The HCU Herald

Back to School Edition

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HCU HERO: CATCHING UP WITH SAMANTHA FROM INDIANA

Samantha was first featured as the May 2018 HCU Hero. Samantha was a toddler in 2018, but now will be entering Kindergarten this fall! Also, during this time, Amber, her mom, has become an important part of the low protein community with her amazing chef skills!

My name is Amber Gibson. I live a wonderful life in Brownsburg, Indiana with my husband, Ben, and my two kids, 8-year-old Denon and 5-year-old Samantha. We also have a cat named Indy.

First, a little background- my husband and I met in culinary school in Indianapolis. We graduated in 2010 together. From there I worked in a restaurant in a Marriott in downtown Indy for about 7 years. There I gained experience in food service, quality control and food safety, and menu development. After my son was born, I wanted a job where I did not have to work so many hours and I could still be with him to care for him. I took a job doing some data entry for an accountant, who is also my father. While this job does get the bills paid, my strongest desire to cook and bake keeps me in the kitchen

In 2015 our daughter Samantha was born. A week later we received news that her newborn screen test showed her homocysteine levels were too high. A few months later we got the rough diagnoses - she had homocystinuria (HCU). While we were terrified by the news, we were more bewildered. We were not sure how to make the foods for her, what her care was going to take, or what could possibly happen in the future.

Her first year was great and her levels were where they should be. Then the stomach flu hit her in fall 2016, as well as her older brother. After that Samantha refused her necessary formula.
We tried everything - smoothies, mixing with baby cereal, flavorings, etc.. As a few months went by, she started to show signs of protein malnutrition. With the guidance of her metabolic doctor, we chose to try an NG tube. We did this for a few months, hoping it would trigger Samantha to drink her formula. Unfortunately, it did not work, and we had to go the g-tube route. So now not only do we have to monitor her daily protein intake, we have to give her formula through the tube three times a day. It is very stressful and time consuming throughout our day. Her levels remain high, but she is doing great. Samantha is a very happy, sassy, silly little girl. We are thankful to God every day for her and this condition.

When I first began making food for Samantha, some of the recipes I tried were just okay. They really seemed to lack flavor and decent substance. As I looked at recipes through other websites, I began to really think “how could I make this lower in protein?” I also wanted to make recipes that are easy to understand, have 2 grams of protein or less in a serving, and that do not require a lot of special ingredients that are hard to find. I began playing around in the kitchen. Some things turned out well, others needed a little more work. It is always trial and error in the kitchen.
I love it!

One of the things that drives me to make specific recipes is to try to make foods that not only taste good but will also look very similar to our everyday foods. I hope with these recipes she will not feel she is missing out on something, but able to enjoy things just as we do. I wish the same for all of those in the allied metabolic disorders community. I really want to make meals that have great flavor. I have been able to exercise what I learned in culinary school to create new foods and recipes that work well for the HCU community and the allied disorders community. I love doing this to help everyone, and I love that my daughter has shown me how.

You can find Amber’s recipes on Cookforlove.org and https://hcunetworkamerica.org/hcu-community-cook-book/

BACK TO SCHOOL WITH AMAZON SMILE

amazonsmile
You shop. Amazon gives.

Your shopping makes a difference

Shop using the HCU Network America Amazon Smile link for all your back to school shopping and Amazon will donate to HCU Network America!

Want to make your purchases count?

Good news! **AmazonSmile is now available in the Amazon Shopping app** on iOS and Android mobile phones.

AmazonSmile customers can now support HCU Network America in the Amazon shopping app on iOS and Android mobile phones! Simply follow these instructions to turn on AmazonSmile and start generating donations.

1. Open the Amazon Shopping app on your device
2. Go into the main menu of the Amazon Shopping app and tap into 'Settings'
3. Tap 'AmazonSmile' and follow the on-screen instructions to complete the process

If you do not have the latest version of the Amazon Shopping app, update your app. Click here for instructions.

COME FUNDRAISE AND RAISE AWARENESS WITH US!

GO THE EXTRA MILE FOR HCU

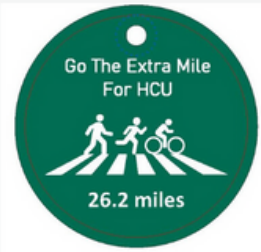
VIRTUAL RACE BENEFITING HCU NETWORK AMERICA

WALK, RUN, RIDE | SEPTEMBER 2020

Per individual: $25

Per Family (up to 4): $40

Register at: https://runsignup.com/Race/IL/Batavia/GoTheExtraMileforHCU



FRONT

BACK

HCU Network America | RECORDATI RARE DISEASES GROUP Focused on the Few™ | aeglea BIOTHERAPEUTICS

info@hcunetworkamerica.org | https://hcunetworkamerica.org | 630-360-2087

HCU COMMUNITY COOK BOOK

Smokey O's

Makes 2 servings

Ingredients:

- 124 g Aproten Anellini, dry
- 2 TBSP Ketchup
- 1 tsp Bragg's Coconut Aminos
- 1/4 tsp Garlic Powder
- 1/4 tsp Smoked Paprika
- 1/8 tsp Chili Powder
- 1/8 tsp Salt

Nutritional Information

- Serving size: 75 g
- Protein per serving: 0.7 g
- Calories per serving: 240

Directions:

1. In a small bowl add the ketchup, coconut aminos, garlic powder, smoked paprika, chili powder, and salt. Mix until combined and set aside.
2. Cook anellini as directed on the package. Drain and dump into a serving bowl. Add sauce and gently combine. Serve immediately.

THANK YOU, CHEF AMBER GIBSON

COOK FOR LOVE:
LOW PROTEINCOOKING DEMOS

If you, or a loved one requires a low protein diet and you haven't heard of Cook for Love, you are definitely missing out!

In May, Brenda, the founder of Cook for Love, started hosting Facebook live cooking demos. Now with three under her belt and with thousands of views - we are proud to share with you two new events added for July!

July 15, 2 pm ET and July 29 ET
Subjects: TBD
To register, follow:
https://www.facebook.com/pg/nationalpkunews/events/

About Cook for Love:
Cook for Love evolved out of sheer stubbornness in 2008. As a mom, Brenda refused to accept that her daughter had to eat foods that she did not find palatable. Providing nourishment is one of the most basic responsibilities of any parent. The stakes are just so much higher and the road so much more complicated when your child is diagnosed with PKU or any other IEM. When Brenda received that devastating phone call, she too was lost and did not know where to begin. The kitchen seemed like a good place to start. Cooking for a person is an expression of love. Never is that statement more true when your child's ability to reach their potential is dependent upon the foods they eat.

Ten years later Brenda remains astounded by the metabolic community's support and the delicious recipes they too have created. Facebook was not the right platform to share recipes so Cook for Love joined forces with PKU News and How Much Phe to create a community based recipe site to provide even more variety to those with metabolic disorders. All of the recipes are run through How Much Phe so you can be confident that the protein content is accurate.

Cook for Love is committed to creating low protein foods that taste delicious. We have all struggled in our kitchens and by sharing our recipes we hope you get to avoid some of the frustration we experienced. We provide step by step instructions and videos for making meals and treats that you and your loved ones will truly enjoy.

Whether you love to cook or are doing it solely out of love, please join us as we share new recipes and our experiences.

NAVIGATING SCHOOL WITH HCU

A Elementary Experience

by Bridgett Zaidi

Having your child's school agree to and cook low protein meals can seem so daunting! Most people don't even know what a metabolic disorder is, let alone how to prepare a low protein meal.

I was a nervous wreck when Kaden first started school, but I knew with him spending more hours in the day at school than at home, I needed help from the school to provide him with a balanced variety of meals. Every child wants a feeling of belonging and to not stand out, so Kaden was excited to buy a hot lunch, go through the lunch line like his friends and have that lunch cafeteria experience. He is now in the 5th grade and he's still able to get that experience through establishing the following groundwork:

For a public school, your first step would be to set up a 504. A 504 is a law abiding document you create with the school for special accommodations due to disabilities. Ask your child's school for a 504 meeting and bring a doctor's note stating your child's diagnosis. Be prepared to provide all accommodations you would like your child to have. By law, these accommodations have to be provided to your child once the school signs off on it. These are the 504 accommodations we were able to get for Kaden as reference:

Kaden's 504

1. Cafeteria is to cook a low protein meal 3 days a week. Menu or meal rotation is to be created and not changed unless parent is notified. Cafeteria staff is only to serve foods approved of by parents
2. Child is allowed separate snacks to be kept in the classroom
3. Child is allowed to use the nurse's fridge/freezer for food storage as needed
4. Child is to receive medical formula daily after lunch
5. Daily communication or pictures of lunch or foods eaten at school

Have the school district cafeteria manager attend the 504 meeting, as well as the school's cafeteria manager. Provide them the meals you want them to cook and what serving size you want your child to have. You can have them provide a written menu or you can agree on a rotation. The school district cafeteria manager is responsible for creating menus and ordering foods for the school, so they incorporate a menu and food order for your child to go along with the district.

Below is an example of the rotation we setup for Kaden. His rotation changes a bit each year at his discretion.

Monday: low protein food, one of these choices

- 3 Tweekz
- Cambrooke bread stick
- ½ Flavis pizza crust with pizza sauce and broccoli
- Cambrooke bigger bagel
-

Wednesday: Tacos

- 2 corn taco shells, shredded lettuce, diced tomatoes,1 oz of salsa

Friday: French fries

- 100 grams of cooked, french fries, dipping sauce of his choice

Kaden with his two younger brothers.

When we created this menu, the cafeteria manager was able to tell me all the fruit and vegetables they serve as sides and the measurement they serve. Kaden is allowed to pick whatever fruit/vegetable combinations he'd like, as well as what juice he'd like to drink. If your school has a side or drink you don't want your child to have, ask the cafeteria manager to notify staff of the "allergy". Most schools have a place where allergies or food restrictions can be referenced for students and seen by all staff. Kaden has some of the following restrictions; no milk, peas, corn - which come up on the computer screen every time he pays for his lunch.

The school is not allowed to charge extra for your child's meal in Arizona, but keep in mind that this might vary state to state. The low protein foods ordered are covered by the district under the 504 document and the disabilities act.

The process of having the school serve Kaden lunch has evolved over the years. When Kaden first started to buy lunch, we had the cafeteria send before and after pictures of his plate. This gave me some comfort that they were executing his lunches correctly. They kept a school tablet in the kitchen for the staff to use. On days he bought school lunch, they took a picture before he had lunch & when he was done eating. He would take his tray to a lunch aide for an after picture. Both pictures were emailed to me daily by 3 pm. We stopped doing before and after pictures of lunch in the 4th grade when we felt he was responsible enough to let us know what he ate that day

Couple of other things to note:

- Cambrooke does have school lunch support! They can help your school put together an individual menu for your child, as well as educate the staff on how to prepare all foods.
- Snacks

in the classroom are easy to make available to your child if you choose. I bring in a plastic bin to keep in the classroom, full of protein free snacks that Kaden is allowed to eat from freely. We do gluten free pretzels, fruit snacks, fruit cups and spoons, individual bags of freeze dried fruits, etc. When the box was down to the last few snacks, the teacher sent it home to be refilled. We also keep a box of popsicles in the nurse's freezer for when the class has birthday/classroom treats Kaden can't have.

NAVIGATING SCHOOL WITH HCU

A High School Experience

by Will Hummel

My name is Will Hummel, and I've just finished my freshman year of high school. Although I've been feeling quite bored lately, as I'm sure many of you have, I'm feeling optimistic on how this whole situation is going to pan out. With all the craziness that has been 2020, life right now is not how it has been to say the least. In regards to my homocystinuria, not much has changed in my day to day treatment and routine, but I feel I'm becoming more independent, and it's getting easier. Good news is I made the JV baseball team, but the bad news is we never got to play a game, not even a scrimmage! Despite that, I have continued throwing baseball with my dad and hitting at our local ball park. Once the restrictions are lifted, I hope to spend lots of time making memories with friends. We also have two beach trips planned for this summer, where I'm excited to connect with family and relax.

Thank you for your love and continued support,
Will

A College Experience

by Benjamin Lewis

For nearly everyone who does it, heading off to college (or, for those of you abroad, university) brings a mix of emotions. Yes, there is a lot of excitement, but that comes with some degree of worry and likely a healthy dose of stress. That is understandable, as it is a big change, particularly for freshmen. For many, the experience represents the first time that they are on their own, away from family and long-standing friends. These young adults must take on a new, higher level of responsibility and independence. For anyone, it can be one of the bigger challenges they have faced to that point. For those of us who live with HCU, and our families, the worry, stress, and the challenge associated with transitioning to college – and, really, true adulthood – is only amplified. We must navigate all the same changes as our peers with the added 'bonus' of independently managing our disorder through complexities such as entirely new schedules, meal plans, social situations, and more. It can be tough! Although, take some comfort in the fact that you are a lot less like to gain the 'freshman fifteen' when on diet. Kidding aside, I would like to take this opportunity to share a bit about my experience as someone with HCU who attended college and was able – with a little trial and error – to achieve success in managing my disorder along the way. Hopefully, in doing so, others with HCU who are off to college will be able to see the same level of success

The success I experienced in navigating college with HCU was due in no small part to a couple of steps that I took before I ever stepped foot on campus. The first step was to factor in my disorder and dietary needs when evaluating schools. For me, it was important to visit each of the schools I was considering whenever possible so that I could tour the dining halls and meet with dining staff to better understand how they would accommodate my needs. Ultimately, those accommodations were an important part of my decision as to which school to attend. For me, it appeared (key word; more on why later) that Rensselaer Polytechnic Institute (RPI) in Troy, NY fit best with my criteria across not only my dietary needs, but also academics, campus life, career prospects, and other important factors. Once I had decided on attending RPI, I took that second important step that I thought would set me up for success, which was to meet with one of the coordinators for the school's dining services. For my freshman year, the plan we made was for me to access and prepare my own low protein foods from an area dedicated to people with various dietary needs, as well as, access the normal dining options available to all students. We also planned for my formula to be delivered to the campus post office on a monthly basis. Having taken these steps, it appeared to my family and I that I was heading into my freshman year with all the arrangements necessary to manage my HCU, stay on diet, and keep up with formula.

As it turns out, those plans were not as solid as we thought. Freshman year was, well, essentially a failure when it came to having all the arrangements needed to manage my disorder effectively. Taking time to prepare my own low protein foods meant my new friends were often done eating by the time I sat down to join them, and I would not say DIY meal prep left me with a wide variety of tasty or healthy options. After some time, I just about gave up on the low protein foods and cobbled together meals from what I could find among the options available to all students. On top of that, the three heavy boxes of formula (HCU Coolers) I needed each month were being delivered to a building that was over a quarter mile from my dorm room. Every four weeks, I had to trek up to the campus post office, borrow a hand truck, and wheel the three heavy boxes halfway across campus back to my room. It. Was. A. Pain. The steps I took before going to school were important. However, I discovered during freshman year that the arrangements made were not as 'user friendly' as I had thought and HCU was an additional burden over the course of that year. Heading into sophomore year, it was time to go back to the drawing board.

After that freshman year failure, my parents and I requested a meeting with the dining staff and shared a simple sentiment: that really did not work, so fix it. That may seem a little harsh, but remember that you pay a lot of money to go to college (cost of attendance at RPI for 2020-2021: $75,824… crazy, I know) and everyone deserves to get a satisfactory experience in exchange for that enormous cost. The dining staff heard us loud and clear, and we completely changed the plan for sophomore year. First, they tasked one of the lead chefs, Jason, in the dining hall nearest to my dorm with cooking for me. Yes, I was essentially assigned my own personal chef. Second, we arranged to have my formula delivered to that same dining hall, which was only a short walk from my dorm – a much shorter distance than the quarter mile to the post office. Having sorted all that out, I then sat down with Jason and we talked through my dietary restrictions and my preferences. That was incredibly important to the success of the new arrangements because I was able to educate him on all of the dos and don'ts of the diet, which, as we all know, are not always easy to understand at first. During our conversation, there was one more thing I did that led to success: I choose to give up some of my picky eating habits to allow Jason more flexibility to cook up tasty and healthy food. I knew that he was already taking on a big challenge in

having to find low protein foods and I wanted to be as flexible as possible within those boundaries to set him up for success. Our efforts, and complaints paid off. Jason found his groove and he, and then another chef named Chris, prepared some great meals for the remaining three years I spent at RPI. And I had a much easier time keeping a supply of formula available with deliveries coming closer to my home away from home. With the new arrangements, HCU was no longer a drag on my college experience. In fact, working with Jason and Chris was an enjoyable part of my time at RPI, and it was even a bonus for others too. Jason and Chris were excited to have the opportunity to do some creative cooking with limited ingredients and there were even some perks for my friends, as the two chefs were able to access fresh fruits and other rare treats not normally available to students. There was one time Chris 'borrowed' some pricey mushrooms that had been reserved for a private VIP donor dinner to use in one of my meals and another instance where Jason honored a request from one of my good friends, Deborah, and delivered her some fresh strawberries. Experiences like these meant that accommodating HCU went from a major burden to a major highlight a part of my college experience.

I know my story above contains a lot of info! Let me summarize some of the aspects of my experience that are, hopefully, helpful for any readers who they themselves are about to go off to college:

- Do consider your disorder and dietary needs when looking at schools. Dining is an important part of the college experience, and you will see greater success across the board if you account for that.
- Don't forget to make arrangements for your formula, betaine, and other necessary medications. And remember that college life can be busy, and schedules can be hectic, so think carefully about how easy it will be for you to access those things on-demand and amid an ever-changing schedule.
- Don't be afraid to push the school and dining staff to think 'outside the box' in order to meet your needs. You're paying a large sum to have a great college experience, and they should support that.
- Do what you can to turn HCU into a positive part of your college experience. It can be! It can take some effort and planning, but make sure you're setup for success and enjoy your time at school!

Here's the last meal that Chris prepared for me before I graduated! I miss benefiting from his cooking skills!

HCU SELF-MANAGEMENT TIMELINE

An important part being a parent with a child who has HCU is helping yourself and your child manage HCU successfully. The self-management timeline supplies an overview of what to expect as your child becomes more independent in managing their care. This flexible guide suggests a gradual release with age appropriate goals to make this happen.

Homocystinuria (HCU) Self-Management Timeline

Age	Tasks
0-6 months	• Parents learn about and adjust to HCU
6-7 months	• Parents start to offer low-protein solid foods • Introduce cup with water
8-9 months	• Parents introduce finger foods
10-15 months	• Parents consider final weaning from bottle (discuss transition with your clinic)
2-3 years	• Learn the concept of "formula first" • Learn to distinguish "yes" and "no" foods • Transition from infant formula to child/adult formula
4-5 years	• Start learning how to count foods - "how many" • Start learning how to use a scale – "how much"
5-6 years	• Help with formula preparation • Learn how to deal with other's curiosity about HCU
7-10 years	• Prepare formula with decreasing supervision • Choose after school snack • Learn to pack school lunch • Begin to list foods on food record • Begin weighing food regularly on scale
10-12 years	• Begin to prepare and consume formula independently each day (with parental monitoring)
13-14 years	• Increasing self-monitoring (with continued parent support) in formula preparation and consumption • Independently manage total protein/met intake for the day • Learn menu planning • Responsible for food records
15-17 years	• Competent to perform and primarily responsible for all aspects of self-management with continued parent support • Able to schedule blood draw • Able to explain the basics of HCU – "What is it?" • Responsible for remembering recent blood levels

18 years	• Transition to adult-based clinic care
	• Ready to live independently, including:
	  ○ Formula preparation and consumption
	  ○ Food preparation and records
	  ○ Setting and keeping own appointments on regular basis
	• Parents act as consultants

Adapted from: University of Washington University. *PKU and the Self-Management Timeline* [PDF file]. Retrieved from https://depts.washington.edu/pku/pdfs/selfmanagetmln.pdf

BACK TO SCHOOL RESOURCES:

(ALL LINKS IN BLUE ARE HYPERLINKS- JUST CLICK)

- Educators Guide for Classical HCU
  - Our Educators' Guide to HCU is designed to spring-board that discussion between you, the school nurse and classroom teacher(s). In our Educators' Guide we give you an easy explanation of HCU, Helpful Tips for Teachers and Nurses, Educational and Nutritional Accommodations tools, as well as ways to ensure students are not left out of classroom celebrations. We know that teachers don't have a lot of time, so this two page guide is the perfect amount of content to help get the conversation started.
- Daycare Guide for Classical HCU
  - For many parents the first time you leave your child with HCU under the care of someone else, it will likely cause a lot of stress and anxiety. Try to breathe and remember, you are not the first parent who has gone through this! To help support you in this new chapter of raising a child with HCU we have developed a Caretakers Guide for HCU. Our Caretakers Guide to HCU will help you explain what Homocystinuria is, what foods are allowed, and how your child's caretaker can help make this transition as smooth as possible for you and your child.
- **School lunch program**
  - Proper nutrition during school hours is essential for all students. Too many school age children with metabolic disorders refuse to eat when they feel stigmatized. Parents report that young students receiving a Cambrooke Foods meal at school avoids binging on prohibited foods and have better energy throughout the day. All of us, parents, educators, and food companies, can play a part in keeping these students well fed.
  - Requirements for providing nutrition services to students with special needs are based on: The Rehabilitation Act of 1973, The Individuals with Disabilities Education Act (IDEA) of 1990, and the Americans with Disabilities Act of 1990.
  - Section 504 of the Rehabilitation Act of 1973 mandates that students with disabilities not be excluded from any program which receives Federal Financial Assistance.
  - Link to Cambrooke School Lunch Program: Parents Guide
  - Link to Cambrooke School Lunch Program: Food Service Guide
- Back to School with HCU: Working with your child's teachers, school nurse and caretakers Webinar recording
- Educators Guide for MMA+HCU
  - Our Educators' Guide to Methylmalonic Acidemia with Homocystinuria (MMA+HCU) is designed to spring-board that discussion between you, the school nurse and classroom teacher(s). In our Educators' Guide we give you an easy explanation of MMA+HCU, how high levels may impact your child, how teachers and nurses can help, possible medicine side effects, helpful tips for success, and educational accommodations and additional services that might benefit your student. We know that teachers don't have a lot of time, so this two page guide is the perfect amount of content to help get the conversation started.
- Educators Guide for Methylcobalamin Disorders: CblE and CblG
  - Our Educators' Guide to Cobalamin E (CblE) and Cobalamin G (CblG) is designed to spring-board that discussion between you, the school nurse and classroom teacher(s). In our

- (Educators guide for Methylcobalamin Disorders - Cont.) Educators' Guide we give you an easy explanation of CblE and CblG, how high levels may impact your child, how teachers and nurses can help, possible medicine side effects, helpful tips for success, and educational accommodations and additional services that might benefit your student. We know that teachers don't have a lot of time, so this two page guide is the perfect amount of content to help get the conversation started.

- **Educators Guide for MTHFR**
  - Our Educators' Guide to Methylene tetrahydrofolate reductase (MTHFR) is designed to spring-board that discussion between you, the school nurse and classroom teacher(s). In our Educators' Guide we give you an easy explanation of MTHFR, the difference between severe MTHFR and the common form, how high levels may impact your child, how teachers and nurses can help, possible medicine side effects, helpful tips for success, and educational accommodations and additional services that might benefit your student. We know that teachers don't have a lot of time, so this two page guide is the perfect amount of content to help get the conversation started.

Our educational tool-kits are continuing to expand for all the homocystinurias. Early this fall, HCU Network America's Cobalamin Steering Committee will start completing a special education parent handbook for those with Cobalamin disorders.

For a full list of toolkits, checklist, guides, and infographics, please visit: https://hcunetworkamerica.org/toolkits-and-checklist/

If you have ideas for educational materials, please email Danae' Bartke, HCU Network America's executive director at dbartke@hcunetworkamerica.org

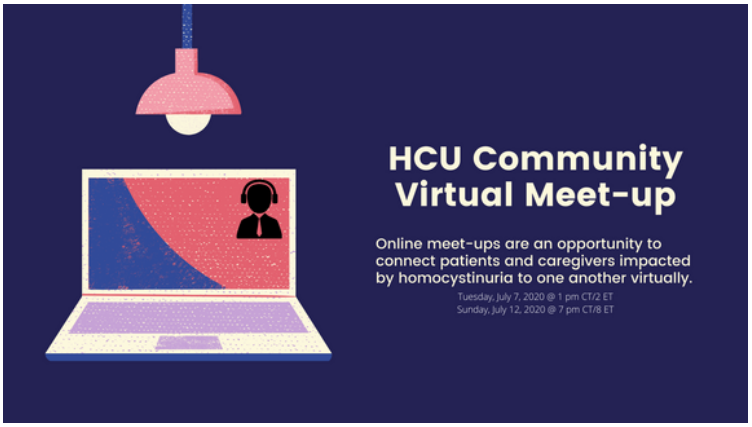
EVENTS

Come check out our Virtual Homocystinuria Meet-ups!

Join our virtual meet-up for a chance to meet, connect, and learn from other patients and caregivers who are facing similar challenges. Whether it's navigating adherence issues, insurance, clinic visit, or life transitions, you are not alone.

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

For Classical Homocystinuria



For MMA+HCU patients and caregivers - CblE and CblG families welcome (different than Classical HCU)

NEW: For Kids with Classical HCU ages 7 and up!

CALLING ALL RARE ARTIST!

The 2020 Everylife Foundation Rare Artist Contest opened for submissions via Facebook and email on June 16th. Everylife's goal with the Rare Artist Contest is to celebrate the talents of the rare disease community and spread awareness with each piece and the artist behind them. Anyone who is connected to rare is encouraged to enter, they accept entries from ages 4+

Who can enter into the contest?

Anyone connected to the rare disease community can submit artwork, including caregivers, patients, physicians, siblings, and friends. We have three different categories dependent on age; anyone who is ages 4+ can enter. You do not need to be a professional artist or hold any sort of credentials in order to enter into the contest.

Anyone can participate in the voting portion of the contest for the public vote via **Facebook**. We ask that all individuals participating in voting respect the rules. Voters are allowed one vote per art piece every 10 days. You do not have to have a submission in the contest to vote. You do not have to be affiliated with a rare disease in order to vote. The spirit of the contest is about spreading awareness. We encourage you to share your artwork with your rare disease community, to increase your public vote count.

What are the prizes?

Contest awardees are granted cash prizes and an opportunity to showcase their art work at the Rare Artist Reception during **Rare Disease Week on Capitol Hill.** When entering into the contest, we ask that the artwork entered represents the age of the artist. If you are submitting on behalf of someone else, please submit by the age of the artist, not of your own.

Cash prizes according to age groups are as follows;

- Children (4-11) – $100
- Teen (12-18) – $250
- Adult (19+) – $500

Additionally, your artwork will be uploaded to the Rare Artist Website Gallery. Rare Art will also showcase throughout the year at various patient and industry events.

EVERYLIFE FOUNDATION FOR RARE DISEASES
10 YEARS OF ADVOCACY

Deadline to apply is 10/01/2020 @ 5 pm EST. Submit your work for the public vote on **Facebook.** For those who do not have a Facebook account, or DO NOT wish to participate in the public vote, please send submission to **lcundiff@everylifefoundation.org**

orphan technologies

Orphan Technologies has initiated a first in human study of OT-58, an enzyme therapy that addresses the underlying enzyme deficit for patients living with classical homocystinuria. The goal of this trial is to evaluate the safety and efficacy of OT-58 in patients with classical homocystinuria and identify the appropriate dose. Patients between the ages of 12 and 65 years of age with classical homocystinuria may be eligible to join. For additional information on criteria for eligibility, please go to: https://clinicaltrials.gov/ct2/show/NCT03406611?cond=Homocystinuria&rank=1

There are four sites currently open to enrollment in the US, and 3 new sites will open in the coming months:

- **Children's Hospital of Philadelphia – *open to patient enrollment***
- **Boston Children's Hospital – *open to patient enrollment***
- **Indiana University – *open to patient enrollment***
- **Children's Hospital Colorado – *open to patient enrollment***
- **University of Miami – *not yet open to enrollment***
- **Icahn School of Medicine at Mount Sinai – *not yet open to enrollment***
- **Vanderbilt University Medical center -*not yet open to enrollment***

Once site restrictions lift due to Covid-19, enrollment will continue.

Payment for time and travel may be available to patients who participate in this trial.

To inquire about participation into the trial, please email: info@orphantechnologies.com

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/

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