

AMERICAN PORPHYRIA FOUNDATION

2019 MEDIA KIT



porphyriafoundation.org

PORPHYRIA

Porphyria is not a single disease but a group of eight inherited genetic disorders that differ considerably from each other. A common feature in all Porphyrias is the accumulation in the body of porphyrins or porphyrin precursors. Although these are normal body chemicals, they normally do not accumulate. Precisely which of these chemicals builds up depends on the type of Porphyria.

The terms porphyrin and porphyria are derived from the Greek word porphyrus, meaning purple. Urine from some Porphyria patients may be reddish-purple in color due to the presence of excess porphyrins and related substances in the urine, and the urine may darken after exposure to light.

CAUSE

Porphyria arises as a result of a malfunction in one of the eight steps in the body's synthesis of a complex molecule called heme. Heme is essential for the transport of oxygen to cells in the body. If any step in the synthesis of heme is blocked, an intermediate chemical accumulates in the cell, resulting in oxygen depletion. Those intermediate chemicals, known as porphyrins or porphyrin precursors, are the substances of which heme is composed. Each type of Porphyria represents a deficiency of a specific enzyme needed for the synthesis of heme.

TYPES OF PORPHYRIA

ACUTE

Acute Intermittent Porphyria
Variegate Porphyria
Hereditary Coproporphyria
Erythropoietic Protoporphyria

Acute porphyria attacks generally evolve and become more severe over several days, especially the abdominal pain; two of these, Variegate Porphyria and Hereditary Coproporphyria, may also have skin symptoms of blistering after sun exposure.

CUTANEOUS

Porphyria Cutanea Tarda
Congenital Erythropoietic Porphyria
ALA-D Porphyria

Cutaneous Porphyrias present with blistering and scarring of the skin, pain, and/or redness and swelling in sun-exposed areas.

ABOUT THE APF

Supporting the Porphyria community since 1983, the APF's mission is to improve the health and well-being of all individuals and families impacted by Porphyria. The APF maintains a focus on education, advocacy, support services and research for the prevention, treatment and cure of the Porphyrias. Additionally, the APF serves patient advocates to public, private, and government agencies interested in funding research and educational programs. Its Scientific Advisory Board is made up of the world's foremost experts in Porphyria management, diagnosis, and research.

SCIENTIFIC ADVISORY BOARD

The Scientific Advisory Board is made up of the world's foremost experts in Porphyria management, diagnosis, and research. They have written or approved the medical information on the APF's website. Many of the APF's SAB members have over 40 years experience working on Porphyria, from conducting cutting-edge research, and writing peer-reviewed article for major medical journals to authoring the chapters on Porphyria in medical school textbooks. Doctors worldwide consult with these Porphyria specialists for help with diagnosis and treatment of their patients.

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PROTECT THE FUTURE

The Protect the Future campaign was established to attract and train the next generation of doctors and specialists in the field of Porphyria. Over the next decade, ninety percent of our valued Porphyria experts will retire. These men and women have led Porphyria research, testing and treatment for the past 30 years. Without financial support, there is a real risk of losing knowledge of the disease, quality testing, diagnosis, and treatment, and ultimately a cure.

Protect the Future supports young doctors who work and study with long-time experts, seeing patients and doing research, in order to gain the expertise they will need to care for the U.S. Porphyria patient population for decades to come.

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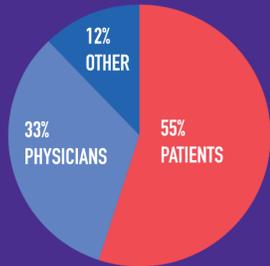
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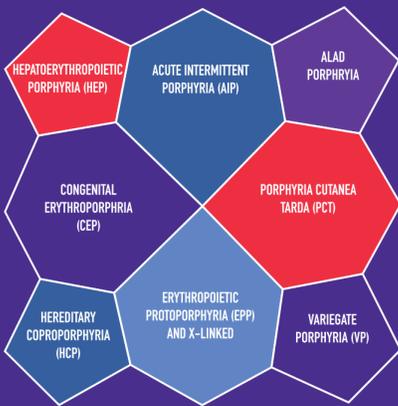
AMERICAN PORPHYRIA FOUNDATION

MEMBERSHIP

Membership Database over 10,000



OTHER (GOVT. INDUSTRY, MEDIA, DONORS)



People with porphyria experience:

PAIN, ISOLATION, AVOIDANCE OF TRIGGERS, LACK OF TREATMENT

PORPHYRIA CENTERS AND SATELLITE LOCATIONS



MISSION

The APF is dedicated to improving the health and well-being of individuals and families affected by Porphyria.

ABOUT PORPHYRIA

Porphyria is a group of eight rare inherited genetic disorders that differ considerably from each other. A common feature in all Porphyrias is the accumulation in the body of *porphyrins* or *porphyrin precursors*. Although these are normal body chemicals, they normally do not accumulate. Precisely which of these chemicals builds up depends on the type of Porphyria. The terms *porphyrin* and *porphyria* are derived from the Greek word *porphyros*, meaning purple.



PHYSICIAN EDUCATION PROGRAMS

- » Maintain, update and expand comprehensive website, brochures, pamphlets, books and educational materials for each type of porphyria, genetics, and research
- » Develop new educational programs and services for purposes of research, treatment, and diagnosis
- » Distribute materials on porphyria treatment
- » Provide updated Safe and Unsafe drug list for acute porphyrias
- » Facilitate referral and consultation services for patients and physicians
- » Produce and distribute updated Emergency Room, Primary Care Physician Guidelines
- » Produce Emergency Room Kits for Acute Porphyrias and EPP
- » Develop additional educational programs for physicians and patients to introduce new treatments and/or diagnostic techniques
- » Host physician and patient education conference calls with experts
- » Produced Award Winning *Porphyria Live* video

... And so much more!!!



PATIENT EDUCATION PROGRAMS

- » Maintain, update and expand comprehensive website, brochures, pamphlets, books and educational materials for each type of porphyria, genetics, and research
- » Develop new educational programs and services for purposes of research, treatment, diagnosis,
- » Distribute materials on porphyria treatment
- » Engage and assist in Health Insurance assistance and billing problems
- » Develop and deliver educational porphyria programs
- » Update relevant new information
- » Update on research ALL THE TIME
- » Participate in convention exhibits
- » Deliver patient educational meetings
- » Develop and deliver patient education programs for physician relationships
- » Educate on FDA drug approval process
- » Educate on congressional process
- » Promote research process and participation
- » Arrange conference calls with experts
- » Provide expert consultation with patients and physicians

... And so much more!!!



SUPPORT & ASSISTANCE PROGRAMS

- » Maintain Telephone Hotline, assisting patients nationally and internationally
- » Contact with up to 50 patients per day
- » Answer website, mail, email and telephone questions daily
- » Facilitate and maintain support group services
- » Host programs for caretakers training and support
- » Expedite patient diagnosis, support, testing and treatment problems
- » Facilitate appointments and physician consultations with porphyria experts
- » Help facilitate testing, diagnostic and treatment process when needed
- » Assist with Medicare and Medicaid issues
- » Assist in securing Social Security disability
- » Assist patients with any of their needs and support
- » Assist Veterans with PCT/Agent Orange issues



... And so much more!!!



REMEMBER ... RESEARCH IS THE KEY TO YOUR CURE!

RESEARCH SUPPORT

- » Procure government research funding
- » Distribute research updates
- » Locate patient volunteers for research and facilitate their involvement
- » Advise physicians of ongoing and new research
- » Collaborate with research Investigators



INTERNATIONAL SUPPORT

- » Facilitate APF Global Partners Program
- » Communicate with international Porphyria experts
- » Support International Congress of Porphyrins and Porphyria
- » Fund attendance of expert physicians & Protect the Future physicians
- » Provide guidance to countries to develop Porphyria association
- » Guide international patients seeking help



ADVOCACY

- » Advocate for all issues related to Porphyria with legislators, the FDA, NIH, etc.
- » Affiliations: National Organization for Rare Disorders, Genetic Alliance, NIH Coalition of Patient Advocacy Groups, Alliance for Stronger FDA, EveryLife Foundation, Rare Disease Legislative Advocates, Global Genes, The Haystack Project
- » Participation in Rare Disease Day® - patient involvement
- » Participation in Rare Disease Week - legislative involvement

FACTS



7,000 known rare diseases

90% have no treatment



80% are genetic



DONATE TODAY



WWW.PORPHYRIAFOUNDATION.ORG | 866-APF-3635

4915 St. Elmo Avenue, Suite 105
Bethesda, Maryland 20814



PORPHYRIA AWARENESS

April 6-13, 2019



FOR IMMEDIATE RELEASE: 04/02/18

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PERSONAL STORIES BRING ATTENTION TO OBSCURE, LIFE-THREATENING DISEASE
American Porphyria Foundation to Host Porphyria Awareness Week April 6 - 13

(BETHESDA, MD) – Porphyria affects less than 200,000 Americans. Due to the wide array of symptoms and the rarity of the condition, porphyria is misdiagnosed and misunderstood. The [American Porphyria Foundation](http://www.porphyriafoundation.org) wants to change that.

The non-profit porphyria research and advocacy organization is hosting [Porphyria Awareness Week](#) April 6 – 13 to spread the word about Porphyria.

“Porphyria Awareness Week has grown substantially in previous years and now represents a push for global awareness of porphyria research efforts and treatment,” APF Development Director Kristen Wheeden said. There is no cure for Porphyria, but with early detection and regular treatment, people with the diagnosis live life in caution.

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Perhaps the best way to understand this complicated group of disorders is through the personal experiences of people who live with them each and every day. “We receive stories from all over the world,” Wheeden says, referring to a robust [“Member Stories”](#) section of the APF’s website. The site displays testimonials organized by each of the eight porphyria sub-types. “The stories here are personal. People use them as a way to share their journeys, to connect with others who experience the isolation of porphyria, and as a powerful tool to heal.”

Throughout Porphyria Awareness Week, the APF will continue to educate others on porphyria by collecting and distributing personal stories on [Twitter](#), [Instagram](#) and [Facebook](#). Visit the [Porphyria Awareness Week 2019 landing page](#) for more information, a listing of special events, and a media kit. Participate in the [click campaign](#) fundraiser for the APF and read incredible stories of porphyria warriors all over the world on the [Member Stories](#) section.



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CONTACT

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For the all the latest in porphyria, visit porphyriafoundation.org/news



porphyriafoundation.org