# The HCU *Herald*

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**Time to Celebrate:**

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- **Save the Date: 2022 Land of the Free, Home of the Brave HCU Patient/Family Conference**

Live better, together!

# Join the 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.)

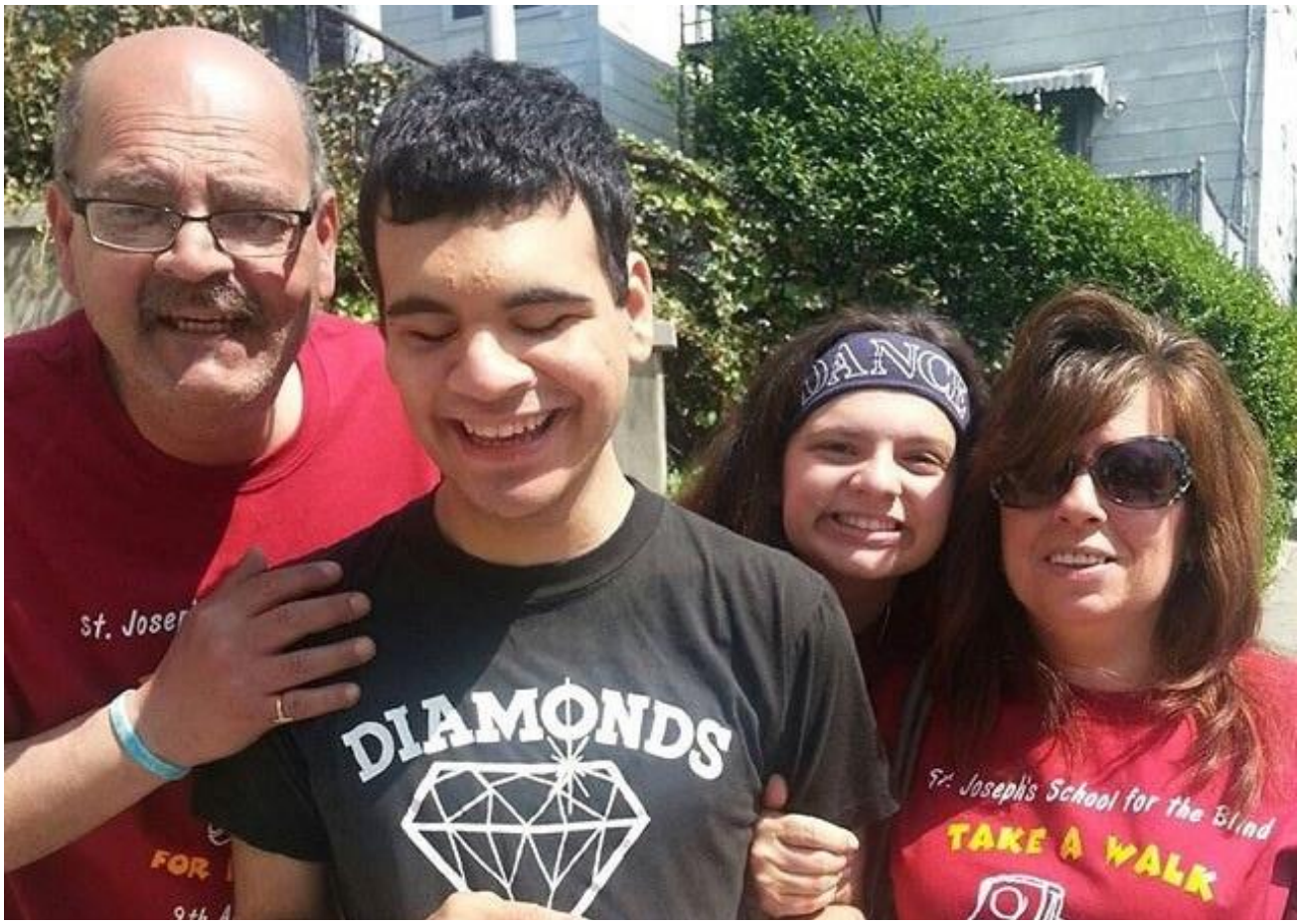
**What will this information be used for?**

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/

# HCU HERO:
# PETER, COBALAMIN C




My name is Victoria, my brother Peter is 23 years old and has MMA CblC. He was diagnosed at 2 and a half years old through bloodwork. My parents kept questioning about his vision. His neurologist had given a blood slip and she didn't think he had a disorder, but she said just in case she wanted to do the bloodwork. He had the blood work done, and sure enough he had it. Then, they sent out a sample of his skin to see what exact type he had, which is CblC.

If you look at Peter you wouldn't know that he has this disorder because he is always smiling, laughing, and so incredibly happy. He enjoys life every day and is an inspiration to many including me, his little sister. Sometimes my family and I feel bad for Peter because he is 23 and he could have graduated from college or been part of a sports team and instead he has this disorder that prevents him from doing so. However, every time we feel that way we always say "Look at Peter, he's smiling and he is happy. That's all that matters." This disorder affected our lives because we think of all the things he could be doing. We can't just get up and go on vacation for the day or get up and go anywhere as other families could. We try our best and make the best of it. In the beginning, my parents were more paranoid and nervous because this was a rare and very new disorder at the time; most doctors didn't even know about it. Now, at 23 years old you never truly get the hang of it but Peter is happy, healthy, and that is all that matters.

Recipes from

# LET'S GET COOKING

## Cooking Demos for the Homocystinuria Community with Chef Amber Gibson featuring FLAVIS

### WHIPPED FETA DIP

Nutritional Information:
*Makes 6.8 servings*
Serving size: 2 TBSP
Protein per serving: 0.2 g
Calories per serving: 110

### ROASTED VEGETABLE TOASTED SANDWICH

Nutritional Information:
*Makes 4 Servings*
Serving size: 1 Sandwich
Protein per serving: 1.9 g
Calories per serving: 303

### BASIC RISOTTO

Nutritional Information:
*Makes 3 Servings*
Serving size: 1/3 cup
Protein per serving: 0.5 g
Calories per serving: 177

Click recipe name for ingredients and directions

# You're RARE We CARE

**Introducing NEW Homactin AA Plus Powder In Refreshing Lemon Lime**

*Continuing to innovate for our #SmallButMighty communities!*

**15 PE HOMACTIN™ AA** METHIONINE FREE

Lemon Lime Plus POWDER


- **Great Fresh Flavor:** Lemon Lime
- **Flexible For All Ages:** 15g PE & 150 kcals
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- **Optimized Bone Health Profile**

## Aprotide Low Protein Pasta

Low price @ $8.99 per bag!

Order at 866 456 9776


Fusilli


Stelline


Spaghetti

Eat Well. Live Well. Ajinomoto

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# SPEAK UP FOR THE MEDICAL NUTRITION EQUITY ACT


1. **The best way that you can help make sure that the Medical Nutrition Equity Act (MNEA) moves this Congress is by asking contacting your members of Congress NOW.** Please go to nutritionequity.org/contact-congress and use the simple form to send an email to your members of Congress asking that they co-sponsor the bill. It doesn't matter if you have sent an email before. We encourage them to keep asking your members of Congress to sign-on until they do so.
2. **Please also ask contribute stories to the website.** The patient story form is here and the one for medical providers is here. We currently have ZERO or very few stories from a few key states, including Maine, Rhode Island, Mississippi, and several others.
3. **If you have had a meeting with a congressional office in the last few months asking them to co-sponsor the bill, please make sure that you are following up with those offices to see if they have any questions, or what they need to become co-sponsors.** The coalition has created a webpage with a wide-range of resources that should answer most questions that come up, but if you don't see what you need, please let me know.

**We can get MNEA passed if we all work together to build the support that we need!**

**The Patients & Providers for Medical Nutrition Equity Coalition**

# URGENT ACTION REQUIRED: CONVINCE MEDICARE TO COVER FORMULA

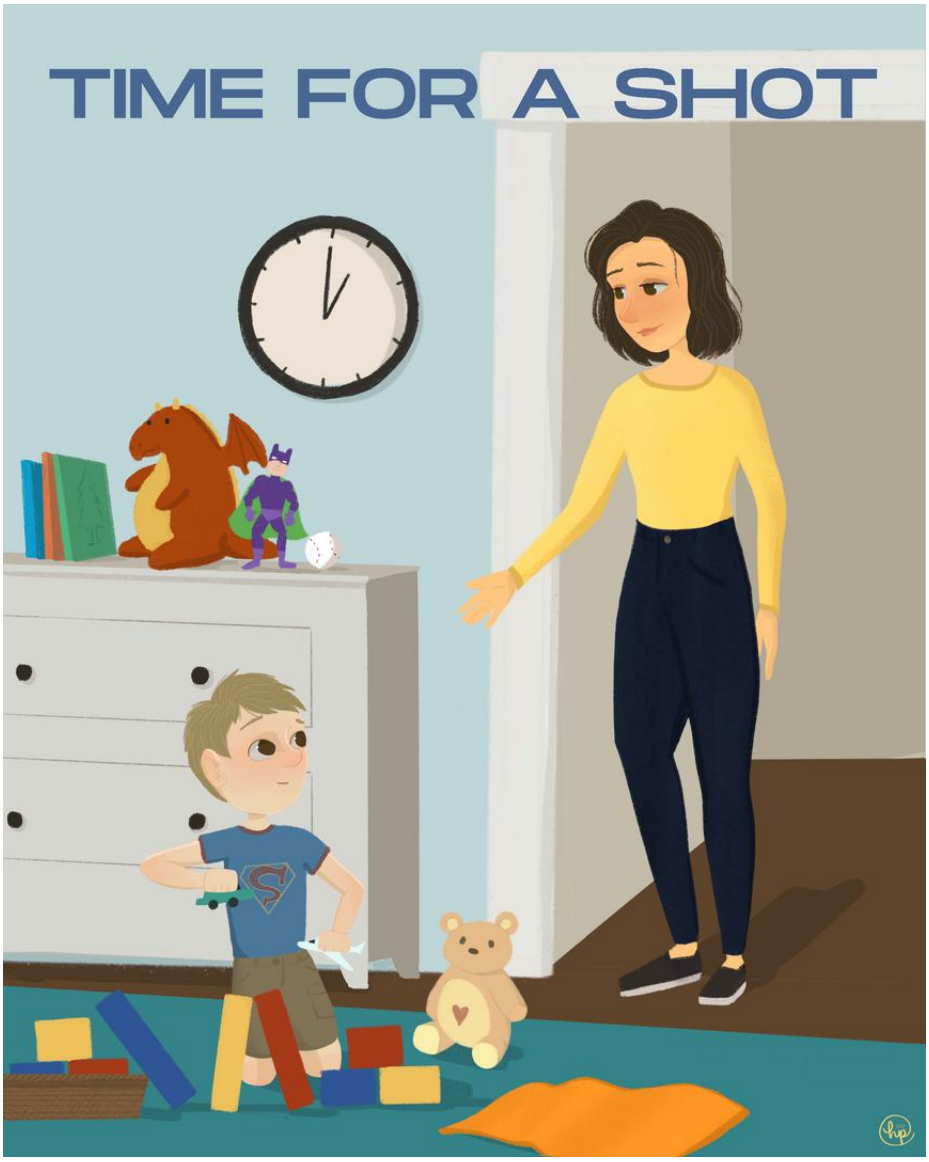

**The United States Department of Health and Human Services (HHS) has announced that it may rescind or reconsider National Coverage Determination 180.2 ("NCD") which has been used to deny coverage for orally-ingested medical formula for patients with inborn errors of metabolism. When the rule was originally written, inborn errors of metabolism (IEM) were not considered; the current announcement gives us an opportunity to convince HHS that oral formulas are essential treatment for IEM and should be covered by Medicare. We need everyone in the community to submit a public comment to that effect by 5pm on September 13th, 2021.**

**We have created the following form to help you easily compose the text to submit to HHS: https://pheed.me/aancd**

<u>These are the steps:</u>

1. Fill out the form with your name, email, and your role in making the comment (parent, caregiver, medical professional) as well as tbe disorder(s) you represent.
2. Write a personal argument on why medical formula is essential to the treatment of the disorder. This should be as detailed and thorough as possible. For patients and caregivers, share as much as you are comfortable with about the disorder, the burdens of treatment, and your needs for formula. For medical professionals, include as much scientific background as possible.
3. We'll send you draft text you can copy and paste into the HHS web site, which will include a list of relevant medical literature.

# NEW RESOURCE:
# A SOCIAL STORY: TIME FOR A SHOT



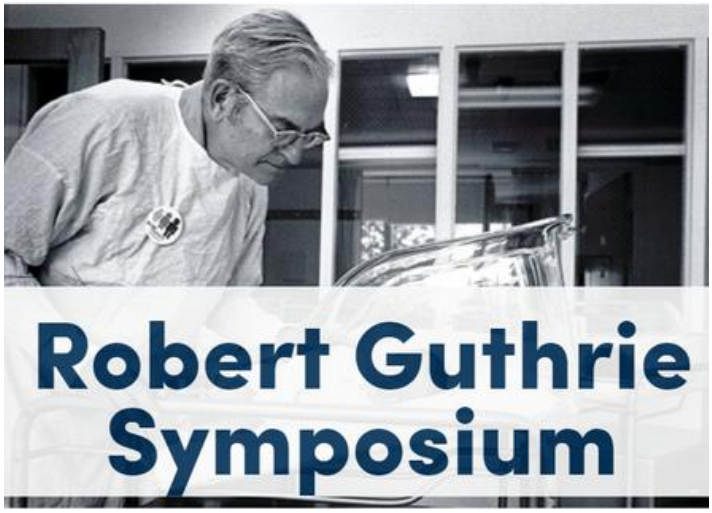

**A Social Story: Time for A Shot**

Navigating a rare disorder is full of challenges; but you don't need to do it alone. As a community of families with patients diagnosed with Homocystinuria Cobalamin defects, our goal is to support and provide resources to help you care for yourself and your child.

Giving a young child a shot can cause a lot of stress and anxiety, for all involved. We hope this social story will help provide an opportunity for you to teach your child why they need to get a shot, how to ease the process and educate them on the importance of medication management.

This will be available in Spanish later this month, please check the website!

# TIME TO CELEBRATE!
# SEPTEMBER IS NEWBORN SCREENING AWARENESS MONTH




## In case you missed it:
## Robert Guthrie Symposium

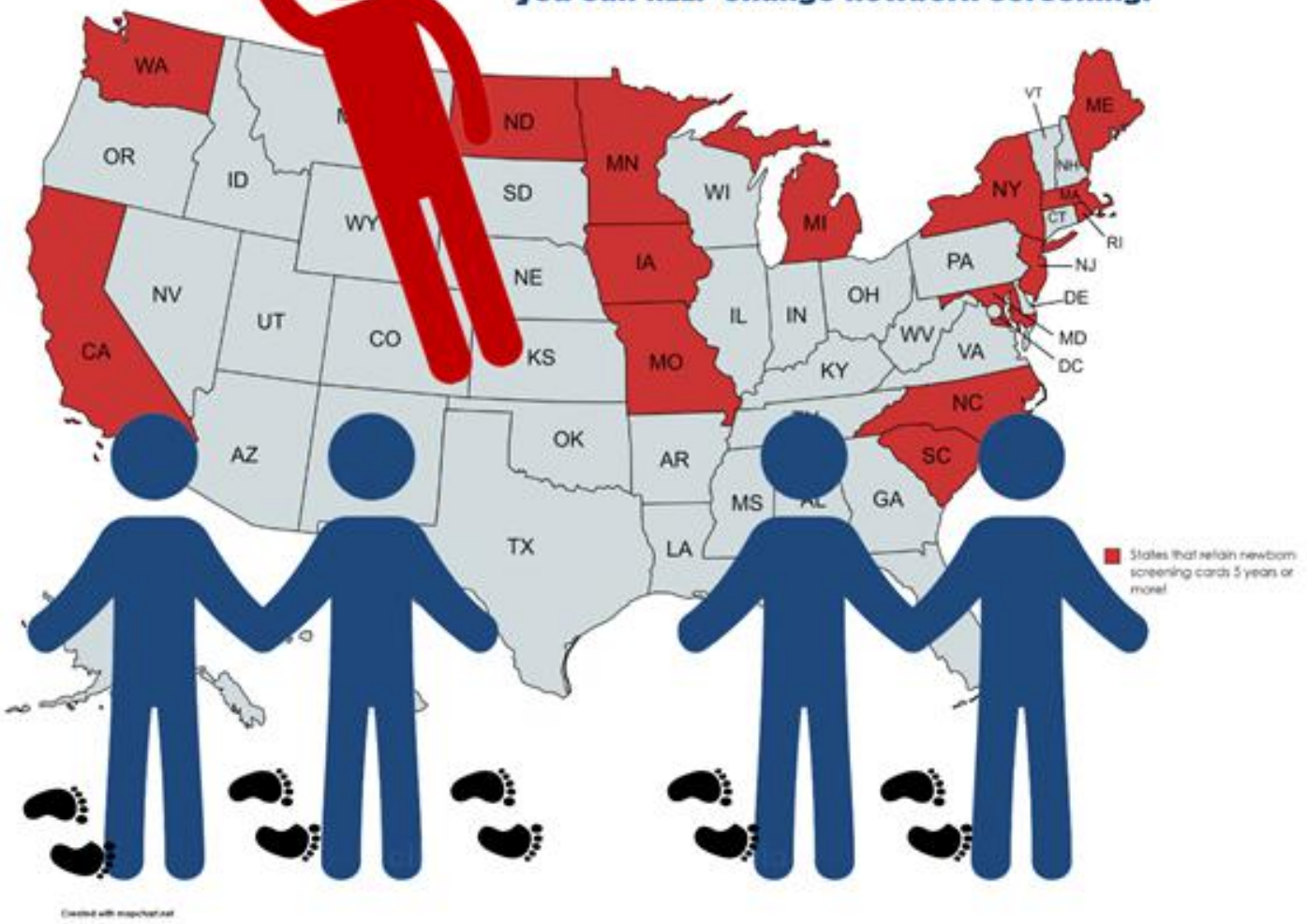
The Guthrie Symposium on newborn screening and metabolic disorders is a half-day educational event honoring the life and legacy of Robert Guthrie, MD, PhD, how he developed the first newborn screening test for PKU which then lead to HCU and many other disorders, and his attachment to the University at Buffalo and Oishei Children's Hospital.

This annual symposium is a forum for world-renowned physicians and scientists to share their knowledge with providers, families and community stakeholders. The speakers discussed pioneering research and clinical practices in genetic and metabolic disorders.

# 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_____
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 complete the survey online: https://hcunetworkamerica.org/survey-on-classical-homocystinuria-patients-missed-by-newborn-screening/

# Why Do Families Need Navigate Newborn Screening?

Newborn screening (NBS) is a health screen that checks for serious conditions at birth. NBS is a life-saving service, available to the nearly 4 million babies born in the United States each year. To better understand family preferences for NBS education, Expecting Health surveyed **819 participants** made up of parents, expecting parents, individuals with NBS conditions, or family members of individuals with NBS conditions.

## LIMITED NEWBORN SCREENING AWARENESS

**2 out of 3 participants** are aware of NBS.

**1 out of 3 participants** aware of NBS can correctly identify a definition of NBS.

## DISPARITIES IN NEWBORN SCREENING EDUCATION

Participants living in HRSA-defined medically underserved areas (MUA) may experience disparities in NBS education compared to those living in other areas.

**55% of participants in an MUA** were previously aware of NBS compared to **67%** of those living in other areas.

**50% of participants in an MUA** learned about NBS before birth - the optimal time - compared to **61%** of those in other areas.

## FAMILY LEARNING PREFERENCES

An **online module** was the preferred format compared to other educational formats.

**Family stories** were considered very helpful to learn about NBS.

Participants use **social media** to connect with others about NBS and other health topics.

Informed by this data, Expecting Health developed ***Navigate Newborn Screening***, a free online learning module that helps families just learning about newborn screening and provides opportunities to become leaders in the newborn screening system.

**Sign up today:** https://expectinghealth.myabsorb.com?KeyName=NavigateNBS_HCUNA

Have questions? Contact **Annie Evans at aevans@geneticalliance.org**

Navigate Newborn Screening
An Expecting Health Program

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $400,000 with 0 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S.Government.

# Navigate Newborn Screening

An Expecting Health Program

## WHAT IS NAVIGATE NEWBORN SCREENING?

**Navigate Newborn Screening** is a free, learning opportunity that gives families information on one of the most common tests newborns get - newborn screening. The module can help families just learning about screening as well as those looking to be leaders in this system.

**In this module, you will learn about:**

- The newborn screening process
- Newborn screening results
- Types of conditions detected
- Questions to ask your healthcare provider
- How to tell your newborn screening story
- Additional newborn screening resources

## WHY LEARN ABOUT NEWBORN SCREENING?

- Newborn screening is **a state-run public health service** that ensures all babies are screened for certain conditions that can cause serious health problems.
- Newborn screening usually happens when your baby is between **24 and 48 hours**.
- In the U.S, all states require newborn screening, but **not every state screens for the same conditions.**
- **Only 1 in 3 people** can correctly identify the definition of newborn screening.

## BENEFITS OF PARTICIPATING

Learn about the most common screening test

Gain leadership and advocacy skills

Options to attend national conferences or meetings

***Sign up today*** https://expectinghealth.myabsorb.com?KeyName=NavigateNBS_HCUNA

Interested but have more questions? Contact **Annie Evans at aevans@geneticalliance.org**

Expecting Health

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $2,000,000 with 0 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S.Government.

# GET READY, OCTOBER IS HCU AWARENESS MONTH



HCU Network America — Hcunetworkamerica.org — info@hcunetworkamerica.org

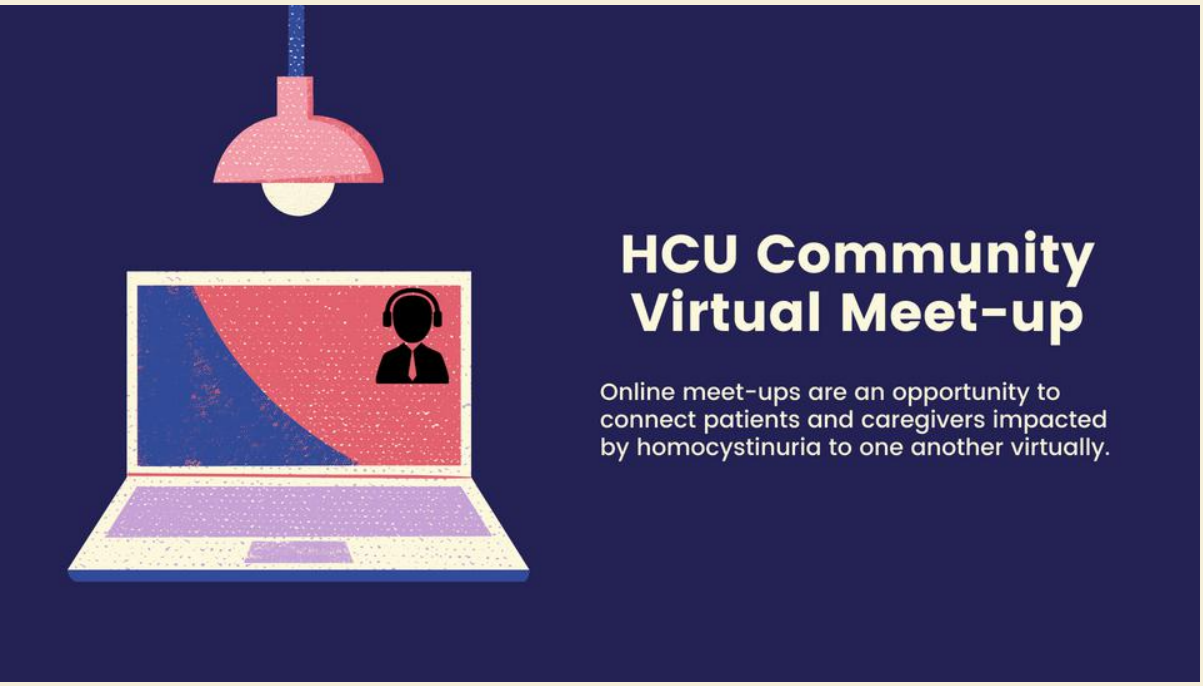
# GET READY
# GRAB YOUR AWARENESS GEAR!



**HCU Awareness T-Shirt!**

Did you know it's our 5th year anniversary? We are bringing back our original two shirts!

- Support our race Fundraisers this fall and Help Henrietta Rescue the Cure from the Homocysteine Hydra this Fall!
- This October, we will be launching the Go Blue for HCU T-Shirt Campaign – this will not be our ordinary t-shirt campaign – so stay tuned for details




Sunday, October 3 at 2 pm CT | 8 pm Ireland & UK

## Online meetups are an opportunity to connect other patients and caregivers.

- **Struggling with treatment? Or you are having trouble getting it covered?**
- **Having health issues, you aren't sure if it's related to the diagnosis, or just a normal person thing?**
- **Or just looking to connect?**

**Come join us for one of our Community Meetup**

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


Sunday, October 17 at 10 am CT | 4 pm Ireland & UK

# HCU Awareness Month Activity List

- ☐ Change your social media picture to the HCU Awareness Ribbon
- ☐ Start a HCU fundraiser
- ☐ Share an infographic about HCU
- ☐ Share a patient story
- ☐ Share your diagnosis story
- ☐ Challenge your friends to the same amount of protein and three normal protein shakes a day #ToastTocHCU
- ☐ Share a pic of an item that has the same amount of protein you can have
- ☐ Share your daily diet record –completed
- ☐ Share a low-protein meme
- ☐ Share your favorite low protein recipe! Bonus if you cook it and share a pic
- ☐ Dining out, low protein style. Where do you like to eat?
- ☐ Share a pic of what your grocery store haul looks like
- ☐ Real cost of HCU: Grocery Cost Comparison #Medical Nutrition Equity Act, or share some patients with HCU require injectable B12. B12 on average is $300-400 a month and most insurance companies don't cover it!
- ☐ Share a picture or video capturing all the medication you take (this includes formula for those who need it).
- ☐ Share a picture of your first pair of glasses, or a device that helps you navigate or communicate due to lack of vision
- ☐ Share something you wish people understood about HCU
- ☐ #HaikuforHCU—Write and share a Haiku describing life with HCU
- ☐ Wear jeans for your rare genes #ItsInOurGenes
- ☐ Wear your HCU Shirt and share a pic online—#HopeConnectsUs
- ☐ #GoBlueforHCU
- ☐ #HCUAwareness post in a public place
- ☐ Share with a stranger what HCU is and why it's important to you
- ☐ #Create4Cure—Create a work of art that brings awareness for HCU— can be a song, dance, a painting—get creative!
- ☐ #High5forHCU—List 5 ways HCU makes you a stronger, better person
- ☐ All states test for classical HCU, but many are still missed
- ☐ Share a picture of you and a HCU buddy! Or tag a friend who is of great support
- ☐ #FacesofHCU—Share a picture of you saying, I am one of the 1 in 200,000 people with HCU
- ☐ #Hope4HCU—Share 4 things that give you hope and encouragement
- ☐ Share the HCU timeline—if you know other facts, let us know!
- ☐ Cutting Edge of HCU: Share about a therapy that is in the works!

To find additional information and resources, visit:
https://hcunetworkamerica.org/hcu-awareness-month/

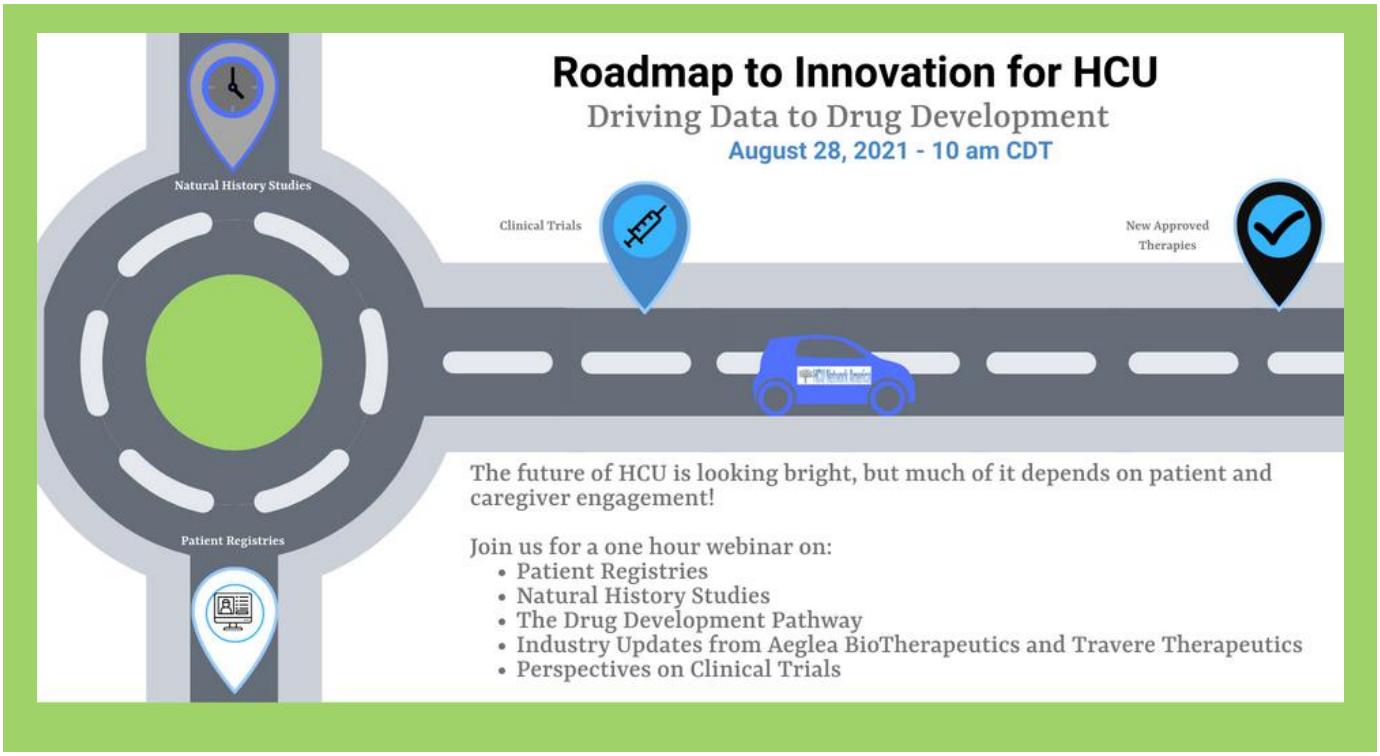
# RESEARCH: NEWS AND EVENTS

## The Importance of Natural History Studies to the Homocystinuria Community

Like most rare diseases, Homocystinuria is not well-studied and poorly understood by the medical community. Researchers and biotech companies rely on natural history studies for a baseline understanding of the disease so they can can develop better therapies, which would need to go through clinical trials in order to be approved.

While Classical Homocystinuria does have a natural history study it's outdated. The last natural history study was published in 1985 based upon 629 patient data collected from published papers and questionnaire's. For reference, b6, b12, and folic acid were just starting to be regularly used for management of classical homocystinuria. Now we have the low protein (methionine more specifically) diet, medical formula and Cystadane. With improved therapy, our baseline understanding has changed and needs to be reassessed to reflect so.

You can learn more about natural history studies, patient registries, and the drug development pipeline by visiting our YouTube Channel and watching our webinar on Roadmap to Innovation for HCU.



# NATURAL HISTORY STUDIES
# A PATIENT EXPERIENCE

## Behind the Scenes:
## Why I Chose to Join Orphan Technologies Natural History Study

The patient who shared their experience will remain anonymous to protect the integrity of the data collected by the Natural History Study for Cystathionine Beta Synthase (Classical Homocystinuria)

**September 2017**
On an early fall morning I sat in the activity room at work. There was a lot on my mind that morning, but the thing that was pushed to the forefront of my mind was the Orphan Technologies (now supported by Travere) Natural History Study for Homocystinuria. I had been considering it and thought about joining, but obligations at work made me question my decision. While I was sitting in there, I told my coworker Lisa about wanting to go to Atlanta. After she responded I decided to go ahead and join the study.

**October 2017**
As a patient I was genuinely frustrated with the lack of treatment options and the cost of the medications, so I sent an email to a contact about joining. The person responding pointed out that I was not in close proximity to a study location. The fact that this disease is so rare and that treatment options are so limited is part of why I chose to go ahead despite the distance it would take to get to Atlanta. I had experience traveling for medical care so traveling to a study visit was not an inconvenience, but an opportunity to give back. It was also a chance to travel and to get to know a place I had never been to. Before I joined the study, I had only been there in passing when flying and leaving out of Hartsfield- Jackson Airport, also known as ATL. After the first visit what was once foreign became familiar.

**March 2018**
March 9, 2018, was my first study visit, which was also known as the baseline visit. At this visit they started with blood work. The visit also included a physical where we discussed my medications and the way Homocystinuria has manifested. During this time, I handed in a three-day diet record which requires you to record everything you eat and drink leading up to the visit. The National Institutes of Health (NIH) Toolbox is a series of cognitive tests which was another part of the visit. Later that afternoon, I had an eye appointment where my eyes were dilated and evaluated. A dual -energy x-ray absorptiometry, also known as a DXA/DEXA scan was also performed to assess for osteoporosis.

**September 2018**
Six months later I went back Atlanta, or more specifically Emory. This time the visit was much shorter and consisted of blood work, a physical and the NIH Toolbox. That is a part of every appointment. Once a year they do the DEXA scan, and eye appointment. Through participating I know I have contributed and am grateful for the opportunity.

*Note* Since joining this study, Orphan Technologies has been acquired by Travere Therapeutics*

# JOIN THE NATURAL HISTORY STUDY

TRAVERE™ THERAPEUTICS

## Natural History Study is Recruiting!

Travere (previously Orphan Technologies) began a natural history study (NHS) of HCU in 2016 to better understand how to best develop a novel treatment for HCU. They currently have 62 patients enrolled to date, and hoping up to enroll up to 100.

**Key Criteria:**

- Age 5-65 years old
- Confirmed diagnosis of HCU
- Clinic visit for testing and bloodwork every 6 months
- Willingness to provide diet diaries for 3 days prior to clinic visits

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**Components of the Study (free of charge to participants)**

- DXA Scan (bone exam)
- Blood draws
- Eye exam
- Cognitive testing
- Physical exam

**Study locations:**

- US
  - Boston
  - Philadelphia
  - Atlanta
  - Indianapolis
  - Denver
  - Washington DC
- **Salford, UK**
- **Dublin, Ireland**

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**Objectives**

- Study homocysteine changes over time
- Study the complications of HCU overtime
- Study what treatments are being used
- Evaluate impact of diet

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**To learn more or enroll:**

- Visit: https://clinicaltrials.gov/ct2/show/NCT02998710
- Call: 1-877-659-5518
- Or email: medinfo@travere.com

# EXPLORE NEW RESEARCH!


Join us Saturday, October 9, 2021 at 11 am Central time (US/Canada) | 5 pm United Kingdom While Dr. Andrea Bordugo of University of Verona Italy shares his center's experience on administering hydroxocobalamin by a subcutaneous catheter device. Some patients/caregivers may have heard of having a port installed for injections, and this is that concept that will be reviewed.

Register now: https://www.eventbrite.com/e/167915442609


**In case you missed it:**

**NGRI AND NCATS Virtual Meeting:**

**Scientific Updates on Organic Acidemias and Homocystinurias**

The National Human Genome Research Institute (NHGRI) and the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health co-hosted a virtual meeting on "Scientific Updates on Organic Acidemias and Homocystinurias."

For over 15 years, the Organic Acid Research Section (OARS) of NHGRI has worked on organic acidemias with clinical and scientific partners to develop genomic and small molecule therapies for a number of the enzymatic defects in the propionyl-CoA and vitamin B12 (cobalamin) metabolic pathways.

This meeting brought together researchers, clinicians, families and patient advocates from around the world to discuss the natural history, disease pathophysiology, genetics and treatments for rare inborn metabolic errors. They also reviewed the opportunities and challenges that patients and their physicians face in several upcoming small molecule, enzyme replacement and genomic phase I/II clinical trials.

To view the recording, please visit:
https://youtube.com/playlist?list=PL1ay9ko4A8skIZF0gqyODwcDH3g3M1q6e

# SAVE THE DATE!


**We have a new date for our 2022 Land of the Free, Home of the Brave, HCU Patient/Family - Expert Conference. Come join HCU Network America, The Organic Acidemia Association, and the Propionic Acidemia Foundation for our first joint conference, June 25-26, 2022 in Bethesda, Maryland. There will be combined keynote speakers, disease specific speakers, breakout sessions, networking sessions and more! Mark your calendar now. We are still monitoring the pandemic, we will have details about registration and the program later this year.**

# FUNDRAISE HELPS KEEP OUR MISSION ALIVE!


NFL Football season is almost here! Do you want to join a fantasy football league and help a great cause? Samantha S. has created a fantasy football league and all you have to do is click the link below to sign up and venmo her $10. Half of the winnings will go to Homocystinuria - HCU Network America and the other half will go to the winner!

When you venmo her please write HCU Fantasy Football

**The draft will be September 3rd at 6 pm!**

https://football.fantasysports.yahoo.com/f1/1073909