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Dear HCU Community,

As we near the end of 2023, I wanted to take a moment to express my deepest gratitude for your continued support and generosity throughout the year. Your contributions as a loyal HCU Network America donor directly impact the lives of people born with homocystinuria and enable the organization to help families navigate their condition and advocate for better practices.

HCU Network America is here to help this special group of people with the support and resources they need to navigate daily life. But we can't do it without your help! As a 501(C) (3), we need your donations, which are tax deductible, to continue with our mission and meet our goals. Your contribution can make a huge difference in the lives of all HCU patients and their families.

We would like to share an excerpt from one family's story:

*When Amy was still a young child and before receiving a proper diagnosis, one neurologist suggested that she might be having "mini-seizures" when it appeared that she was staring into space. She had an abnormal EEG in the office, showing micro-seizures when provoked, but a 72-hour video EEG was normal. She continued to walk with severe "in-toeing" but the pediatric orthopedic thought she would grow out of it. Similarly, her pediatrician was unconcerned. In April of 2020, Amy had her first focal seizure while on a walk with her dad. She collapsed and was staring at the sky and was unresponsive to her dad's attempt to get her attention. After about 3-4 minutes, she came to, and he was able to support her enough to get her home. She was diagnosed with epilepsy and began taking medication to control the seizures. We also had her tested for autism, and she was diagnosed with that in 2021. A few months later she had another seizure during which only half of her body was seizing. There is some debate among her doctors as to whether this was actually a stroke. Around this time her unusual gate became more pronounced. In early 2022 we did genetic testing and learned about the Severe MTHFR deficiency. Her homocysteine level was over 200. It is better controlled now, with her numbers between 70-80. However, in May of 2023, Amy told us that she was having trouble seeing and that she was seeing "dots". After a visit to a retina specialist, we were told that her optic nerve was swollen and that we should take her to the ER. She ended up having a spinal tap to relieve the intracranial hypertension.*

*It is hard to write about how having a child with special needs impacts the entire family, although the effects are considerable. We struggle to practice patience, with our children and ourselves, knowing that we are all experiencing a sense of loss. Our other children have had to be independent, and while ultimately this may benefit them in some ways, losing time with parents because they are busy with caretaking and the logistics that come with frequent therapies and doctors' appointments will no doubt have impacted them, as being independent and being forced to be independent are very different situations. We are so proud of Amy. She is our HCU hero because she demonstrates strength on a daily basis when she takes her medicine and suffers from its side effects without complaint. She has accepted her condition with grace and by example, teaches us to practice patience and inclusivity.*

HCU Network America was there to support this family at one of the most devastating times in their life. Since our inception in 2016 we have communicated with metabolic clinics all over the country to reach out to new patients and provide them toolkits which are filled with helpful tips and guidelines for living with HCU. We also financially support research that can help find new treatments!

Here are some of the highlights that your donations helped with over this past year:

- Created over a dozen resources to aid those living with HCU in their transition to adulthood.
- Expanded our NORD Medical Assistance Program to cover medical formula in addition to low protein foods.
- Hosted 3 round table discussions with newborn screening stakeholders across the country with over 80 participants. Here we shared problems in our newborn screening system and potential solutions.
- Published our first paper with data from the HCU Data Collection program, powered by Rare-X.
- Presented a poster on *Understanding the Burden of Classical Homocystinuria (HCU) from the Patient's Perspective: A Qualitative Study* at the annual symposium for the Society for the Study of Inborn Errors of Metabolism (SSIEM).
- Awarded our first grants for Cobalamin G and Severe MTHFR
- Hosted an Externally Lead, Patient Focused Drug Development (ELPFDD) meeting with key stakeholders, including the FDA.

Our goal this year is \$50,000. Thanks to an anonymous donor, any funds you donate up to December 31, 2023 will be matched up to \$25,000. In addition, if your employer matches charitable donations, they will match those too! If you personally know a patient with HCU, you can donate in their honor. We need your help, and appreciate **any** donation.

Take a minute to look at our website to see what we are up to and meet some of our “heroes“: <https://hcunetworkamerica.org>. You can donate through our website or by mail.

Thank you once again for your unwavering support. Together, we can make a lasting impact and bring about positive change in the lives of those who need it most. Wishing you and your loved ones a joyful holiday season and a prosperous New Year.

With heartfelt gratitude,

*Danae' Bartke*

Danae' Bartke

HCU Network America, Executive Director

**Donor levels:**

- **Leadership Circle** - \$5,000 or more  
Donor's name, HCU Patient's name and photo on homepage of website, along with certificate donation
- **HCU Champion** - \$1,000 or more  
Donor's name, HCU Patient's name and photo on HCUNA donation page along with donation certificate
- **HCU Supporter** - \$500 or more  
Donor's name, HCU patient's name on website, along with a donation certificate
- **HCU Ally's** - \$100 or more
- Donor's name and HCU patient's name listed on website

4 ways to donate:

1. Use the enclosed slip and envelope
2. Go to <https://bit.ly/donate-hcu>
3. Text HCU2023 to 44-321
4. Scan the QR Code



### HCU Network America Annual Giving

I am pleased to enclose my tax-deductible contribution

Check Enclosed  Visa  MasterCard  Discover  AMEX

Credit Card # \_\_\_\_\_ Expiration Date \_\_\_\_\_ Security Code \_\_\_\_\_

Signature \_\_\_\_\_

Name as it appears on Credit Card \_\_\_\_\_

Billing Address for Credit Card \_\_\_\_\_

Donor Level or other amount: \_\_\_\_\_

In memory or honor of \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Please send me more information about HCU Network America

***Thank you for supporting homocystinuria community!***

