

Contact Register



Did you know that just under one year ago we launched our contact register?

What is the contact register?

The contact register is a secured private survey that allows you to share information on you or your family member with HCU with HCU Network America (Via Danae' Bartke, Executive Director). This includes where you are from, your relationship to homocystinuria, the patient's birthdate, gender, their exact diagnosis (e.g. CBS, cobalamin, or MTHFR), how they were diagnosed, and if the patient was diagnosed through newborn screening. This information is kept confidential and will not be shared unless you give us permission to do so. By registering, you will be able to identify other affected patients in your state and request their contact information, and you will be able to access information posted over time that can only be shared with the patient community. (For example, we may have webinars that the expert presenter does not want to be publicly available, but is willing to share with the HCU community.)

What will this information be used for?

HCU Network America strives to inform and provide resources for patients and families, create connections, and support advancement of diagnosis and treatment of HCU and related disorders. In order to succeed in our mission, the input you provide helps us plan events, develop resources and educational tools, and to help better to insure that everything is being done to guarantee timely and accurate diagnosis from birth. It also allows us to have informed conversations with doctors, pharmaceutical companies, and law makers. Your information helps us understand the landscape better so we can better advocate for you!

How do I participate?

The contact register form takes approximately 3-5 minutes to complete. You can find the form either by visiting our website and clicking on the "Contact Register" tab, or you can fill it out by going directly to: <https://hcunetworkamerica.org/contact-register/>

Or, fill out the form on the back and leave it in the box at the front desk labeled Contact Register

Your full name (First and Last)

Your phone number

(___) ___ - ____ - ____
Your Email address

Your address:

City:

State:

Zip code:

Relationship to HCU: (Circle one)

Patient / Parent / Caregiver

Patients name (First and Last) (if different from above)

Date of birth (MM/DD/YYYY) __ / __ / ____	Gender: (Circle one) Male or Female	Age at Diagnosis:	Diagnosed by Newborn Screening (Circle one) Yes / No
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Type of HCU (Circle one)

Classical HCU (CBS deficiency) / MTHFR / Cobalamin If Cobalamin, which one: _____

Type of Diagnosis (Circle one)

Clinical Diagnosis / Biochemical Diagnosis / Genetic Diagnosis

Are there any other individuals in the family that have one of the homocystinurias: Yes / No
Provide names, birthdate, gender, age at diagnosis, and if they were diagnosis by newborn screening,

Do you wish to participate in the patient directory: Yes / No

If yes, please select areas you wish to share to help you connect with other affected families:

Diagnosis, State, Year patient was born, Email, Phone Number

Do you wish to sign up for the HCU E-News (Monthly newsletter) ? Yes/ No

By signing here, you are acknowledging that the information you provided is correct.

Signature: _____

Date: _____