ACTH Therapy for Infantile Spasms

Your child will be starting ACTH therapy. This means that they will take a medicine that is injected every day for about 1 to 3 months. The purpose of the medicine is to reduce infantile spasms. This handout explains infantile spasms and gives details about ACTH therapy.

What are infantile spasms?
Infantile spasms are a type of epilepsy that usually occurs in babies. Epilepsy is a condition where a child has seizures that happen time after time. When infantile spasms happen, your child’s whole body might suddenly jerk or move in a way that looks like they have been startled. This is a normal response when it happens every once in awhile. But when it happens over and over again, like a pattern, it might be infantile spasms.

How long will the spasm last?
The actual spasm only lasts only a few seconds, but they often happen over and over again in a row. These are called “clusters” of spasms. Clusters can last for as long as two to three minutes. Your child might cry after the cluster of spasms. The seizures may happen more often when your child is waking up or going to sleep.

Who has infantile spasms?
Infantile spasms can happen to children starting when they are 3 months old until they are 2 years old. Most infantile spasms happen when children are between 3 months old and 1 year old.

When should I call my child’s doctor about infantile spasms?
• If your child has a pattern of sudden full-body moving or jerking, and it does not seem to be in response to something else happening, like seeing something surprising.
• Your child seems to have clusters of sudden full-body jerking movements.
• Your child seems to have a delay in development. For example, they might be taking a longer time than expected to start talking or walking.

What is Adrenocorticotropic Hormone therapy (ACTH)?
ACTH is a hormone that is produced by the pituitary gland in the brain. Injections, or shots, of ACTH are used to help reduce infantile spasms. We do not know exactly why ACTH shots work to reduce infantile spasms.
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ACTH therapy is done through intramuscular injections. This means giving a shot to your child into a muscle in their leg every day for 1 to 3 months. Your child’s neurologist will talk to you about exactly how long your child needs treatment.

ACTH is only available through a special mail order pharmacy. Talk with your insurance company or provider to get approval before your child starts the treatment. You can call the Neurology nursing line to get help with this if you need to.

To start ACTH therapy, your child will have to stay in the hospital for 1 to 2 days. It is very important for you to be at the hospital during your child’s stay because you will learn how to give your child an ACTH shot. You will also learn about the side effects of ACTH treatment and how to watch your child to avoid having these happen.

Your child will be sent home from the hospital when you and your child’s neurologist feel that you are ready to give your child the treatment. They will make sure that you are able to give ACTH shots to your child and that you know how to watch for and what to do about side effects. After discharge from the hospital, you will keep giving shots of ACTH to your child every day at home.

When will my child’s infantile spasms decrease or stop?

ACTH therapy works differently for every child. For most children, it takes several weeks before seizures slow down or stop. For other children, it might work right away. For some children, ACTH therapy will not work, and they will still have spasms.

Because it is different for everyone, your child’s neurologist will watch your child to see if they need to change anything. They might change the dose or amount of ACTH that your child is taking, or make other decisions about treatment. Your child will probably need to get scheduled for EEGs to see how well ACTH treatment is working.

What are the common side effects of ACTH therapy?

The side effects that happen while your child is on ACTH therapy are temporary and should go away when the therapy stops. While they are on ACTH therapy, your child might:

• Feel irritable or fussy.
• Feel hungrier than usual.
• Retain fluid, look puffy and gain weight.
• Have acne.
• Have higher blood pressure than usual.
• Be more likely to get sick. It is important for your child not to be around people who have the flu, colds, or other contagious illnesses. For this reason, it is important to avoid having your child in daycare while on ACTH therapy.
How can I help my child when they are fussy?

It can be hard to take care of your child when they are feeling irritable and fussy. Here are some things that may help you calm or soothe your child:

- Rocking
- Soft music
- A warm bath
- Bundling in a blanket

If you would like to learn more about soothing your baby, ask your neurologist or Neurology nurse.

What happens when my child leaves the hospital?

Before your child is discharged from the hospital, they will be scheduled for a follow-up visit in the Neurology clinic. ACTH therapy can cause problems for some children, and it is important that your child’s primary healthcare provider checks often to see how they are doing. Some of the things that needed to be checked every week are:

- Blood pressure
- Urine, to check glucose levels
- Weight

Sometimes, stools or bowel movements need to be checked, to make sure there is no hidden blood in them.

You can do some of these tests at home. Other tests need to be done at your child’s primary doctor’s office, at a clinic or by a visiting nurse service.

When do I give my child the ACTH shot?

- Give your child an ACTH shot every day before 10 a.m.
- It is important not to stop giving your child the medicine all of a sudden. This can cause them to have worse side effects and can reduce the chances for the treatment to work.
- If you feel that your child is having problems with the medicine, call your child’s neurologist and ask for advice.
- Check the amount of medicine you have left so that you do not run out. We can help you get a refill, but we need at least 5 business days to get it for you.

It is very important that you do not run out of ACTH. It takes a little longer to get than most medicines, because you cannot get it in pharmacies, only through the mail. It can be dangerous for your child to miss their shots of ACTH in the middle of treatment. For that reason, it is very important that you tell your child’s healthcare team as early as possible before you are going to run out.
When should I call my child’s doctor about problems with treatment?

Call your child’s primary doctor if your child:

• Seems sick. Call if they have a fever, signs of a cold, flu, diarrhea, ear infection or other illness
• Has a sudden change in the way they act, or if there is a big change in how they walk, talk, move or do other activities
• Feels very tired or exhausted
• Pees (urinates) more or less than usual
• Has blood in their stool or bowel movements
• Has redness or swelling in the area that you gave them the ACTH shot

What should I do if I have questions during the treatment?

If you have any questions during ACTH treatment, you should contact the Neurology department right away:

• Monday through Friday, you can call one of the nurses in the Neurology office: 206-987-2078.
• If you call after hours or during weekends or holidays, call 206-987-2000 and ask the hospital operator to page the Neurology resident on call.
• If your child is not feeling well and you cannot contact your primary care provider, bring them to the Emergency Department at Children’s.