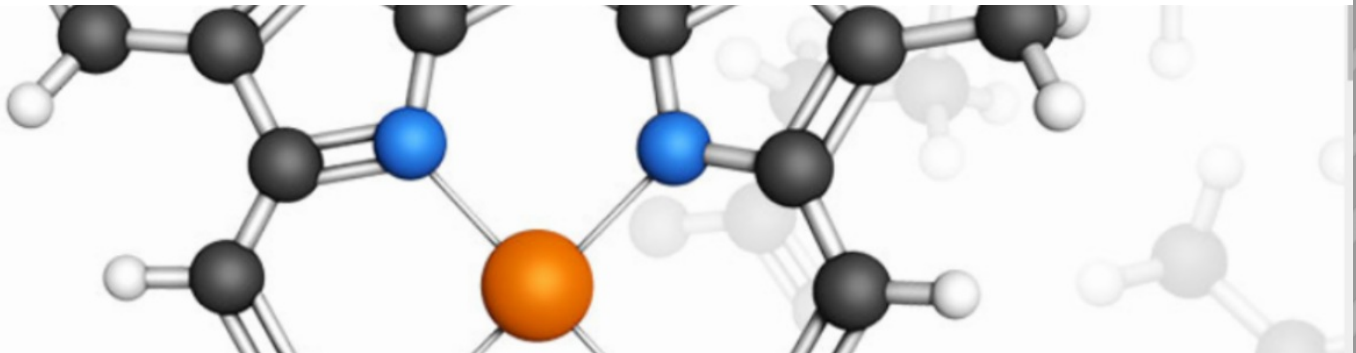




UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

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Advancing Awareness, Research & Therapies

Hello Member,

PORPHYRIA TOGETHER NEW FACEBOOK GROUP!



[JOIN US online!](#)

We welcome you to join Porphyria Together, a new closed Facebook group where you will find helpful information in a safe community setting. We will support each other in asking and answering questions, and guiding our lives with porphyria. UPA is committed to supporting and improving the quality of life of porphyria patients and their supporting caregivers and family members. We are pleased to respond to the many requests for this online forum!

UPA ON YOUTUBE – SCIENTIFIC ADVISORY BOARD VIDEO SERIES

The esteemed members of the UPA Scientific Advisory Board contributed to a video series highlighting responses to questions regarding porphyria diagnosis, management, and treatment. Visit the UPA YouTube channel to hear the physician experts discuss the porphyrias. You'll also learn some wonderful history of their experiences and their view on what is ahead for the porphyrias!



WHAT'S UP WORKSHOP – NOVEMBER 9 @ 7PM ET | 4PM PT



We look forward to seeing you at our upcoming WHAT'S UP WORKSHOP! This virtual session will be focused on [Porphyria Life Hacks + Lessons Learned](#) and will be moderated by UPA President's Council Member, [Claire Richmond](#)! Come share your experiences and learn from others. Most of all, come to spend some time with a community that understands you! **Register HERE** and UPA will send you the zoom link information.

[Register HERE](#)

CUTANEOUS PORPHYRIAS RESEARCH UPDATE

ATTENTION EPP FRIENDS! A PHASE 2 CLINICAL TRIAL



DISC MEDICINE has initiated a PHASE 2 clinical trial for patients with EPP. Complete this form to **learn more**.



EPP/XLP CIMETIDINE RESEARCH STUDY

A research study on CIMETIDINE for patients with EPP/XLP is underway. Email info@porphyria.org to learn more.

ACUTE HEPATIC PORPHYRIAS RESEARCH UPDATE

New Research Opportunities in AHP

AHP PATIENT EXPERIENCE RESEARCH

We're looking for individuals who are experiencing symptoms or who are on prophylactic (preventive) treatment for AHP. You do not have to be on treatment to participate. Your participation in this research will include taking a ~15 minute online survey. Some individuals may be asked to participate in an additional 60-minute telephone interview with a member of our research team. After your participation, you will be compensated for your time. To participate, please complete this form:

Click Here

AIP: Identification of AIP Predisposing and/or Protective Genes

While some people have frequent attacks, most never develop any symptoms. The goal of this study is to find other genes that may make a person with AIP more or less likely to develop acute attacks. This might enable us to predict who will be symptomatic, as well as prevent and better treat AIP. Contact UPA on **info@porphyria.org** or call **1800-868-1292**.

- Age 12+
- Diagnosed AIP and symptomatic at some point
- You are a relative of someone with AIP

AIP Interviews

Two porphyria expert physicians are seeking 6 patients with AIP for a 60-minute virtual interview. The discussion will entail your detailed experience with acute attacks. Contact UPA on **info@porphyria.org** or call **1800-868-1292**.

- Age 18+
- Repeated acute attacks

FOR OTHER ONGOING RESEARCH STUDIES, **CLICK HERE**

UPComing

ACG 2022

ACG 2022, the premier conference in Gastroenterology, took place October 24-26. UPA was on site to educate and create awareness about porphyria. Scientific Advisory Board member and Porphyria

Expert, Dr. Herbert Bonkovsky (Atrium Wake Forest Baptist Health), held a poster presentation on a recent study of the Porphyrias Consortium. The poster highlighted results that treatment with Harvoni in patients with both Porphyria Cutanea Tarda (PCT) and Hepatitis C (Hep C) can cure Hep C and lead to remission in PCT. Thank you to Herbert Bonkovsky, MD for leading this important research in the most common type of porphyria!

UPA will educate pediatric dermatologists on diagnostics, management, and treatment of the cutaneous porphyrias at the upcoming **Pediatric Dermatology Research Alliance (PEDRA)** conference in Bethesda, MD, November 4-5.



The American Association for the Study of Liver Diseases will host the annual Liver Meeting on November 4-8 in Washington, DC. Members of the UPA Scientific Advisory Board will be presenting on a panel regarding a "Mystery Diagnosis" including unexplained diffuse abdominal pain – a

hallmark symptom of Acute Hepatic Porphyria (AHP). Also, Dr. Cynthia Levy (University of Miami) will present on EPP and liver issues. We look forward to hosting porphyria experts in our hometown!

The American Society of Hematology will hold its 64th Annual Meeting, December 10-13, in New Orleans, LA. This is another important opportunity to educate healthcare professionals in hematology about diagnosing, managing, and treating porphyria. UPA will assist our porphyria experts in spreading the word about the porphyrias to treating hematologists.



Add United Porphyrias **INSTA, FACEBOOK, TWITTER** to your social media feeds.



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