

AlylamAct 

Genetic Testing and
Counseling Program^{*†} for
**Primary Hyperoxaluria
Type 1 (PH1)** Offered at
No Charge[‡]

Benson, living with PH1

Your doctor will help you
determine if genetic testing
through Alylam Act[®] is
the right choice for you.

*While program is sponsored by Alylam Pharmaceuticals,
all services are performed by independent third parties.

†Both genetic testing and genetic counseling are available in the U.S. and Canada.

‡To patients, healthcare professionals, or payers.

About primary hyperoxaluria type 1 (PH1)

What is PH1?

PH1 is a rare, inherited disease that causes overproduction of oxalate, a substance that is normally only present in small amounts. Oxalate is a waste product that cannot be further broken down or used by the body, and is primarily eliminated by the kidneys. **PH1 is the most common and severe type of the primary hyperoxalurias.**



John, living with PH1

Why is diagnosis important?

Testing as early as possible can help shorten the often long time it takes for PH1 to get diagnosed. Adults can wait several years or more between their first symptom and receiving a PH1 diagnosis. This is important because the disease can progress in ways that aren't predictable and could lead to the development of kidney stones and chronic kidney disease.

What tests can help diagnose PH1?

While a healthcare professional will typically use a urine test to measure the urine oxalate excretion level, in a diagnostic workup of individuals suspected of primary hyperoxaluria, genetic testing can help confirm a diagnosis of PH1.

Why is family screening important?

PH1 is inherited through families. **If someone has PH1, their siblings have a 25% chance of also having the disease.**¹ It is important that siblings of a person with PH1 and other at-risk family members consider getting tested with a genetic test. Consultation with a geneticist or certified genetics counselor is recommended.

How it works



1

Get started

Ask your doctor about genetic testing for PH1 through Alynlam Act®

2

Provide a sample for genetic testing

- Provide a sample using an Invitae® sample collection kit (ask your doctor about sample collection options), **or**
- Ask your doctor about the at-home specimen collection option offered by Invitae where you can collect a sample and send it back

3

Review results

Receive results in 10-21 days. They will be sent directly to your doctor for review

4

Post-test genetic counseling (optional)*

Speak with a genetic counselor to review your test results and what the results may mean for you and your family

*Both genetic testing and genetic counseling are available in the US and Canada.

The Alynlam 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 Alynlam 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
- Alynlam receives de-identified patient data from this program, but at no time does Alynlam receive patient-identifiable information. Alynlam may use healthcare professional 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 Alynlam product
- No patients, healthcare professionals, or payers, including government payers, are billed for this program

Genetic testing process

If your doctor determines you are eligible, genetic testing is available through Invitae, a CLIA-certified independent genetic testing company.



- 1 Ask your doctor to follow the instructions found at [invitae.com/alnylam-act-ph1](https://www.invitae.com/alnylam-act-ph1)



- 2 Provide a blood, saliva, or buccal swab sample for genetic testing



- 3 Check back with your doctor within 10-21 days for your results

ASK YOUR DOCTOR
about providing a sample from
your home for testing

Genetic counseling process

If you decide to get a genetic test for PH1, and you reside in the U.S., genetic counseling is also available through Invitae.



- 1 To start the process, call **800-436-3037** or create an account on Invitae's patient portal at www.invitae.com/ signup



- 2 You may check your genetic test results or schedule a post-test genetic counseling session on the portal



- 3 After your genetic counseling session, a summary report will be available in the portal and will be sent to your doctor within 5 business days

GENETIC COUNSELORS are able to help you understand the testing process and your results. Genetic counselors can also assist with family variant testing.

Make more informed decisions about your health

Why is genetic testing important for PH1?

Because PH1 is a genetic disease, genetic testing can help identify your risk and can help confirm a diagnosis of PH1 by looking for mutations in the *AGXT* gene. Genetic testing may also help to shorten the time to diagnosis and prevent misdiagnoses.

What is genetic counseling?


Genetic counseling can help you and your family members learn more about PH1 and the chances of inheriting the disease, and what may happen after a diagnosis.

How much does genetic testing and counseling cost through Alylam Act®?

Alylam Act® is a sponsored program, and the genetic testing and counseling services are offered to eligible patients at no charge.

Will any genetic or personal information be shared with Alylam?

While Alylam receives de-identified patient data from this program, at no time does Alylam receive identifiable patient information. Third-party companies that support Alylam Act® abide by applicable data privacy laws, including HIPAA and PIPEDA.



Talk with your doctor
today about genetic
testing for PH1



Reference: 1. Cochat P, Rumsby G. *N Engl J Med.* 2013;369(7):649-658.

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