Helping Hunter Syndrome Patients

(NAPSA)—"Hunter syndrome is my gift, my curse and my life," says Kyle Plunkett, a 14-year-old who battles this rare disease every day.

Hunter syndrome, also known as Mucopolysaccharidosis II (MPS II), is a genetic disease that primarily affects boys. The disease interferes with the body's ability to break down and eliminate waste from cells; the waste builds up and causes health problems. For most patients, symptoms usually appear in early childhood.

Approximately 2,000 people worldwide have Hunter syndrome. Like many other rare diseases, experts believe the condition is underdiagnosed because of its rarity and the symptoms can be misinterpreted as signs of other common ailments, such as a cold.

For children with Hunter syndrome, symptoms such as recurrent ear infections and chronic runny noses may begin to surface at the age of one. Because these are common complaints, physicians may not suspect Hunter syndrome until several years later, when respiratory and heart problems emerge. Kyle was seen by multiple specialists before being diagnosed at age 3.

Outwardly, other changes may begin taking place, such as delayed growth, a protruding stomach, or curled fingers from having stiff joints. A "coarsening" of facial features is also common, including a prominent forehead, nose with a flattened bridge or enlarged tongue. Because of these symptoms, children with Hunter syndrome often look alike.

Kyle, a 14-year-old Hunter syndrome patient.

For several years, Kyle and more than 100 other Hunter patients participated in clinical trials evaluating a treatment for Hunter syndrome. When the therapy was approved recently in the United States, Kyle said he felt like a pioneer in medical history.

A rare disease is not so rare when it affects you or someone you know. There are over 6,000 conditions classified as rare or "orphan" diseases, each affecting less than 200,000 people in the United States. Other well-known orphan disorders include cystic fibrosis and muscular dystrophy.

More information about Hunter syndrome is available at www.hunterpatients.com. Or contact Shire HGT at (866) 888-0660.