

Rare Stories – Sällsynta Stories, summary

On Rare Disease Day, the 29th of February 2020, Rare Stories (Sällsynta Stories), a rare film event, was celebrated in Stockholm, Sweden!

As one of the first countries ever to celebrate Rare Disease Day in 2008, Rare Diseases Sweden has a long standing tradition of drawing attention to the lives and needs of people living with rare diseases (PLWRD) on leap day.

This year, ceremonies flagging for rare diseases were organized all over Sweden, from university hospitals to major shopping malls, aiming to both educate and inform the broad public, policy makers and politicians. One of the largest Swedish events, the film event Rare Stories, was organized in Stockholm by Rare Disease Sweden, the umbrella organisation for nearly 16.000 PLWRD, together with partners from several orphan drugs companies and Film and Tell, a company producing films that help shaping public opinions for creating change.

A unique film event

Rare Stories was a unique film event bringing together members, relatives and loved ones, clinicians, researchers, politicians, decision maker and other stakeholders. The festival was opened by the Swedish minister of health, Lena Hallengren (social democrats) and the rare disease youth advocate Scott Sjölander.

Six touching movies and three panels

During the day, six touching and straight-ahead movies were shown, telling the stories of individuals and families living with a rare disease.

Challenges and solutions for PLWRD were discussed in three panels discussions focusing on “being a relative to someone living with a rare disease”, “the long way towards diagnose” and “the future for PLWRD” and bringing together perspectives of PLWRD, relatives, clinicians, politicians and researchers.

Prizes

Community prizes were awarded by the rare disease community to Kalle Mohammar for being an inspiring young adult living with a rare disease (<https://www.kickstarter.com/projects/1530582156/kalle-och-hans-drommar>) and to doctor Karel Duchon and professor Anders Fasth for their tireless work for PLWRD, providing help and support “above and beyond” ordinary healthcare. Visitor’s prizes for best long movie was awarded to Daniel Gonçalves for his film “My Name is Daniel”.

Media

Beyond the about 150 visitors on location, with the help of broadcasting on television, radio, in print and via social media, Rare Stories achieved a social and medial reach of about 5 million people.

Swedish public surveys commissioned by Rare Disease Sweden in September 2019 and March 2020 documented an overall public educative effect of Rare Disease Day activities in Sweden that led to an increase from 46% to 49% of the Swedish public recognizing the term “Rare Disease” (“sällsynta diagnoser”).

More information about Rare Stories can be found (in Swedish) on the homepage of the event Sällsynta Stories (<https://www.sallsyntastories.org/>) and on the homepage of Rare Disease Sweden (<https://www.sallsyntadiagnoser.se/verksamhet/sallsynta-dagen/>) and (<https://www.sallsyntadiagnoser.se/in-english/>) in English.