The HCU *Herald*

Featuring...

2026

HCU Hero
Masen from Canada

January 2026

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

HCU HERO: MASEN FROM CANADA

Masen was born on May 25, 2013 in Surrey, British Columbia, Canada, a city just outside of Vancouver. Back in 2021 after diagnosis when we first shared our story with HCU Network America, from what we understood, Classical Homocystinuria ("HCU") was not a part of the newborn screening panel at the time of Masen's birth, however, that information was incorrect, and Masen was in fact among the approximately 50% of missed at birth scenarios. He was tested, but it came back as a false negative. Under the assumption Masen was perfectly healthy, we went home with our happy, and we believed healthy, newborn baby boy.

As a bit of background, it was just before kindergarten when we went for a routine eye exam and learned that Masen needed glasses. This wasn't a big concern, and Masen rocked his new glasses. It was 2 years later during a further routine eye exam that our eye doctor became concerned and thus began months of further testing, blood draws and living in fear, until we finally got Masen's diagnosis of Classical HCU at age 8.

Our world turned upside down as we learned of the health risks and of the tools in which to manage this new path. Masen learned the importance of his low protein diet, his formula intake, and essentially a whole new world for an 8-year-old little boy.

HCU HERO:
MASEN FROM CANADA

Regular blood draws and the new diet and formula was not an easy transition, and we did our best to explain to him in an age-appropriate way as to why we had to make these changes.

Masen underwent two separate and painful eye surgeries to remove the lenses from his eyes due to being at a high risk of lens dislocation. This happened in 2022, and Masen has done very well with his contact lenses ever since.

Today, Masen is a healthy, active, funny 12-year-old. He is an avid hockey player, works hard in school and keeps us laughing every day. He loves his family, sports (watching and playing) and travelling. We have been on multiple vacations, including cruises and Disney, since diagnosis. If you asked him his favorite subject in school, he would say “recess and gym”.

It is extremely rewarding to look back over the last 4 years since diagnosis and see what we were able to accomplish by travelling and showing Masen he can still do so much while he navigates the diet and the difficulties that can come along with living with HCU. Having him continue in sports and social events while keeping his diet on track has been equally rewarding.

HCU HERO:
MASEN FROM CANADA

Now that he's older he very much helps keep track of his protein and by mid-day you we will usually hear him double check by saying "what am I at for the day?" so that he can plan his dessert and snacks accordingly for the remainder of the day. This routine has provided stability as he has fallen into a healthy pattern of what to eat and when.

He knows he can manipulate his day by adding more medical foods if he wants to indulge in something a bit higher in protein that evening. He is learning to plan, and this is an extremely important part of the diet. We are very proud of him, and this is the exact scenario that we hoped we would reach back at diagnosis.

Further, what has come with time and age, is being more open with Masen about the risks of HCU. We do not wish to cause our son unnecessary fear and anxiety, but the reality is he must be aware and on the look out for more serious health concerns, such as blood clots. Having this conversation with our 12-year-old wasn't easy, but it was necessary, and we believe it further drove home the impof diet and formula more so than what he already understood. We feared this conversation back at diagnosis, but it went much better than we ever could have anticipated.

HCU HERO: MASEN FROM CANADA

Masen prefers to drink his formula at home and remains very much under the radar at school and in sports and many social situations. We respect his choice not to discuss and share his HCU with those he doesn't wish to. While our family and friends are extremely supportive, we understand as his parents that while we like to share, educate and advocate, and Masen is okay with that for now, Masen wants to go about his life and not draw any extra attention to himself day to day.

Having said that, Masen loves going to conferences and openly drinks his formula in front of everyone in those situations. The power of community and being a part of HCU Network America is more valuable to us than we could ever put into words. We are grateful to everyone here and would love to see everyone at the upcoming conference in July. We cannot wait to attend!

FOOTBALL SQUARE FUNDRAISER

SUPER BOWL

TBD VS TBD

FEB 8TH @ 6:30 EST

$20 PER SQUARE 4 CHANCES TO WIN

$100 PAYOUTS 1ST-3RD QUARTER

$200 PAYOUT AT END OF THE GAME

TO PARTICIPATE:
STEP 1: VENMO @TOM-HAWKINS-1
*LAST FOUR DIGITS OF PHONE NUMBER: 1300
STEP 2: EMAIL TOM TO RECIEVE ACCESS TO BOARD!
EMAIL: TMMYHWK09@GMAIL.COM

ALL FUNDS RAISED SUPPORT HCU NETWORK AMERICA'S EDUCATION & OUTREACH PROGRAMS!

When? **Monday January 19, 2026**

Place your online order for pickup or delivery on Monday, January 19th!

Where? **Panda Express locations nationwide**

www.pandaexpress.com

How? **Online orders only**

Apply code **9011020** in the fundraiser code box during online checkout at www.pandaexpress.com or via App

28% of sales will be donated to HCU Network America!

LOWER-PROTEIN MEAL OPTIONS

MEAL IDEA #1:

- 1 Veggie Spring Roll = ~2 g
- Mixed Veggies (1/2 portion) + Sweet & Sour sauce = ~2 g
- 1 Fortune Cookie = 1 g

= ~ 5 g protein

MEAL IDEA #2:

- 1 Veggie Spring Roll = ~2 g
- Mixed Veggies (1/2 portion) + Sweet & Sour sauce = ~2 g
- White Steamed Rice (1/2 portion) = ~3.5 g
- 1 Fortune Cookie = 1 g

= ~ 8.5 g protein

MEAL IDEA #3:

- 2 Veggie Spring Rolls = ~4 g
- Mixed Veggies (1/2 portion) + Sweet & Sour sauce = ~2 g
- White Steamed Rice (1/2 portion) = ~3.5 g
- 1 Fortune Cookie = 1 g

= ~ 10.5 g protein

*Esitmations are approximate. For full nutritional info, visit https://www.pandaexpress.com/

Help us maximize the impact!

CLICK HERE To visit HCU Network America + Panda Express fundraising page & share on your social media channels!

28% of sales will be donated to HCU Network America!

See previous page for details.

RARE DISEASE DAY IS COMING!

RARE DISEASE DAY®

Mark your calendars...

...for February 28, 2026!

One out of every 10 Americans is living with a rare disease.

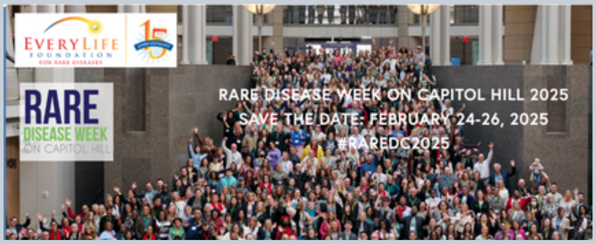
Rare Disease Day takes place worldwide, typically on or near the last day of February each year, to raise awareness among policymakers and the public about rare diseases and their impact on patients' lives.

How can I participate on Rare Disease Day?

Share your story: Just by sharing your story with others, you're spreading awareness. Whether it's through social media, at school or at work, or in line at the grocery store, each interaction counts!

Wear your awareness: Wear one of your HCU Network America shirts or sweatshirts on Rare Disease Day! And when folks ask you about it, tell them a little bit about YOUR story living with HCU!

Attend an event: There are a number of in-person or virtual events that you can attend! Below are a few options - click each image to check them out and register!



RARE DISEASE DAY ON CAPITOL HILL

RARE DISEASE WEEK ON CAPITOL HILL
SAVE THE DATE: FEBRUARY 24- 26, 2026
#RAREDC2026

Registration opens January 7th, 2026!

Rare Disease Week on Capitol Hill empowers and inspires hundreds of advocates each year. The connections you make during the week will impact rare disease patients for generations to come.

Hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases), this multi-day event brings together rare disease advocates from across the country to make their voices heard by their Members of Congress. Participants are educated on policy proposals impacting the rare disease community and provided opportunities to advocate for policy changes directly to their Members of Congress. No matter one’s connection to rare disease or their advocacy experience level, all are welcome.

Click here to learn more, and to register to attend!

LET US KNOW!

Planning to attend?

We'd love to connect you with others in our community who will be attending!

WEAR YOUR AWARENESS

GRAB YOUR GEAR!

RARE DISEASE DAY

FEBRUARY 28

Shirts and Bags available for the month of February at:
https://www.bonfire.com/store/hcu-haberdashery/

Grab your gear!

https://www.bonfire.com/store/hcu-haberdashery/

Order by February 5 to receive in time for Rare Disease Day!

Scholarship opportunity!

flok The Guthrie-Koch Scholarship

- **Do you have Classical HCU?**
- **Are you a *high-school senior* or *current student* pursuing an undergraduate degree or technical school?**

If you answered ‘yes’, you are eligible to apply for the Guthrie-Koch Scholarship Program!

The Guthrie-Koch Scholarship Program was founded in 1997 to recognize outstanding young adults with PKU pursuing higher education and provide financial support to these efforts, but has now been expanded to include young adults with Classical HCU and other metabolic disorders!

Click here to learn more and to start your application!

The application deadline is March 15, 2025.

Click Here

you're invited!

To a Kendra Gives Back event benefitting HCU Healthcare Network America

DATE & TIME

January 3rd 2pm-4pm

DETAILS

Shop instore at Kendra Scott Grand Blvd for 20% of the proceeds of your purchase to Give Back to **HCU Healthcare Network America, on 1/3**. Can't make it? Shop online at Kendrascott.com and enter code **GIVEBACK-KQPEJ** at Checkout to give back. **1/3-1/4.**

KENDRA SCOTT

GET READY FOR...

HCU NETWORK AMERICA'S

2026 CONFERENCE

MORE LAUGHS, MORE COMMUNITY, MORE HOPE

It's A FAMILY AFFAIR

In The City of Brotherly Love

July 10-12, 2026
Philadelphia, PA

- Patient Focused Panels
- Breakout Sessions
- KidsZone and Teen Zone
- Community Building Opportunities

- Dedicated Science Day for Families and Professionals
- Scientific Poster Session
- HCU Hero Award Banquet
- Networking Opportunities

Patient & Family Conference

REGISTER NOW

HCU NETWORK AMERICA

Classical HCU | Cobalamin Disorders | Severe MTHFR

FRIDAY AGENDA

- 7:00am Registration & Breakfast
- 8:30am Welcome and Opening Comments

Professional Track

- 9:00am Rare-X for Research & Medical
- 9:45am HCU Network America Research Grant Recipient Presentations
- 12:00pm Lunch
- 1:30pm Biotech Research and Clinical Trial Updates
- 3:15pm Ask the Experts Panel

Family Track

- 9:00am What is Homocystinuria?
- 9:45am Treatment Guidelines
- 10:30am Q&A Panel
- 11:00am What is ERT, Chaperone Therapy, Gene Editing, Gene Therapy
- 12:00pm Lunch
- 1:30pm Classical HCU & Remethylation Research Overview
- 2:45pm Research: What you should know and ways to get involved

Return to Entire Group

- 3:45pm Closing Comments, Optimizing Self Care
- 4:30pm Cocktails, Appetizers and Posters
- 5:30pm Dinner & HCU Hero Award Ceremony

SATURDAY AGENDA

- **7:00am Registration, Breakfast, Vendors open**
- **8:30am Welcome and Keynote**
- **9:00am Panel: “It’s a Family Affair”**
- **10:30am Panel: Family Planning**
- **12:00pm Lunch**
- **1:30pm Newborn Screening**
- **2:30pm Breakout Sessions #1**
- **3:30pm Breakout Sessions #2**
- **4:15pm Conclusion**
- **4:30pm Parents Pick-Up from Kidzone**

SUNDAY AGENDA

- **7:00am Breakfast**
- **8:30am Community Building Activities**
- **12:00pm Lunch**
- **12:00pm Conclusion of Conference**

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!

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!

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

The latest episode

Ben welcomes Alicia to the table!

Alicia shares her daughter's journey to a diagnosis, the trials that come with learning about a rare disease and an update on how she is doing! Her story highlights the importance of connection to a patient community who supported her question to ensure proper managment of her rare diagnosis.

Growth, Developmental Issues, and Regression Surveys

Top Developmental Concerns

- Coordination
- Communication
- Vision

23% Reported loss of skill and regression

11% Reported seizures

Developmental issues were reported in 48% of the community

Complete the Survey
https://rare-x.org/homocystinuria/

December Recap

Tour At The Promin Headquarters

Collaboration, connection, and community

From chairing the HCU breakout session at Metabolic Support UK's Community Conference to touring Promin's UK headquarters, our Executive Director Danae' Bartke had the opportunity to engage in meaningful conversations around HCU care, advocacy, and future therapies.

She's incredibly thankful for the warm welcome and inspiring discussions—and says the Promin tour felt like visiting Santa's workshop!

Here's to continued collaboration and supporting the global HCU community together.

MSUK Conference Recap

December Recap

HCU NETWORK AMERICA

At ASH25

Earlier this month, we had an incredible experience exhibiting at this year's American Society of Hematology conference #ASH25
Our time there helped us shine a spotlight on the critical differences between inherited homocystinuria and hyperhomocystinemia—while underscoring why early diagnosis, access to treatment, and ongoing management are truly lifesaving for our community.
We also connected with industry partners, clinicians, researchers, and allied health professionals who share our commitment to advancing care. These new relationships open the door to meaningful research collaborations and deeper data insights that can drive progress for all affected by homocystinurias.
Most importantly, the conference reaffirmed our role as a trusted partner in education, patient support, and research within the hematology community. We're grateful for the engagement, the conversations, and the shared dedication to improving lives.

December Recap

COMMUNITY IN ACTION

Orlando, FL

While in Orlando for #ASH25 earlier this month, Danae (Executive Director), Brittany (Research Coordinator), and Grace (Board member), took time to meet up with local families.

As part of our mission, we strive to connect with families to deepen our connection and understanding of the Homocystinuria experience, and make sure families feel supported in their journey. We are so thankful for our families who came out and met with us!

COMMUNITY SPOTLIGHT

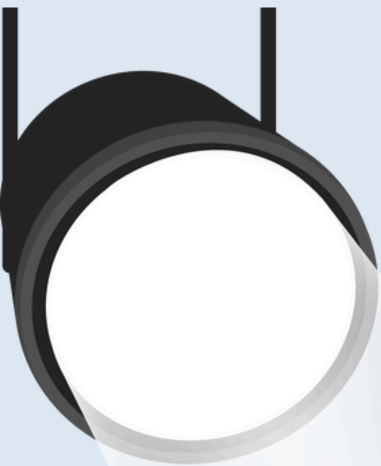
Today I had the privilege of spending the day on Capitol Hill to participate in Healthcare Nutrition Council (HNC)'s "Food is Medicine in Clinical Care" Congressional Briefing & Hill Day as a patient advocate on behalf of HCU Network America, the HCU community, and the broader rare disease patient population.

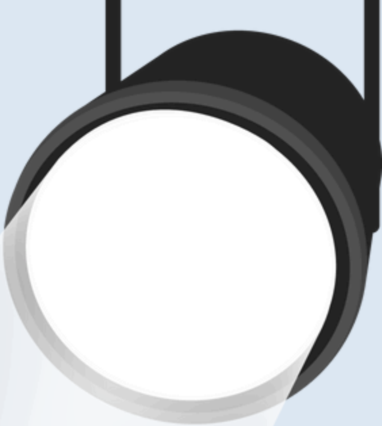
Enteral nutrition, oral nutrition supplements, and specialized medical foods and formulas are vital to effectively treating conditions that impact millions of Americans. In many cases, as with HCU, these form the backbone of treatment and are absolutely critical to patients' quality of life, health, wellbeing, and prognosis.

It is essential that these products are accessible and affordable for patients, whether that be under private insurance, Medicare, Medicaid, or other programs. Sadly, that's not guaranteed today. A number of bills have been proposed in Congress to support access to enteral nutrition, oral nutrition supplements, and medical foods and formulas under certain programs and for certain populations, and I am grateful to have spent the day with staff from House and Senate offices to convey the impact these protections have on patients.

In particular, I am heartened to see fellow Bay Stater Representative James P. McGovern is sponsoring, and has introduced, the Medical Foods & Formulas Access Act of 2025 (H.R.5684), which includes inherited metabolic disorders, such as HCU, in its scope. I hope to see it and similar bills passed into law in order to ensure or improve access for patients who need these medically necessary treatments to survive and thrive.

-BENJAMIN LEWIS





COMMUNITY SPOTLIGHT

MELANIE'S APPEARANCE ON CHILD LIFE ON CALL PODCAST

CLICK HERE

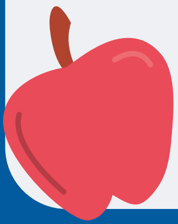
UPDATED RESOURCES

Classical - Educators' Guide Series

Cbl, MMA+HCU Educators' Guide Series

Cbl, Isolated Educators' Guide Series

Severe MTHFR - Educators' Guide Series



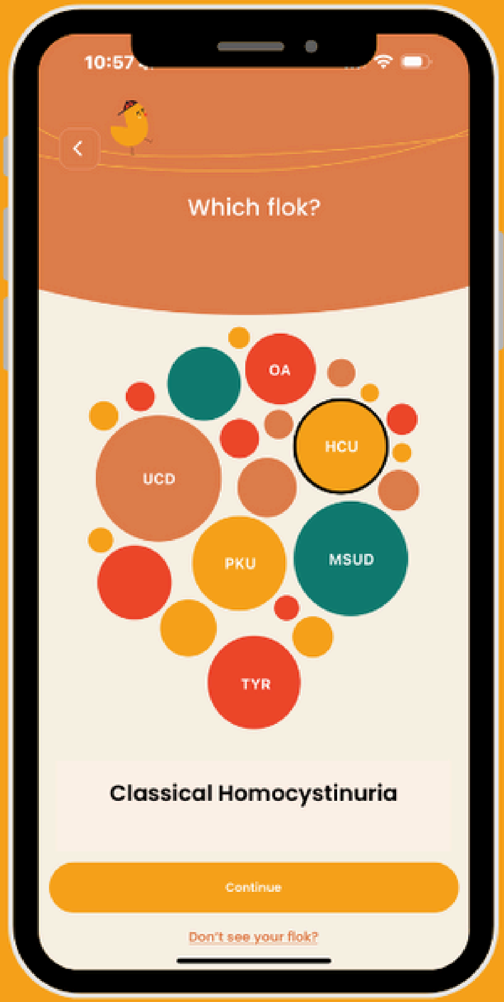
Start using the flok app today!

Welcome to the next generation of metabolic care for the CLASSICAL HCU COMMUNITY

The flok app is
now in Open Beta
in the United States.

Download at flok.org/app

flok



Big news!

The flok app is now in Open Beta, available for download to everyone in the U.S.!

Jump in and start exploring – the app helps you manage your diet and build a full picture of your metabolic health – including symptoms & moods, activity, medications, and lab tests.

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)

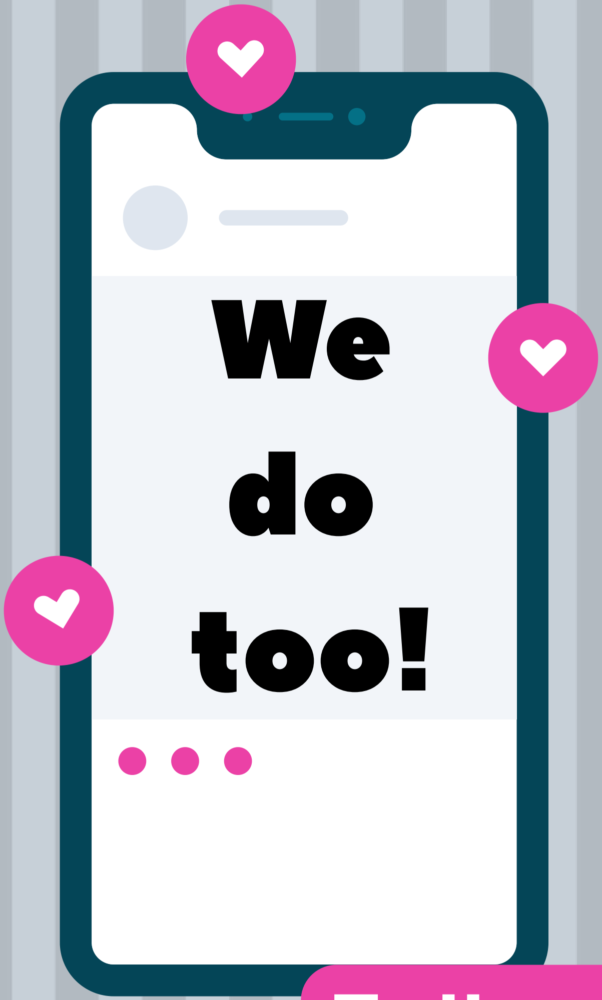
How?

- **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??



We do too!

Follow us

@hcu_network_america

HCU Network America

@HCUAmerica