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## Porphyria

Porphyrias are a group of genetic disorders caused by problems with how your body makes a substance called heme. Heme is found throughout the body, especially in your blood and bone marrow, where it carries oxygen.


There are two main types of porphyrias. One affects the skin and the other affects the nervous system. People with the skin type develop blisters, itching, and swelling of their skin when it is exposed to sunlight. The nervous system type is called acute porphyria. Symptoms include pain in the chest, abdomen, limbs, or back; muscle numbness, tingling, paralysis, or cramping; vomiting; constipation; and personality changes or mental disorders. These symptoms come and go.

Certain triggers can cause an attack, including some medicines, smoking, drinking alcohol, infections, stress, and sun exposure. Attacks develop over hours or days. They can last for days or weeks.


Porphyria can be hard to diagnose. It requires blood, urine, and stool tests. Each type of porphyria is treated differently. Treatment may involve avoiding triggers, receiving heme through a vein, taking medicines to relieve symptoms, or having blood drawn to reduce iron in the body. People who have severe attacks may need to be hospitalized.

*NIH: National Institute of Diabetes and Digestive and Kidney Diseases*

### Start Here

- Porphyria [<https://www.mayoclinic.org/diseases-conditions/porphyria/symptoms-causes/syc-20356066?p=1>] (Mayo Foundation for Medical Education and Research)  
Also in Spanish [<https://www.mayoclinic.org/es/diseases-conditions/porphyria/symptoms-causes/syc-20356066?p=1>]
- Porphyria [<https://www.niddk.nih.gov/health-information/liver-disease/porphyria>]  (National Institute of Diabetes and Digestive and Kidney Diseases)

### Diagnosis and Tests

- Porphyrin Tests [<https://medlineplus.gov/lab-tests/porphyrin-tests/>]  (National Library of Medicine)  
Also in Spanish [<https://medlineplus.gov/spanish/pruebas-de-laboratorio/pruebas-de-porfirina/>]
- Porphyrins and Porphyria Diagnosis [<https://porphyriafoundation.org/for-patients/about-porphyria/testing-for-porphyria/diagnosis/>] (American Porphyria Foundation)

### Treatments and Therapies

- Porphyria Treatment Options [<https://porphyriafoundation.org/for-patients/about-porphyria/treatment-options/>] (American Porphyria Foundation)

### Living With

- Diet and Nutrition in Porphyria [<https://porphyriafoundation.org/for-patients/diet-and-nutrition/>] (American Porphyria Foundation)
- Weight Loss and Acute Porphyria [<https://porphyriafoundation.org/for-patients/diet-and-nutrition/weight-loss-acute-porphyria/>] (American Porphyria Foundation)



## Related Issues

- Glucose Effect in Acute Porphyrias [<https://porphyriafoundation.org/for-patients/diet-and-nutrition/the-glucose-effect-in-acute-porphyrias/>] (American Porphyria Foundation)
- Porphyria Cutanea Tarda and Agent Orange [<https://www.publichealth.va.gov/exposures/agentorange/conditions/porphyria-cutanea-tarda.asp>] (Department of Veterans Affairs)


## Specifics

- Acute Intermittent Porphyria (AIP) [<https://porphyriafoundation.org/for-patients/types-of-porphyria/aip/>] (American Porphyria Foundation)

## Genetics

- Learning about Porphyria [<https://www.genome.gov/Genetic-Disorders/Porphyria>]  (National Human Genome Research Institute)
- Porphyria: MedlinePlus Genetics [<https://medlineplus.gov/genetics/condition/porphyria>]  (National Library of Medicine)

## Clinical Trials


- ClinicalTrials.gov: Porphyrias [<https://clinicaltrials.gov/search?cond=%22Porphyrias%22&aggFilters=status:not%20rec>]  (National Institutes of Health)

## Journal Articles

References and abstracts from MEDLINE/PubMed (National Library of Medicine)

- Article: Sunscreen and Photoprotection Habits for Patients With Porphyria and Non-Porphyric Photosensitivity... [<https://www.ncbi.nlm.nih.gov/pubmed/40546020>]
- Article: Comparative effectiveness of human hematin and heme arginate in the management... [<https://www.ncbi.nlm.nih.gov/pubmed/40545748>]
- Article: Blood levels of neurotransmitters in Yusho patients: An approach via the... [<https://www.ncbi.nlm.nih.gov/pubmed/40028778>]
- Porphyria -- see more articles [<https://pubmed.ncbi.nlm.nih.gov/?term=%22Porphyrias%22%5Bmajr%3Anoexp%5D+AND+humans%5Bmh%5D+AND+english%5Bla%5D+AND+%22last+2+Years%22+%5Bedat%5D+NOT+%28letter%5Bpt%5D+OR+case+reports%5Bpt%5D+OR+editorial%5Bpt%5D+OR+comment%5Bpt%5D%29>]

## Find an Expert

- American Porphyria Foundation [<https://porphyriafoundation.org/>]
- National Institute of Diabetes and Digestive and Kidney Diseases [<https://www.niddk.nih.gov>] 

## Patient Handouts

- Delta-ALA urine test [<https://medlineplus.gov/ency/article/003457.htm>] (Medical Encyclopedia)  
Also in Spanish [<https://medlineplus.gov/spanish/ency/article/003457.htm>]
- PBG urine test [<https://medlineplus.gov/ency/article/003596.htm>] (Medical Encyclopedia)  
Also in Spanish [<https://medlineplus.gov/spanish/ency/article/003596.htm>]
- Porphyria [<https://medlineplus.gov/ency/article/001208.htm>] (Medical Encyclopedia)  
Also in Spanish [<https://medlineplus.gov/spanish/ency/article/001208.htm>]
- Porphyrins blood test [<https://medlineplus.gov/ency/article/003372.htm>] (Medical Encyclopedia)  
Also in Spanish [<https://medlineplus.gov/spanish/ency/article/003372.htm>]
- Porphyrins urine test [<https://medlineplus.gov/ency/article/003614.htm>] (Medical Encyclopedia)



## MEDICAL ENCYCLOPEDIA

Delta-ALA urine test [<https://medlineplus.gov/ency/article/003457.htm>]

PBG urine test [<https://medlineplus.gov/ency/article/003596.htm>]

Porphyria [<https://medlineplus.gov/ency/article/001208.htm>]

Porphyrins blood test [<https://medlineplus.gov/ency/article/003372.htm>]

Porphyrins urine test [<https://medlineplus.gov/ency/article/003614.htm>]

TBG blood test [<https://medlineplus.gov/ency/article/003374.htm>]

## National Institutes of Health

The primary NIH organization for research on *Porphyria* is the National Institute of Diabetes and Digestive and Kidney Diseases [<https://www.niddk.nih.gov>]

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