The HCU Herald

world HOMOCYSTINURIAS awareness day 18 may

Featuring...

HCU Hero
Aemae from Florida

May 2023

HCU NETWORK AMERICA

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

HCU HERO: AZMAE FROM FLORIDA

It was April 15, 2016. A regular hot, humid, and summer-like feel of Florida's weather and I was sitting waiting at my obstetrician's office to be seen. I was due for my second checkup for the week because my due date was approaching. During this time the doctor was becoming curious on whether my growing baby was small simply due to its genetic makeup or perhaps due to a more serious cause. I was 36 weeks pregnant when I first heard the doctor mention the possibility of having a uterine growth restriction, which can often indicate a number of things, one being the possibility of a genetic disorder. This was my first pregnancy, and upon hearing this news, I was feeling very anxious and hopeless. Although I couldn't see what was ahead of me, I knew I didn't want to listen to the "what ifs" and "could be". And so, more tests were performed, but they were inconclusive. I wanted to keep a positive mindset, but I knew something was unfolding. I continued wishing and hoping for the best; after all, I'm a firm believer that everything happens for a reason. I had always wanted to be a mother and would dream about having my own family - creating memories to talk and laugh about at family gatherings. This was the role that I desired the most: to be called "mom".

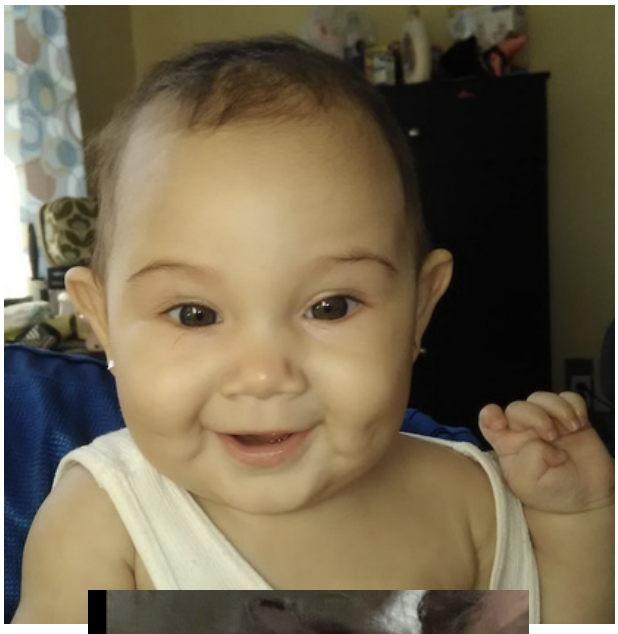
Working in the medical field has assisted me in gaining knowledge about a wide range of scenarios and medical conditions. During the time of my pregnancy, I was working in a pediatric extended daycare so, I was familiar with babies, toddlers, and adolescent children with severe medical conditions. I've heard and witnessed miraculous things, but regardless of the experiences I've had, nothing I knew became relevant to how I was feeling and going through. I felt absentminded and my vision seemed clouded. I believe depression was setting in - I felt so discouraged. I thought I was doing everything "the right way". I was eating healthily and exercising regularly, and I just didn't understand how this could be happening now, so late into my pregnancy. I went to all my appointments and did all the recommended tests. But regardless of all the obstacles I was encountering, I wanted to remain calm for the sake of the baby that was still developing.

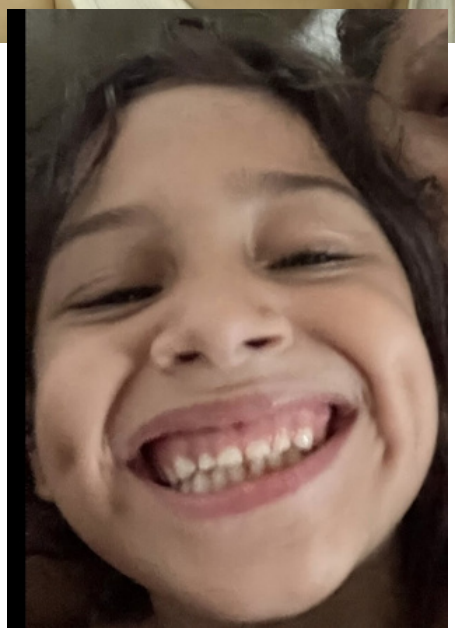
HCU HERO: AZMAE FROM FLORIDA

Throughout my entire pregnancy, I kept the gender of the baby a surprise; not even I wanted to know until the day I gave birth. On April 17th I was sent to Winnie Palmer Hospital in Orlando, FL to begin induction. The baby was not growing, and my amniotic fluid was too low. On the 19th of April, at 12:57 am, weighing 5 pounds and 7 ounces, my beloved arrived, and I named her Azmae.

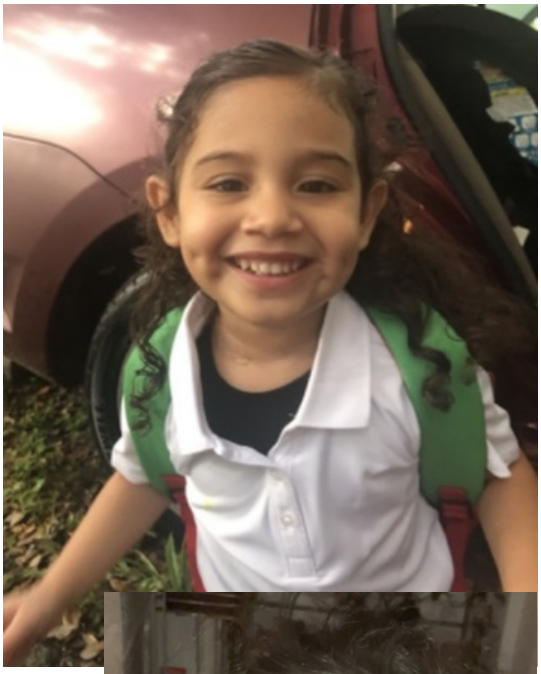
At 3 1/2 weeks old, Azmae was diagnosed with a metabolic disorder called homocystinuria with methylmalonic acidemia. This was recognized by the newborn screening that was conducted at birth and confirmed again during her first checkup with the pediatrician. Prior to being diagnosed, Azmae seemed very lethargic. She appeared to be getting more yellow, as the days rolled by, she wasn't nursing well or gaining weight. It was difficult for her to stay awake and the little time that she was, she was mostly vomiting. For the first few weeks of life, I would syringe-feed her breast milk. I would attempt to bottle-feed her but that was mostly unsuccessful. During the first month of birth, we were mainly in the hospital. When she was admitted into Nemours Children's Hospital, she weighed 4 pounds and 2 ounces. She was diagnosed with infant jaundice around the same time they confirmed her metabolic disorder. Even though being admitted to the hospital helped Azmae establish the care she needed, she still wasn't improving as fast as the doctors wanted. It came to a point where I knew I was fighting against statistics, and physiology. Due to her failure to thrive, the care team was requesting her to have a gastrostomy tube. This tube would be inserted through the wall of her abdomen directly into the stomach. Her medication and liquid food would've been given through this internal nutrition. However, Azmae eventually gained the weight she needed in order to be discharged from the hospital, without the insertion of the G-tube.

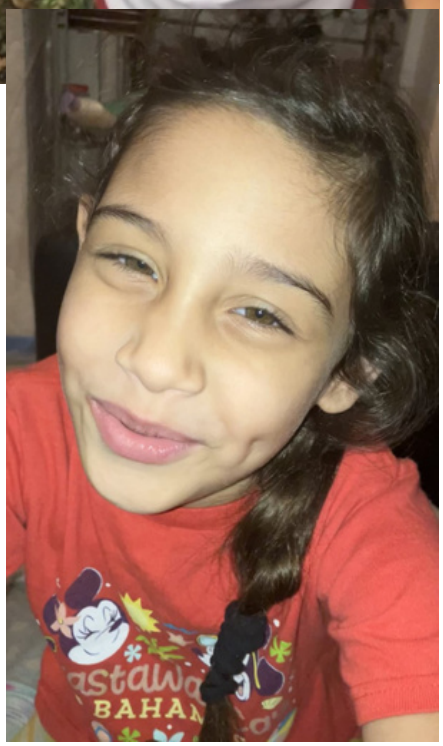
As the months and years passed, testing and regular checkups from her doctors became a norm for our everyday lifestyle. Her breast milk was fortified with a high-calorie formula for about 3 months, which radically assisted in her weight gain. Azmae was permitted into school at the age of 3. She has an IEP and a 504 plan established at school and that is evaluated and updated yearly. She sees an occupational therapist, physical therapist, and speech therapist that assist in improving her quality of life. She has a cardiovascular doctor, who sees her once a year for her ventricular septal defect. She sees an ophthalmologist every 6 months due to macular degeneration, and a neurologist for her nocturnal seizures. Azmae is now a stable, functional, and thriving 7-year-old and visits her geneticist yearly.





As a mother, my journey with my daughter who has complex medical needs has brought with it all sorts of emotions. Azmae has faced many health issues that have made everyday life more difficult, but I believe by providing love and support through it all, has sustained her. Despite the constant visits to the doctors and the hospital stays, my daughter has always been resilient, showing strength beyond her years. She has taught me more about strength, courage, love and living a full life than any other person. Challenges will always be presented throughout our lives but with determination, I hope one day she'll help inspire others to finish strong. As a mother, it has been my role to help her develop the resilience she needs to face the challenges that are ahead. I want to instill in her that she is not weak and that she can overcome anything she puts her mind toward.





I believe in advocating for her needs, seeking out resources and support, and encouraging her to pursue her passion and dreams despite the difficulties she has. Her daily battle has taught me to remain consistent by encouraging me to stay strong. Most days she is a very joyful, curious girl and some days she is worn out. When I'm tired and weak, her smile drives my determination to pursue answers and keep pushing. My goal is to engage with those with the same genetic makeup. Together we have a voice, and we can be seen.

"When I'm tired and weak, her smile drives my determination to pursue answers and keep pushing."

In 2019, we were invited to the NIH (National Institute of Health) by Dr. Charles P. Venditti and his genetic team to participate in a study of cobalamin C deficiency. During this visit, we discussed her daily lifestyle and schedule. It was suggested to us that we administer 30 mg per ml of hydroxocobalamin daily. This helped tremendously with bringing her homocysteine levels to 28. Although she is not on any special diet, the dietician at the NIH recommended that we transition to a plant-based diet as she grows older.

Through our journey together, I have come to appreciate and truly understand the power of perseverance. We've been able to overcome some of the most difficult obstacles that life has thrown our way. Although Azmae is a tiny human being, she is a brave free thinker and acts benevolently while remaining assured. She is quick to forgive and always is the first to extend her hand to help. This is how she displays her heroism every day, and this is why I call her my hero.

To read Azmae's story on our website, visit
https://hcunetworkamerica.org/azmae/

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

Need help getting started?

Email LCarter@hcunetworkamerica.org!

May 2023, HCU & You: Ask Methia

Dear Methia,

I need help explaning my HCU to my friends!

I am a 15-year-old with classical HCU. As I have gotten older, my friends have taken an interest in what I can and cannot eat. It seems to puzzle them, and they ask me questions like "Why can you not eat what we are eating?" or "What is that drink you are always drinking?". I get a little embarrassed and am not sure what to say to them! I do think they are asking out of genuine curiosity which makes me want to help them understand. But I find myself saying "I have homocystinuria", and they seem to look at me with confusion just based on the long name!! It does sound pretty cool having more than my parents to talk about HCU stuff with, so I do want to tell them. Where do I start?!

Thanks!
Confused Kid

Dear Confused Kid,

It's great to hear that your friends are interested in learning more about you! Sounds like you have found some great friends. It can be intimidating to explain HCU and the diet, and you are not alone! I am proud of you for wanting to share and bring your friends along on your journey.
To begin, I would think about it as a process. You and your parents did not learn everything about HCU overnight, and you also cannot expect your friends to understand it all after one conversation either. So, give them grace as they learn from you! You can start with the basics:

1) **What is HCU?**

- Homocystinuria (HCU for short) is a genetic condition where your body is lacking in an enzyme, cystathionine-β-synthase (CBS). As a result, your body cannot break down the amino acid methionine, which is found in proteins that we eat. Depending on what science class you are in, you may be able to relate it to something you are or have learned!

2) **So what does that mean?**

- It means that you must limit the amount of protein that you eat, as eating too much protein will cause a toxin to build in your body and make you sick. You can explain that you will not get sick like a cold or the flu, but if you eat too much protein over time it can affect your vision, bones and joints, you have a higher risk for blood clots and it could affect how you are able to learn. I always suggest modifying this for you specifically as it may be different from someone else with HCU.

3) **How did you get HCU?**

- You inherited it from your parents. HCU is what we call in genetics, autosomal recessive, meaning that there is a 1 in 4 chance to pass down the HCU gene to a baby when both mom and dad carry this gene. Since your biological mom and dad both carried a gene for HCU when they conceived you, the genes came together and you received 1 of these genes from each. This then resulted in you having HCU. You can go back to science class, or even ask your teacher to review the Punnett square to see how it works!

May 2023, HCU & You: Ask Methia

4) **I have never heard of it though, why is that?**

- You are super rare! HCU occurs in about 1 in 200,000-300,000 people in the world. Do not forget to remind your friend how special you are. They likely already know this because of your many talents, but having HCU is a superpower all in itself!!

5) **So what CAN you eat?!**

- A lot of things! But mostly fruits, vegetables, some breads and specialty foods. This topic could take a lifetime to get through, and is very specific to each person with HCU. I would start with the foods you avoid and do not eat, likely meat and other high protein foods, and then talk about what you like to eat most!

6) **How do you grow if you do not eat much protein?**

- Formula!! We can't forget about this! Your formula is super important and provides you the protein and vitamins and minerals you need and cannot get without eating other high protein foods. You have basically been on a special protein shake since you were born! If you do not drink this, your body will not get enough nutrition, specifically "safe protein" (protein that does not have the amino acid, methionine, the one that your body cannot break down) that helps you grow, learn, and get stronger! If they ask if they can try it, it will not hurt them, but only a sip because you need that to be healthy! Also, it may taste strange to them, trying it for the first time. Remember you have been on this for many years and have developed a taste for it, your friends have not. I am sure there is a food that they eat that you may turn your nose up to!

These topics may be enough to get you and your friend started on the journey to learning and understanding all there is to know about HCU. As you know there is so much to learn and it is a process. There are many things that are specific to you that also may come up! Be patient with yourself and your friend as you go along. Remind them that knowing everything about HCU is great, but being able to support you is really what is most needed. They can help by learning to read a food label or asking what you can and cannot have before getting food for a hang-out or event. They can even remind you to drink your formula *(sorry, had to!)*. I love that your friends are interested, and being able to share this part of you with them is so important!

Sincerely,
Methia

Creamed Spinach and Kale

Makes about 7 servings | Serving 3 oz | 1.9 g protein and 103 mg PHE

Ingredients:

- 1 TBSP Butter
- 1/4 c Diced Raw Onions
- 3 clove(s) Garlic, minced
- 170 g Kale, frozen, thawed
- 125 g Violife Just Like Cream Cheese Original
- 56 g Follow Your Heart Parmesan Style Shredded
- 2 oz. Violife Just Like Mozzarella Shreds
- 4 fl.oz. Rice milk
- 170 g Spinach, frozen, thawed and excess water squeezed out

Directions:

1. In a medium skillet over medium heat, melt the butter. Once heated, add the onions and sauté until translucent and aromatic. Add the garlic and sauté for another minute. Next add the kale and sauté for about two minutes. This will allow the kale to soften.

2. Now add the cream cheese and rice milk. Continue to cook over medium heat, stirring occasionally until the cream cheese has melted and is creamy. Add the cheeses and stir until melted and creamy. If too thick, add a little more rice milk. Add the spinach and stir well. Season as needed with salt and pepper. Serve immediately.

HCU in the News

CUMBERLINK.COM

'Nothing but positive': Mechanicsburg's Will Hummel overcomes limitations of HCU to produce on pitching mound

Christian Eby
Apr 5, 2023 Updated Apr 7, 2023

Mechanicsburg starting pitcher Will Hummel could see and feel the changes after adding 35 pounds of weight since the end of the 2022 baseball season.

An offseason bulk is standard for a high school athlete looking to take a step forward in the next season. Muscle mass can help improve strength and durability, and in Hummel's case, it's changed the way he can throw a baseball.

But Hummel's process in gaining that muscle, and the precautions taken throughout, were unique. At two weeks old, Hummel was diagnosed homocystinuria, a rare but potentially serious inherited condition where the body can't process the amino acid methionine. In an effort to avoid severe symptoms, Hummel abstains from high-protein foods like meat and dairy and sticks to a specific, low-protein diet.

Hummel struggled with maintaining weight throughout his life, but through his offseason training and finding ways to get extra calories into his diet, Hummel said his mindset changed entering this spring.

Click **here** to continue reading

Thank you to ***The Sentinel*** for allowing us to share this publication.

NORD®

CLASSICAL HOMOCYSTINURIA MEDICAL ASSISTANCE PROGRAM

MEDICAL ASSISTANCE

What is the purpose of this program?

Having a rare disease is difficult. Adding in the complex care required to treat or manage that disease and figuring out how to pay for it makes a rare diagnosis even harder.

NORD's Classical HCU Medical Assistance Program offers eligible individuals diagnosed with Classical Homocystinuria financial support to pay for the low protein foods necessary in managing this HCU diagnosis.

NORD's HCU Medical Assistance Program opened thanks to a generous donation from the HCU Network America.

Who is eligible to apply?

This program is designed to help patients who:

- Have a diagnosis of Classical Homocystinuria.
- Are a United States citizen or U.S. resident of six (6) months or greater with evidence of residency such as a utility bill showing the patient's name and address.
- Meet the program's financial eligibility criteria.

What is the application process?

Patients may be referred to the program by their health care provider, their case managers, or they may self-refer.

A NORD Patient Services Representative will guide the applicant through the application process and verify eligibility for inclusion in the HCU Program.

Awards are based on meeting eligibility criteria, funding availability, and are made on a first-come, first serve basis.

NORD is Here for You

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD was founded by families struggling to obtain access to treatments and whose advocacy for change led to the passage of the Orphan Drug Act in 1983. NORD assists eligible patients (those with medical and financial needs) in affording the treatments and medical services their healthcare professionals have prescribed.

Alone we are rare. Together we are strong.®

How do I get more information and apply?

Contact NORD's Classical HCU Medical Assistance Program

Monday-Thursday 8:30am – 7:00pm ET
Friday 8:30 am – 6:00pm ET

203-616-4327

203-635-4163

hcu@rarediseases.org

US MAIL to: NORD
Attention: HCU Program
55 Kenosia Avenue
Danbury, CT 06810

What assistance does NORD provide?

NORD's program can assist eligible individuals with the expense of purchasing low protein foods:

- The Classical HCU Medical Assistance Program assists eligible individuals with out-of-pocket costs to purchase low protein foods. Individuals approved for assistance in this program will be issued a PEX card. The PEX card is a prepaid expense card to be used for the purchase of low protein foods only.
- *Upon receipt of the card, the cardholder will contact NORD to request card activation. The card will be funded based on program award caps set for the program (this cap will be discussed with individuals upon enrollment in the program..*
  - *> It is necessary for the individual to submit receipts on a monthly basis evidencing card utilization for the purchase of low protein foods for the previous month.*
  - *> Funds will not be added to the card until the previous month's receipts have been received by NORD.*
  - *> The card may only be utilized for the purchase of low protein foods up to the monthly program limit.*

Once a patient is accepted into the assistance program(s) how long are they eligible?

Awards are issued for a calendar year.

Patients are encouraged to reapply annually if continued assistance is needed.

Program assistance is dependent on funding availability.

What happens if an applicant does not meet the criteria of the Electronic Income Verification?

The NORD Patient Services Representative will offer to e-mail, fax, or mail the brief program application and disclosure forms to the patient. The applicant may then complete the application, sign the disclosure form, provide the appropriate financial documentation to verify financial need, and return them via fax, email, or USPS mail.

How does NORD demonstrate compliance with regulations required of charities?

- NORD independently designs its patient assistance programs based on the needs of specific patient communities.
- No pharmaceutical company or donor controls or influences our programs.
- Our patient assistance decisions are based on consistently applied financial eligibility criteria and diagnosis only.
- Patients have their choice of health care provider, treatment and treatment location, and can make changes at any time.
- Patients' privacy and well-being are priorities at NORD. We do not share or provide patient names or data with donors, nor do we disclose or identify donors to patients. Patients are able to make the choices that are best for them because NORD's assistance covers all FDA-approved products available for a diagnosis. Our programs also help with more than medication: patients can use their funds to pay for other physician prescribed services related to their diagnosis, such as laboratory and diagnostic testing, physical and occupational therapy, durable medical and adaptive equipment, and travel to medical appointments.

NORD®

rarediseases.org

Industry News

Dear HCU Community,

It is with much sadness and disappointment that I share Aeglea is halting all work for Classical Homocystinuria. You may have seen our press release stating our Phase 1/2 study in Classical Homocystinuria did not provide the data expected based on earlier results and is not sufficient to discuss a potential Phase 3 study with regulators. Given this situation, we do not have enough money at Aeglea to be able to fund the subsequent work and therefore we're looking for strategic alternatives. Ideally, we are looking for alternatives with companies having the resources the focus, and a shared goal of bringing these therapies to the broader HCU community.

I am forever grateful to all the patients, caregivers, and physicians that so generously shared of themselves and supported our efforts. I am hopeful the other treatments in development continue to advance quickly towards approval to provide many treatment options for this underserved community.

-Tricia Sterling, VP, Patient Affairs

To view the press release from Aeglea, visit: https://bit.ly/3UASAEa

New Resources

Let's help you *Transition to Adulthood*!

We're adding more resources to supplement our *Transition to Adulthood* milestones guide!

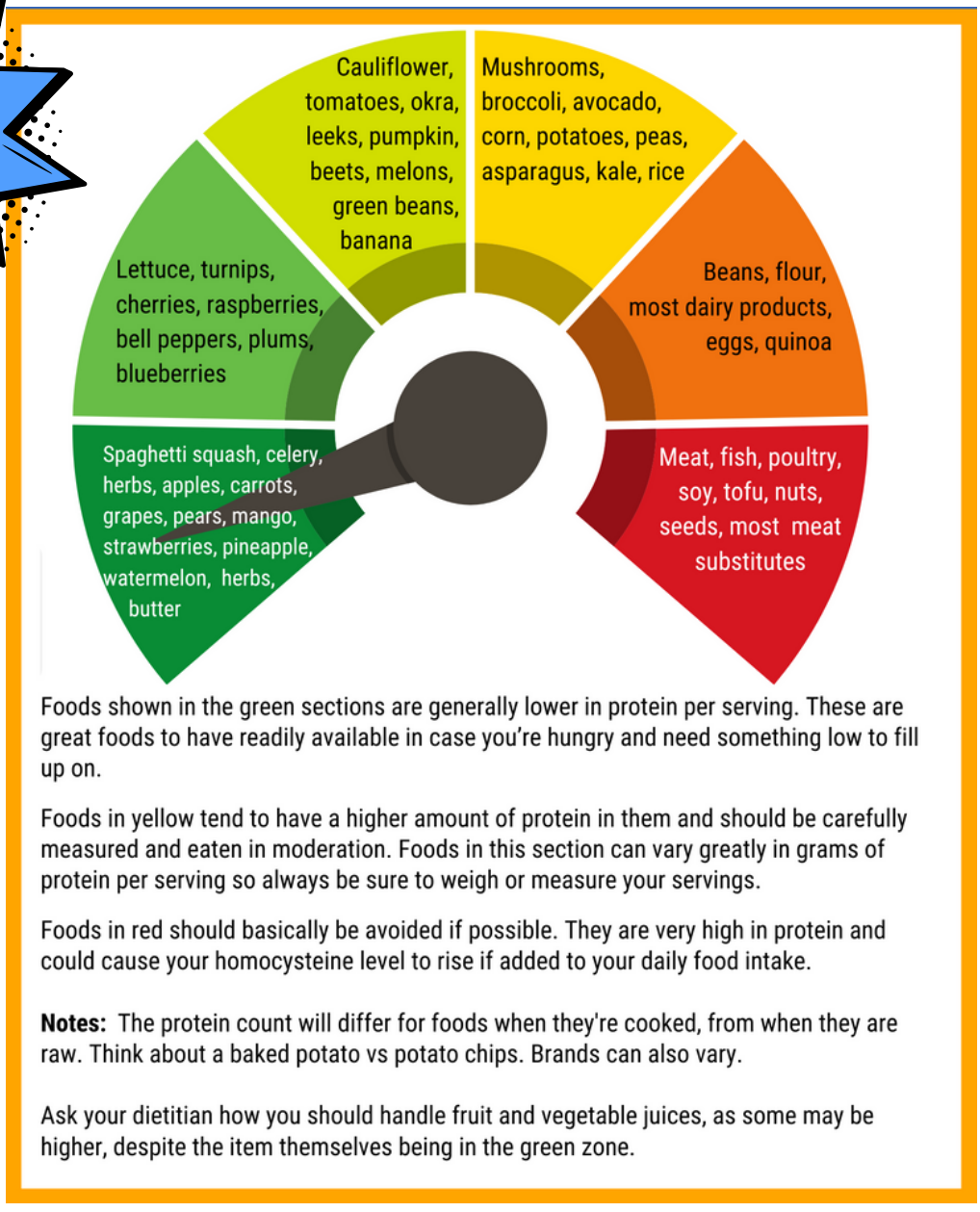
Medications and Medical Nutrition

I have a general understanding of what foods are safe for me to eat.

CLICK HERE

to download this resource

Classical HCU



Foods shown in the green sections are generally lower in protein per serving. These are great foods to have readily available in case you're hungry and need something low to fill up on.

Foods in yellow tend to have a higher amount of protein in them and should be carefully measured and eaten in moderation. Foods in this section can vary greatly in grams of protein per serving so always be sure to weigh or measure your servings.

Foods in red should basically be avoided if possible. They are very high in protein and could cause your homocysteine level to rise if added to your daily food intake.

Notes: The protein count will differ for foods when they're cooked, from when they are raw. Think about a baked potato vs potato chips. Brands can also vary.

Ask your dietitian how you should handle fruit and vegetable juices, as some may be higher, despite the item themselves being in the green zone.

Click **here** to access our *Transition to Adulthood* guide & additional resources!

New Resources

Let's help you *Transition to Adulthood*!

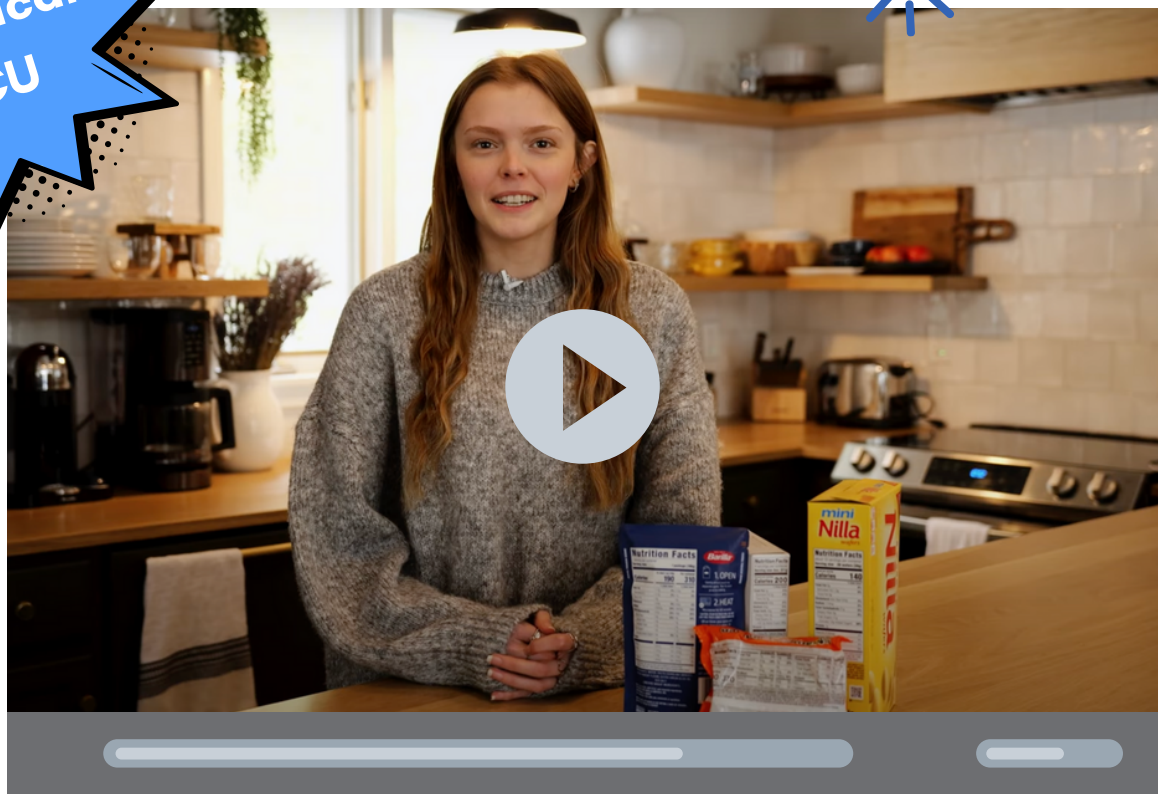
We're adding more resources to supplement our *Transition to Adulthood* milestones guide!

Medications and Medical Nutrition

I can read a nutrition label.

Classical HCU

Click video to watch!



THANK YOU!

*A very special 'Thank you!' to **Gabbi**, **Chloe** and **Brendan** for creating this amazing resource for our community!*

Click **here** to access our *Transition to Adulthood* guide & additional resources!

New Resources

Let's help you *Transition to Adulthood*!

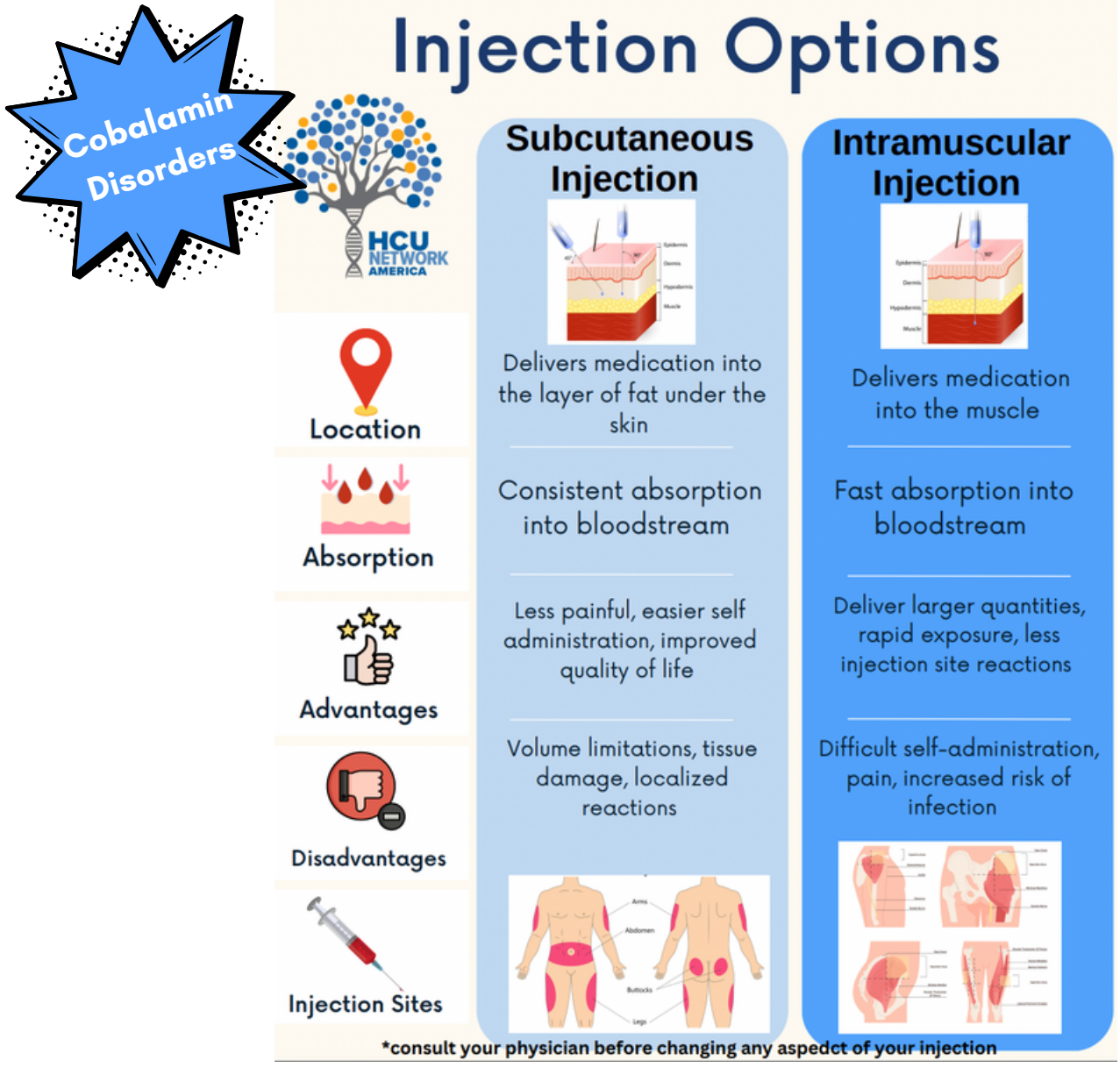
We're adding more resources to supplement our *Transition to Adulthood* milestones guide!

Medications and Medical Nutrition

- ☑ I can give myself an injection.
- ☑ I know how to prepare my injection.

CLICK HERE

to download this resource



Click **here** to access our *Transition to Adulthood* guide & additional resources!

world HOMOCYSTINURIAS awareness day 18 may

WORLD HOMOCYSTINURIAS AWARENESS DAY

Help Bring Sunny Skies For our HCU HEROES Futures

BASKET RAFFLE & LIVE STREAM
May 18, 2023 | 5 pm ET

$5,000 Match for all funds raised!

ON SALE 5/11

MULTIPLE BASKETS TO CHOOSE FROM

BONUS RAFFLE FOR ALL DONATIONS OR TICKET SALES OVER $100!

Benefiting

HCU Network America's conference scholarship fund.

HTTPS://BIT.LY/HCURAFFLE2023

SEPTEMBER 1-30, 2023

HCU HEROES

RACE FOR RESEARCH

WALK / RUN / RIDE

More swag available for fundraisers!

Per Individual: $30

Per Family (up to 4 – 1 mailing address): $75

Save the date: Registration opens June 1, 2023

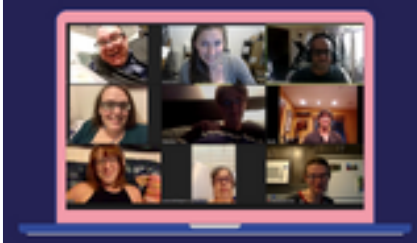
aeglea

HCU NETWORK AMERICA

UPCOMING EVENTS

Find all events at: https://hcunetworkamerica.org/virtual-meet-ups/

Classical HCU Community Virtual Meet-up



Online meet-ups are an opportunity for patients impacted by classical homocystinuria to connect with one another virtually.

Sunday, May 7, 2023
4 pm PT | 7 pm ET

HCU NETWORK AMERICA

Classical HCU Teen meetup

Saturday, May 13, 2023 | 3 pm ET

Classical HCU teen (10-22) meetups are an opportunity for teens with Classical HCU to connect, learn, and share their experiences.

Meet your teen leader: Landon

Landon is a 16-year-old with Classical HCU from West Virginia. He enjoys theater, his adorable puppy Milo, and getting to meet new people!

Register at: https://bit.ly/HCUTeen

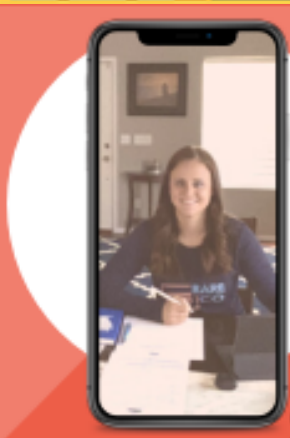
Classical HCU Parent-Caregiver Meetup

Parents, Grandparents, and Caregivers of "kids" of all ages with classical HCU need support too!

Sunday, May 21, 2023 | 4 pm PT / 7 pm ET

Meet your meeting facilitator!

Danielle is a patient with Classical Homocystinuria diagnosed through the Newborn Screening Program in New York City. She resides in Winter Park, FL with her husband Irving, 3 sons and 3 dogs. Thankfully, having HCU is all she knows and has experienced minimal negatives and multitudes of positives. Danielle comes from a large family that serves as an amazing support system which continuously feeds her passion of servant leadership amongst the HCU community. Danielle is excited to lend her experience as a patient, traveler, foodie, and learning and development professional within the "big 5" health care companies to promote that living with a rare disease while simultaneously obtaining success in your passions is possible.



Cobalamin Disorders with HCU Community Virtual Meet-up

Online meet-ups are an opportunity to connect patients and caregivers impacted by cobalamin disorders with elevations of homocysteine to one another virtually.

Saturday, May 27 2023 | 9 am PT | 12 noon ET | UTC+4

Meet your meeting facilitator:

Brittany Parke lives in the Denver suburbs of Colorado with her husband, Robert and three children, Alexis, Riley, and Grayson. While their family is just beginning the journey with Grayson who was diagnosed with Cbl G, they have been involved in the rare diseases community since the birth and death of their son Drew in 2011. Brittany loves to read, run and spend time outside with her family.

UPCOMING EVENTS

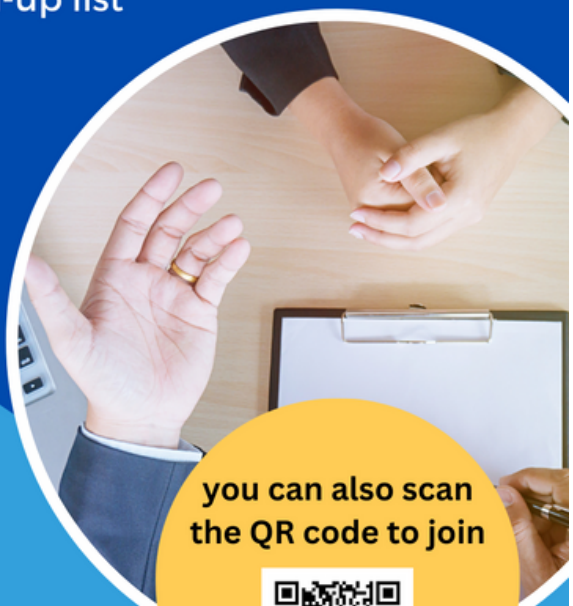
Find all events at: https://hcunetworkamerica.org/virtual-meet-ups/

SURVEY PARTICIPANTS NEEDED!

Attention patients & caregivers of ***Classical HCU***, ***Cobalamin Disorders***, & ***Severe MTHFR***!

You are invited!

Petri Bio is working on a potential solution for HCU. We are trying to better understand the specific needs of those with HCU and the families that care for them. Please click through this 1-min survey to provide your feedback and join the sign-up list for our future products!



If you...

- Have been diagnosed with Homocystinuria (HCU) or another rare metabolic disorder
- Are a caregiver for someone who has been diagnosed with HCU or another rare metabolic disorder
- A researcher/healthcare specialist in the field of HCU or other metabolic disorders

We want to hear from you!

Join Now

More information

https://petribio.com/
info@petribio.com

Click here to take the brief survey!

MAY FUNDRAISING REMINDER

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 2022 we received approximately $45,000 in corporate matching gifts!

How Does this Benefit my Employer?
Companies of all sizes match donations their employees make to nonprofits because it's an easy way for them to support good work in their communities. Corporate Social Responsibility (CSR), is an important factor in how the public perceives brands and companies these days.

Corporate matching gifts are an efficient and straightforward way for companies to build relationships with charities.

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
- BP (British Petroleum) 1:1
- Gap Corporation 1:1
- ExxonMobil 3:1
- CarMax 1:1
- Johnson & Johnson 2:1
- Microsoft 1:1
- Pfizer 1:1
- Coca-Cola 2:1
- Avon 2:1
- IBM 1:1
- And many, many more!

Did you know some companies will match donations from their retired employees?

RESEARCH

Our Rare-X Data Collection program continues to grow!

LET'S CELEBRATE!

We've recently added 5 patients in 3 new states & 1 new country!
We are officially have representation on all inhabited continents!!!

Join the global movement & Be Counted!

https://homocystinuria.rare-x.org/

HCU NETWORK AMERICA

HOMOCYSTINURIAS DATA COLLECTION PROGRAM

RARE X

HOMOCYSTINURIAS
DATA COLLECTION PROGRAM

The Digestive System Survey

"She vomited a lot and was on 13 different formulas before diagnosis. I had a feeling that she had reflux due to all the vomiting. Her doctor ordered an Upper GI test, and it was confirmed that she did have reflux. Medications were not helping, and I had a mother's instinct that something was wrong."

- Misty, Mother to Sienna - MMA w/ HCU Coabalamin C

Complete the Survey

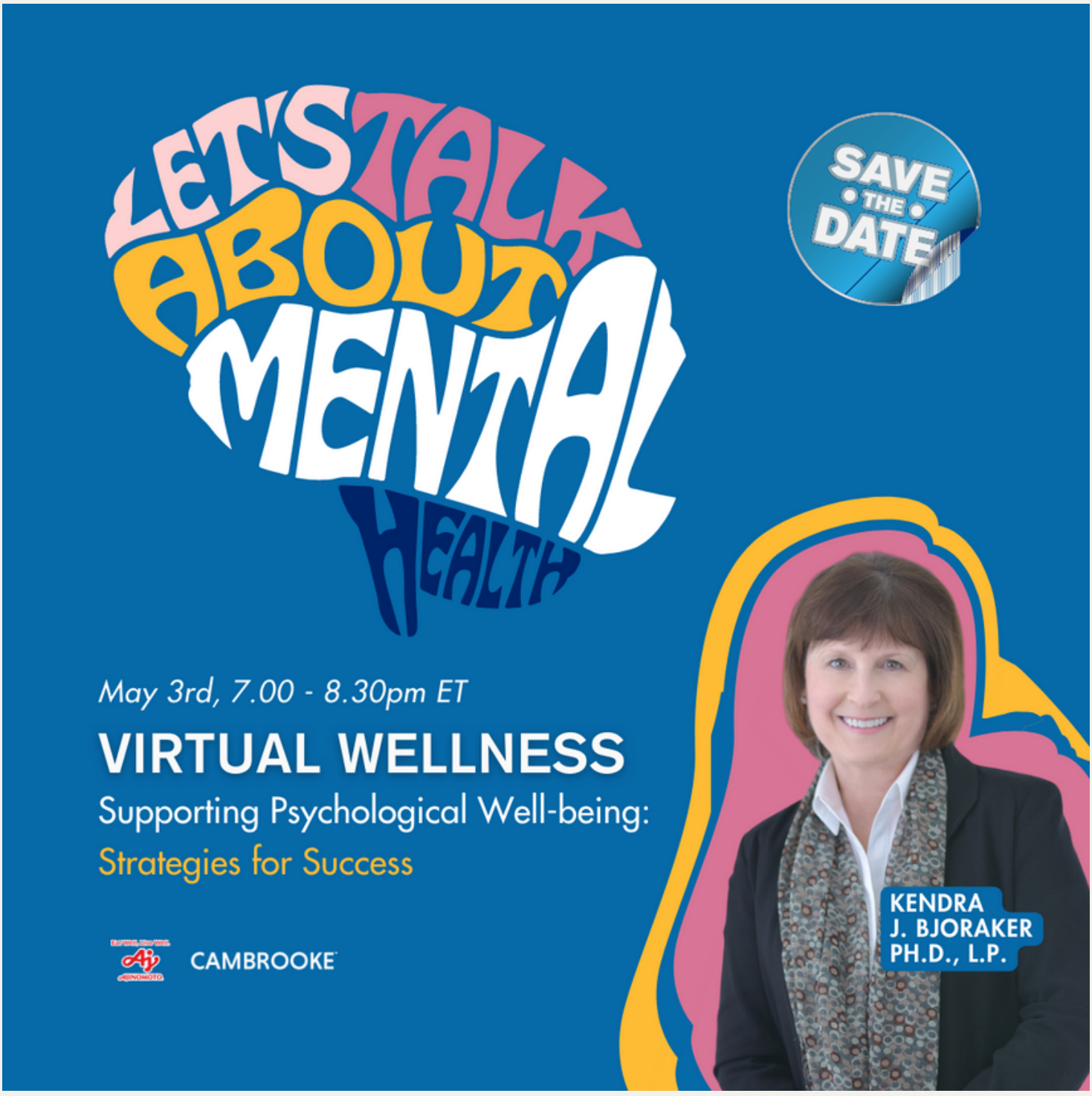
homocystinuria.rare-x.org

HCU NETWORK AMERICA

HCU Network Australia

POWERED BY RAREX

EVENT ANNOUNCEMENT



Click here to register for this event!

This spring, Cambrooke is supporting the HCU Community with 15 PE HOMACTIN™ AA METHIONINE FREE Plus POWDER

CHECK OUT OUR LINE OF LOW PROTEIN FOODS AT CAMBROOKE.COM


BROOKLYN DOGS


CAMBURGERS


SHAKE 'N' CHEESE


YUCA TATER HOME FRIES

Request a sample today!

Call Customer Service at 866 456 9776, option #2, for assistance

Eat Well, Live Well.
AJINOMOTO

CAMBROOKE™

NUTRICIA Lophlex® LQ

Where will you drink your HCU Lophlex® LQ?

Brought to you by Nutricia North America.
HCU Lophlex LQ is a medical food for the dietary management of Homocystinuria for individuals over 4 years of age. Must be used under medical supervision.

NUTRICIA

Acappella

NOW ENROLLING

ACAPPELLA Study on Classical Homocystinuria

Travere Therapeutics is enrolling children and adults with classical homocystinuria (HCU) in a ACAPPELLA Study. The goal is to learn more about classical HCU and the course of the disease. Information gained from this study may help to improve understanding of HCU and help other patients, families, healthcare providers, and researchers to design new clinical research studies and therapies. No investigational medicine will be given to participants.

Approximately 150 participants will take part at sites in the US, Europe, and other countries around the world. The study will include three key stages (screening, enrollment, and observational follow-up) and will last approximately 6.5 years.

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

- **Have been diagnosed with HCU**
- **Are 1–65 years of age**

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

For additional information about the ACAPPELLA Study, please go to: https://www.clinicaltrials.gov/ct2/show/NCT02998710

You may be able to receive payment for time and travel when you participate in this study. Talk with your doctor and family members about joining the ACAPPELLA Study. Sites are open and currently enrolling participants.

For new participants, we now have an option for the study to come to you! (decentralized site). Please inquire to learn more.*

If you have any questions, please email:

medinfo@travere.com

For more information, please scan the QR code or visit www.hcuconnection.com

*Restrictions apply

MA-PE-22-0004. March 2023

TRAVERE™ THERAPEUTICS

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://bit.ly/3OJuF1W

FOLLOW US