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Advancing Awareness, Research & Therapies

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Contact:

[Kristen Wheeden](#), President, United Porphyria Association

Phone: 1-800-868-1292 Email: kristen@porphyria.org

GLOBAL PORPHYRIA DAY (APRIL 19) BUILDS AWARENESS AND BRINGS ATTENTION TO RARE DISEASE

April 18, 2023 (Bethesda, MD) – United Porphyrias Association (UPA) announced today they are launching a new social media campaign designed to elevate awareness and understanding and to raise funds in support of the rare disease, porphyria. “This is my porphyria story” encourages patients, families, doctors, researchers and pharmaceuticals to share their story on Global Porphyria Day on April 19, 2023.

“A rare disease is one that impacts up to 200,000 Americans and one-in-ten people globally. Porphyria is a group of ultra rare diseases that can be difficult to diagnose and cause unimaginable pain. United Porphyrias working to live up to our name – uniting the global porphyria community to improve the quality of life of the porphyria patient community,” said UPA President Kristen Wheeden.

“Porphyria is a group of rare genetic disorders that affect the production of heme – a critical component of hemoglobin that helps red blood cells carry oxygen throughout the body. Heme is an essential building block for life, built like a stop sign. If anything goes wrong with any of the eight-sides, it causes a different type of porphyria.”

Presenting with a wide array of symptoms that are mostly invisible, the porphyrias are often misdiagnosed and misunderstood by the medical community. United Porphyrias Association is working closely with an internationally respected scientific advisory board and global patient advocate community to raise awareness, leading to earlier diagnosis, increased research, and access to therapeutics.

The United Porphyrias Association is committed to improving the quality of life of the porphyria patient community and is relentlessly focused on advancing disease awareness, research, and therapies in all the porphyrias. For more information on Porphyria, Global Porphyria Day, and the United Porphyrias Association, visit www.porphyria.org.

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