**Rare Disease Facts**

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

It is estimated that 15 million children⁵ 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

1 in 10 Americans have a rare disease.

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

There are more than 10,000 known rare diseases³ and fewer than 5% have an FDA-approved treatment.⁴

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

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.

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
2. ojrd.biomedcentral.com/articles/10.1186/s13023-018-0936-x
4. ojrd.biomedcentral.com/articles/10.1186/s13023-023-02790-7
5. ojrd.biomedcentral.com/articles/10.1186/s13023-022-02299-5
6. ncbi.nlm.nih.gov/pmc/articles/PMC10049067
7. ojrd.biomedcentral.com/articles/10.1186/s13023-021-02061-3

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