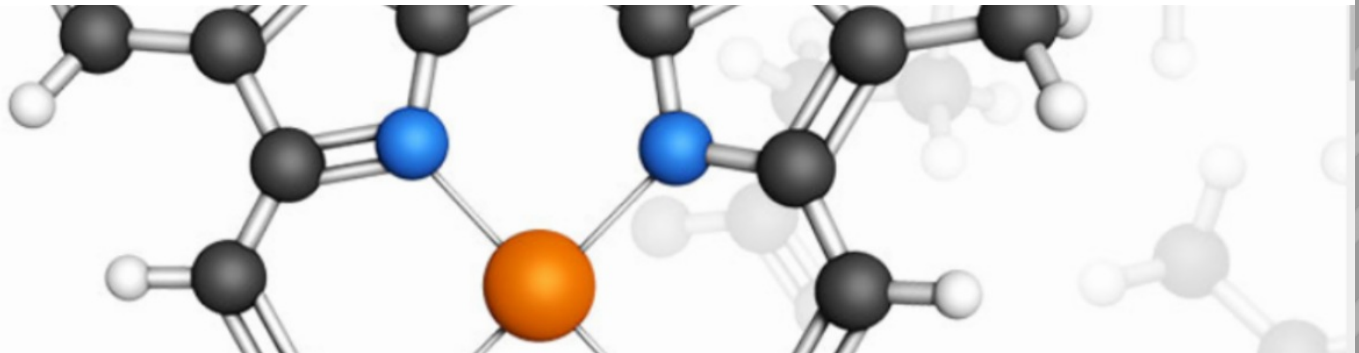




UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

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Advancing Awareness, Research and Therapies

Hello Member,



The **International Congress of Porphyrins and Porphyrins (ICPP) 2022** in Sofia, Bulgaria is fast approaching! Organized by the **European Porphyria Network (Epnet)**, this congress brings together patients, researchers, experts and scholars for three days of networking and learning from the best in the field.

UPA is excited to participate in both the Scientific Conference and Patient Day. Members of the **UPA Scientific Advisory Board** will Chair and/or Present during sessions of the Scientific Program. **Dr. Karl Anderson (UTMB)**, **Dr. Robert Desnick (MSSM)**,

Dr. Amy Dickey (MGH), **Dr. John Phillips (UofU)**, **Dr. Bruce Wang (UCSF)**, and Dr. Makiko Yasuda (MSSM) will join global colleagues discussing current and emerging topics in the porphyrias.

Kristen Wheeden, UPA President, will Chair a **Patient Day** session titled *Global Patient Advocacy Updates*. During this session, presenters from the UK, US, and Switzerland will offer global updates on advocacy, and developments in the erythropoietic and acute hepatic porphyrias.

ICPP is sponsored by our pharmaceutical partners – Alnylam Pharmaceuticals, Clinuvel Pharmaceuticals, Disc Medicine, Mitsubishi Tanabe Pharma, and Recordati Rare Diseases.

If you can't get to Bulgaria, we'll bring Bulgaria to you! Make sure to follow UPA on our social media channels as we come to you live on September 4th!



AHP- EDUCATING LAB STAFF

[Email UPA](#)

ACUTE HEPATIC PORPHYRIA (AIP, HCP, VP) – INTERESTED IN EDUCATING LAB STAFF?

In a session titled **CONNECTING THE TUBE TO THE PATIENT**, UPA is co-hosting an educational panel discussion for a prominent laboratory that processes labs for the porphyrias.

Typically, laboratory staff do not often have the opportunity to meet the patient community. Interested patients will educate attendees on the diagnostic journey, typical symptoms, and what it means to receive a diagnosis.

To participate, email info@porphyria.org or call 800-868-1292.



EPP/XLP CHILDREN AND PARENTS NEEDED

CHILDREN/PARENTS NEEDED FOR EPP/XLP INTERVIEWS

UPA is seeking children with EPP or XLP and their parents/guardians to participate in a research study for a pharmaceutical company.

The study consists of a 1-hour web-based interview where you will give us your opinion about a daily e-diary that we are developing to use in future EPP/XLP clinical trials for children.

To participate, you must be a parent/guardian of a child with EPP or XLP, ages 6-11. You must also consent to an interview with your child aged 6-11. For participation, you and your child will each receive \$100 for the interview.

If you are interested in learning more about the study, please contact Kristen Wheeden at kristen@porphyria.org or call 800-868-1292.

[EMAIL NOW](#)



NEW! PRIVATE FACEBOOK GROUP FOR MGH PORPHYRIA CLINIC

You asked, we listened. UPA has initiated a private Facebook group for patients (and caregivers) who attend the Porphyrria Clinic at Massachusetts General Hospital (MGH) in Boston, Massachusetts. Patients were interested in coordinating appointments to network and meet others with porphyria.

[EMAIL UPA](#)

To Join, search **Porphyrria Clinic Connection – MGH** on **FaceBook** or contact UPA.

We can't wait to welcome you!

BOSTON... HERE WE COME!

Join United Porphyrrias and the Massachusetts General Hospital (MGH) Porhyria Center leaders **Dr. Amy Dickey** and Dr. Rebecca Karp-Leaf for an educational and networking event. Bring your questions and meet others who are impacted by porphyria. Contact UPA for registration and address information.

[REGISTER HERE](#)



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