RARE FAMILIES, REAL LIFE

RARE DISEASE CAREGIVERS ARE UNSUNG HEROES

Caring for someone with a rare disease touches all aspects of life.



🛗 8.9 years

average time a rare caregiver spends caring for their loved one

Over 21% are caregivers for 15+ years



RARE DISEASE

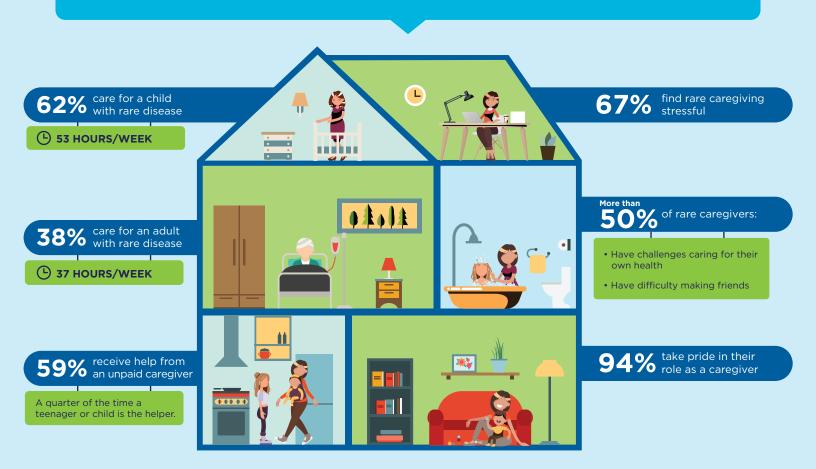
Any condition affecting less than 200,000 people in the U.S. There are ~7,000 rare diseases. Most do not have FDA-approved treatments



RARE CAREGIVER

Family or friend who provides unpaid care to one of the 25 million Americans living with rare diseases

RARE CAREGIVING IS A FULL-TIME UNPAID JOB



Rare caregiving impacts their home, school, and work lives — and the healthcare system is challenging.

