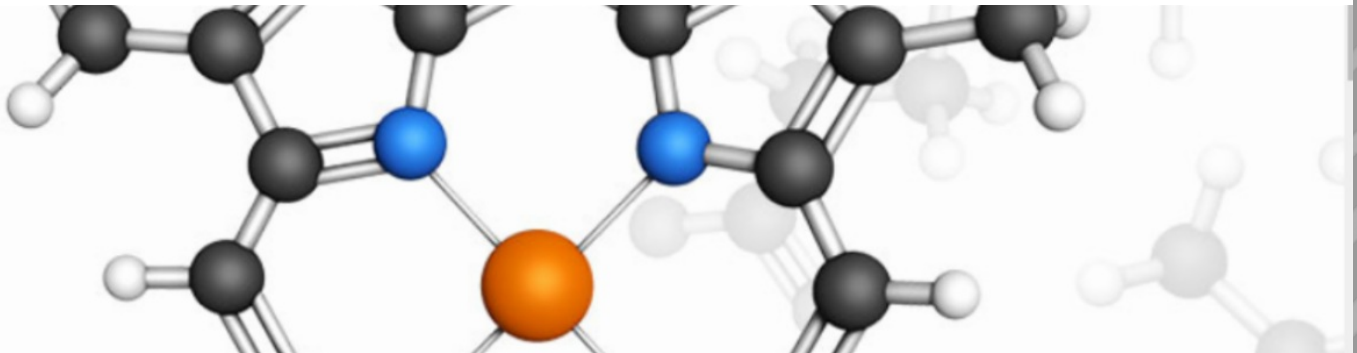




UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

Sign Up



Advancing Awareness, Research and Therapies

Hello Member,

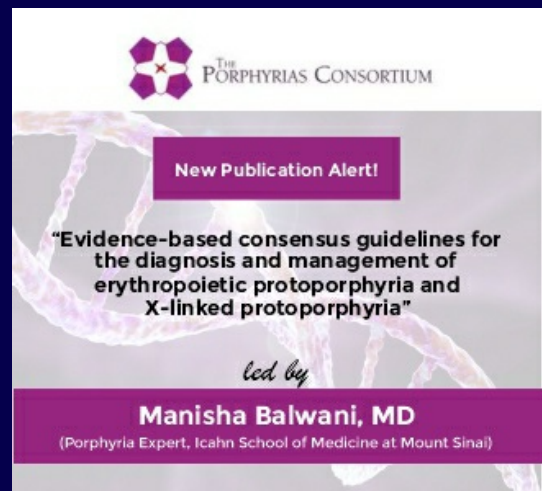
Alert! New Publication for EPP and XLP

Physicians of the **Porphyrias Consortium**, led by Manisha Balwani, MD (Porphyria Expert, Icahn School of Medicine at Mount Sinai), have released an important publication "***Evidence-based consensus guidelines for the diagnosis and management of erythropoietic protoporphyria and X-linked protoporphyria***" in the Journal of the American Academy of Dermatology.

These guidelines address the diagnosis, monitoring, and management of patients with EPP and XLP. The publication includes guidelines for issues such as management of anemia, monitoring liver function, Vitamin D deficiency, and pregnancy among other topics.

Currently available online with a subscription, it will also become available in print.

Thank you to our specialists for their work in creating guidelines for our community. Stay tuned for upcoming resources developed by the UPA based on this work.



LEARN MORE



A CHRONIC PAIN CRISIS

2022 SURVEY REPORT



Pain Awareness Month

September is Pain Awareness Month, a campaign led by the **US Pain Foundation**. Research shows that 50 million Americans live with chronic pain. Porphyria patients experience both acute and chronic pain as a common thread among patients.

Key findings from a recent report (**A-Chronic-Pain-Crisis-US-Pain-2022-FINAL.pdf** (uspainfoundation.org)) indicate that “**Chronic pain has devastating consequences on function, quality of life, and mental health**” which restricts the ability

to participate in routine activities.

Some participant results:

- Only 18% of respondents are employed full-time
- 79% feel stigmatized by their healthcare providers
- 79% take prescription medications, 77% agreeing that medications are the most helpful treatment

UPA will be highlighting pain facts and opportunities to engage through the remainder of September on social media platforms. Please join in the pain awareness campaign by sharing these posts and your porphyria pain journey.

#PainAwarenessMonth #Porphyria Pain #Porphyria Together

That’s a Wrap – ICPP 2022

The International Conference on Porphyrins and Porphyrins 2022, highlighting a robust Patient Day, was a terrific success. Physicians, researchers, patients, and advocates joined to share important studies and advances in research. Thank you to the organizers from the European Porphyria Network (Epnnet) and the organizers in Bulgaria who hosted a memorable event.

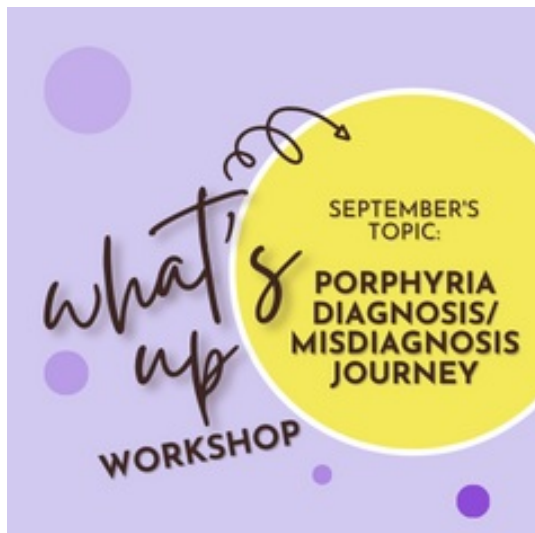


UPA was excited to attend and left inspired to continue our advocacy work and support of our physicians who also serve on the United Porphyrias Association Scientific Advisory Board.

Click on **LEARN MORE** for Kristen Wheeden’s column, *Hope in Action*, about the event.

LEARN MORE

WHAT'S UP WORKSHOP!



Welcome to this new workshop series brought to you by the UPA President's Council.

The workshop will bring our community together - across the porphyrias - to discuss topics that impact us. The discussion will guide the development of new resources. For us, by us!

You are invited to join the first What's Up Workshop on **Thursday, September 29th at 6pm Central**. The topic: **PORPHYRIA DIAGNOSIS/MISDIAGNOSIS JOURNEY**. The workshop will be moderated by Claire Richmond.

[EMAIL NOW](#)

Please email info@porphyria.org to register.

The logo for the United Porphyrias Association, featuring a stylized 'U' and 'A' made of geometric shapes, with the text 'UNITED PORPHYRIAS ASSOCIATION' and 'Advancing Awareness, Research & Therapies' below it.

Link UP Patient Meetings

Boston, MA Massachusetts General Hospital (MGH) Sunday, October 25, 4-6 pm	WINSTON-SALEM, NC Atrium Wake Forest Baptist Health Tuesday, October 18th, 5:30-7:00 pm
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Email info@porphyria.org to register and receive location information

Upcoming! American Academy of Dermatology and Coalition of Skin Diseases Legislative Conference

United Porphyrias Association will participate in an important conference on Capital Hill in Washington, DC next week to share issues that impact our patient community. Porphyria is often diagnosed by dermatologists – the issues that face nearly 84 million Americans with dermatological diseases also impact our community.

- Lack of treatments



Upcoming!

American Academy of Dermatology
and Coalition of Skin Diseases
Legislative Conference

- Invisible symptoms
- Delayed diagnosis

This is an opportunity to lift UP our voices to legislators who can make a difference in our lives. Do you have a story or a picture for us to share at the events? Please email to info@porphyria.org.

Your story matters.

EMAIL NOW

Add United Porphyrrias **INSTA, FACEBOOK, TWITTER** to your social media feeds.



NEED HELP PAYING FOR YOUR MEDICATIONS?

OUR FRIENDS AT HEALTHWELL ARE HERE TO HELP!

Healthwell offers up to \$4,000 in financial assistance to help with the cost of insurance premiums or medication copayments associated with the treatment and management of the various forms of Porphyria.

To learn more about the fund, determine eligibility and apply for assistance, click the link below or call (800) 675-8415.

LEARN MORE



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

Donate



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800-868-1292

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