Health Alert

Rare Genetic Disorder Brings Families Together

(NAPSA)—While the bonds that unite families are usually associated with positive events, such as weddings or holidays, those bonds can be more challenging when entire families are impacted by a hereditary disease. Christie Hardin knows this firsthand. For years, she and more than 30 members of her extended family have lived with hereditary angioedema, or HAE, a rare genetic disorder that can cause severe swelling in various body parts including the hands, feet, face, gastrointestinal tract and airway. But now, on-demand treatments are helping generations of families affected by HAE take more control of their lives.

New treatments are helping families that share a hereditary disease, such as HAE, gain more control over their lives.

Living with the Disease

"As a child, I could remember my mother having swelling attacks in just a matter of minutes and my brothers would miss school due to painful abdominal swelling that would leave them both bedridden for days," recalls Hardin. "It wasn't until my teens, when I started experiencing the same painful swelling, vomiting, nausea and limited mobility, that I understood the severity of HAE."

HAE affects an estimated 6,000 to 10,000 people in the United States, and is caused by a genetically inherited deficiency of a protein in the blood called C1-esterase inhibitor. Symptoms are often misdiagnosed as allergic reactions, colitis and appendicitis. While inaccurate diagnoses result in prescriptions for ineffective treatments and unnecessary exploratory medical procedures, a single accurate diagnosis can often lead to answers for an entire family suffering from the symptoms of HAE. Even with an accurate diagnosis, patients like Hardin struggle to get their family members engaged in learning more about and managing their condition while seeking appropriate treatment options.

"Education and understanding are the foundation of managing any condition," said Hardin. "As an advocate for HAE awareness, I've encouraged many patients, especially my family, to become their own advocates."

Treatment Options

On-demand treatment for HAE can decrease the duration of an attack from days to less than an hour, providing patients and their physicians with the option to develop an HAE treatment plan tailored to meet their unique needs. Hardin—who, after receiving treatment, encouraged other family members to work with their physicians to develop a treatment plan—credits these new therapies with giving families like hers control of their lives again. Patient assistance programs ensure that all eligible patients have access to therapy.

"While HAE is a lifelong condition, thanks to the availability of therapies, my entire family can now live their lives knowing these attacks are treatable," said Hardin.

To learn more, visit www.haeday.org.