KIDNEY STONES MAY BE A SIGN OF **SOMETHING MORE.**

There are many diseases that present with stones—primary hyperoxaluria type 1 (PH1) is one of them. In PH1, early diagnosis and disease management are critical.

Print this form, complete the questions within each of the three sections, and review your answers with your healthcare provider to discuss if you or your child should be tested for PH1.

This discussion guide is not validated by any medical organization and does not replace the opinion of a trained medical physician.

Kidney stones are the most common symptom of PH1.

PH1 is a rare, progressive disease that can lead to kidney failure and damage to other organs. Symptoms of a kidney stone can include:

- Pain in the side of the body
- Painful and/or bloody urination
- Urinary tract infections

How many kidney stones have you had? _____ How old were you when you had your first stone? _____

Have you ever seen a nephrologist (kidney doctor)? ☐ Yes ☐ No ☐ Not sure

If you've had multiple kidney stones, or if your child has had a stone, ask your doctor about seeing a nephrologist.

PH1 is passed down through families.

PH1 goes beyond kidney stones—it is an inherited disease that can affect family members in different ways. Because of this, it's important for siblings and family members to consider getting tested for PH1 as well.

Has anyone in your family had a kidney stone? ☐ Yes ☐ No ☐ Not sure

If yes, who in your family has had stones? _____

Some tests can indicate if you may have PH1, and a genetic test can help your doctor confirm it.

PH1 is characterized by the continuous overproduction of oxalate, a waste product that cannot be further broken down or used by the body, and is eliminated by the kidneys.

- Continuous overproduction of oxalate can lead to kidney failure and damage to other organs, which can be permanent. This buildup of oxalate can also form kidney stones.
- Oxalate can be measured in a urine or blood test, and kidney function can be measured using a specific type of blood test.

Have you ever had your oxalate levels tested? ☐ Yes ☐ No ☐ Not sure

Have you ever had a blood test to check how your kidneys were working? ☐ Yes ☐ No ☐ Not sure

Ask your healthcare provider if genetic testing for PH1 may be right for you.

If your healthcare provider decides that genetic testing is the next step for you or your child, one option is to receive genetic testing and counseling through the Alnylam Act® program, offered at no charge. See the next page for more details.

Prepare for your appointment: Tips for talking to your healthcare provider

- Write down any symptoms you've experienced, even if they may seem unrelated
- Make a list of all medications, vitamins, or other supplements that you take
- If possible, take a family member or friend along to help you remember what you discuss

Ensure your voice is heard: Some questions to consider asking your healthcare provider

- What's the likely cause of my kidney stones? Are there any other possible causes?
- Do I have any kidney stones right now?
- What type of kidney stones have I had?
- What kinds of tests might I need?
- Do I need to plan for follow-up visits?
- Do you have any educational materials that I can take with me?

Notes

Use this space to write down any notes or additional questions you may have for your healthcare provider.

Alnylam Act®: One option for genetic testing and counseling

If you haven't been diagnosed with PH1, you or your healthcare provider can request genetic testing and counseling through the Alnylam Act® program if you meet certain criteria. The test is done using a blood, saliva, or buccal sample. Siblings and family members may also be tested through Alnylam Act®.

The Alnylam Act® program was created to provide access to genetic testing and counseling to patients as a way to help people make more informed decisions about their health.

- While Alnylam provides financial support for this program, tests and services are performed by independent third parties
- Healthcare professionals must confirm that patients meet certain criteria to use the program
- Alnylam receives de-identified patient data from this program, but at no time does Alnylam receive patient-identifiable information. Alnylam may use healthcare professionals' contact information for research purposes
- Both genetic testing and genetic counseling are available in the US and Canada
- Healthcare professionals or patients who use this program have no obligation to recommend, purchase, order, prescribe, promote, administer, use, or support any Alnylam product
- No patients, healthcare professionals, or payers, including government payers, are billed for this program

For more information and program rules, download a brochure at AlnylamActPH1.com.

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