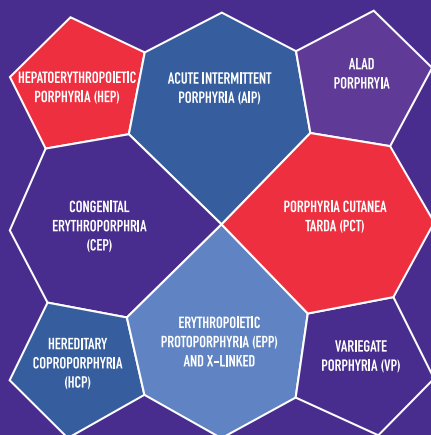
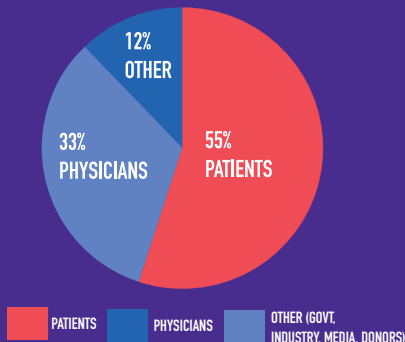




AMERICAN PORPHYRIA FOUNDATION

MEMBERSHIP

Membership Database over 10,000



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