

IAMRARE[®] Program

National Organization for Rare Disorders (NORD[®])



ADVANCING PATIENT-CENTERED RESEARCH

What if we could accelerate research for rare diseases?

We can – through the power of the IAMRARE[®] program.

IAMRARE[®] Overview

Developed by the National Organization for Rare Disorders (NORD[®]), the IAMRARE program is designed to meet your current and future research needs. Whether you are starting out with a patient registry, launching your first natural history study or establishing a multi-stakeholder collaborative for your disease, our software and support services can be customized to meet your research goals.

Key Software Features

- **EASY-TO-USE:** Secure, mobile-friendly, cloud-based platform creates a simple user-experience.
- **CONFIGURABLE CONSENTS:** Allows for complex, multivariate customization.
- **MULTILINGUAL:** Supports English, Spanish and French, with additional languages to be added.
- **ROLE-BASED:** Functionality and access privileges associated with user roles.
- **DATA STANDARDS:** Supports the capability to include both industry standard/validated surveys and disease-specific customization.
- **DATA SHARING:** Facilitates sharing secure de-identified data to collaborate with researchers.

Program Highlights

- **PATIENT GROUP OWNED:** Patient advocacy groups own and control their data.
- **SUPPORT, TRAINING & MENTORSHIP:** Our subject matter experts provide hands-on support, IRB-reviewed templates and other resources to help organizations successfully implement and manage their program.
- **WEB-BASED EDUCATION SERIES:** “Rare Disease Drug Development: What Patients and Advocates Need to Know,” developed by NORD through a collaborative grant from the FDA
[Critical Path Public-Private Partnerships Grant Number U18 FD005320 from the US Food and Drug Administration].
- **PEER NETWORK:** Connect and learn from researchers and patient advocacy groups that are part of the IAMRARE[®] program community.

What Others Are Saying

“Our IAMRARE registry currently contains seven surveys, 2,000 registered users and became the anchor of PDSA’s research program.”

- *Caroline Kruse, President & CEO, Platelet Disorder Support Association (PDSA)*

About IAMRARE[®]

(As of 2023)



50+

patient-powered
natural history studies



18,000+

Enrolled participants



Representing

75+ rare
diseases



25+

peer-reviewed
publications

Learn more
and sign up at
iamrare.org



ABOUT NORD

Since 1983, NORD has fought to improve the health and well-being of people with rare diseases by driving advances in care, research and policy. We’re an independent and bipartisan nonprofit dedicated to reimagining a future where every person with a rare disease and their families live their best lives.



rarediseases.org

Alone we are rare. Together we are strong.[®]

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