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UNITED PORPHYRIAS ANNOUNCES GLOBAL PORPHYRIA DAY, MAY 18, 2025

TO SHINE LIGHT ON PAINFUL REALITIES OF LIVING WITH RARE CONDITIONS

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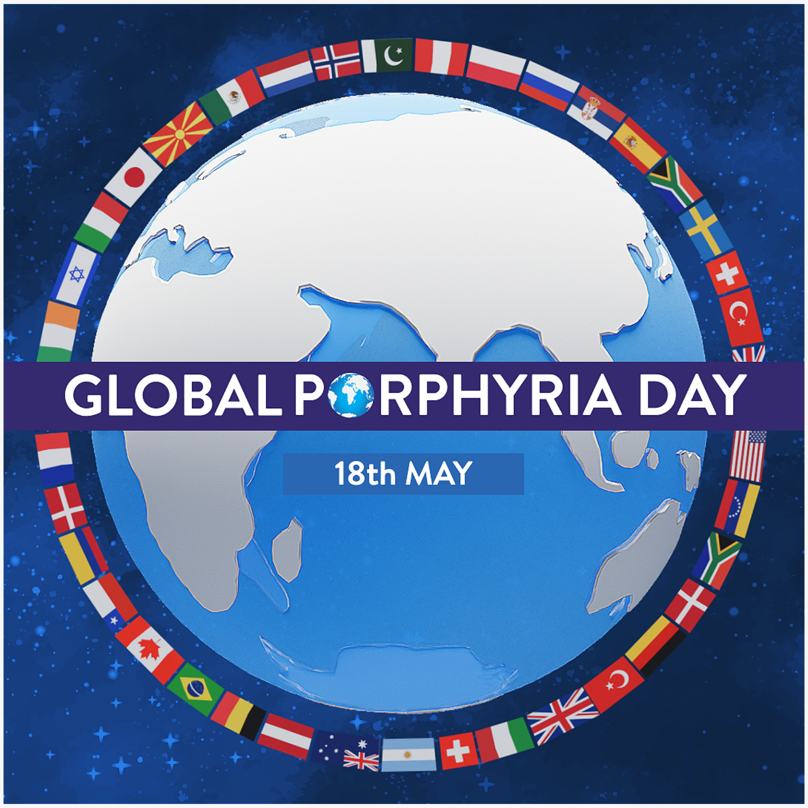

Global Porphyria Day 2025

The United Porphyrias Association (UPA) is marking Global Porphyria Day 2025 on May 18 by focusing on the painful realities of living with porphyria with the theme “Real People, Real Pain.”

Porphyria refers to a family of eight rare, genetic disorders affecting the body’s ability to produce heme, an essential molecule for transporting oxygen in the blood and many other biological processes. A malfunction in one of the enzymes involved in heme production leads to a buildup of natural chemicals called porphyrins or porphyrin precursors, which cause a range of debilitating and painful symptoms. The porphyrias are divided into two major clinical groups:

Acute Hepatic Porphyrias (AHP)
These forms primarily affect the nervous system. Symptoms include severe abdominal pain, nausea, vomiting, confusion, muscle weakness, paralysis, and, in some cases, life-threatening attacks.

Patient Descriptions: “Feeling like my body is being pulled apart and I’m filled with jagged, fractured bones”; “As if my muscles are being twisted and wrung out like a wet cloth.”

Cutaneous Porphyrias
These types cause extreme sensitivity to light. Sun exposure can lead to burning, tingling, itching, swelling, blistering, and long-term skin damage such as infections or scarring. Reactions can start within minutes and last for days.

UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

UPA logo

Patient Descriptions: “As if boiling sulfuric acid trapped under my skin”; “Like holding a lit match to my skin.”

Patients often wait years and sometimes decades for a diagnosis. Porphyria is often misunderstood and access to appropriate treatments and knowledgeable specialists can be limited. For some types of porphyria, there are no effective pain medications, resulting in negative mental health, family, and employment impacts.

> “
> Porphyria isn’t always visible, but the impact is very real. Global Porphyria Day gives us the opportunity to raise our voices together, so no one must walk this journey alone.”
>
> *Kristen Wheeden*

UPA is dedicated to creating a world free from the pain and challenges of porphyria through education, advocacy, and research. The organization’s internationally respected Scientific Advisory Board partners with the patient community to advance care and improve outcomes.

“We are proud to be part of this global effort,” said Kristen Wheeden, UPA President. “Porphyria isn’t always visible, but the impact is very real. Global Porphyria Day gives us the opportunity to raise our voices together, so no one must walk this journey alone.”

Participants around the world are encouraged to wear purple and share their stories with their family, friends, and broader community.
Together, this diverse community is helping shorten the diagnostic journey, increase public and medical awareness, and accelerate access to effective treatments.

To learn more about Global Porphyria Day and how to get involved, visit www.porphyria.org.

About the United Porphyrias Association
The United Porphyrias Association is a nonprofit organization dedicated to improving the quality of life for people living with all types of porphyria. UPA advances disease awareness, research, education, advocacy, and access to care through close collaboration with the global porphyria community. Ou name reflects the belief that meaningful progress takes a united effort. Patients, caregivers, clinicians, researchers, industry partners, regulatory leaders, and advocates all play a vital role in improving patients’ lives.

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