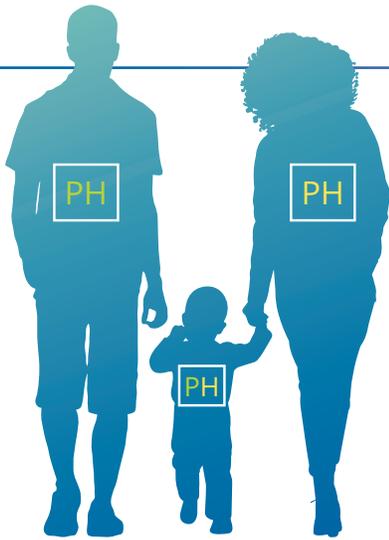


Talk to your family about **primary hyperoxaluria (PH)** and kidney disease

This guide will help you explain PH to your family and encourage them to get tested



Primary hyperoxaluria (PH) is a rare liver disease that runs in families

PH is a genetic disease, which means it's passed down from parents to children. To have PH, both of your parents must pass on the genetic changes that cause it. PH causes kidney stones that damage the kidneys.

If you have PH, there is a chance that your siblings and your children may also have it. It's important to share information about it with your family, so they can take steps to keep their kidneys healthy.

Follow these steps to talk with your family



Start the conversation by asking a question or saying that you care

For example, you could say:

"I've told you that I have primary hyperoxaluria, or PH. How much do you know about it?"

"I want both of us to live long, healthy lives."

"I hope we'll both be around for a long time."

"I want to help you be healthy so we can both keep doing the things we love."



Share the facts about PH

Explain what PH is:

"PH is a rare liver disease that causes oxalate to build up in your body and damage your kidneys. Oxalate is a natural chemical in your body and in some foods. With PH, your liver doesn't make enough of a certain protein to prevent oxalate from building up."

Explain that PH runs in families:

"PH is passed down from parents to child. The most common type is PH1. To have PH, you must have 2 copies of the gene that causes PH: one copy from each of your parents. If each parent has only one copy of the gene, they won't have PH, but can pass it down. Each of their children will have a 25%, or 1 in 4, chance of having PH."

Let them know that PH can cause serious kidney damage:

"Your kidneys remove oxalate from your body through urine (pee). When oxalate levels are high, the extra oxalate combines with calcium in your kidneys to form kidney stones and calcium oxalate crystals in your urine."

"Over time, kidney stones and crystals damage your kidneys and can cause them to stop working. This is called kidney failure."

Kidney stones are the most common symptom of PH

Symptoms of a kidney stone include:

- Pain while urinating
- Blood in your urine
- Sharp pain in your back or lower belly
- Feeling sick to your stomach or throwing up



Encourage your family to get tested for PH

Tell them how doctors can do tests to see if they have PH or the gene that causes it:

"The tests include:

- Urine tests to measure oxalate in your urine
- Blood tests to see oxalate levels in your blood and check how well your kidneys are working
- Genetic (DNA) tests to see if you have the gene mutation, or change, that causes PH"

"The sooner you get tested, the sooner you can take steps to keep your kidneys healthy! Let's call your doctor's office to schedule a visit."