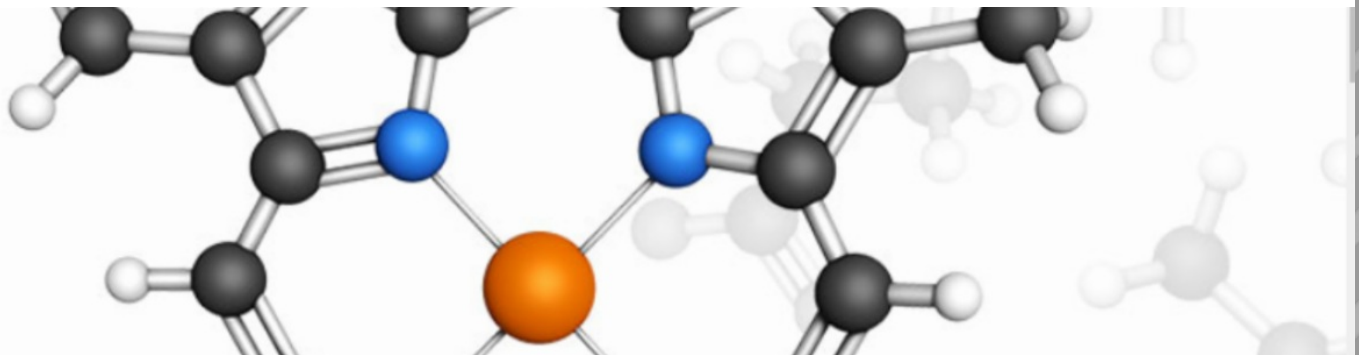




UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

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Advancing Awareness, Research and Therapies

Hello Member,

linkUP with...
DR. KARL ANDERSON, PORPHYRIA EXPERT
UNIVERSITY OF TEXAS MEDICAL BRANCH

 THE PORPHYRIAS CONSORTIUM

Virtual Patient Education Meeting

Join us on Thursday, July 28th at 7PM Eastern, for a Virtual Porphyria Q and A Session with Dr. Karl Anderson, Porphyria Expert and Chair of UPA's Scientific Advisory Board. All are welcome! Click the link below to register.

[REGISTER HERE](#)



"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 Porphyrrias Scientific Advisory Board will present alongside international clinicians and researchers. United Porphyrrias is committed to bringing the latest in emerging treatments and therapies to our patient community.

[READ MORE](#)



EXPANDING OUR REACH

patientworthy®
RARE PATIENT NEWS. WELL DONE.



The United Porphyrrias Association is proud to partner with Patient Worthy, an amazing online publication that provides relevant information to rare disease patients, caregivers and advocates alike. Read more about Patient Worthy by clicking the link below.

[READ MORE](#)



The United Porphyrrias Association is pleased to be selected as an associate member of the Coalition of Skin Diseases. This relationship will help spread critical awareness regarding the porphyrias and further our critical advocacy efforts.

[LEARN MORE](#)

Living Life with a Rare Disease

Our friends at Alnylam 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. It is such an amazing story that it was featured in USA Today.

Click below to read more.

[Amalia's Story](#)



PORPHYRIA RESEARCH

You Can Make a Difference- Participate in Porphyria Research

Are you looking to participate in much-needed research in the porphyrias?

There are multiple studies that currently need participants, and more on the way. Contact UPA at info@porphyria.org for more information or to make sure we contact you for future research. Together, we can make a difference.

Some studies seek to better understand the burden and impact of living with porphyria while others study a potential treatment. They all need patient involvement – let's unite to make a difference in your disease!

Expert physicians of the Porphyrias Consortium are seeking patients for multiple studies, including:

ALL PORPHYRIAS:

Longitudinal Study – this is a long-term observational study that evaluates diagnosed patients to better understand the impact of porphyria.

PROTOPORPHYRIAS:

EPP and XLP:

Cimetidine- Now enrolling! The objective of this study is to determine the efficacy and safety of oral cimetidine administration for treatment of the protoporphyrias.

EPP:

Disc Medicine/Bitopertin – Study sites not yet active! This is a phase 2 clinical trial of bitopertin to evaluate the safety, tolerability, efficacy, and protoporphyrin IX concentrations in participants with EPP.

AHP (all types):

Assessment of Medication Sensitivity in Acute Hepatic Porphyria (AHP) – This study is designed to better understand acute porphyria attacks that may have been caused by a medication.

[Get More Info](#)

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](#)

Reach Out to UPA!



6701 Democracy Boulevard,
Suite 300, Bethesda, MD 20817
(800) 868-1292

[Donate](#)



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800-868-1292

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