

Rare diseases facts

A disease is qualified "rare", when it has got a low frequency or appears rarely in a population.

In Europe a rare disease is defined to occur in less than 1 per 2.000 people.

It is estimated that there are about 7.000 known rare diseases in the world.

Rare diseases are an important public health problem, because they concern millions of people in Europe. It can be assumed that nearly 5% of the European population are suffering from a rare disease.

Rare Disease Day is an awareness event that takes place every year on the last day of February, February 28 or February 29 in Leap Years

80% of rare diseases are genetic. They caused by mutations (changes) in a single gene.

By now 5% of rare diseases have an approved treatment.

Most rare diseases start in childhood.

People who have a rare disease wait on average 6 years to get an accurate diagnosis.

The slogan for rare diseases in 2023 is: Alone we are rare, together we are strong.