

## PRESS RELEASE

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### Sobi launches enhanced corporate sustainability initiative

[Swedish Orphan Biovitrum AB \(publ\)](#) (Sobi™) announces today, on [Rare Disease Day](#), the launch of an enhanced corporate sustainability programme with a strong connection to the company's strategy of providing sustainable access to treatments for rare diseases.

As part of the new sustainability strategy, Sobi has identified several focus areas that are important for both the stakeholder communities and Sobi's business. Sobi's stakeholders include the communities of patients and caregivers affected by rare diseases, the local communities around the globe in which Sobi operates, the community of companies that form the biopharmaceutical industry, shareholders and the communities of individual employees who comprise Sobi. The topics we understand to be of most importance to these communities and to the business are:

- **Responsibility:** this includes complying with all applicable laws and regulations; a key priority here is responsible tax management.
- **Compliance and ethics:** this includes acting ethically and with integrity; a key priority is patient safety and ethical practices and collaborations, including transparency of transactions with healthcare organisations and transparency of clinical trial results.
- **Value:** this includes mission-driven top concerns for stakeholder communities – sustainable access to treatments for rare diseases, and strategic research and development of new medicines.

"Sobi has a vision of becoming a global leader in providing access to innovative treatments that make a significant difference for individuals with rare diseases," said Guido Oelkers, Sobi CEO. "Sustainability is a vital part of our vision and overall corporate strategy. A sustainable business entails a commitment to responsibility for patients and employees, reduced environmental impact from operations and treatment, as well as long-term sustainable profitability so that we can continue to reinvest in developing new therapies for rare diseases and serve our communities for many years to come."

Examples of Sobi's recent progress and commitments to sustainability include:

- **Secure and sustainable supply:** Sobi provides access to 36 products across 72 countries. These products are medicines that have an important impact on patients, and in many cases are essential for life. Ensuring secure, reliable, sustainable supply of these medicines is therefore one of Sobi's highest priorities. Sobi's understanding of the complex healthcare environments across all the regions we work in has enabled supply and access to treatments whose introduction to the health system would otherwise have been delayed or prevented. Sobi also continues its long-standing commitment to provide emergency supply services to patients.

- **Sustainable access to medicines:** Sobi is committed to playing an active role in the dialogue with stakeholders, governments and healthcare systems across the world, to ensure that patients get timely and sustainable access to the medicines they need, irrespective of where they live and the level of development of their local healthcare system.

Sobi is also working with developing countries to lay the foundation for sustainable access to treatments for rare diseases, often in partnership with governments and organisations to secure long-term change. Sobi and its collaboration partner Bioverativ have pledged to donate up to 1 billion international units of clotting factor between 2015 and 2025 for people with haemophilia in developing countries to enable predictable supply of clotting factor treatment. The World Federation of Hemophilia is leading this treatment initiative, which up to the end of 2017 had provided treatment for over 15 000 people. Sobi is also taking a leading role in the [PARTNERS programme](#), recently established by the European Haemophilia Consortium, to bridge the gap between the recognised minimum haemophilia treatment recommendations and the volume of therapy available in several European countries with developed healthcare systems but highly limited budgets. Through such collaborative partnerships with national member organisations, government health systems and healthcare providers, Sobi is working actively to transform donation programmes into sustainable access. For people living with hereditary tyrosinaemia type 1 (HT-1), efforts are ongoing to secure government approval and long-term access to treatment in Eastern Europe, Asia and the Middle East. And in the US, Sobi provides financial assistance for eligible patients in need of treatment with its medicines.

- **Strategic research and development:** Sobi has set out to create a self-sufficient R&D pipeline within the coming 5-10 years. Sobi reinvests earnings into building further understanding of and in the research and development of treatments for rare disease in the core areas of Haemophilia, Inflammation and Genetics & Metabolism.

Sobi will present its Annual and Sustainability reports on 15 April 2018.

#### **Sobi affiliates increase commitments to corporate social responsibility**

In addition to the new global programme, Sobi's affiliate organisations across North America and Europe also reiterated their commitment to rare diseases and to sustainable business through actions of corporate social responsibility (CSR).

Sobi North America, for example, launched a CSR programme that includes a commitment to patient access to Sobi's products as well as initiatives designed to increase volunteerism and philanthropy within the North American operation. The organisation has established two team-wide volunteer days to provide employees with opportunities to support their communities, supplementing its existing unlimited vacation policy which

can also be used for volunteering. The affiliate also initiated its first donation/matching programme to support the Sobi team in the [US National Organization for Rare Disorders' \(NORD's\) 7,000 Mile Rare Movement Challenge](#), which seeks to raise awareness and funding for the 7,000 rare diseases identified to date.

“The Sobi North America team has always been committed to serving our communities, but this new plan adds intention and structure to our grassroots efforts, with the goal of maximising our impact,” said Rami Levin, Head of Sobi in North America. “We are also committed to ensuring the patients we serve can access the medicines we provide, and we have committed to evaluate every request for support in this area and to strive to achieve a meaningful solution.”

In the UK and Republic of Ireland (RoI), Sobi supports leading charities such as the Cambridge Rare Disease Network, CLIMB (Children Living with Inherited Metabolic Disorders) now known as Metabolic Society UK, and Findacure and over the years, many UK meetings on Rare Disease Days. Sobi also supports a number of Haemophilia voluntary groups in the UK and RoI. Neil Dugdale, General Manager of Sobi UK and RoI acts as a trustee for a new rare disease charity, Rare Disease Nurse Network (RDNN) which aims to provide specialist nurse support for those affected by rare diseases. Sobi is also a sponsor of Medics4RareDiseases which is launching today on Rare Disease Day. This educational group reaches out to medical students and doctors in training with a view to improving the rare disease patient journey and reducing the diagnostic odyssey. Sobi provides many support materials free of charge for patients whose illnesses fall within the company's therapeutic area of interest in order to raise disease awareness. Sobi has also been invited to give evidence to the All Party Parliamentary Group on Rare Disease (APPG) to help ensure rare diseases receive the government support and funding that they require.

“The Sobi affiliate in the UK and RoI has always played an active role with many communities associated with rare diseases,” said Neil Dugdale. “As Sobi aims to become a leader in rare disease, we will continue to champion the rare disease patient, as well as fight for patient access to the most innovative drugs within the UK and RoI.”

The RoI has recently become the first country in Europe to give every person with haemophilia A and B access to the newest generation of haemophilia treatments, extended half-life therapies, a demonstration of Sobi's desire to provide patient access to these innovative products.

In Italy, Sobi is supporting an international cinema festival dedicated to rare diseases – A Rare Look – described as “a real narrative journey, through cinema, in the world of rare diseases”.

In Spain, Sobi in partnership with local haemophilia organisations, held a photo exhibition and competition late last year designed to raise awareness of haemophilia, a rare bleeding disorder; after judging in Madrid, the exhibition went on tour to several major regional hospitals.

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**About Sobi™**

Sobi™ is an international speciality healthcare company dedicated to rare diseases. Our vision is to be recognised as a global leader in providing access to innovative treatments that make a significant difference for individuals with rare diseases.

The product portfolio is primarily focused on treatments in Haemophilia and Specialty Care. Partnering in the development and commercialisation of products in specialty care is a key element of our strategy. Sobi has pioneered in biotechnology with world-class capabilities in protein biochemistry and biologics manufacturing. In 2017, Sobi had total revenues of SEK 6.5 billion and approximately 850 employees. The share (STO:SOBI) is listed on Nasdaq Stockholm. More information is available at [www.sobi.com](http://www.sobi.com).

**For more information please contact**

Media relations

Charlotte af Klercker, Head of Communications & Sustainability (acting)

+46 70 873 40 95

[linda.holmstrom@sobi.com](mailto:linda.holmstrom@sobi.com)

Investor relations

Jörgen Winroth, Vice President, Head of Investor Relations

+1 347 224 0819, +1 212 579 0506

[jorgen.winroth@sobi.com](mailto:jorgen.winroth@sobi.com)