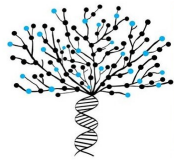


# HCU Herald

**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.**

## **Pregnancy and Homocystinuria**



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**HCU Hero: Amanda N.**

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# Heroes of HCU

## Amanda N. from Texas

There are a lot of things I know about that I shouldn't. Most 32-year olds are not acquainted with the word Homocysteine and have no idea about elevated levels. There are things you learn about when you deal with chronic illness and this is one of the many things I have learned about since being diagnosed with Homocystinuria.

### Chasing Rabbits:

#### Neck Injury= Diagnosis of Homocystinuria?

The neck injury I had sustained while playing basketball was an unlikely catalyst for change. When my minor injury didn't get better I ended up in a chiropractor's office. My chiropractor was in the same office as my primary care provider and the two providers discussed my case. Days turned into weeks and weeks turned into months. My family was called into my PCPs office and he told us he wanted to rule out Marfan's Syndrome. I went for my first echocardiogram and it was unremarkable. A few weeks later, we followed up and my doctor told us about Homocysteine and what it is. Next, we checked my homocysteine levels for the first time. When we got the results, they were very high and my doctor started working to find a geneticist to confirm the diagnosis of Homocystinuria. I started supplementing with B-6 and B-12 while I waited for to hear about the next steps.

We waited and waited... Fall turned into spring. I was 17 years old and I was in my senior year high school when I had my first appointment with Genetics at Texas Children's Hospital. When I got there, I saw Dr. Vernon Sutton. He took time to explain Homocystinuria to us and ordered more blood work to see where my homocysteine levels were at. We waited some more and eventually the diagnosis was confirmed. I had Homocystinuria.

A new diagnosis brought changes I hadn't seen coming before my first appointment with Genetics. Almost immediately I started taking Cystadane. Not long after that I turned 18 and shortly after I was a high school graduate. A few months later I started my freshman year of college.



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This is just the beginning of Amanda's incredible diagnostic story! To read her entire patient story in it's full length visit: <https://hcunetworkamerica.org/amanda--texas>

# HCU and You: Ask Methia

Dear Methia,

## How do I Prepare for the Unexpected?

I just entered my freshman year of high school. Most things are going great – I love meeting new people and am really enjoying after-school activities. One thing that I am having trouble with, though, is making the right choices at these after-school events with my new friends. Eating out with a change in routine is hard! I've even started declining certain invitations, like going out to dinner, because I don't know if there will be anything I can eat. How can I make things easier?

Love,  
*Socially Antisocial*

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Dear *Socially Antisocial*,

We know that low protein diets can really be tough in certain situations, including eating while on-the-go and out at restaurants. Remember, though, that many people have varying dietary restrictions and that a lot of venues and brands are becoming sensitive to these restrictions. Here are some tips for simplifying decision-making when eating out, and choosing the right snacks when out with your friends:

**When you can prepare, pack your own snacks.** If you know you have an activity after school, such as practice for a sporting event, pack some extra low-protein snacks (and formula!) in your lunch to have right before you start. Being prepared is key, and allows you to avoid scrambling at the vending machine for a last minute compliant snack.

**Have a list of foods handy for when you might not be prepared.** We can't always be 100% prepared for everything that happens in our daily lives. If you have a last minute change of plans that might make sticking to your diet more difficult, such as going to a friend's house after school instead of home, keep a running list (either on paper, or on your phone) of compliant meals and snacks. You can note the serving size and amount of protein that each serving yields so that you can continue to track your intake for the day. Eventually, you will come to memorize some of these values, but documenting them to start leaves little room for error and can ease some anxiety when the unexpected happens.

**Ask restaurants if they have their nutrition information available.** Believe it or not, servers and chefs are VERY used to being asked this question. Many conditions require that people keep a close eye on what they are eating, including food allergies, Celiac disease, hypertension, and high cholesterol. You should never feel ridiculous for asking for nutrition information, and most places will provide it to you!

**A small gram scale in your backpack can make a big difference.** Weighing some foods might be a big part of your daily routine, and not knowing an exact quantity might cause some anxiety. Keeping a gram scale with you, one that is small and portable, can help you to feel more comfortable during an impromptu outing with friends and family.

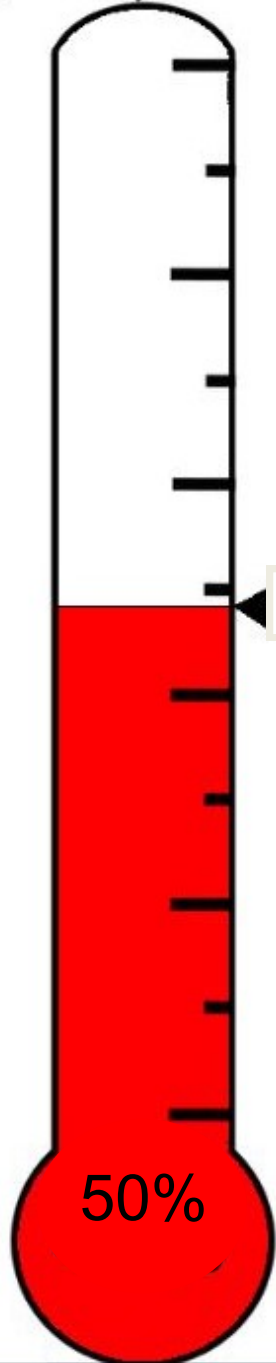
As always, your dietitian is an excellent resource and can give you tips on how to ease the worry surrounding this change in your routine!

Sincerely,  
*Methia*

# Annual Appeal Highlights

Thank you to everyone who donated!

\$20,000



**\$10,079**

Our annual appeal started in October with HCU Awareness month. We had a good start to the month with several fundraisers hosted on behalf of HCU Network America. We ended October with \$1,905 towards our \$20,000 goal. A special thanks to Danae' Bartke, Amber Gibson, and Cole and Sarah Sullivan for hosting their fundraisers for HCU Network America!

In November we had another wonderful opportunity to raise awareness and funds for HCU Network America through Giving Tuesday. Our #GivingTuesday campaign raised another \$4,000! A special thanks to Danae Bartke, Margie McGlynn, Lori Parrish, and Kristin Rapp for their Facebook Fundraisers.

In December, as our annual appeal was about to come to a close, we sent out an email recapping our accomplishments of the past year. Because of our successful inaugural campaign we were able to accomplish a lot in 2017! With this email we were able to take in \$4,174 to continue our mission in 2018!

While we did not meet our financial goal, we are still very thankful for the generous donations from our supporters! We couldn't have had a successful 2017 without you!

# Upcoming Events

## 2018 Conference Registration Now Open!



### Taking the Lead for HCU

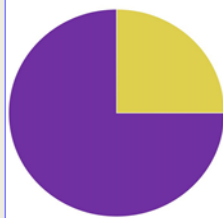
Save the Date ~ April 21 & 22, 2018

**The first HCU Network America Conference**

Westford, Massachusetts

Adults

Children

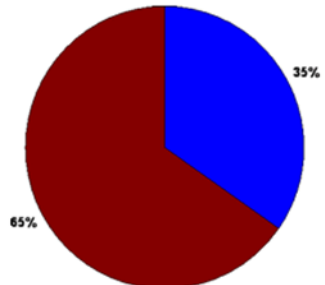


Patients

Parents

Relatives

Spouse/  
Significant other



Do you plan on attending? [register today](#)



# Pregnancy and Homocystinuria



From as early as I can remember, I knew I always wanted to have my own family. I grew up in a large family; the third of 8 kids. There always seemed to be a baby around, literally!

Growing up, my cousin and I had dreams of moving to Australia and starting our families there. We were going to each have 4 kids each and of course 2 sets of twins. So practical, I know. We would practice our fantastic 7 year old mothering skills on our cabbage patch dolls and my younger brothers. We were sure we were going to be fantastic mothers; my brothers might have begged to differ.

In 1995, at the age of 10, I was diagnosed with homocystinuria. We weren't sure exactly what that would mean in the long run for us; we just knew it came with deadly consequences if untreated. As puberty found its way into my life, my geneticists told me I'd likely never be able to have my own kids because of the risks pregnancy posed to me. Homocystinuria causes elevated risk for blood clots and so does pregnancy. It was not the news I really wanted to hear because I knew I wanted to have my own family. I eventually accepted that while I may not be able to give birth to my own kids, adoption was still a strong option.

By the time I was in my early 20s, the science had started to change and my doctor told me if I wanted to have my own kids I would have to get better control of my Homocysteine levels. Since I was still in college, having kids wasn't on my radar and I just brushed it off, knowing if I got my act together I could have kids one day.

I pursued a bachelors degree while working full time, not leaving much time to take care of myself. Because of my neglect I ended up having a blood clot. While most people don't view a blood clot as a good thing, I view mine as a life altering experience that put my life on the right path. Not long after my blood clot I started attending low protein cooking classes and metabolic meetings. It really helped me feel part of a community. I met people who had much more strict protein restrictions than myself and I told myself if they can do it, then I can too! It was the first time I was following the diet and taking my formula the correct way.

In 2011, a few years after my blood clot, I met the man who would become my husband. In 2014, we got married and now we are expecting our first child! I'm 14 weeks and due June 30th. The pregnancy has been fairly smooth and uncomplicated.

I would like to think it's been so smooth because of the preparation up to the pregnancy and my follow-up care during pregnancy. Back in May, well before I was pregnant, I met with maternal fetal medicine specialist and a hematologist to discuss the possibility of pregnancy for a patient with homocystinuria. I have also been closely tracked by my dietitian and geneticists. As your baby grows, your nutritional needs will change and your medications may have to change too, so it's important to follow up with your care team regularly.

I will be documenting the rest of my pregnancy on a blog I have just started:

<https://hcu-thenextgeneration.weebly.com>

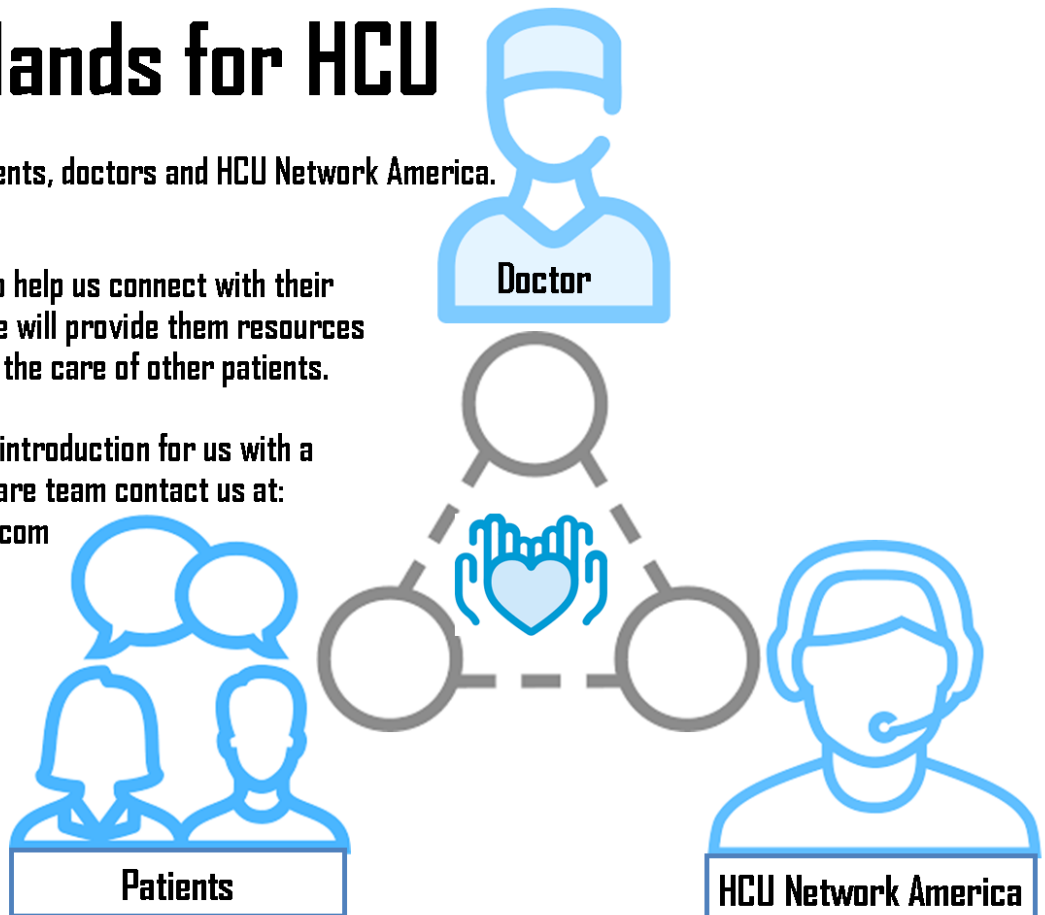
# Ways to Get Involved

## 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.

## Amazon Smile

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.

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

## Company Matching

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

[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: Amanda N. from Texas**

**HCU and You: *Ask Methia*: Angela Pipitone**