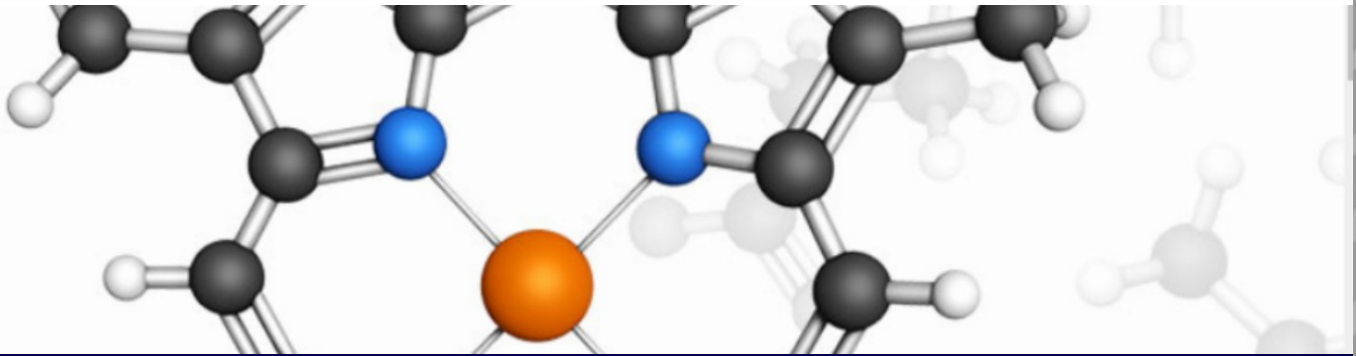




UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

Get in Touch



Advancing Awareness, Research and Therapies

Hello Member,



GLOBAL EPP CONNECT **Sunday, June 26th, 11AM EST**

United Porphyrias Association is proud to share an invitation for EPP patients, families, and caregivers! In coordination with **Global Porphyria Advocacy Coalition (GPAC)**, the umbrella organization for porphyria patient advocacy groups across the globe, we are delighted to invite you to a virtual meeting.

EPP Connect is a first ever event to bring EPP patients together from across the world.

The gathering will be on Zoom and will last 1 ½ hours. There will be breakout rooms in different languages and for different age groups too – all are welcome!

We are very excited and look forward to meeting all of you who are affected by EPP, whether a patient, parent or caregiver – we can't wait to talk with you all!

Once registered, an email confirmation will be sent and Zoom details for the gathering will be emailed directly to you in the week of the meeting!

All attendees must register!
Click below to register

[Register Here](#)

DRUG SAFETY IN ACUTE HEPATIC PORPHYRIA

Recent work in **Acute Hepatic Porphyria (AHP)** includes a study about drug safety that was implemented by a team of researchers. **Herbert Bonkovsky M.D.**, Porphyria Expert, and Christopher Ma M.D., (both of Wake Forest School of Medicine) spearheaded the experimental work.

The study of drug safety in AHP is ongoing and UPA is pleased to support this important effort.



 Wake Forest™
Baptist Health

DRUG
SAFETY



[Read the Publication Here](#)

The experts of the **Porphyrias Consortium** recommend the **NAPOS Drug Safety in AHP list** as the most updated resource.

[NAPOS DRUG SAFETY LIST](#)



HEALTHWELL
FOUNDATION®

When health insurance is not enough.®

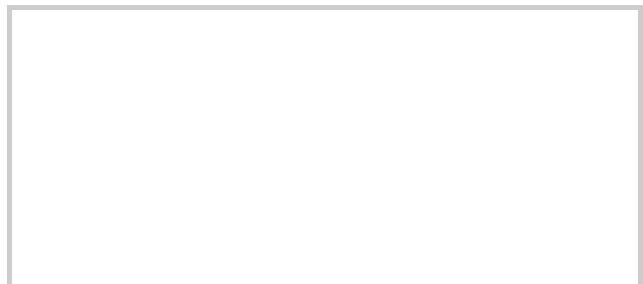
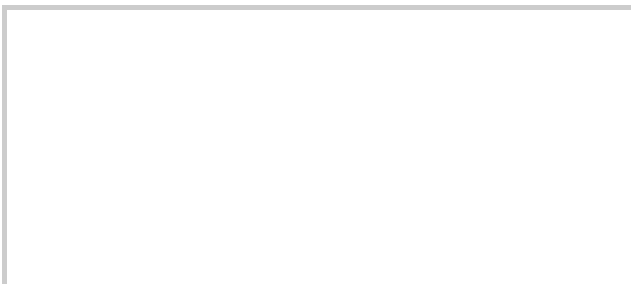
of the various forms of Porphyria.

To learn more about the fund, determine eligibility, and apply for assistance call (800) 675-8416 to speak to a HealthWell representative, visit www.healthwellfoundation.org or call **United Porphyrias** for support at (800) 868-1292.

PORPHYRIAS FUND

HealthWell offers up to \$4,000 in financial assistance to help reduce the cost of insurance premiums or medication copayment associated with the treatment and management

[APPLY HERE](#)





NORD PLATINUM

The United Porphyrias Association is now officially a platinum member of NORD (The National Organization for Rare Disorders)!

NORD Platinum level membership represents the highest level of integrity and transparency for patient advocacy organizations involved in medical research, drug development, medical education, and registries in the U.S.

The platinum seal is not only a stamp of approval and accountability for our organization but also a way to bring national attention to the porphyrias community.

We are proud to be a part of such a wonderful organization and to harness the collective power of 300 rare disease groups working together.

To read more about NORD click below.

[LEARN MORE](#)



GLOBAL GENES

The United Porphyrias Association is pleased to announce not only our membership in the **Global Genes** Global Advocacy Alliance, but we are also proud to be a founding member.

The mission of Global Genes Mission is to provide hope for the more than 400 million people affected by rare disease around the globe.

They fulfill their mission by helping patients find and build communities, gain access to information and resources, connect to researchers, clinicians, industry, government, and other stakeholders, share data and experiences, stand up, stand out, and become effective advocates on their own behalf.

To read more about Global Genes click below

[LEARN MORE](#)

MAKE YOUR VOICE HEARD

Share your experience in seeking a diagnosis for your rare disease or for someone you care for!

Take 20 minutes to complete the new global Rare Barometer survey.



This survey is open to people living with a rare disease and their family members from any country in the world and is translated in 26 languages!

Click below to take the survey

TAKE THE SURVEY

Rise UP. Speak UP.



UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

6701 Democracy Boulevard,
Suite 300, Bethesda, MD 20817
800-868-1292

Donate



United Porphyrias Association | 6701 Democracy Boulevard, Suite 300, Bethesda, MD 20817

[Unsubscribe kristen@porphyria.org](mailto:kristen@porphyria.org)

[Update Profile](#) | [Constant Contact Data Notice](#)

Sent by info@porphyria.org in collaboration
with



Try email marketing for free today!