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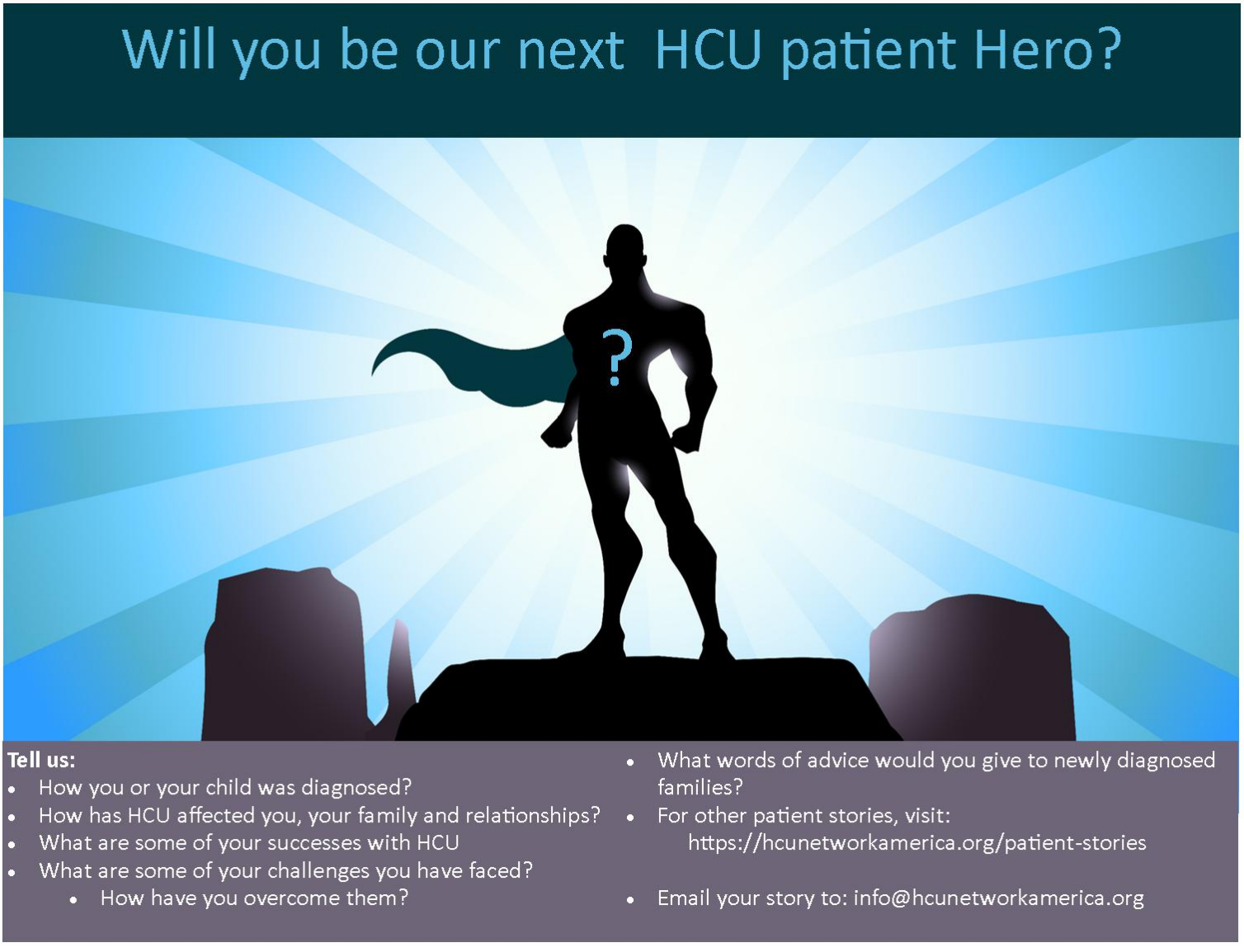
Tell us about you and help us clean up your inbox!

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

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



HCU HERO: MASEN FROM CANADA

Masen was born in May of 2013 in a city just outside of Vancouver, British Columbia, Canada. At that time, Homocystinuria ("HCU") was not a part of the newborn screening tests, but would be added approximately one year later. After getting a good report from newborn screening, we went home with our happy (and we believed healthy) newborn baby boy.

Masen was the sweetest baby and brought us so much joy and happiness. He ate well, slept well and was such an easy going and happy little guy. We never had any serious worries about his health or well-being.

Around toddler age, when Masen would catch a cold (which was really only once or twice a year), we would end up in the emergency room as he would often have trouble breathing. Over the years this occurred less and less, and in the past 2 years it has not been an issue. We keep an inhaler on hand in case he catches a cold, and we use it as needed. This can be common among many children, so this was never a red flag.

Just before kindergarten, we went for a routine eye exam and learned that Masen needed glasses. This wasn't a big concern either, as again, it's quite common and it also runs in our family. Masen rocked his new glasses, and somehow looked even more adorable than we already thought him to be! Masen thrived in kindergarten, making new friends and learning new things. However, within these first few years of school it became apparent that he was struggling with learning to read and write. It takes a little extra help and some hard work but Masen always catches up to where he needs to be when he puts his mind to it. He is a very hardworking kid.

During this past year, Masen's vision prescription started to become worse and more difficult to keep up with. After a few eye doctor appointments, months of living in fear with many unknowns, and lots of medical tests, a very astute eye doctor made the decision to have our pediatrician send Masen for blood work. This is where our HCU journey began; we just didn't know it quite yet.

Masen was officially diagnosed with HCU on June 25, 2021, at just over 8 years old. Our world was turned upside down as we learned of the health risks and of the tools with which to manage this new path. We continue to work hard daily to overcome the challenges that this diagnosis has brought us. Masen has always been a fantastic eater, and now most of his favorite foods will be items he will likely

never eat again. While it has been extremely difficult to take away his favorite foods, Masen happily tries the new low protein foods that we are introducing to him, and we celebrate together when he enjoys something new. He has to endure bi-weekly blood draws in order for us to help keep him healthy. He drinks his formula daily without complaint and has memorized what supplements he has to take throughout the day and when. As his parents, we could not possibly be more proud of him.

Masen is an active, energetic, friendly and resilient little boy, who loves to play sports, watch Pokémon and make everyone laugh. His quick wit and sarcasm are brilliant. He is extraordinary in every way and braver than anyone I know.

While I said that Masen is resilient, we hate that he has to be, and we long for a day where his daily life will not have to be managed with such a strict diet and supplementation in order to stay healthy. Until then we will continue to celebrate our victories and take this new path that we are on one day at a time.

Slow Cooker Vegetarian Pot Pie

Author: Amber Gibson

Servings: 7.4
Serving Size: 6 oz.
Protein Per Serving: 1.4 g
Calories Per Serving: 74

Cold winter nights call for food that doesn't just warm the body, but also the soul! This is a great hearty meal for everyone to enjoy. **I did not account for any biscuits in the nutrition information**. This way it is open to any option. I used canned biscuits when I first made this: I rolled out the dough and used cookie cutters to make smaller shapes to fit my daughter's diet. You can use any biscuit or crackers or bread with this. Enjoy!

Ingredients:

- 1 20-oz. can (280g) Canned Jackfruit, Seeds removed and roughly chopped
- 50g Diced Onion
- 2 clove(s) (6g) Garlic, fresh cloves, chopped
- 70g Shredded Carrots
- 50g Diced Celery
- 150g Small Diced Potatoes
- 90g Diced Parsnips
- 3 c (711g) Vegetable Broth
- 1 packet(s) (31g) Seasoning & Broth, Golden or Rich Brown, dry
- 2 tsp (2g) Bay Leaf, dry, about one leaf
- 2 tsp (2g) Rosemary, fresh, chopped
- 1 tsp (1g) Thyme, fresh
- 45g Diced Button Mushrooms

Creamy Mix

- 1 TBSP (8g) Wheat Starch
- 2 tsp (5g) Cornstarch
- 1 c (235g) Rice Dream, Original

Directions:

1. Put all ingredients into the slow cooker EXCEPT the mushrooms and the creamy mix. Stir to combine. Turn slow cooker on high and cook for three hours until all vegetables are tender.

2. For the creamy mix: Place the wheat starch and cornstarch in a 2-cup measuring cup. Add the one cup of rice milk and whisk until the starches are well combined with the rice milk. Add the mixture and the mushrooms to the slow cooker with the other vegetables and stir to combine. Cook until thickened, about another hour. Season with salt and pepper to taste and serve hot.

NOTES

For the jackfruit, be sure to rinse well and drain before chopping. You do not want it chopped too small. Just enough to be uniform in size to the other vegetables. You can also use vegetarian "chicken" flavored broth if you can find it in stores.

Triple Ginger Cake

Author: Amber Gibson

Servings: 9
Serving Size:1 slice
Protein Per Serving: 0.8 g
Calories Per Serving: 371

Ingredients:

- 320g MIxQuick Baking Mix, gently packed, about 2 cups
- 1 1/2 tsp (3g) Ginger, ground
- 1/2 tsp (2g) Cinnamon, ground
- 1/2 tsp (3g) Salt, Table
- 1 tsp (5g) Baking Powder

Wet Ingredients

- 8 TBSP (112g) Butter, regular or unsalted, softened
- 1/2 c (110g) Sugar, Brown, packed
- 2 banana(s) (236g) Banana, fresh, peeled, medium, mashed
- 2 TBSP (30g) Mayonnaise
- 1 tsp (2g) Minced Fresh Ginger Root
- 1/4 c (40g) Chopped Candied Ginger
- 1/2 c (120g) Coffeemate Nondairy Creamer

Directions:

1. Preheat oven to 350 degrees. Spray an 8x8 pan with cooking spray and set aside.

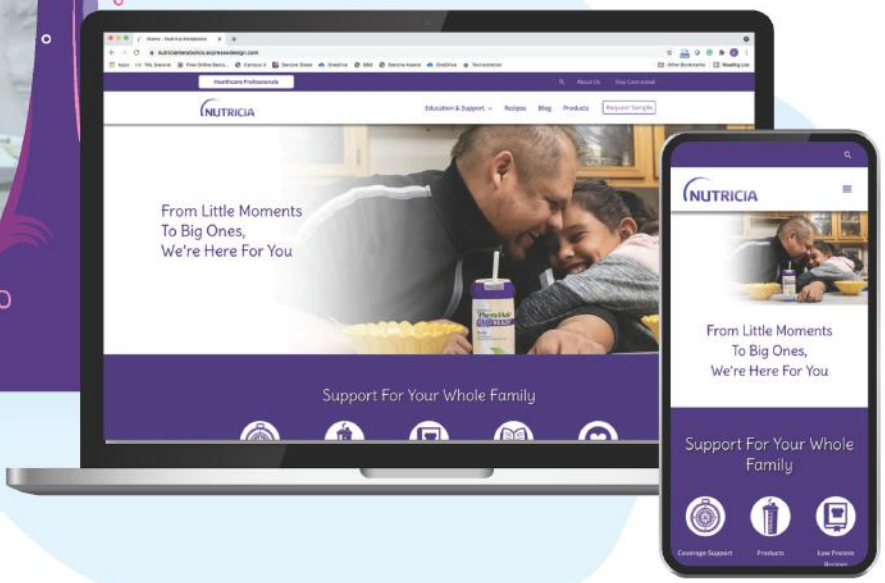
2. Combine the dry ingredients in a medium bowl and gently whisk to combine. Set aside.

3. In the bowl of a stand mixer with the paddle attachment, cream the butter and brown sugar until light and fluffy. Add the bananas and mix just until combined. Now add the mayo and mix for 30 seconds. Add the fresh ginger and the candied ginger. Mix for another 30 seconds.

4. Now add 1/3 of the dry ingredients and mix just until combined. Add 1/4 cup of the nondairy creamer and mix just until combined. Repeat until all ingredients are mixed, ending with the dry ingredients.

5. Pour into prepared 8x8 pan. Bake for 45 to 50 minutes, or until a toothpick inserted in center comes out clean.

NEW
NutriciaMetabolics.com
HAS LAUNCHED



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NUTRICIA

*Often we share information from our Network Affiliates - this information is not an endorsement for the product. Consult your medical team to make sure it's right for you

December 2021: HCU and You: *Ask Methia*

Dear Methia,

Introducing Solids to my Baby—Help!

Our six-month-old baby with classical homocystinuria (HCU) is finally ready to start solid foods! I've been so excited for this moment, but also dreading it because I know this is going to add another moving target to their diet. How should I introduce solids? Will it be the same as it was with my older child?

Sincerely,
Rooting for Baby

Dear *Rooting for Baby,*

This is an equally exciting (and nerve-wracking) moment in childhood development, and HCU adds a "unique twist" to navigating the world of solid foods – that's for sure! Your child is ready for solids when they are able to hold up their head independently, can sit with support, and begin to show interest in what you are eating. While starting solids on a low protein diet can initially look very similar to initiation on a regular diet, there will of course be some significant differences as the diet progresses. Here is what you can expect:

- ⇒ **Your dietitian and geneticist will give you a target goal (either in milligrams of methionine or grams of protein) from solid foods, which will be adjusted over time.** At six months of age, your child's main source of nutrition is still either breast milk/infant formula AND their medical food. As your child's diet evolves, their intake of solid foods will increase and their intake of breast milk/infant formula will decrease. Your care team will give you several resources to track natural protein/ methionine, whether it is an online resource such as the USDA Nutrient Database, HowMuchPhe, or nutrient analysis booklets. One thing that will remain constant is their need for medical food (methionine-free protein).

- ⇒ **The diet starts with small amounts of pureed foods.** Fruits have very little natural protein and a few tablespoons of applesauce or pears add a negligible amount of methionine. Other pureed fruits (like bananas), vegetables, and rice cereal have more protein. Typically, those foods will have to be "counted" toward a daily target. However, depending on what your child's protein tolerance is and what their specific needs are, some foods may be "free." This is something you and your care team can address together.

- ⇒ **Your child will be ready to tackle more textures as they gain more experience and confidence with solids.** Diced, mashed, and cooked/soft finger foods (like puffs and low protein pasta) can be introduced once you and your care team feel comfortable with your child's progress. It's likely that your clinic will ask you to measure/weigh quantities of certain food to keep track of your baby's daily protein intake.

- ⇒ **A food log will be essential during this time.** This will help you stay on track in meeting your child's daily intake goals. This is also very helpful so that you look back on your child's intake patterns. Your dietitian will likely ask for a diet recall at follow-up visits, and food logs make this easy AND helpful for your care team to evaluate and set new goals.

- ⇒ **One new food can be introduced every 5-7 days.** This is important from a food allergy standpoint, as introducing two foods at the same time will make it hard to detect any potential allergens if there is a reaction.

It's important to remember that there is no such thing as a "silly question" when it comes to your child's diet and medical care. I always say that it is better to ask your dietitian and be reassured, than to assume something is fine (and potentially be incorrect!). Your team is here to support you throughout this process.

Sincerely,
Methia

NEWS YOU SHOULD KNOW

Open Enrollment Ends soon!

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

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

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

Contact Raenette at raenettef@compassionworksmrs.com | (973) 832-4736

Bethesda, Maryland | June 25-26, 2022

HCU Network America

Organic Acidemia Association

NEWS YOU SHOULD KNOW

New **Potential** Therapies Announced!

- November 9, 2021 Synlogic and Gingko Bioworks announced the nomination of SYNB1353, an investigational Synthetic BioticTM medicine for the treatment of homocystinuria (HCU). Synlogic expects to file an investigational new drug (IND) application with the U.S. Food and Drug Administration (FDA) for SYNB1353 and begin clinical development in 2022. SYNB1353 is an engineered strain of the probiotic bacteria E. coli Nissle (EcN) which consumes methionine within the gastrointestinal tract, preventing methionine absorption and conversion to homocysteine in plasma.
    - Read the Press Release: https://www.prnewswire.com/news-releases/synlogic-and-ginkgo-bioworks-announce-investigational-synthetic-biotic-medicine-for-the-treatment-of-homocystinuria-301419469.html

- November 22, 2021 Codexis, Inc announced their biotherapeutic development program for classical homocystinuria for CDX-6512, which contains the enzyme methionine-gamma-lyase. CDX-6512 is designed to degrade methionine in both the stomach and upper intestine, which decreases absorption on methionine and its conversion to homocysteine. Kristen Skvorak, PhD Translational Scientist at Codexis, recently shared in a presentation given at the International Congress of Inborn Errors of Metabolism that when given to HCU mice, they demonstrated up to a 45% decrease in total homocysteine, 4 hours after protein challenge. Similar results were found in non-human primates with regard to methionine levels.
    - Read the Press Release: https://ir.codexis.com/news-events/press-releases/detail/313/codexis-presents-pre-clinical-data-highlighting-its

RESEARCH OPPORTUNITIES

Travere Therapeutics has announced a new cohort for their COMPOSE Phase 1-2 study, previously known as TVT-058 (and OT-058). They are actively recruiting for 4 patients to join this otherwise closed trial.

Learn more or apply

HCU Caregiver Interviews

ZS Associates, a market research company, is conducting a study on the lives of Classical HCU patients and caregivers. If selected the study will involve participating in a 60-minute online interview. Generous compensation is available.

You must:

- Be a parent of a child with Classical HCU
- Have a child between the ages of 2-18
- Live in the US

If interested, please click on the link below to take the survey. Should you qualify for the study the market research company will reach out to you directly to get your interview scheduled.

Participate in the HCU Caregiver Survey

RESEARCH OPPORTUNITIES

We will be launching in soon - sign up to get an email when we launch!
https://hcunetworkamerica.org/homocystinuria-data-collection-program-email-contact/

To learn more visit:
https://hcunetworkamerica.org/homocystinurias-data-collection-program

OUR $25K MATCH IS BACK!

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

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

See our appeal letter on the next two pages, or you can print it from here

amazonsmile
You shop. Amazon gives.

AmazonSmile donates 0.5% of your purchase (before taxes and rebates) on all eligible products to your charity of choice. This may not sound like a lot, but if you're like many others who prefer the convenience of ordering gifts and necessary items online, imagine how quickly it could add up!

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

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

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

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

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

Best practices for using Amazon Smile on a desktop
Now that your account is set up to use Amazon Smile, it is important to note that Amazon only makes donations to HCU Network America when you checkout from your cart from this smile.amazon.com. This is the only way HCU Network America gets any donations from Amazon Smile.

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

HCU Network America
15 S Mallory Ave
Batavia, Illinois 60510

(630) 360-2087
info@hcunetworkamerica.org
http://www.hcunetworkamerica.org
Tax ID Number: 81-3646006

We have seen the reopening of the country in many ways throughout 2021, along with some set backs. We are grateful for the scientific advances that allowed for a vaccine to protect our vulnerable population. Despite many positive advances we recognize that challenges remain that affect your lives. We sincerely hope you have been able to successfully manage these challenges.

These times are extra demanding for people with unique medical needs and special diets, who spend time at clinics and waiting for life giving medical supplies. People with HCU must balance all the variables in their lives that affect their health and that is tough, especially this year, and can sometimes seem overwhelming.

HCU Network America is here to help this special group of people with the support and resources they need to navigate daily life. We are proud of the reach we have and the way these communities have knit themselves together. But we can't do it without your help! As a 501(C) (3), we need your donations, which are tax deductible, to continue with our mission and meet our goals. What you do to help us can make a huge difference in the lives of all HCU patients and their families.

We would like to share a story of a family's journey of diagnosis.

> *Our son was born in the spring when flowers and trees are coming back to life after a long, cold winter. Just like the excitement we feel when we see the beautiful world we live in blooms, our son brought incredible joy and happiness to our family. As our second child, we had experience with a newborn already and began to have concerns early on in his life. He slept all the time, he struggled to latch and nurse and had low muscle tone. Despite bringing these concerns to our pediatrician and insisting upon their seriousness, nothing was ever done about it.* ***At 2 ½ months, our son began to have serious seizures*** *that caused him to stop breathing. While admitted to our local children's hospital PICU,* ***he was diagnosed with a metabolic disorder, a Homocystinuria Cobalamin defect.*** *His initial Homocysteine level was over 250 (normal levels should be less than 15), and his Methionine was less than 2 (normal levels should be over 20). Even though we had a diagnosis it took several days to acquire the necessary medication to begin treatment;* ***it was too late****. Despite the medication dramatically improving his levels, he suffered from severe brain damage due to the toxic imbalance of amino acids in his body. Our son passed away at 3 ½ months. We were devastated. Fast forward 8 years, our second son was born. Due to a better understanding of our ability to pass the disorder on to our children, we tested InVitro and discovered he had the same markers as our first son. We were able to deliver our son at Colorado Children's Hospital in their special unit and he was tested and began treatment at birth.* ***Since his diagnosis of Cobalamin G,*** *we have built an incredible support network through HCU Network America. I am so grateful for the resources and community we have found through the many virtual meet ups. We were even able to meet another family recently with a son who has the same diagnosis.* ***Early diagnosis, treatment and resources*** *is what has made it possible to say that our son is now two and a half and thriving!!* ***No family should have to live with the grief of a lost child when there are treatments available to help them live happy, healthy lives.***

You can imagine what that felt like and at that time there was no network to give this family support and vital information. In June of 2016, HCU Network America was incorporated; bringing hope to families living with HCU that they had advocates to help them get the latest and best advice from the medical community. HCU Network America also financially supports research that can help find new treatments. Since 2016 we have communicated with metabolic clinics all over the country to reach out to new patients and provide them toolkits which are filled with helpful tips and guidelines for living with HCU.

Here are some of the highlights that your donations helped with:

- Help fund Research Grant: In 2021, we have put out a call for Expressions of Interest, to award our third research grant in collaboration with HCU Network Australia.
- Launched the first Data Collection Program for Homocystinuria to help accelerate research.
- Published three guides, including a Parent Handbook to Special Education Services, Off to College, and Back to Care.
- Launched a Back to Care Program to assist Classical HCU patients who are returning to diet.
- Published a children's book to support medication management of Cobalamin disorders.
- Provide a consultant with experience in medical insurance to fight for coverage for medications and food at no cost to HCU patients
- Support for community meetups and monthly community newsletter.

Our goal this year is $50,000. Thanks to an anonymous donor, any funds you donate up to December 31, 2021 will be matched up to $25,000. Please consider a donation to HCU Network America in 2021. If you personally know a patient with HCU, you can donate in their honor. We need your help and appreciate any donation. In addition, if your employer matches charitable donations, they will match those too!

Take a minute to look at our website to see what we are up to and meet some our "heroes": https://hcunetworkamerica.org. You can donate through our website or by mail.

Thank you for all you do to help us - we will all get through this year and we look forward to 2022!

Thank you,
Danae' Bartke
Danae' Bartke
HCU Network America, Executive Director

Donor levels:

- **Leadership Circle** - $5,000 or more
  Donor's name, HCU Patient's name and photo on homepage of website, along with certificate donation
- **HCU Champion** - $1,000 or more
  Donor's name, HCU Patient's name and photo on HCUNA donation page along with donation certificate
- **HCU Supporter** - $500 or more
  Donor's name, HCU patient's name on website, along with a donation certificate
- **HCU Ally's** - $100 or more
  Donors name and HCU patient's name listed on website

4 ways to donate:

1. Use the enclosed slip and envelope
2. Go to https://hcunetworkamerica.org/donate
3. Text HCU2021 to 44-321
4. Scan the QR Code

WHAT'S YOUR STORY?

More than 30 million Americans are living with one or more rare diseases.
Each one of us has a story. We want to hear yours.

Today, the EveryLife Foundation for Rare Diseases launched *What's Your Story?*, a new online rare disease story bank for advocates like you to share your experiences on a wide-range of issues impacting the rare disease community.

What's Your Story? presents a series of questions covering topics ranging from difficulty in getting diagnosed to challenges in gaining access to therapies, to facing discrimination in the workplace, and more. You are also invited to upload photos and videos that help illustrate your rare disease journey. Advocates of any age are welcome to submit stories.

Share Your Story With Us

Benefits of sharing your story:

Influence rare disease policy.

Educate policymakers.

Inspire other advocates.

Be entered to win a $1,500 donation to the patient advocacy organization of your choice! Submit your story by March 2nd, the final day of Rare Disease Week on Capitol Hill 2022 for the chance to win one of three donations.

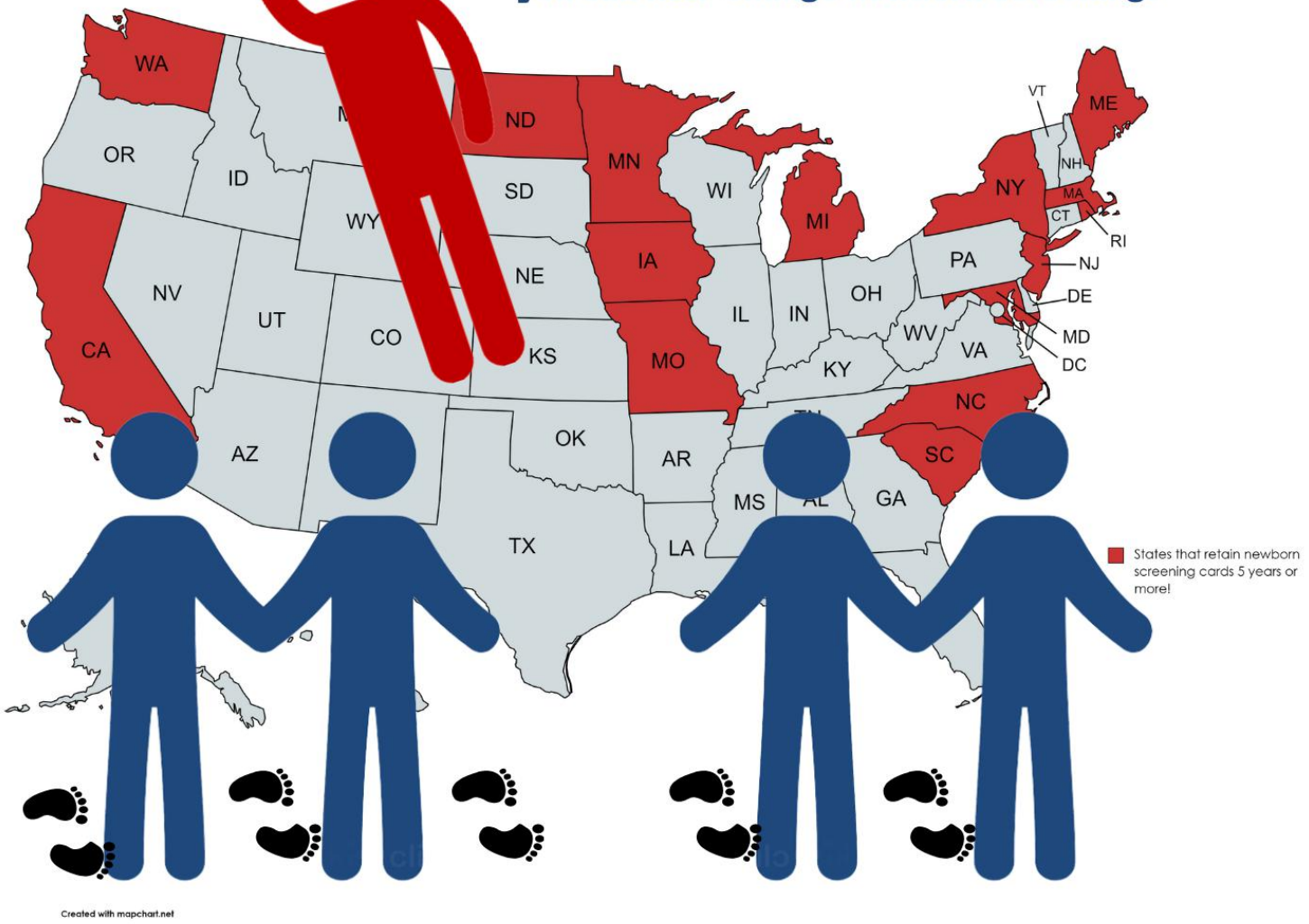
Stories submitted through *What's Your Story?* will help advance rare disease policy priorities through ongoing advocacy efforts to advance the equitable development of and access to lifesaving diagnoses, treatments, and cures. Submissions may be shared during meetings with Members of Congress or with the public via social media, online or in the press.

EVERYLIFE FOUNDATION FOR RARE DISEASES

Were you or your child born in one of the highlighted states below?

Were you or your child diagnosed with Classical HCU,Cobalamin with HCU or Severe MTHFR?

If you answered yes, you can HELP change newborn screening!



Emory University is conducting a newborn screening research study on these disorders!

Contact Angela Wittenauer MSN, FNP-C, RN: alwitte@emory.edu | 404-778-8489

Director, Newborn Screening Follow Up Program | Emory Univ. Dept. of Human Genetics

CALLING ALL PATIENTS WHO WERE MISSED BY NEWBORN SCREENING AT BIRTH!

WE HAVE AN OPPORTUNITY TO HELP CHANGE THE PROCESS BUT NEED YOUR STORY TO GIVE US THE EVIDENCE TO BUILD OUR CASE

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 patient's 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?

If you or your loved one were missed at screening, we need to hear from you ASAP so we have enough evidence to bring about change. Contact Danae if you can help us, and she will lead you through the process that is outlined below.

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.

On the following page you will find the letter portion. We ask you to give to your clinic, followed by the survey form:

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 vie-email at: FICICIOGLU@email.chop.edu

Sincerely,
Can Ficicioglu, M.D., Ph. D.
Director of Newborn Metabolic Screening Program, Children's Hospital of Philadelphia

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_____

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
Or online: https://hcunetworkamerica.org/survey-on-classical-homocystinuria-patients-missed-by-newborn-screening/