



INTERNATIONAL PORPHYRIAS SYMPOSIUM 2023

ADVANCING THE SCIENCE & ART

OCTOBER 26-29, 2023 BETHESDA, MD

LEARN MORE

Dear Member,

Join us October 26-29, 2023 in Bethesda, Maryland for the **International Porphyrrias Symposium: Advancing the Science & Art**.

The program will feature US and international experts and will explore the clinical manifestations of each porphyria, and the latest advances in their diagnosis, management and treatment, including newly approved and emerging therapies.

This year, we're also thrilled to offer a special **Patient Day** on Sunday, October 29!

Visit the website



THE PORPHYRIAS CONSORTIUM



UNITED PORPHYRIAS ASSOCIATION



APEX
AMERICAN PORPHYRIAS
EXPERT COLLABORATIVE

SYMPOSIUM OVERVIEW

SCIENTIFIC CONFERENCE

Featured Sessions

- ✓ Preliminary Porphyrrias Introductory Course
- ✓ Western Hemisphere Porphyrria Research & Advocacy Forum with speaker from Argentina, Brazil, Canada, Colombia and Mexico
- ✓ Recent Advances in The Porphyrrias

See full agenda



Joint Accreditation

In support of improving patient care, this activity has been planned and implemented by the University of Arkansas for Medical Sciences and the United Porphyrins Association. University of Arkansas for Medical Sciences is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC) to provide continuing education for the healthcare team.

AMA Credit Designation

The University of Arkansas for Medical Sciences designates this live activity for a maximum of 25.0 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

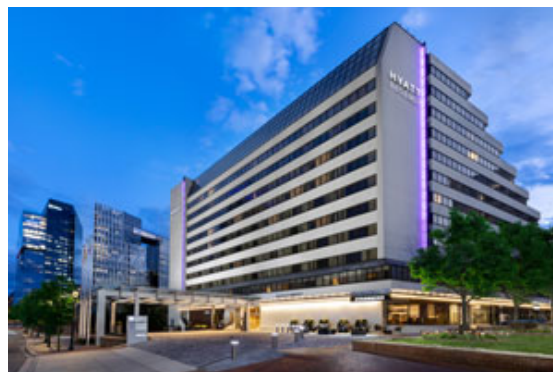
Call for Abstracts

The deadline to submit abstracts for poster and oral presentations is September 1. Organizers anticipate selecting up to 6 abstracts for oral presentations throughout the meeting. More information and submission guidelines are [here](#).

Plan Your Trip

The symposium will be held at the **Hyatt Regency Bethesda** in the Bethesda Arts and Entertainment district with over 200 restaurants, theaters, galleries, and boutiques nearby, and direct subway access to the sites and monuments of Washington, DC.

A limited block of discounted rooms is available at the Hyatt Regency Bethesda until October 5, 2023, or until the room block fills, whichever comes first. **Book now!**



Registration now open!

Register before September 1 for early bird pricing.

Register

PATIENT DAY, OCTOBER 29, 2023

Network and Meet-Up with Your Porphyria Friends and Community!

At UPA everything starts with the patient. This October, join us for a special Patient Day as part of the International Porphyrias Symposium!



Patient Day will bring together patients and their supporters to learn from porphyria experts and fellow patients, raise awareness and look to the future for porphyria.

- Sunday, October 29, 2023
- Online or in-person in Bethesda, Maryland

Free to attend! Registration is required.

Register Today!

What's on the Patient Day agenda?

Morning Session Highlights

- Porphyria 101
- Present Therapeutics, Future Advances & Research: Where Are We Headed?
- Patient Point-of-View

Afternoon Concurrent Session Highlights

Acute Hepatic Porphyrias

- Important Issues in AHPs: A Discussion
- Pain and Neurology in AHPs
- Treatment guidelines and patient resources

Cutaneous (Skin) Porphyrias

- EPP/XLP Consensus Guidelines
- Photosensitivity & Light Dosimetry in Cutaneous Porphyrias
- Current Studies & New Treatments in the Cutaneous Porphyrias

- AHP Power Study
- Ask the Experts: Panel Discussion

- Shadow Jumpers: Sun Avoidance & Emotional Health
- Ask the Experts: Panel Discussion

Is there financial support to attend?

NORD's **Rare Disease Education Support Program** provides financial support for registration costs and limited assistance with associated travel and lodging costs for conference participation.

Interested applicants may apply for financial assistance to advance their knowledge, participate in collaborative opportunities, network with peers, medical professionals, researchers, advocacy groups and subject matter leaders.



[Learn more](#)

GET INVOLVED IN RESEARCH!

Sharing the most recent research and understanding is a key purpose of the symposium.

There are multiple studies going on right now that need your patient expertise. Check out our current opportunities and find out how you can participate [here](#).

OR

contact UPA at 1-800-868-1292 or info@porphyria.org for more information

AIP Interview Study-Fully Enrolled

Thank you to the patients who participated in AIP interviews with our Porphyria Experts to better understand patient experience and understand the progression of symptoms from prodrome (early symptoms).

Longitudinal Study of the Porphyrrias

This long-term follow up study is recruiting patients with different porphyria types to improve our understanding of the progression of porphyria over time and will help to develop new treatments. This observational study includes approximately 1500 participants, evaluated annually for 5+ years.

If you are diagnosed with EPP, XLP, CEP, VP, AIP, HCP, PCT, HEP, or ADP, you're eligible to participate! Learn more [here](#).

[Learn more](#)

Bitopertin Phase II Trial for EPP

Participant recruitment is now underway for a Phase 2 clinical trial on Bitopertin, an investigational treatment 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).



Fast Facts

- 9 of 10 anticipated study sites are now active and accepting participants!
- 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

If you may be interested fill in a [confidential interest form](#).

[Fill out an interest form](#)

disc)medicine

Cimetidine in EPP and XLP Study

Patients with Erythropoietic Protoporphyrin (EPP) or X-Linked Porphyria (XLP) are 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 protoporphyrin IX (PPIX) levels which may impact photosensitivity.

Participating Study Sites:

- Dr. Amy Dickey, Massachusetts General Hospital
- Dr. Karl Anderson, University of Texas Medical Branch
- Dr. Herbert Bonkovsky, Atrium Wake Forest Baptist Health

Fast Facts:

- 3 study sites in the US
- 20 total participants needed

- Patients ages 15+ are eligible
- Patients currently on Scenesse (afamelanotide) are eligible

Of interest, a recent study in Denmark indicated the potential for cimetidine to lower protoporphyrin IX (PPIX) in patients with erythropoietic protoporphyria. See the research article [here](#).

[Learn more](#)

STAY IN TOUCH!

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