The HCU Herald

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Focused on the Few®

At Recordati, we focus on the few - those affected by rare diseases. They are our top priority and at the core of everything we do.
Our mission is to reduce the impact of extremely rare and devastating diseases by providing urgently needed therapies. We work side-by-side with rare disease communities to increase awareness, improve diagnosis and expand availability of treatments for people with rare diseases.

We are proud to support the mission and vision of the HCU Network America

RECORDATI RARE DISEASES GROUP
Focused on the Few®

www.recordatirarediseases.com / us@RecordatiRare NP-RRD-US-0285

HCU HERO: MATTHEW (CBLC) FROM LOUISIANA

My name is Karen, mom to Matthew. Our story begins way back in 1989 when my husband and I were expecting our fourth child. We were so excited to add another beautiful child to our family. Never did we imagine after having three healthy babies, we would have a child with a rare genetic disorder. But this life is never predictable.

When I was pregnant with Matthew, I took the alpha fetoprotein test because my dad's family has a history of spinal bifida. The test was negative for spinal bifida, but showed a high possibility of the baby having Down's syndrome. We didn't proceed with amniocentesis because we had no plan to abort, so we just waited and prayed. Matthew was born in late April of 1990 via caesarean section since my other 3 kiddos were delivered this way. He was a beautiful baby and did not have Down's syndrome so we were thrilled. But that excitement was very short lived. First, he had some breathing issues and his lungs seemed a little underdeveloped. Then we were told he had a heart issue and we were sent to a larger hospital nearby in New Orleans, Louisiana. The heart issue is called pulmonary stenosis, and we were told we would have to watch it closely and if it got worse as he grew, he would need to have surgery. So far, his heart is ok, some thickening of the lining, but all in all he is doing ok.

Next came feeding issues; he vomited everything we fed him. We tried so many formulas, nothing would stay down. When he wasn't vomiting, he was gagging. It was nightmarish gagging. We ran tests to check his stomach, but there were no issues. Then while dealing with this he kept having ear infections as a newborn. We finally took him to an ENT specialist and he said Matthew needed tubes in his ears at 2 months old. He also said Matthew had something called laryngomalacia, the throat muscles were so weak and floppy that it caused his vomiting and gagging. He said time would fix the problem. Our next issue was his eyes; they operated independently and shook a lot. I took him to a pediatric eye doctor who said he had strabismus and nystagmus and needed surgery on both eyes. He had surgeries to correct this.

By the time he was 5 months old he still could not support his head or trunk. I finally took him to yet another doctor who I credit for saving Matthew's life. She took one look at him and knew something was wrong with him, really wrong. You see, all this time I took him to countless doctors and they concluded that I was just looking for issues because of the trauma of thinking he was going to have Down's syndrome. Yes, my fourth child and they didn't think I knew what a 5-month-old should look and act like. 😣 The neurologist I saw started with bloodwork, ordered an EEG, and urinalysis. The EEG

showed brain damage. Urinalysis showed Methylmalonic aciduria. As sad as I was to hear this news, I was ecstatic to know I wasn't crazy! Dr. Tardo connected me to Dr. Shapiro, a geneticist at Tulane hospital in New Orleans. .

The very first visit he gave Matthew a hydroxocobalamin injection and Matthew stopped the constant gagging and vomiting. It was miraculous... for a little while. We learned to give him the daily injections, Carnitor and Cystadane. Life was good for 6 weeks and then more problems! He started screaming day and night, vomiting again, and having violent fits. Again, I took him to see various doctors! No answers. Then one day I noticed his eyes were rolling downwards. I rushed him to my pediatrician, and he said it was called sunset eyes and to get him to New Orleans right away. He had hydrocephalus; fluid buildup on the brain. We had to place a VP (ventriculoperitoneal) shunt from his brain to his stomach to drain the fluid. The next 8 years were hell. The shunt constantly broke or clogged requiring more surgeries. Not to mention all the stomach bugs he caught, and he even caught chicken pox (which almost killed him)! Eventually things got better and he started gaining weight, walking and "talking" or should I say communicating with those who were around him daily.

Left to Right: Tommy, Karen, Allison, Matthew, Rachel and Adam

All this being said, my other three children were amazing throughout Matthew's lifetime. I don't know how I managed to keep up with them and their activities and also Matthew and all his doctors and therapies, but we did it! There is plenty more I could say about Matthew, but I am afraid it would be a book when I am done.

Matthew is a happy, healthy young man. Still in diapers and needs total assistance for bathing, brushing teeth, dressing, feeding, etc. His siblings and their children adore him. He loves to bowl, watch movies, play video games, and go to Disneyworld. He is now almost 32 years old, weighs 215 lbs., walks, kind of talks, and unfortunately still has shunt issues! We just had to replace it this past summer!

Life is tough as I am now almost 62 years old and a grandmother to 6 beautiful grandkids plus Matthew! Seems the physical part is starting to affect my back and knees, but I will survive.

My heart goes out to all of you reading this since we are all in the same boat.

<u>But the joy that Matthew brings out in all who meet him tells me he is certainly a gift from God and was put on this earth to show us all what pure love is.</u>

Karen and Tommy

The grandkids: Jane, George, John, Scarlet, Audrey and Laura

SCHOLARSHIP OPPORTUNITIES

Living with a rare disease means managing unique challenges, including frequent doctor visits, rigorous treatment regimens and hospitalizations, and exposure risks. While quality and duration of life continues to improve thanks to improved diagnosis and treatment approaches, individuals living with rare diseases still face disparities in achieving traditional life milestones.

That's why The EveryLife Foundation for Rare Diseases established the #RAREis Scholarship Fund – to enrich the lives of adults living with rare diseases by providing support for their educational pursuits. Thanks to the support of Horizon Therapeutics RAREis, one-time awards of $5,000 each will be granted to up to 32 recipients for the Fall 2022 semester.

Applications for Fall Semester 2022 will close April 22, 2022
Learn more and apply here: https://everylifefoundation.org/rare-scholarship/

WILL YOU BE OUR NEXT HCU HERO?

Tell us:

- How you or your child was diagnosed?
- How has HCU affected you, your family and relationships?
- What are some of your successes with HCU
- What are some of your challenges you have faced?
  - How have you overcome them?
- What words of advice would you give to newly diagnosed families?
- For other patient stories, visit: https://hcunetworkamerica.org/patient-stories
- Email your story to: info@hcunetworkamerica.org

Marinated Jackfruit BBQ

***Yields 5.6 servings* | Serving Size: 2 oz. | Protein per serving: 1.1 g | Calories per serving: 82**

Ingredients:

- 1/2 c Vegetable Broth
- 1/2 c Barbecue Sauce

Marinade

- 1 20-oz. can Jackfruit, canned, drained, seeds removed
- 1 tsp Garlic Powder
- 1 tsp Onion Powder
- 2 TBSP Bragg's Coconut Aminos
- 1/2 tsp Ginger, ground
- 1/2 tsp Liquid Smoke
- 2 TBSP Apple Cider Vinegar
- 2 fl.oz. Red Wine
- 2 fl.oz. Vegetable Broth

Notes

- You can omit the red wine and just use extra broth in the marinade.

Directions:

1. Prepare the jackfruit by removing seeds, rinsing well, and squeezing excess water from the jackfruit. Combine jackfruit and all ingredients for the marinade in a bowl. Gently toss together to coat the jackfruit. Place in a sealable container and marinate for at least 30 minutes.
2. In a medium saucepan add the marinated jackfruit, the 1/2 cup vegetable broth, and the 1/2 cup BBQ sauce. Bring to a simmer over medium heat and cook until the jackfruit is soft and can be pulled apart with a fork. It should take about 15 to 20 minutes. In the meantime, preheat the oven to a low broil and line a baking sheet with foil. Spray baking sheet with cooking spray.
3. Remove cooked jackfruit from the saucepan and place it on a prepared baking sheet. Pull gently with two forks. Place into oven to broil making sure to check often. Remove once the jackfruit has browned. It should only take a few minutes. Serve immediately

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: Omelet
Lunch: Nuggets and Pretzels
Dinner: Pasta Alfredo

T
Breakfast: Cereal & Fruit
Lunch: Pizza and Salad
Dinner: Tacos

W
Breakfast: Pancakes
Lunch: Soup and Salad
Dinner: Spaghetti and "Meat"balls

T
Breakfast: Yogurt & Muffin
Lunch: Portabello Wrap
Dinner: Macaroni and Cheese

F
Breakfast: Waffle and fruit
Lunch: Asian Stir Fry Pasta
Dinner: Burger and Pretzels

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.

April 2022, HCU and You: Ask Methia

Dear Methia

Low-protein camp, is it to good to be true?

This summer, for the first time EVER, I will be going away to summer camp. I'll be attending with other people my age who also have HCU, and other conditions that require them to follow low protein diets. I am excited to spend a week away from my parents, but I am also terrified! My parents plan my meals and make my formula every day. What if the camp doesn't know about my specific dietary restrictions, or they don't make my formula the right way? What if I don't like being away at camp? Am I worrying all for nothing?

Sincerely,
Summertime Scaries

Dear *Summertime Scaries,*

Going to summer camp is one of many "rites of passage!" Not only will you be able to experience being away from home, but you will be connected with people to whom you can truly relate. There are many camps around the country that are specifically for people with inborn errors of metabolism. The primary focus of most of these camps is, of course, to have fun and connect with your peers. However, the underlying purpose is to empower you to make healthy choices, and begin to take charge of your own medical condition. Here are some things you can expect:

- Everyone will be aware of your diet restrictions. You will be, possibly for the first time ever, among peers who understand your low protein diet. The camp staff and volunteers will be educated about low protein diets (many are metabolic dietitians), and the nutrition content of all of your foods will be disclosed. The staff will know how much formula you are supposed to take and how much protein you can have, as it is information they will collect ahead of time. Rest assured, though – by the end of the week, you will start to feel more comfortable calculating things on your own!
- Camp will be fun, but educational. The week will be full of fun activities and making new friends, but rest assured that the camp staff will have teachable moments worked in throughout. This might be a combination of classroom-style learning, group breakout sessions, and hands-on learning.
- The focus will be to increase independence. Right now, the idea of tracking your own intake seems really scary. When the time comes for you to leave your parents/guardians home, management of your HCU diet will be your responsibility. Think of camp as the first set of "baby steps" to learning how to manage your diet and formula for yourself.

While going away to camp can feel a little stressful, remember that you are going to be in an incredibly supportive environment, surrounded by people who have the same daily obstacles that you do. I guarantee that you will leave camp with both new friends and new tools for managing your HCU!

Sincerely, Methia

FAMILY CAMP

Registration **NOW OPEN!**

June 2-5, 2022
In-person in Oregon
Virtual program available worldwide

- Community
- Family Fun
- Low Pro Food
- Research

Registration is NOW OPEN for both in-person and online programs! Details at pkunews.org/camp

Join the Low Protein Family Camp group to be a part of the fun and remember, camp welcomes individuals with any IEM (not just PKU!), their family, and friends. See you at camp!

STATEMENT ON METABOLIC FORMULA SUPPLY ISSUES AS A RESULT OF THE ABBOTT PRODUCT RECALL

A coalition of IEM organizations have released an updated statement from on supply issues related to the Abbott recall. This site will serve as a clearing-house for updates from these support organizations as the situation develops: https://www.metabolicformula.org/

3/15/2022: As you are likely aware, the FDA has placed a manufacturing and shipping hold on all products produced at Abbott's Sturgis, MI. plant due to reports of bacterial infection in several infants who consumed their Similac, Alimentum, or EleCare powdered infant formulas. Abbott has voluntarily recalled these products. All of Abbott's metabolic formula products are produced in this plant and are therefore affected by the manufacturing and shipping hold. There have been no reports of bacterial infection in individuals using these products and no metabolic products have been recalled. It is not known when this hold will be lifted.

The undersigned organizations have consulted with metabolic dietitians from across the U.S. and Canada, and representatives of Genetic Metabolic Dietitians International (GMDI), the Southeast Regional Genetics Network (SERN), Abbott, Nutricia, and Vitaflo, among others.

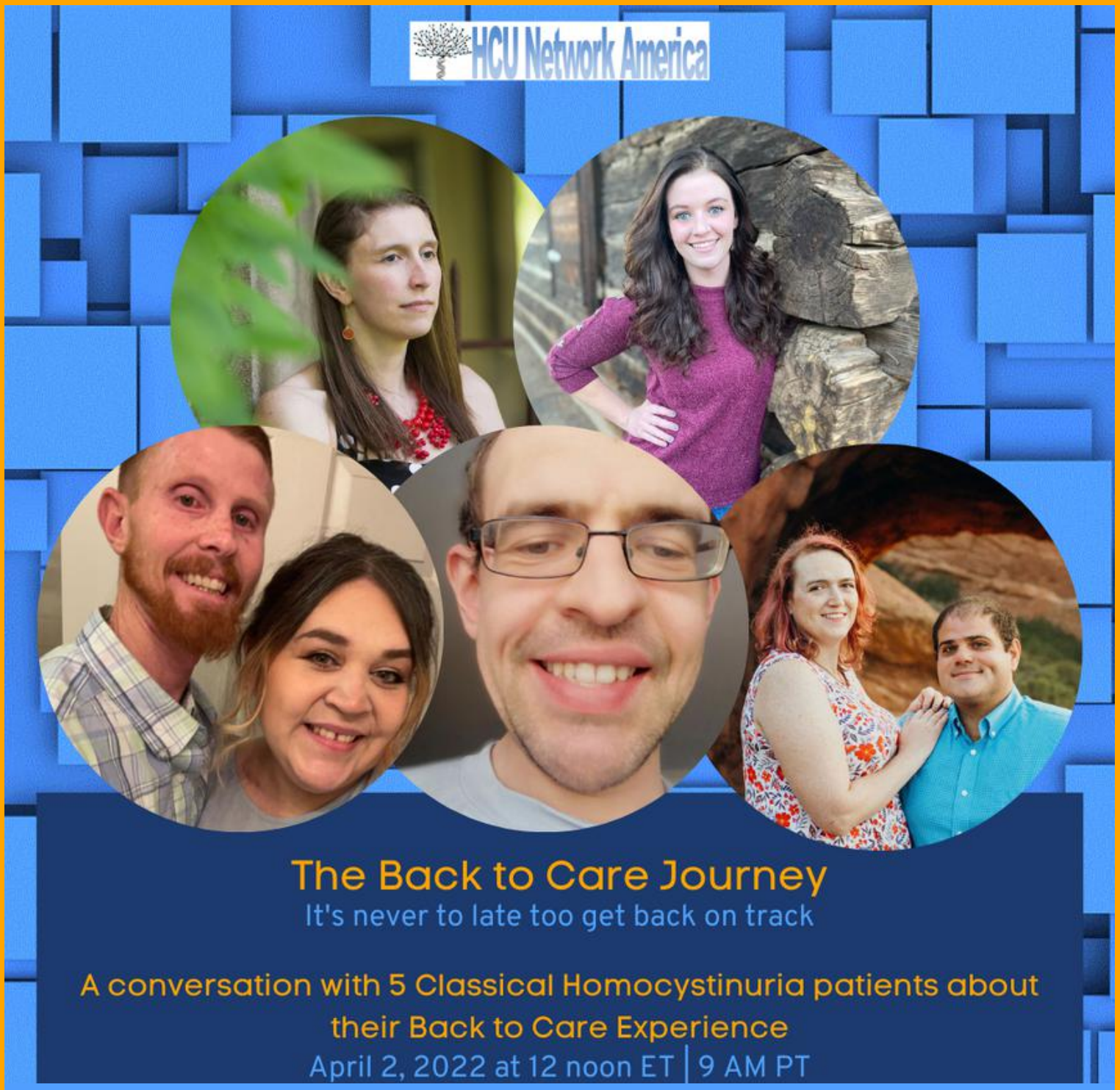
While we hope that the situation at the Abbott plant will be resolved quickly, and that the FDA will release the hold and allow Abbott to resume manufacturing and shipping of metabolic products, we have concluded that the most prudent course of action is for all metabolic patients to work with their clinicians to transition to a new formula as soon as possible as the timeline cannot be predicted.

Please be patient with your clinical teams as they reach out to you to facilitate this transition. This situation has placed an enormous burden on staff on top of their regular responsibilities. Please also understand that some metabolic disorders put people at higher risk of decompensation, and hospitalization, than others. Clinical teams must prioritize those patients, but rest assured they are working hard to make sure all patients have sufficient supply of a formula that is palatable and meets their nutritional needs. Your dietitians understand the challenges involved in changing formula and are doing their best to provide alternatives which will be acceptable to each patient.

We have been in contact with the FDA to express our concerns. They are well aware that metabolic formulas are essential to the health of our community and have issued a statement specifically regarding the metabolic products.

We will stay on top of this situation and keep you informed as new information becomes available.
Abbott Homocystinuria Products effected:

Hominex-1
Hominex 2
Pro-Phree



We know it's easy to stray away, but as patients age, they realize the importance of keeping in contact with their clinic, following their diet, and keeping themselves all around healthy!

Join our patient-moderator Danae, and patients Valerie, Janet, Ashley and Aimee as they share their personal journey that led them back to care.

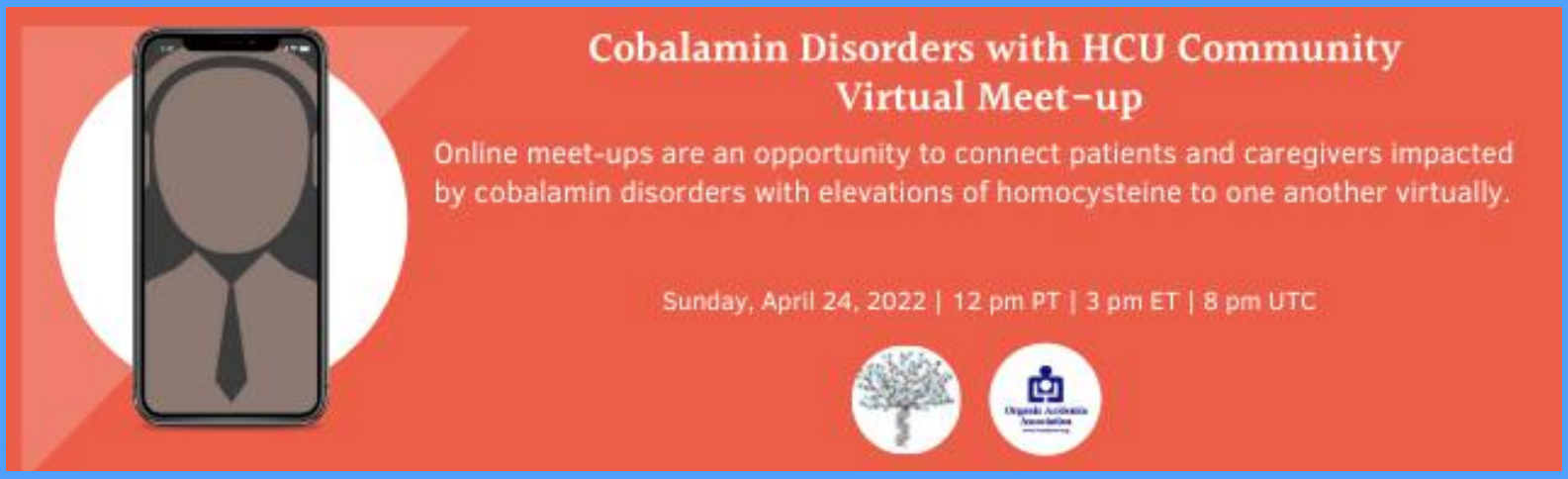
Register here: https://www.eventbrite.com/e/276087052807

Learn more about the HCU Network America Back to Care program at https://hcunetworkamerica.org/back-to-care

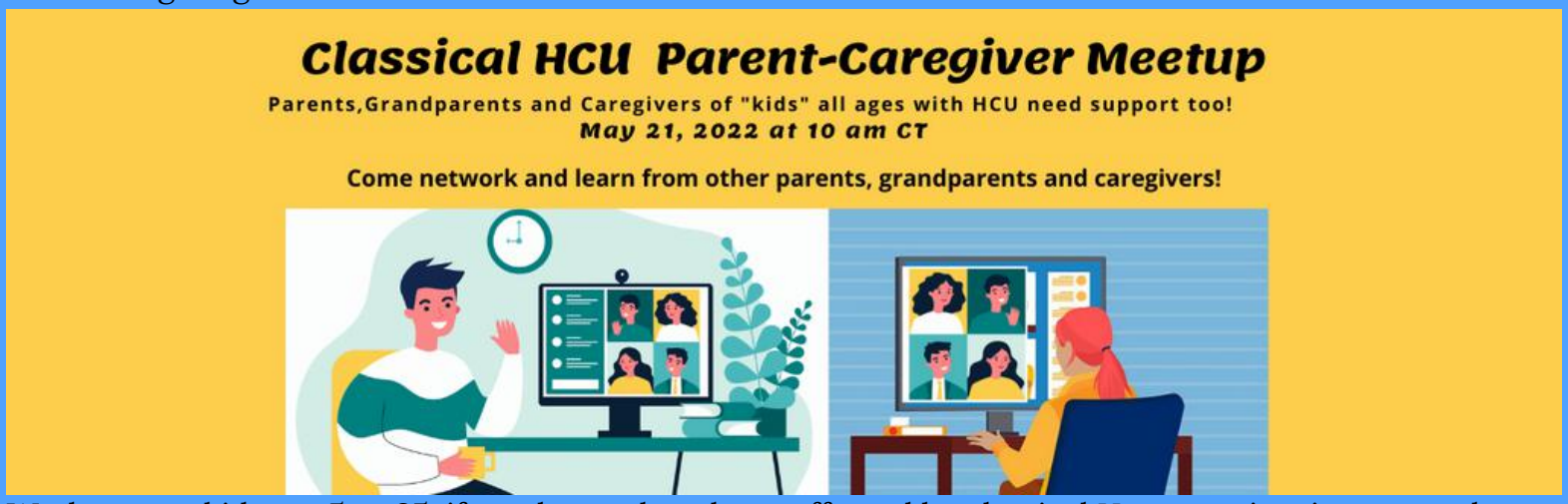
UPCOMING EVENTS

Register now at:
https://www.eventbrite.com/o/hcu-network-america-30163980100

Join HCU Network America and Chef Amber as she demonstrates for us 3 quick and easy low protein dishes! All low protein patients and caregivers are welcome!



Join our host Brittany Parke, a Cobalamin G mom for networking, tips, tricks and the support we all need when navigating a rare disease!

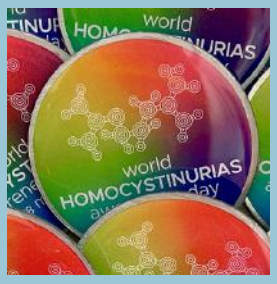


Wether your kids are 5 or 25, if you have a loved one effected by classical Homocystinuria you need support! Come join our host, Elizabeth Carter for our Spring Parent-Caregiver meetup!

world HOMOCYSTINURIAS awareness day

18 MAY 2022

JOIN THE GLOBAL MOVEMENT



Want a World Homocystinurias Awareness Day pin?

Email us at dbartke@hcunetworkamerica.org
Suggested donation is $5 per pin to cover shipping and handling.

To stay up to date on events planned,
follow the movement on Facebook at:
https://www.facebook.com/HCUGlobalAware

T-Shirt Raffle

April 1 - May 17, every donation of $5 (or increment of $5) to HCU Network America earns a raffle ticket to be entered to win a Homocystinuria - Go Blue for HCU T-Shirt

Tickets can be purchased through our Facebook Fundraiser Event page or by emailing us: info@hcunetworkamerica.org

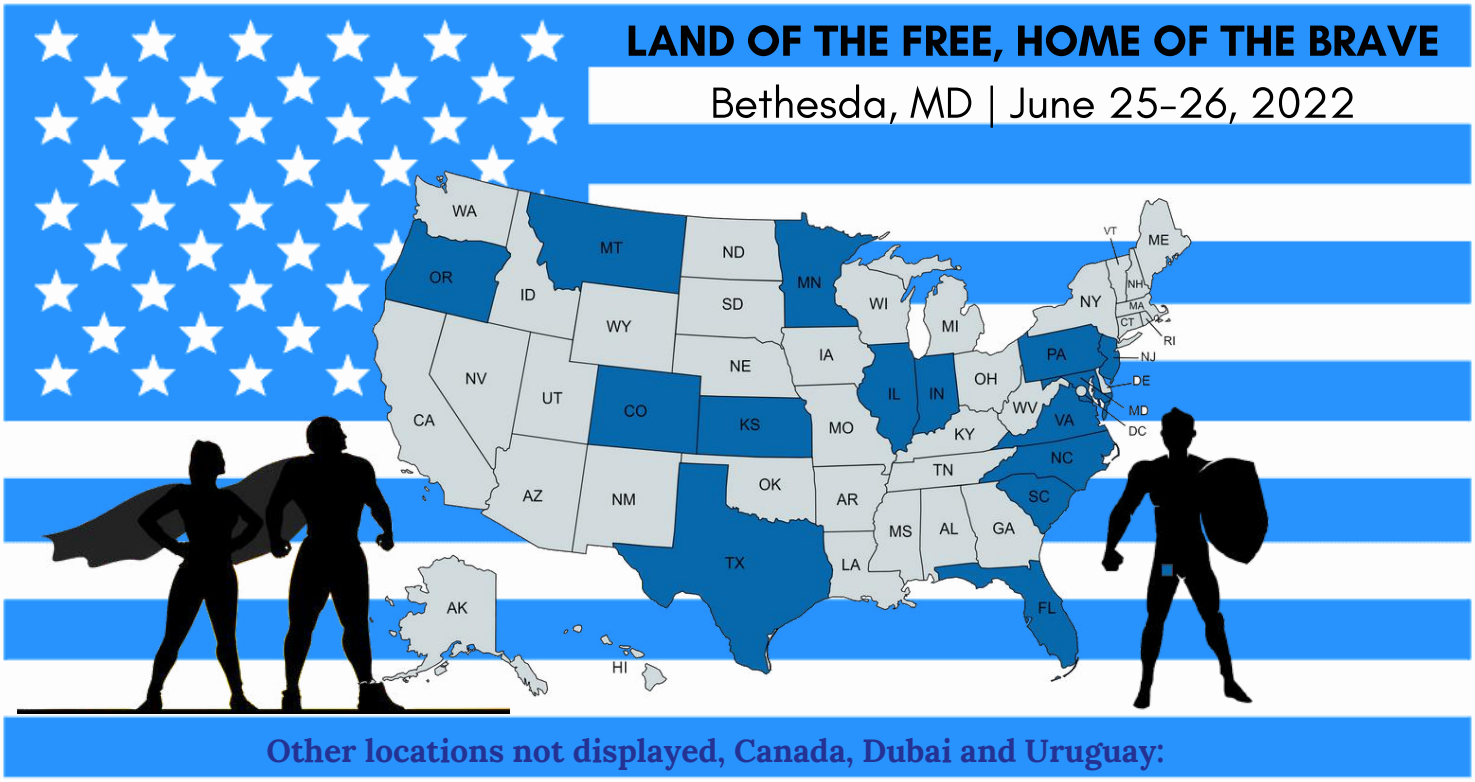
3 Winners will be announced via Facebook Live on May 18, 2022

Get ready for World HCU Awareness Day!

- **You can purchase a raffle ticket: https://www.facebook.com/donate/366933448650459/**
- **or buy your shirt here: https://www.bonfire.com/go-blue-for-hcu-2022/**

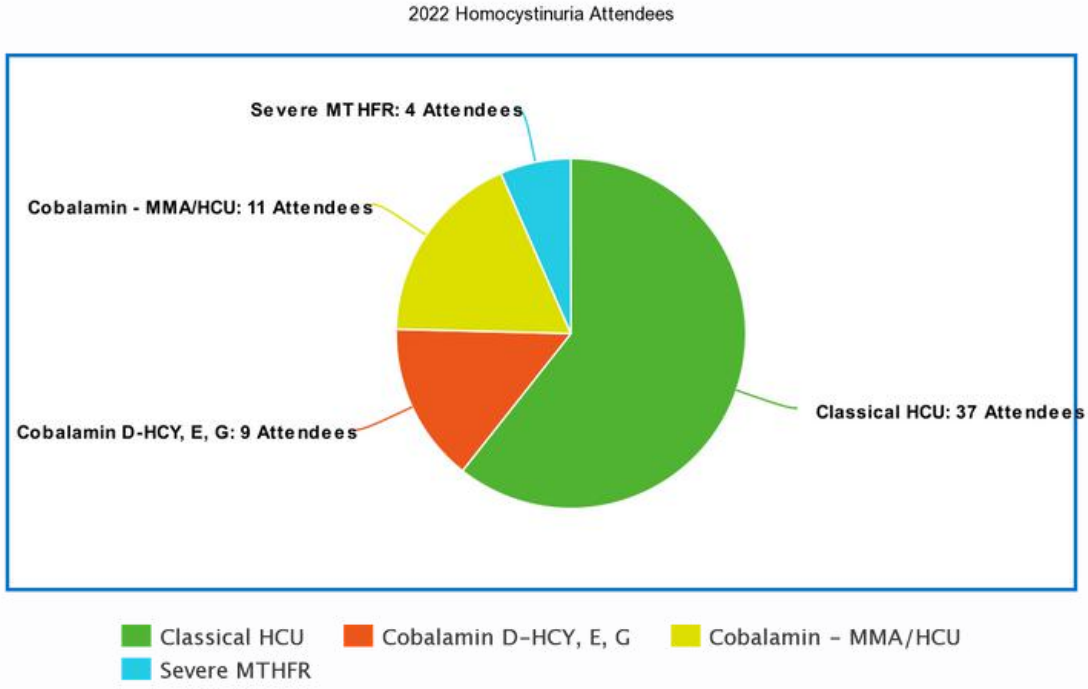
Share with friends and family.

HCU Heroes Unite!



Just 3 months until we reunite with our HCU family!

Join us in Bethesda, MD for HCU Network America's third homocystinuria conference, Land of the Free, Home of the Brave. Join families from across the country in celebrating our brave HCU Heroes. Registration runs till Friday, June 3, 2022! Register at: https://hcunetworkamerica.org/2022-conference



- *All attendees 2+ must wear a mask at all times.
- **All attendees 5+ will be required to show proof of vaccination.
- ***Attendees under the age of 5 will have to present a negative PCR dated no more than 3 days prior to the event.

Attention: Volunteers Needed

For HCU Network America, Organic Acidemia Association and Propionic Acidemia Foundations Conference:
Land of the Free, Home of the Brave
(An "educational meeting" for patients and families affected by homocystinuria, a rare genetic disease)

Pooks Hill Bethesda Marriot | 5151 Pooks Hill Rd, Bethesda, MD 20814

We are now seeking volunteers to assist in our children's program:

- Arts & Crafts
- Educational Lessons
- Stories
- Games
- Hands on activities
- And more!!!

Children's program will take place during the main session of the conference.
(Saturday 8:00-5:30 and Sunday from 8:00-12:00)

Please see available slots at: https://signup.com/go/miiZeeB
or
Direct your contact with days and times of availability to:
Danae' Bartke, Executive Director at
info@hcunetworkamerica.org

Dear Families,

On behalf of the HCU Network America, Organic Acidemia Association and Propionic Acidemia Foundation, we offer our deepest condolences on your loss. We would like to honor your loved one during the upcoming 2022 HCUA, OAA & PAF Conference by having a Hero Remembrance photo poster displayed during the conference's dinner banquet.

If you would like to share a picture of your hero, please email Raymonde Degrace, degracemr@gmail.com. Please include your Hero's first name, type of homocystinuria, state and/or country, birthdate and Angel date. Photos must be received by Friday, June 3, 2022.

With Love,
Danae Bartke, HCU Network America
Kathy Stagni, Organic Acidemia Association
Jill Chertow, Propionic Acidemia Foundation

SEPTEMBER 1-30, 2022

More swag available for fundraisers!

Per Individual: $30

Per Family (up to 4 – 1 mailing address): $50

Save the date:

Registration opens June 1, 2022

APRIL FUNDRAISING REMINDER

Not using Amazon Smile? It's easy, here's how

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 as, 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, the first time you go it will ask you to designate an organization. Type in HCU Network America and select us from the list (or go to our direct link: click here). 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.

Best practices for using Amazon Smile

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 url. This is the only way HCU Network America gets any donations from Amazon Smile. Since this is the case here are some best practices to help you make the most of your Amazon Shopping.

Desktop Users:

If you do your Amazon shopping from you desktop/laptop then you can simply bookmark/favorite this url and do your shopping from this web page

Mobile Users:

Most Amazon shoppers use the app on their mobile or tablet. If you are using your smartphone, be sure to download the Amazon Smile App and follow the directions.

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

RESEARCH OPPORTUNITIES

The HCU Networks (HCU Network America and HCU Network Australia) 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.

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.

Since RARE-X is a nonprofit, there is no cost to you or the HCU community. RARE-X's mission is to serve patients and drive research towards therapeutic development.

Contribute to a brighter future for homocystinuria, register now at:
https://homocystinuria.rare-x.org

HOMOCYSTINURIAS
DATA COLLECTION PROGRAM

The Homocystinurias affect multiple systems of the body!

The most common areas of the body effected are:

- The Central Nervous System (brain)
- Ocular (eyes)
- The Cardiovascular System (heart)
- The Skeletal System (bones)

But many patients experience symptoms outside of these areas!

Your quality of life matters!

Having Homocsytinuria takes a toll on our mental and phyiscal health, our our relationships, and finances. We need to hear from patients and caregivers to learn how to better support their needs.

Complete the Health and Development, and Quality of Life Survey's by May 8, 2022 to have your experience be part of the HCU Network America Conference in June!

HCU Network America HCU Network Australia POWERED BY RARE X

Compose

COMPOSE Study

A study that looks at how safe pegtibatinase is and how well it works in people with classical homocystinuria (HCU)

NOW ENROLLING

Travere Therapeutics has initiated a first-in-human study of pegtibatinase, a new, investigational human enzyme therapy that targets the underlying enzyme deficiency that causes HCU.

The goal of this study is to learn how safe and effective pegtibatinase is and how well it works in people with HCU at different dosage levels.

Approximately 32 subjects will participate in sites in the US. The study will include three key stages (screening, treatment, and extension) and will last approximately 150 weeks.

You (or your child) may be eligible to participate in the COMPOSE Study if you:

- **Have been diagnosed with HCU**
- **Are 12–65 years of age**

You (or your child) will need to meet all other study criteria to take part in the COMPOSE Study.

For additional information on criteria for eligibility, please go to: www.clinicaltrials.gov/show/NCT03406611

Payment for time and travel may be available to subjects who participate in this study.
To inquire about participation in the study, **please contact**:

HCUConnect@labcorp.com

TRAVERE™ THERAPEUTICS

MA-497. August 2021

Live better, together!

Contact Register

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/

It's with heavy hearts, we announce the loss of one of our communities own.

Amanda Jane Nethery

April 19, 1985 - March 13, 2022

Amanda Jane Nethery was born April 19, 1985, and she went to live with Jesus on March 13, 2022, after a lifelong struggle with several severe illnesses. She was born at Darnall Army Medical Center at Fort Hood, Texas. Her family moved immediately to Huntsville, Texas, where she attended school. Upon graduation, she attended and graduated from Texas A&M. She was a fourth generation Aggie on both sides of her family and very proud of her Aggie heritage. She then attended and graduated from Southwest Baptist Theological Seminary in Fort Worth with a Master's degree.

Amanda's true passions were going on mission trips and travel. She went on ten mission trips with the Jesus Film Project, a division of Cru (Campus Crusade), raising all funds necessary to get to the mission field, do the work assigned, and get herself home. She could also talk about all the African, European and Asian airports and the best (and worst) places to eat in those airports. She had grown in her love for nursing. When she left this earth, she was actively involved in taking nursing courses, and was working as a CNA, as well as substitute teaching, which she swore she would never do because her mother was a teacher.

Amanda hated to be known as "the sick girl." Consequently, most people never knew about all the different conditions and illnesses she was plagued by. She loved her family, taking every opportunity to join in frequent family gatherings. She and her daddy loved to go eat wings, go to movies, and find adventures to go on.
Amanda was preceded in death by her grandparents Joel and True Reese; Bettyanne Pratt Nethery; M.J. Nethery, Jr.; and Clyde Reese.

She is survived by her parents, Dr. and Mrs. M. J. Nethery (Skipper and Cindy); her brother and wife Nicholas and Jennifer Nethery; and, her four nephews, Clyde, Graham, Bryce and Reid. She loved those little boys like they were her own, and they loved her right back. Also surviving are uncles Neil (Stacy) Nethery, Larry (Carol) Nethery, and Carolyn Reese.

The family of Amanda Jane Nethery appreciate all the support and acts of kindness we are receiving during this time. Amanda fought the good fight (2 Timothy 4:7), but we will miss her forever.

Visitation will be held on Monday, March 28, 2022 at First Baptist Church in Huntsville at 10:00 am, with a memorial service beginning at 11:00 am. Memorial condolences may be made to the family at www.shmfh.com.

If anyone chooses to make a memorial gift in honor of Amanda, the following are things that were important to her:
-The Jesus Film Project, a part of Cru
-samaritanspurse.org (Samaritan's Purse)
-HCU Network America