The HCU Herald

Featuring...



HCU Hero

Carter from Georgia

November 2026

HCU NETWORK AMERICA

All things Homocystinuria: patient stories, resources, research, events and more!

HCU HERO: CARTER FROM GEORGIA

When Carter was just a few weeks old, his family received an unexpected call about his newborn screening results. Follow-up testing confirmed that he had classical homocystinuria (HCU), and his homocysteine levels continued to rise despite initial treatment with vitamin B6. At just three months old, Carter began betaine and Hominex-1 formula, helping bring his levels down into the 20s.

In his original HCU Hero story at six months old, Carter's mom shared the fears and uncertainties of navigating a rare diagnosis, from managing a low-protein diet to wondering what the future would hold. Finding HCU Network America and connecting with other families helped her realize that they were not alone.

Now, two years later, we're catching up with Carter and his family to hear how their journey has evolved, the milestones they're celebrating, and what life with HCU looks like today.



Carter has been thriving since diagnosis! You would never think he had a metabolic disorder like HCU just by looking at him. He runs, he plays, he talks your ear off and is just so smart!

Everything that comes with HCU has just become second nature to us. The making of his daily formula, his betaine medication, checking every nutrition label (still- because you never know when they will decide to change the recipe and include extra protein :))

The struggle with finding foods that he can eat within his daily protein allowance (10g of protein) is not too hard- it's just making sure he eats all that was accounted for. He's in his toddler stage right now (2.5 years old) so some food ends up on him/the floor and some in his belly! It's get tricky sometimes because he HAS to eat his daily allowance of protein to make sure his levels do not get out of whack since he is taking Betaine. We are SO grateful for his protein allowance- I do believe if he was still at 5g of protein daily (or less) it would be much harder. It's crazy how much 1g of protein can mean so much to us but others who are not going through a low protein diet do give it a second thought.

HCU HERO: CARTER FROM GEORGIA

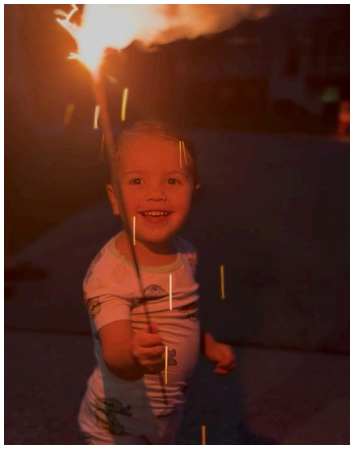
I once questioned how life would be like for him around other children or his cousins who can eat whatever they want. Luckily, it does not affect him right now. I do still worry how it will affect him when he gets older, but I try my best not to let food be the main focus of each and every day. We keep low protein foods & snacks easily accessible to him and simply tell him “no” and give another option if he is out of protein for the day or if someone else has something high in protein that he wants.





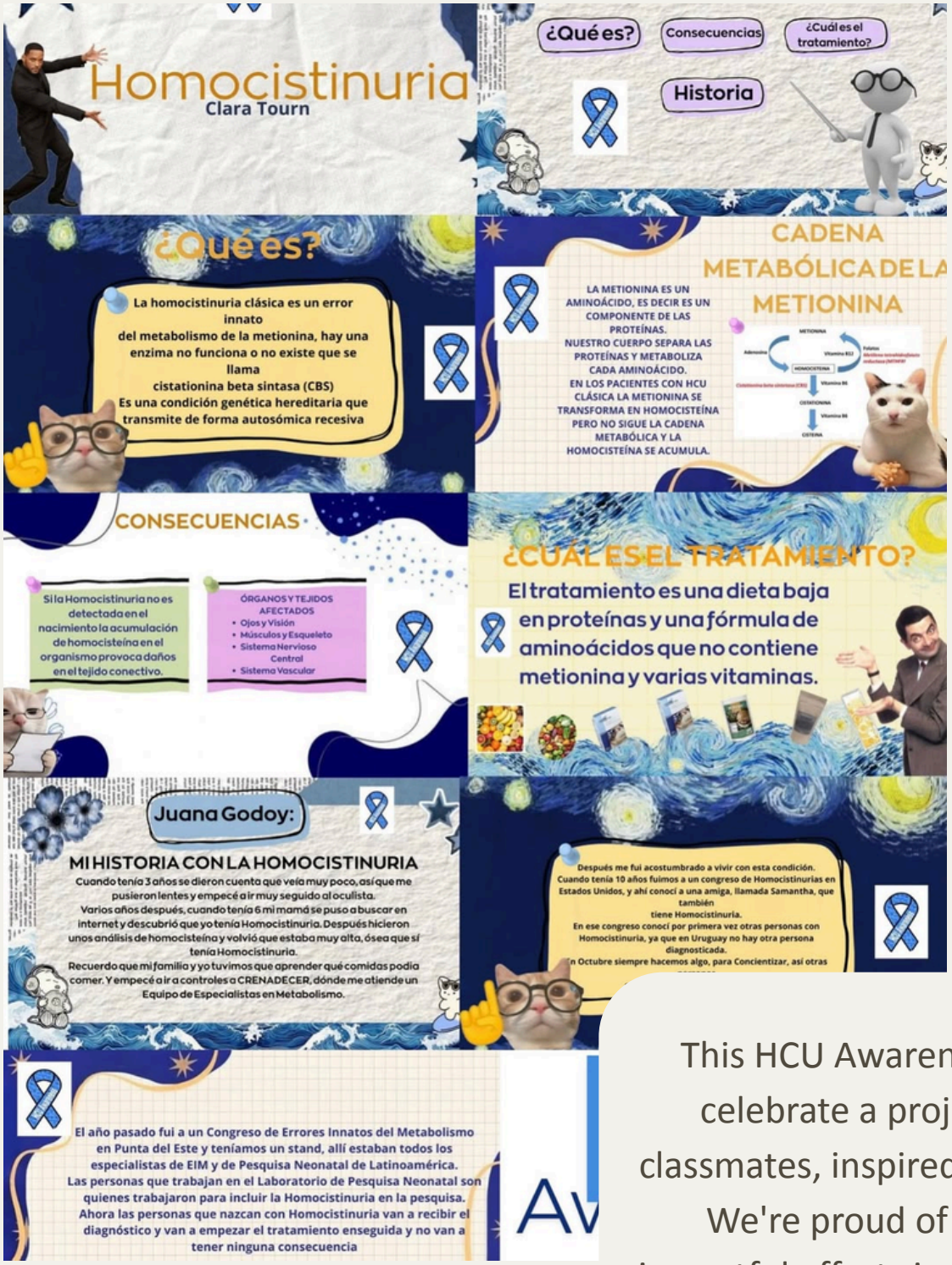
Carter has not had any issues or complications post diagnosis. He gets his blood drawn every 6 months at this point (he’s being so brave about it now!), we visit with his geneticist virtually every 6 months as well. They are so happy with his progress. The newborn screening really saved him! To think of all the complications he could have at this point if he were missed at the newborn screen.

We are thankful for our community, his doctors, and newborn screening.



HCU Awareness Month

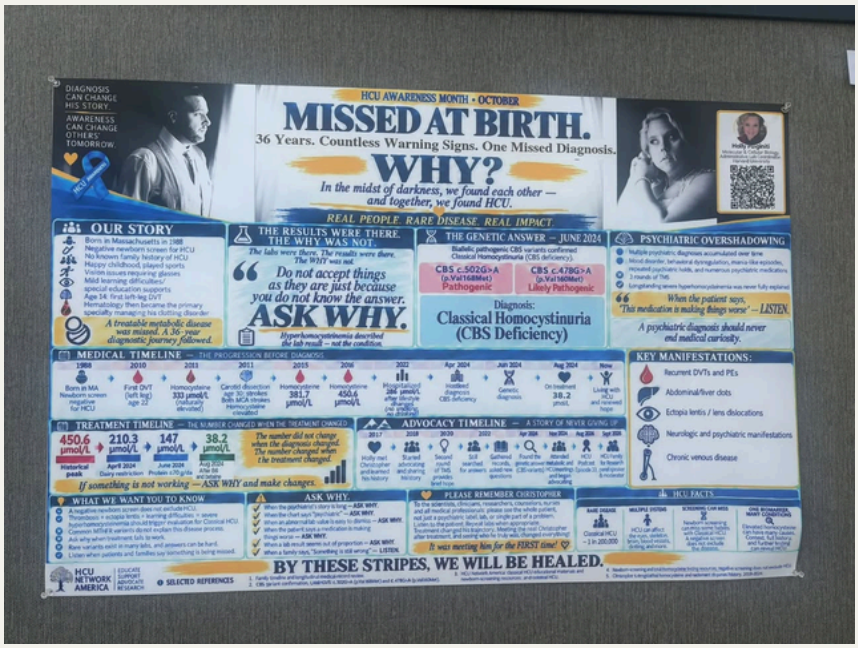
Spotlight



This HCU Awareness Month, we celebrate a project by Juana's classmates, inspired by her advocacy. We're proud of Juana for her impactful efforts in raising awareness and educating others!

HCU Awareness Month

Spotlight





"Missed at birth. 36 years. Countless warning signs. One missed diagnosis. WHY?"

At the Boston Children's Hospital Pediatric Rare Disease Summit at Harvard Medical School, Holly presented a poster sharing her husband's journey with classical homocystinuria (HCU) and advocating for others with undiagnosed rare diseases.

October Recap



Last month, our executive director, Danae' Bartke, attended the SIMD NAMA (Society of Inherited Metabolic Disorders, North American Metabolic Academy) annual workshop in Itasca, IL, representing HCU Network America. Danae met with trainees in medical & biochemical genetics & share the resources and support that HCU Network America provides. It was an excellent opportunity to start building relationships with our future providers!

October Recap

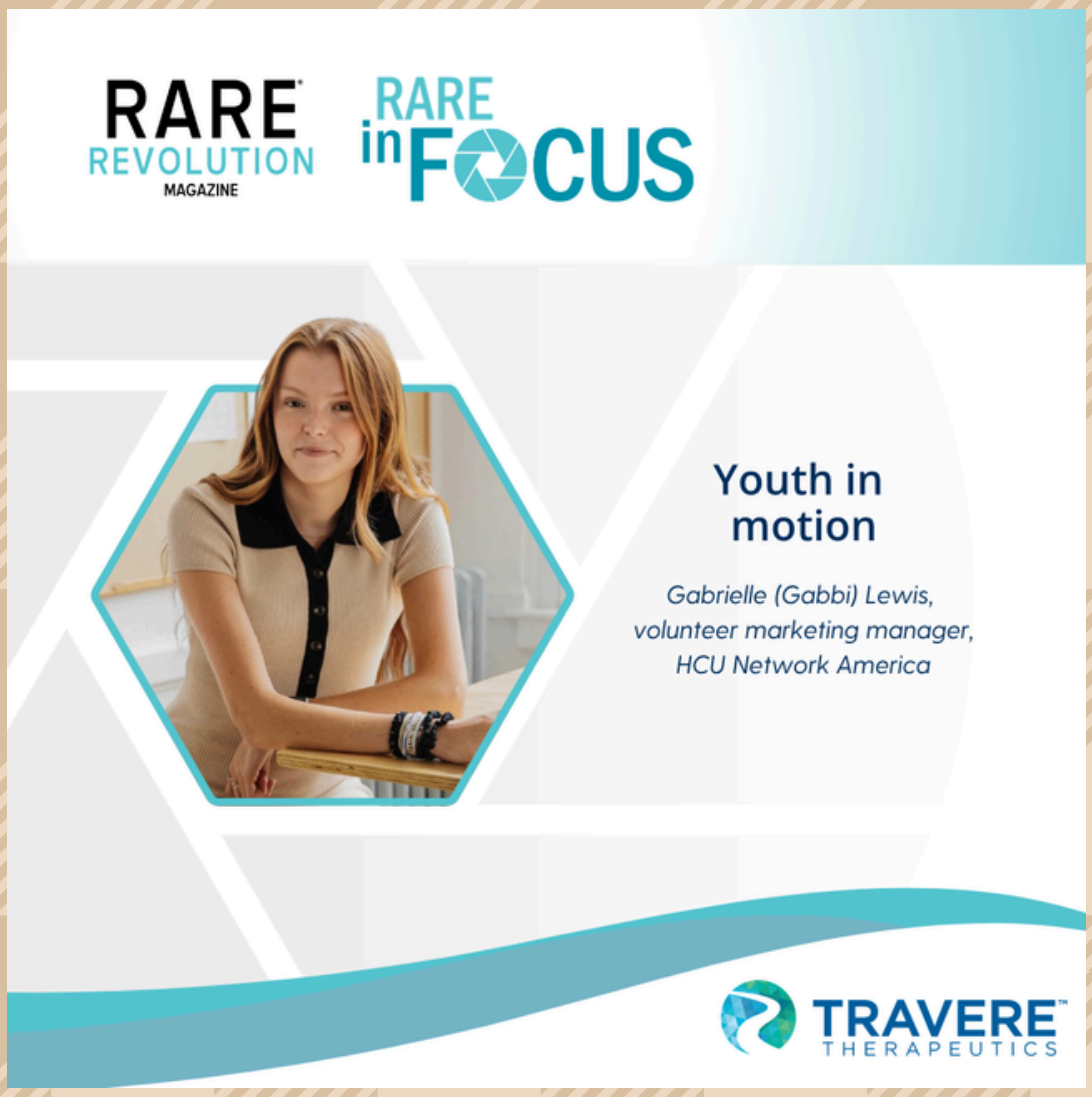




In October, HCU Network America participated in the APHL Newborn Screening Symposium, where Executive Director Danae' Bartke and Coordinator Grace Talbert joined professionals to discuss newborn screening and public health policy. They presented three posters on early diagnosis and strategies to reduce false negatives in HCU screening. A roundtable discussion, co-led with Shawn Moloney and Kostas Petritis, attracted over 100 attendees, focusing on improving HCU screening and the benefits of adding total homocysteine as a marker. The team appreciated the chance to represent the HCU community in national conversations on newborn screening.

Rare Revolution Magazine

In collaboration with Travere Therapeutics, RARE Revolution Magazine features Gabbi Lewis's perspective on navigating HCU as a young adult and building independence while managing a rare condition.



READ MORE

Rare Revolution Magazine

In collaboration with Travere Therapeutics, RARE Revolution Magazine shares Pamela Penrose and Elizabeth Gonzales's perspectives on HCU diagnosis, treatment, and the importance of early intervention.



READ MORE

Rare Revolution Magazine

In collaboration with Travere Therapeutics, RARE Revolution Magazine looks toward the future of HCU care, highlighting community perspectives and hopes for continued progress.



READ MORE

Rare Revolution Magazine

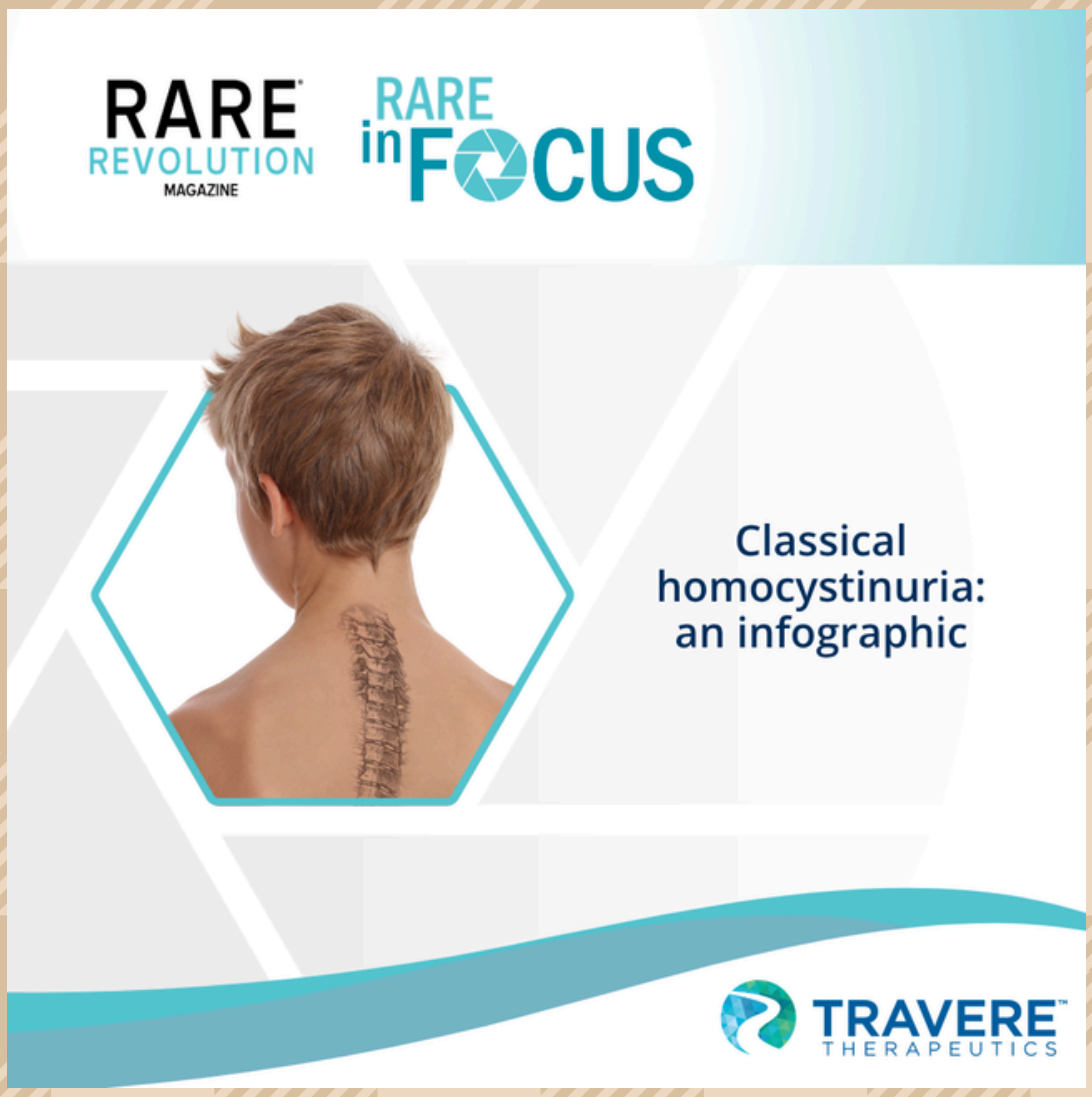
In collaboration with Travere Therapeutics, RARE Revolution Magazine features Professor Sufin Yap's insights into HCU research, diagnosis, and opportunities to improve patient care.



READ MORE

Rare Revolution Magazine

In collaboration with Travere Therapeutics, RARE Revolution Magazine shares an educational infographic explaining classical HCU, helping patients, families, and healthcare professionals better understand the condition, its symptoms, diagnosis, and management.



READ MORE

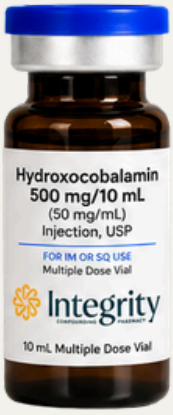
Upcoming Events

HCU NETWORK AMERICA

Integrity COMPOUNDING PHARMACY

Fall 2026 Webinar

Cobalamin Disorders & Compounded High-Dose Hydroxocobalamin: What You Need to Know



From understanding treatment to making injections easier, explore high-dose hydroxocobalamin, practical injection tips and tricks, and available compounded therapy options.

Meet Our Speakers!

Mary Riedy, PharmD, BCPPS
Understanding Cobalamin Disorders & Compounded High-Dose Hydroxocobalamin

Chanel Suares, RD
Compounded High-Dose Hydroxocobalamin: Options and Pharmacy Support

Brittany Parke
Injection Tips & Tricks: Making Treatment More Manageable

Integrity Metabolic Support Team:
Amy Chapin, PharmD
Alison Hall, PharmD

Available during Q&A portion to answer any pharmacy support questions

Tuesday, November 17, 2026

7 PM EST
(6PM CT, 5 PM MT, 4 PM PT)

REGISTER HERE

Raising Joy

Double Good

Give Good. Get Good. That's Double Good!



When you buy Double Good's award-winning premium popcorn, 50% of your purchase goes to support HCU Network America!

100% contactless!
The product ships directly to the buyer.

To create your own pop-up store:
1) Download the Double Good App
2) Enter our event code: RJXCTB
3) Tap 'my store' to create & personalize your pop-up store

Buy here:
https://s.dgpopup.com/62d7zuo1

Nov. 5 @ 5 pm to Nov. 12 @ 5 pm



As an added bonus, **all our proceeds will be doubled** as part of our end-of-year match!

HCU NETWORK AMERICA

MEET SAM AND JUANA



For most children, friendship happens naturally. A new classmate sits beside you at school, you discover you love the same game, or you find yourself laughing together at lunch. For children living with a rare disease, finding that kind of connection can be much more difficult.

The person who understands what it means to live with your disease, your dietary restrictions, your treatments, and all the questions that come with them may not live down the street—or even in the same country. They may be thousands of miles away.

For Juana, that distance has always been especially real.

Growing up in Uruguay, Juana had very few opportunities to meet other children who understood what it meant to live with homocystinuria. Her family could explain HCU to the people around her, but there was something they could not provide: another child who simply understood because they were living it, too.

Then, at an HCU Network America conference in Bethesda, Juana met Samantha.

The girls could not speak the same language. Samantha did not speak Spanish, and Juana did not speak English. But the language barrier did not stop them. In the Kids Club, they found a way to communicate through smiles, games, gestures, and the excitement of discovering another child who had HCU. When Juana returned home, she told her uncle,

> *"I have a new friend and her name is Samantha and she has HCU and she is okay."*

HCU NETWORK AMERICA

That last part mattered.

For Juana, meeting Samantha meant seeing another child who was living with the same disease and was okay. Samantha understood dietary restrictions and the uncertainty of rare disease, but she was also simply a kid. She laughed, played, made friends, and enjoyed herself. For the first time, Juana had someone who understood a part of her life that so few other people could.

Samantha understood that feeling, too. Growing up with HCU meant learning that there were foods she could not eat and limits she had to navigate every day. Her mom, Amber, worked to find meals and recipes that helped Samantha feel included, and Samantha eventually began creating recipes of her own.

Although the girls lived on opposite sides of the world, they shared an understanding that very few people could offer one another.

After that first conference, their families helped them stay connected through messages and video calls. But distance is difficult, especially for children. The girls grew older, life changed, and eventually their conversations became less frequent.

Still, the friendship never disappeared.

Years later, Juana learned she might finally have the chance to see Samantha again at another HCU Network America conference. Her family had previously saved in hopes of attending another conference, only to realize they could not make the trip. This time, when Juana learned they were going, she knew exactly who she was going to see.

After years apart, she was going to see Samantha again.



{Anna and Juana attending the Sleimpn XIII Latin American Congress on Inborn Errors of Metabolism and Neonatal Research}


{Sam and her family}

Amber was not initially sure Samantha would be able to attend either. The distance and logistics were significant. But when Anna reached out and explained that this might be their last opportunity to see one another for the foreseeable future, Amber knew they had to find a way.

The girls finally reunited.

For three days, the years between them seemed to disappear. They talked and played together, discovered new foods at the grocery store, did makeup, ate sushi, participated in conference activities, and spent time with each other's families.

Their families described those days as a "perfect bubble." No one had to explain HCU. No one had to explain why they were reading an ingredient label, why a food was not an option, or why finding the right treatment could carry so much weight. Everyone understood.

And most importantly, the girls had each other.



{Anna and Juana saying their heartfelt goodbye}



{Anna, Juana, Sam, and Amber at the 2026 HCU Network America Conference in Philadelphia, PA}

Eventually, they had to say goodbye. They knew they could continue messaging, but neither family knew when they would be able to bring the girls together again.

> *"As they said goodbye, Juana said simply, "I'll miss you."*

Those words carried the weight of the little girls who had crossed a language barrier to become friends, the years they spent apart, and the precious days they had just shared.

Because without HCU Network America, they likely never would have found each other.

That is what connection means in a rare disease community.

An HCU Network America conference is more than a gathering of patients and families. It is a place where someone who may have never met another person with HCU can suddenly find someone who understands without needing an explanation. It brings together families separated by geography, language, and circumstances and reminds them that they are part of something larger than themselves.

Eventually, they had to say goodbye. They knew they could continue messaging, but neither family knew when they would be able to bring the girls together again.

For Juana and Samantha, HCUNA brought two little girls together from opposite sides of the world—and years later, brought them together again.



Your support helps make those connections possible.

A gift to HCU Network America can help a child find the friend who understands, a parent find the family who gets it, or a patient find a community where they never have to explain why their life is different.

We cannot know where the next friendship will begin. It could be across the country, across a language barrier, or across an ocean.

But we know these connections matter.

This holiday season, help HCU Network America continue bringing patients and families together despite the boundaries between them—and help make the next friendship possible.

Matching Gift Challenge

In honor of our10-year anniversary,the Lewis Family,Margie McGlynn, the Bonucci Family,and theKellyFamily have cometogether tooffer a $40,000 match.



During the winter holidays, warmth and generosity can be felt near and far. We ask every patient and family to help us raise funds to continue our homocystinuria community outreach, education, and advocacy initiatives to educate providers and be there for families like Everett and Clementine's. Please share our appeal letter with your colleagues, friends, and family.

Three Easy Ways to Donate

Click here to donate
https://bit.ly/HCUMatch2026

By check
HCU Network America
15 S. Mallory Ave
Batavia, IL 60510

EMPLOYEE MATCHING PROGRAM

Did you submit for your Employers Corporate Matching Gifts Program?

What are Matching Gifts?
Corporate matching gifts are a type of gift giving in which companies financially match donations that their employees make to nonprofit organizations. When an employee makes a donation, they need to request the matching gift from the employer, who then makes their own donation. Companies usually match at a 1:1 ratio, but some will match 1:2 or 2:1.

Why are Corporate Matching Gifts Valuable?
Corporate matching gifts are valuable because they are free money for your nonprofit of choice, HCU Network America! Your donation has double the power without you having to give double the amount.

Does HCU Network America Really Benefit?
If corporate matching gifts weren't valuable, we wouldn't be sending this letter. In 2020 we received approximately $45,000 in corporate matching gifts!

How Do I Find out if my Employer has a Corporate Matching Gifts Program?
Your company website or websites such as doublethedonation.com make it easy for you to search and see if your employer takes part in corporate matching gifts. If you can't find it online, please consult with your employee handbook, HR rep or manager to find out.

How Do I Request my Donation is Matched by my Employer?

1. The donor completes their donation
2. The donor submits matching gift request
3. Company reviews donation and nonprofit eligibility and reaches out to nonprofit
4. Nonprofit verifies the donation was made
5. If eligible, the nonprofit will receive the matching gifts request!

Top Matching Gift Companies

Company Match Ratio

- General Electric 1:1
- Gap Corporation 1:1
- ExxonMobil 3:1
- Johnson & Johnson 2:1
- Microsoft 1:1
- Pfizer 1:1
- Coca-Cola 2:1
- And many more!

Did you know some companies match retired employees donations?



2026 End of Year Appeal

Together We Keep Hope Moving Forward

What is Giving Tuesday?

It's a global generosity movement unleashing the power of radical generosity. GivingTuesday was created in 2012 as a simple idea: a day that encourages people to do good. Since then, it has grown into a year-round global movement that inspires hundreds of millions of people to give, collaborate, and celebrate generosity. *This year, Giving Tuesday will be* ***December 1st.***

How do I get involved?

We're asking you to assist us in reaching our $10,000 GivingTuesday fundraising goal.

To get started:

- Set up your own GivingTuesday fundraiser on GoFundMe, Facebook, or Instagram!
- Start to reach out to your friends and family in advance and get them to pledge a donation on December 1st!
- Let them know that by giving to HCU Network America, they are supporting programs and resources that directly benefit the patients and caregivers of our community.
- Remind them that *all donations* are tax-deductible AND will be matched by **the Lewis Family, Margie McGlynn, the Bonucci Family, and the Kelly Family up to $40,000.**

Keep an eye on HCU Network Amrica's social media on 12/1!

We will be posting about Giving Tuesday and will include a link to our donations page, so if you'd prefer, you can share our posts instead of setting up your own fundraiser.

GIVING TUESDAY

IN CASE YOU MISSED IT...

The HC&U Podcast is back!!!

HC&U is a podcast about Homocystinuria, sponsored by HCU Network America and hosted by Ben & Lindsey.

Meet your hosts!



The latest episode



Welcome to the HC&U Podcast! We are Ben and Lindsey, your hosts. We are so excited to be starting this as extra resources for the Homocystinuria community. We hope you like our content!

In this episode, Claire shares her daughter Kira's remarkable journey from a sudden, life-threatening stroke at age four to a diagnosis of Classical Homocystinuria (HCU). She reflects on the fear, resilience, and determination that carried their family through multiple surgeries, recovery, and the challenges of managing a rare metabolic disorder. Today, Kira is a thriving, vibrant young girl whose story is a powerful testament to hope, strength, and the importance of HCU awareness.

To Listen:
https://hcunetworkamerica.org/hcu-podcast/
or click below on your favorite option!

LISTEN ON Spotify

Listen on Apple Podcasts

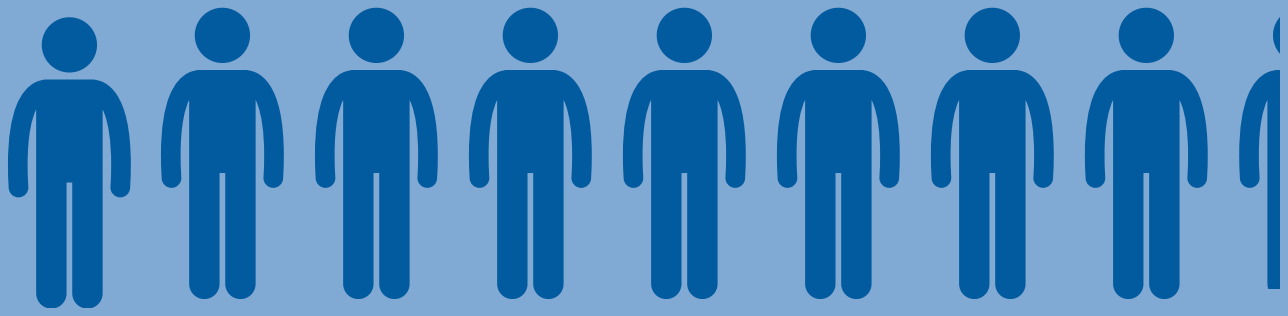
LISTEN ON iHeartRADIO

Listen on amazon music

HOMOCYSTINURIAS
DATA COLLECTION PROGRAM

POWERED BY RARE X

Of the 81 participants who took the Head-to-Toe Survey
Here are the top 5 areas the data is pointing too





53
Vision Issues



48
Brain/Nervous System



36
Bones/Cartilage /Connective Tissue



36
Sleep



40
Digestive Issues

Complete the Head to Toe Survey at
https://homocystinuria.rare-x.org

CANPKU+ CANPKUT HCU

HCU NETWORK AMERICA

HCU Network Australia

POWERED BY RARE X

Customize Your Kit For Free!



At HCU Network America, we believe that one of the most important steps to empowering patients and caregivers is giving them the support and tools needed to succeed! We know that a new diagnosis can be overwhelming and riddled with concerns and questions. To us, one way to combat those feelings, and give you the confidence you need, is by providing you with one-on-one support, educational resources, and practical tools, such as scales, cooler bags, and more! Our request for a kit survey allows you the opportunity to request a one-on-one introductory call (with more opportunities to connect), and then a customized kit to the patient's needs. Don't want a call or a Zoom? That's fine too - we are happy to send you the customized kit.

Request your kit now -
https://www.surveymonkey.com/r/HCUKitSurvey

**Kits can only be sent to patients in the continental US. However, we are happy to connect virtually and share the educational materials with you via weblinks*!

Contact Register

What?

- **What** is it?
  - A secure private survey for individuals or families affected by Homocystinuria
- **What** will I share?
  - Patient's birthdate, gender, exact diagnosis, and how they were diagnosed
- **What** will my info be used for?
  - Confidential and will not be shared unless we have permission
  - Helps HCUNA achieve our goals

Why?

- **Why** should I join?
  - Able to find other families and patients in your state and request contact information
  - Access to exclusive materials (ex: we may have a webinar that a presenter doesn't want to share publicly but is okay sharing with just our community)



How?

- **How** do I participate?
  - The form takes 3-5 minutes to complete
  - Visit our website and click on "contact register" tab or...

Click Here

Follow Us!

Do you have social media??



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HCU Network America

@HCUAmerica