Building Better Evidence:

How High-Quality Data Advances Rare Disease Research

This free online course guides learners through the basics of rare disease health data, preparing and empowering patients and advocates to make informed decisions, advocate effectively, and contribute to research.

Now available on RareEDU® at Learn.RareDiseases.org

How Patient Data Supports Drug Development

In this module, explore how patient-generated data can inform drug development, clinical trial design, and research priorities.





Why Recruitment and Retention Matter in Rare Disease Research

Learn how recruitment and retention affect rare disease research, why it is important for study participants to reflect the broader disease community, and how patient advocacy organizations play an important role in these efforts.

What is Good Data and Why Does it Matter?

Through examples from rare disease research, explore how data collection practices, retention of study participants, and study design all can affect the quality of clinical trial results.



RDCA-DAP®
Rare Disease Cures Accelerator
Data and Analytics Platform

CRITICAL PATH INSTITUTE

NORD®
National Organization for Rare Disorders