

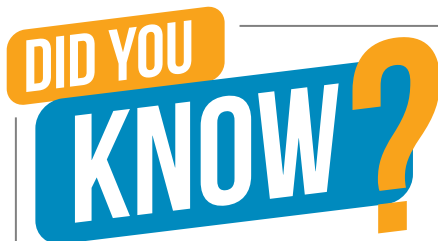
Get to Know the Facts About Rare Disease



From small towns to large cities, rare disease is an **urgent public health challenge**, and no family is immune.

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



There are more than **10,000 known** rare diseases.³ Fewer than 5% have an FDA-approved treatment.⁵



1 in 10 Americans have a rare disease.⁴

That is more than **30 million** of our loved ones, friends, colleagues and neighbors.²



Approximately 80% of rare diseases have a genetic origin.⁶

No individual or family is immune from a rare disease.



An estimated **15 million children**⁷ in the U.S. have a rare disease, and sadly, 30% will not live to see their fifth birthday.⁸



Direct medical costs for people with rare diseases are **3-5 times higher** than those for non-rare diseases. Yearly, they amount to an estimated **\$400 billion**, which is comparable to cancer and Alzheimer's.⁹



It can take **five or more years** on average for a person with a rare disease to get an accurate diagnosis.¹⁰



Founded in 1983, the National Organization for Rare Disorders (NORD®) is the **trusted voice and leading patient advocacy organization** for more than 30 million Americans with rare diseases.

¹ [fda.gov/patients/rare-diseases-fda](https://www.fda.gov/patients/rare-diseases-fda)

² ojrd.biomedcentral.com/articles/10.1186/s13023-018-0936-x

³ ncats.nih.gov/research/our-impact/our-impact-rare-diseases

⁴ [ibid](#)

⁵ ojrd.biomedcentral.com/articles/10.1186/s13023-023-02790-7

⁶ ojrd.biomedcentral.com/articles/10.1186/s13023-022-02217-9

⁷ ojrd.biomedcentral.com/articles/10.1186/s13023-022-02299-5

⁸ ncbi.nlm.nih.gov/pmc/articles/PMC10049067

⁹ ojrd.biomedcentral.com/articles/10.1186/s13023-021-02061-3

¹⁰ <https://genomemedicine.biomedcentral.com/articles/10.1186/s13073-022-01026-w>

