spotlight on health

Young Woman Finally Diagnosed And Treated After Years Of Suffering From Rare Blood Disorder

Mom Refused To Give Up Search For Information To Help Her Daughter Overcome Debilitating Illness

(NAPSA)—Megan Railling was a normal high school student whose life was abruptly put on hold when she was stricken with persistent, severe abdominal pain at the age of 16. She spent most of the next three years in the hospital enduring excruciating pain, including nerve damage that paralyzed her from the waist down. Her doctors ran countless tests and could not identify her condition. After three years, Megan was afraid they had given up.

"I asked my mom if I was going to die," said Megan. "No one knew what was causing the pain or the paralysis."

Megan's mom was desperate to find the cause of Megan's suffering, and conducted exhaustive research online and in medical journals. An article about a condition called acute intermittent porphyria (AIP) outlined symptoms remarkably similar to Megan's, including severe abdominal pain, gastrointestinal problems and nerve damage. Her mom brought the article to Megan's doctors and asked them to test for the condition.

Megan was tested and diagnosed with AIP, a condition for which there is an FDA-approved treatment option called Panhematin® (hemin for injection).

"I was relieved to discover the cause of my pain and learn that treatments are available to help me live with the condition," Megan said. "Now I've got my life back, the paralysis is gone, and I'm looking forward to attending medical school in the fall."

AIP is one type of porphyria, a group of genetic disorders associated with enzyme deficiencies affecting heme production—the component of hemoglobin that carries oxygen throughout the body. Depletion of the heme pool caused by certain triggers in individuals with an enzyme deficiency results in an overproduction of porphyrins and their precursors. A buildup of these chemicals in vital organs can cause acute, sometimes life-threatening attacks.

For thousands of Americans, AIP is a painful part of their everyday lives. Unfortunately, many don't even know the name of their condition. If left untreated, the disease can cause long-term neurological damage. Due to its wide range of symptoms, which often mimic other disorders, porphyria can remain undiagnosed for many years.

"I feel lucky to have been diagnosed after just three years, as I know other AIP patients who suffered for much longer before diagnosis," Megan said. "I hope my story helps those unknowingly suffering from AIP—or any undiagnosed disease—to take a cue from my mom and be proactive, work closely with health care professionals and, most importantly, never give up."

For more information about porphyria, visit www.porphyriafoundation.com.

Note to Editors: March 28 – April 4 was declared National Porphyria Awareness Week.

PANHEMATIN should only be used by physicians experienced in the management of porphyrias in hospitals where the recommended clinical and laboratory diagnostic and monitoring techniques are available. PANHEMATIN therapy should be considered after an appropriate period of alternative therapy (i.e., 400 g glucose/day for 1 to 2 days).

PANHEMATIN is contraindicated in patients with known hypersensitivity to this drug. PANHEMATIN is made from human blood and therefore may contain infectious agents, such as viruses, that can cause disease including Creutzfeldt-Jakob disease. Drugs such as estrogens, barbituric acid derivatives, steroid metabolites and anticoagulants should be avoided during PANHEMATIN therapy. Reversible renal shutdown has occurred with administration of excessive doses. Because phlebitis has been reported after administration of PANHEMATIN through small arm veins, a large arm vein or a central venous catheter should be utilized for administration.

For more information, please see full Prescribing Information, including Boxed Warning at www.lundbeckinc.com.