

## PATIENT & CAREGIVER EDUCATION

# Sodium Phenylbutyrate

This information from UpToDate® Lexidrug™ explains what you need to know about this medication, including what it's used for, how to take it, its side effects, and when to call your healthcare provider.

### **Brand Names: US**

Buphenyl; Olpruva; Pheburane

### **Brand Names: Canada**

Pheburane

### **What is this drug used for?**

- It is used to treat urea cycle problems.
- This drug is not for use to treat sudden high ammonia levels. Be sure you know the signs of high ammonia levels. Sudden high ammonia levels need emergency medical care and can be deadly. Talk with the doctor.

## What do I need to tell the doctor BEFORE my child takes this drug?

- If your child is allergic to this drug; any part of this drug; or any other drugs, foods, or substances. Tell the doctor about the allergy and what signs your child had.
- If your child is taking any of these drugs: Divalproex, haloperidol, or valproic acid.
- If your child has a rare hereditary health problem like glucose-galactose malabsorption, fructose intolerance, or sucrase-isomaltase deficiency. Some products have sucrose.
- If your child weighs less than 44 lb (20 kg). Some brands are not for use in children who weigh less than 44 lb (20 kg).

This is not a list of all drugs or health problems that interact with this drug.

Tell the doctor and pharmacist about all of your child's drugs (prescription or OTC, natural products, vitamins) and health problems. You must check to make sure that it is safe to give this drug with all of your child's other drugs and health problems. Do not start, stop, or change the dose of any drug your child takes without checking with the doctor.

## **What are some things I need to know or do while my child takes this drug?**

- Tell all of your child's health care providers that your child is taking this drug. This includes your child's doctors, nurses, pharmacists, and dentists.
- Have your child's blood work checked often. Talk with your child's doctor.
- Have your child follow the diet plan your child's doctor told you about.
- Have your child wear disease medical alert ID (identification).
- If your child is on a low-sodium or sodium-free diet, talk with the doctor. Some of these products have sodium.
- If your child's weight changes, talk with the doctor. The dose of this drug may need to be changed.

### **If your child is pregnant or breast-feeding a baby:**

- Talk with the doctor if your child is pregnant, becomes pregnant, or is breast-feeding a baby. You will need to talk about the benefits and risks to your child and the baby.

## What are some side effects that I need to call my child's doctor about right away?

**WARNING/CAUTION:** Even though it may be rare, some people may have very bad and sometimes deadly side effects when taking a drug. Tell your child's doctor or get medical help right away if your child has any of the following signs or symptoms that may be related to a very bad side effect:

- Signs of an allergic reaction, like rash; hives; itching; red, swollen, blistered, or peeling skin with or without fever; wheezing; tightness in the chest or throat; trouble breathing, swallowing, or talking; unusual hoarseness; or swelling of the mouth, face, lips, tongue, or throat.
- Signs of too much acid in the blood (acidosis) like confusion; fast breathing; fast heartbeat; a heartbeat that does not feel normal; very bad stomach pain, upset stomach, or throwing up; feeling very sleepy; shortness of breath; or feeling very tired or weak.
- Signs of electrolyte problems like mood changes; confusion; muscle pain, cramps, or spasms; weakness; shakiness; change in balance; an abnormal heartbeat; seizures; loss of appetite; or severe upset stomach or throwing up.
- Feeling very tired or weak.

- Dizziness or headache.
- Upset stomach or throwing up.
- Feeling sleepy.
- Feeling confused.
- Change in hearing.
- Memory problems or loss.
- A burning, numbness, or tingling feeling that is not normal.
- Swelling.

### **What are some other side effects of this drug?**

All drugs may cause side effects. However, many people have no side effects or only have minor side effects. Call your child's doctor or get medical help if any of these side effects or any other side effects bother your child or do not go away:

- Decreased appetite.
- Bad taste in your child's mouth.
- Change in body odor.

### **If your child has menstrual periods:**

- No period or other period (menstrual) changes.

These are not all of the side effects that may occur. If you

have questions about side effects, call your child's doctor. Call your child's doctor for medical advice about side effects.

You may report side effects to your national health agency.

### **How is this drug best given?**

Give this drug as ordered by your child's doctor. Read all information given to you. Follow all instructions closely.

#### **Powder and tablet:**

- Give this drug with meals.

#### **Powder:**

- Shake before use.
- Mix powder with liquid or soft food.
- Use only the scoop that comes with the powder to measure powder.
- If mixed with food, give the dose right away. Do not store for future use. If mixed with water, you may store at room temperature or in a refrigerator for up to 1 week.
- Those who have feeding tubes may use this drug. Use as you have been told. Flush the feeding tube after this drug is given.

## **Oral pellets:**

- Give this drug with food.

## **Oral pellets (bottle):**

- Only use the measuring device that comes with this drug.
- Have your child swallow the pellets with a drink like water, fruit juice, or protein-free infant formula. You may also sprinkle the pellets on a spoonful of apple sauce or carrot puree. Do not let your child chew the pellets. Do not mix the pellets into a liquid. Have your child swallow the pellets right away.
- If your child has a feeding tube, talk with your child's doctor before giving this drug.

## **Oral pellets (packets):**

- This drug comes with 2 packets for each dose. One packet has a Mix-Aid to help the drug dissolve in water. One packet has the drug in it. Be sure you know which packet has the Mix-Aid and which packet has the drug.
- To mix this drug, first pour the contents of the Mix-Aid packet into water in a cup. The amount of Mix-Aid and water to use depends on the dose. Be sure you know how much to use. Stir until dissolved. Then, add the contents of the packet with this drug in it and stir.

- Have your child drink the whole dose within 5 minutes after stirring. After drinking, pour more water into the cup and have your child drink to be sure the whole dose is taken. Be sure you know how much extra water to use.
- If your child has not taken this drug within 30 minutes after mixing, throw it away.
- If your child has a feeding tube, talk with the doctor before giving your child this drug. This drug is not for use with all types of feeding tubes.

## **What do I do if my child misses a dose?**

### **Powder and tablet:**

- Give a missed dose as soon as you think about it, with a meal.
- If it is close to the time for your child's next dose, skip the missed dose and go back to your child's normal time.
- Do not give 2 doses at the same time or extra doses.

### **Oral pellets (bottle):**

- Give a missed dose as soon as you think about it, with food.
- If it is less than 3 hours until the next dose, skip the missed dose and go back to the normal time.
- Do not give 2 doses at the same time or extra doses.

## **Oral pellets (packets):**

- Give a missed dose with food as soon as you think about it on the same day your child misses the dose.
- If you do not think about the missed dose until the next day, skip the missed dose and go back to your child's normal time.

## **How do I store and/or throw out this drug?**

### **All products:**

- Store at room temperature in a dry place. Do not store in a bathroom.
- Keep all drugs in a safe place. Keep all drugs out of the reach of children and pets.
- Throw away unused or expired drugs. Do not flush down a toilet or pour down a drain unless you are told to do so. Check with your pharmacist if you have questions about the best way to throw out drugs. There may be drug take-back programs in your area.

### **Oral pellets (bottle), powder, and tablets:**

- Keep lid tightly closed.

### **Oral pellets (bottle):**

- After opening, throw away any part not used after 45 days.

## General drug facts

- If your child's symptoms or health problems do not get better or if they become worse, call your child's doctor.
- Do not share your child's drug with others and do not give anyone else's drug to your child.
- Some drugs may have another patient information leaflet. If you have any questions about this drug, please talk with your child's doctor, nurse, pharmacist, or other health care provider.
- If you think there has been an overdose, call your poison control center or get medical care right away. Be ready to tell or show what was taken, how much, and when it happened.

## Consumer Information Use and Disclaimer

This generalized information is a limited summary of diagnosis, treatment, and/or medication information. It is not meant to be comprehensive and should be used as a tool to help the user understand and/or assess potential diagnostic and treatment options. It does NOT include all information about conditions, treatments, medications, side effects, or risks that may apply to a specific patient. It is not intended to be medical advice or a substitute for the medical advice, diagnosis, or treatment of a health care provider based on the health care provider's examination

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If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

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