RARE DISEASES NEED UNIQUE SOLUTIONS AND TOOLS

Patient-powered natural history studies are transforming how individuals and their caregivers inform and shape medical research and translational science for rare diseases.

NORD’s IAMRARE® Registry Platform is designed with input from patients, organizations and rare disease experts. This easy-to-use system allows organizations to rapidly launch a high-quality, customized registry that collects research-grade, longitudinal natural history data.

IAMRARE PLATFORM FEATURES:

• NORD’s Registry Platform utilizes a cutting-edge, cloud-based design that is mobile-friendly, secure and easy-to-use.
• Responsive and adaptive survey design enhances the participant experience and enables natural history data tracking.
• Automated survey reminders encourage long-term participant engagement.
• Role-based permissions allow for flexible project management.
• Data visualization tools provide participants with real-time aggregated data for comparison to other patients.
• Sub-studies encourage multistakeholder collaboration and minimize community fragmentation.
• Study resources include standardized surveys and access to rare disease Institutional Review Board (IRB) expertise.

AS OF 2021:

40+ rare conditions
125,000+ survey submissions received to date
13,600+ enrolled participants

FOR MORE INFORMATION ABOUT THE IAMRARE REGISTRY PLATFORM:

Visit: rarediseases.org/iamrare-registry-program
Email: research@rarediseases.org
Donations to NORD may be made by contacting orphan@rarediseases.org.