

Understanding _____'s PH1

(name)

This confidential handout is to let you know that this person has a chronic disease called primary hyperoxaluria type 1, also known as PH1. While the disease stays mostly invisible, here's some perspective to help you understand how to support them in their management.

What to know & how you can help

There are a few important things to know about people with PH1:



THEY NEED TO DRINK LOTS OF WATER

Making a plan for restroom use so the person with PH1 does not have to always get permission can help accommodate this need in a way that is not disruptive or intrusive.



THEIR ATTENDANCE MAY BE AFFECTED

People with PH1 may have frequent appointments with their care team, and may have to miss events from time to time.*



THEY MAY NOT FEEL WELL

People with PH1 may experience great pain or discomfort, feel ill or tired, or experience feelings of anxiety and isolation.



THEY MAY NOT WANT TO TALK ABOUT HAVING PH1

People with PH1 may not want the attention on them. Be sensitive to their feelings and do not draw unnecessary attention to special accommodations they may need.

*Some people with PH1 have to undergo dialysis. In these cases, attendance is likely to be more severely affected.



If you have any concerns or questions, please contact _____ at (_____)_____. In case of emergency, always call 911 first.

If you would like to know more about PH1, visit [TakeOnPH1.com](https://www.TakeOnPH1.com)

Write down any additional notes for helping this person with their PH1:

