The HCU *Herald*

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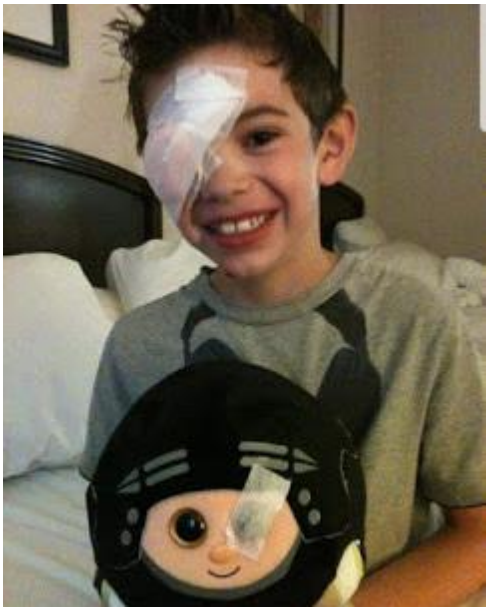
HCU HERO:
NATHAN FROM CANADA

Nathan, was born with HCU, but was not diagnosed with the disorder at birth. Fortunately, he is B-6 responsive - meaning his levels can be controlled with high doses of B vitamins, but it wasn't until he started developing eye problems that he was tested for the disorder, and began
treatment.

Nathan was diagnosed with Homocystinuria when he was almost 7 years old. Unfortunately, Ontario didn't start newborn screening until 2006 and Nathan was born in 2005. A routine eye exam was held at his school and a note was sent home to say that we should have his eyes checked. We took him to see an optometrist and as soon as she looked into his eyes, she quickly referred him to see an Ophthalmologist. I noticed for quite some time that Nathan's iris's "jiggled" or "rippled" when he moved them and I knew it wasn't normal, so I mentioned that to the ophthalmologist. She did some tests and told us that both his lenses have dislocated and wanted us to see a cardiologist and geneticist. She said Nathan may have Marfan's Syndrome or another connective tissue disorder.

His father and I were in shock and very concerned because we were told this would affect his entire body and could potentially shorten his life. He had an echocardiogram as they thought he had a murmur, but it thankfully came back normal. From there he had genetic testing at Sick Kids hospital in Toronto. It was a long 3 month wait for the results to come back. In March of 2012 we got the diagnosis. Nathan has Classical Homocystinuria. His father and I were terrified; we read so much about HCU and saw some very grim statistics. We had no idea what this disease was going to do to our son, especially since he was diagnosed so late. The doctors told us that this was a very rare and serious disorder and said Nathan could have a heart attack, stroke or seizures and that he is also very prone to blood clots.

His blood and urine were tested and his homocysteine levels came back at 300 (normal is 4-14) and his methionine levels were over 400. His doctor immediately had him start taking high doses of vitamin B6 and then eventually vitamin B12, folic acid and Betaine. Luckily Nathan is responsive to these meds, so he doesn't need to follow a metabolic diet, but he will always have to limit his protein intake as his body is missing the enzyme to break it down properly. Looking back from when Nathan was a year old, his father and I knew something wasn't right with our son. When Nathan was 6 months old, my sister and I witnessed him having a small seizure. It was about 5-10 seconds in length but it was enough for me to take him to the emergency room. Waiting for 3 hours with a crying baby then being told by the doctor that it was nothing, was completely infuriating; I knew something was wrong!



As time went on, Nathan was behind with walking and learning and had many sensory issues. We took him to his pediatrician, begging him to help us figure out what was wrong with Nathan. We had him tested for many things but all came back negative. He saw a speech-language therapist to help him with his comprehension. He also saw an occupational therapist for his fine motor skills. He had an x-ray for knocked knees and saw a specialist because he had problems with drooling when he was 4. All of these things were because of Homocystinuria! If we only knew then what we know now, he wouldn't have had any of these problems!

We were told by Nathan's ophthalmologist that he wouldn't have to have surgery until he was into his teen years, but his vision continuously declined, and his lenses were almost completely detached. We had to wait 3 months for the Ontario Government to approve the lenses that his doctor wanted to use. Finally, in June 2013, he had a 3-hour surgery on one eye and again in July on his other eye. Before his surgery, his vision was 20/80 in 1 eye and 20/120 in the other eye. Today they are both 20/40 and he wears progressive glasses as his eyes can no longer naturally focus.

Since his diagnosis we had a few trips to the ER for chest pain and shortness of breath, all tests thankfully came back ok! An EEG was done when he was 9 because he had a lot of myoclonic jerking at night. The neurologist that read the EEG diagnosed him with epilepsy as he had epileptiform activity and was going to start him on anti-seizure medications. I asked for a second opinion so he had two 24hr EEGs done at Sick Kids hospital over the next 2 years, both with abnormal waves but not epileptiform so we were told just to watch for any signs but he may never have a seizure!

Nathan has improved immensely with his sensory issues and learning, not to mention his overall health. We see amazing changes with our son. Nathan is now 15 years old and very tall; he's 6'2". He loves playing hockey and downhill skiing and will continue having blood tests, eye exams, MRI's, echocardiograms and other routine tests throughout his life. Fortunately, we know with the help of his doctors, Nathan will enjoy a long happy life!

HCU COMMUNITY COOKBOOK

Amber's Kitchen

CINCO DE MAYO MENU

JACKFRUIT CHILI LIME SOUP

Yields 10 Servings
Serving Size: 4 oz
Protein per serving: 0.9 g
Calories per serving: 29

JACKFRUIT CARNITAS FILLING

Yields 5.2 Servings
Serving Size: 40 g
Protein per serving: 0.7 g
Calories per serving: 79

SWEET POTATO ENCHILADA FILLING

Yields 5.38 Servings
Serving Size: 1/4 c
Protein per serving: 1.1 g
Calories per serving: 114

MEXICAN CHOCOLATE BANANA CAKE

Yields 9 Servings
Serving Size: 86 g
Protein per serving: 1.5 g
Calories per serving: 203




Find these recipes at https://hcunetworkamerica.org/hcu-community-cook-book/

THIS WEEK'S MENU

M

Breakfast: Cereal
Lunch: Fajita Rice Bowls
Dinner: Pasta Alfredo

T

Breakfast: Yogurt, Fruit & "Granola"
Lunch: Pasta Salad
Dinner: Burger and Pretzels

W

Breakfast: Yogurt & Muffin
Lunch: Grilled cheese and Tomato Soup
Dinner: Tacos

T

Breakfast: Toast and Apples
Lunch: Nuggets and fries
Dinner: Macaroni and Cheese

F

Breakfast: Smoothie
Lunch: Pizza and Salad
Dinner: Burger and Pretzles

For HCU Network America, 2021 is all about Back to Care. We know it's easy to stray away, but as patients age, they realize the importance of keeping in contact with their clinic, following their diet, and keeping themselves all around healthy! As part of this initiative we will be bringing to you a weekly meal plan every other month. We are hoping that this will make the transition of Back to Care just a little bit easier! Be on the lookout for more helpful resources this year to help guide you Back to Care!

Each day has meals for <10 of protein day, 20-30 of protein day, and 30-40 of protein day.

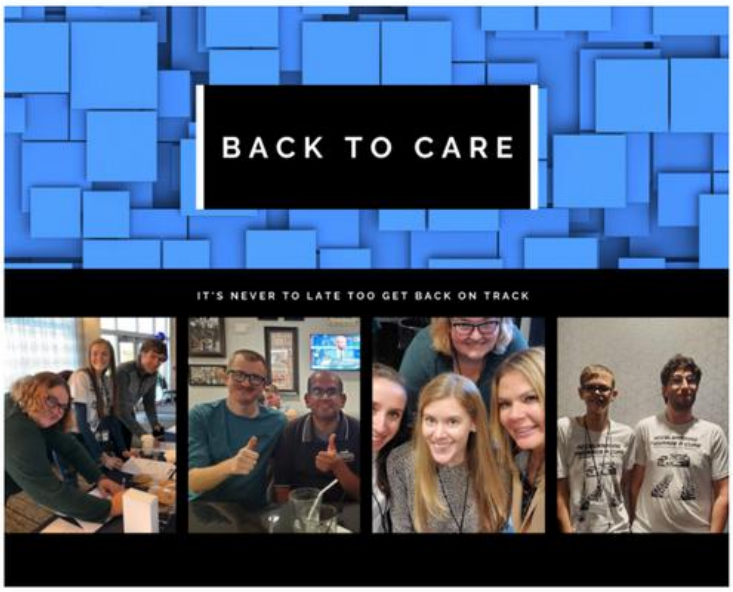
Shopping List

Click each day to view the week long menu!

Disclaimer: This meal plan is intended to be a foundation or guide to what meals could look like on a low protein diet. It does not take into account individual caloric, protein and formula requirements, which are all patient-specific. Please consult with your metabolic geneticist and dietitian prior to making any significant dietary changes or following any meal plans of which you are unsure.

*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.

NEW RESOURCES



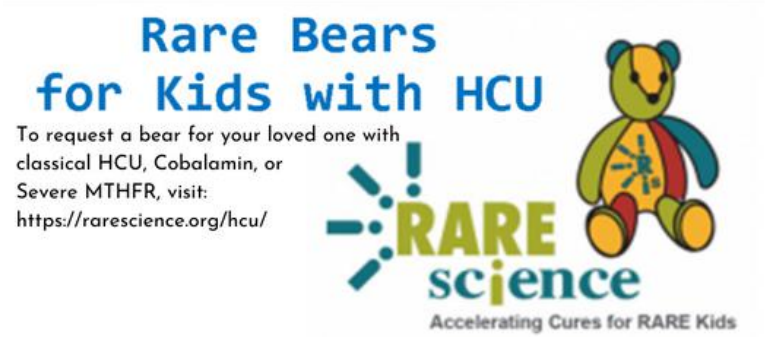
For HCU Network America, 2021 is all about Back to Care. We know it's easy to stray away, but as patients age, they realize the importance of keeping in contact with their clinic, following their diet, and keeping themselves all around healthy! We are excited to launch a new Back to Care section of our website. This new section will have resources on what is HCU, managing our diet and support. We have compiled the many resources we have already and condensed them to one page to help make this next chapter a bit easier. We are hoping that this will make the transition of Back to Care just a little bit easier! Be on the lookout for more helpful resources this year to help guide you Back to Care!

Visit the Back to Care page: https://hcunetworkamerica.org/back-to-care/

Our Cobalamin Steering Committee has also been very busy this year! They have already finished the Parent Handbook for Special Education Services (for all Homocystinurias) and now they are back at it with a new wonderful video for Cobalamin (Cbl) patients affected by Homocystinuria (Cbl C, D, E, F, G, J, and X) on why they need Hydroxocobalamin (B12) injections!

Watch the video here: https://youtu.be/rHLmuD5MMLI

RARE BEARS FOR RARE KIDS!



We are thrilled to announce that the Rare Bears for HCU Campaign in partnership with Rare Science has been re-opened!

To enroll in the RARE Bear Program and to request a RARE Bear, please click the link and complete the form: https://www.rarescience.org/hcu/

- Those who have already received a bear, are not eligible
- Date for gifting will be announced later
- You will not receive a confirmation email or be notified when your bear has been shipped

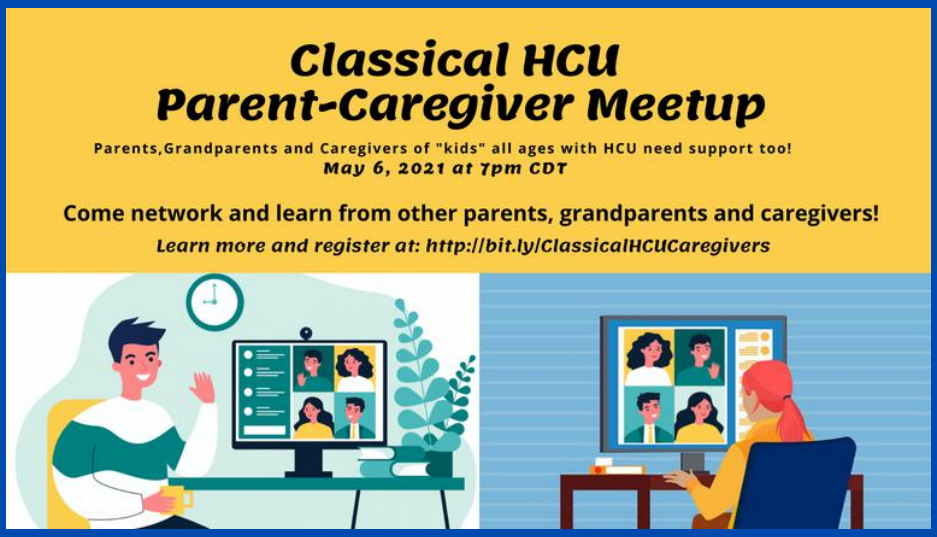
COVID IMPACT SURVEY

It's been quite a year: do you have 3 minutes to help your community? As we move toward reintroduction of the Medical Nutrition Equity Act in Congress, we are particularly interested in how COVID-19 may have affected your access to medical care and treatment for your (or your family member's) Inherited Metabolic Disorder (IMD). US Residents, please take this short survey, the results of which will be shared with the community. Thank you!

http://pheed.me/2021covidimpact

UPCOMING EVENTS

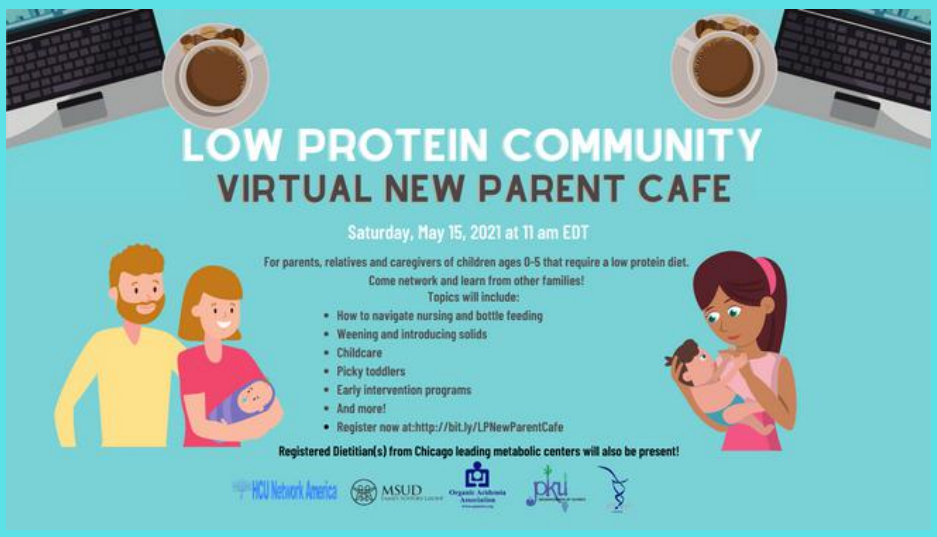
Click the image to learn more or register



Whether your child is 5, 15, or 25, parents, grandparents and caregivers of those with HCU need support!

Come join us Thursday, May 6, 2021 at 7 pm CDT | 8 pm EDT | 10 am Sydney, Aus.

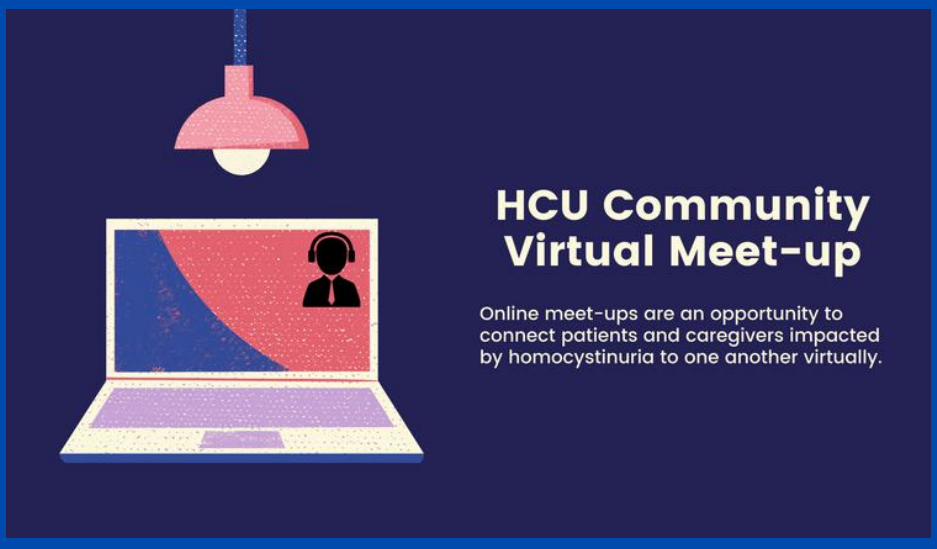
Register at:
https://bit.ly/ClassicalHCUCaregivers



When you first learn your child has HCU and will need a low protein diet, it's overwhelming! There is so much to wrap your head around and you likely have a million questions those first few years!

Come join us Saturday, May 15, 2021 at 10 am CDT | 11 am EDT | 4 pm UK

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

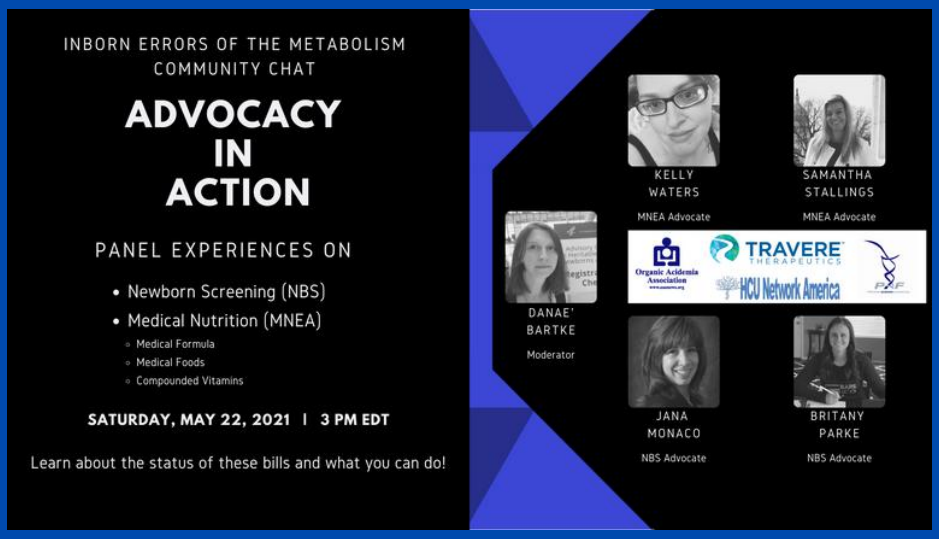


- Struggling with the diet and formula?
- Feeling in a food rut?
- Don't like your formula, or having trouble getting it covered?
- Having health issues you aren't sure are HCU related, or just part of being an adult?
-

Come join us Sunday, May 16
at 2 pm CDT | 3 pm EDT | 8 pm UK
Register at:
http://bit.ly/HCUMay16Meetup

UPCOMING EVENTS

Click the image to learn more or register



- Were you diagnosed through newborn screening?
- Do you struggle with coverage for low protein foods, formula, or b12 injections?

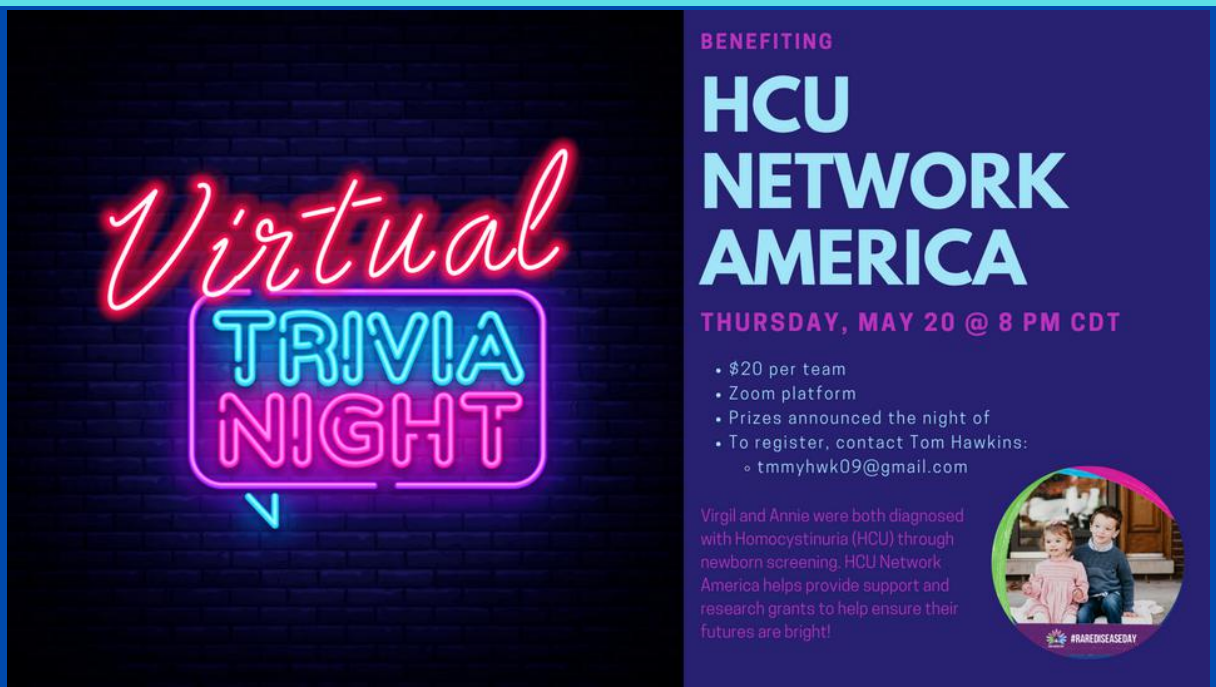
Find out what is happening in the advocacy world that could change this and what you can do in either 1 minute or more.

Come join us May 22 at 2 pm CT | 3 pm ET
Register at: https://bit.ly/IEMAdvocacy

- Struggling with your b12 injections?
- Are you unsure if symptoms are related to Cbl, or just part of life?
- Curious what other therapies may be helpful?

Come join us May 23 at 7 pm CDT | 8 EDT

Register at:
http://bit.ly/CblMay23Meetup



You're Invited

Chef Neil
Virtual Cooking Demo

May 12, 2021
12:00–1:00 pm EDT

Join our very own Chef Neil for a Virtual Cooking Demo with low protein recipes that capture the spirit of summer! You will have the chance to ask Chef Neil any questions you have about low protein cooking or recipes you wish to create.

We will also demonstrate how to make two recipes with Vitaflo formulas. When you register, you will have the option to request Vitaflo product samples to be sent directly to your home so that you can re-create the formula recipes. Sample requests will be shared with your clinic/ healthcare provider to obtain approval prior to shipping.

CLICK HERE TO REGISTER!

Always consult your healthcare professional to determine which recipes are appropriate for your diet.

Vitaflo products are for use under medical supervision.

Vitaflo®

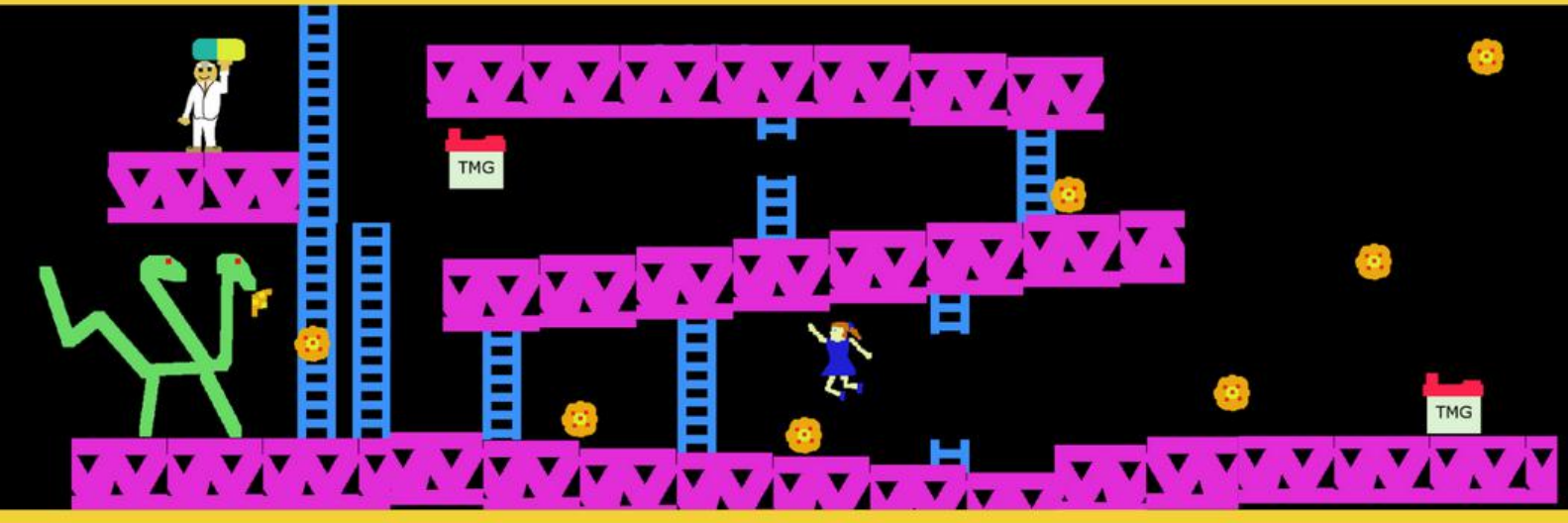
Innovation in Nutrition

A Nestlé Health Science Company

Help Henrietta rescue the cure from the Homocysteine Hydra!

RACE FOR RESEARCH

Walk, Run, Ride | September 1-30, 2021



Per individual: $30

Per Family (up to 4): $50

Registration: Coming soon!

HCU Network America

RECORDATI RARE DISEASES GROUP
Focused on the Few

MAY FUNDRAISING REMINDER

Did you submit for your Employers Corporate Matching Gifts Program?

What are Matching Gifts?
Corporate matching gifts are a type of gift giving in which companies financially match donations that their employees make to nonprofit organizations. When an employee makes a donation, they need to request the matching gift from the employer, who then makes their own donation. Companies usually match at a 1:1 ratio, but some will match 1:2 or 2:1.

Why are Corporate Matching Gifts Valuable?
Corporate matching gifts are valuable because they are free money for your nonprofit of choice, HCU Network America! Your donation has double the power without you having to give double the amount.

Does HCU Network America Really Benefit?
If corporate matching gifts weren't valuable, we wouldn't be sending this letter. In 2020 we received approximately $45,000 in corporate matching gifts!

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

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

How Do I Find out if my Employer has a Corporate Matching Gifts Program?
Your company website or websites such as doublethedonation.com make it easy for you to search and see if your employer takes part in corporate matching gifts. If you can't find it online, please consult with your employee handbook, HR rep or manager to find out.

How Do I Request my Donation is Matched by my Employer?

1. The donor completes their donation
2. The donor submits matching gift request
3. Company reviews donation and nonprofit eligibility and reaches out to nonprofit
4. Nonprofit verifies the donation was made
5. If eligible, the nonprofit will receive the matching gifts request!

Top Matching Gift Companies

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

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

GET INVOLVED

Calling All Nevada, Florida, & Illinois Residents! Registration for the RARE on the Road is now OPEN!

You're invited to participate in a RARE on the Road Virtual State-Specific Training and Networking event! Brush up on your rare disease advocacy skills and connect with other advocates in your area.

Join the EveryLife Foundation for Rare Diseases and Global Genes this May to...

- Discuss what advocacy means to you and the different ways to make your voice heard and advance change for the rare disease community...
- Participate in a guided, step-by-step workshop on how to tell your own rare story, no matter the audience...
- Network with rare disease advocacy leaders and peers from your local community...
- Gain insights and updates on COVID-19 vaccination distribution in your state...
- Learn next steps for connecting with even more rare disease community members in your state to keep the momentum going on your advocacy journey.

Registration is now OPEN! Don't miss the opportunity to build upon the skills and interests already in your toolbelt while virtually meeting others in your state to share experiences and ideas.

**Note: You must be a resident of the state event you select to attend.*

May 4, 2021: Virtual State-Specific Training and Networking Event | Nevada
May 11, 2021: Virtual State-Specific Training and Networking Event | Florida
May 18, 2021: Virtual State-Specific Training and Networking Event | Illinois

Click Here to Register Now

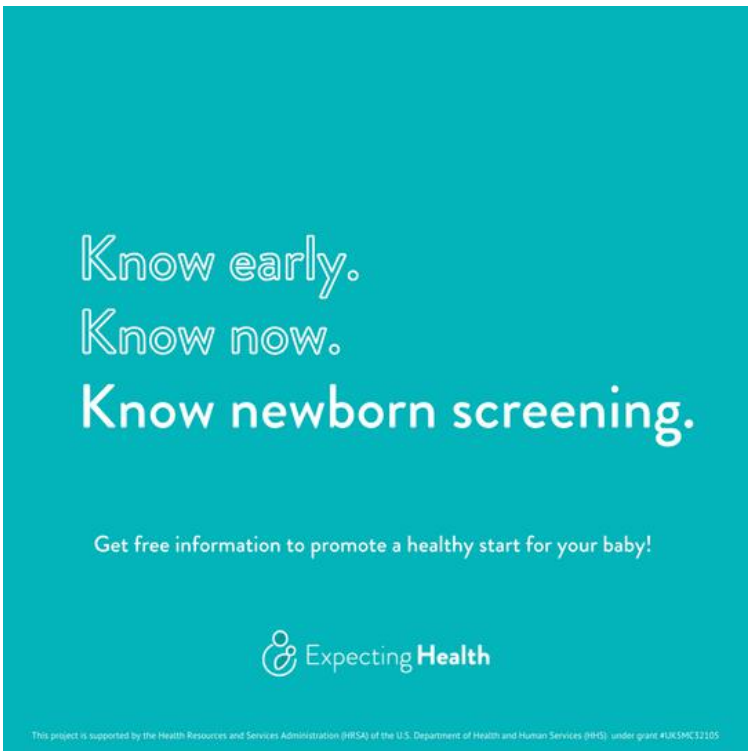
GET INVOLVED

Rare Disease Week on Capitol Hill 2021
July 14th to July 22nd

New dates, new format... same life-changing experience!

Rare Disease Week on Capitol Hill brings together rare disease community members from across the country to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators. While we had hoped to host this event in-person, for the safety of all advocates, Rare Disease Week will be going virtual for 2021.

Registration now: https://everylifefoundation.org/rare-advocates/rare-disease-week/



Get a head start on learning about your baby's health. Learn more about #newbornscreening through Expecting Health's Navigate Newborn Screening FREE online educational module.

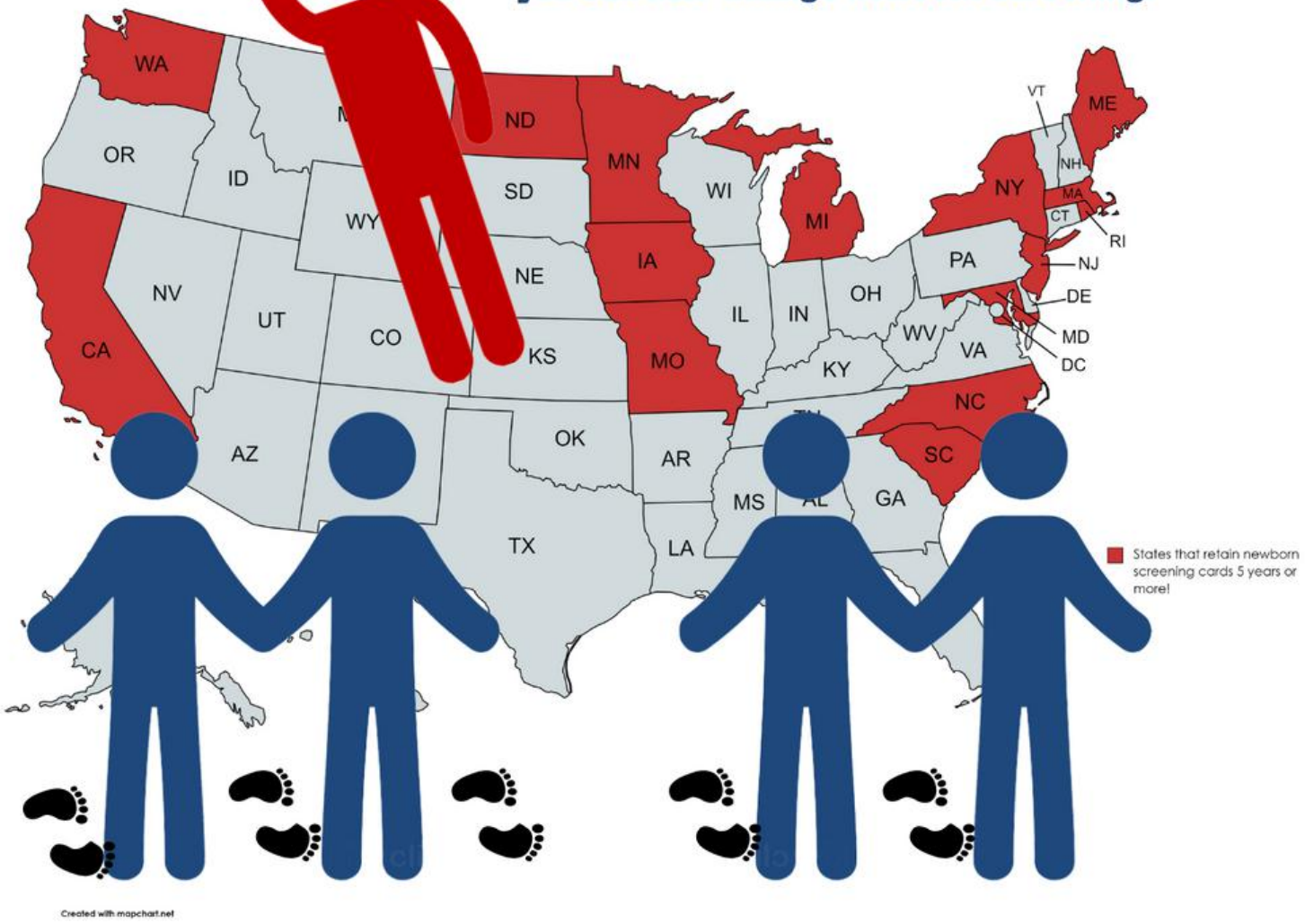
Sign up at:
https://expectinghealth.myabsorb.com/?KeyName=NavigateNBS_HCUNA#/login

#NavigateNBS

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

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/