



Navigating Your Child's Rare Disease Diagnosis

If your child has a rare disease, you are not alone!

- 6,000 to 8,000 rare diseases exist, and some may have no formal name.
- Rare diseases affect 6% to 10% of the global population, and 1 in 10 Americans have a rare disease.
- Approximately 2/3 of Americans with a rare disease are children.
- Average time for diagnosing a rare disease in the U.S. is 7.6 years. Since they are rare, little information is typically known about the disease making them difficult to diagnose.
- Studies indicate that once the child's disease is diagnosed the caregiver's level of stress decreases.
- About 75% of rare diseases affect the child's quality of life from birth. In many cases, the care needed for a child with a rare disease can span through their lifetime.
- Receiving a diagnosis can be overwhelming to a caregiver because it can change every aspect of family life, including future plans.

Online Resources exist to support families:

Genetic and Rare Disease Information Center (GARD)

<https://rarediseases.info.nih.gov/>

National Organization for Rare Disorders (NORD)

<https://rarediseases.org>