

THE HCU HERALD

Featuring...

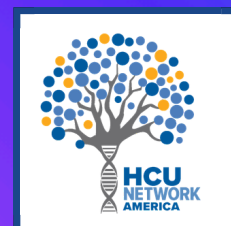


HCU Hero

Matthew from the UK



September 2026



All things Homocystinuria: patient stories, resources, research, events and more!

HCU Hero: Matthew From The UK



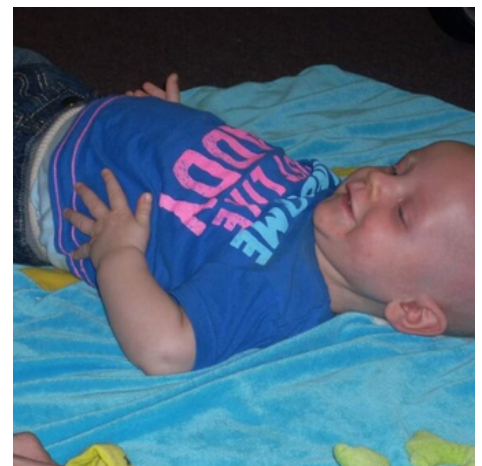
Matthew was born in February 2012.

Like any parents, my wife and I were excited about the future. We looked forward to watching our little boy grow, learn and experience the world around him. But as the months passed, we began to realize that Matthew wasn't reaching the developmental milestones that other children his age were achieving.

We were initially told that he had a global developmental delay. As time went on, we were also told that he showed autistic traits. We accepted those explanations, but deep down we felt there was something more. Over the next few years,

Matthew underwent numerous investigations. He had brain scans, blood tests, urine tests and countless hospital appointments. Time after time we were told that the results were normal, yet we still didn't have an explanation for why our little boy was struggling so much.

What we didn't know at the time was that Matthew had been born before homocystinuria was included in England's newborn heel prick screening program. Matthew was born in February 2012, and screening for homocystinuria (HCU) was not introduced until January 2015. This meant that he was never screened for HCU at birth through the national newborn blood spot program.



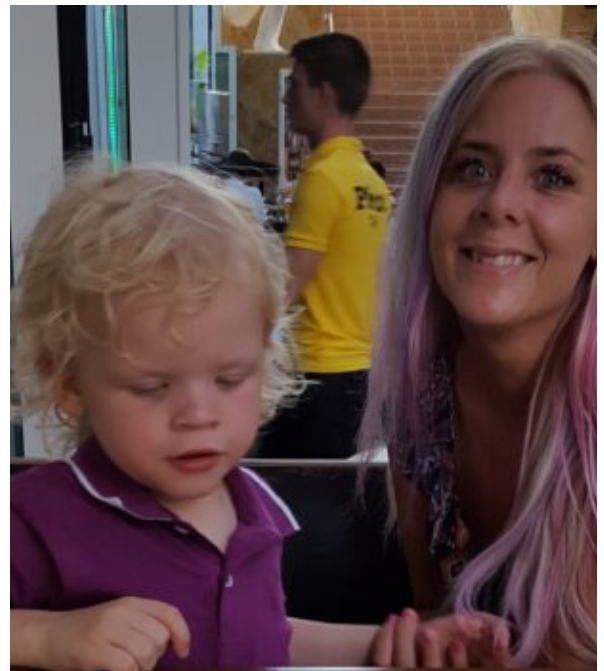
HCU Hero: Matthew From The UK



When Matthew was seven years old, everything changed. He was finally tested for a rare inherited metabolic disorder called homocystinuria, or HCU. The result came back positive. By the time Matthew received his diagnosis, the condition had already had a significant impact on his development. He had become severely learning disabled and struggled with excessive drooling, despite many attempts to manage the symptom. Looking back, it was heartbreaking to realize that the underlying cause had remained undetected for so many years.

Following his diagnosis, Matthew was started on pyridoxine, also known as vitamin B6. Thankfully, he responded well to the treatment, meaning he has pyridoxine-responsive HCU. He also began a specialist low-protein diet and metabolic treatment, which continues to play an important role in managing his condition today.

Around this time, doctors had also considered testing Matthew for another rare genetic condition, neurofibromatosis type 1 (NF1). However, because he had already been diagnosed with homocystinuria, and because the coexistence of both conditions is exceptionally rare, further testing did not initially go ahead.



HCU Hero: Matthew From The UK

Two years later, when Matthew was nine years old, genetic testing was finally carried out. The results confirmed that he also had neurofibromatosis type 1. Wanting to better understand everything Matthew had been through, I requested copies of all his medical records. As I read through them, I found several inconsistencies and findings that raised important questions.

One of Matthew's earlier brain MRI reports described changes that included findings consistent with a previous infarction. I also found documentation showing that some of his blood and urine samples had deteriorated during transport because they had not been handled under the recommended conditions. In some cases, samples took more than seven days to reach the laboratory before testing. From what I could see within the records, some of those samples were not repeated after they had deteriorated. As parents, reading those records was incredibly difficult.



We will never know exactly what difference an earlier diagnosis might have made to Matthew's life, and it would be wrong to speculate. However, we do know that early diagnosis and treatment of homocystinuria can significantly improve outcomes for many children. Like any parent, you cannot help but wonder what might have been different if those answers had come sooner.

Matthew's story is not about blame. It is about awareness. It is about recognizing that rare diseases do exist, that parents know their children better than anyone, and that sometimes the rarest diagnoses need to be considered. It is about the importance of early diagnosis, appropriate testing, and ensuring that no family spends years searching for answers if those answers can be found sooner.

Although Matthew's journey has been incredibly challenging, it has also given our family a purpose. His diagnosis inspired both me and my wife to become advocates for children and families living with rare diseases, particularly homocystinuria, neurofibromatosis type 1 and autism.

HCU Hero: Matthew From The UK

We created Special Needs Parents UK, with Facebook and Instagram communities dedicated to raising awareness, sharing information and supporting families who may be facing similar challenges. I am also active on TikTok and YouTube, where I regularly create videos about Matthew's journey, life as a special needs parent, rare disease awareness, and the everyday realities of caring for a child with complex needs. Our hope is simple: that by sharing our experiences, we can help another family feel less alone, encourage earlier diagnosis, and raise awareness of conditions that so many people have never heard of.

Everything we do is because of Matthew. He is the reason we continue to speak out, create content, and advocate for greater awareness. If his story helps even one child receive an earlier diagnosis, one parent trust their instincts, or one family find hope during difficult times, then sharing it has been worthwhile. This is Matthew's story. But it is also a story shared by countless families living with rare diseases.



Our message is simple.

Never stop asking questions.

Never stop believing your instincts as a parent.

And never underestimate the power that sharing one child's story can have in changing the lives of others.



I genuinely believe this is a story that deserves to be heard. It has the potential to raise awareness not only of HCU and NF1, but also of the importance of newborn screening, listening to families, and recognizing rare diseases earlier. I hope it helps many other parents and children in the years ahead.

HCU Hero: Matthew From The UK



September Is Newborn Screening Awareness Month!



What started as a PKU heel-prick blood test developed by Dr. Robert Guthrie (whose own niece had PKU!) in 1960 has evolved into the robust system we know today.

Check out our 'Newborn Screening at a Glance' infographic to learn more!



Click [here](#) to download & share!

NEWBORN SCREENING

at a glance



NEWBORN SCREENING IS A LIFE-SAVER

NBS is a public health program that screens newborns for **serious but treatable** health conditions.

Early detection and **timely treatment** can help prevent serious complications, such as developmental delays, illness, and death.



Approximately **12,000 babies** are diagnosed with a condition through newborn screening in the United States **each year**.

blood test

IT CONSISTS OF 3 PARTS
& IS PERFORMED WITHIN THE FIRST 24-48 HOURS OF LIFE

hearing screen

For the blood test, a healthcare provider pricks the baby's heel to collect **a few drops of blood**, which are then placed on a special paper and sent to a lab for testing. The blood test can detect certain genetic, metabolic, hormonal, and functional disorders

heart screen

IT'S A SCREENING, NOT A DIAGNOSTIC TEST

If a screening test returns an out-of-range result, it indicates a higher risk of a particular condition, but **it does not confirm a diagnosis**. Further diagnostic testing is needed to confirm whether the baby actually has the condition.



NBS IS A FEDERAL PROGRAM, BUT VARIES FROM STATE TO STATE

These differences include the specific **conditions tested**, the **policies for follow-up**, and the **methods** used.

While most states screen for the majority of the RUSP* conditions, some states choose to screen for additional conditions not included in the RUSP. Conversely, some states may not screen for all RUSP conditions due to various factors like cost, infrastructure, or prevalence in the population.

RUSP = Recommended Uniform Screening Panel; a list of conditions that the U.S. Department of Health and Human Services (HHS) recommends for inclusion in state newborn screening programs. The RUSP serves as a guideline for states to determine which conditions should be part of their newborn screening panels.

Continued investment in our Newborn Screening programs ensures that **all babies** have **the best possible start in life**.



September Is Newborn Screening Awareness Month!

Newborn Screening & Homocystinuria



The approximate number of babies with Classical HCU that are missed at Newborn Screening (however, some reports suggest up to 80% are missed.)



The number of states that screen for classical homocystinuria. Classical HCU was added to the RUSP (Recommended Uniform Screening Panel) in 2007, thanks to the Newborn Screening Saves Lives Act.

The RUSP

(Recommended Uniform Screening Panel)

- The RUSP is a list of disorders that the Secretary of the Department of Health & Human Services *recommends* for states to screen as part of their state universal newborn screening programs.
- Disorders on the RUSP are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments.
- Each state ultimately determines what disorders its NBS program will screen for.
- Most states screen for the majority of disorders on the RUSP & some states also screen for additional disorders.
- Massachusetts was the first to adopt HCU newborn screening - in 1968! By 2009, all 50 states were screening for HCU.

<https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp>

Current Screening Method for classical HCU & its limitations

- Uses methionine level
- Methionine isn't elevated in most HCU patients in 24-48 hours after birth, especially those who are breastfed.
- Each state's newborn screening lab sets its own methionine cut-off to indicate a positive screen.
- A normal methionine level at birth is between 20-30.
- If a lab sets its methionine cut-off too high it will miss patients.

“Elliott's classical HCU was missed at newborn screening because his methionine level was not yet elevated enough to receive a positive screen. His level was 44 and to receive a positive screen in South Carolina, it must be 65.”

-Liz Carter, mom of Elliott, diagnosed with classical HCU at age 2 1/2



Cobalamin Disorders & Severe MTHFR



- Combined Cobalamin Disorders are a part of the RUSP Secondary Conditions. This means they are picked up as a result of a different disorder, typically Methylmalonic acidemia. These conditions are Cobalamin C, F, J, K, X and TC II.
- Some states set a low methionine cut off and these will flag the conditions above, but also flag isolated Cobalamin Disorders, Cbl D, E, G & Severe MTHFR.

New developments give hope for the future

In 2023 the CDC came up with a 1st tier multi-plex approach that would allow total homocysteine to be the primary marker in screening for Homocystinuria.

The goal? A more accurate screen, and identifying all babies with homocystinuria at birth.



Learn more:

<https://hcnetworkamerica.org/newborn-screening/>
<https://academic.oup.com/clinchem/article/69/5/479/2068836?login=false>



Click here to
download &
share!

Hear From Our Community

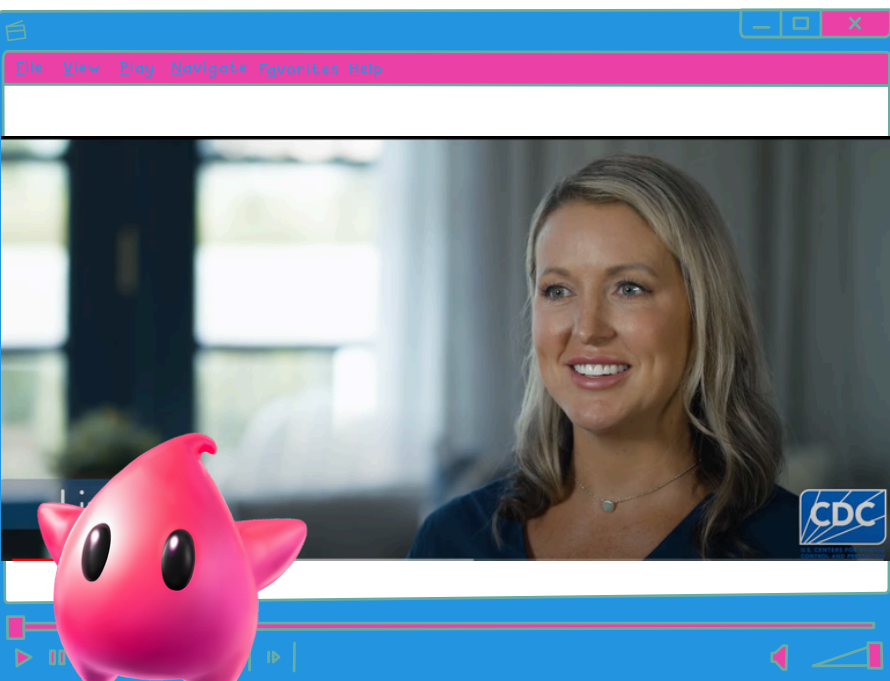


History of Homocystinuria Newborn Screening with HCU Pioneer, Dr. Harvey Levy

HCU Network America Vice President Mark Lewis interviews the world-renowned Dr. Harvey Levy about his involvement and the history of newborn screening for the Homocystinurias.



[Click to watch](#)



CDC Newborn Screening: "Homeward Bound"

Liz, the mom of a child with homocystinuria who was missed by Newborn Screening, shares her family's story.



[Click to watch](#)



How Can I Get Involved?



Advocate for Change!

Ways to Get Involved in newborn screening advocacy:



Share your newborn screening experience with HCU Network America



Sign our petition to show your support for NBS revisions



Share our 'Missed Diagnosis Newborn Screening' Survey with your clinic



PUBLIC INFORMATION

1



Advocacy Tips, Tricks & Ideas

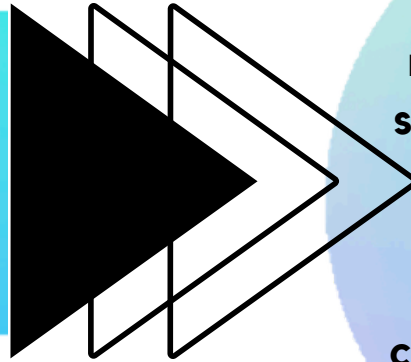
- ▶ Share one (or both!) of our infographics, [along with something about your newborn screening story if you'd like], to social media during the month of September!
- ▶ Don't want to create your own posts for social media? That's ok! Keep an eye on HCU Network America's posts and share them!
- ▶ Check out [Baby's First Test NBS Awareness Social Media Toolkit](#)! It's got some ready-made posts and graphics that you can use!
- ▶ Use the hashtags: #NewbornScreening & #2025NBS to give your posts more visibility!
- ▶ Not a social media person? No worries! Make it a point to tell someone (a friend, teacher, coworker, doctor, or even the barista at your coffee shop!) that September is Newborn Screening Awareness Month and share a little bit with them about your (or your child's) newborn screening story.

HCU Awareness Month is Coming!



There are many ways that you can participate in HCU Awareness Month.

One way is by hosting a fundraiser!



Not only do fundraisers raise vital funds to help us support the Homocystinuria community, they spread awareness of the Homocystinurias and the challenges of living with the conditions.

Not sure how to get started?

Let our Fundraising committee help!

Email
info@HCUnetworkamerica.org

Click [here](#) for a list of additional HCU Awareness and Fundraising Event Ideas!

Upcoming Events

2026

NEWBORN SCREENING BOOTCAMP

Empowering Advocates to Advance Life-Saving Screening

September 24, 2026

Learn about and discuss developments in newborn screening with experts and patient advocates currently navigating the newborn screening process.

Register Now!

READY, SET, RACE!

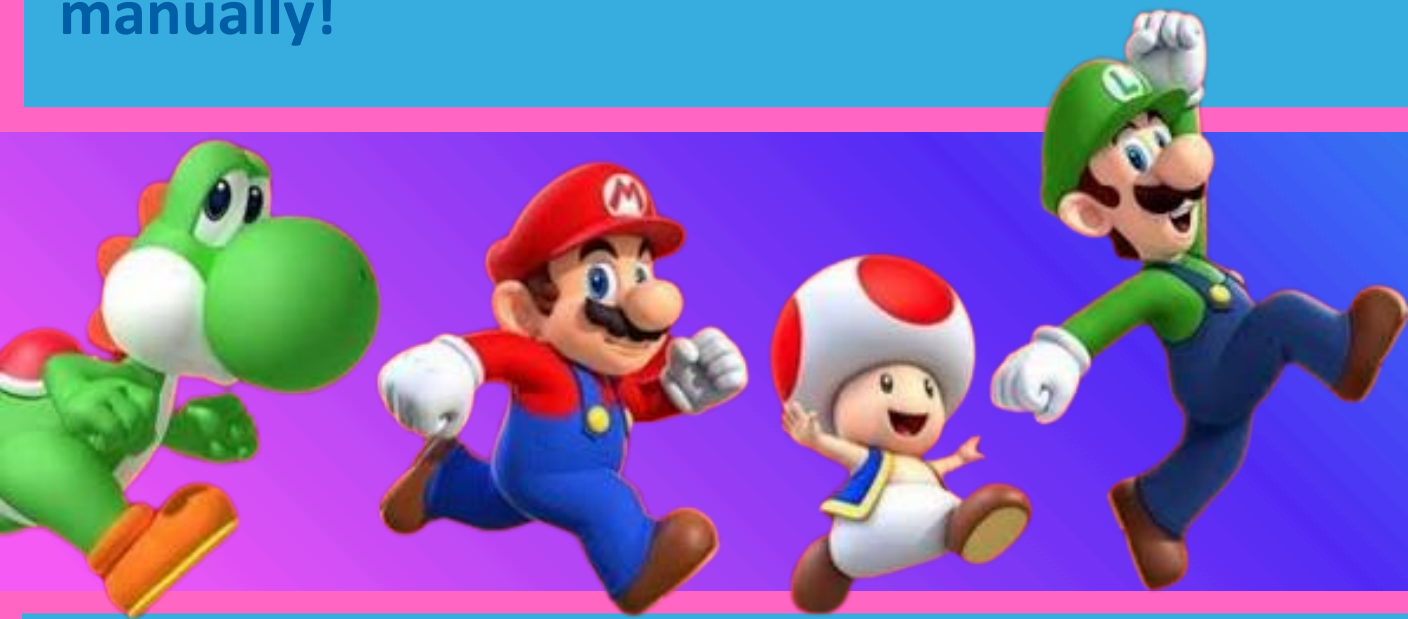
Our Race for Research has officially left the start line!

It's still not too late to join the fun!

You can sign up (with as little as \$5 to participate!) here!

Don't forget to log your miles!

Racers can visit your team's race page to log miles manually!



THANK YOU to our amazing sponsors for helping to make this year's Race for Research a success!



Syntis Bio



**RECORDATI
RARE DISEASES**

Focused on the Few[®]

RESEARCH WE HAVE FUNDED THANKS TO YOU!



2025

Vasu Sethuraman, PhD



Investigating the Therapeutic Potential of Intestinal Methionine Elimination via Oral Enzyme Therapy in HCU

2025

Kenneth Maclean, PhD



Combining taurine and formate/betaine treatment to improve clinical outcome and drug safety in classical CBS deficient Homocystinuria.

2025

Tomas Majtan, PhD



Crystallography-based fragment screening to develop pharmacological chaperones for classic homocystinuria

2024

Dr. Ferdinand von Meyen



Establishing MTHFR- and Cobalamin G- deficient cerebral organoids: an in vitro disease model for investigating novel therapies

2024

Dr. Brian Gilfix



Aminoglycosides for the Treatment of Inborn Errors of Vitamin B12 Metabolism

2022

Devinder Kaur, PhD



Development of Reference Ranges for Additional Newborn Screening Markers for Early Detection of the Homocystinurias: Classical Homocystinuria and Remethylation Disorders

2022

Silvia Vilasi, PhD



Identification of Compounds to Rescue MMACHC Functional Deficiency in CBLCL Disease

2022

Thomas McCorvie, PhD



Crystallography-based fragment screening to develop pharmacological chaperones for classic homocystinuria

2019

Tomas Majtan, PhD



Evaluation of benefits of thiol-based reductants in classical homocystinuria

2018

Kenneth Maclean, PhD



New Metabolic strategies for improving the treatment of homocystinuria due to CBS deficiency and remethylation defects

Scan the QR Code to learn more!



Scan the QR code to learn more!

Meet The Teams



Proudly sponsored by:



Hunt for Research

Brooke's Blazers

Classical Champions

Amy's Army

Team Cobalamin C

Team Butterstick

The Mighty MTHFRs

Team Hawkins

Super Matteo Squad

CanPKU+ Racers

Never Lewis Hope

Grayson's Gang

Ellie's Entourage

Team Recordati

Team Casey

Team Will For HCU

Galloping For HCU

Helix Hustlers

Unicorn Phoebe

Miles for Marcus

Miles for Andy

HOMOCYSTINURIAS

DATA COLLECTION PROGRAM

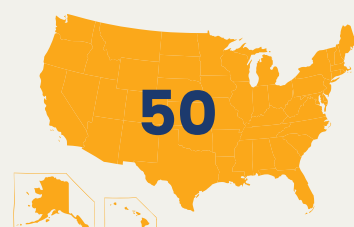
POWERED BY **RAREX**



Newborn Screening & the Homocystinurias



Approximate number of babies with Classical HCU that are missed at Newborn Screening



States that screen for Classical Homocystinuria

Some suggest up to 80% are missed!

Classical HCU was added to the RUSP (Recommended Uniform Screening Panel) in 2007, thanks to the Newborn Screening Saves Lives Act.

Cobalamin Disorders & Severe MTHFR

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**METABOLIC
SUPPORT**
Living well with a
rare disease



**HCU
NETWORK
AMERICA**

HCU Network Australia

IN CASE YOU MISSED IT...



The HC&U Podcast is back!!!

HC&U is a podcast about Homocystinuria, sponsored by HCU Network America and hosted by Ben & Lindsey.

Meet your hosts!



Welcome to the HC&U Podcast! We are Ben and Lindsey, your hosts. We are so excited to be starting this as extra resources for the Homocystinuria community. We hope you like our content!



To Listen:

<https://hcunetworkamerica.org/hcu-podcast/>
or click below on your favorite option!



The latest episode



Brittany shares her family's journey after her daughter, Anniston, was diagnosed with Homocystinuria (HCU) through newborn screening. As a new parent, Brittany was suddenly faced with a rare diagnosis, feeding challenges, a strict medical diet, and countless unknowns. She reflects on the fears, lessons, and victories that followed—from learning to manage HCU during infancy to watching Anniston grow into a thriving second grader, honor roll student, and talented young artist.

[CLICK HERE](#)**HCU**
NETWORK
AMERICA

2026 Conference Menu Highlights

MONDAY

- CFL Phelafel Pita Sandwich

- [CFL Phelafel \(0.5 g.protein per Phelafel\)](#) [CLICK HERE](#)
- [BFree Gluten-Free Stone-Baked Pita \(2 g.protein per pita\)](#) [CLICK HERE](#)
- Serve with Faux-hini Dressing (at bottom of Phelafel recipe), tomatoes, lettuce, cucumber, red onion, and olives



TUESDAY

- CFL Phelafel with Cauliflower Couscous

- [CFL Phelafel \(0.5 g.protein per Phelafel\)](#) [CLICK HERE](#)
- [Cauliflower Couscous Version 1 \(make without nuts\) \(2.2 g protein per 1 cup\)](#) [CLICK HERE](#)



WEDNESDAY

- Vitaflo™ Recipe California Rolls (0.7 per 1 piece)

[CLICK HERE](#)

- Vitaflo™ Recipe Katsu Jackfruit Sushi (0.6 per 1 piece)

[CLICK HERE](#)

THURSDAY

- [CFL Kentucky Fried Cauliflower \(1.3 g for 4 florets\)](#)

[CLICK HERE](#)

- [CFL Potato Salad \(2.3 g for ½ cup\)](#)

[CLICK HERE](#)

FRIDAY

- [CFL Mac and Cheese \(0.5 g.per 1 cup\)](#)

[CLICK HERE](#)

- Green Beans (0.9 g per 0.5 cup)



BREAKFAST

- So Delicious Yogurt w/ Berries
- [Promin Pancakes](#)
- [CFL Granola Bar](#)
- [Promin Muffins](#)

SNACKS

- Low Protein Energy Balls (see below)
- Pirate Booty
- Absolutely Gluten Free Everything Flatbread with Field Roast Original Chao Cheese

NOTES

- All items and recipes are hyperlinked.
- All breakfast are 2 g or less
- All snacks are 1 g or less
- **Meals should be used for lunches and dinner to reduce time spent cooking.**
- Please verify all information using the flok app.



Banana Bread Energy Balls

No-bake energy balls · Makes 12

[CLICK HERE](#)

Ingredients



Oat flour
½ cup



Instant oats
½ cup



Banana
1, mashed



Cookie butter
1 tbsp



Coconut
¼ cup,
desiccated



Honey /
maple syrup
2 tbsp



Cinnamon
Pinch

⚠ Allergen: wheat

Instructions

1

Combine all ingredients

Mix with hands in a bowl until a dough forms

2

Adjust consistency if needed

If too wet, add more oats or oat flour

3

Roll into 12 bite-sized balls

Use about 1 tablespoon of dough per ball

4

Chill to set

Place in the fridge for 20–30 minutes

⌚ Chill time
20–30 min

Nutrition

Whole recipe
777 cal
14.5g protein

Per ball (+12)
65 cal
1.2g protein



Cookie Butter Crunch

No-bake energy balls · Makes 12

[CLICK HERE](#)

Ingredients



Instant oats
1 cup



Cookie butter
½ cup, crunchy



Honey
2 tablespoons



Cinnamon
1 teaspoon



Salt
Pinch

⚠ Allergen: wheat

Instructions

1

Mix cookie butter and honey

Stir until smooth and fully combined

2

Add oats, cinnamon, and salt

Stir until everything is evenly coated

3

Roll into 12 bite-sized balls

Use about 1 tablespoon of dough per ball

4

Chill to set

Place in the fridge for 20–30 minutes

⌚ Chill time
20–30 min

Nutrition

Whole recipe
1,100 cal
13.5g protein

Per ball (+12)
90 cal
1.1g protein





Carrot Cake Energy Balls

No-bake energy balls · Makes 12



[CLICK HERE](#)

Ingredients



Grated
carrots
1 cup, fresh



Oat flour
1 cup



Cookie
butter
2 tbsp



Honey /
maple syrup
3 tbsp



Cinnamon
1 tsp



Ground
ginger
½ tsp



Nutmeg
½ tsp



Vanilla
½ tsp



Coconut
½ cup,
desiccated

⚠ Allergen: wheat

Instructions

1

Combine all ingredients

Mix with hands in a bowl until a dough forms

2

Roll into 12 bite-sized balls

Use about 1 tablespoon of dough per ball

3

Dust in desiccated coconut

Roll each ball in coconut to coat

4

Chill to set

Place in the fridge for 20–30 minutes

🕒 Chill time
20–30 min

Nutrition

Whole recipe
1,035 cal
17.8g protein

Per ball (+12)
90 cal
1.5g protein





**Now
Enrolling**



Company: TraveTherapeutics

Total time in study: About 9 months

Goal: To learn more about classical homocystinuria (HCU),
and how safe and effective pegtibatinase may be in patients with HCU

Phase: This is a Phase 3 study that follows a Phase 1/Phase 2 study called COMPOSE

Who can take part?

- ✓ People with a diagnosis of HCU
- ✓ People 12 to 65 years of age

**Other factors and restrictions
also apply**

What is the study drug?

- ✓ Participants will receive
pegtibatinase or placebo
(an inactive medication)

Why participate in the study?

- ✓ You may help others with HCU
- ✓ You will help contribute to new research
and further understanding of HCU
- ✓ You will receive additional monitoring
and testing



Study locations include:
United States, Europe,
the Middle East, Asia
Pacific, and South
America.



About 70 people
with HCU will
take part in
the study.



Payment for time and
travel may be available
to participants and their
caregivers.

Periods during the study



SCREENING PERIOD

To check if
the right
study is
for you



PRE-TREATMENT PERIOD

To understand
your current diet
and how to keep
it stable during
the study



STUDY TREATMENT PERIOD

To receive pegtibatinase
or the placebo



FOLLOW-UP PERIOD

To check your
health after
the Study
Treatment
Period

After completing the **HARMONY Study**, it may be possible for participants to join a long-term follow-on study and continue or start receiving pegtibatinase.

To find out more, please contact:
MedInfo@traverse.com



For more information,
please scan the QR code or
visit:

www.hcuconnection.com



COMPOSE Study

A study that looks at the safety of pegtibatinase and how well it may work in people with classical homocystinuria (HCU)

NOW ENROLLING

Traverse Therapeutics has added a pediatric group to study pegtibatinase, a new, investigational human enzyme therapy that targets the underlying enzyme deficiency that causes HCU.

The goal of this study is to learn more about the safety and efficacy of pegtibatinase at different dosage levels in children with HCU.

Up to 15 participants will take part in the study at sites in the United States, France, and Qatar. The study, including a screening period, diet standardization period, and an open-label treatment period, will last up to 42 weeks (~10 months). There is also an option to join a long-term extension study (ENSEMBLE).

Your child may be eligible to participate in the COMPOSE Study if they:

- Have been diagnosed with classical HCU
- Are 5 to 11 years of age
- Are currently receiving treatment for HCU

Your child will need to meet all other study criteria to take part in the COMPOSE Study.



For additional information on criteria for eligibility, please go to:
www.clinicaltrials.gov/show/NCT03406611

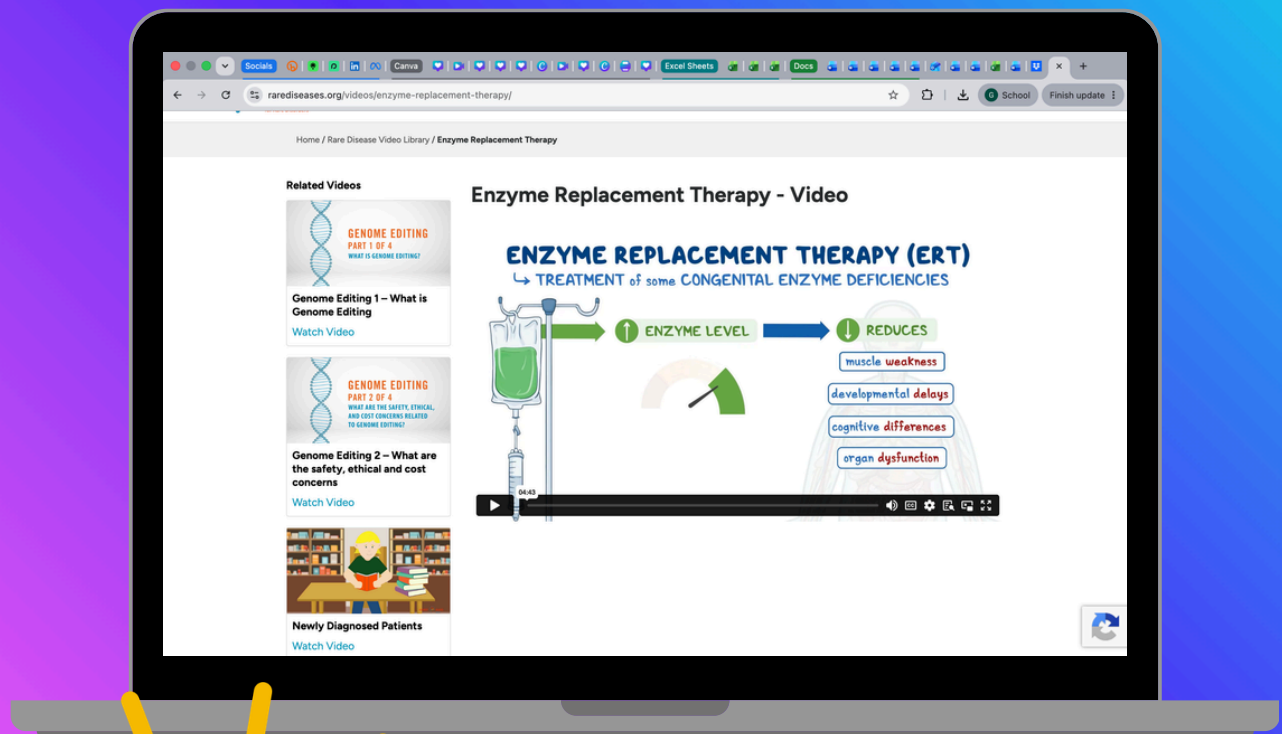
Payment for time and travel may be available to subjects who participate in this study.
To refer a patient to the study, please contact:

MedInfo@traverse.com

Visit www.hcuconnection.com for more information.



Curious About Enzyme Replacement Therapy?



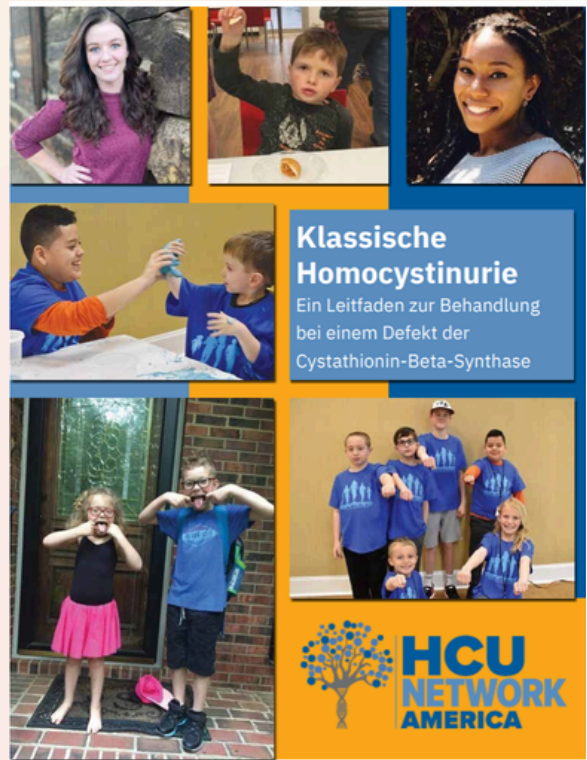
WATCH VIDEO



Alert!

NEW RESOURCE

CLASSICAL
HCU GUIDE
HAS BEEN
TRANSLATED
INTO GERMAN!



CLICK HERE



Updated Resource!



CARETAKERS GUIDE TO HCU



? What is HCU?

Homocystinuria (Ho-mo-cys-tin-uria), or HCU, is a rare inherited metabolic condition. People with HCU cannot break down the amino acids **methionine** (me-thahy-uh-neen) and **homocysteine** (hō-mō-'si-stə-,ēn) in their bodies.

Methionine (Met) is found in most foods that contain protein. HCU is a severe medical condition that can be treated with a special HCU medical formula, a diet low in protein and Met, and some vitamins and other medicines.



➤ Cause and Effect

Normally Methionine breaks down into another amino acid, homocysteine (HCY) (hō-mō-'si-stə-,ēn). The byproduct homocysteine (HCY) also builds up and has very unhealthy and dangerous side effects when protein (more specifically Met) is ingested. High HCY levels are harmful to the eyes, skeletal, vascular and central nervous systems.



To help prevent these issues, those with HCU must follow a special diet with low protein and drink their HCU formula throughout the day

Possible Complications of High HCY

- 👁 Severe nearsightedness
- 👁 Lens dislocation
- 🧠 Cognitive deficits
- 👤 Behavioral problems
- 👤 Clumsiness
- 🦵 Long limbs
- 💧 Blood clots
- 🧠 Strokes



What is a low protein diet?

The majority of the HCU diet is composed of fruits, vegetables and specialty low protein foods.

Permitted:

May still need to be counted

- Fruit: Apples, Papaya, Pears, Strawberries, Tangerines
- Veggies: Bell Peppers, Cabbage, Celery, Eggplant, Tomatoes
- Butter and Oils
- Medical Low Protein Food



Limited Amounts:

Allowed, but in limited quantities

- Fruit: Avocado, Figs, Jackfruit, Kiwi, Oranges
- Veggies: Brussel Sprouts, Corn, Peas, Potatoes
- (Some) Sugary Cereal
- Popcorn



Not Allowed:

Not allowed unless okayed by parent

- Meat
- Nuts
- Grains
- Most Dairy
- Beans
- Eggs
- Legumes



This information is not intended to take the place of medical advice or care you receive from your health care professional and intended for information purposes only. Permitted foods and quantities will vary. For a full list of permitted foods, please consult the child's metabolic care team.



To learn more about Homocystinuria, please visit: <https://hcunetworkamerica.org>

Support

Communicate

Customize Your Kit For Free!



At HCU Network America, we believe that one of the most important steps to empowering patients and caregivers is giving them the support and tools needed to succeed! We know that a new diagnosis can be overwhelming and riddled with concerns and questions. To us, one way to combat those feelings, and give you the confidence you need, is by providing you with one-on-one support, educational resources, and practical tools, such as scales, cooler bags, and more! Our request for a kit survey allows you the opportunity to request a one-on-one introductory call (with more opportunities to connect), and then a customized kit to the patient's needs. Don't want a call or a Zoom? That's fine too - we are happy to send you the customized kit.

Request your kit now -

<https://www.surveymonkey.com/r/HCUKitSurvey>

**Kits can only be sent to patients in the continental US. However, we are happy to connect virtually and share the educational materials with you via weblinks!*



- **What** is it?
 - A secure private survey for individuals or families affected by Homocystinuria
- **What** will I share?
 - Patient's birthdate, gender, exact diagnosis, and how they were diagnosed
- **What** will my info be used for?
 - Confidential and will not be shared unless we have permission
 - Helps HCUNA achieve our goals

- **Why** should I join?
 - Able to find other families and patients in your state and request contact information
 - Access to exclusive materials (ex: we may have a webinar that a presenter doesn't want to share publicly but is okay sharing with just our community)

What?

Why?

Contact Register

How?

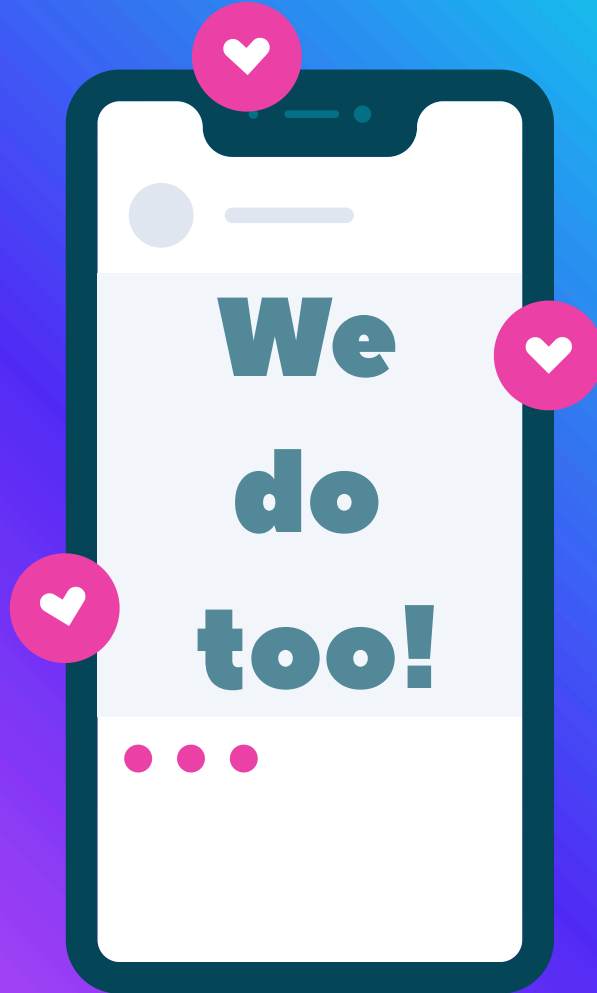
- **How** do I participate?
 - The form takes 3-5 minutes to complete
 - Visit our website and click on "contact register" tab or...

[Click Here](#)

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