



# What is ACTH Therapy (Corticotropin/ACTHAR Gel) for Infantile Spasms?

My child's name: \_\_\_\_\_

## My child's adrenocorticotrophic hormone (ACTH) therapy dosing plan:

Dates:	How much?	How often?
	_____ units (_____ mL)	___ times per day
	_____ units (_____ mL)	___ times per day
	_____ units (_____ mL)	___ times per day
	_____ units (_____ mL)	___ times per day
	_____ units (_____ mL)	___ times per day

## What is ACTH therapy for infantile spasms?

Your child will be starting adrenocorticotrophic hormone (ACTH) therapy. ACTH is a hormone produced by the pituitary gland in the brain. This medicine is injected into the thigh muscle to reduce infantile spasms. **Infantile spasms (IS)** is a type of epilepsy that usually occurs in babies and is often associated with development problems. A **spasm** is a type of seizure caused by a brief disruption of electrical activity in the brain. **Epilepsy** is a brain disease that causes people to have recurrent seizures. Most often, infantile spasms happen in children 3 months - 2 years old. When infantile spasms happen, your child's whole body may jerk or move in a way that makes it look like they have been startled.

## What are the common side effects of ACTH therapy?

- Feeling irritable or fussy
- Feeling hungrier than usual

- Weight gain, retaining fluid (looking puffy)
- Higher blood pressure
- Increased risk of getting sick
- Blood in the stool

**Will my child be taking any additional medications while taking ACTH?**

**Antacid medicine**

Your child’s doctor will prescribe an antacid medicine to stop stomach ulcers from happening.

What medication?	How much?	How often?
	_____ mg (_____ mL) by mouth	___ times per day while on ACTH

**Antibiotic**

Your child may have trouble fighting infections while on ACTH so your doctor will prescribe an antibiotic.

What medication?	How much?	How often?
Bactrim	_____ mg (_____ mL) by mouth	<u>2</u> times per day on Monday, Tuesday and Wednesday of each week while on ACTH and for an additional 4 weeks after ACTH treatment is completed.

**What should I monitor for while my child is taking ACTH?**

- Monitor your child’s urine output. If you notice an increase in wet diapers, please call your doctor. This may mean your child has a high blood sugar.
- Don’t give your child any over the counter cough or cold medications without talking to your doctor first.

- Don't schedule any vaccines during ACTH therapy. You can schedule vaccines after your child has been off of ACTH for 2 months.
- Don't allow your child to be around children or adults who are sick.
- Good hand washing is important for anyone caring for your child. This reduces the spread of infection or illness.
- In the winter months, all family members should get the flu shot to further reduce the spread of infection or illness.
- Be sure to travel with your medicine. Please keep ACTH in a cooler when traveling.

## How do I inject ACTH?

It can be a challenge to give your child an ACTH injection for the first time. This handout should help by explaining how to prepare and give your child the intramuscular (IM) injection.

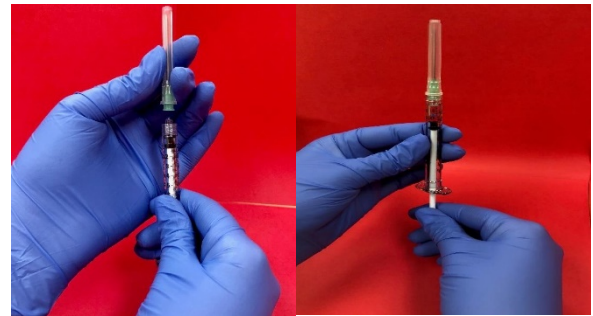
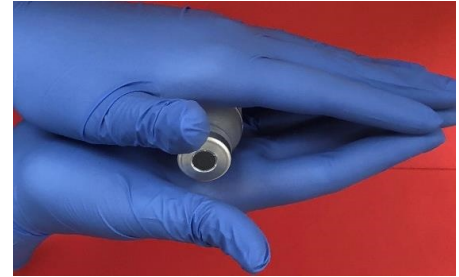
### Before you start

1. Wash your hands with soap and water or clean your hands with an alcohol based gel like Purell.
2. Gather all supplies and place them out on a clean towel. The supplies you will need are:
  - ACTH
  - Syringe
  - Larger needles used to draw up the ACTH
  - Smaller needles used to inject the ACTH
  - Alcohol wipes
  - Cotton balls or gauze
  - Band aids

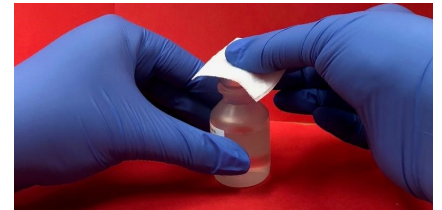


## Preparing the dose

1. Warm the ACTH gel by rolling it between your hands until it becomes liquid. ACTH must be stored in a refrigerator when not in use, but avoid giving ACTH injections without warming it first. This can be uncomfortable for your child.
2. Put together the larger needle and syringe. Make sure the needle is screwed all the way into the syringe.



3. Wipe the top of the ACTH vial with the alcohol wipe.
4. Put the needle into the vial and push on the plunger to inject the air from the syringe into the ACTH vial.



5. Turn the vial upside down. Slowly withdraw the prescribed dose of ACTH gel from the vial into the syringe.

**If there are bubbles present in the syringe:**

- Keep the needle in the rubber stopper with the vial upside down.
- Tap gently on the syringe so air bubbles rise to the top.
- Slowly push the air bubbles back into the vial and then pull back on the plunger to pull up the exact dose.



6. Once you have drawn up the exact dose, remove the needle from the vial and recap the needle.
7. Pull back on the plunger to remove and save any medicine left in the larger needle for the injection. You will switch to a smaller needle before injecting.

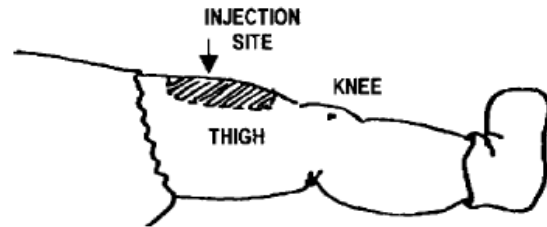
8. Change the needle to the smaller needle before injecting.
  - Be very careful not to waste any of the medicine. Changing the needle wastes medicine and you may run out before therapy is complete.
  - It can be dangerous for your child to miss shots of ACTH in the middle of their treatment. Tell your child's healthcare team as soon as possible if you are going to run out of ACTH.



## Giving your child the intramuscular injection:

1. Lay your child on a blanket.
2. Change which thigh you use each day, alternating between right and left.
3. Find the large muscle of the thigh.

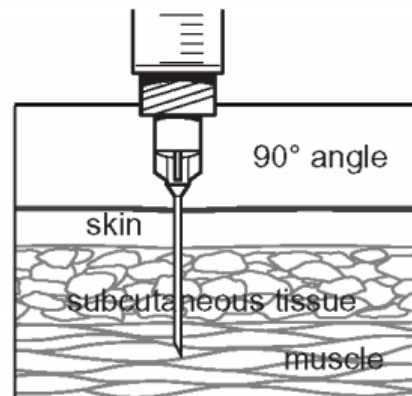
This muscle is on the front part of the thigh between the knee and hipbones. Avoid areas near the knee and hip joints.



4. Clean the thigh site with an alcohol wipe and let it dry.



5. Hold the syringe like a dart and insert the needle into the thigh.  
Intramuscular injections are given at a 90-degree angle.



Adapted from <http://www.immunize.org/catg.d/p3084.pdf> on 3/16/2013. We thank the Immunization Action Coalition.

6. Draw back on the plunger and check for blood. If you see blood, withdraw the needle. Put a new needle on the syringe and choose a different place on the leg to inject.
7. Slowly inject the ACTH.

8. Take out the needle and apply gentle pressure to the injection site with the cotton ball or gauze.
9. If your child is still bleeding after a few seconds, put on a band-aid.
10. Comfort your child.
11. Return the ACTH to the refrigerator.

Disclaimer: This document contains information and/or instructional materials developed by Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

Patient Education by [Michigan Medicine](#) is licensed under a [Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International Public License](#). Last Revised 07/2019