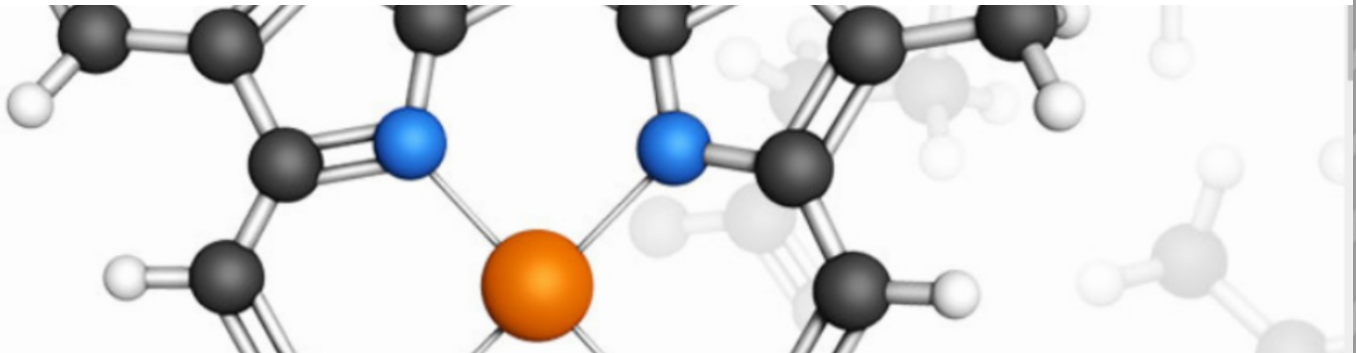




**UNITED PORPHYRIAS**  
ASSOCIATION  
Advancing Awareness, Research & Therapies

[Sign Up](#)



## Advancing Awareness, Research & Therapies

Hello Member,

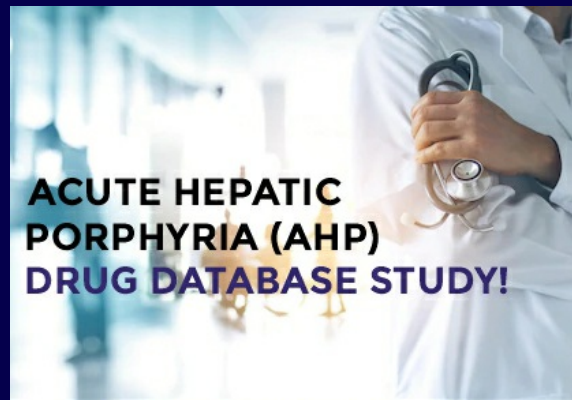
### NATIONAL ORGANIZATION FOR RARE DISORDERS HOLDS RARE DISEASE SUMMIT IN WASHINGTON, DC



United Porphyrias will engage at the NORD Breakthrough Summit 2022 occurring Oct 17 +18. Expert speakers from the FDA and NIH will be sharing critical insights impacting the rare disease community. We look forward to reporting information directly to you, our porphyria community. Kristen Wheeden will moderate a session of fellow patient advocates during the conference.

### ACUTE HEPATIC PORPHYRIA (AHP) DRUG DATABASE STUDY!

REMINDER! The AHP Drug Database Study is in need of participants. This study information on acute attacks that may have been caused by a medication, as well as safe use of certain newer medications where little clinical data in AHP patients is available. Anyone with a diagnosis of AHP (including Acute Intermittent Porphyria, Hereditary Coproporphyria, and Variegate Porphyria) is eligible.



Participants needed for data collection

[Learn More](#)

**ATTENTION EPP FRIENDS!**  
**ANNOUNCING A PHASE 2 CLINICAL TRIAL**



What a great response so far! The EPP community never fails to come together. 75 total participants are needed and recruitment is *underway* for a Phase 2 clinical trial on Bitopertin, an investigational treatment by Disc Medicine for Erythropoietic Protoporphyrin.

This is a Randomized, Double-blind, Placebo-controlled Study of Bitopertin to Evaluate the Safety, Tolerability, Efficacy, and Protoporphyrin IX (PPIX) Concentrations in Participants With Erythropoietic Protoporphyrin (EPP).

Submit your interest in learning more: [Click here](#)

**Fast Facts**

- 10 study sites across the US
- 75 participants needed
- Patients ages 18+ are eligible
- Inclusion/Exclusion criteria will apply
- The study drug is an oral medication
- Study includes an optional open-label extension

Contact [info@porphyria.org](mailto:info@porphyria.org) or **1-800-868-1292** anytime.



**EPP/XLP CIMETIDINE  
RESEARCH STUDY**

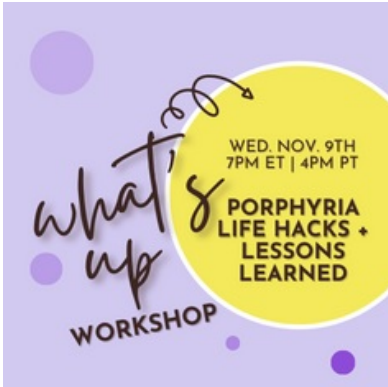
Patients with EPP or XLP needed for an FDA-sponsored research study on cimetidine. The study will assess whether cimetidine (a medication normally used to treat gastrointestinal issues such as ulcers or acid reflux) can reduce the level of protoporphyrin in your blood and if it can effect your symptoms.

**Dr. A. Dickey** at Massachusetts General Hospital, Dr. K. Anderson at the University of Texas Medical Branch, and Dr. H. Bonkovsky at Atrium Wake Forest Baptist

Health are currently recruiting patients with EPP who are 15 years of age or older.

Patients currently on Scenesse (afamelanotide) are eligible!

## WHAT'S UP WORKSHOP!



[SIGN UP](#)

Do you want to learn from others and share your Life Hacks and Lessons Learned living with porphyria?

Sign up for the WHAT'S UP WORKSHOP on November 9th at 7pm Eastern/ 4pm Pacific! We hope you join the conversation and get to know others in your porphyria community.

Email [info@porphyria.org](mailto:info@porphyria.org) to request Zoom login information.

## WELCOME TO LIZ ALLAN!



**Liz Allan** has joined United Porphyrias as our Director of Operations. With her significant experience in research, rare disease, clinical studies, and business - she will be an asset to our entire community.

Liz can be reached on [liz@porphyria.org](mailto:liz@porphyria.org).

**Welcome!!**

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



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