

ACTH for infantile spasms

What are infantile spasms?

Infantile spasms are a type of seizure involving sudden, uncontrolled movements of the neck, trunk, or extremities. They are most often seen in infants 4 to 6 months of age. The seizures tend to increase in frequency and severity over several weeks.

How is it treated?

Infantile spasms rarely respond to the usual anti-seizure medicines. Treatment is usually daily injections of adrenocorticotrophic hormone (ACTH). It is not fully understood how it works for this condition, but starting ACTH therapy early has been shown to improve outcomes. ACTH is usually given for a period of weeks to several months.

How do I give the ACTH?

You will be taught how to give the injections. Try to give the ACTH at about the same time each day, usually in the early morning.

Store ACTH in the refrigerator. Before giving it, warm it by holding the bottle in your hands. Follow the directions for drawing up and giving the medicine. See the education sheet “Injections (intramuscular).”

What should I do if a dose is missed?

If a dose is missed, give it as soon as you remember. If two doses are missed, call the doctor.

Are there any precautions about other medicines?

Ibuprofen (Motrin® or another brand) should not be given while on this medicine.

Be sure to check with your child’s doctor before any immunizations are given. Some vaccines should not be given during ACTH therapy.

What are the side effects?

Common side effects that go away when therapy is finished:

- irritability
- acne
- weight gain
- increased appetite
- “moon face”
- change in sleep habits
- frequent urination
- glucose (sugar) in the urine

More serious possible side effects:

- hypertension (increased blood pressure)
- hyperglycemia (increased sugar in the blood)
- gastrointestinal bleeding

When should I call the clinic?

- fever
- any signs of illness
- exposure to infectious disease
- vomiting
- extreme irritability
- blood in stools (bowel movements)
- any change in consciousness

What else do I need to know?

Because ACTH can suppress the immune system, your child may have trouble fighting infections. Keep your child away from others who are ill or have a contagious illness such as chickenpox or measles. Watch for any signs of infection very closely. It is very important to see the doctor at **any** sign of illness, even if it seems minor.

Follow-up visits are very important to see how your child is doing on ACTH therapy. Your doctor will monitor the blood pressure, check the urine for glucose (sugar), and watch for serious side effects.

Never stop giving ACTH without talking to your doctor first. Stopping the use of ACTH suddenly can make your child very ill.

Arrangements may be made for a nurse to visit your home to help you with problems that may arise.

You should know the names of all the medicines your child is taking. **Share this information** with anyone involved in your child's care. Please remember to bring the medicine container when your child goes to the clinic or Emergency Department.

Always make sure you have enough medicine on hand. Each time you refill your prescription, check to see how many refills are left. If no refills are left, the pharmacy will need 2 or 3 days to contact the clinic to renew the prescription.

Check the label and expiration date before giving each dose. Ask your pharmacist what to do with outdated or unused medicines. If there is no "take-back" program put them in the trash.

If too much ACTH is given, call the Poison Control Center at 1-800-222-1222.

Afterwards, please call your child's doctor to report that this happened.

Questions?

This sheet is not specific to your child but provides general information. If you have any questions, please call the clinic.

For more reading material about this and other health topics, please call or visit the Family Resource Center library, or visit our Web site: www.childrensmn.org.

Children's Hospitals and Clinics of Minnesota
Patient/Family Education
2525 Chicago Avenue South
Minneapolis, MN 55404
11/07 ©Copyright