Hypopituitarism

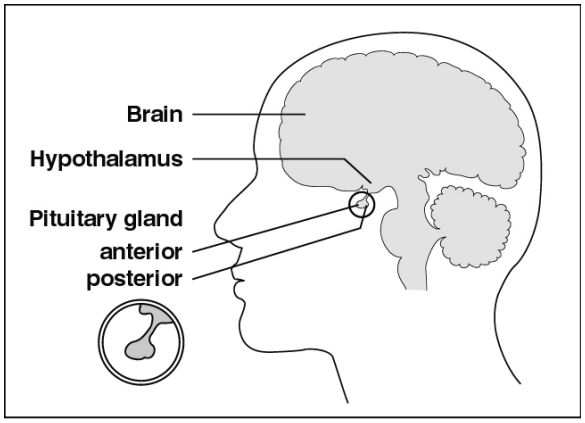
This handout will explain hypopituitarism, its symptoms and treatments. Your nurse or doctor will answer any questions you have.

Hypopituitarism

Hypopituitarism is when you have low levels of one or more hormones made by the pituitary gland. "Hypo" means "less than normal." You may also hear the term "panhypopituitarism." This term means **all** these hormones are low or missing ("pan" means "all").

Pituitary Gland

The pituitary is a pea-sized gland found in the middle of the skull. This gland will release its hormones in response to messages sent from the part of the brain called the hypothalamus.



The pituitary is called the "master" gland. This is because its hormones tell all the other endocrine "target" glands, to produce their own hormones. The **"target" glands** are glands that make **hormones** in response to signals from the pituitary gland. These are the:

- Thyroid gland
- Adrenal gland
- Ovaries
- Testes (testicles)

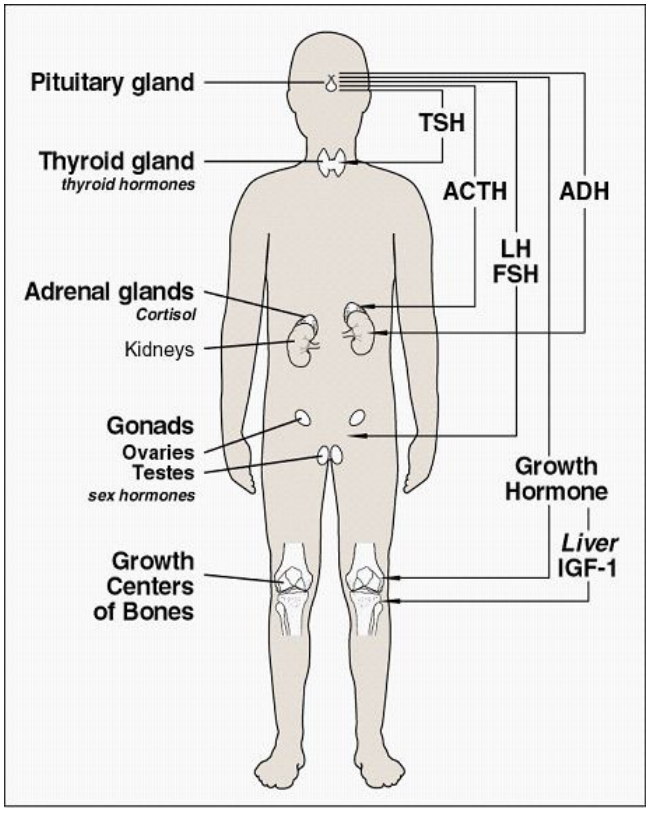
Hormones

Hormones are the chemical messengers. They are released from a gland into the bloodstream. The bloodstream then carries the hormones to the tissues and organs of the body that use them.

Hormones of the Pituitary

The pituitary makes many kinds of hormones that the body needs to function. These include:

- Thyroid stimulating hormone (TSH)
- Adrenocorticotrophic hormone (ACTH)
- Growth hormone (GH)
- Gonadotropins-follicle stimulating hormone (FSH)
- Luteinizing hormone (LH)
- Antidiuretic hormone (ADH)



Cause of Hypopituitarism
In many cases, we do not know the cause. In most cases, it does **not** run in families. Some causes may include:

- The pituitary or hypothalamus did not form normally before birth
- Tumor in the pituitary area of the brain
- Severe head injury
- Infection in the central nervous system (such as encephalitis)
- Radiation therapy to the pituitary part of the brain
- Removal of the pituitary gland

Hormones
Hypopituitarism is almost always permanent, but it can be treated. When your body does not release enough of the pituitary hormones, the target glands (thyroid, adrenal, ovaries, or testes) are not getting the correct messages.

Without normal levels of the target gland hormones, your body cannot function as it should. We will teach you about each hormone and what it means if you lack this hormone.

Treatment
Treatment involves replacing the hormones with a pill, a shot, or nasal (nose) spray. Your body can use these hormones in place of the natural ones that your body is not making.

Staying Healthy
You can still have a healthy life with hypopituitarism. To have a healthy life, you must:

1. Understand your condition.
2. Take the correct hormone replacement treatment.
3. Have regular clinic visits with your doctor.

Medicines
Know your medicines and take them as prescribed. Talk to your doctor, nurse or pharmacist if you are not sure how to take them. They can tell you ways to help you take them on time.

Medic-Alert Bracelet
If you have ACTH and/or ADH deficiencies, you need always wear your Medic-Alert bracelet. This information can be life-saving in case of accident or sudden illness.

Tell People Around You
You may need to tell new people in your life (teacher, roommate, spouse) about your medical needs. This is very important if you are cortisol dependent. If you are not sure how to explain your needs, use this guide, or talk to your nurse or doctor.

Thyroid-Stimulating Hormone (TSH) Deficiency

The thyroid is a small gland found in the neck, in front of the windpipe. It makes and releases thyroid hormones. A lack of thyroid-stimulating hormone means the thyroid is not making this hormone. Thyroid hormones are needed for physical and mental growth.

How is it diagnosed?
To figure out if you are lacking thyroid hormones, your doctor will:

- Ask about your symptoms.
- Perform a physical exam, which includes growth rate during childhood and adolescence.
- Order blood tests that measure levels of the thyroid hormones and thyroid-stimulating hormone. These tests are called a T_4, T_3, and TSH levels.

Treatment
Your doctor will prescribe a daily pill to replace the hormone. The pill often prescribed is called Synthroid® (levothyroxine sodium). You will likely need to take it for the rest of your life.

Follow-Up
You will need clinic visits and blood tests to make sure you have the correct amount of hormone replacement. Also, watch for symptoms of too little or to much of the hormone, see below.

Too Little Medicine
- Feeling cold (often when others do not feel cold)
- Cool, dry skin
- Constipation
- Fatigue and increased sleep
- Slow growth in height and/or weight gain
- Poor appetite
- Acting calm and quiet
- Coarse, dry, thin hair

Too Much Medicine
- Feeling hot (often when others do not feel hot)
- Moist, sweaty skin
- Diarrhea
- Trouble sleeping, feeling nervous or restless
- Short attention span
- Normal or rapid growth in height and/or weight loss
- Increased appetite
- Feeling irritable
- Fine hair which can sometimes fall out

Adrenocorticotrophic Hormone (ACTH) Deficiency

A lack of the hormone ACTH results in a lack of **cortisol.** This hormone is made by the adrenal glands. These two glands are found on top of the kidneys in the middle of the back.

Cortisol keeps the body's blood sugar at a normal level. It also helps the body deal with physical stress, such as fever or injury. To figure out if you are lacking cortisol, your doctor will:
- Ask about your symptoms.
- Perform a physical exam, which include checking your height and weight.
- Order blood and urine tests to measure amounts of cortisol.

Treatment
If too little cortisol is being made, your doctor will proscribe a pill called hydrocortisone (Cortef®). You will take this 2-3 times daily throughout life. If for **any** reason you cannot take the medicine by mouth, it must be given as a shot.

The dose prescribed will be enough for normal daily tasks when you are well. **It is very important that the dosage be increased with fever, some illnesses, and injury.** Guidelines for how to handle these times are outlined in a *Health Facts for You* called "Guidelines for the Child Who is Cortisol Dependent." Your nurse and doctor will tell you about this important information.

Again, you need to be aware of the symptoms that may suggest too little or too much cortisol (hydrocortisone).

Too Little Cortisol

- Weakness or extreme tiredness
- Illnesses such as colds and flu seem to be more severe and last much longer than expected
- Nausea or vomiting
- Diarrhea
- Cold, clammy skin
- Fast pulse
- Fast breathing
- Dizziness
- Confusion
- Severe pains in abdomen, legs, lower back
- Lower than normal body temperature

Too Much Cortisol

- Decreased growth rate
- Increased weight, especially in the face and abdomen
- Increased bruising

Growth Hormone (GH) Deficiency

Growth hormone is a pituitary hormone. It affects the growth of bone and body tissues. Unlike the other hormones discussed, GH does **not** stimulate a specific target gland. This hormone stimulates the body's organs, bones, and tissues.

When lacking enough growth hormone, a child grows very slowly. In time the child is much smaller and younger looking than the child's peers. The child may have a slightly chubby or "baby face" look.

To figure out if you are lacking growth hormone, your doctor will:

- Perform a physical exam and check your growth rate. Your height over a certain length of time will be compared to your past growth rate.
- Order a blood test to measure GH (taken after a 6-hour fast and an oral or injected medicine).
- Order a bone age x-ray of the hand that tells us how slow or fast your bones are growing.

Treatment

If you are found to be lacking growth hormone and you are not growing as you should, growth hormone can be replaced with a shot. GH does not work if given by mouth. It is most often given once a day. You will need GH until your growth is complete or when you reach an adult height. When GH deficiency is severe, you may need to continue GH treatment into adulthood to maintain healthy bones, muscles, and energy level. The clinic nurse will teach you or your parent to give the GH shots at home.

Side Effects

Side effects from taking GH are few and rare. They may include:

- Swelling, which should go away on its own.
- Higher than normal blood sugar levels (rare).
- Headaches or pain in your hips or legs (contact your doctor right away if you have these symptoms).

Follow-Up

You will need your growth rate watched closely. You will have clinic visits every 3-6 months. You will have your height and weight checked and may also have bone age x-rays and blood tests.

Gonadotropin (FSH, LH) Deficiency

Gonadotropins are the hormones that begin the process of sexual growth.

In **girls**, these hormones tell the ovaries to make the hormones that cause:

- Breast development
- Menstrual periods
- Other changes such as, rapid growth in height and change of body shape

In **boys**, these hormones tell the testes (testicles) to begin making sperm. Testosterone is the hormone that causes:

- Increased size of the penis and testes
- Facial hair growth
- Lower voice
- Other body changes such as, rapid growth in height and muscle mass

If you are missing some or all of the other pituitary hormones, you may be missing gonadotropin hormones as well. We may not know for certain until you are near the teen years when puberty should be starting.

To figure out if you are lacking growth hormone, your doctor will:

- Perform a physical exam of breasts in girls and genital areas in both sexes.
- Check your growth rate.
- Order bone age x-ray.
- Order blood tests.

Treatment

If you appear to be lacking these hormones, replacement of the sex hormones is the treatment needed to begin sexual development.

Treatment for Girls

Sex hormones in girls are estrogen and progesterone. Sex hormones are given either in pill (oral) or patch form for girls.

Pills: If pills are used, one estrogen hormone pill (Premarin®) is taken per day. After some months, a second pill, a progesterone hormone (Provera®), is added for some of the days of the month.

A monthly "cycling" schedule is maintained to mimic the way the ovaries should be making hormones. At the end of each monthly cycle, a menstrual period or bleed will occur for a number of days. These periods are often a bit shorter and involve less bleeding than periods in girls who produce their own hormones.

After several cycles, your doctor may change to a single pill that combines both hormones. This is the same kind of pill as oral birth control pills.

Patch: Another method is with a skin patch that only contains estrogen. Skin patches are worn on the hip or buttock and changed once or twice a week.

Side Effects

Side effects of estrogen are:

- Increased height
- Slow growth of breast tissue
- Change to a more feminine body shape
- Mood changes and mood swings
- Increased appetite
- Slight changes in voice
- Interest in sexual activity

These sex hormones **do not** cause pubic and underarm hair to grow. Patients with hypopituitarism may not have much pubic or underarm hair growth.

Treatment for Boys
The sex hormone replaced in boys is testosterone. Sex hormones for boys are most safely given by injection (shot) or by placing a gel or patch onto the skin.

Hormone (testosterone) injections: These are given into a large muscle in the hip or the thigh every 3-4 weeks. Most often, these shots for younger teen boys are given by the nurse or doctor in your local doctor's office. Some parents and boys prefer to learn how to give the shots themselves. The clinic nurse can teach you how to prepare and inject the testosterone.

Testosterone gel or patch: For older teen boys, and grown men, a gel or patch may be prescribed instead of the shots. The gel is applied onto the skin each day, and the patch is placed on the skin and changed each day. Your doctor, nurse or pharmacist can teach you how to apply these and about what areas of skin to use.

Side Effects
Side effects of testosterone are:

- Increased height
- Growth of underarm, pubic, and some body hair
- Increase in the size of the penis
- Starting to have penis erections and ejaculation
- Increased muscle throughout the body with a gradual change to a masculine body shape
- Mood changes and mood swings
- Increased appetite
- Voice changes, deeper voice
- Interest in sexual activity

The size of the testes does not change much as they are not making the testosterone.

Follow Up
Patients will need clinic visits every few months when starting sex hormone treatment. Sometimes, doses need to be changed to make sure that these body changes are not taking place too slowly or too quickly. For the same reason, you will also have bone age x-rays of the hand and blood tests.

Once growth is complete and a dose is figured out, visits will be much less often. These hormones are given well into adult life. While it is not life threatening to stop these hormones, they provide a means to a normal adult life. As the teens and young adults mature, they are able to have normal sexual function. Lack of gonadotropins can affect fertility. You may wish to consult with fertility specialists in the future. Later in adult life, you with your doctor's guidance may decide to stop or decrease hormone replacement.

Antidiuretic Hormone (ADH) Deficiency

The back (or "posterior") part of the pituitary acts as a storehouse for an important hormone called ADH. ADH helps the body to retain the water that it needs to work as it should.

ADH deficiency is also called **diabetes insipidus** or "D.I." This is not the same as the more common diabetes mellitus or "sugar diabetes." When ADH is lacking, the kidneys cannot concentrate urine. The two most common symptoms are:

- Excessive thirst
- Frequent urination, often very dilute, pale-colored urine

This can lead to severe dehydration. Severe dehydration calls for urgent medical treatment.

To figure out if you are lacking ADH, your doctor will:

- Ask you about your symptoms such as, increased urination and thirst, and weight loss.
- Order both blood and urine tests.

Treatment

If you have ADH deficiency, ADH can be replaced with a medicine called desmopressin or DDAVP. This comes either as a pill or a nasal spray. This medicine helps the body in the same way that ADH does. It allows the body to hold onto the fluid it needs. The doctor, nurse, or pharmacist will teach you how to use it. Most often, it needs to be given at least once per day throughout life. You should be aware of the signs of too little or too much ADH.

Sometimes, the normal dose may not work as well when you have a cold, allergy, or other cause of nasal congestion. It is important to clear the nose of mucous before the medicine is given. Infants and young children may need to have the mucous cleared by using a bulb syringe. Your nurse and doctor will teach you what to do during an illness or emergency.

Too Little ADH

- Frequent and increased urination of pale-colored urine
- Increased thirst
- Dehydration, if fluid intake not enough, such as:
    - Dry tongue
    - Sunken look to eyes
    - Tearless cry
- If untreated, it can lead to increased sleepiness and, in time, coma.

Too Much ADH

- Decreased urine output, very dark colored urine
- Decreased thirst
- Less urine output than intake of fluids
- Weight gain (puffiness)
- If untreated, can lead to confusion, increased sleepiness, and, perhaps, seizures

When to Call

Let your doctor know if you have any symptoms of too little or too much desmopressin. Your dose of medicine may need to be changed.

Who to Call

To learn more, call your doctor or nurse. You can also contact the American Family Children's Hospital Pediatric Specialty Clinic at **(608) 263-6420**.