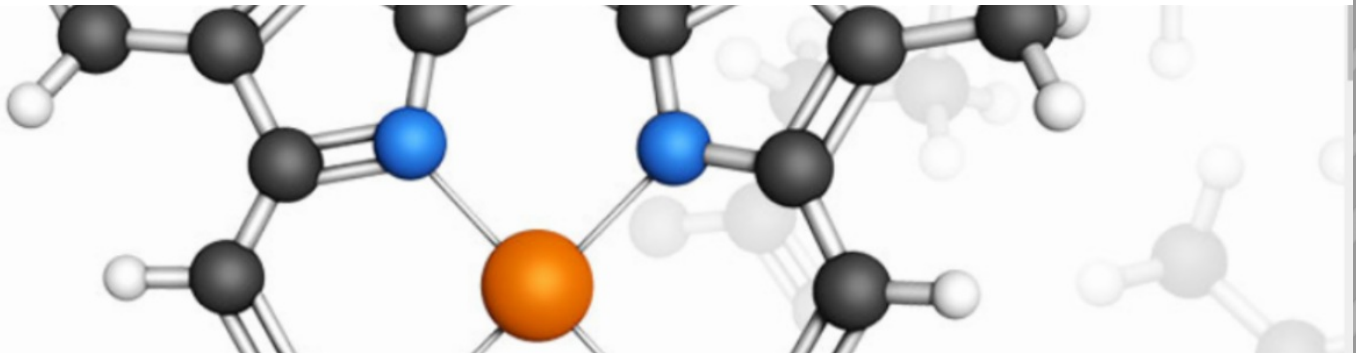




UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

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Advancing Awareness, Research and Therapies

Hello Member,

ATTENTION EPP FRIENDS! ANNOUNCING A PHASE 2 CLINICAL TRIAL



disc)medicine

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 or [click here](#).

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

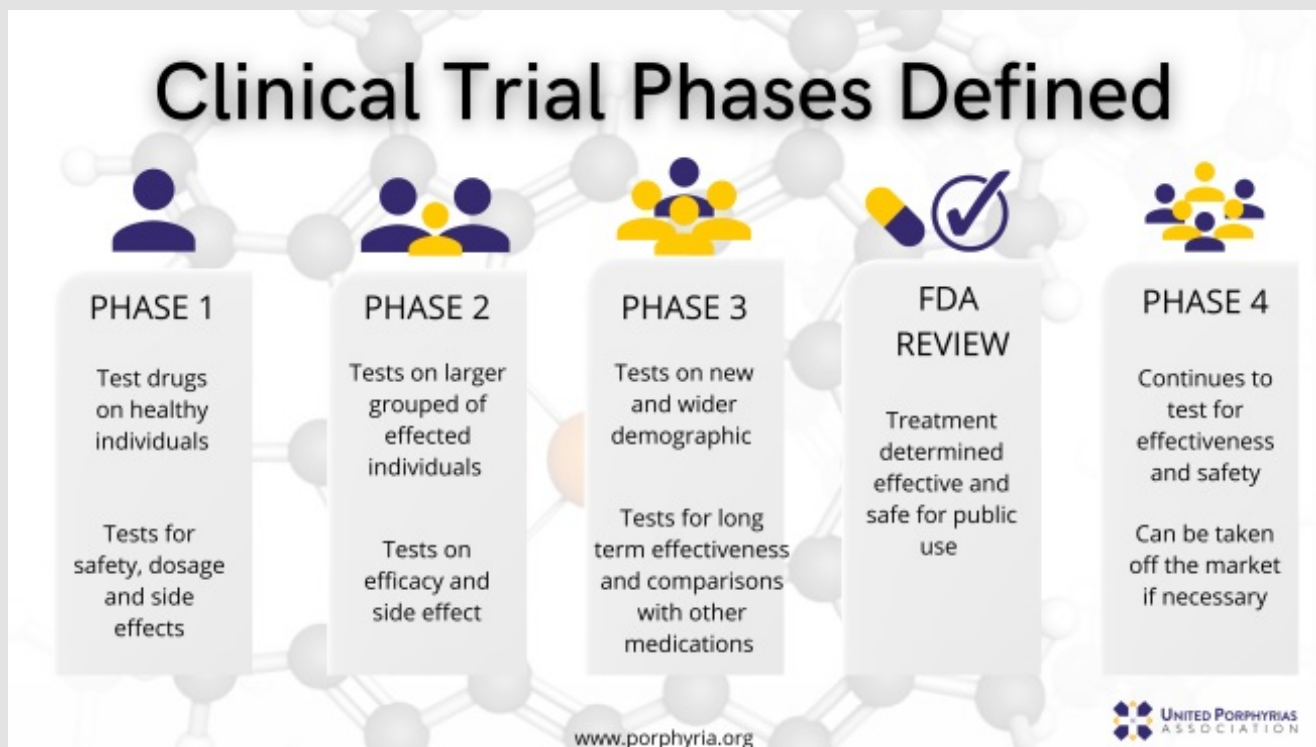
To learn more, contact United Porphyrias Association on 800-868-1292 or email kristen@porphyria.org. UPA will connect you with a study site when recruitment begins.

Email Now

WHAT IS A CLINICAL TRIAL?

There are typically four phases of clinical trials that bring a drug through the research process to FDA review. A Phase 2 trial helps to determine the right dosage and effectiveness in treating a particular disease.

To get to a Phase 2 trial, a Phase 1 has confirmed that the treatment is safe in humans. A successful Phase 2 trial can lead to a Phase 3 trial, which determines safety and effectiveness in a greater number of people.



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

MEMBER HIGHLIGHT

Meet Rob. Rob is a fierce Porphyria Warrior and dear friend of the United Porphyrias Association. Rob is a devoted UPA volunteer, advocate and proud member of the United Porphyria's Presidents Council. If you would

like to share your story, please email info@porphyria.org. We would love to hear from you.

[Read More](#)



"THROUGH THE PAINTINGS"

Our friends at Alnylam Pharmaceuticals have developed a powerful patient experience captured in a video series. Porphyria Champion, Amalia shares her experience with Acute Hepatic Porphyria (AHP) and how her art helped her on her journey.

[Read More](#)

MENTAL HEALTH ACTION DAY

This is the day to take action on your own mental health, as well as supporting those you love. If you don't know where to start, check out [MentalHealthThisHealth.us](https://www.mentalhealththishealth.us) a new resource designed to help those beginning their mental health journey. Join United Porphyrias Association in spreading the word using **#MentalHealthAction** and help us move from a culture of awareness to action.

[Learn More](#)

**Make time.
Breathe.
Connect.
Take action.**

Thurs
May 19

[MentalHealthThisHealth.us](https://www.mentalhealththishealth.us)

"THINKING PORPHYRIA, WORKING TOGETHER"

The International Congress on Porphyrins and Porphyrias (ICPP) will take place in Sofia, Bulgaria this September 4-7, 2022. The conference will bring



together patients, researchers, experts and scholars for three days of networking and learning from the best in the field.

Members of the esteemed United Porphyrins Scientific Advisory Board will present alongside international clinicians and researchers.

Patient Day will be held on Sunday, September 4th. Patients and patient group leaders from around the world will gather to lift our voices and share stories. Interested in joining? Email info@porphyria.org.

[Read More](#)

Reach Out To Us



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