



HCU Network America

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We have seen the reopening of the country in many ways throughout 2021, along with some set backs. We are grateful for the scientific advances that allowed for a vaccine to protect our vulnerable population. Despite many positive advances we recognize that challenges remain that affect your lives. We sincerely hope you have been able to successfully manage these challenges.

These times are extra demanding for people with unique medical needs and special diets, who spend time at clinics and waiting for life giving medical supplies. People with HCU must balance all the variables in their lives that affect their health and that is tough, especially this year, and can sometimes seem overwhelming.

HCU Network America is here to help this special group of people with the support and resources they need to navigate daily life. We are proud of the reach we have and the way these communities have knit themselves together. 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. What you do to help us can make a huge difference in the lives of all HCU patients and their families.

We would like to share a story of a family's journey of diagnosis.

*Our son was born in the spring when flowers and trees are coming back to life after a long, cold winter. Just like the excitement we feel when we see the beautiful world we live in blooms, our son brought incredible joy and happiness to our family. As our second child, we had experience with a newborn already and began to have concerns early on in his life. He slept all the time, he struggled to latch and nurse and had low muscle tone. Despite bringing these concerns to our pediatrician and insisting upon their seriousness, nothing was ever done about it. **At 2 ½ months, our son began to have serious seizures that caused him to stop breathing.** While admitted to our local children's hospital PICU, **he was diagnosed with a metabolic disorder, a Homocystinuria Cobalamin defect.** His initial Homocysteine level was over 250 (normal levels should be less than 15), and his Methionine was less than 2 (normal levels should be over 20). Even though we had a diagnosis it took several days to acquire the necessary medication to begin treatment; **it was too late.** Despite the medication dramatically improving his levels, he suffered from severe brain damage due to the toxic imbalance of amino acids in his body. Our son passed away at 3 ½ months. We were devastated. Fast forward 8 years, our second son was born. Due to a better understanding of our ability to pass the disorder on to our children, we tested InVitro and discovered he had the same markers as our first son. We were able to deliver our son at Colorado Children's Hospital in their special unit and he was tested and began treatment at birth. **Since his diagnosis of Cobalamin G,** we have built an incredible support network through HCU Network America. I am so grateful for the resources and community we have found through the many virtual meet ups. We were even able to meet another family recently with a son who has the same diagnosis. **Early diagnosis, treatment and resources is what has made it possible to say that our son is now two and a half and thriving!! No family should have to live with the grief of a lost child when there are treatments available to help them live happy, healthy lives.***

You can imagine what that felt like and at that time there was no network to give this family support and vital information. In June of 2016, HCU Network America was incorporated; bringing hope to families living with HCU that they had advocates to help them get the latest and best advice from the medical community. HCU Network America also financially supports research that can help find new treatments. Since 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.

Here are some of the highlights that your donations helped with:

- Help fund Research Grant: In 2021, we have put out a call for Expressions of Interest, to award our third research grant in collaboration with HCU Network Australia.
- Launched the first Data Collection Program for Homocystinuria to help accelerate research.
- Published three guides, including a Parent Handbook to Special Education Services, Off to College, and Back to Care.
- Launched a Back to Care Program to assist Classical HCU patients who are returning to diet.
- Published a children's book to support medication management of Cobalamin disorders.
- Provide a consultant with experience in medical insurance to fight for coverage for medications and food at no cost to HCU patients
- Support for community meetups and monthly community newsletter.

Our goal this year is \$50,000. Thanks to an anonymous donor, any funds you donate up to December 31, 2021 will be matched up to \$25,000. Please consider a donation to HCU Network America in 2021. If you personally know a patient with HCU, you can donate in their honor. We need your help and appreciate any donation. In addition, if your employer matches charitable donations, they will match those too!

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 for all you do to help us - we will all get through this year and we look forward to 2022!

Thank you,

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
Donors name and HCU patient's name listed on website

4 ways to donate:

1. Use the enclosed slip and envelope
2. Go to <https://hcunetworkamerica.org/donate>
3. Text HCU2021 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!

