During World Haemophilia Week, we caught up with Sobi's Head of Haematology, Philip Wood

Could you introduce yourself and your role at Sobi?

I am the Head of Haematology and Senior Vice President of Sobi. I have more than 20 years’ experience working within the haemophilia field. After joining Sobi in 2012, I led the launch of the first extended half-life haemophilia treatments in Europe and am currently responsible for the development of Sobi's haematology franchise.

What is Sobi's vision for the future of haemophilia?

In the summer of 2018, Sobi undertook a large-scale, pan-European ethnographic study of the lives of people living with haemophilia. This in-depth research exposed the challenges, aspirations, perceptions, behaviours and unmet needs related to life with haemophilia and inspired Sobi to create the Liberate Life vision.

Liberate Life is a positive message that represents not just our vision for the future of haemophilia, but an inspirational call-to-action for involvement from the broader haemophilia community. It is our dedication to challenging the status quo of conventional treatment methods, and to creating better possibilities through better care.

Liberate Life is based on the fundamental criteria that treatment should always allow people living with haemophilia to feel safe, be protected from bleeds, have long-term joint health protection and feel unburdened by haemophilia.

On World Haemophilia Day 2020, Sobi released the 2020 Haemophilia Index examining the quality of life for people with haemophilia in Europe. What are the main findings of your report?

The index found that European haematologists reported high levels of treatment satisfaction and physical activity among people with severe haemophilia, showing that with access to appropriate treatment, they are able to live active lives.

In Europe, Italy reported the highest levels of physical activity among people living with severe haemophilia, while Germany indicated the highest quality of life. Both Switzerland and Sweden reported the greatest patient satisfaction levels.

Globally, half of the countries featured in the index rely entirely on the World Federation of Hemophilia Humanitarian Aid Program to provide medication for haemophilia treatment.

What does that tell us about the importance of humanitarian aid for the international haemophilia community?
We know that there is still a lot of variation in access to treatment around the world. We believe that just like anybody else, people living with haemophilia should have the right to pursue the opportunities they desire in life no matter where they live.

Over the past five years, 17,223 patients have received treatment through the WFH Humanitarian Aid Program as a direct result of the donations provided by Sobi and Sanofi Genzyme. Nearly 1,400 people with haemophilia have initiated prophylactic treatment, of which 441 were under the age of four.

At Sobi, we are proud to be working with the community to help patients reach for the many possibilities that advances in care have allowed.

Have you recognised difficulties in patient’s ability to access their treatments due to COVID-19? What needs to be done in order for treatments reach the patients that need them?

Specific questions have arisen from NMOs around the supply of medicines. We understand that people living with rare and complex conditions around the world rely on the safe and secure supply of our treatments every day. As of today, Sobi is not aware of any interruption to the safe and secure production, supply and logistics of Sobi products. We remain committed to serving the rare disease community by providing timely and secure access to Sobi treatments across the globe.

During the COVID-19 crisis, we have focused on core patient support activities such as:

- Listening to patient organisations and Haemophilia treatment centres to detect signs of distress/breakdown in access to care, support them through these challenges, and ensure continuity of access to treatments.
- Creating new possibilities for PwH to engage with HCPs and ourselves via technology aided interactions ie. webinar events with NMOs, Global patients steering committee.
- Responding to challenges of accessing treatment by patients-where traditional collection from hospitals is threatened, by innovating new means of treatment access in the community.
- Conducting regular communication with NMOs and EHC to understand critical issues on a needs basis and providing support where requested.

Faced with this uncertain and changing health situation, our team at Sobi remains mobilised to continue helping health professionals to mitigate the crisis and to explore and develop new forms of digital work and education. We remain committed to working together for the well-being of our patients and healthcare professionals.
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