PATIENT & CAREGIVER EDUCATION

Cysteamine (Systemic

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

Cystagon; Procysbi

Brand Names: Canada

Procysbi

What is this drug used for?

- It is used to treat nephropathic cystinosis.

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 breast-feeding a baby:

- Be sure your child does not breast-feed a baby while taking this drug.

This drug may interact with other drugs or health problems.

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 avoid tasks or actions that call for alertness until you see how this drug affects your child. These are things like riding a bike, playing sports, or using items such as scissors, lawnmowers, electric scooters, toy cars, or motorized vehicles.
- Have your child's blood work and other lab tests checked as you have been told by the doctor.
- Alcohol may interact with this drug. Be sure your child does not drink alcohol.
- This drug may raise the chance of ulcers or bleeding from the stomach or bowel. Talk with the doctor.
- 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:

- If your child is pregnant or gets pregnant while taking this drug, call the doctor right away.

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:

All products:

- 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 fluid and electrolyte problems like mood changes, confusion, muscle pain or weakness, fast or abnormal heartbeat, severe dizziness or passing out, increased thirst, seizures, feeling very tired or weak, decreased appetite, unable to pass urine or change in the amount of urine produced, dry mouth, dry eyes, or severe upset stomach or throwing up.
- Ringing in ears.
- Dizziness or passing out.
- Feeling sleepy.
- Eye pain.
- Stomach pain; black, tarry, or bloody stools; throwing up blood; or throw up that looks like coffee grounds.
- Upset stomach or throwing up.
- Decreased appetite.
- Depression.
- Low white blood cell counts have happened with this drug. This may lead to a higher chance of getting an infection. Call your child's doctor right away if your child has signs of infection like fever, chills, or sore throat.
- A very bad skin reaction (toxic epidermal necrolysis) may happen. It can cause very bad health problems that may not go away, and sometimes death. Get medical help right away if your child has signs like red, swollen, blistered, or peeling skin (with or without fever); red or irritated eyes; or sores in the mouth, throat, nose, or eyes.
- Raised pressure in the brain has happened with this drug. Most of the time, this will go back to normal after this drug is stopped. Sometimes, loss of eyesight may happen and may not go away even after this drug is stopped.

Call the doctor right away if your child has a headache or eyesight problems like blurred eyesight, seeing double, or loss of eyesight.

- Very bad skin problems like stretch marks, joint problems, and bone problems like broken bones and deformed bones have happened with this drug. Call the doctor right away if your child has any skin changes or bone or joint pain.

All delayed-release products:

- A severe bowel problem called fibrosing colonopathy has happened with this drug. Call the doctor right away if your child has stomach pain, throwing up, weight loss, bloody or long-lasting diarrhea, or is not able to control bowel movements.

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:

- Diarrhea.
- Feeling tired or weak.
- Change in body odor.
- Bad breath.
- Eye irritation.
- Flu-like signs.
- Nose or throat irritation.
- Ear pain.

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.

Immediate-release capsules:

- Have your child swallow whole. Do not let your child chew or crush.
- You may sprinkle contents of capsule on food.
- Keep giving this drug to your child as you have been told by your child's doctor or other health care provider, even if your child feels well.

Delayed-release capsules:

- Have your child swallow whole. Do not let your child chew or crush.
- Give this drug with fruit juice (not grapefruit juice) or water.
- You may sprinkle contents of capsule on up to 1/2 cup (4 ounces/120 mL) of applesauce or berry jelly. The contents may also be mixed in 1/2 cup (4 ounces/120 mL) of fruit juice (not grapefruit juice). Do not let your child chew. Give within 30 minutes of mixing.

Delayed-release granules:

- Sprinkle granules on up to 1/2 cup (4 ounces or 120 mL) of applesauce or berry jelly. May also be mixed in 1/2 cup (4 ounces or 120 mL) of fruit juice (not grapefruit juice). Do not let your child crush or chew granules. Give within 30 minutes of mixing.

All delayed-release products:

- Keep giving this drug to your child as you have been told by your child's doctor or other health care provider, even if your child feels well.
- Give at least 30 minutes before or 2 hours after a meal.
- If your child cannot take this drug without eating, your child can eat a little bit of food (about 1/2 cup) within 1 hour before taking this drug through 1

hour after taking it.

- Always give with a little bit of food or always give on an empty stomach.
- Have your child avoid high-fat food close to when your child takes this drug.
- Those who have feeding tubes may use this drug. Use as you have been told. Flush the feeding tube after this drug is given.
- If your child takes other drugs, they may need to be given at a different time than this drug. Check with the doctor or pharmacist about the best time to give them.

What do I do if my child misses a dose?

Immediate-release capsules:

- Give a missed dose as soon as you think about it.
- If it is less than 2 hours until 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.

All delayed-release products:

- Give a missed dose as soon as you think about it.
- If the next dose is less than 4 hours away, 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.

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

All products:

- Store at room temperature protected from light. Store 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.

Delayed-release capsules:

- Store in the original container. Do not take out the antimoisture cube or packet.
- Keep lid tightly closed.

Delayed-release granules:

- Do not open until you are ready to use.
- Throw away any part of the opened packet after the dose is given. Do not store opened packets for future use.

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

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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 to search our virtual library.

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