



IN PARTNERSHIP WITH



UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies



WHO WE SERVE

UPA serves individuals and families impacted by porphyria and the treating and expert healthcare professionals who provide care and initiate critical research.



OUR VISION

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.



OUR MISSION

The United Porphyrias Association envisions a world where patients are free from the pain and challenges of porphyria.

How skin conditions
IMPACT
patients



The porphyrias are divided into the “acute hepatic porphyrias” (AHPs) and “cutaneous porphyrias,” depending on the primary symptoms. AHPs present with sudden attacks of severe stomach pain, among other symptoms, which last for several days; types may also have skin symptoms of blistering after sun exposure. The cutaneous porphyrias present with blistering and scarring of the skin, pain, and/or redness and swelling in sun-exposed areas.



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OUR STORY

UPA was established by a team of patients, physicians, and researchers focused on advancing awareness, research, and therapies powered by scientific and clinical expertise with the belief that collaboration among key stakeholders is essential for innovation. UPA leadership is guided by a Board of Directors, Scientific Advisory Board, and President's Council to ensure patient centricity.

HOW WE MAKE AN IMPACT

United Porphyrias Association collaborates with patients, physicians, researchers, pharmaceutical partners, regulatory bodies, and fellow organizations focused in rare disease to impact awareness, research, and therapeutics for the porphyrias. Our leadership, staff, and governing boards work together to ensure earlier diagnosis, effective management, therapeutics and access to them.



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SCAN TO LEARN MORE ABOUT UPA



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AT A GLANCE HOW WE PROVIDE SUPPORT

United Porphyrias Organization supports the patient and healthcare professional community through research, education, awareness, advocacy, and patient support.

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