# **Press Release**



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# Shire calls for improved rare disease diagnosis on Rare Disease Day 2015

- New awareness materials posted on Shire.com highlight the challenging diagnosis journey many people with a rare disease face
- Average time to diagnosis for rare diseases is around 5 years and typically involves 2-3 misdiagnoses<sup>1,2</sup>
- An accurate diagnosis may be the first step to improving the care for those living with a rare disease<sup>1,3</sup>

**Zug, Switzerland – 23 February 2015** – Shire plc (LSE: SHP, NASDAQ: SHPG) today announced its support of Rare Disease Day 2015 by calling for improvements in the journey to diagnosis for those living with a rare disease. Under a new educational initiative, "*Diagnosis Doesn't Have to be Rare*", Shire is launching a series of educational materials for Rare Disease Day, highlighting the often challenging rare disease diagnosis journey many patients face. The materials aim to help raise awareness of rare diseases, as knowledge and information are critical to early diagnosis and play a major role in empowering patients and their families.

The theme for this year's Rare Disease Day, "Living with a Rare Disease", acknowledges that developing and facilitating access to diagnostics and treatments could change the day-to-day reality for someone with a rare disease. Are Disease Day takes place annually on the last day of February, and is coordinated at the international level by the European Organisation for Rare Diseases (EURORDIS) and by National Alliances and Patient Organizations at the national level.

Many people with a rare disease continue to experience low quality of life and high levels of disability.<sup>3</sup> Surveys have shown that it may take several years (on average five years) before patients with a rare disease receive the right diagnosis, with visits to different physicians and possible misdiagnoses along the way.<sup>1,2,3</sup>

"Rare Disease Day is symbolic in the solidarity it brings to everyone with an interest in helping those with rare diseases," said Emmanuel Dulac, Head of the Rare Diseases Business Unit at Shire. "At Shire, we believe in the importance of raising awareness of the barriers to diagnosis in an effort to improve this challenged pathway, which is why we're launching our educational initiative today. Shire believes the pathway to improve diagnosis can only be achieved by all stakeholders joining together to find solutions to help ensure accurate diagnosis of rare diseases at an early stage."

There is limited public, patient and physician knowledge of the signs and symptoms to look out for, due to the vast number of rare diseases as a whole (approximately 7,000 identified<sup>1,5</sup>), and the rarity of those diseases individually. Physicians may only come across some of these rare conditions once (if at all) in the duration of their careers. How long the diagnosis takes often depends on whether a physician has seen the rare disease before.<sup>1</sup>

Rare diseases can often hide behind the symptoms of more common illnesses, which can make diagnosis extremely challenging and often lead to misdiagnosis. Misdiagnosis can force patients to see multiple doctors, take multiple tests and treatments, and lead to unnecessary hospital visits. The longer it takes to receive a diagnosis, the more physicians a patient and their family must see.

Shire is committing to helping raise awareness of rare diseases, including the diagnosis challenges, and implementing initiatives to support an improved diagnosis journey. Shire will continue to introduce these new initiatives under the "*Diagnosis Doesn't Have to be Rare*" campaign umbrella throughout 2015, with activities in partnership with the rare disease community directly aimed at improving the diagnosis journey.

To view the diagnosis journey educational materials, and keep up to date on new initiatives, visit: www.Shire.com/RareDiagnosis.

# For further information please contact:

#### Media

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# **NOTES TO EDITORS**

Shire enables people with life-altering conditions to lead better lives.

Our strategy is to focus on developing and marketing innovative specialty medicines to meet significant unmet patient needs.

We focus on providing treatments in Rare Diseases, Neuroscience, Gastrointestinal, and Internal Medicine and we are developing treatments for symptomatic conditions treated by specialist physicians in other targeted therapeutic areas, such as Ophthalmics.

# www.shire.com

# References

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