

BARRIERS TO RARE DISEASE DIAGNOSIS, CARE AND TREATMENT IN THE US:

A 30-Year Comparative Analysis



NORD® led a study, published in 1989, to identify the barriers and facilitators of rare disease diagnosis, care, and treatment in the United States. In 2019, NORD conducted a second study to comparatively assess how the experiences of rare disease patients have changed over time.

88%



of people reported that they would consider using an investigational treatment in 2019, **compared to 62% in 1989**

36%



of respondents had been diagnosed with a rare disease within the first year in 2019, **compared to 51% in 1989**

17%



of individuals in 2019 had already relocated or were considering relocating to access care for their rare disease, compared to just **8% in 1989**

16%



of individuals in 2019 reported that they had already participated in a clinical trial for their rare disease, **compared to 12% in 1989**



2%

of respondents in 2019 reported that they did not have health insurance **versus 9% in 1989**

Download the full report: bit.ly/3lOz5Gk

Alone we are **rare**. Together we are strong.®

NORD: Fighting for the rare community every day for nearly 40 years. NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient support services. NORD Headquarters: 55 Kenosia Avenue, Danbury, CT 06810 Tel: 203.744.0100 Fax: 203.263.9938 ©2020 NORD. All rights reserved. NORD®, its icon, tagline and Rare Insights® are registered trademarks of The National Organization for Rare Disorders. NORD is a 501(c)(3) charity organization. NRD-2088



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