

Explaining Primary Hyperoxaluria (PH) to Others



A conversation cheat sheet

One aspect of living with a rare disease can be the difficulty of explaining your condition to others, especially when you look healthy. Remember that you don't have to explain it. That's your decision.

If you do want to explain what PH is and how it affects you, it can help if you have some preplanned information to share with people who have questions about your condition. You can also direct them to a site like **UnderstandingPH.com** for answers instead.

Here are some of the questions you may get, along with some ideas for how you can respond.

Q. I've never heard of PH. What causes it?

A. PH is a very rare genetic disease. It causes my body to make too much oxalate, which can build up to excessive levels and cause kidney stones and permanent kidney damage. When it's more severe, it can even cause damage to other organs in my body.

Q. How did you get it?

A. PH is a genetic disorder, so I was born with it.

Q. Why do you have so many appointments?

A. Some appointments are to monitor my kidney health and to make sure my PH is in check. This is important because my kidneys could go into decline without me realizing. Other appointments are for monitoring kidney stones to determine whether I'll need a kidney stone removal procedure.

Q. Do you really have to drink that much water? What happens if you don't?

A. Yes! Drinking lots of water helps my body dilute the oxalate, helping protect my kidneys. For me, drinking water is a little like a person with diabetes taking insulin. If I don't drink enough water all day every day, I can have serious health consequences, including kidney stones and major kidney damage.

Helping children explain PH

Here are some suggestions for helping your child explain their condition to others.



I have a rare disease that can make my kidneys not work as well.



Sometimes I can get kidney stones or get sick from this.



I have to drink a lot of water all day every day to help my kidneys stay healthy.

Questions can come from many places

Friends, family, coworkers, and even strangers may have questions about PH.

Find resources for people with PH and answers to frequently asked questions at UnderstandingPH.com.

