

OKLAHOMA RARE DISEASE IMPACT

How many people in Oklahoma have rare diseases?

According to the National Organization for Rare Disorders, there are over 10,000 rare diseases that together affect more than 30 million Americans. This equates to 1 in 10 Americans, or one on every elevator and four on every bus which equates to approximately **395,000 Oklahomans** based on the 2020 Census reported population of 3,959,353 (https://data.census.gov/profile/Oklahoma?g=040XX00US40_). Putting this into perspective, the number of Oklahomans affected by rare disease is approximately equal to the populations of Norman, Edmond, Moore, Lawton and Tahlequah COMBINED (population data gathered from the 2020 Census data).

1 in 10

Who is affected by rare disease?

A rare disease is a condition that affects fewer than 200,000 Americans. Many—but not all—rare diseases are genetic. Nearly 80% of rare disorders are genetic. Some are apparent at birth while others do not appear until much later in life. Approximately two-thirds of Americans with rare diseases are children. **We are all connected to someone who has a rare disease.** Rare diseases are an important public health concern. Every childhood cancer is also considered a rare disease. Rare Disease patients wait an average of 6-8 years (some many more) before receiving a confirmed diagnosis and the diagnostic journey is costly to both families and state health systems.

Care

Patients and families report seeing an average of 7 specialists. Many times, rare disease patients have to travel out of Oklahoma for care, due to specialist shortages, which means Oklahomans are spending their money in other states. **95% of rare conditions do not have an FDA approved treatment which is challenging for care and management of symptoms.**

Financial Impact

There are many ways rare disease impacts patients and families financially. A few examples are loss of income due to losing a job or inability to find employment due to disability, loss of income due to caregiving (loss of tax revenue for the state), prescription and equipment costs, etc.

What is the Impact on the Average Rare Disease Family?



Impact on the Average Rare Disease Family data is from The EveryLife Foundation for Rare Diseases. (2021). The National Economic Burden of Rare Disease Study https://everylifefoundation.org/wp-content/uploads/2021/02/The_National_Economic_Burden_of_Rare_Disease_Study_Summary_Report_February_2021.pdf

