

# New Survey Reveals the Plight of Haemophilia Patients in the UK

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As world experts gather for the World Federation of Haemophilia global congress, the survey results demonstrate the need for patients having more support and control in their own haemophilia care

London, United Kingdom – May 22, 2018 – Shire Pharmaceuticals Limited today released results from a new UK patient survey which showed that three quarters of haemophilia sufferers are living a life of pain and worry due to their condition. The release of these findings coincide with the start of the World Federation of Haemophilia congress, taking place in Glasgow this week, where leading experts are gathering to discuss the latest challenges and developments in haemophilia care.

Haemophilia is a largely hereditary condition where people experience longer-than-normal bleeding due to an absence or deficiency of clotting factors in their blood. Shire's "My Life With Haemophilia" survey found that the excessive bleeding associated with haemophilia impacts daily life for 93% of people, with 54% worrying about their next bleed, 53% saying they are in pain and 70% admitting they have to avoid physical activities, including sports and over half of respondents (54%) avoiding certain social events.

Unsurprisingly, the survey also revealed that 68% want to see additional types of treatments being more widely available. Furthermore, eight in ten people (80%) called for a greater understanding and wider discussion of haemophilia within the community, particularly in relation to educating friends, family and colleagues about their condition. They also wanted to improve their own understanding of their care pathway, with 46% wishing to be informed enough to take a more active role in the decisions being made about their treatment and care. 67% said they would like more opportunities to meet & talk to others living with haemophilia and 39% said they would like more access to online support tools.

"As our world experts meet to consider solutions for addressing the greatest needs in haemophilia, it is important to remember the people actually affected by this condition. By understanding more about the challenges they face, and their unique experiences of living with haemophilia, we as a community, and they as health experts, can begin to provide the solutions they need in order to continue to live healthy and productive lives," said Jefferson Courtney, Haemophilia Society

However, despite many of the survey findings being bleak, there were some positive insights too with almost a quarter of respondents (23%) saying they were proud of their ability to live normal and healthy lives despite their condition.

Alan Walshe, Head of Haematology Franchise Shire UK comments, "The survey findings demonstrate that there is still more to be done in the care of haemophilia patients in the UK. It appears that patients are looking for a more personalised approach to treatment and care, that allows patients to achieve the best lives they can despite the challenges of their condition. This survey comes as part of a broader campaign and commitment from Shire to help society better understand and support those living with haemophilia in the UK."

The “My Life With Haemophilia” study findings, which are based on a survey of 74 people living in the UK with haemophilia, build on other work being done by Shire, in collaboration with the Haemophilia Society. The #MyLifeinPictures campaign, was launched on 22nd May 2018 to share the unique perspectives of people living with haemophilia and raise awareness across the UK.

For more information on the campaign visit: Shire My Life with Haemophilia  
(<https://www.shirepharmaceuticals.co.uk/patients/my-life-in-pictures>)

For further information please contact:

Erin Collett: [Erin.collett@edelman.com](mailto:Erin.collett@edelman.com)  
+44 (0)7976 353066

Laura Craggs: [Laura.craggs@edelman.com](mailto:Laura.craggs@edelman.com)  
+44 (0)7896 890792