Press Release

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Shire Launches Report that Quantifies the Health, Psycho-social and Economic Impact of Rare Diseases

New findings reveal the substantial burden of rare diseases due to lack of resources, financial challenges and emotional unrest

Lexington, Massachusetts, US – April 9, 2013 – Shire plc (LSE: SHP, NASDAQ: SHPG) today launched a Rare Disease Impact Report, which uncovers the health, psycho-social, and economic impact of rare diseases on patient and medical communities in the United States (US) and United Kingdom (UK). The report, developed in collaboration with an external advisory board of thought leaders in the medical, advocacy, health policy and health economics fields, will be distributed at the World Orphan Drug Congress in Washington, DC (April 9-11) and is available for immediate download at www.rarediseaseimpact.com.

According to more than 1,000 survey responses from a multi-stakeholder audience sample, the Rare Disease Impact Report reveals[1]:

- It takes, on average, more than seven years in the US and five years in the UK for a patient with a rare disease to receive a proper diagnosis
- On the journey to diagnosis, a patient typically visits up to eight physicians (four primary care and four specialists) and receives two to three misdiagnoses
- Physicians (both primary care and specialists) often don't have the time, resources and information to properly diagnose/manage patients with rare diseases, compared to more common diseases
- Due to the uncertainty, the lack of available information, resources, and economic strains, rare diseases take a major emotional toll on patients and their caregivers

“This Impact Report brings to light the specific barriers to quality care that exist for patients with rare diseases; particularly the challenges in getting an accurate diagnosis, adequate information and ongoing care,” says Nicole Boice, founder and CEO, Global Genes | RARE Project, a leading rare and genetic disease patient advocacy organization. “I am thrilled that Shire engaged Global Genes in this initiative and hope it will inspire the rare disease community to work together to better meet the needs of rare disease patients and their families.”

Rare diseases are conditions that affect a small portion of the population but are often chronic, progressive, degenerative, life-threatening and disabling.[2] While individual rare diseases are uncommon and disparate, collectively, there are approximately 7,000 different types of rare diseases and disorders affecting an estimated 350 million people worldwide.[3] Despite the progress that has been made over the past few decades to help improve the quality of life for patients managing these complex diseases, there are still significant gaps in care and barriers facing the community at large.

“The findings from our Rare Disease Impact Report are sobering,” says Flemming Ornskov, MD, Chief Executive Designate, Shire. “As a leader in rare diseases, Shire hopes that this report will help drive forward a collaborative effort with the patient and medical communities to address the unmet needs identified.”

Rare Disease Impact Report Findings[1]

Across the groups surveyed, findings center around three overarching challenges:

There is a lack of resources and information to address these less common illnesses

- Physicians (both primary care and specialists) often don't have the time, resources and information to properly diagnose/manage patients with rare diseases, compared to more common diseases
    - The majority of physicians surveyed reported it is more difficult to address the needs of a rare disease patient in a typical office visit (92% in the US, 88% in the UK agreed) and more office visits are required to diagnose a rare disease patient (98% in the US, 96% in the UK agreed)
    - In addition, more than half of physicians stated there aren't enough opportunities to network with other physicians who treat rare diseases (54% in the US, 62% in the UK agreed)
- From a patient and caregiver perspective, around half of those surveyed stated they received conflicting information from different health care professionals about treatment options (60% in the US, 50% in the UK agreed)
    - In fact, more than half of patients and caregivers stated they needed to provide their healthcare professionals with information on their rare disease (67% in the US, 62% in the UK agreed)
- As a result of these challenges, on average, it takes 7.6 years in the US and 5.6 years in the UK for a patient with a rare disease to receive a proper diagnosis, based on survey results. Along the way, the average patient visits four primary care doctors, four specialists and receives two to three misdiagnoses

The economic impact of diagnosing and managing rare diseases is significant. The journey to diagnosis and beyond comes with a steep price tag for many coping with a rare disease. The long road, which frequently includes numerous tests and physician visits, can become financially overwhelming, particularly for those in the US as compared to the UK

- Payor respondents reported several factors contribute to the higher costs of care for rare disease patients compared to more common diseases, including the need for more diagnostic tests (100% in the US, 80% in the UK agreed) and more costly diagnostic tests (100% in the US, 90% in the UK agreed)
- Payors also found it difficult to make rare disease coverage decisions due to the lack of standards and guidelines. Almost all payors surveyed indicated there is less information/data available to help determine the standards of care for rare diseases (95% in the US, 90% in the UK agreed)
- Although 90% of patients surveyed reported they had health coverage in the US:
    - 55% of US respondents incurred direct medical expenses not covered by insurance compared to 18% of respondents in the UK not covered by the National Health Service
    - 37% of respondents borrowed money from family and/or friends to pay for expenses in the US compared to only 21% of respondents in the UK

Due to the uncertainty, the lack of available information, resources, and economic strains, rare diseases take a major emotional toll on patients

- Patient respondents reported several emotional difficulties managing their disease including depression (75% in the US, 69% in the UK agreed), anxiety and stress (86% in the US, 82% in the UK agreed), isolation from friends/family (65% in the US, 57% in the UK agreed), and worry based on future outlook of disease (90% in the US, 91% in the UK agreed)
    - For those rare disease patients where treatment options are limited, overall they worry more, feel more depressed, interact less and feel more isolated from

family and friends, compared to patients with rare diseases for which there are available treatments

Data Collection

In January 2013, Shire HGT conducted online surveys over a four-week period among US and UK rare disease patients and their caregivers; physicians treating patients with rare diseases; payors who handle reimbursements for healthcare plans and government/institutions; and thought leaders in the rare disease space. Surveys were fielded through the market research agency, ORC International and also distributed by advocacy group partners Global Genes and the Genetic Alliance UK.

The Rare Disease Impact Report Advisory Board

An external advisory board anchored by thought leaders in the medical, advocacy, health policy and health economics fields lent their expertise to the development of the Impact Report. Advisory board members include Nicole Boice, Founder and CEO, Global Genes | RARE Project; Dr. Priya S. Kishnani, Division Chief, Medical Genetics, Duke University Medical Center; Tomas Philipson, Daniel Levin Professor of Public Policy Studies, The University of Chicago; Alastair Kent, Director, Genetic Alliance UK; Dr. Christian J. Hendriksz, Clinical Lead, Adult Inherited Metabolic Disorders, Salford Royal NHS Foundation Trust; and Mike Drummond, Professor of Health Economics, University of York.

Please visit www.rarediseaseimpact.com to get more information and view the full Impact Report.

For further information please contact:

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NOTES TO EDITORS

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

Through our deep understanding of patients' needs, we develop and provide healthcare in the areas of:

- Behavioral Health and Gastro Intestinal conditions
- Rare Diseases
- Regenerative Medicine

as well as other symptomatic conditions treated by specialist physicians.

We aspire to imagine and lead the future of healthcare, creating value for patients, physicians, policymakers, payors and our shareholders.

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FORWARD - LOOKING STATEMENTS - "SAFE HARBOR" STATEMENT UNDER THE PRIVATE SECURITIES LITIGATION REFORM ACT OF 1995

Statements included in this announcement that are not historical facts are forward-looking statements. Forward-looking statements involve a number of risks and uncertainties and are subject to change at any time. In the event such risks or uncertainties materialize, Shire's results could be materially adversely affected. The risks and uncertainties include, but are not limited to, that:

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and other risks and uncertainties detailed from time to time in Shire's filings with the U.S. Securities and Exchange Commission, including its most recent Annual Report on Form 10-K.

References

1. Shire HGT. Rare Disease Impact Report. http://www.rarediseaseimpact.com. Published April 2013.
2. European Organisation for Rare Diseases (EURORDIS) website. "Rare Diseases: understanding this Public Health Priority." http://www.eurordis.org/IMG/pdf/princeps_document-EN.pdf. Accessed March 20, 2013.
3. Global Genes website. "RARE Facts and Statistics." http://globalgenes.org/rarefacts/. Accessed March 20, 2013.