HYPEROXALURIA GLOBAL ALLIANCE
A Community Without Boundaries

Primary Hyperoxaluria (PH)

A Guide for Patients, Families, and Caregivers

Hyper (too much) – **oxal** (oxalate) – **uria** (in the urine)

What is Primary Hyperoxaluria (PH)?

PH is a rare condition you are born with. It means your body makes too much of a substance called oxalate.

With PH, the extra oxalate can cause problems:

Kidney Stones
This is often the first sign.

Buildup in Kidneys (Nephrocalcinosis)
Oxalate can collect inside the kidney tissue.

Kidney Problems
Over time, the extra oxalate can damage the kidneys and affect how well they work.

You are not alone!

The Hyperoxaluria Global Alliance (HGA) offers support and guidance. **Knowing about PH early is the best way to keep your kidneys healthy.**

What Causes PH? (Types of PH)

PH happens because of changes in certain genes that affect liver enzymes. **A genetic test can show your PH type and help your doctor choose the best treatment:**

PH Type	Problem With This Liver Enzyme
PH1	AGT enzyme
PH2	GRHPR enzyme
PH3	HOGA enzyme

Symptoms and Signs

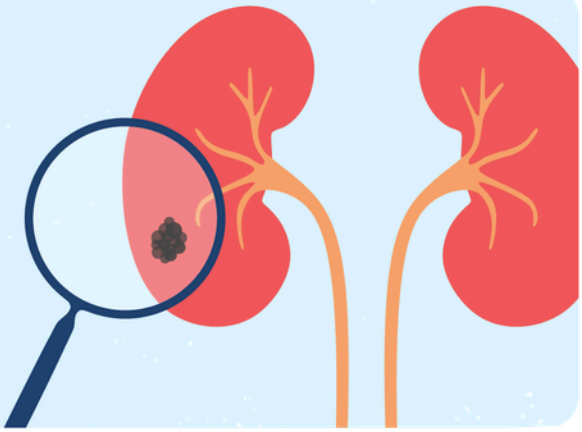
The main symptoms and signs of PH are related to the kidneys:

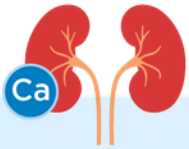
Kidney Stones

Stones can be painful. Even just one stone in a child requires medical evaluation.

Stones can cause:

- Pain in the back, side, or belly.
- Blood in the urine.
- Pain or trouble when urinating.

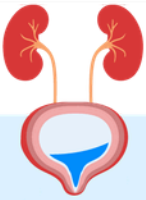




Calcium deposits in the kidneys (nephrocalcinosis).



High oxalate in the urine (checked with specialized urine lab test).



Urinary tract infections (UTIs).



Kidney function decline (kidneys aren't working well).

What to do?

Children with kidney stones (even just one) **or adults** with recurrent stones should be evaluated and may need **genetic testing for PH.**

Check lab results: Ask your doctor about blood or urine tests if they show high oxalate or changes in kidney function.

Report UTIs or other kidney changes to your doctor promptly.

Diagnosis and Testing

To find out if you have PH, your doctor may use:

Medical history & physical exam: Checking your symptoms and family history.

Urine & blood tests: To check oxalate levels and kidney health.

Imaging: To look for stones or deposits in the kidneys.

Genetic testing: This is typically the most appropriate test to diagnose PH and tell you which type you have.

TIP

Getting tested early can help protect your kidney health.

Available Treatments

Treatments help protect your kidneys and lower the amount of oxalate in your body.

Drink lots and lots of water every day! This helps flush the kidneys.

Vitamin B6: In some people, particularly those with PH1, Vitamin B6 may help lower oxalate levels. Your doctor can advise if this is appropriate for you.

Citrate Therapy: Helps stop new kidney stones from forming.

RNAi Therapies: These medicines help reduce the amount of oxalate the liver is producing. This can protect your kidneys and lower the chance of kidney stones.

Liver and Kidney Transplant: In some people with serious kidney damage, a transplant can replace the liver enzyme and give the kidneys a fresh start. Your healthcare team will explain if this is needed and help you understand all options.

TIP

Work closely with a **specialist, like a nephrologist or urologist,** to find the best plan for your care.

Join the Global Patient Registry



The **OHF Patient Registry** is the most important way you can help PH research worldwide.

Why It Matters:

Helps Researchers: Experts around the world learn how PH affects people of all ages.

Tracks New Treatments: It helps track how well new medicines are working.

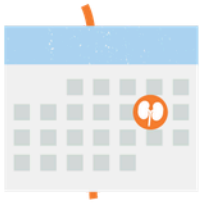
Supports Cures: The data helps researchers find new treatments and future cures.

Your Information Is Safe

- The Registry keeps your data secure and anonymous.
- Your personal details are never shared.
- You choose what information to provide.
- **Visit the HGA to learn more.**

Moving Forward After a PH Diagnosis

A diagnosis is the first step toward better care.



See Your Specialists: Regularly visit a nephrologist or urologist to help manage your PH and protect your kidney health.

Discuss Treatment: Talk openly with your doctor about managing PH and your treatment plan.





- **Connect with the HGA:** Your trusted resource for support, education, and connecting with the PH community.
- **Visit WeAreHGA.org**

Join the OHF Patient Registry: Help research that leads to new treatments and future cures.



TIP

Regular check-ups and following your treatment plan are the best ways to protect your health. **The Global Alliance is here to support you every step of the way.**

Disclaimer: This guide is for educational purposes only and does not replace medical advice. Always consult your healthcare provider for diagnosis and treatment. The Hyperoxaluria Global Alliance (HGA) is a program sponsored by the Oxalosis & Hyperoxaluria Foundation (OHF).

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