RARE DISEASE FACTS

1 in 10 Americans has a RARE DISEASE. 30 million people have a serious, lifelong condition. More than half are children.

Holding hands, they would circle the globe about 1.5 times.

What is a RARE DISEASE? Any disease, disorder, illness or condition affecting fewer than 200,000 people in the United States is considered RARE.

7,000 RARE DISEASES exist, and fewer than 500 have FDA-approved treatments.

ONLY 5% of RARE DISEASES have treatments. Patients with RARE DISEASES are frequently misdiagnosed or undiagnosed.

80% of RARE DISEASES are genetically based.

Many RARE DISEASES result in premature death of infants & young children or are fatal in early adulthood.

What can you do to help?

Visit us and Donate at: rarediseases.org
About 1/3 of all NEW drugs approved by FDA now are for RARE DISEASES, and in 2015 it was 47%.

There are 100 types of cancer. Approximately 50% of people with cancer are battling a RARE cancer. RARE cancers include brain, pancreatic, ovarian, thyroid, and stomach cancers; leukemia and lymphoma; and all pediatric cancers.

There are more Americans who live with a RARE DISEASE than ALL of those who have either HIV, Heart Disease or Stroke.

Families & private foundations provide about 3% of ALL medical research funding in the U.S.

75% of NORD Members are actively funding RARE DISEASE medical research.


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