HCU Herald

Presented by HCU Network America

Connecting for a Cure.
There have been a lot of things happening for the HCU community & for HCUNA.
We strive to keep you informed and connected.

Inside this Issue:

Heroes of HCU:
Charlotte from Virginia

Charlotte is my first born and I really didn't put any thought into the newborn screening. She was born at home so there was no hospital requiring me to have it done but thankfully my midwife serves on a board for newborn screenings and made sure I knew how important is was to have it done. I still didn't think it was very important, but had it done anyways. After she was born, and the test was done I completely put it out of my mind thinking I would never hear anything about it again.

When Charlotte was about 2 weeks old we got a call from my midwife saying she had tested positive for Homocystinuria. She told me she had never heard of it, but it could be a false positive because the test took so long to get to the labs and it was exposed to cold temperatures since it was January. She came and performed a second screening and told us in the meantime we needed to establish a pediatrician in case further tests were needed. We went to a pediatrician within a couple days and told her what was going on. She assured us that the condition was rare and there were many benign reasons for her levels to be high. She said that Charlotte most likely wouldn't have the disorder. I felt so relieved and put the whole thing out of my head. A few days later the test came back, and it was also positive.

A blood test specific for testing homocysteine levels was ordered and we went to our local hospital to have it done. Much more blood was needed for this test than the newborn screening. Because Charlotte was only three weeks old and so small the phlebotomy tech had a tough time getting the blood sample. She tried three times and then called in a doctor who specializes in premature babies to try. It still wasn't enough, and they had to do a heel prick to get the last little bit needed. My three-week-old 7 pound baby was pricked a total of 5 times. I was so upset I felt like I was going to pass out.

After this test came back confirming elevated homocysteine levels, we met with Dr. Wilson, a genetic specialist, and Barb Goodin, a dietitian at UVA. They tried to assure us that this disorder was very rare and that there were benign reasons for her elevated levels that would sort themselves out. They also let us know that if she does have it she will be fine and live a normal life. They started her on a formula called Hominex-1 and some vitamin B-6 just in case. In the meantime, they ordered yet another test to check her homocysteine levels. At this point I felt in my gut that she had it and wished that they would just diagnosis her already.

Her results came back, and her levels were still elevated. It was at this point they decided to do genetic testing. A short while later I got a call confirming she had Homocystinuria and she was not responding to the vitamin B-6. Charlotte was 2 months old at this point. I felt relieved to finally have a diagnosis but at the same time I was devastated. I felt so unsure of what her future would look like but thankfully Dr. Wilson and Barb assured us she would be completely normal and live a regular life. She would just need a low protein diet, medical formula, and some supplements and medications. They have been such a wonderful team for Charlotte and our family and we are so thankful for them.

Her diagnosis has affected our family tremendously. Having to weigh and track her food everyday can sometimes be a struggle. Some days are so hectic that having to stop and track everything can be stressful. Going out to eat, family functions, birthday parties, or traveling requires a good deal of planning ahead and making sure there are things she can eat, and if not, bringing her food myself. My family also checks the nutrition labels on all the foods we eat to see if they're Charlotte friendly. Before we never paid any attention to food labels.

Victories for us are finding new foods Charlotte likes that comply with her diet. Since she's three and autistic she is extremely picky about food. So, finding something she likes is always a major victory. I recently made her some pizza with a gluten free pizza crust and she liked it so much she not only asked for seconds but asked for thirds! And because it was so low in protein I could give her those three pieces of pizza. I did a major happy dance that evening. I'm also lucky enough to have an amazing family who always make sure to have food for her, are always on the lookout for new things for her to try and took the time to learn how to weigh and track her food so they can watch her for me.

We have struggled with finding foods she likes. She doesn't like a lot of the low protein foods I've ordered for her and often refuses to even try them. Just about every low protein recipe I've made she has refused to try. I often feel like her diet isn't varied enough. It was also hard after her younger sister was old enough to eat solid food. Before there was mommy and daddy foods and Charlotte foods. But when she saw her sister eating the same things as my husband and me, she wanted to eat them too. Explaining to a two-year-old that she can't have the same foods as her sister was hard. I also feel a little self-conscious weighing her food in public. I worry that people will misinterpret what I'm doing and assume I'm counting her calories to keep her slim.

What I would say to someone who is new to Homocystinuria is to just stop and breathe. Everything will be okay. There are many different variations of normal and while this version may seem hard to navigate you will make it through. Don't do what I did and focus on all the things that go wrong and all the hardships you or your child could face. Just take things a day at a time and focus on the victories, big and small. And when you feel lost, reach out for help. We have a great community of people full of knowledge and experience who are always willing to lend a helping hand. You are not alone.

Expanding Food Choices

Children become picky eaters for a variety of reasons. Some children restrict the foods they eat because of sensory reasons. These children might reject food because of the smell or the texture of a food. Some children restrict foods because of fear of a negative consequence like choking or gagging. This type of restriction often occurs after a negative event, but it can also occur without a clear reason. And, some children just don't seem interested in food or eating.

For children and adults with HCU, food choice is an important part of medical management, and choices of foods is made difficult by the need to avoid high protein foods as well as restrict grains and some fruits and vegetables. As far as I know, there are no research studies that have looked at the issue of picky eating in children with HCU. However, studies of other metabolic disorders, like PKU, suggest that children with similar diets are more inclined to be at the extreme end of picky eating.

I want to acknowledge that many different strategies and viewpoints exist for when, what, and how children should eat. For this article, I want to focus on one strategy for increasing the variety of foods that children eat. I want to introduce the idea of *practice foods*.

Pick two or three possible practice foods that your child is likely willing to introduce to her diet. Your child then chooses the food to eat as her first practice food. For the initial practice food including junk foods as choices is fine. The first goal is to practice the process of introducing new foods. The idea is to eat a practice food each day, at least once per day, for several weeks to become used to the new flavor/texture/smell.

Start with very small portions and stick with a single food for an extended period. For example, if your child selects blueberries she might start with a single blueberry as her practice food. At the end of a practice food your child should be able to eat a small portion of that food. Sticking with blueberries as an example, the end goal might be a ¼ cup after 2 or 3 weeks.

Do not negotiate on quantity. Overall children should be allowed to determine how much food they need to eat to feel full. For practice foods, the goal is to use a small amount, and for the parents to pick the amount. Again, it is important for the parents to pick a small amount of food that can be easily eaten.

The priority of practice foods will vary by family but generally you want to start with foods that you think your child is most willing to eat regardless of nutritional value. Second, prioritize practice foods that have more nutritional value and are generally preferred foods for children. Third, prioritize foods that are commonly eaten by the rest of the family.

Don't expect the child to *like* the foods initially. Many children don't like an unfamiliar food. It takes time and repeated experience to become comfortable with new foods. Warmth and praise are an important part of celebrating your child's success. Definitely provide encouragement for your child eating their practice foods, but the conversation focuses on praise for sticking with the practice food rather than a discussion of whether or not the child liked the food.

What to do if your child flat out refuses to eat their practice food? Hopefully including your child in making the decision about the practice food will avoid all-out refusal. This is where building some buy-in before starting the process really helps. Enlist help - children can get in the habit of telling one or both parents “no.” Sometimes picky eaters do best when a new food is introduced by someone new. If you’re not having any success, use a mild tone of voice to let your child know that you have an expectation that they will try new foods, and continue with your family meal as you normally would.

I want to again recognize that families establish a wide range of routines and traditions when it comes to meals. This is one, and certainly not the only, strategy for helping expose children to new foods. This article is part of an ongoing series as part of the HCU and You: Tips and Advice. Share your questions or ideas for future articles at HCUNetworkAmerica@gmai.com

Sincerely,
Ben

Benjamin Goodlett, PhD, is a psychologist who specializes in working with children and families affected by metabolic disorders.

New News

The Rare Runner to Run the Miami Marathon

Kristin is the Vice President of HCU Network America, an HCU patient, and an avid runner. On January 27, 2019 she'll be running in the 2019 Fitbit Miami Marathon.

How did she get into running?

Kristin got into running about 12 years ago. She says her love of running started with the Broad Street 10 miler in Philadelphia. The thing she remembers most about that race was the expression of pride on her parent's faces when she crossed the finish line. She later found running could be an outlet for dealing with tough times, such as the loss of her father in 2007 to cancer or the daily struggle with managing the HCU diet.

Inspired by the 1st HCU Conference in 2011, she started thinking of ways she could connect her passion for running with her desire to help others struggling with rare disease. While doing some research on the internet, she discovered the Running for Rare Disease (RFRD) Team, a group of dedicated Individuals who run marathons to raise awareness and funding for the rare disease community. In 2012, she joined the team first as a patient partner. Later that same year, she was asked if she'd like to join the team as a runner in the 2012 Boston Marathon.

She completed the marathon and was invited back to the team the following year for the 2013 Boston Marathon. In 2013, she ran in honor of Will Hummel, a fellow HCU patient. That year, Kristin was denied crossing the finish line due to the bombing attacks. She was able to run until about mile 24.5 and then all runners were detoured by the authorities to a safer area away from the finish line. Kristin was unharmed. In fact, the bombing only strengthened her resolve to raise awareness & funding for HCU. She immediately increased her fundraising goal and set her eyes on crossing the finish line in 2014. Kristin returned to run the 2014 Boston Marathon in honor of Will Hummel, but she also dedicated each mile to an additional 25 HCU patients. In 2014, she crossed the finish line in honor of all 26 patients.

Fast forward to 2018, Kristin has now completed 12 full marathons and has raised over $25,000 for the National Organization of Rare Disorders (NORD) and $5,000 for the American Liver Foundation. The funds she's raised for NORD have contributed to a restricted research grant for HCU and have helped support NIH's undiagnosed diseases program. She's also completed multiple half marathons, several century bike rides, and even a triathlon.

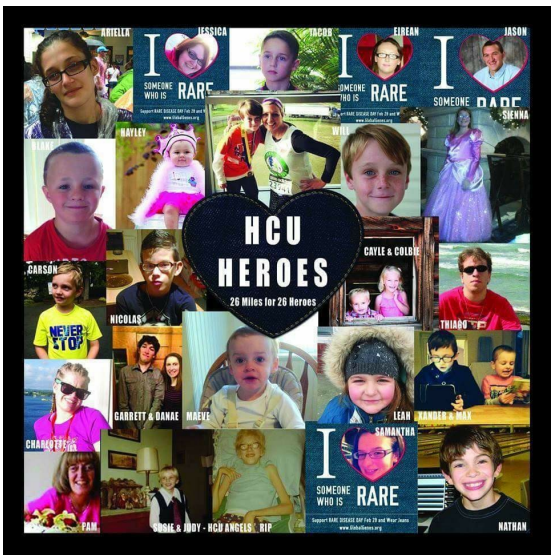
What are her hopes for the race?

In January, Kristin hopes to cross the finish line at lucky #13, the Miami Marathon. This will be the first time in 2 years that Kristin has set out to complete a full marathon distance, which is 26.2 miles. Since she's just getting back into running from a bit of a break, the only running goal she's set for race day is to reach the finish line before the course time limit of 7 hours.

What are her fundraising goals for this Miami Marathon Challenge?

Kristin is setting an aggressive fundraising goal of $10,000 for HCU Network America. She will be dedicating each mile of the race to a different HCU patient. More information on how you can get involved as a patient partner and a link to her fundraising page will be coming soon! Watch for updates on the HCU Network America Facebook page and in the next HCU Herald.

Click to donate to Kristin's Miami Marathon Challenge



New News

What should a clinic visit look like?

You may meet with:

The people who are helping treat you or your child's homocystinuria should be working as a team. They each play an integral part in the patients' health. Not all clinics will have each of the people listed below, but if they do, they each play a very important role. Understanding each person's role will help you advocate for your best care.

Geneticist
- Conducts physical exam,
- Consults with patient on family and medical matters
- Confirms diagnosis
- Discusses family medical background

Dietitian
- Discusses diet
- Makes sure the patient is getting enough nutrients
- Answers food related questions
- May provide food related games

Nurse
- Tracks or screens for developmental progress
- May organize educational groups and training

Social Worker
- Helps with access to low protein foods, formula or other medication
- Assist with various stages of diet management
- Assist with school related diet resources

Clinical Psychologist
- Conducts social and cognitive developmental assessments
- ensures patient is socially and cognitively on track

What to bring:	They may perform:

• A list of your current medication and dosage
• Bring your diet log
• Be honest about how you are handling the diet,
  ◦ They can't help you if they don't know you are having difficulties
  ◦ A false diet log in conjunction with labs can lead to prescribed diet changes which could be hurtful!
	• A height and weight check
	• Measure the circumference of your head
	• Routine labs, such as methionine, homocysteine, plasma amino acid panel, B12, Folate and Prealbumin
	• Cognitive and social assessments
	• Annual eye exams
	• Checks spine for scoliosis
	• Dexa Scans – every 3-5 years

Clinic Visit Infographic with FAQ

Upon diagnosis many people have questions about what to expect from their clinic visits. Usually our first visit to a whirlwind of people elicits emotions and you might not remember who you met, or the role they play. In addition to that, you might be unsure of what you should bring, or you may be nervous what will be done during your visit. We've tried to create a simple infographic that spells out who you may meet, what to bring, what things may be done. On the back is a frequently asked questions.

Click here to view and download the infographic and FAQ

Thank you to our Patient -Parent Advisory Committee for your development and support with this Infographic!

EMERGENCY I.C.E. INFORMATION

Emergency Preparedness Toolkit

When you have HCU or any other special dietary needs, being ready to handle difficult situations requires special planning, in addition to the typical things everyone needs to consider in the event of an emergency or natural disaster. Here are some key things to think about and discuss with your family today.

People with HCU require specialized care and medical foods, both of which may be unavailable or in limited supply in the event of an emergency. You may not be able to follow your diet perfectly during an emergency but it is important to adhere to it as closely as possible and continue to take your formula and other medications! Emergencies usually cause confusion and stress; if you take the proper steps, sticking to diet doesn't have to be one of them. Some emergencies allow you to stay at home (such as when you lose power), others require you to evacuate. It is important to prepare for both of these possibilities before they happen!

Prepare yourself in advance; download the Emergency Preparedness Toolkit today!

Click here to download the Toolkit

Thank you to our Patient -Parent Advisory Committee for your development and support with this toolkit!

HCU Community Cook Book

In May, we announced that we had added Amber Gibson as our HCU Network America recipe coordinator. Since then, Amber has developed recipes that we have shared with our organization. Some of these have been shared in our newsletter, but we have been quietly adding them to our website too!

Head over to our website and check out our newly added *HCU Community Cook Book.* Currently the website features 6 sections, beverages, breakfast, starters/salads/soups and such, dinner and dessert. At this point, the website only features recipes from Amber. If you have a recipe you'd like to share on our site, please email us and we will add it. We will need to know how may servings it makes, how much protein per serving, how many calories per serving, prep and cook time. If it calls for a special item, like nondairy creamer, please be specific with what brand you are using in your recipe for protein calculation.

Click here to visit the HCU Community Cook Book

New News

HCU Network America Brochure, Now available in Spanish!

We have been listening to your feedback and wanted to let the community know that, we are now starting to translate specific items into Spanish. If there are resources you as a community would like to see available in Spanish, please let us know. We will do our best to get them translated in a timely manner.

You may download the brochure via our website by clicking here. If you would like to a hard copy, please email us with your mailing address and we will send it to you. Our email address is: HCUNetworkAmerica@gmail.com.

Global Research Map Webinar, Recap

A webinar on Research for HCU was held on Tuesday, October 23rd that featured Margie McGlynn, President of HCU Network America. Margie updated the research map that was presented at the Patient/Family Meeting in April 2018, and highlighted several research programs that have made progress since April:

1. Enzyme Replacement Therapy – OT58, a synthetic version of the CBS enzyme being developed by Orphan Technologies, will be given to the first HCU patient in a Phase I trial 4Q2018
2. Gene Therapy – AAV8 containing DNA for CBS enzyme, has progressed in a mice study by Warren Kruger and will be completed 4Q2018
3. Cellular Therapy – a new program was announced by Rubius Therapeutics using Engineered Red Blood Cells to metabolize HCY
4. Alternative Enzyme – Aeglea Biotherapeutics presented a poster with results of a mouse study using homocysteinase, a recombinant human enzyme that metabolizes HCY, which showed the product lowered HCY, stopped disease progression and improved survival of the mice
5. Formate – a new project to modify the metabolic pathway using formate was awarded a grant from HCU Network America and HCU Network Australia (pending signing of the research agreement by University of Colorado). This is the first grant awarded under a new global grants process which is co-sponsored by the two HCUNAs. The grant was awarded to Ken Maclean, who will study the administration of formate in combination with betaine in a mouse model of HCU. The Hempling Foundation for HCU Research will fund HCU Network America's contribution. Dr. Maclean will also utilize funding from the Will Hummel Foundation.

We are thankful for all of the researchers who are bringing hope to the HCU Community that better therapies will be available to make life easier in the future!

Click here for video of webinar

Click here for slides presented on research map

HCU Awareness Month, Recap

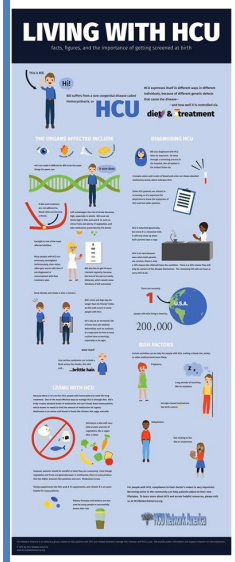
October was a very busy month for HCU Network America. October marked the second HCU Awareness Month Campaign and with it brought a lot of opportunities to share and spread awareness for Homocystinuria.

Recordati Click Campaign

During the month of October, Recordati Rare Diseases created a click campaign that benefited for the HCU community. For every "click" Recordati Rare Diseases donated a dollar to HCU Network America. Thank you Recordati for partnering with us to raise awareness and funds to the homocystinuria community!

Social Media Reach

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



At the beginning of the month, we shared our infographic on HCU caused by CBS Deficiency. This post helped lay the ground work for the month, by explaining what Homocystinuria is, how it's treated and the symptoms. This is a good way to lay out why treatment is so important. The post was seen by over 2,500 people because of the almost 70 shares it received in our community! Talk about spreading awareness for HCU!

Another very compelling post we had was thanks to our president and co-founder Margie McGlynn. Margie shared a video with the community that was made by her children in honor of her two sisters who passed away from Homocystinuria in the early 1970s.

If you missed the video, or would like to re-watch it, click here

Our most popular post was an infographic comparing the cost of low protein foods to regular foods. Not only was this infographic shared within the HCU community, but it spread like wildfire in the metabolic community. The infographic was shared over 500 times! This could not be more fitting as we try to push for the passing of the Medical Nutrition Equity Act!

HCU Awareness Month Fundraising Recap

Thank you to all the families who fundraised on behalf of HCU Awareness Month!
From Facebook donations alone, we have raised $9,970!

Top to Bottom, L to R, : Joanna Ball, Mayes Family
Gibson Family, Sullivan Family, Lewis Family,
Jessica Karnes, Pam Penrose, Kristin Rapp, Piccini Family
Carter Family, Carvalho Family, Bartke Family

Not pictured, Helga Nemaric

Upcoming Events

What is # GivingTuesday?

#GivingTuesday is a global day of giving powered by social media and collaboration. Celebrated on the Tuesday following Thanksgiving (in the U.S.) and the widely recognized shopping events Black Friday and Cyber Monday, #GivingTuesday marks the beginning of the charitable season, when many focus on their holiday and end-of-year giving.

How do I get Involved?

Facebook

This year Facebook and PayPal are partnering to Match $7Million dollars worth of donations! Facebook and PayPal will match donations starting at 5 am PST on November 27 and continue matching donations to non-profits until the $7M match runs out.

We encourage you to reach out to your Facebook family in advance and get them to pledge a Facebook donation first thing on November 27th

Directions to complete your fundraiser on the next page.

Share your Story

Record your story and share it on your Facebook Fund-raiser.

Tell them:

- Your name and where you are from
- When you were diagnosed
- How the diagnosis has affected you
    - Give them a walk through of your daily life
        - Formula and Medications
        - Weighing out food
        - Keeping a food log
    - Any other negative side effects
- What their donation would mean to you and your family

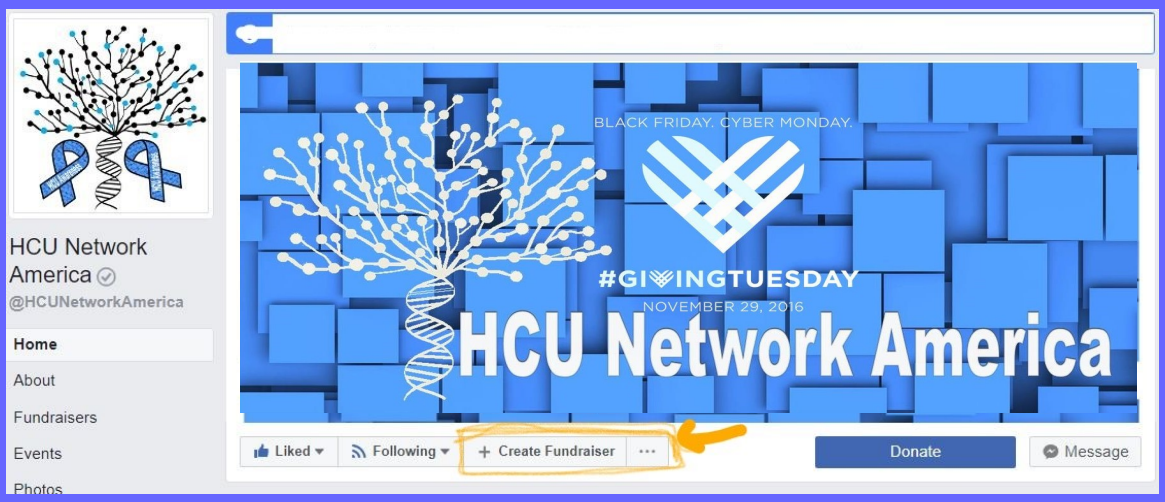
Annual Appeal Letter

Not on Social Media? Use the Thanksgiving parties as a chance to share our annual appeal letter. In it include a picture of the person in your family affected by HCU. Include a description on how HCU has impacted you and your family and what their donation would mean to you.

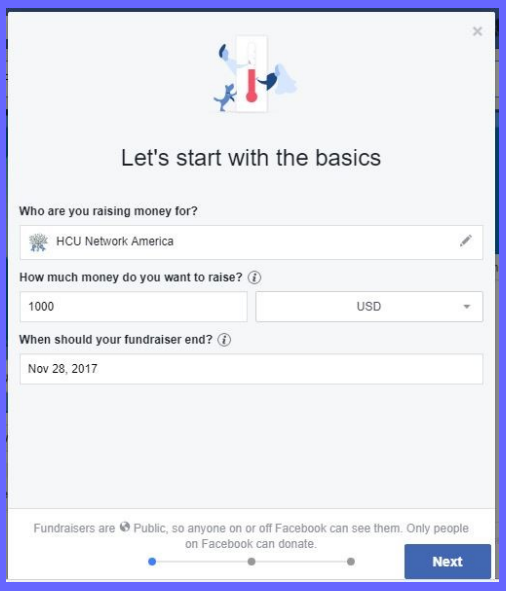
Click here to Print the appeal letter

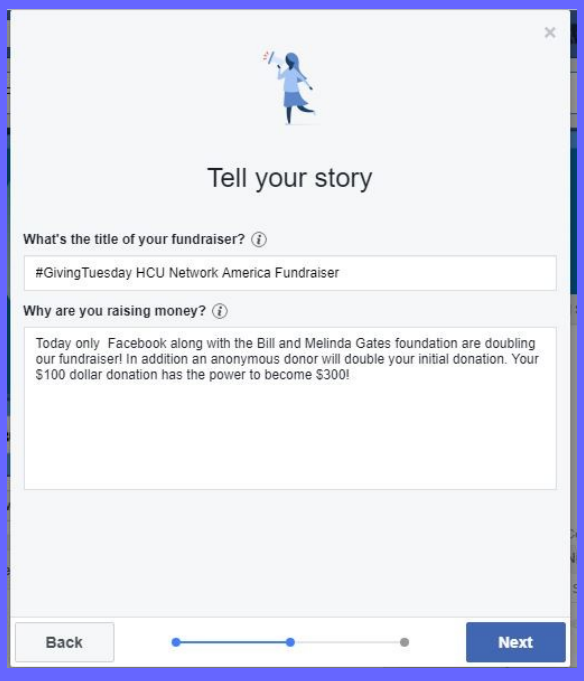
Facebook Fundraiser Setup!

1) On Facebook, head over to our page, HCU Network America. Once on the page, look for the button that says “+ Create Fundraiser”



2) After you click the “+Create Fundraiser” then make sure it says you are raising money for HCU Network America. Change the amount to $1,000 and set the end time for November 27, 2018.

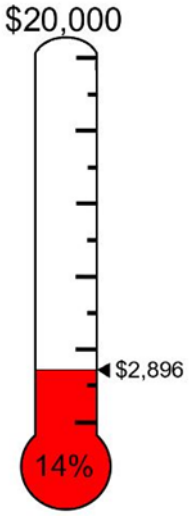




3) Edit the title of your fundraiser. Then in the “Why are you raising money?” Explain that today only, Facebook along with Paypal are doubling your fundraiser. In addition an anonymous donor will double your initial donation, making a $100 donation turn into a $300 donation! Set this up by Monday, November 26th, . Ask your family and friends in advance to donate right at 5 am PST on Tuesday the 27th to make sure we get the match before it runs out—or put their donation on your credit card exactly at 5 am PST and let them reimburse you.

Also explain what HCU is and how it affects you and your family.

Double Your Impact!



*Thermometer does not reflect Facebook donations or fundraisers for the month of October

Thanks to an anonymous donor, any funds you help raise from October through December 31 will be matched up to $20,000!

Need information to complete your match?
Visit: https://hcunetworkamerica.org/company-matching/

November Marks Beginning of
Open Enrollment for Health Insurance

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

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

HCU Network America has contracted Raenette Franco of Compassion Works Medical to assist you with your needs. Raenette can help you find a policy that works for you, or work with your current policy to help you get low-protein foods, medical formula, betaine and "supplements" covered.

There is no fee to work with Raenette, but we do urge you to contact her immediately if you do need a new policy. Open enrollment for 2019 ends December 15, 2018.

You may contact Raenette:
raenettef@compassionworksmrs.com
(973) 832-4736

2019 Rome Conference

See the link for more info: https://www.hcunetworkaustralia.org.au/patient-expert-meeting-2019/

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 to. By registering, you will be also be able to identify other affected patients in your state and request their contact information, and you will 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 and provide resources for patients and families, 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/

Newborn Screening Survey for Classical Homocystinuria

But we have newborn screening for HCU...

According to recent statistics, approximately 25-50% of patients are missed by newborn screening for Homocystinuria. There are multiple factors that can play into these numbers. Currently it is federal mandate that all states screen for Homocystinuria through the newborn screening test, but there are no set standards. Meaning, every state or region can set their own methionine cut offs. A handful of states also do tier two testing—meaning they have a second round of newborn screening, making it more likely for homocystinuria to be picked up. Another factor that plays into the effectiveness of the test, is how elevated the patients levels are at the time of the test. Patients who are pyridoxine (B6) responsive, or have more functioning CBS enzyme, are less likely to be picked up by the newborn screening

So how can you help?

Talk to your geneticist about the newborn screening survey and urge them to complete it! This will help us build support for changes to the process to increase the likelihood that HCU patients will be diagnosed at birth.

Here is the letter portion we would ask you to give to your clinic, followed by the survey form:

The Letter:

To Whom this may concern,

I would appreciate your support in answering a brief survey to help support efforts to improve newborn screening for classical homocystinuria.

I have been working with HCU Network America, a patient advocacy and support group for Homocystinuria (HCU), for whom I serve as a medical advisor. One of their key goals is to improve newborn screening for HCU, as it is estimated that over half of patients are missed by the current screening process and often are not diagnosed until they have developed serious clinical symptoms. To build support for an improved process, we are collecting information on patients missed by the current screening process, which we intend to then publish in a consolidated case report.

Could you please support our efforts by completing the attached brief questionnaire, and sending it to me via e-mail at:

Newborn Screening Survey for Classical Homocystinuria

Survey on Classical Homocystinuria (HCU) Patients Missed by Newborn Screening

Do you have any patients with classical HCU missed by NBS and diagnosed later based on symptoms?

( ) Yes ( ) No

If yes, at what age were the patients diagnosed, and what year were they born and in what state?

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Would you be willing to provide information to contribute to a "Case Report" we plan to publish on patients missed by Newborn Screening?

What is the name and address of your clinic and the best contact person for further information:

Clinic Name _____

Clinic address _____

Contact Person:

Name _____

E-mail _____

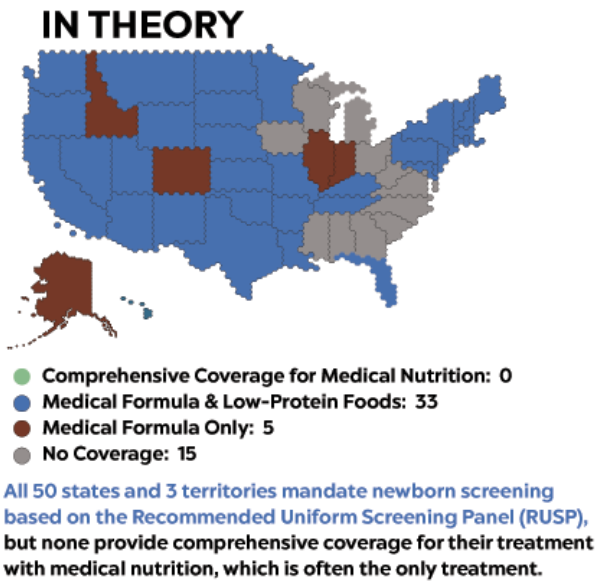
Phone _____

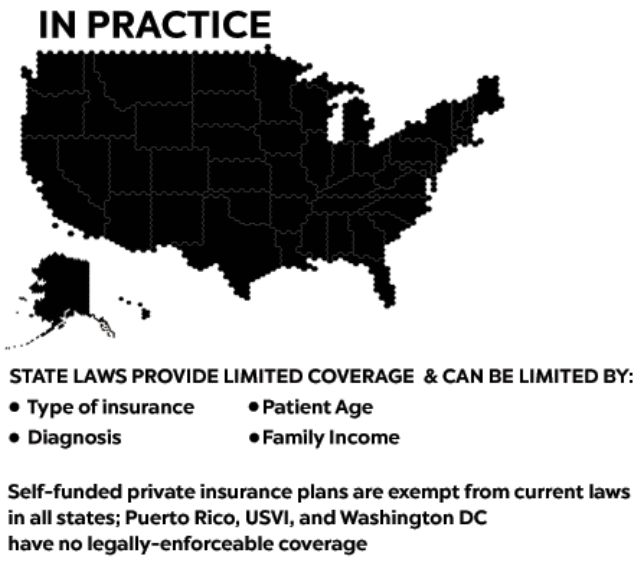
Please send completed survey to Dr. Can Ficicioglu at **ficicioglu@email.chop.edu**

Ways to Get Involved

PATIENTS & PROVIDERS FOR MEDICAL NUTRITION EQUITY

The **Patients and Providers for Medical Nutrition Equity Coalition** is a group of patient organizations (including HCU Network America) and clinicians involved with disorders that require medical nutrition to maintain health. We are working to pass the **Medical Nutrition Equity Act** (S-1194, HB-2587), which will extend the coverage for medical nutrition that Congress passed in 2016 for TRICARE patients to other Insured Americans who have inherited metabolic disorders/inborn errors of metabolism and other disorders on the Recommended Uniform Screening Panel, medical and surgical conditions of malabsorption, Immunoglobulin E and non-Im-mu-no-glob-u-lin E-mediated allergies to food proteins, inflammatory or immune mediated conditions of the alimentary tract, and other diseases or conditions determined appropriate by the Secretary of Health and Human Services.





For many in congress they know very little, if anything about Homocystinuria or other inborn errors of the metabolism. Your stories of inadequate medical food and formula coverage will help paint the picture of the struggle we face daily feeding ourselves and our children with these rare and life threatening conditions.

Please share your stories about how you have been impacted by inadequate medical food and formula coverage! Visit https://medicalnutritionequityfor.us/share-your-story/ and share your story now

To learn more about Patients and Providers for Medical Nutrition Equity Coalition and how you can get involved, please visit: Https://medicalnutritionequityforus.com

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

OBITUARY

Zakary Tyler Edwards

MAY 6, 2010 – OCTOBER 24, 2018

Zakary Tyler "Zakie" Edwards, 8, went to play ball with the Angels in the Outfield Wednesday, October 24, 2018 at Brenner Children's Hospital.

Zakie was born May 6, 2010 in Davidson County, a son of Brian and Amanda Edwards. He loved sports, especially playing baseball and his church, Wayside Tabernacle Freewill Baptist Church. Zakie was a third grade student at Pilot Elementary School. He was a selfless, loving child who thought of others more than himself.

Surviving are his parents; three brothers, Gavin, Brayden and Hunter Edwards; maternal grandparents, Kenneth and Mary Stevens; paternal grandparents, Ralph and Ann Edwards; a paternal great-grandmother, Ruby Dickens; cousins, aunts and uncles, and a host of friends.

A Celebration of Zakie's life was held Sunday, October 28 at 2 p.m. at Wayside Tabernacle Freewill Baptist Church, 3035 Upper Lake Rd. Thomasville, NC 27360 by Pastor Jimmy Garrett and Pastor Mike Barnes. Burial was followed in Holly Hill Memorial Park Cemetery. The family received friends at Thomasville Funeral Home Saturday from 5 to 8 p.m.

To make a donation in honor of Zackie a PayPal fund has been set up for his family.

Click here do donate

VOLUNTEER

GET INVOLVED

You can make a difference!

Our fundraising committee is looking for volunteers!
E-mail HCU Network America and we will connect you

We'd like to thank the following content contributors:

Editor in Chief: Danae' Bartke
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