# REGULARLY MONITOR YOUR URINARY CYSTINE LEVEL WITH A 24-HOUR URINE TEST

Cystine stone prevention starts with knowing your cystine level. Do you know yours?

Elevated cystine level >250 mg/L

Cystine stone formation

### WHY YOU NEED TO PERFORM A 24-HOUR URINE TEST

When you have cystinuria, cystine builds up in your urine. If not managed properly, this buildup can lead to the formation of cystine stones.

A 24-hour urine test can measure your cystine level. Your test results will show if your cystine level is above the solubility limit, generally 250 mg/L.

• Above 250 mg/L: you may be at risk of forming a stone

Even though cystine builds up over time, you may not feel any obvious pain until a stone event occurs.

Regular monitoring of your cystine level is essential to preventing the next stone.



Partner with your doctor to make a 24-hour urine test a regular part of your management plan.

### WHAT TO EXPECT ONCE YOU'VE SUBMITTED YOUR URINE SAMPLE

The results of your 24-hour urine test will be sent directly to your doctor. It is important to review these test results with him or her as soon as they become available in case changes need to be made to your management plan.

If your test results show that your cystine level is above 250 mg/L, your doctor may suggest immediate changes to your management plan. These changes can include:

- Increasing your fluid intake (≥3 L/day)
- Adjusting your pH with alkalizing agents
- Reducing sodium and protein in your diet
- Adjusting your dosages of medications, and other cystinuria treatments



Remember, the key to avoiding stone events is adhering to your management plan to bring—and keep—your urinary cystine level below 250 mg/L.

#### **PLAN FOR STONE PREVENTION**

The tips below can help you make the 24-hour urine test a regular part of your management plan. Scheduling your 24-hour urine tests and follow-up appointments in advance can set you up for success.



Pick a date to perform your 24-hour urine test and mark it on your calendar.

We know life gets busy, so scheduling your 24-hour urine test in advance guarantees that you set aside the time you need to complete it.

You plan for important events in life—shouldn't this be the same? When it comes to your health, cystine stone prevention should always be top of mind. 2

Review test results with your doctor as soon as they become available.

If your test results show that your cystine level is **above 250 mg/L**, work with your doctor to make immediate changes to your management plan.

If your cystine level is **below 250 mg/L**, continue with your management plan and remember to routinely monitor your cystine level using the 24-hour urine test to make sure your plan is still working. 3

Partner with your doctor to create a 24-hour urine test schedule.

Avoid the stress of having to shuffle your schedule around last minute. Plan ahead to make the 24-hour urine test feel like just another part of your routine.

For patients taking other certain cystinuria treatments, it is recommended that they perform a 24-hour urine test the first month after initiating treatment-and every 3 to 6 months thereafter-to assess how well it's working.

Even if you are not currently taking other cystinuria treatments, it's important to routinely test your cystine level to make sure it's not above 250 mg/L.

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Continue to stick to your management plan to prevent the next stone.

Because cystinuria is a genetic disease—meaning you inherited it from your parents—you will always be at risk for stones. Since certain factors may cause your cystine level to change over time, ongoing and active management will be a necessary part of preventing stones.

Knowing your cystine level puts you in position to help prevent the next stone.



# STAY AHEAD OF CYSTINE STONES USING THE 24-HOUR URINE TEST

Visit **PreventCystineStones.com** to learn more about cystinuria and the importance of routinely monitoring your cystine level.

