# PRESS RELEASE

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## People with haemophilia and female carriers in Sweden have higher risk of anxiety, depression and pain, based on treatment patterns

People with haemophilia have an increased risk of acute and chronic pain, and long-term disability, associated with bleeds. Anxiety and depression are other factors negatively affecting their quality of life. These were among the results of the MIND study, which aims to identify patterns of prescribed pain, anti-depressive and anti-anxiety medication and management of pain, depression and anxiety in people with haemophilia in four Nordic countries.

The results of the MIND study also show that people with haemophilia in Sweden have a substantially higher prescription of analgesics than the general population. They also have an increased prescription of neuroleptics and anti-depressants, which indicates that anxiety and depression are overrepresented in people with haemophilia. A similar prescription pattern could be seen among female carriers of the genes for haemophilia, which leads to a reduced ability of the blood to clot. These results have today been presented orally by Sobi™ at ISTH 2019: the 27th Congress of the International Society on Thrombosis and Haemostasis, in Melbourne, Australia.

Armin Reininger, Head of Medical and Scientific Affairs at Sobi, says that pain, anxiety and depression have not been extensively investigated in people with haemophilia despite the severity of these comorbidities, and associations between them have been studied even less. “Sobi is committed to liberating life for people with haemophilia. These results suggest that even in a country such as Sweden, with well-established use of prophylactic treatment and high levels of access to treatment, there is a need for further research to address knowledge gaps and enable people to live a life beyond haemophilia,” he says.

The MIND study is based on patient registry data and surveys. In this analysis, current and retrospective treatment patterns of prescribed medication in 1550 people with haemophilia in Sweden, over an 11-year period (2007-2017), were analysed to explore associations with their background and complication characteristics, and compare prescribed medication use between this group and the general population.

The study shows a substantially higher prescription of analgesics in people with haemophilia in Sweden as compared to controls; this suggests a need for increased focus on improved bleed protection and prevention of problems such as arthropathy as well as a continued focus on pain management. The increased prescription of neuroleptics and anti-depressants demonstrates that anxiety and depression are overrepresented in people with haemophilia and underscores the importance of identifying and managing the broad population including non-frequent healthcare users. A similar prescription pattern was seen in female

carriers, suggesting a need for high medical attention in this population and further research to address knowledge gaps.

**Abstract:**

- People with Haemophilia and Female Carriers in Sweden have a Higher Risk of Developing Anxiety, Depression and Pain Based on Treatment Patterns as Compared to Matched Controls: Data from a Registry Study over a Period of 11 Years: Monday 8 July. Oral Communication Session: Hemophilia Clinical 1; 10:45-12:00, Presentation # OC 32.3

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**About haemophilia A and B**
Haemophilia is a rare, genetic disorder in which the ability of a person's blood to clot is impaired. Haemophilia A occurs in about one in 5,000 male births annually, and more rarely in females. Haemophilia B occurs in about one in 25,000 male births annually, and more rarely in females. The World Federation of Haemophilia estimates that approximately 196,000 people are currently diagnosed with haemophilia A and B worldwide.[i]

People with haemophilia A or B experience bleeding episodes that can cause pain, irreversible joint damage and life-threatening haemorrhages. Prophylactic infusions of factor VIII or IX can temporarily replace the clotting factors that are needed to control bleeding and prevent new bleeding episodes.[ii] The World Federation of Hemophilia recommends prophylaxis as the optimal therapy as it can prevent bleedings and joint destruction.[iii]

**About Sobi™**
At Sobi, we are transforming the lives of people affected by rare diseases. As a specialised international biopharmaceutical company, we provide sustainable access to innovative therapies in the areas of haematology, immunology and specialty care. We bring something rare to rare diseases – a belief in the strength of focus, the power of agility and the potential of the people we are dedicated to serving. The hard work and dedication of our approximately 1050 employees around the globe has been instrumental in our success across Europe, North America, the Middle East, Russia and North Africa, leading to total revenues of SEK 9.1 billion in 2018. Sobi's share (STO:SOBI) is listed on Nasdaq Stockholm. You can find more information about Sobi at www.sobi.com.

**For more information please contact**
Paula Treutiger, Head of Communication & Investor Relations
0733 666 599
paula.treutiger@sobi.com

Linda Holmström, Corporate Communication & Investor Relations
0708 734 095
linda.holmstrom@sobi.com

[i] The WFH Annual Global Survey 2017 https://news.wfh.org/now-available-report-annual-global-survey-2017/
[ii] World Federation of Hemophilia. About Bleeding Disorders – Frequently Asked Questions. Available at: http://www.wfh.org/en/page.aspx?pid=637. Accessed on 4 July 2019.
[iii] World Federation of Hemophilia. Guideline for the management of hemophilia, 2nd edition. Available at: http://www1.wfh.org/publication/files/pdf-1472.pdf. Accessed on 4 July 2019.