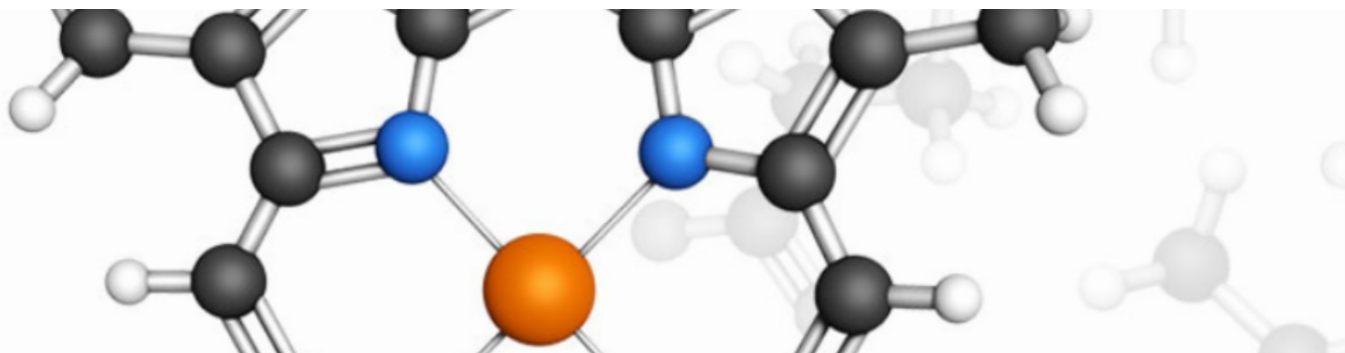




UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

Get in Touch



Advancing Awareness, Research and Therapies

Hello Member,



July 3rd
STAY OUT
OF THE
SUN DAY

National Stay Out of the Sun Day

National **Stay Out of the Sun** Day falls on July 3rd each year.

Yes! A national holiday devoted to staying indoors and giving your body a break from the sun. This is natural for our porphyria friends that are impacted by sun-induced pain or blistering. However, this is a day designed to spread awareness in the general public about the potential impact of the sun.

Join UPA this July 3rd and stay out of the sun. Use the hashtag **#OutoftheSunwithUPA** so we can see how you are spending your day! The most creative idea wins UPA gear!



PORPHYRIA RESEARCH

You Can Make a Difference- Participate in Porphyria Research

Are you looking to participate in much-needed research in the porphyrias?

There are multiple studies that currently need participants, and more on the way.

Contact UPA at info@porphyria.org for more information or to make sure we contact you for future research. Together, we can make a difference.

Some studies seek to better understand the burden and impact of living with porphyria while others study a potential treatment. They all need patient involvement – let's unite to make a difference in your disease!

Expert physicians of the Porphyrins Consortium are seeking patients for multiple studies, including:

ALL PORPHYRIAS:

Longitudinal Study – this is a long-term observational study that evaluates diagnosed patients to better understand the impact of porphyria.

PROTOPORPHYRIAS:

EPP and XLP:

Cimetidine- Now enrolling! The objective of this study is to determine the efficacy and safety of oral cimetidine administration for treatment of the protoporphyrias.

EPP:

Disc Medicine/Bitopertin – Study sites not yet active! This is a phase 2 clinical trial of bitopertin to evaluate the safety, tolerability, efficacy, and protoporphyrin IX concentrations in participants with EPP.

AHP (all types):

Assessment of Medication Sensitivity in Acute Hepatic Porphyria (AHP) – This study is designed to better understand acute porphyria attacks that may have been caused by a medication.

[Get More Info](#)

Porphyria patients are at the center of all porphyria research!
There are multiple studies going on **NOW** that need your patient expertise.
Check out Latest News in Research projects and recruitment and how to participate.

[Latest News](#)



**Living Rare, Living Strong
Patient and
Family Forum**



Success!
Global Porphyria Advocacy Coalition
Global EPP Connect Event

GPAC, the international umbrella organization for porphyria advocacy groups, hosted a successful **Global EPP Connect** event on Sunday, June 26. Several dozen patients and caregivers gathered over Zoom to meet peers and discuss issues related to EPP/XLP.

There were several breakout rooms that discussed issues such as Emotional Health, Tips and Tricks, and Treatments and Trials. Several participants had never before met another person with their disease!

As a leader on the "Cross Border Connections" team of GPAC, Kristen Wheeden helped to organize and moderate this event along with patient advocacy leaders from Belgium, Canada, France, Spain, and UK. We look forward to hosting more events in the near future!

Rise UP. Speak UP.

As a Platinum Member, United Porphyrias was proud to attend **NORD's Living Rare, Living Stronger Patient and Family Forum** in Cleveland, OH.

UPA is dedicated to finding avenues that may impact your life and management of porphyria.

Important subjects included "Building and Quarterbacking Your Care Team," "Beyond Coping: Resiliency While Rare" – and a focus on *hope* while living with a rare disease.

We left inspired to bring even more resources to patients and caregivers.



HAPPY FOURTH OF JULY!

United Porphyrias Association wishes you and yours a safe and happy holiday weekend!



Reach Out to UPA!



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[Donate](#)



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