

## PRESS RELEASE

Stockholm, Sweden, 28 February 2020



Rare Disease Day February 29

### **New research uncovers the toll rare diseases take on relationships**

**According to a new survey from rare disease company Sobi, 28 per cent of people living with a rare condition, and their caregivers, say the disease has caused a relationship to end. 41 percent state that a rare disease has prevented them from starting a new romantic relationship.**

There are approximately 6,700 rare diseases affecting fewer than 1 out of 2,000 people. Approximately 350 million people around the world are diagnosed with one or more rare diseases<sup>i</sup>.

“This is the first time we have studied how rare diseases can affect relationships. We know that close relationships are a vital part of life and we believe that is particularly relevant for people living with a rare condition,” said Jennifer Cain Birkmose, Global Head of Patient Access and Community Engagement at Sobi.

28 percent of the respondents in Sobi’s study said a rare disease was the reason a relationship ended. Almost half (43 percent) said the disease has been a barrier in all their relationships, either romantic or friendship. 41 percent believed the disease has prevented them from starting a new romantic relationship.

Cain Birkmose said that the study results also highlight the effect on the people closest to those living with a rare disease.

“It’s important to keep in mind that broader networks of family, friends and care teams are also impacted. Rare Disease Day is a reminder to listen closely to the rare disease community to gain a deeper understanding of their needs, so we can then work together to raise awareness and improve treatment possibilities,” she said.

### **About the study**

- The survey was conducted online in the USA, Italy, Germany, Spain, Sweden and the UK among patients and caregivers
- Patients had to have a rare medical condition from the [National Organisation for Rare Disorders list](#).
- Caregivers had to be caring for someone with a rare medical condition from the NORD list
- Fieldwork took place from the 5<sup>th</sup> until the 13<sup>th</sup> February and 200 interviews were conducted in total
- Research was conducted on behalf of Sobi by Phoenix Marketing International

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### For more information

Rare Disease Day: [www.rarediseaseday.org](http://www.rarediseaseday.org)

Rare diseases: <https://www.rarediseaseday.org/article/what-is-a-rare-disease>

### About Sobi

Sobi is a specialised international biopharmaceutical company transforming the lives of people with rare diseases. Sobi is providing sustainable access to innovative therapies in the areas of haematology, immunology and specialty indications. Today, Sobi employs approximately 1,300 people across Europe, North America, the Middle East, Russia and North Africa. In 2019, Sobi's revenues amounted to SEK 14.2 billion. Sobi's share (STO:SOBI) is listed on Nasdaq Stockholm. You can find more information about Sobi at [sobi.com](http://sobi.com).

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<sup>i</sup> [www.agrenska.se/Sallsynta-diagnoser/](http://www.agrenska.se/Sallsynta-diagnoser/)