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The year 2020 has been an extraordinary challenge to us all. Everyone at HCU Network America hopes that you and your loved ones are managing to get through this safely, and if you have suffered from COVID-19 illness or losses in any way, you have our deepest sympathies.

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 have to 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 daughter had just turned 3 in the spring of 2012 when she suffered a large blood clot on the brain and a series of small strokes. After a week's stay in a children's hospital we were released without any explanation as to the cause of the large blood clot. Six weeks later, during our follow up, the doctors ordered extended blood tests which resulted in a test coming back with elevated homocysteine levels. The level of homocysteine in our daughter's blood was so high that it was actually toxic to her body and prone to clot. It was shortly after this test result came back that we had our explanation to the blood clot as well as a new lifelong diagnosis - our daughter had Homocystinuria. During our crash course on this rare metabolic disorder we learned that she was born with this & that it is hereditary - it was recommended that we have our 18 month old son tested as well. His results came back positive - both of our children were diagnosed with HCU. Homocystinuria was missed on initial newborn screening for both of our children and the state we reside in doesn't offer a second newborn screening where HCU should be flagged. Thankfully the doctors were able to diagnose our daughter correctly after her event and fortunately we were able to get our son on the treatment regimen preventing any events for him. So began our journey with Homocystinuria.

You can imagine what that felt like and at that time there was no HCU Network America 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:

1. Help fund Research Grant: In 2020, HCU Network America, in partnership with HCU Network Australia, issued its second research grant in the amount of \$40,000 to Dr. Tomas Majtan, PhD from the University of Colorado Anschutz Medical Campus, Aurora for the evaluation of benefits of thiol-based reductants in classical Homocystinuria
2. Expand understanding and awareness of the need for new therapies for Classical Homocystinuria by conducting Patient-Listening Session with the FDA
3. Distributed Improved Newborn Screening Talking Points for the Homocystinurias to medical professionals and professional Inherited Metabolic Disorder Organizations
4. Helped secure session on improved Newborn Screening for the Homocystinurias at the Association of Public Health Laboratories 2020 Newborn Screening Symposium
5. Published an Emergency Planning Guide with Emergency Protocol Template for all Homocystinurias
6. Published educators guide for Cobalamin Disorders and MTHFR
7. Provide a consultant with experience in the insurance industry to fight for coverage for medications and food at no cost to HCU patients
8. Support for bi-monthly community meetups

Our goal this year is \$50,000. Thanks to an anonymous donor, any funds you donate up to December 31, 2020 will be matched up to \$20,000. Please consider a donation to HCU Network America in 2020. 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 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 2021!

Thank you,
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 on website along with a donation certificate
- HCU Friend - \$99 or less
Donor's name listed on website