NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

Sample Social Media Posts

NORD’s new data literacy course is a new, free resource that can help your patient and caregiver community better understand the power of their data and how to harness that data to advance rare disease research and care. We hope these social media posts help you share this resource with your community!

Facebook or LinkedIn: General Overview

Understanding your health data shouldn’t be overwhelming.

That’s why our partners at the National Organization for Rare Disorders (NORD) created a free course, “From Records to Research: Making Sense of Health Data for Rare Diseases” to help people living with rare diseases learn:

- How data from doctor visits, devices, and daily life is connected
- How that data is protected and used in research
- How that data helps advance rare disease care and treatment

Available now, this self-paced course is mobile-friendly and designed for anyone (no technical background needed!). Take the course today and feel more confident navigating care, using digital tools and apps, and considering research participation.

Learn more at https://learn.rarediseases.org/courses/from-records-to-research-making-sense-of-health-data-for-rare-diseases/

#RareDisease #HealthData #PatientAdvocacy

Facebook or LinkedIn: Patient-Focused

Your health data is powerful. It not only helps doctors provide better care but also fuels research that can lead to new treatments for rare diseases.

That’s why the National Organization for Rare Disorders (NORD) created “From Records to Research: Making Sense of Health Data for Rare Diseases,” a free, online course designed to help rare disease patients, families and advocates understand how health data works and why it matters.

Take the course and share it with your community to support informed, empowered decision-making. Start here: https://learn.rarediseases.org/courses/from-records-to-research-making-sense-of-health-data-for-rare-diseases/

#RareDisease #HealthData #DataLiteracy

Instagram

Whether you or a loved one are living with a #RareDisease, health data is everywhere – in medical records, apps, and medical devices. But what does it all mean? And how can it be used to improve care and research?

Discover the answers in a free, self-paced course from the National Organization for Rare Disorders (NORD), which will help you:

- Understand where health data comes from
- Learn how its protected and used in research
- Gain confidence navigating your care with the help of digital tools

Available for everyone, everywhere, today! Tap the link in our bio to get started.

#HealthData #PatientEmpowerment

[Link in bio: https://learn.rarediseases.org/courses/from-records-to-research-making-sense-of-health-data-for-rare-diseases/]

Twitter/X

Your health data tells a story, and it can improve care and advance #RareDisease research. @RareDiseases offers a free, 90-minute course so you can learn:

- Where health data comes from
- How its protected, shared and used
- Why it matters for patients and families

Start here: https://learn.rarediseases.org/courses/from-records-to-research-making-sense-of-health-data-for-rare-diseases/

#DataLiteracy #PatientEmpowerment