



HEALTHWELL
FOUNDATION®

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News Release

HealthWell Foundation® Makes a Difference in the Lives of People Living with Rare Disease

March 29 – April 5 is National Porphyria Week

Gaithersburg, MD (March 27, 2008) – The HealthWell Foundation, a non-profit, national charitable organization dedicated to providing financial assistance to patients with serious illnesses, has been helping patients with acute porphyria receive treatment for this relatively little-known condition. National Porphyria Awareness Week, sponsored by the American Porphyria Foundation (APF), is March 29 – April 5, 2008.

“Acute porphyria is not only painful, but is also extremely difficult to diagnose,” said 38-year-old Doug of Blacklick, Ohio, whose doctors first believed that he had appendicitis or possibly a chronic intestinal illness. After numerous additional tests, he was diagnosed with acute intermittent porphyria (AIP) in July 2005. “It was a relief to finally know what was wrong, but I was worried about how to afford treatment, even though I have insurance.”

At the time of diagnosis, Doug was completing his masters degree in nursing, specializing as an adult nurse practitioner and clinical nurse specialist in infectious disease and oncology. It was Doug's good fortune to be introduced to a physician who cares for porphyric patients at the James Cancer Hospital at Ohio State University. Once diagnosis was confirmed, a treatment plan was created to address his AIP. AIP is a very rare disease, and often asymptomatic. For reasons unknown, patients like Doug can become symptomatic one day, and very ill the next.

While Doug was relieved to have a definitive diagnosis, the cost of office visits, frequent ER visits or hospitalizations and prescription drug treatment had a steep price tag, even with insurance.

Doug applied for support from the HealthWell Foundation, and HealthWell now provides financial assistance to Doug for his insurance premiums and the out-of-pocket expenses for the porphyria treatment prescribed by his doctor.

APF sponsors National Porphyria Week each year to raise public awareness of this rare but serious condition, which affects the nervous system or skin. There is currently no cure, but, once diagnosed, proper treatment can manage the disease and minimize its symptoms.

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“Because porphyrias are difficult to diagnose, it is so important that we raise public awareness of the disease,” said Desiree Lyon, Executive Director of the American Porphyria Foundation. “The HealthWell Foundation has been a critical resource to an underserved community of patients who don’t have a lot of places to turn.”

Based on his own experience, Doug stated, "HealthWell has been a terrific gift and a bright spot in the lonely and often isolated feelings I had after the diagnosis and first treatments of the disease. Because of my amazing experience with HealthWell, I will be donating money back to them as soon as I can, to pay it forward for another person in need."

The HealthWell Foundation was established to assist patients with conditions such as acute porphyria to cover the out-of-pocket costs associated with treatment. The Foundation also currently offers assistance for the treatment of many other life-threatening or chronic diseases, including breast and colorectal cancers, asthma, non-Hodgkin’s lymphoma and rheumatoid arthritis, among others.

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Since 2003, the HealthWell Foundation® has helped more than 45,000 patients with serious and chronic conditions meet their cost-sharing obligations for treatment. HealthWell is an independent 501(c)(3) non-profit association that provides financial assistance to cover the cost of prescription drug coinsurance, co-payments and deductibles, health insurance premiums, and other selected out-of-pocket healthcare costs. The Foundation considers individual financial, medical and insurance situations when determining assistance eligibility. For more information, please visit www.healthwellfoundation.org.