

Rare Disease Facts



It is estimated that **15 million children**⁵ in the U.S. have a rare disease and sadly, 30% will not live to see their fifth birthday.⁶

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, heart failure and Alzheimer's.⁷

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 diseases³ and fewer than 5% have an FDA-approved treatment.⁴



1 in 10 Americans have a rare disease.

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



In 1983, NORD's founders pioneered the passage of the Orphan Drug Act, the **world's first law incentivizing drug development for rare diseases**. Everyday, NORD continues to fight and protect incentives for rare disease drug development.



Most rare diseases are genetic or have a genetic component. No individual or family is immune from a rare disease.³

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](https://www.ojrd.biomedcentral.com/articles/10.1186/s13023-018-0936-x)
³ [ncats.nih.gov/research/our-impact/our-impact-rare-diseases](https://www.ncats.nih.gov/research/our-impact/our-impact-rare-diseases)
⁴ [ojrd.biomedcentral.com/articles/10.1186/s13023-023-02790-7](https://www.ojrd.biomedcentral.com/articles/10.1186/s13023-023-02790-7)
⁵ [ojrd.biomedcentral.com/articles/10.1186/s13023-022-02299-5](https://www.ojrd.biomedcentral.com/articles/10.1186/s13023-022-02299-5)
⁶ [ncbi.nlm.nih.gov/pmc/articles/PMC10049067](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10049067)
⁷ [ojrd.biomedcentral.com/articles/10.1186/s13023-021-02061-3](https://www.ojrd.biomedcentral.com/articles/10.1186/s13023-021-02061-3)

