Alexion Launches Every Day with HPP™ Campaign in Support of Hypophosphatasia (HPP) Awareness Week

Release Date:
Monday, October 27, 2014 4:51 pm EDT

Terms:
Company News
— Campaign highlights unique stories and experiences of the HPP community to raise awareness —

CHESHIRE, Conn.--(BUSINESS WIRE)--Alexion Pharmaceuticals, Inc. (NASDAQ:ALXN) today announced the launch of the Every Day with HPP™ campaign in support of the third annual Hypophosphatasia (HPP) Awareness Week Oct. 26–Nov. 1, 2014. HPP Awareness Week is a national public awareness effort to focus attention on HPP and its impact on patients with HPP and their caregivers, families, friends and supporters. HPP is a genetic, lifelong and progressive ultra-rare metabolic disease that can damage bones and vital organs and can have severe consequences at any stage of life. HPP Awareness Week offers those living with HPP the opportunity to spread the word about this ultra-rare disease and establish powerful connections with others in the HPP community.

The Every Day with HPP campaign encourages patients with HPP, caregivers, their loved ones and people interested in supporting the HPP community to share their stories of challenges, hopes and aspirations by submitting a photo of a handwritten sign on which they have completed the sentence “Every Day with HPP, I____.” These photos and messages will be displayed on EveryDayWithHPP.com, creating an authentic snapshot of everyday life with HPP. Additional information on HPP, tools, videos and downloadable resources will also be featured on the website.

“At Alexion, we are driven every day by our commitment to develop and deliver life-transforming therapies for patients worldwide who suffer from severe and life-threatening diseases, including HPP. Initiatives like HPP Awareness Week further inspire us in this mission,” said Leonard Bell, M.D., Chairman and Chief Executive Officer of Alexion. “We are pleased to support the entire HPP community in the effort to raise awareness of this ultra-rare, chronic and progressive disease.”

In patients with HPP, defective bone mineralization can lead to destruction and deformity of bones, profound muscle weakness, seizures, respiratory failure and premature death.1-5 Patients with HPP often experience symptoms in their bones, joints and muscles, as well as in major organs including the brain, lungs and kidneys.1,6 Because of the progressive nature of HPP, new symptoms can appear at any age and symptoms can worsen over time, causing significant disability.1,4,7-10 The devastating outcomes of HPP include fatal seizures and breathing problems in infants; skeletal bowing, frequent fracture and delays in growth and development in children; and debilitating functional impairment and frequent, non-healing fractures in adults.1,4,5,7,11-16

“The goal of HPP Awareness Week is to spread awareness and education about HPP and support patients with HPP and their loved ones so they don’t feel isolated and alone,” said Deborah Sittig, President and Founder of Soft Bones. “The Every Day with HPP campaign highlights what it’s like to live with this devastating disease. Through the unified efforts of everyone in the HPP community, it is my hope that we will increase awareness of HPP and ultimately better the lives of patients and families with HPP.”

To learn more about hypophosphatasia or to participate in the Every Day with HPP campaign, please visit EveryDayWithHPP.com.

About Hypophosphatasia (HPP)

HPP is a genetic, chronic and progressive ultra-rare metabolic disease characterized by defective bone mineralization that can lead to destruction and deformity of bones, profound muscle weakness, seizures, respiratory failure and premature death.1-5

HPP is caused by mutations in the gene encoding an enzyme known as tissue non-specific alkaline phosphatase (TNSALP).1-2 The genetic deficiency in HPP can affect people of all ages.1 HPP is traditionally classified by the age of the patient at the onset of symptoms of the disease, and pediatric-onset HPP is defined as manifestation of the first symptom prior to 18 years of age.

HPP can have devastating consequences for patients at any stage of life.1 In a natural history study, infants who had their first symptom of HPP within the first 6 months of life had high mortality, with an overall mortality rate of 73% at 5 years.16 In these patients, mortality is primarily due to respiratory failure.1,5,16 In patients surviving to adolescence and adulthood, long-term clinical sequelae include recurrent and non-healing fractures, debilitating weakness, severe pain and the requirement for ambulatory assistive devices such as wheelchairs, wheeled walkers and canes.1,4

About Alexion
Alexion is a biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development and commercialization of life-transforming therapeutic products. Alexion is the global leader in complement inhibition and has developed and markets Soliris® (eculizumab) as a treatment for patients with paroxysmal nocturnal hemoglobinuria (PNH) and atypical hemolytic uremic syndrome (aHUS), two debilitating, ultra-rare and life-threatening disorders caused by chronic uncontrolled complement activation. Soliris is currently approved in nearly 50 countries for the treatment of PNH and in nearly 40 countries for the treatment of aHUS. Alexion is evaluating other potential indications for Soliris in additional severe and ultra-rare disorders beyond PNH and aHUS, and is developing other highly innovative biotechnology product candidates across multiple therapeutic areas. This press release and further information about Alexion can be found at www.alexionpharma.com.

REFERENCES

6 Whyte MP. Hypophosphatasia. 2001:5313-5329.

Contact:
Alexion:
Media
Irving Adler, 203-271-8210
Executive Director, Corporate Communications
or
Kim Diamond, 203-439-9600
Senior Director, Corporate Communications
or
Investors
Elena Ridloff, 203-699-7722
Executive Director, Investor Relations