FOR PROVIDERS

AlnylamAct®

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

Consider genetic testing and counseling for your patients; Alnylam Act® provides one option for eligible individuals.

*While program is sponsored by Alnylam Pharmaceuticals, all services are performed by independent third parties.
†Both genetic testing and genetic counseling are available in the US and Canada.
‡To patients, healthcare professionals, or payers.

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About primary hyperoxaluria type 1 (PH1)

What is PH1?

PH1 is a progressive genetic disease that is potentially life-threatening and often presents with calcium oxalate kidney stones. Calcium oxalate crystals are insoluble and toxic and lead to serious disease manifestations, including recurrent kidney stones, nephrocalcinosis, progressive renal failure, and multiorgan damage from systemic oxalosis once the disease advances.[1-3]

Eloise, living with PH1

What is the role of genetic testing in PH1?

Due to the unpredictable progression of the disease, patients with PH1 benefit from early and accurate diagnosis. 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.[2,4-6]

Is family genetic testing important?

PH1 is an autosomal recessive disorder and may affect multiple individuals within a family. If you have a patient with PH1, consider genetic testing siblings and other at-risk family members. Consultation with a geneticist or certified genetics counselor is recommended to accelerate diagnosis.[5,7]

Questions about variant of uncertain significance (VUS) results? PreventionGenetics Clinical Consult Services are available to help aid in interpretation and resolution of VUS results. To discuss, please email **support@preventiongenetics.com** or call **(715) 387-0484.**

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About Alnylam Act®

What is Alnylam Act®?

Alnylam Act® is a sponsored, no-charge, third-party genetic testing and counseling program for patients with a family history or suspected diagnosis of PH1. The Alnylam Act® program was developed to reduce barriers to genetic testing and counseling to help people make more informed decisions about their health.

What genes are tested through Alnylam Act®?

Genetic testing for PH1 offers 2 testing options: PreventionGenetics Primary Hyperoxaluria Panel (*AGXT, GRHPR*, and *HOGA1* genes) and PreventionGenetics Nephrolithiasis Panel (45 genes). The PreventionGenetics Nephrolithiasis panel tests for changes in the *AGXT* gene as well as for changes in other genes associated with nephrolithiasis that have symptoms that may overlap with PH1.

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

Through the Alnylam Act® program, the genetic testing and counseling services are provided at no charge to patients, healthcare professionals, or payers, including government payers.

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 professional contact information for research purposes
- Both genetic testing and genetic counseling are available in the U.S. 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

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Getting Started

Once the decision to undergo genetic testing and counseling has been made:

Step 1 Determine eligibility for genetic testing*

To be eligible for genetic testing through Alnylam Act®, patients must be **in the U.S. and Canada** and meet the requirements below:

- Suspected diagnosis of primary hyperoxaluria with **ONE OR MORE** of the following symptoms:
  - Family history of primary hyperoxaluria **OR**
  - Adult (≥18 years old)- Elevated urinary oxalate OR Elevated plasma oxalate **OR**
  - Children (<18 years old) with one of the following:
    - Failure to thrive **AND** impaired kidney function
    - Nephrolithiasis
    - Nephrocalcinosis
    - Elevated urinary oxalate OR Elevated plasma oxalate

Step 2 Order a genetic test

Start your order

- Request PreventionGenetics specimen collection kits to get started at **www.preventiongenetics.com/ph1**
- Complete the PreventionGenetics requisition form for Alnylam Act® (PH1), and fax it to **(715) 406-4175**, or insert the form in the specimen collection kit before shipment
- Note: You can also place an order for a genetic test through the online ordering portal at: **Alnylam.preventiongenetics.com**

Submit patient sample

- Collect a sample using PreventionGenetics's specimen collection kit
- Follow the collection and shipping instructions inside the PreventionGenetics collection kit
- Note: PreventionGenetics offers the ability to send specimen collection kits directly to patients

Review results

- Receive results in 3-4 weeks on average
- Receive a notification email once the test results are ready. If you created an online account, you can view the status of your order by logging into your account

*Refer to the Alnylam Act® PH1 requisition form for full details of eligibility criteria.

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Getting started *(continued)*

Step 3 Genetic Counseling (optional)

Alnylam has partnered with a third-party, Genome Medical, to provide no-charge genetic counseling services to any patient who enrolls in the Alnylam Act program.

Refer patient for genetic counseling*

Select pre-test and/or post-test genetic counseling when filling out the test requisition form

Prepare patient for the appointment

We recommend the patient sets aside thirty minutes free from interruptions or distractions. The patient may consider asking family members about their family medical history ahead of the appointment. It is helpful for the genetic counselor to understand if any family members have been diagnosed with medical conditions and at what age they were diagnosed

Receive results

Genome Medical will email the patient a summary report through the online portal. The patient may then share the report with you**

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

**If the test result is negative, Genome Medical will provide the patient with an educational video explaining the results.

FOR QUESTIONS ABOUT GENETIC TESTING AND COUNSELING

Contact PreventionGenetics at
PreventionGenetics.com/contact
or **(715) 387-0484**

References: **1.** Hoppe B. *Nat Rev Nephrol*. 2012;8(8):467-475. **2.** Milliner DS, Harris PC, Cogal AG, Lieske JC. https://www.ncbi.nlm.nih.gov/books/NBK1283/. Updated November 30, 2017. Accessed October 16, 2019. **3.** Cochat P, Rumsby G. *N Engl J Med.* 2013;369(7):649-658. **4.** Ben-Shalom E, Frishberg Y. *Pediatr Nephrol*. 2015;30(10):1781-1791. **5.** Cochat P, Hulton SA, Acquaviva C, et al. *Nephrol Dial Transplant*. 2012;27(5):1729-1736. **6.** American Urological Association. https://www.auanet.org/guidelines/kidney-stones-medical-mangement-guideline. Published 2014. Accessed October 16, 2019. **7.** Edvardsson VO, Goldfarb DS, Lieske JC, et al. *Pediatr Nephrol*. 2013;28(10):1923-1942.

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