Patients Rally To Raise Awareness Of Rare Disease

(NAPSA)—Nina Smith is one of the approximately 25 to 30 million Americans with a rare disease. She lives with hereditary angioedema (HAE), which causes painful, unpredictable and potentially life-threatening swelling attacks throughout her body, including her arms, legs, face, abdomen and upper airway. People like Nina often struggle for years to obtain an accurate diagnosis because conditions like HAE are so rare and often thought to be other, more common conditions.

"I first experienced HAE symptoms at age 6," Smith said. "I was in the first grade and had gone out to the playground for recess with the other children when my belly suddenly began hurting so badly I could hardly breathe. The only way I could get any relief at all was to lie in the dirt curled up in a ball." Living with HAE meant dealing with attacks during vacations, holidays and birthdays. When she was in her 30s, she experienced an HAE attack in her throat that affected her breathing. The thought of not being there for her children was terrifying.

Smith is a nurse who considers herself a patient advocate first and foremost, especially for the HAE community. She grew up with symptoms of HAE but she was not accurately diagnosed with HAE until she was 50 years old. That's when she began looking for others in her family who may also have symptoms and devoted herself to raising awareness of HAE.

Thirty years ago, the Orphan Drug Act was passed to help the pharmaceutical industry focus on rare disease treatments. Since that time, more than 400 rare disease treatments have been approved by the FDA. As scientific understanding of rare diseases evolves and advocacy organizations like the National Organization for Rare Disorders (NORD) and the US Hereditary Angioedema Association (US HAEA) promote awareness and provide patient support, times are different for people like Smith.

Nina Smith, patient advocate and one of the approximately 25 to 30 million Americans with a rare disease.

"The HAE community celebrates HAE Day annually to raise awareness of hereditary angioedema around the world," said Janet Long, Executive Vice President of the US Hereditary Angioedema Association (www.HAEA.org), the advocacy and support organization for HAE patients throughout the country. "This is a new era for HAE patients. It is important that all families affected by HAE are made aware that there are many resources available now to help them."

Raising awareness of HAE is especially important to Smith, because today there are treatment options and a supportive community of physicians, advocates and people living with HAE.

"We have certainly come a long way and I hope you'll remember that no matter what, we have it in us to be proactive about our health," Smith said.

That is why she became a Patient Ambassador for Shire (www.shire.com), a pharmaceutical company focused on rare diseases like HAE, to help raise awareness about HAE and the support available.

For Smith, HAE Awareness Day means continuing to speak out about HAE, and encouraging patients to take an active role in their health—not just one day a year, but throughout their lives.