

# The HCU *Herald*



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**Tell us about you and help us clean up your inbox!**

In order to provide the best user experience and programs, please let us know a little bit more about you. We are hoping to define your email experience, so you don't get as many emails from us in the future. These questions will give you a more tailored experience.

<https://us14.list-manage.com/survey?u=f4df0c738edbf7df6565df2fe&id=842cefb887>

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## Brenda's Thanksgiving Survival Guide

**Just because you need a low protein diet, doesn't mean you have to miss out on the Thanksgiving Feast!** Check out Brenda's Thanksgiving Survival Guide that will be **sure to please everyone**, this Thanksgiving. Visit <https://cookforlove.org/articles/17> and download the guide and recipes now!



# HCU HERO: AIMEE FROM MARYLAND



My life before age 8 was like any other "normal" kid, with the exception that my mom took me to a lot of specialists. She instinctively knew that something was not quite right for a few reasons. Firstly, I grew excessively fast, to the point that there was a time I could only walk on tiptoe because my bones grew faster than my muscles. I did not grow hair until I was 4. I was extremely sensitive to light and sound; I still am. My eyeglass prescriptions also kept changing dramatically. I believe before I had my lens replacement surgeries, that my eyeglass lenses were between  $\frac{1}{4}$ - $\frac{1}{2}$  inch thick. When my optometrist noticed that my original lenses were detached, we had our first clue as to a diagnosis.

After being misdiagnosed with Marfan Syndrome, I was finally diagnosed with HCU. My family owned a restaurant so I grew up eating steak and

lots of other delicious meats. Overnight I felt like someone pulled the sheet out from underneath me. I was originally limited to 5 grams of protein a day and struggled to eat the plastic-tasting low protein food at the time. My family was so supportive of helping me through my transition. The old protein shakes were vile. I will never forget my mother and grandmother sitting with me at the kitchen table for 2-3 hours encouraging me to get a shake down.

I was mad at the diagnosis. I was mad that my peers were given another reason to view me as "weird". I was also mad at my doctors for misdiagnosing me, not knowing back in the mid-1990s how to properly test my levels, and (in my mind) for giving me this disorder. My mom and I also found out after my diagnosis, that I was borderline as a baby but they never told her. I could have grown up without the knowledge of what foods that were bad taste like.

I continue to experience a lot of inner turmoil related to diet. I feel conflicted between eating what I want (and feeling guilty) or following my diet (and not feeling guilty), but also not seeing or experiencing any immediate improvements. As those with the diagnosis know, it is hard to push yourself to make the necessary changes toward compliance because there are no visible or immediate negative effects to going off diet, like a person with diabetes may have. That said, I will never forget seeing a girl with her family in the waiting room of my geneticist who was not feeling well. Doctors told her she was going to need to be admitted to the hospital. I knew that I wanted to live, and not get sick, but I also wanted to live happily and my way. Needless to say, this was confusing for young me to process.

As I have gotten older, my concept of what it means to be happy and stay alive has changed. I appreciate how lucky I am to be healthy, despite my diagnosis. I have reached an age where I am comfortable accepting support from loved ones and others with HCU. Being home during this COVID pandemic really helped me evaluate my life and how I want to live it. I got engaged and married last year. My husband and I want to start a family soon. Now it is not me against the world, it is me making the necessary changes to live a long life and achieve my dream of having my own family. I am fortunate that I have had a chance to grow and mature to live for something beyond myself.

I am so grateful to my husband, mother, and the rest of my family for their patience and support throughout this process. I am also grateful for Danae and the HCU foundation, in addition to the scientists working on improved newborn screening, as well as a possible cure.





# Cambrooke is excited to support the HCU Community

**FRESH, FRUITY,**  
*Feel Good*

## HCU FORMULA

We continue to innovate so you have more variety and choices.

*you're rare...we care!*

- ✓ Great Refreshing Flavor: **Lemon Lime**
- ✓ Flexible for all ages: **15g PE & 150 kcals**
- ✓ Low Volume: **Mix with 5 oz water**
- ✓ Optimized Bone Health Profile: **Vitamin K2 and - PRAL**



## Is Your Pantry Ready for the Cooler Weather?



Visit [cambrooke.com](http://cambrooke.com) to find easy, tasty & Hearty Recipes that will keep you warm this season.



Baked Mini-Frittatas



Cheddar Broccoli Soup



Yuca Tater Bake



"Chicken" Parmigiana



Soft Pumpkin Cookies

To request a sample visit [samples.cambrooke.com](http://samples.cambrooke.com)

To place an order call **Customer Service** at 866 456 9776, option 2



# THIS WEEK'S MENU

Each day has meals for <10 grams (g) of protein/day,  
20-30 g. of protein/day, and 30-40 g. of protein/day.

M

**Breakfast:** Waffles & Fruit  
**Lunch:** Grilled Cheese & Fries  
**Dinner:** Southwestern Salad

T

**Breakfast:** Cereal & Fruit  
**Lunch:** Pita Pockets  
**Dinner:** Veggie Pasta

W

**Breakfast:** Cinnamon Roll & Fruit  
**Lunch:** Soup & Salad  
**Dinner:** Burger & Pretzels

T

**Breakfast:** Pancakes & Fruit  
**Lunch:** Burrito Bowl  
**Dinner:** Broccoli Alfredo Pasta

F

**Breakfast:** Biscuits and Gravy with Fruit Salad  
**Lunch:** Veggie Wrap & Chips  
**Dinner:** Chunky Veggie Pasta

## Shopping List

Click each day to view the week long menu!

**Disclaimer:** This meal plan is intended to be a foundation or guide to what meals could look like on a low protein diet. It does not take into account individual caloric, protein and formula requirements, which are all patient-specific. Please consult with your metabolic geneticist and dietitian prior to making any significant dietary changes or following any meal plans of which you are unsure.

# NEWS YOU SHOULD KNOW



## Flavis Brand Discontinuation Alert for US Customers

Effective December 31, 2021 Flavis.us products will no longer be available in the United States. Place your orders NOW.

PKU News & Homocystinuria - HCU Network America have attempted to work with both Schär (parent company of Flavis) and Vitaflo VitaFriends to ease this transition, but the decisions were finalized long before we were informed that changes were being made.

Here is the statement from Schär : After transferring parts of our Medical Nutrition business to Vitaflo (Nestlé Health Science) this past July, Flavis was no longer able to sell its products directly to patients with inborn errors of metabolism, or third parties who served those patients. With this change, Flavis business operations have become unsustainable for the US market. We would like to thank the IEM community for being such a strong supporter of the Flavis brand from the beginning. We hope to be able to bring the Flavis brand back to the US in the future.

PKU News/HCU Network America asked Vitaflo for information on whether they will be providing a low-protein foods brand to US customers, but have only been told that a statement will be forthcoming. We will provide you with information as soon as we receive it.

**2021**  
**Open**  
**Enrollment**



## November Marks Beginning of Open Enrollment for Health Insurance

Do you find your insurance coverage inadequate for low protein foods, formula, betaine, or supplements? Don't fret—November marks the beginning of open enrollment for new health insurance policies.

Feeling overwhelmed? Not sure what policies cover your doctors and your medications? Don't worry, we can assist you with that!

Raenette Franco of Compassion Works Medical is able to assist you with your needs. Raenette can help you find a policy that works for you, or work with your current policy to help you get low-protein foods, medical formula, betaine and "supplements" covered. There is no fee to work with Raenette, but we do urge you to contact her immediately if you do need a new policy. Open enrollment for 2021 ends December 15, 2021.

Contact Raenette at [raenettef@compassionworksmrs.com](mailto:raenettef@compassionworksmrs.com) | (973) 832-4736



# HCU AWARENES RECAP

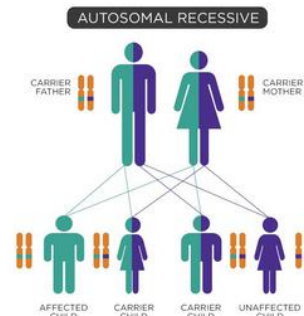
## Social Media Reach

Social Media is a powerful tool when you are using it to raise awareness. Not only does HCU Awareness Month bring attention to our organization and the actual disease, but it also draws attention to other issues related to homocystinuria. We see a lot of growth thanks to those who follow along with us and share. During the month of October, we gained 59 Facebook, 20 Twitter, and 15 Instagram followers. Over the course of the month, we reached thousands of people! We can't thank our community enough for participating in HCU Awareness month!

**With 9 shares, our HCU Awareness 2021 Day 2 fact had the most shares.**

*#HCUAwareness2021: #HCUFact 2 - #Homocystinuria follows an autosomal recessive pattern. This means that both parents have to be carriers in order to have a child with one of the homocystinuria's. The one exception is Cobalamin X - which in addition to being autosomal recessive is X-linked.*

## AUTOSOMAL RECESSIVE INHERITANCE



**With 11 shares, our HCU Awareness 2021 Day 10 activity post had the most shares.**

Day 10 of #HCUAwareness2021 : Real Cost of HCU: Grocery Cost Comparison.

This chart doesn't even touch the cost of formula or some of the required supplements, such as B12. Formula is like a protein shake minus the amino acid methionine. While protein shakes come in large containers and run \$20-60 a month, medical formula cost families hundreds, sometimes even thousands of dollars each month.

B12 comes in many forms, pills, liquids, sprays and injections, but the only kind Cobalamin Patients should receive is the injectable kind (SubQ Hydroxocobalamin). On average, B12 is \$300-400 a month.

While these things are medically necessary, the insurance coverage varies greatly by state. Some states there is absolutely no coverage for low protein food, formula or supplements.

**Thank you to everyone who participated in activities and shared during our 2021 HCU Awareness Month!**

Cost of Low Protein Foods			
Comparing Common Products with Their Low Protein Alternatives			
	Low-protein Regular	Loaf of Bread	Loaf of Bread
		\$13.99	\$1.68
	Low-protein Regular	Bag of Pasta (17.5oz)	Box of Pasta (16oz)
		\$11.49	\$1.18
	Low-protein Regular	Box of Rice (500g)	Box of Rice (396g)
		\$11.00	\$2.18
	Low Protein Regular	Yellow Cake Mix (14.4oz)	White Cake Mix (16.25oz)
		\$5.73	\$1.24
	Low Protein Regular	Plain Bagels (8 count)	Plain Bagel (6 count)
		\$13.49	\$2.98
	Low Protein Regular	American Cheese Singles (32 slices)	American Cheese Singles (32 slices)
		\$13.49	\$5.24 (32 slices)
	Low Protein Regular	Cheesy Broccoli Go Pockets (2 count)	Chicken, Broccoli, Cheddar (2 count)
		\$9.99	\$2.00 (2 count)



# HCU AWARENES RECAP

## FABULOUS HCU AWARENESS FUNDRAISERS





# RESEARCH OPPORTUNITIES



## The group would like to identify:

- pregnant females affected with Cobalamin Deficiency or Remethylation Disorder; and
- pregnant females where the foetus is affected with Cobalamin Deficiency or Remethylation Disorder.

## Their goals are:

- to document clinical management throughout the pregnancy, with a focus on therapeutic options
- to review the safety data of betaine and hydroxycobalamin as therapies
- to review the acute and long-term clinical maternal and foetal outcomes
- to develop consensus guidelines on their management

## Contact:

Dr. Karolina M. Stepień, Salford Royal NHS Foundation Trust, Manchester, ENG | [karolina.stepien@nca.nhs.uk](mailto:karolina.stepien@nca.nhs.uk)



# RESEARCH OPPORTUNITIES

# HOMOCYSTINURIAS DATA COLLECTION PROGRAM

STRENGTH IN NUMBERS



## About The Homocystinurias Data Collection Program

The HCU Networks have partnered with RARE-X to drive a Data Collection Program for the homocystinurias. The RARE-X platform enables the gathering, structuring and sharing of critical patient data at scale. This patient data will help accelerate research, drive disease understanding and enable the development of new diagnostic tools and future treatments and cures.

The HCU Networks are building the Homocystinurias Data Collection Program to:

- Inform researchers how homocystinurias impact patients and change over time
- Enable better data to use in drug development and clinical trials
- Give patients the opportunity to participate in clinical trials
- Reduce the time it takes to study new medicines
- Accelerate the time to get treatments to patients
- Enable the use of data as a placebo (instead of actual patients) in a clinical trial

## Privacy and Security for Patient Data Collection

The Homocystinurias Data Collection Program is patient-owned and enabled by RARE-X technology. All data governance, consent support, and data security are delivered by RARE-X. Privacy is something RARE-X takes seriously and patient names are never revealed.

## Watch the webinar from October 30th and learn more

[https://youtu.be/9KuS\\_Ey9KO0](https://youtu.be/9KuS_Ey9KO0)

**An email will go out later this month with the link to sign up!**

# RESEARCH OPPORTUNITIES

## HCU Networks Research Grants

2021



GRANT RECIPIENT



2019



KEN MACLEAN

2018



TOMAS MAJTAN

### Scientific Advisory Board



Prof Henk Blom



Prof Viktor Kožich



Prof Matthias Baumgartner



Prof Warren Kruger



Dr Andrew Morris



Dr Kimberly Chapman

### Patient Representatives



Margaret McGlynn



Tara Morrison

HCU Network Australia

HCU Network America

A common goal of the HCU Networks is to accelerate research on homocystinurias. Our HCU patient community fundraising efforts have enabled research grants to become a reality for the HCU Networks. Each year we have witnessed an increase in Expressions of Interest submitted by researchers. It is inspiring to see the momentum growing and rewarding to bring further interest to the field of homocystinuria research, so that patients with HCU and related disorders can have better treatments available to manage their disease. To learn more visit <https://hcunetworkamerica.org/our-projects/>





# Support us when you shop this holiday season

Buy your gifts and holiday essentials at  
[smile.amazon.com](https://smile.amazon.com). You shop. Amazon donates.

**amazon**smile

## What is Amazon Smile?

Amazon Smile is a simple and automatic way for you to support HCU Network America every time you shop, at no cost to you. When you shop, you'll find the exact same low prices, vast selection and convenient shopping experience all with the added bonus that Amazon will donate a portion of the purchase price to us.

## How do I set it up?

Simply, go to [smile.amazon.com](https://smile.amazon.com), the first time you enter the site it will ask you to designate an organization. Type in HCU Network America and select us from the list. It is important to note that in order for the donations to go to HCU Network America, you **MUST** check out from this url every time - see best practices below for some pointers on how to do this.

## What if I'm already set up and would like to switch to HCU Network America?

1. From your desktop, simply select "Your Account" from the navigation at the top of any page
2. Then select the option to "Change your Charity". From your mobile browser, select "Change your Charity" from the options at the bottom of the page.
3. Type HCU Network America in the search bar and search for the charity.
4. Select HCU Network America charity to update your account

If you are still having trouble, visit <https://hcunetworkamerica.org/amazon-smile/> for the steps with images of how to.

## Best practices for using Amazon Smile on a desktop

Now that your account is set up to use Amazon Smile, it is important to note that Amazon only makes donations to HCU Network America when you checkout from your cart from this [smile.amazon.com](https://smile.amazon.com). This is the only way HCU Network America gets any donations from Amazon Smile.

**Shopping from your phone?** Android and iPhone users, rejoice - you can now shop Smile.Amazon from the app - check out the instructions here- <https://www.amazon.com/b?ie=UTF8&node=15576745011>



## What is Giving Tuesday?

GivingTuesday is 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.

## How do I get involved?

### Give Signup

This year Give Signup is giving away \$50,000 in grants to organizations that raise at least \$100 on their platform on Giving Tuesday. Organizations must be one of the first 500 to raise at least \$100 through their GivingTuesday campaign on November 30, 2021.

We are asking you to assist us in reaching our \$10,000 GivingTuesday fundraising goal. We ask that you to go ahead and set up a individual fundraiser on our Give Sign up Giving Tuesday Campaign page and start to reach out to your friends and family in advance and get them to pledge a donation first thing on November 30th!

## How do I set up a Give Signup fundraiser

Headover to our Giving Sign up GivingTuesday campaign page at: <https://www.givesignup.org/DonationWebsite/HopeConnectsUs/Campaign/HopeConnectsUs> and click the Become a Fundraiser Button. It will walk you through a series of prompts.

Please feel free and customize the personal message and let your donors know how HCU Network America resources, tools and events have benefited you!

You can then connect your campaign to your Facebook page and share via email. In order for donations to be matched by GiveSign up, they must come through your Givesignup fundraising link!





# OUR \$25K MATCH IS BACK!

**That's right, you heard us right!** Thanks to two anonymous donors, any **funds** you help raise from October through December 31, 2021 **will be matched up to \$25,000!**



**We are asking every patient and family to help us raise funds for homocystinuria.** During the winter holiday's warm hearts and generosity can be felt near and wide. During this time, we ask that you share our appeal letter with your colleagues, friends and family.

**See our appeal letter on next two pages, or you can print it from [here](#)**





**HCU Network America**

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Batavia, Illinois 60510

(630) 360-2087

[info@hcunetworkamerica.org](mailto:info@hcunetworkamerica.org)

<http://www.hcunetworkamerica.org>

Tax ID Number: 81-3646006

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:

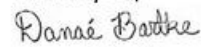
- Help fund Research Grant: In 2021, we have put out a call for Expressions of Interest, to award our third research grant in collaboration with HCU Network Australia.
- Launched the first Data Collection Program for Homocystinuria to help accelerate research.
- Published three guides, including a Parent 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

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



# FOURTH INTERNATIONAL HOMOCYSTINURIAS PATIENT EXPERT VIRTUAL MEETING 30 NOVEMBER 2021

hosted by:



supported by:



sponsored by:



Register at:

<https://www.hcunetworkaustralia.org.au/event/4th-international-homocystinurias-patient-expert-meeting/>

HCU Network America, Organic Acidemia Association, Propionic Acidemia Foundation  
2022 Conference

## LAND OF THE FREE, HOME OF THE BRAVE



Bethesda, Maryland | June 25-26, 2022







Live better, together!

## **Join our Contact Register and Patient Directory!**

### **What is the contact register?**

The contact register is a secured private survey that allows you to share information on you or your family member with HCU with us. This includes where you are from, your relationship to homocystinuria, the patient's birthdate, gender, their exact diagnosis (e.g. CBS, cobalamin, or MTHFR), how they were diagnosed, and if the patient was diagnosed through newborn screening. This information is kept confidential and will not be shared unless you give us permission. By registering, you will be able to identify other patients in your state and request their contact information. You will also be able to access information posted over time that can only be shared with the patient community. (For example, we may have webinars that the expert presenter does not want to be publicly available, but is willing to share with the HCU community.)

### **What will this information be used for?**

HCU Network America strives to inform patients and families with resources, create connections, and support advancement of diagnosis and treatment of HCU and related disorders. The information you provide helps us succeed in our mission - plan events, develop resources and educational tools, and ensure everything is being done to support timely and accurate diagnosis from birth. It also allows us to have informed conversations with doctors, pharmaceutical companies, and law makers. Your information helps us understand the landscape better so we can better advocate for you!

### **How do I participate?**

The contact register form takes approximately 3-5 minutes to complete. You can find the form either by visiting our website and clicking on the "Contact Register" tab, or you can fill it out by going directly to: <https://hcunetworkamerica.org/contact-register/>



Trying to figure out a perfect gift for someone cooking with the low protein diet in mind? Check out this great list of ideas for every level cook! <https://pkunews.org/kitchenwishlist/>