

# Fact VS Fiction

## Understanding Porphyria: No Vampires Here

(NAPSA)—Many of the world's myths and legends have some basis in fact, which is why they are perpetuated through the centuries. In one case, the idea of a race of nefarious monsters—specifically, vampires—may actually have sprung from a very real and potentially deadly disease that affects thousands of people worldwide.

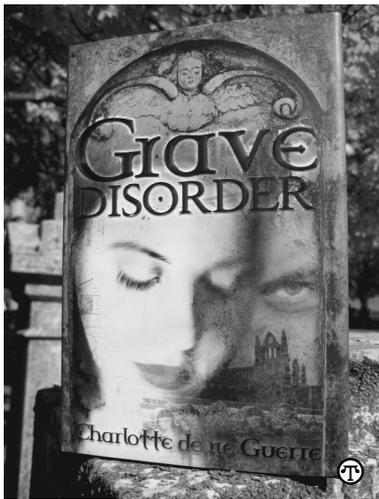
Porphyria is not a single disease but a group of at least eight disorders. Symptoms vary, but among them are some that have, in ancient times, given credence to the legend of the vampire. These include excruciating stomach pain, severe headaches, tachycardia (rapid heartbeat), muscle weakness that can take on a state of paralysis from sensitivity to sunlight, and comas that last for days, giving one the appearance of having awakened from the dead.

### Genetic Disorder

In reality, porphyria can only be passed genetically through families. It is extremely hard to diagnose and can be painful or even deadly. The root of the disease is in defective enzymes that are involved in the body's manufacturing of heme—a vital substance for all body organs. Heme consists of an iron atom surrounded by a porphyrin molecule and is a part of hemoglobin, which carries oxygen to all parts of the body.

Unfortunately, the legend is bigger than the disease that spawned it; even today, people with porphyria are accused of being vampires. But vampires are only a myth created many centuries ago when medicine couldn't explain the problem.

"It's just absurd to think that drinking blood is a way to revitalize anyone!" says Desiree Lyon Howe, director of the American Porphyria Foundation (APF).



"Drinking blood means it goes into the digestive system and merely passes through; it doesn't replace the blood in your body."

Charlotte de ne Guerre, a sufferer of porphyria, recently wrote a novel—inspired by her life story—that will shed light on the subject and dismiss the vampire stigma. In the book, "Grave Disorder," de ne Guerre lays out two tales that are separated by centuries but joined by the one truth.

### Spanning The Centuries

The Baroness Elysia von Eschenbach is a young 17th-century noblewoman who doesn't understand the bizarre physical breakdowns that have plagued her. She is betrothed to the arrogant son of a wealthy Frenchwoman who is more interested in Elysia's title and land, but the consequences of having the disease are even more dire. When she absorbs too much sun, drinks wine and eats the wrong foods, she lapses into a near-death coma at her wedding...only to wake up after her abrupt funeral.

The other tale concerns a contemporary American woman,

Claire Foster. She knows she's not crazy and that her symptoms are not all in her head, and yet, like many people today, she struggles to understand why she's suffering and is unable to find a doctor who will take her condition seriously, much less accurately diagnose her illness. Both tales are engaging from the onset of the story and build to a climax that will enable the reader to understand the plight of those who suffer with porphyria.

Ms. de ne Guerre spent her professional career as a Certified Quality Engineer for Abbott Laboratories. Even though the orphan drug Panhematin was manufactured by Abbott and coincidentally passed right across her desk, it was several years later that a diagnostician in an emergency room finally gave a name to her condition. She wrote this novel of intrigue not only to delight readers, but to bring understanding of the disease porphyria and help break the stigma that it is thought to be the disease of the vampires.

### Understanding The Disease

APF is eager for the understanding as well. There are many people who are afraid to seek treatment because of the stigma, and then, of course, there are many more who are needlessly suffering because the majority of today's doctors are simply unaware of the disease.

Yet people with porphyria can lead very productive lives, such as Lauren Warren, who finished fourth in the Ford IRONMAN USA Lake Placid Triathlon, thus qualifying her to join athletes around the world in the famous IRONMAN World Championships. Could a vampire do that? To learn more about the disease and treatments, visit [www.porphyrifoundation.com](http://www.porphyrifoundation.com).