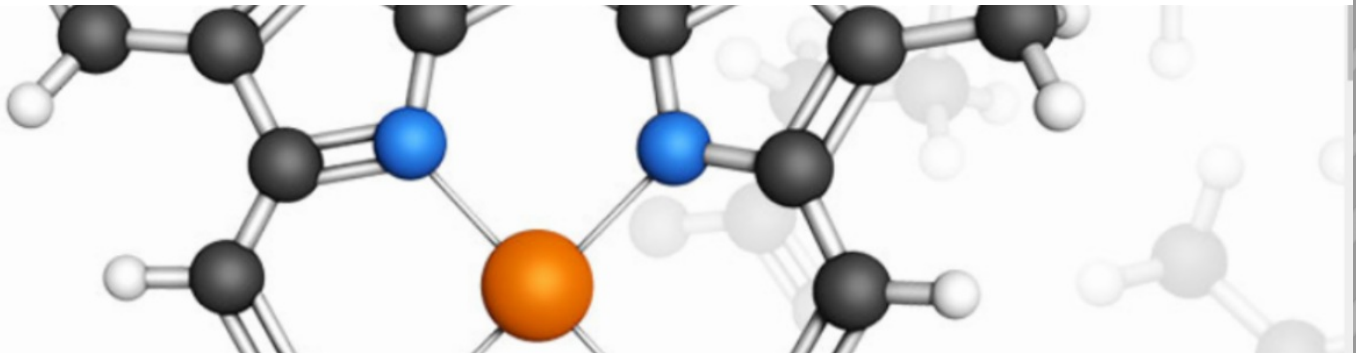




**UNITED PORPHYRIAS**  
ASSOCIATION  
Advancing Awareness, Research & Therapies

Get in Touch



## Advancing Awareness, Research and Therapies

Hello Member,



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

**United Porphyrrias 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 globe.

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!

# ATTENTION EPP FRIENDS! ANNOUNCING A PHASE 2 CLINICAL TRIAL



disc)medicine



## DISC MEDICINE IN AUSTRALIA

Disc Medicine is also on track to implement a Phase 2 clinical trial to assess dose-response and tolerability to the treatment of Bitopertin that will take place in Australia.

This six-month trial will include 20 participants.

As an Open-Label study, each participant will receive the active drug, and have the opportunity to join an extension of the trial after the initial 6 months.

Thank you to our Australian friends who will participate in this important research!

To learn more about clinical trials, [click here](#).

Disc Medicine has announced a Phase 2 clinical trial for participants with Erythropoietic Protoporphyrin (EPP).

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)**.

- Ten study sites are anticipated
- 62 participants (age 18+)
- Potential enrollment for adolescents ages 12-17
- 24-week trial
- Oral medication (Bitopertin)
- Inclusion/Exclusion criteria will apply
- Must reside in the US

For detailed information visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) or [click here](#).

Disc Medicine is a Massachusetts-based pharmaceutical company focused on Hematology. To read the press release, [click here](#).

**To learn more, contact United Porphyrias Association on 800-868-1292 or email [kristen@porphyria.org](mailto:kristen@porphyria.org). UPA will connect you with a study site when recruitment begins.**



## PC PILOT AND FEASIBILITY PROGRAM

The Porphyria Consortium (PC) is providing a novel support mechanism for trainees, postdocs, and junior faculty who want to pursue new directions in porphyria.

The PC leadership welcomes applicants from across the U.S. and will strive to provide a rapid review and constructive comments for applicants.

Support: \$30,000 of funding in a single sub-contract to the institution of the applicant. These funds are to include a maximum of 8% in indirect costs to the award institution. These awards ideally suited for trainees who want to master a new expertise or acquire a new skill to enhance their competitiveness for independent funding.

[Learn More Here](#)



## PARTICIPANTS NEEDED

Anylam Pharmaceuticals in review study, is open for 3 more participants – **if you were in phase 2 or 3 and are still on Givlaari, contact us today!**

The objective of these interviews is to capture, in the patients' own words, the symptoms and impacts of AHP and their experiences over the time they have received givosiran.

Interview participants will each receive \$100 in appreciation of their time.

### Next Steps...

***If you qualify and are interested in participating in an interview or just want to learn more about this study, please contact Kristen Wheeden of the UPA by email or telephone:***

Telephone: 800-868-1292

[Email Now](#)

## MEMORIAL DAY 2022

The United Porphyrias Association wishes you a safe and peaceful holiday as we take inspiration from the brave soldiers to become good citizens of our nation...

Greetings on the occasion of Memorial Day!!!



Rise **UP**. Speak **UP**.



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**Donate**



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