

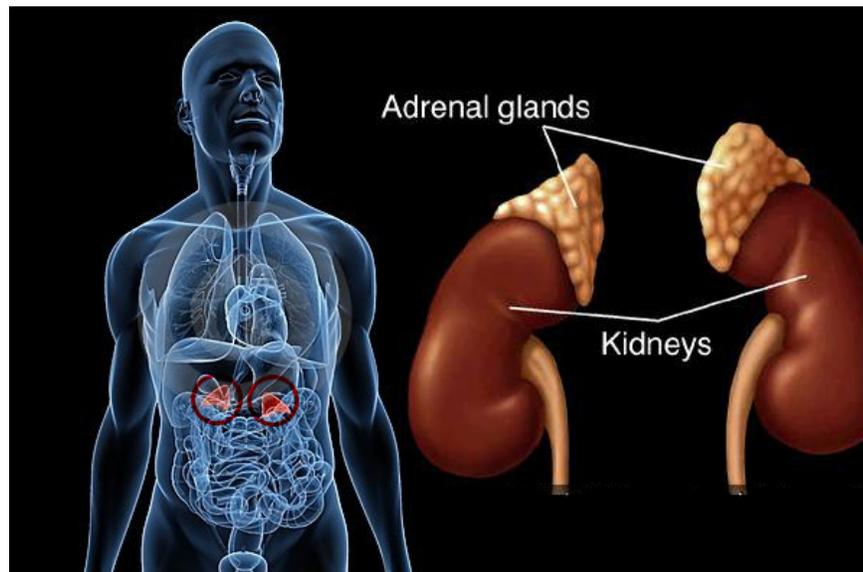
Cortisol Replacement Therapy Booklet

Stress dosing with oral Hydrocortisone and Solu-Cortef intramuscular injection

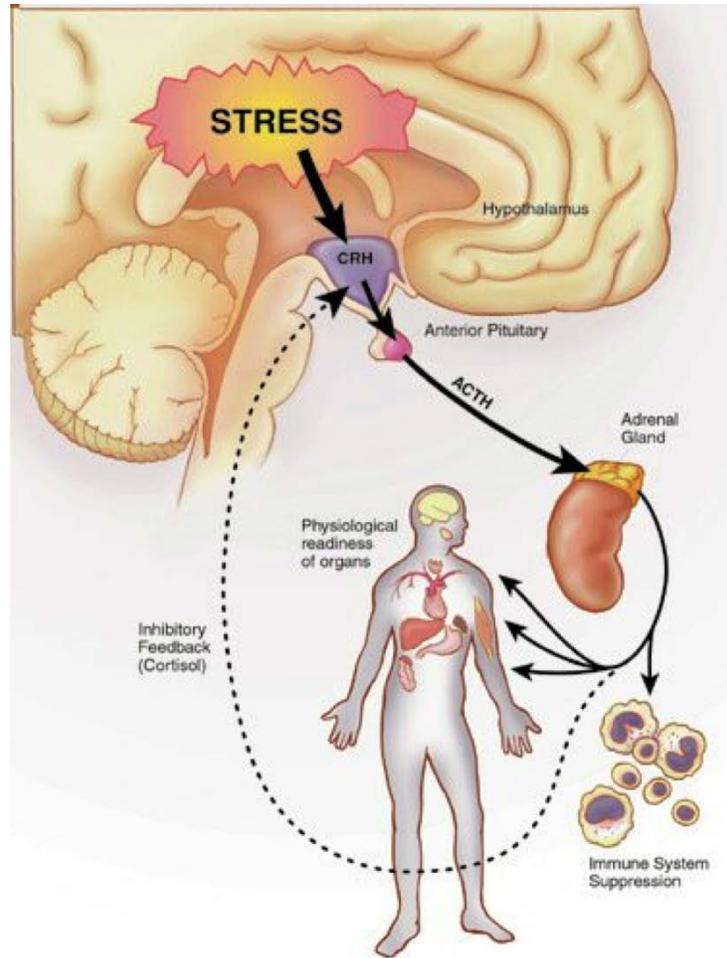
The purpose of this booklet is to answer the most frequently asked questions by families whose child has cortisol deficiency and need medication to replace cortisol. In addition to this booklet, a nurse will also be available to come speak with you and review this information face to face. Please don't hesitate to ask us questions! We understand that your child's diagnosis has been stressful for you and we want you to be as comfortable with your child's care as possible.

Your child has been diagnosed with cortisol deficiency. Cortisol deficiency can be caused by many different conditions, including CAH (congenital adrenal hyperplasia), panhypopituitarism, Addison's disease, or adrenal insufficiency. As you now know, your child requires cortisol replacement with daily steroids.

Cortisol is a hormone that is produced by the adrenal glands. The adrenal glands are small, triangle shaped organs that sit on top of the kidneys.



Cortisol production and release is regulated by the pituitary gland in the brain. The pituitary gland senses how much cortisol is in the blood stream. If there is too little, it releases a hormone called ACTH, which tells the adrenal glands to make more cortisol. If there is too much cortisol, the brain releases less ACTH, which in turn, decreases cortisol.



Cortisol keeps our bodies running. It is essential for life! It functions in the body to:

- Maintain fluid and salt balance
- Keep blood sugar levels normal
- Maintain normal blood pressure
- Help the body fight infections

For these reasons, cortisol is critical for life. Without cortisol, the body cannot keep a normal blood pressure, which can lead to shock and even death in serious situations. If your child takes all of their medication, there should be no cause for concern.

Under normal conditions, if your child was sick, had an injury or surgery; the body would naturally double or triple the production of cortisol to keep the body running and help with recovery. However, since your child cannot produce cortisol, we have to mimic this action with his/her medication. The most common medication used for replacement is called Hydrocortisone (Cortef). This medication is given 3 times per day and can be in a liquid or pill form. Other medications that can be used are Prednisone (given 2 times per day) and Decadron (given once daily). All of these medications are steroids and can be used for other purposes as well. Steroids can cause side effects if the doses are too high. You don't have

to worry about this because we closely monitor your child's dose and make changes based on his/her weight or blood tests. We are very careful to use only the needed dose of medication and no more.

It is extremely important to take the medication at the same time each day and without missing a dose. Forgotten doses need to be given within 2-3 hours of the intended dose time. Again, this medication is necessary for your child's survival. Missed doses can be extremely harmful to your child, so please make sure that all caregivers are educated on this important medication. Set timers on your phone, alarm clock, or mark your calendar with stickers to help remind you.

Daily doses of Hydrocortisone are given in pill or liquid form, depending on the age of your child. Our bodies need more cortisol during times of illness and physical stress. During these times, you will need to give your child more of their daily medication. We advise that our patients either double or triple their dose of medication depending on the severity of the illness and the providers directions. We will provide you with your child's specific doses and needs. An example of double or triple dosing:

	Normal Dose	Double Dose	Triple Dose
Morning	1 pill	2 pills	3 pills
Afternoon	½ pill	1 pill	1 ½ pills
Bedtime	½ pill	1 pill	1 ½ pill

	Normal Dose	Double Dose	Triple Dose
Morning	2 mL	4 mL	6 mL
Afternoon	2 mL	4 mL	6 mL
Bedtime	1 ½ mL	3 mL	4 ½ mL

Your child's dose:

	Normal Dose	Double Dose	Triple Dose
Morning			
Afternoon			
Bedtime			

How do I know if my child is sick enough to need extra hydrocortisone for stress dosing?

Below is the basic rule of thumb when deciding whether or not to stress dose your child.

- Fever higher than 101 degrees Fahrenheit
- Serious trauma such as a broken bone, head injury, concussion, auto or bike accident resulting in serious injury
- Seizures
- Viral illnesses that would keep the child home from school, such as vomiting and diarrhea
- The child must be able to swallow the oral dose of steroids

- Surgery and dental procedures. Call our office for these types of doses, especially for surgery. We need to give special orders any time your child has to have anesthesia.

Mild illnesses such as a cough, runny nose, or increased emotional stress or stress from sports do not require extra steroids. However, if you are in doubt or need reassurance, do not hesitate to call us for guidance. You know your child better than anyone. If you have a “gut feeling” that something is wrong or if your child isn’t acting like themselves, this could be a signal that they need more cortisol or stress hormone. On the other hand, if you feel that your child is getting stress dosed frequently, please let us know. Look for signs of overtreatment such as weight gain, round face, poor growth, easy bruising, or if they seem to get infections easily.

How long do I continue to give oral stress dose medication?

Lower the child’s steroid dose to the normal dose when:

- Their temperature is below 101 degrees Fahrenheit
- Trauma or medical issue is stable

Your child’s provider will let you know if they want you to return to the normal dose or do a gradual “taper”. Here are some examples of how to lower stress dose back to normal.

Example of Normal Dose

Morning	1 pill
Afternoon	½ pill
Bedtime	½ pill

Sick Day-Triple Dosing

Morning	3 pill
Afternoon	1 ½ pills
Bedtime	1 ½ pills

1st Day Feeling Better

Morning	2 pills
Afternoon	1 pill
Bedtime	1 pill

Day 2 Normal Doses

Morning	1 pill
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Afternoon	½ pill
Bedtime	½ pill

With time, you will be comfortable with stress dosing with little to no direction. However, please know that you need to call your child’s provider if they have been receiving stress doses for more than 2 full days.

What do I do if my child is not taking or keeping down the oral medication?

If your child is sick and is refusing to take oral medication, or cannot keep the oral medication down due to vomiting: give the dose as usual. If the dose comes back up, wait 30 minutes and repeat the dose. If the medication stays down for at least 30 minutes, you can assume that this dose was given. You should use stress dose steroids while the child is vomiting (double or triple the normal amount and can return to normal dosing once the child feels better). Keep a record of the number of times your child vomits, has diarrhea, as well as how much your child has been drinking. Offer small amounts of clear liquids frequently, such as 1 ounce every 15 minutes. Call the doctor if your child is unable to keep anything at all down. They may require a trip to the Emergency Room for IV fluids or require a shot of SoluCortef.

Watch your child closely for other signs of acute cortisol deficiency such as:

Confusion, dazed, dehydration, dizziness, fatigue, floppiness, headache, lethargy, listless, pale skin, not urinating at least 1 time in 8 hours, restless, or weakness.

You should keep an injectable form of hydrocortisone with you at all times. There should also be one at school and at any place where the child stays regularly (i.e- grandparent’s house). You should be able to get this medication at your local pharmacy with a prescription from our office. Always be aware of the medication’s expiration date. You don’t want to be in an emergency situation and realize that your medication is outdated.

When to give the injection

- **Repeated vomiting (more than once)**
- **Repeated episodes of diarrhea (more than 3)**
- **Unconsciousness (unable to wake up)*Give immediately, call 911, then our office**
- **Surgery (our office will give you an oral dose to give the night and morning of as well as orders for the person giving your child anesthesia)**

A nurse will be coming to give you a hands on demonstration of how to give an injection. This is something that you must learn to do in order to keep your child safe. You will need an emergency kit that contains the SoluCortef, syringes with needles, and alcohol wipes.

The medication comes in a Mix-O-Vial or ACT-O-Vial



There is fluid on the top and medication powder on the bottom. There is a rubber stopper separating them. You activate the vial by pushing down firmly on the top of the vial while it is resting on a flat surface.

The following is a step by step of how to prepare and give an emergency injection of SoluCortef.

1. Wash your hands and gather injection emergency kit: needle, syringe, alcohol pad, and vial of hydrocortisone (Solu-Cortef Mix-O-Vial).
2. Mix the medication by pushing down on top of the vial to release the cork into the vial.
3. Gently swirl the vial to mix medication, take off the top of the vial, and wipe down the rubber stopper with alcohol.
4. Take the cap off the syringe needle and insert into the vial through the rubber stopper.
5. Draw up the medication and replace the needle cap. Know how much your child's dose is in mg and how many ml it is of the hydrocortisone.
6. Select the site for the intramuscular injection- It is typically the outer portion in the middle of the thigh.
7. Use the alcohol to clean the skin at the injection site.
8. Take the cap off the needle and hold the syringe like a pencil.
9. Using your thumb and first two fingers, grasp the skin and push down lightly.
10. Dart the needle into the thigh, going at a 90 degree angle.
11. Hold the syringe in place and pull back the plunger to make sure you don't see blood, meaning you are in a blood vessel. If you do (which would be rare), withdraw syringe and discard. Prepare another syringe with medication and inject in a slightly different site.

(However, if this is the only dose, continue with the same syringe, injecting in a slightly different site).

12. After injecting the medication, place tissue or cotton ball near the needle and pull the needle out quickly. Cover with bandaid if needed. You may massage the muscle to help ease any pain.

13. Place the needle and syringe in a hard, unbreakable container.

14. Call Doctor / 911 or go to hospital if necessary.

Things to always remember:

- The medication needs to be stored in a cool dry place.
- The needle and inside of the syringe are sterile, meaning they are completely germ free. If the needle touches anything before you give the injection, replace it with another sterile needle before giving the injection.
- After the injection is given, activate the safety needle cover and dispose of the needle in a plastic container that you cannot see through (empty bleach bottle, laundry detergent bottle, etc) and secure the lid. Write "Do Not Recycle" on the outside of the bottle and duck tape the lid to the bottle prior to discarding the full sharps container. You can also buy a sharps container from your local pharmacy.

What do I do after the injection is given?

Call our office when the injection has been given to your sick child. The doctor can help you decide what other steps need to be taken in order to keep your child safe and healthy.

What if I give a shot that isn't necessary?

It is always better to "over" treat your child than to "under" treat your child when they are sick or appear to be stressed. You cannot hurt your child by giving a shot of SoluCortef that may later appear to have been unneeded. On the other hand, not giving a shot when needed could lead the child to go into shock, which is potentially life threatening.

What if there is an emergency and I'm not there?

We understand that you as parents cannot be with your child constantly. Due to this, your child will need to wear a medical identification bracelet that lists their medical condition. Statements

such as “requires hydrocortisone”, “Adrenal Insufficiency”, “CAH”, etc are very helpful to others in an emergency situation with someone that is unfamiliar.