or location is important to avoid the development of local bumps in the skin called lipohypertrophy. This is a rare occurrence even when injections are administered in a similar location.

14) Is it advisable to give the injection when my child is sleeping?

This is a frequently asked question that only parents can decide. The trust between parent and child is important to maintain by being honest with each other. Generally, it is recommended to give the Growth Hormone injection at bedtime. Talk with your child about their concern or anxiety related to the injection and offer options, including giving the injection when the child is sound asleep (examples of options or choices to offer the child: the injection is given before or after brushing their teeth, reading a story, etc). Some parents report that when sound asleep, their child does not appear to respond to an injection in the buttock or legs, while others report that a child may have difficulty falling asleep due to fear of the injection.

15) I don't feel I can give the injections to my child. Is this a normal reaction?

This is a normal reaction of conscientious parents who have concerns or fears about hurting their child. A child may express discomfort or unhappiness following an injection. The child needs reassurance that the discomfort will diminish as they get used to the injections. The parent can reinforce the benefit of the injection as an important part of their daily health routine and maintaining a positive attitude.

16) What if I forget an injection?

You may make up an injection by giving extra the following days. Remember, the total weekly dose remains the same. Additionally, if you are using an injection pen and the last dose in the pen doesn't allow for a full injection, it is acceptable to make up the

difference the following night rather than giving two shots on the same night to complete the dose.

**If you have missed injections because of insurance delays, do not make up the missed doses as you will run out of medication before your insurance authorizes the next shipment or refill.

17) What if my child wants to discontinue the injections, but there is potential for more growth?

Children need to be encouraged to continue their therapy for full effectiveness. Once a child has “caught up in size” to their peers, it is common for them to lose the motivation to take their daily injections. For this reason, it is important to discuss the other effects of growth hormone such as building strong bones and lean muscle mass from the beginning of therapy so that your child doesn’t focus on “growth” as the only factor. Our bone mass is being built up until we reach around 20 years of age. At around 30 years of age, our bone density or strength begins to decline. This makes it important to build up strong bones when we are young. If your child is ready to stop therapy and growth remains, it is important that you discuss this with your physician. If your child has almost reached their final adult height, it is unlikely to cause any problems. However, if your child has several inches of growth remaining, you need to consider the long-term implications such as bone density and final adult height. The MAGIC Foundation has a free video available “Just Say YES To Growth Hormone” which can be ordered by calling 1-800-3MAGIC3. This video is teens talking to teens about why they chose to stay on treatment.

18) What should I do if I run out of growth hormone medicine?

It is recommended that you be aware of your growth hormone supply and call your pharmacy or home health care program prior to running out. Make sure that the prescription is refillable and that your insurance company’s authorization is current. Your physician will have to submit periodic reports to your insurance to renew your authorization. It is your responsibility to know when your authorization expires and speak with your physician’s growth hormone coordinator to understand the process. Generally speaking, you need to order your refill at least one week in advance of taking your last dose to avoid interruptions in treatment.

19) How often will my child need to visit the endocrinologist and what additional tests need to be taken during the course of therapy?

Usually, children treated with growth hormone will be evaluated every 3 months. The frequency of visits will be determined based upon your child’s unique circumstances. Periodically, blood testing is necessary to monitor IGF-1 and/or IGF-BP3 levels (used to adjust growth hormone doses) and thyroid levels. Bone age (x-ray of left hand/wrist) and the lab work are recommended at least on a yearly basis. There is an increased incidence of the need for thyroid hormone replacement (oral medication taken once daily) and other endocrine deficiencies may be co-existing.

20) Insurance and growth hormone:

Because growth hormone is an expensive and long-term therapy, essentially all insurance companies require that the medication be prior authorized and the authorization will have to be continually renewed. Initial authorization can take several weeks; some companies offer a limited supply of medication while the insurance authorization is pending. This means it is very important that you take the medication as prescribed for the best results and you keep your appointments as recommended. If your child doesn’t grow well because you frequently skip injections, your insurance company can deny therapy. It is common for your insurance formulary to periodically change, mandating a change in the brand of growth hormone you are prescribed. Generally speaking, you cannot appeal to remain on your original product until you have tried the brand currently on your formulary. A change in product should not impact your child’s response to growth hormone.

21) Does treatment for Attention Deficit Disorder (ADD) impact my child’s growth or effect growth hormone therapy?

Medications for ADD and growth hormone can be taken together. Your endocrinologist will watch closely to make sure your child is still gaining weight, which is necessary for optimal growth. Your child may need to consult with a pediatric dietitian, try a different stimulant medication, or take weekends and / or summer breaks from their ADD medication to allow for normal weight gain.

22) Suggestions for how to respond to negative reaction or comments concerning treating my child with growth hormone.

The decision to treat a child with growth hormone is a personal decision, made by the parent(s) after evaluation and consultation with medical specialists. Well-meaning people may offer unsolicited opinions about the use of growth hormone, without knowledge of all the factors involved with the parent’s decision. In general, it is best not to become defensive or offer lengthy explanations about your decision, rather acknowledge the person’s interest or concern and state you prefer to not discuss your child’s private medical issues. Also, you may want to encourage the person to visit the MAGIC Foundation’s website to learn more about the topic of Growth Hormone. <https://www.magicfoundation.org/www>

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Major
Aspects of
Growth
In
Children

A national non profit organization created to provide support services for the families of children afflicted with a wide variety of chronic and/or critical disorders, syndromes and diseases that affect a child's growth. Some of the diagnosis are common while others are very rare.

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The MAGIC Foundation *For Children's Growth*

Not an illusion or magical, but the caring for children and their families

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Dedicated to the growth and overall development of children

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