

# HOMOCYSTINURIAS

## DATA COLLECTION PROGRAM

STRENGTH IN NUMBERS

### THE FACTS

The Homocystinurias Data Collection Program (HDCP) enables the comprehensive collection of data so we can accelerate research and drive medical advancement for the homocystinuria community. Data is critical in driving medical advancements for the HCU community and your participation in the HDCP is one of the most important and critical efforts you can do. By registering, being counted, and answering questions about how homocystinuria has affected you, you can help researchers better understand the disorder and develop future treatments and cures.

#### WHO CAN SIGN-UP?

- Anyone with one of the homocystinurias or their caregiver.

#### WHAT DO I NEED?

- A computer, tablet, or phone with internet connection.
- An email address.

#### WHAT IF I NEED HELP?

- Access the User Guide or [support@rare-x.org](mailto:support@rare-x.org) for questions.

#### WHAT KIND OF INFORMATION IS COLLECTED?

- Basic demographics
- Health and treatment history.
- Family history.

#### WILL MY INFORMATION BE PRIVATE?

- Yes. Your de-identified data will only be shared with those whom you want to have access to it, and only for reasons you determine are appropriate.

#### WHO OWNS THE DATA?

- Patients and caregivers who contribute data to the HDCP own and manage their data. They decide who has access to it and how it's shared.

#### DO I NEED TO UPDATE MY INFORMATION?

- Yes. Update annually or if symptom change. You will be notified of new surveys.

#### CAN I STOP BEING PART OF THE PROGRAM?

- Yes. You can stop taking part at any time for any reason.

### WHY REGISTER?



ENHANCED DATA TO ADVANCE RESEARCH



BETTER UNDERSTANDING OF DISEASE



ACCELERATING THE DEVELOPMENT OF NEW TREATMENTS



IMPROVED HEALTH OUTCOMES FOR PERSONS WITH HOMOCYSTINURIA

CONTRIBUTE TO A **BRIGHTER** FUTURE FOR HOMOCYSTINURIA

For more information or to register visit: <https://homocystinuria.rare-x.org>