



## CYSTINE STONES ARE ALWAYS FORMING

With cystinuria, it's only a matter of time before urinary cystine buildup leads to cystine stones. These stones can be painful and may even require surgical intervention. You can ignore the buildup—or you can prevent it. *Which will you choose?*

PREVENT

IGNORE



## STONE PREVENTION IS POSSIBLE— AND IT STARTS WITH YOU

Understanding how cystine stones form and the importance of getting on the right management plan are key steps toward preventing cystine stones.

# WHAT IS CYSTINURIA AND WHY DO I NEED TO MANAGE IT?

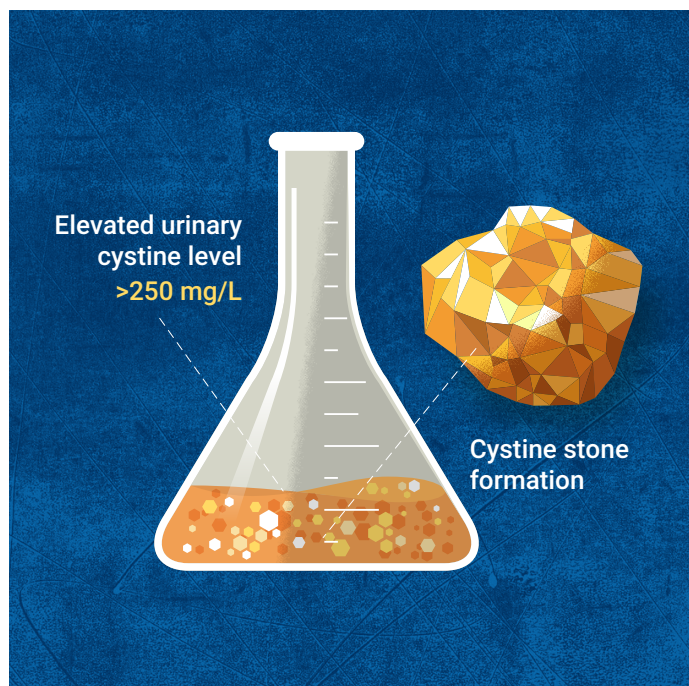
Cystinuria is a rare, lifelong, and serious genetic disorder. People with cystinuria are born without the ability to properly remove excess cystine from their urine. Because of this, cystine builds up in the urine, leading to the formation of a specific type of kidney stone called cystine kidney stones.

It's important to understand that, because cystinuria is genetic, it won't go away over time and, therefore, requires ongoing monitoring and management.

## Managing your urinary cystine level is the key to avoiding cystine stone events

Think of it this way: just as people with high cholesterol need to routinely monitor their cholesterol to know if their levels are controlled, people with cystinuria need to routinely monitor their urinary cystine levels to prevent new stones from forming.

The goal of managing cystinuria is to keep your urinary cystine level below the solubility limit (generally <250 mg/L) and prevent the next stone. When urinary cystine levels are above 250 mg/L, cystine is no longer soluble—or able to dissolve—and it builds up in the urine, leading to the formation of stones.



**Do you know your urinary cystine level? The 24-Hour Cystine Urine Test** is the best way to measure and monitor your urinary cystine level—the test is simple and free through the **Cystinuria Management Program**. Talk to your doctor to learn more.

# HOW CAN I MANAGE MY CYSTINURIA?

Partner with your doctor to establish a management plan that's best for you. Your plan may include making changes to your lifestyle, taking certain medications, and routinely monitoring your urinary cystine level to reduce your risk of forming cystine stones.



## Drink 3 to 4 liters of water per day

**Why?** Drinking water reduces the concentration of cystine in your urine, which makes cystine more soluble—or able to dissolve. When cystine is soluble, your risk of forming cystine stones is reduced.

**TIP:** Carry a refillable water bottle with you at all times. It's good practice to stay hydrated—but it's especially important for people with cystinuria.



## Take an alkali medication to help maintain a urine pH of 7.0

**Why?** Cystine stones tend to form in highly acidic environments. Taking a medication, such as potassium alkali, can help you maintain an optimal urine pH, which may help prevent the next stone.

**TIP:** Have your doctor regularly test the pH level of your urine. If your pH is too acidic, your doctor may need to adjust the dose of your medication.



## Follow a low-sodium and low-animal-protein diet

**Why?** Maintaining a low-sodium and low-animal-protein diet reduces the amount of cystine your body excretes—or gets rid of—which reduces your risk of forming cystine stones.

**TIP:** Opt for home-cooked meals and unprocessed foods like fruits, vegetables, and certain nonanimal-protein sources. Processed foods and restaurant meals tend to have a high salt content.



## Take a cystine-binding thiol drug

**Why?** When lifestyle changes aren't enough, cystine-binding thiol drugs can remove excess cystine from your urine to help lower cystine below the solubility limit (generally <250 mg/L).

**TIP:** Schedule time with your doctor to talk about how cystine-binding thiol drugs can help you lower your urinary cystine level to prevent stones from forming.



## **STONE PREVENTION IS POSSIBLE WITH THE RIGHT MANAGEMENT PLAN**

Work with your doctor to establish a management plan that's right for you. When cystinuria is properly managed, you may prevent the next stone. But when cystinuria is not managed properly, you will continue to form cystine stones.

Stones can be painful, difficult to pass, and may require surgery to remove. Repeat surgeries may damage your kidneys over the long term.

On top of the pain caused by recurring stones and repeat surgeries, cystinuria can have a negative impact on the mental health of those affected.



To learn more, visit [PreventCystineStones.com](http://PreventCystineStones.com).