

## Isotretinoin for Neuroblastoma

Isotretinoin (EYE so TRET in oin) is a form of vitamin A that is very concentrated. It can only be obtained by prescription. The oily liquid comes in a soft capsule. Brand names for this medicine are Amnesteem®, Absorica®, Claravis®, Myorisan® and Zenatane®.

Isotretinoin is used to treat neuroblastoma, the most common type of cancer in children. This medicine is given along with other immunotherapy (cancer fighting) drugs during the active stage of illness. It may also be ordered to be taken during the maintenance phase of therapy.

Usually isotretinoin is given after the child has received the medicine 131I-Metaiodobenzylguanidine (MIBG) and has had a Bone Marrow Transplant (BMT).

### Warnings

If your child is allergic to retinoids, he should not take this medicine.

**When handling this drug, extreme care needs to be followed by women who are pregnant or breastfeeding. Isotretinoin can cause severe birth defects and can pass into breast milk. Someone else will need to give this medicine to your child.**

Because of the dangers of birth defects with isotretinoin, your child, your child's doctor, and your pharmacy **must** register with the iPLEDGE™ program. To do this, go to [www.ipledgeprogram.com](http://www.ipledgeprogram.com). Failure to register means that your child will not get the medicine. When your child needs more medicine, the doctor will have to write a new prescription each time.

### How to give

Isotretinoin can be given by mouth whole, buried in food whole, or dissolved and mixed with food.

Always wear disposable gloves if there is a risk of touching the liquid inside the capsule.

If the medicine is removed from inside the capsule and then mixed with food, it must be given within 1 hour. Isotretinoin is extremely sensitive to light and air. The medicine will degrade or change into a different chemical very shortly. Your child may not receive the proper dose.

*Continued on page 2*

## How to give, continued

Isotretinoin is better absorbed by the body when taken with foods high in fat like whole (4%) milk, ice cream, pudding, peanut butter or whipped cream. Parents may try any favorite food to help the child take the medicine, such as oatmeal, mashed potatoes, applesauce or yogurt.

### To give by mouth, try one of the following options:

- Swallow with a drink or bury the whole pill in a favorite high fat food.
- If your child cannot swallow the capsule whole, cut and then bury it in food. Use a sharp knife or clean nail clippers to poke a hole. Or slice off the tip of the capsule. When your child chews, the pill will “pop” open, empty and be easier to swallow.
- Squeeze the contents onto a piece of food.
- Squeeze the contents into 1 to 2 teaspoons of warm whole (4%) milk and mix well. Isotretinoin does **NOT** mix well with drinks made with water or juice.

**Isotretinoin is given every 12 hours.** Sometimes, your child may not be able to take the medicine on schedule.

- For changes in schedule: If you need to change the time that your child usually takes isotretinoin, avoid giving it more than 16 hours or less than 8 hours between doses.
- For missed doses:
  - Less than 4 hours after the scheduled time, still give the dose. The next dose of isotretinoin will be adjusted to 8 hours later.
  - More than 4 hours after the scheduled time, do not take the dose. Resume your regular schedule with the next dose.
  - Never double up on the medicine to make up for a missed dose.
- For vomiting: If the medicine is vomited (thrown up) right after you give it, do not repeat the dose. Some of the medicine may still be in the stomach. If vomiting continues, call the doctor.

### Follow these other guidelines:

- Before giving isotretinoin, read the label on the medicine bottle carefully. Make sure that you are giving your child the right dose and at the right time.
- Wash and dry your hands before and after using the medicine.
- Stay with your child until he or she has taken all the medicine.
- Give this medicine with food.

*Continued on Page 3*

## How to give, continued

- Give it every day as ordered, even if your child is feeling fine. Do not change the doses or stop the medicine without talking to your child's doctor.
- Keep a record of when the medicine is given. See Helping Hand HH-V-1, *Medication Record* or use a calendar.

## Medicine storage

- Store all medicine out of the reach of children.
- Always keep medicine in the original bottle from the pharmacy.
- Do not keep this medicine in the refrigerator. Store at room temperature.
- Light and moisture cause this medicine not to work as well. Keep the bottle tightly closed. Store it in a dark, dry place (not in the bathroom or above the kitchen sink).
- Keep this medicine away from heat or direct sunlight.
- Do not use this medicine after the expiration date printed on the container.

## Drug interactions

- If your child is taking any other medicine or herbal supplements, tell your doctor and pharmacist. Certain medicines should not be taken with isotretinoin.
- Do NOT give your child extra vitamin A. Ask your doctor if it is OK to give a multivitamin.

## Side effects and how to treat them

Each person's reaction to isotretinoin is unique. Many children experience some side effects. These usually go away once treatment is stopped.

- |                                    |                                   |
|------------------------------------|-----------------------------------|
| ▪ Severely dry skin, peeling skin  | ▪ Dry nasal passages, nose bleeds |
| ▪ Dry eyes                         | ▪ Hair loss                       |
| ▪ Itching                          | ▪ Sunburn                         |
| ▪ Red or chapped lips or dry mouth | ▪ Constipation                    |
| ▪ Back, joint or muscle pain       | ▪ Changes in blood tests          |
| ▪ Headaches                        | ▪ Mood changes, irritability      |

*Continued on page 4*

## Side effects and how to treat them, continued

Dry skin is the most common side effect. To help with dryness:

- Apply cream several times a day, especially right after a bath and at bedtime. Generally, creams and ointments are thicker and more effective than lotions. Some products to use are Aquaphor<sup>®</sup>, Aveeno Oatmeal<sup>®</sup>, Aveeno Advanced Care<sup>®</sup>, Bag Balm<sup>®</sup>, Cetaphil<sup>®</sup>, Cabot<sup>®</sup>, Eucerin<sup>®</sup>, Neutrogena Norwegian Formula<sup>®</sup> and Vanicream<sup>®</sup>. Avoid creams with alcohol and fragrance.
- For dry or chapped lips, use nonmedicated lip balms, Aquaphor, Bag Balm, Blistex Cream<sup>®</sup>, Chapstick<sup>®</sup> or Vaseline several times a day. Some patients also find vitamin E and products with lanolin to be helpful.
- Have your child sip or drink fluids throughout the day to stay well hydrated.

## When to call the doctor:

Call your child's doctor if:

- Your child is having any side effects that continue or are very bothersome.
- Your child is exposed to any contagious illness such as chickenpox, shingles and whooping cough (pertussis).

**If your child takes too much of this medicine or if someone else takes this medicine,** call the **Central Ohio Poison Center at 1-800-222-1222** (TTY 614-228-2272). They will tell you what to do.

## Preventive measures

- Isotretinoin makes your child more sensitive to sunlight. Even during the winter, your child needs protection before going outside. He or she should wear a hat, long sleeves and long pants and use sunscreen lotion with a SPF of 30 or more. Apply the sunscreen every 30 minutes if your child is sweating or playing in water.
- Follow the mouth care routine recommended for all patients taking chemotherapy. See Helping Hand HH-II-45, *Mouth Care for Patients Receiving Chemotherapy*.
- Your child's provider will do blood tests before the first dose of isotretinoin is given and from time to time during treatment.

## Tips and other information

- All medicines come with information from the FDA (Federal Drug Administration), called a Med Guide. Make sure the pharmacist gives it to you and that you read it.

*Continued on page 5*

## Tips and other information, continued

- Some pharmacies may not have this medicine. Please ask the nurse to call your pharmacy before you leave the hospital to see if they have this medicine or can order it for you. You may also have the prescription filled at the Nationwide Children's Hospital Pharmacy.
- *The prescription for this medicine cannot be refilled at the pharmacy.* Your child's doctor needs to write a new prescription each time you run out of medicine and need more.
- Bring all your child's medicines with you in the original bottles whenever he or she sees a doctor, goes to an emergency room or is admitted to the hospital.
- When your child goes to other medical appointments or to the dentist, be sure to tell the dentist or doctor that your child is taking this medicine.
- Tell your child's other caregivers that your child is taking this medicine, the side effects, and what to watch for.
- If anyone is at risk of coming in contact with your child's body fluids, vomit, urine or bowel movements, know how to take precautions. Refer to Helping Hand HH-V-37, *Chemotherapy - Safe Handling*.

For more information on giving medicines, ask the nurse for the following:

- Helping Hand HH-V-28, *Medications: How to Give By Mouth*, (if your child has trouble taking medicine)
- Helping Hand HH-V-157, *Medicine Safety*

### QUESTIONS TO ASK THE DOCTOR, NURSE OR PHARMACIST

---



---



---



---



---



---