How It Works

Your Data—Paving the Way to Advance Rare Disease Treatment

It's Your Data—You Control Access
- No cost to you
- Easy-to-use online data collection portal
- You own and control your data at all times
- Full privacy and security
- Helps advance discovery, diagnosis, treatment
- A non-profit built by patient advocates for patient advocates

Standardization Makes Your Data Research-Ready
- Data standardization—By disease, category, phenotype, genotype, location and 100+ other data points—all expert reviewed
- Data access—You decide what information is shared
- Data identity—You can remain anonymous
- Data collection—Intuitive dropdown menu, mobile-friendly
- Data links—Will merge data from multiple sources: medical records, wearables, biosamples, genome sequencing

Gives Researchers Data They Need—Reimagining Data Sharing
- Opens up siloed data
- Supports collaborative research
- Best-in-class data security
- Allows researchers to analyze data from different sources
- Supports research growth for faster cures and treatments
- Levels the playing field: lower cost, existing platform

Right Data for the Right Researchers at the Right Time
- Researchers—ID biomarkers, access to research ready data, analyze data sets together
- Academia—Access to Natural History Data for early R&D
- Biopharma—Has direct access to patients for clinical trials
- Industry—Clinical trial recruiting by phenotype & disease, opportunity to repurpose drug treatments
- Clinicians—Gain insight for treatment strategies
- The World—Faster development of future treatments and cures

Categories of Data Collected
- Demographic
- Family History
- Quality of Life
- Care
- Treatments
- Communications
- Diagnoses
- Physical
- Patient-Reported Outcomes
- Medications

We Provide Guidance—Every Step of the Way
- Support & services for any-size patient group: One patient or many
  - Assistance with data collection
  - Consent guidance
  - Patient enrollment
  - Educational resources and tools
  - “How-to” guides
  - Webinars
  - Videos
- Whole genome testing available, as needed
- Governance that ensures the data has value and is fully usable

A Platform for Rare Disease Data Sharing

More Patients + Right Data + Opportunity to Share = Faster Cures