

RareInsights RARE DISEASE FACTS



What is a RARE DISEASE

Any disease, disorder, illness or condition affecting **fewer than 200,000** people in the United States is considered RARE.¹

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Americans has a RARE DISEASE

30 million people have a serious, lifelong condition.

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Holding hands, they would circle the globe about 1.5 times

More than half are children



RARE DISEASES exist, and fewer than 500 have FDA-approved treatments²

of RARE DISEASES have treatments.²

Patients with RARE DISEASES are frequently misdiagnosed or undiagnosed.

80% of RARE DISEASES ARE GENETICALLY BASED.2





Many RARE DISEASES
result in premature
death of infants & young
children or are fatal
in early adulthood.²

What can you do to help?

Visit us and Donate at: ∜ rarediseases.org







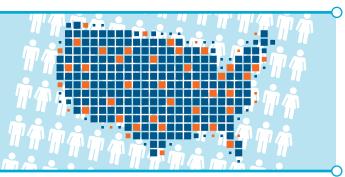




There are 100 types of cancer. Approximately 50% of people with cancer are battling a RARE cancer.

RARE cancers include brain, pancreatic, ovarian, thyroid, and stomach cancers; leukemia and lymphoma; and all pediatric cancers.4

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 of ALL medical research funding in the U.S.⁵



of NORD Members are actively funding RARE DISEASE medical research.

The content of this report has been obtained from government, nonprofit and industry sources. The report is current as of 6/14/2016. 1.) FDA Office of Orphan Products Development (00PD). 2.) "Rare Diseases and Orphan Products: Accelerating Research and Development" Committee on Accelerating Rare Diseases Research and Orphan Product Development Board on Health Sciences Policy. 3.) U.S. FDA Novel New Drug Summaries (2011-2015); calculated average from each report's data. 4.) Memorial Sloan Kettering Cancer Center's Cycle for Survival website; https://www.cycleforsurvival.org/about-cycle-survival; June 2016. 5.) The Financial Times Limited 2016; "Private foundations: Searching for the sweet spot" by Sarah Murray, 6/24/2016, http://www.ft.com/cms/s/0/57c46446-2d51-11e6-bf8d-26294ad519fc.html#axzz4DjtDphuB. 6.) NORD Membership Survey; taken 2014.