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 launch a high-quality, customized registry that collects research-grade, longitudinal natural history data.

IAMRARE PLATFORM FEATURES:

- NORD's Registry Platform utilizes a 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.
- Patient Advocacy Group sponsors maintain ownership of the data in their registry.
- Sub-study capability encourages multistakeholder collaboration and minimizes community fragmentation.

SCAN THE QR CODE TO LEARN ABOUT THE REGISTRY PLATFORM

AS OF 2022:

45+ **rare** conditions

165,000+ **survey submissions** received to date

16,000+ **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**.

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Alone we are rare.
Together we are strong.®