

PRESS RELEASE

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New research reveals true unmet needs among people living with haemophilia

New ethnographic research released by [Sobi™](#) has shown that despite developments in approaches to treatment in recent years, people living with haemophilia (PwH) still carry burdens of the condition on a daily basis.

The study, conducted among 51 people living with haemophilia and 18 healthcare professionals found that there is still an unmet need for more flexible and personalised approaches to treatment to allow PwH to lead lives beyond the bleeding disorder.

“The research shows that most people with haemophilia still live a life far from normal. For PwH, a ‘normal life’ involves living with restrictions and regular burdens of the condition. This is a result of conservative approaches to treatment aiming to achieve basic protection rather than overcoming limitations and expanding possibilities. The study also found that current treatment approaches may not even be sufficient to deliver basic protection,” said Armin Reininger, Head of Medical & Scientific Affairs at Sobi.

UK based Clive Smith lives with haemophilia A, and hopes the findings will encourage the haemophilia community to aim higher.

“People living with haemophilia should have the right to pursue the same opportunities as everyone else. Treatment should always allow them to feel safe, to be protected from bleeds and have long-term joint health protection without feeling burdened by their condition. This is possible in today’s world - treatment plans can be fully personalised to suit individual needs and wishes, but this research shows that there is a need for us to challenge the status quo of current treatment goals together as a community,” he said.

The research was presented by Sobi at the third European Congress of Thrombosis and Haemostasis in Glasgow and again at the European Haemophilia Consortium Congress in Skopje.

For more information about haemophilia, [click here](#).

About the Ethnographic study

51 people with haemophilia (PwH) A and B , with families, and 18 healthcare professionals were included in the study. Researchers interviewed and followed PwH in day-long observations to study them in their social context – not as isolated individuals - and thereby gain a deeper understanding of the underlying reasons for different behaviours.

Main insights from the day-long observations and interviews:

- A 'perceived normality' around the condition
- Treatment was often intended to achieve baseline stability (protection), rather than to overcome limitations but even the former was not always attained;
- People developed their own mental models and care adaptations to navigate treatment uncertainty.
- Challenges were specific to life stages, though care was not necessarily tailored to each stage.

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 1,300 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.

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