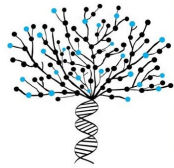


# HCU Herald

**Presented by**



**HCU Network America**

**Connecting for a Cure.**

**There have been a lot of things happening for the HCU community & for HCUNA.  
We strive to keep you informed and connected.**

## 2018 Conference Registration Now Open!



### **Taking the Lead for HCU**

Save the Date ~ April 21 & 22, 2018

**The first HCU Network America Conference**

Westford, Massachusetts

# Heroes of HCU

## Ben M. from Georgia

“Don’t be defined by a metabolic disorder.”

I was diagnosed with Homocystinuria at birth. Thankfully, my family relocated from Kentucky to Georgia in 1987, three years before I was born. This was a tremendous blessing because Kentucky did not screen for HCU in 1990. Because I was diagnosed at birth, I have been able to avoid many of the dangerous side effects of HCU.

Growing up, I had a much more difficult time handling my disorder than I do now. I don’t mean that I had difficulty in following my low protein diet or in taking my metabolic formula because the importance of both of those was instilled in me by my parents. My difficulty came mostly in social settings. I was embarrassed at birthday parties because while everyone else was enjoying birthday cake, I was eating an individually wrapped snack cake. At cookouts or sleepovers, I felt like I stood out because I had to cut my hot dogs in half because of their protein content. I felt like my disorder made me different, so I didn’t like it.

However, as I grew older, I began to care less and less that I ate differently than my friends, and I even became comfortable in discussing my diagnosis with them. Now, it is easier than ever for me to follow my low protein diet since more and more people are turning to vegetarian and vegan lifestyles. This has led to restaurants and grocery stores having more low protein options than ever before.

Today, I am enjoying my 6<sup>th</sup> year of teaching ELA to 7<sup>th</sup> graders and my 4<sup>th</sup> year of coaching middle school basketball and soccer. I have been happily married for three years to a wonderful woman who keeps me in line when it comes to handling my Homocystinuria. Seriously, she is great; the low protein recipes Lindsey comes up with are phenomenal. We enjoy visiting family and friends, watching movies, and hiking together. I am truly blessed to have the love and support of a caring group of people.

I realize that since my disorder was diagnosed at birth, my journey with HCU has been easier than those faced by many other patients. However, if you, your child, or someone you love is dealing with HCU, I can still offer some encouragement. It is going to be ok. It may seem overwhelming at times: the diagnosis, the dietary restrictions, the complete change of lifestyle, but with dedication and perseverance, it is manageable. Seek out others who deal with this disorder, ask questions, do research, use the resources that are available to you. Be an advocate for yourself and others dealing with HCU.

Finally, don’t be defined by a metabolic disorder. That will seem like a silly statement to someone who hasn’t had to deal with one before. Maybe you will have to change how you eat, or you will have to take some medications that you didn’t have to take before, but that is ok. The good news is, you are still able to live a “normal” lifestyle, just with a few modifications.

HCU friends, lettuce turnip the BEET!



# HCU and You: Recipes from the Kitchen



## **Pumpkin Cobbler** by Amber Gibson

### **Ingredients:**

92g CFL Baking Mix  
1 tsp Baking Powder  
¼ tsp Salt  
6 Tbsp (78g) Granulated Sugar  
½ tsp Cinnamon  
¼ tsp Ground Ginger  
1/8 tsp Nutmeg  
1/8 tsp Ground Cloves  
¼ cup Pumpkin Puree  
2 Tbsp Coffee-mate original creamer  
2 Tbsp Butter, melted  
1 tsp Vanilla

### **Topping:**

¼ cup Granulated Sugar  
¼ cup Packed Brown Sugar  
3/4c very HOT Water (Keurig works great for quick hot water)

### **Directions:**

1. Preheat oven to 350 degrees. Lightly spray a small casserole dish with high sides with cooking spray.
2. In a medium bowl, combine flour, baking powder, salt, sugar, and spices. Set Aside
3. In a smaller bowl stir pumpkin, creamer, melted butter, and vanilla until combined. Pour wet ingredients in with the dry ingredients. Mix to create a thick batter. Pour into a small casserole dish.
4. In a separate small bowl stir the sugars together. Spread sugar mixture over the batter evenly. Place the casserole dish on a baking sheet in case of spilling. Pour hot water over the prepared batter without mixing a thing. Place in oven and bake for 40-45 minutes or until the middle is set. Set cool 5-10 minutes before serving.

**Total weight of cobbler: 364g    Serving size: 91g    Protein per serving: 0.42g**



# HCU Awareness Month, Recap

October was a very busy month for HCU Network America! We launched our first, official HCU Awareness Month campaign with great success!

## 31 Days of HCU Awareness

We started HCU Awareness month by releasing our 31 Days of HCU Awareness interactive calendar. Each day the calendar had an activity that challenged members of the HCU community to spread awareness in various ways. Each day brought a new level of awareness and insight into the lives of HCU patients.

Some of the most highlighted and shared activities were Day 3: Share an infographic about HCU, Day 4: Share a Patient Video, Day 6: Share the HCU Timeline, Day 7: Share your diagnoses story, Day 18: Real Cost of HCU, and Day 28: Share a pic of you and an HCU buddy or a pic of you and someone who is of great support! Over the course of the month, we reached 8,580 people and saw our Facebook Page gain 19 new followers, for a total of 210 followers!

## Cooking with Cambrooke

Before HCU Awareness month officially started, our executive director, Danae' Bartke packed her bags and headed to the

Cambrooke headquarters in Ayer, Massachusetts. At the Cambrooke Headquarters, they hosted an event, *Cooking with Cambrooke: and 18 and over event*. The event started with a tour of the Cambrooke headquarters, lead by Lynn Paoella, co-founder of Cambrooke. Following the tour, Lynn lead us to the test kitchen where she demoed several recipes and then guests got to take a turn. From there we took our food to the cafeteria and Dr. Stephanie Sacharow of Boston Children's spoke about the commonalities between HCU and other metabolic disorders and some of the various treatments in development.

It's always great to connect to a larger metabolic community!

## Disorder: A Rare Disease Film Festival

After a short reprieve, Danae' then headed to Cambridge for Disorder, the first ever rare disease film festival. There, she sat on a panel with Dr. Stephanie Sacharow of Boston Children's, RD Angela Pipitone of John Hopkins, Frank Glavin of Orphan Technologies and our moderator for the evening, Mike Walsh. The panel was a wonderful opportunity to showcase how, when patient advocacy organizations, clinics and industry work together we can change the face of any disorder!



# Fundraiser Highlights!



## The Sullivan Family

When the Sullivan family set out to host a Facebook fundraiser for HCU Network America, they set their goal at \$500— they quickly realized that the generosity and support of their friends and family was much greater than expected.

When their fundraiser ended, they had raised \$1,080! Way to go Sullivan family!

## The Gibson Family

When Amber Gibson heard about HCU Network America's HCU Awareness Month, she knew exactly how she was going to fundraise. Unlike our other fundraisers, Amber put her skill set to work and hosted a cook to order bake sale. As Amber baked away, she would lure people in to order by posting pictures of her scrumptious baked goods! When she ended her bake sale, she had raised \$425 dollars! Great work Amber!

You can see one of Ambers delicious recipes in our HCU and You section on page 3.



## The Bartke Family

When Danae' donated her birthday to HCU Network America in August she set her goal at \$250, and ended up at \$340. So when HCU Awareness month arrived she new she could do better. She set her goal for her Awareness Month fundraiser at \$500 and landed right on the money! Along the way she was constantly blown away at the generosity of strangers, the friends of friends and the family and friends who never stop donating to her endless fundraisers!

Keep up the great work, Danae!





# Upcoming Events



## \$2 MILLION MATCH FOR GIVING TUESDAY

On #GivingTuesday, Facebook and The Bill & Melinda Gates Foundation will be matching up to \$2 million of funds raised for US nonprofits through Facebook's charitable giving tools. Donations can be matched up to \$50,000 per nonprofit, with a max of \$1,000 per fundraiser or donate button, until the \$2 million in matching funds run out. **The match will begin November 28th at 8AM EST (5AM PST).** Additionally, Facebook is waiving all fees for donations to nonprofits on #GivingTuesday

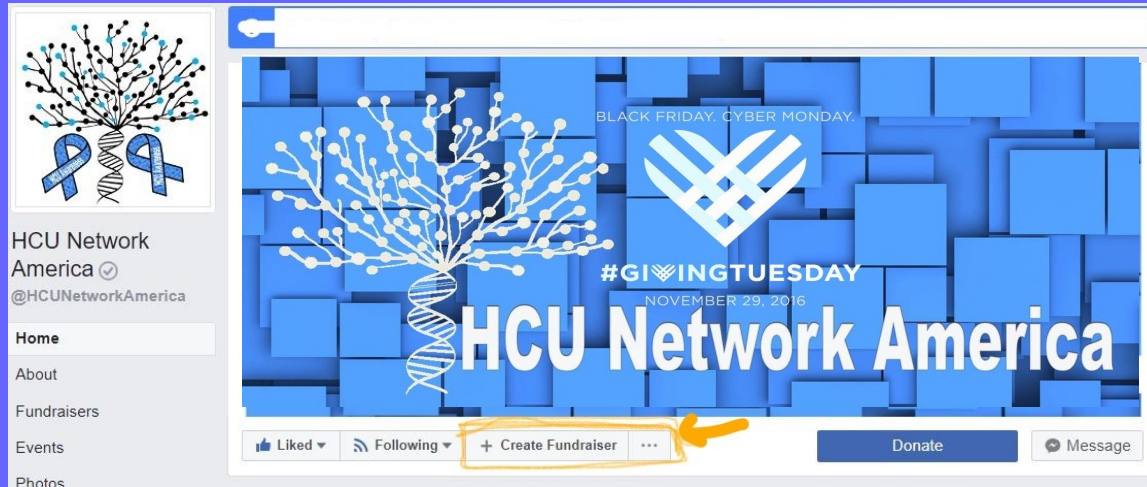
## Why double when you can triple your #GivingTuesday Facebook Fundraiser?

On #GivingTuesday, our anonymous donor will match your fundraiser dollar for dollar as well. Your \$1,000 fundraiser has the potential to become a \$3,000 fundraiser. The tripling affect is for one day only, so mark your calendars for Tuesday, November 28th!

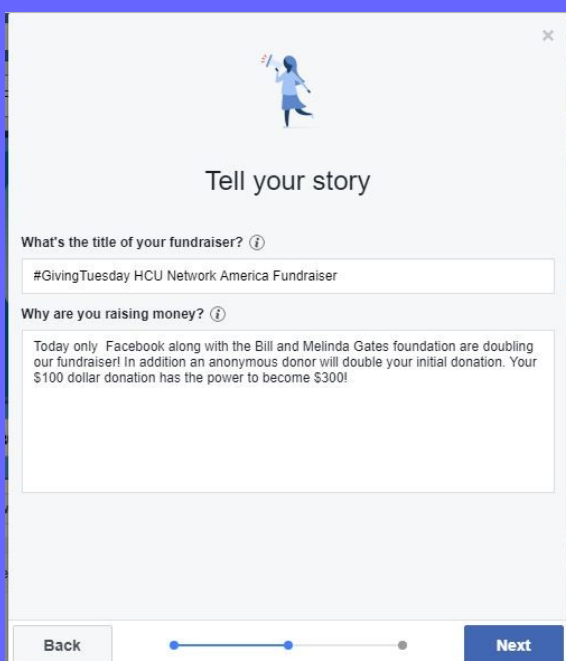
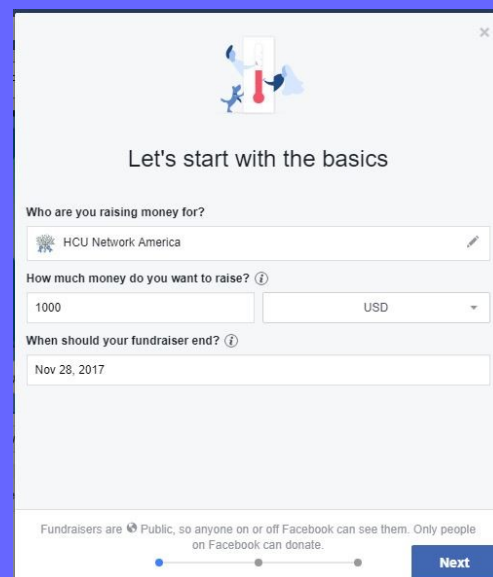
If you are unable to make the #GivingTuesday Fundraiser, remember that the match from our anonymous donor goes from now till December 31st!

# Facebook Fundraiser Setup!

1) On Facebook, head over to our page, HCU Network America. Once on the page, look for the button that says “+ Create Fundraiser”



2) After you click the “+Create Fundraiser” then make sure it says you are raising money for HCU Network America. Change the amount to \$1,000 and set the end time for November 28, 2017.



3) Edit the title of your fundraiser. Then in the “Why are you raising money?” Explain that today only, Facebook along with the Bill and Melinda Gates foundation are doubling your fundraiser. In addition an anonymous donor will double your initial donation, making a \$100 donation turn into a \$300 donation! Also explain what HCU is and how it affects you and your family.

# In Case You Missed it!

## 2018 Conference Registration Now Open!



### Taking the Lead for HCU

Save the Date ~ April 21 & 22, 2018

**The first HCU Network America Conference**

Westford, Massachusetts

**[Click here to Register Now!](#)**

\$20,000



### Our Thermometer is back!

Now through December 31st, all donations up to \$20,00 will be doubled.

**[Click here to donate today](#)**

### Priorities for next year:

- 2018 Patient Meeting
- Medical Nutrition Reimbursement
- Newborn Screening
- New Patient Toolkits
- More Infographics
- Clinic Outreach
- Patient Outreach
- And More!!!

**We are now on Instagram!**



**Follow us at:**

hcu\_network\_america



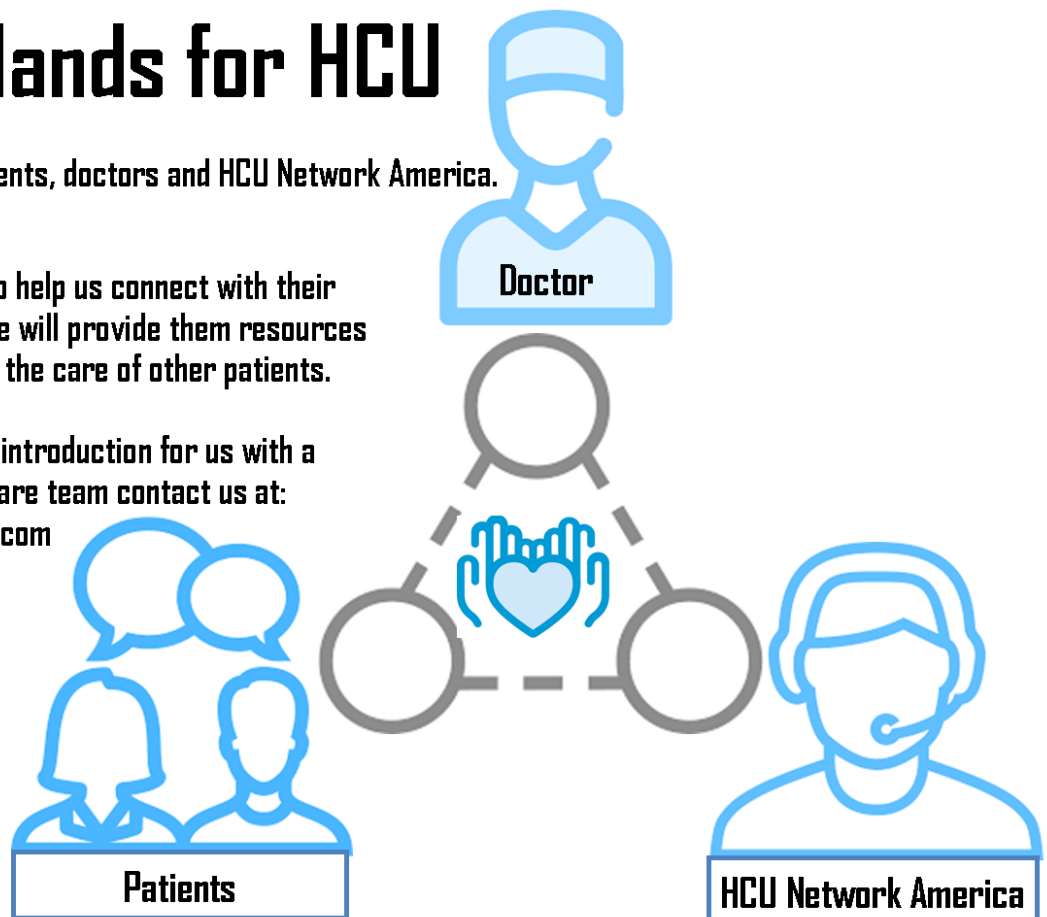
# Ways to Get Involved

## Helping Hands for HCU

A collaborative effort of patients, doctors and HCU Network America.

We are asking for patients to help us connect with their metabolic team. In return, we will provide them resources to help better your care and the care of other patients.

If you are willing to make an introduction for us with a member of your metabolic care team contact us at:  
[HCUNetworkAmerica@gmail.com](mailto:HCUNetworkAmerica@gmail.com)



## Natural History Study

Current sites include: Boston, Philadelphia & Atlanta.

Joining the Natural History Study allows researchers to find out more about Homocystinuria and issues that patients face. Natural history studies help drive new therapies and a cure! If you qualify, we highly suggest you participate if there is a center in your area. You do not have to be a patient at one of these clinics to participate.



*Find great gifts on the  
Holiday Toy List and support  
us at the same time.*

Amazon donates when you  
shop at [smile.amazon.com](https://smile.amazon.com).

**amazon**smile

## Amazon Smile

## Company Matching

Shop Smile.Amazon.com when  
purchasing through Amazon and 0.5% will  
be donated to HCU Network America  
when you designate us as your charity  
of choice.

Did you know that many companies big  
and small may match donations made to  
HCU Network America?

[Click here to find out how!](#)

[Click here to find out more](#)

**[Click to donate directly](#)**

**We'd like to thank the following content contributors:**

**Editor in Chief: Danae' Bartke**

**Heroes of HCU: Ben M. from Georgia**

**HCU and You: *Recipes from the Kitchen*: Amber Gibson**

**HCU Awareness Month, Recap: Danae' Bartke**