



**UNITED PORPHYRIAS**  
ASSOCIATION  
Advancing Awareness, Research & Therapies

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## The Future of Porphyria



Be sure to SIGN UP on  
[WWW.PORPHYRIA.ORG](http://WWW.PORPHYRIA.ORG)  
to receive important news, information, and  
updates on the porphyrias!

Sign UP Today!

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**Rise UP. Speak UP.**

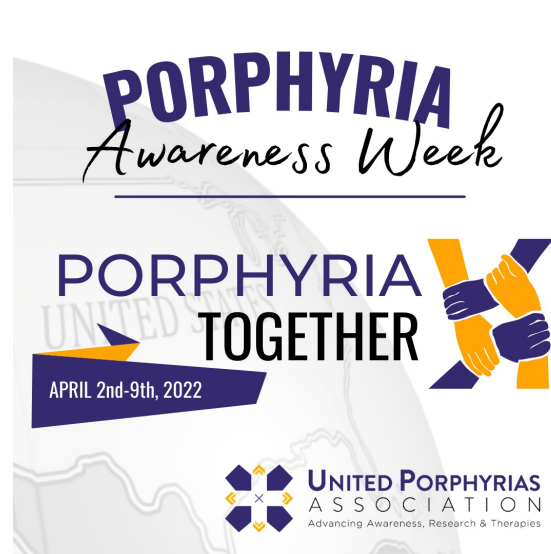
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**PORPHYRIA AWARENESS  
WEEK 2022**

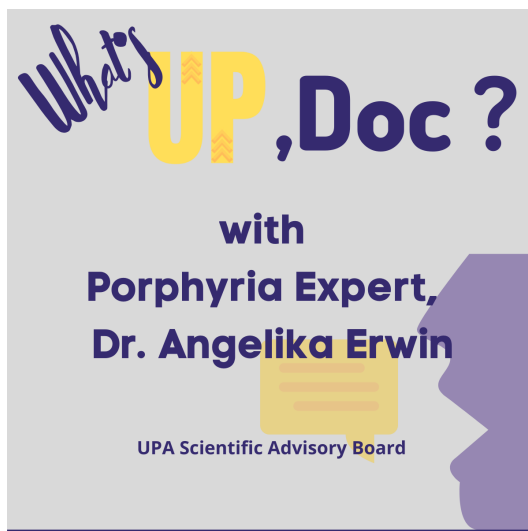
The countdown is on for

Porphyria Awareness Week 2022! Take out your purple swag – or find some [here!](#) – and prep to engage on social media, in your communities, and with healthcare professionals.

Head to [www.porphyria.org](http://www.porphyria.org) for social media banners and posts – along with printable materials. United Porphyrias has connected with patient advocacy groups across the globe to unite our message. **#PorphyriaTogether!**



UPA will be dropping [Porphyria Awareness Week](#) events and information throughout the week!



## WHAT'S UP, DOC?

This week, Dr. Angelika Erwin, Porphyria Specialist at the Cleveland Clinic, responded to a question from a patient with Congenital Erythropoietic Porphyria (CEP). Check out her excellent response [here](#).

### Question of the week:

**What extra precautions should I take when I am having my**

**teeth cleaned or any dental work? I have CEP and want to talk to my dentist in advance.**

### Response:

**This week, Dr. Angelika Erwin provided her response below.**

It is important to discuss your condition with your doctor in advance of any dental care to ensure safety during your appointment. Individuals with CEP have been reported to have thinner tooth enamel, which makes them more prone to developing cavities. Regular dental check-ups are therefore important. The grayish-brownish discoloration (erythrodontia) that is often present in CEP is caused by porphyrin deposition in the teeth. Teeth whitening is usually not effective in treating the discoloration and some patients decide to address this with veneers or crowns (only for cosmetic reasons).

The main concern is protecting you from fluorescent light during your appointment. In CEP, the skin is more sensitive to longer ultraviolet wavelengths (UVA) and to visible light. The most damaging wavelengths are between 400-410 nanometers since porphyrins are majorly activated in this range, with additional peaks described between 500-700 nanometers. To do this, the options include replacement of fluorescent lights with incandescent bulbs or installation of filtering screens in front of the bulbs.

Filters for lighting at your doctor's office are recommended, just like filter films for windows at home and in the car. Filters can typically be attached to any necessary lighting.

Protection for your eyes from visible light is also very important to avoid corneal damage. Good quality sunglasses with UV protection are another option while having dental work.

Remember to schedule an annual exam to make sure you check your Calcium and Vitamin D levels, have an annual eye exam to assess any corneal involvement, and make an annual visit to monitor porphyrins, blood count and liver enzymes.

[Click here to learn more about Congenital Erythropoietic Porphyria \(CEP\):  
https://www.porphyria.org/understanding-my-diagnosis/cep/](https://www.porphyria.org/understanding-my-diagnosis/cep/)

## YOU ARE NEEDED FOR A STUDY ON CANNIBIS AND CAM (Complementary and Alternative Medicine)

Patients with Acute Intermittent Porphyria (AIP) and Erythropoietic Protoporphyrinuria (EPP) anecdotally report using **Complementary and Alternative Medicines (CAMs) and cannabis** to alleviate their symptoms, but this has never been formally assessed. Click the links below to participate in a de-identified survey so we can learn more!

A graphic advertisement for a survey. At the top, the text "You are Needed!" is written in large, bold, yellow font. Below it, in white text on a dark blue background, it says "STUDY NOW OPEN FOR ACUTE HEPATIC PORPHYRIA (AHP) and Erythropoietic Protoporphyrinuria (EPP)". The middle section features a photograph of a person's hand holding a pen, pointing at a digital screen that displays the word "SURVEY" in large, bold, blue letters. The background of the screen is filled with various data visualization icons like bar charts, line graphs, and pie charts. At the bottom of the graphic, there are two logos: the "UNITED PORPHYRIAS ASSOCIATION" logo on the left and "THE PORPHYRIAS CONSORTIUM" logo on the right.

**You are Needed!**

STUDY NOW OPEN FOR  
**ACUTE HEPATIC PORPHYRIA (AHP)**  
and **Erythropoietic Protoporphyrinuria (EPP)**

**SURVEY**

UNITED PORPHYRIAS ASSOCIATION THE PORPHYRIAS CONSORTIUM

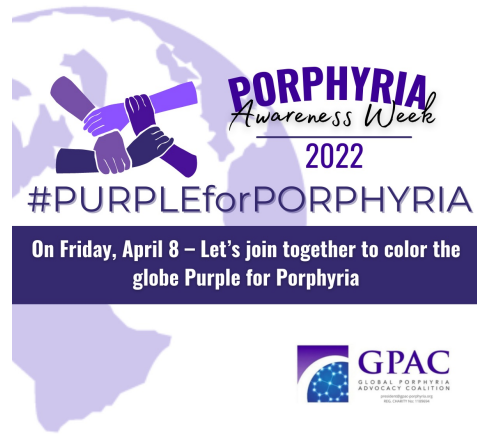
Anyone with [EPP](#) or [AIP](#) who is 18 years or older can participate. If you have never used CAMs or cannabis, you can still participate!

Thank you to those who have already completed this survey. You are appreciated!

ACCESS OTHER ONGOING RESEARCH STUDIES [HERE!](#)

## GLOBAL AWARENESS EFFORT

Get out your **PURPLE** and  
prep for **Porphyr**  
**Awareness Week** – April 2-9,  
2022!



[DONATE](#)

