

PRESSMEDDELANDE

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Rare Disease Day 2021

Pandemic illuminates every day social obstacles of living with a rare condition

40 per cent of Swedes with a rare condition, or their family members, state that a relationship has ended due to a rare condition, according to a study by Swedish biopharmaceutical company Sobi. In addition, 63 per cent say that the disease has prevented them from entering a new relationship.

It has been difficult to maintain social connections during the ongoing pandemic since activities and contacts outside the home have been restricted to avoid spread of infection. For many of the 400,000 people in Sweden living with rare conditions, restrictions affecting social life and external relations can also be a part of regular life.

“When the pandemic is over, it will be important to remember that many people live with restrictions even in their everyday lives. Involuntary loneliness is a risk factor for illness, and we want to contribute to society by using the insights gained from the pandemic to support those living with a rare condition,” says Björn Berglund, General Manager Nordics and Baltics at Sobi.

Four out of ten, or 40 per cent of the respondents in Sobi’s survey in Sweden say that their rare condition has been an issue in a relationship that has ended. Half of them, 53 per cent, say that their condition has been an obstacle in their romantic relationship and 63 per cent disclose that it has prevented them from entering a new romantic relationship.

The survey also shows that family, friends, and other close relatives to those who live with a rare condition perceive that their relationships are affected.

“Our research around rare diseases usually focuses on finding and improving treatments for rare conditions, and with this survey we want to highlight how relationships are affected by having a rare condition. Rare Disease Day is a good reminder of the importance to listen and learn more about all aspects of a life with a rare condition, in order for more to be able to live life to the fullest extent,” says Björn Berglund.

There are approximately 6,000 to 7,000 rare diseases, meaning less than one person per 2,000 is affected. In Sweden, there are an estimated total of around 400,000 individuals who live with one or several rare conditions.

Information about the survey

The survey was conducted online in USA, Italy, Germany, Spain, Sweden and Great Britain and the respondents are patients with a rare disease and their family. The selection criteria includes patients with a condition on the National Organization for Rare Disorders List, and their families. The survey was conducted between February 5–13 2020 and had a total of 200 respondents in all countries with 30 of those in Sweden.

Facts about rare conditions (Source: Sobi and National Centre of Competence for Rare Diseases)

- In Sweden there are an estimated 400,000 individuals living with a rare disease.
- There are an estimated 6,000 – 7,000 rare diseases with an estimated 75 percent of them affecting children.
- The conditions are often life long, complex and mean severe disabilities.
- Individuals with rare conditions and disabilities may need between 40 and 120 different contacts with health care and social services to make everyday life work.
- Rare conditions often mean that there is inadequate knowledge within health care, social insurance services, the school system and other relevant actors.
- Only 300 rare diseases have approved treatments today.
- In Europe, a rare disease is defined as a condition that affects less than one person in 2,000, and they are often inherited, with a harmful defect in the genes that control how the body functions.

More information

About rare diseases: www.agrenska.se/sallsynta-diagnoser

About Rare Disease Day: www.rarediseaseday.org

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 1,500 people across Europe, North America, the Middle East, Russia and North Africa. In 2020, Sobi's revenue amounted to SEK 15.3 billion. 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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