

The HCU Herald

Featuring...



HCU Hero
Patrick from Pennsylvania

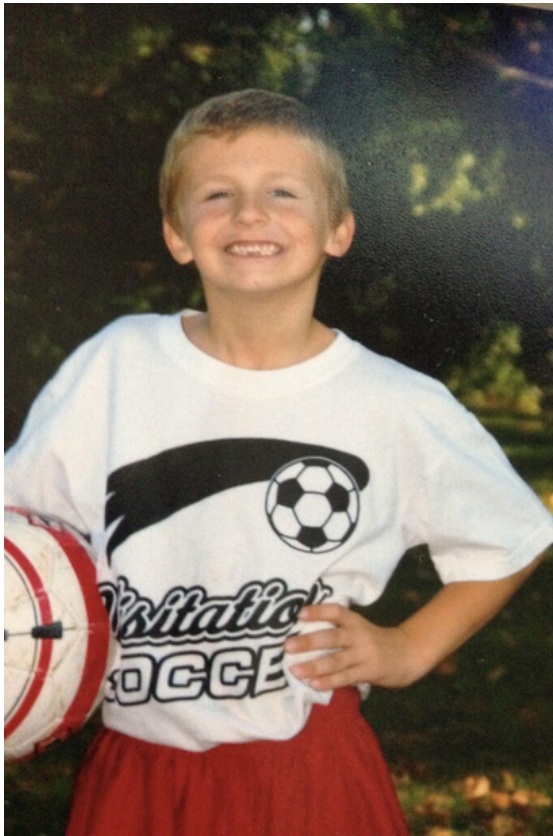


July 2026



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

HCU HERO: PATRICK FROM PENNSYLVANIA



I was diagnosed with classical homocystinuria (HCU) at the age of 9, and the diagnosis did not come easily. I had been tested twice before doctors finally connected the dots, and by then I had already undergone three eye surgeries due to dislocated lenses in my eyes. Since then, corrective lenses, a strict low-protein diet, and daily medical nutrition have become part of my everyday life. Each day, I consume approximately 35 grams of protein, along with 11 grams of betaine and six HCU coolers to help keep my homocysteine levels in check. While maintaining this routine can be challenging at times, I have come to view it as the foundation that allows me to stay healthy, remain active, and continue pursuing the things I love.

Ever since I can remember, sports have been one of the biggest parts of my life. Growing up, I played basketball, soccer, baseball, and lacrosse. Basketball became the center of my athletic journey, and I played from age five through twenty-two. Through sports, I built friendships and found communities of people who supported me not only as an athlete but also as someone managing HCU.

From the beginning, my parents played a huge role in helping me navigate life with HCU. They drove me to practices, made sure I had foods I could safely eat, and constantly reminded me that my diagnosis did not have to define me. Because of their support, I never felt like I had to sit on the sidelines. Instead, I learned how to adapt, prepare, and continue showing up.

Living with HCU meant preparation became part of every practice, game, and workout. The right diet directly affected how I felt and performed. Meal preparation, tracking protein, and staying consistent with my medical nutrition all became part of my routine as an athlete.

HCU HERO: PATRICK FROM PENNSYLVANIA

Over time, I stopped viewing structure as a limitation and started seeing it as something that gave me opportunities.

After college, I found running and it has been something I look forward to the most throughout the week. Running has given me something team sports couldn't: a conversation with myself. It has asked me to trust my training, my fueling, and my body's signals. In 2024, I finished my first half marathon. In 2025, I crossed the line of my first marathon. Those finish lines meant more than distance; they were proof that careful daily choices can add up to extraordinary moments.

Still, managing the diet has not always been easy. Around ages fifteen and sixteen, I started pushing back against the routine. I made excuses about having an upset stomach and stopped taking my coolers consistently. At the time, I wanted to feel more normal and not have to think about HCU every day.

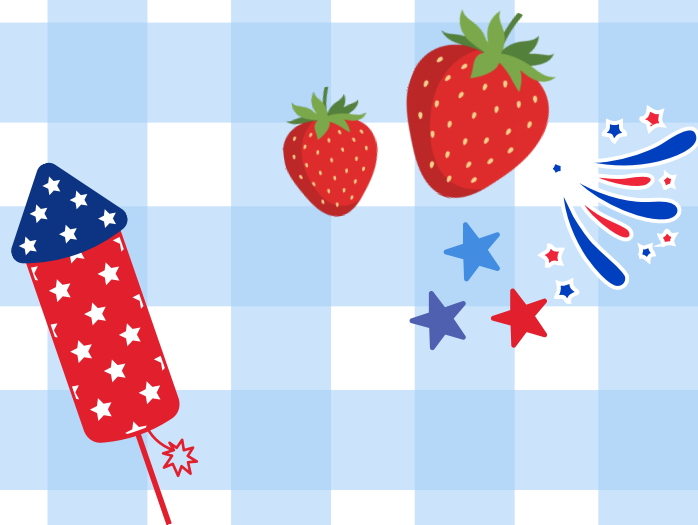
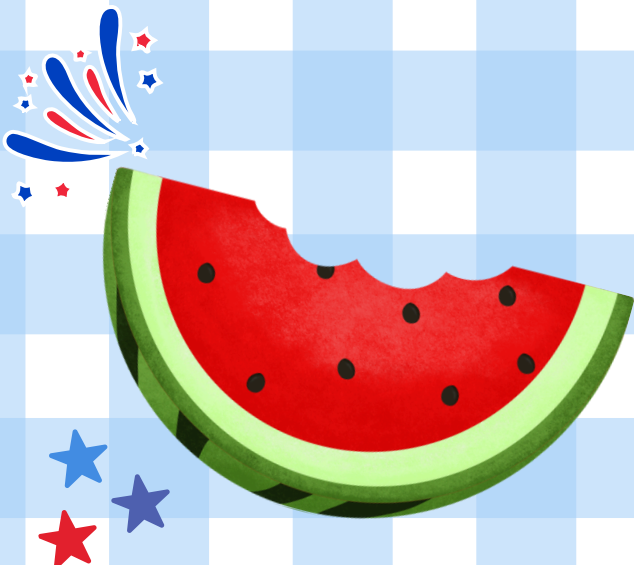


Eventually, though, I paid the price for it. My energy dropped, life became more difficult, and I realized how much my health depended on the habits I had been avoiding. Looking back, that period taught me one of the most important lessons of my life, managing HCU is not about being perfect, but about understanding how much the small daily choices matter. Once I recommitted to taking care of myself, I began feeling healthier, stronger, and more like myself again.

HCU HERO: PATRICK FROM PENNSYLVANIA

I learned a lot from those years and that experience helped shape the way I have approached both my health and athletics moving forward. I became more disciplined, more aware of my body, and more appreciative of the routines that allowed me to continue competing and staying active. Sports taught me how to break large goals into smaller, manageable steps: prepare the meals, take the coolers, and keep moving forward. Over time, those small actions build confidence, and that confidence turns into progress.

I'm proud of what I've accomplished, but I'm even prouder of how I've achieved it with patience, planning, and the support of those around me. My parents' encouragement from an early age allowed me to experience the joy of athletics despite the challenges of living with HCU. My teammates became lifelong friends who supported me both on and off the field. Running later taught me that progress is not always linear, but that consistency, perseverance, and trust in the process can lead to meaningful growth over time.



UPCOMING EVENTS



2026 HCU NETWORK AMERICA CONFERENCE LOADING...



We are so excited to see you!





KNOW Before You Go!

★ YOUR FUN GUIDE TO CONFERENCE SUCCESS ★



PLAN AHEAD

Philadelphia will be especially busy due to America's 250th anniversary and FIFA World Cup events. Plan your travel and reservations now!



PACK SMART

July in Philadelphia can be hot! Pack comfortable clothing for conference sessions and lightweight attire for outdoor activities, including Family Connection Day and teen excursions.



CAPTURE THE FUN

Take lots of photos and videos throughout the weekend! Look for QR codes to easily share your favorite conference moments with us.



BE KIND AND WELCOMING

Kindness and openness matter we all have unique experiences so let's keep conversations respectful and welcoming



HAVE FUN

Have fun at HCUNA 2026 in Philadelphia jump into the science meet great people and enjoy being part of something really special



MAKE NEW CONNECTIONS

Meet attendees from around the world! Connect with families, researchers, clinicians, and industry partners while sharing experiences and building community.

★ **MOST IMPORTANT:** *Be you. You belong here.* ★

Thank you for being part of the HCU Network America community!

Let's make it a conference to remember! ♥

UPCOMING EVENTS



REGISTER HERE



RARE
ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS

Aug
10-21
2026



Rare Across America 2026 is the opportunity to meet with your Members of Congress at their in-district offices and educate them on the issues that are most important to the rare community by sharing your story.

Registration will close on Friday, July 17.

Where?

All Senate meetings will be scheduled virtually and House meetings will be in person at your Member's in-state, in-district office. Rare Disease Legislative Advocates (RDLA) will schedule meetings for you and help you to prepare. No prior advocacy experience is necessary.

When?

Meetings with Members of Congress will take place between August 10th and August 21st. We will be offering training webinars to help advocates prepare for their meetings.

UPCOMING EVENTS

2026

NEWBORN SCREENING BOOTCAMP

Empowering Advocates to Advance Life-Saving Screening

September 24, 2026

 **Washington, DC**

- Learn about and discuss developments in newborn screening with experts
- Hear from patient advocates currently navigating the newborn screening process
- Learn how to get involved in the federal and state
- NBS systems

Register Now!

2026 HCU HEROES

REGISTER HERE



RACE FOR RESEARCH



Cystadane; the last FDA approved drug for the homocystinurias was approved in 1996. That was 30 years ago!



Currently only one clinical trial in progress for classical HCU, but there are none in progress for cobalamin disorders and Severe MTHFR.



In collaboration with other organizations, HCU Network America has issued 10 research grants.



Help us accelerate better treatments for and help raise funds during our Race for



<https://bit.ly/hcurace26>

Pricing

- Register by July 19 to receive a medal
- Register by August 24 to receive a shirt
- Early bird pricing - \$30
- After July 13 - \$35



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!

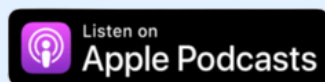


To Listen:



<https://hcunetworkamerica.org/hcu-podcast/>

or click below on your favorite option!



The latest episode



Ben welcomes Brandon to the table!

In this inspiring episode of the HC&U Podcast, Brandon shares the story of his son Mason, who is living with cblC, and how he continues to thrive while participating in a wide range of extracurricular activities and sports. Brandon offers a heartfelt look at Mason's determination, the support behind his journey, and the powerful impact of inclusion, resilience, and community. This episode highlights what's possible when passion meets perseverance—and celebrates the everyday victories that make a big difference.

EXTRA EPISODE ALERT!

The HC&U Podcast has an extra episode!

Enjoy this extra episode featuring the recording from the World Homocystinurias Awareness Day panel!

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!

LISTEN ON  Spotify

Listen on  Apple Podcasts

LISTEN ON  iHeartRADIO

Listen on  amazon music



AMY, SEVERE MTHFR



ISAAC, COBALAMIN C



JACOB, CLASSICAL HCU

**New
Series!**

HCU

**Bite Sized
Episodes!**


A Podcast About Homocystinuria




**Welcome to
the table:
Brittany Parke
SIMD Poster Talk**

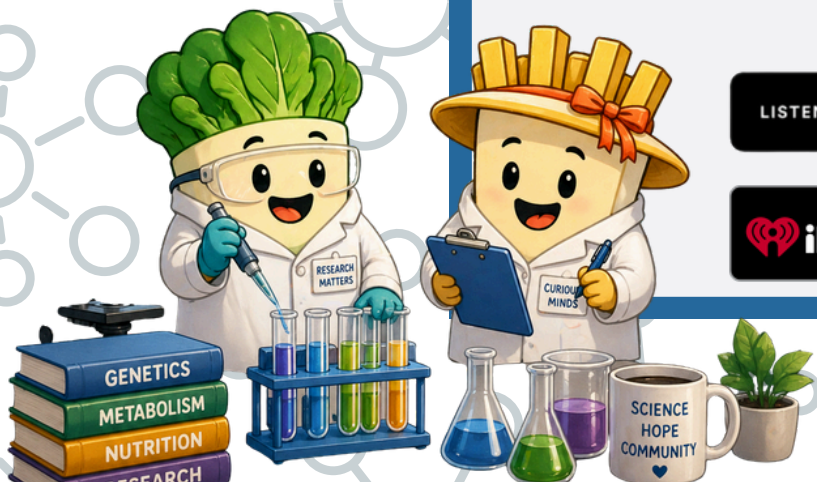
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ILLINOIS LOW PROTEIN FAMILY CAMP

SPONSORED BY
NPKUA
NATIONAL PKU ASSOCIATION

Ally **cambrooke**
BIOMARIN
pentec

SPONSORED BY
NUTRICIA

PTC
PHARMACEUTICALS
Vitality
NUTRITION

CYCLE
SPORTS

August 7 - 9th, 2026

Join us back at the beautiful Great Oak Retreat Center for a weekend away with other PKU and IEM families. Memories will be made, meals will be shared and friendships will be fostered.

FREE for IEM's
\$5 / person
\$25 / family

FUN ACTIVITIES & GAMES FOR THE WHOLE FAMILY!

- SWIMMING + FISHING
- CRAFTING + PAROLE
- BOATING
- ARCHERY + Ziplining
- AND MORE!

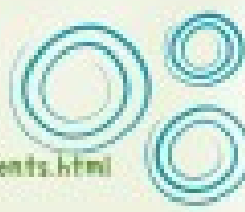


GREAT OAKS RETREAT CENTER
1380 COUNTY RD 900 N
LACON, IL 62540

Information:
danaebartke@gmail.com

REGISTER HERE 

[pkua.org/newsevents.html](#)



HOMOCYSTINURIAS

DATA COLLECTION PROGRAM

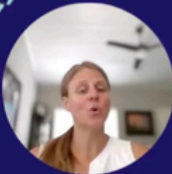
POWERED BY RAREX

SHINE A LIGHT ON HCU



24 COUNTRIES AND 37 US STATES

Welcome to your quarterly



Press Play To Watch!



METABOLIC SUPPORT
Living well with a rare disease



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.

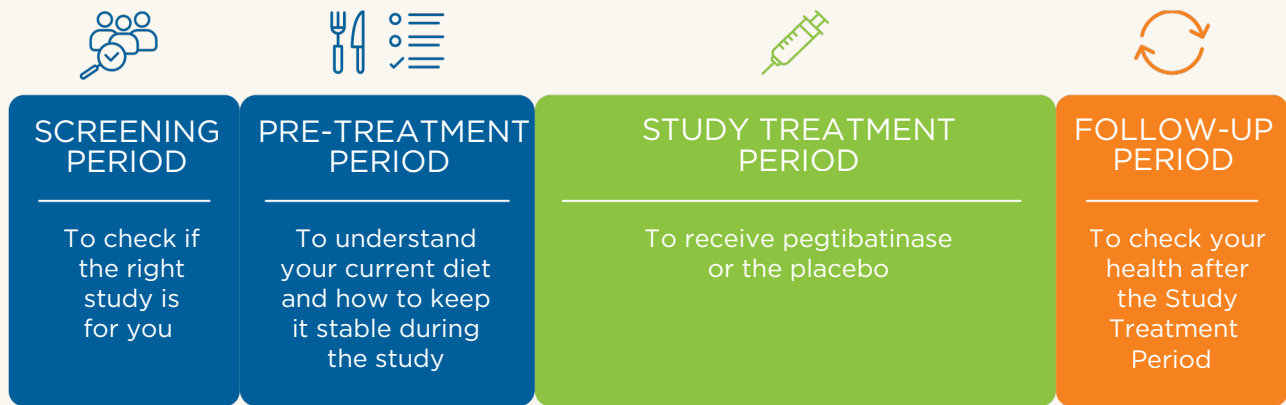


About 70 people with HCU will take part in the study.



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

Periods during the study



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@travere.com



For more information, please scan the QR code or visit:
www.hcuconnection.com

FOURTH OF JULY FLAG CAKE

Protein: .4 grams
Serving Size: 1/12
Cake



Ingredients

- **CAKE:**
 - 1/2 cup sugar
 - 1/2 cup butter, softened at room temperature
 - 1 1/2 cups low protein allpurpose baking mix
 - 2 tsp baking powder
 - 2/3 cup almond milk, unsweetened
 - 2 tsp egg replacer
 - 2 tsp vanilla extract
 - 7 medium-sized strawberries, fresh, sliced
 - 25 small blueberries, fresh
- **BUTTERCREAM ICING:**
 - 3/4 cup butter, softened at room temperature
 - 2 cups confectioners (powdered) sugar
 - 1-2 Tbsp almond milk, unsweetened
 - 1/4 tsp vanilla extract

Instructions

CAKE:

- Preheat oven to 360° F.
- Cream sugar and butter in a medium-sized bowl.
- Add low protein baking mix and baking powder; rubbing together with your hands until it resembles breadcrumbs.
- In a separate bowl combine almond milk, egg replacer and vanilla.
- Add the wet mixture to the dry, and mix until well combined.
- Pour batter into a parchment paper-lined 7 inch square cake tin, and bake in the preheated oven for 15 minutes, or until toothpick inserted in the center comes out clean.
- Remove from oven, place on a cooling rack.

BUTTERCREAM ICING:

Beat the butter in a large bowl until soft. Add half of the powdered sugar and beat until smooth. Add remaining sugar, one tablespoon of almond milk, and vanilla, beating until creamy and smooth. Beat in the remaining milk, if necessary, to reach your desired consistency.

TO DECORATE:

- Spread 3/4 of the icing on top of the cooled cake.
- Make a square with the blueberries in the upper left corner of the cake.
- Place a row of strawberries across the top of the cake like a red stripe.
- Add the remaining icing into a pastry bag fitted with a star tip, and pipe a row of white stripes below the strawberries.
- Alternate rows of strawberries and icing until the flag is completed.

FOURTH OF JULY SHOPPING LIST

Veggie Tray



**Festive Fruit
Plate**



**Gluten Free
Hamburger
Buns**

**Mushroom
Burger**



**Grain-Free
Tortilla Chips**



**Mayo-less
Coleslaw**



**French
Fries**



Popsicles



**Low Pro Chocolate Covered
Pretzel Rods**



Low Pro Pasta Salad



Please check all nutrition labels and consult your doctor if necessary before consuming

Meal Plan

[CLICK HERE](#)



MONDAY

- [Buffalo Cauliflower Tacos \(4.9 g protein per 2 tacos\)](#)

[CLICK HERE](#)



TUESDAY

- [Zucchini Boats \(4.6 g protein per zucchini boat\)](#)

[CLICK HERE](#)



WEDNESDAY

- [Italian Fried Mushroom Sandwich \(5.2 g protein per sandwich\)](#)

[CLICK HERE](#)



THURSDAY

- [Southwest Portobello Mushroom Sandwich \(5 g protein per 1 sandwich\)](#)

[CLICK HERE](#)



FRIDAY

- [CFL Jackfruit Kabobs \(2 g protein per skewer\)](#)

[CLICK HERE](#)



BREAKFAST

- So Delicious Yogurt w/ Berries
- Avocado Toast
- Katz Gluten Free Toaster Pastries
- [Low Protein Smoothie](#)

SNACKS

- Siete Grain Free Dip Chips with salsa
- 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.

- **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](#)

Follow Us!



CUSTOMIZE YOUR KIT FOR FREE!

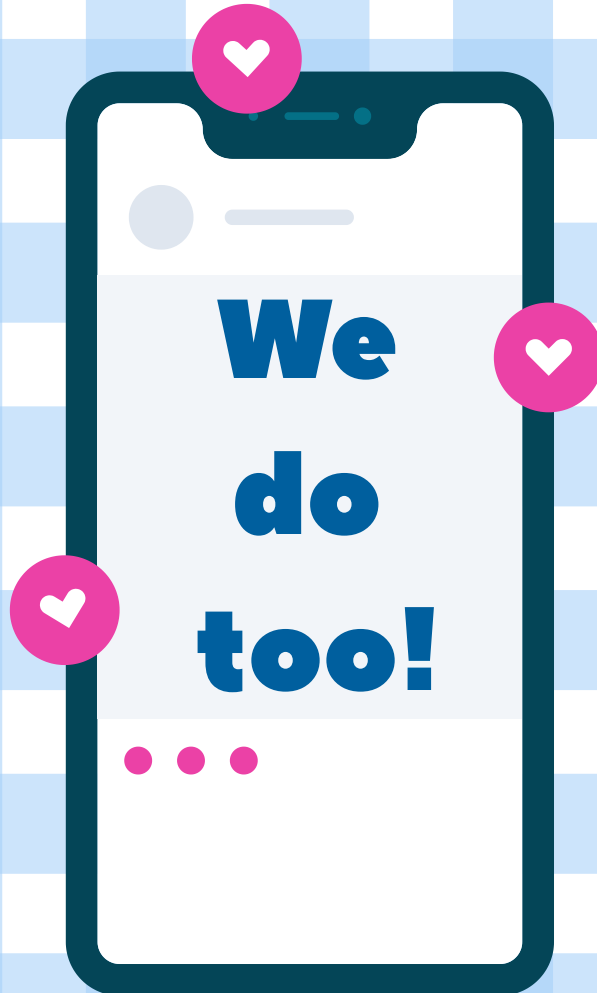


At HCU Network America, we believe that one of the most important steps to empowering patients and caregivers is giving them the support and tools needed to succeed! We know that a new diagnosis can be overwhelming and riddled with concerns and questions. To us, one way to combat those feelings, and 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!*

Do you have social media??



Follow us 



@hcu_network_america



HCU Network America



@HCUAmerica