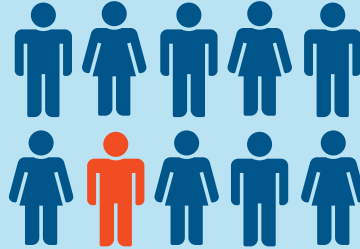


# RARE DISEASE FACTS

**1 in 10**

Americans has a **RARE DISEASE**

30 million people have a serious, lifelong condition.



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



**More than half are children<sup>1</sup>**

## What is a RARE DISEASE ?

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



**7,000**

RARE DISEASES exist, and **fewer than 500** have FDA-approved treatments<sup>2</sup>

**ONLY 5%** of RARE DISEASES have treatments.<sup>2</sup>

Patients with RARE DISEASES are frequently misdiagnosed or undiagnosed.

**80%** of RARE DISEASES ARE GENETICALLY BASED.<sup>2</sup>



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

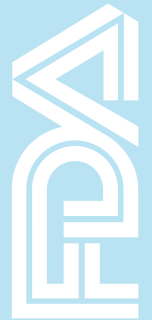
**What can you do to help?**

Visit us and Donate at:  [rarediseases.org](http://rarediseases.org)

# RARE DISEASE FACTS



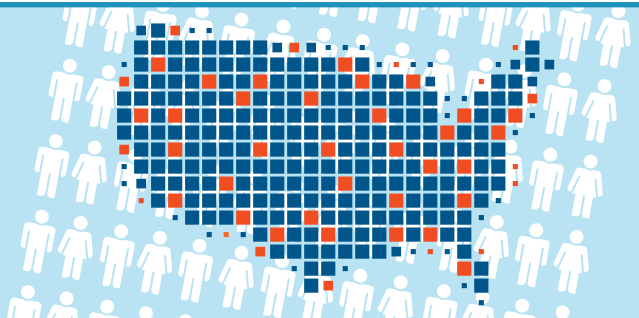
About **1/3** of all **NEW** drugs approved by FDA now are for **RARE DISEASES**, and in 2015 it was **47%**.<sup>3</sup>



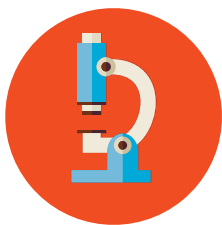
There are **100** types of cancer. Approximately **50%** of people with cancer are battling a **RARE** cancer.

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

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.<sup>5</sup>



**75%** of NORD Members are actively funding **RARE DISEASE** medical research.<sup>6</sup>

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 (OOPD). 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.

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