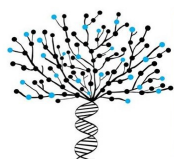


# HCU Herald

**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.**

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# Heroes of HCU

## Samantha from Indiana



Samantha was born in June of 2015. She was a beautiful and healthy baby. When Samantha was about two weeks old we received a phone call from her pediatrician saying her homocysteine levels came back high on her newborn screen. A few months later we had her genetically tested and found the gene that led to homocystinuria. She B6 non-responsive. She began her treatment of formula which was a mix of Prophree and HCY1. Samantha also began vitamins of B6, folic acid, and Poly-Vi-Sol. Her levels were very good and she was developing as any normal baby would. It is one year later and she is still doing great. We struggle some with getting her daily caloric intake, but she is a smart and loving little girl. We are very blessed with this beautiful little girl and thankful to God for her love.



# HCU and You: Recipes from the Kitchen



## Mock Taco Meat

-Makes 13 1/4 cup servings at 0.76g protein per serving

### Ingredients:

- 200g cauliflower florets
- 1 20 oz can Jackfruit in brine, drained and well rinsed
- 80g sliced mushrooms (cremini or white)
- 35g diced onion
- 1 clove garlic, minced
- 2 tablespoons coconut aminos
- 2 teaspoons chili powder
- 1 teaspoon cumin
- 1 teaspoon oregano
- 1 teaspoon smoked paprika
- 1 teaspoon cilantro
- salt and pepper to taste

### Directions :

Preheat the oven to 350 degrees and line a baking sheet with parchment paper.

In a food processor, pulse the cauliflower until it is ground up like rice. Dump into a large bowl. Next, process the mushrooms until they are a similar consistency and add to the bowl with the cauliflower. Next process the Jackfruit to the same consistency as the cauliflower mixture and add to the bowl with the cauliflower mixture.

Sauté the onion and garlic with a little olive oil over medium heat until translucent and fragrant. Add to the cauliflower mixture.

Now add the rest of the ingredients to the large bowl and mix well with a large spoon.

Spread the mixture evenly onto the parchment lined baking sheet. Season with salt and pepper as needed. Bake for 25 minutes.

Give it a little stir, then bake for an additional 15-20 minutes. Serve with choice of lo-pro tortillas, chopped lettuce, tomatoes, avocado slices, non-dairy cheese and salsa.

Can be used as ground beef substitute, just adjust seasonings.



## **Lo-Protein Mini Churros Recipe**

Serving: 2 mini churros 0.13g protein - 12 servings total

1 Quart Frying Oil (the Churros will only use about a 1/4 cup of Oil for the entire batch, so you can save almost all of the Oil for use later.

### **BATTER INGREDIENTS:**

- 1/2 Cup Water
- 2 Tbsp. Butter or Butter Alternative
- 1 Tablespoon Brown Sugar
- 1/2 Teaspoon Vanilla
- 1/4 Teaspoon Salt
- 1/4 Cup Aquafaba
  - the Liquid Drained from a Can of Garbanzo Beans
- 1/2 Cup Cambrooke Baking Mix

### **SUGAR TOPPING:**

- 1/2 Cup Sugar
- 1 Teaspoon Cinnamon

### **Instructions:**

1. While preparing the other ingredients, preheat your Frying Oil in a deep pot to 375 degrees F. It is crucial to the recipe that you maintain 375 degrees throughout the frying process. This may mean waiting a couple of minutes in between batches to make sure the oil returns to the correct frying temp. Otherwise your Churros will be soggy.
2. In a medium pot, add Water, Butter, Brown Sugar, Vanilla & Salt – Whisk to combine & Bring to **just** boiling over Medium Heat. Remove from heat as soon as bubble begin breaking the surface.
3. Add baking mix to Boiling Mixture & stir well with Spatula until mixture starts to smooth out.
4. Add Aquafaba to Mixture until well incorporated & Churro Batter is smooth (no lumps).
5. While Churro Batter is cooling & Oil is Preheating, prepare your Sugar Coating by combining Sugar & Cinnamon in a plate or bowl. Then set-aside for later.
6. Scoop Churro Batter into your 12” Piping Bag fitted with a 1M Star Tip.
7. When Oil has fully preheated to 375 degrees, begin piping 6” Churro strips directly into the oil. Use the blunt end of a knife to cut the batter from the tip. Only fry 4-5 Churros at one time.
8. Allow Churros to fry 1 minute before gently flipping. If the Churros stick to each other, that’s ok, let them be & you can separate them after frying. Continue to fry for a combined total of 4-5 minutes until golden brown.
9. Remove Churros from oil & place on paper-towel lined cooling rack to drain & cool.
10. While Churros are still warm, toss them into the Sugar Cinnamon Mixture & coat them well.

# HCU Chef: Amber G.



My name is Amber I am the mother of a two-year-old with Homocystinuria. I attended culinary school where I met my husband. We both graduated in 2010. I graduated with a pastry arts degree and I have done some cake decorating in the past. I worked as a cook and supervisor at a restaurant called Champions in a downtown Indianapolis Marriott hotel for eight years. While working for Champions, it gave me opportunities to grow as a chef by helping design the menus, organize and prepare food for parties, and placing orders. While I have had special dietary requests from guests of the restaurant, nothing would challenge me more than the special diet necessary for my daughter. She has really broadened my ideas for food and menus. I have more knowledge of different vegetables, fruits, and nondairy products than I could ever imagine having learned in culinary school. Nothing empowers you to learn more than experience. Thanks to my daughter and her needs, I have been able to gain such experience and through this experience, I will share with you the recipes I have been able to create for her and our beloved HCU community. Thank you for this opportunity to be the recipe coordinator for HCU Network America.

We are in the process of adding a recipe section to our website—  
check on Facebook and Twitter to find out when it goes live!



# GMDI Recap

HCU Network America participated in the Genetic Metabolic Dietitians International 2018 conference in Lake Buena Vista, Florida the very end of April.

The 4 day conference brings together patient organizations, metabolic food and formula companies, pharmaceutical companies, and dietitians that all have a vested interest in metabolic disorders. The four days are comprised of poster sessions, keynote speakers, and break out sessions with lots of time to network. The topics that were included were the microbiota and Inborn Errors of Metabolism, Metabolic Medicine and Nutrition: Our patients are our teachers, Bone Health: DXA and Beyond, The simplified Diet in Inborn Errors of Metabolism, Experience in Supporting Breastfeeding in IEMs and more!

During coffee breaks and receptions, the exhibits (this includes the tables like HCU Network America) were open to those in attendance. With each break, we saw a lot of interest in our organization and the resources and materials that we had available to both clinics and patients. At the conference we were able to share our newly published New Patient Toolkit, as well as share our infographic, resource list and the Guidelines for Diagnosis and Management of CBS Deficiency. Dietitians were thrilled to know that there was finally a group for their HCU patients!

At GMDI our efforts to connect with clinics were well noticed. Some who stopped by our table were aware of our organization, but many were not. Like SIMD, we had many dietitians from around the globe excited to see a resource for their Homocystinuria patients. We are a beacon of hope, information and resource for not just those in the US, but also around the world!



**Executive Director, Danae' Bartke with Vitaflo Chefs, Chef Neil and Chef Patrick! They did a lot of low protein demos and provided breakfast and lunch for dietitians and those like Danae' who require a low protein diet!**

# Contact Register



Did you know that just under one year ago we launched our 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 to. By registering, you will be also be able to identify other affected patients in your state and request their contact information, and you will 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 and provide resources for patients and families, create connections, and support advancement of diagnosis and treatment of HCU and related disorders. In order to succeed in our mission the input you provide, helps us plan events, develop resources and educational tools, and to help better to ensure everything is being done to guarantee 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/>



# Taking the Lead for HCU



Thank you to everyone who attended HCU Network America's first conference, "Taking the Lead for HCU".

Over 100 patients, family members and health care professionals attended our 2 day conference in Westford, Massachusetts where we had talks on HCU Guidelines, dietary management, reimbursement support, impact of HCU on the brain, Natural History Study, and Enzyme Replacement Therapy and more. We will have a full conference report available later this month and will publish in our June newsletter.



# Upcoming Events

**HCU Network America**



## **Medical Foods, Formula and Supplements Insurance Reimbursement Webinar**

**Wednesday, May 23, 2018 | 7pm EST.**

For more details, visit: <https://hcunetworkamerica.org/insurance-reimbursement-webinar/>

During this webinar, Raenette will review information such as these coverage statistics:

- 50% of states have some type of insurance mandate.
  - Of those states, 84 % have some type of mandate on both food and formula coverage.
  - The other 16% percent of those states, do have mandates only on formula coverage.

\*Some states may have programs that cover food or formula directly that are not included in these statistics.

Learn how you can get your food, formula and supplements covered by attending our FREE online webinar with Raenette Franco of Compassion Works Medical, LLC. Raenette is a Certified Biller Coder Specialist (CBCS), with over 17 years of experience helping patients get coverage on food, formula, and supplements they need!

To attend this webinar on May 23 at 7 PM EST, please register at:

<https://hcunetworkamerica.org/insurance-reimbursement-webinar/>

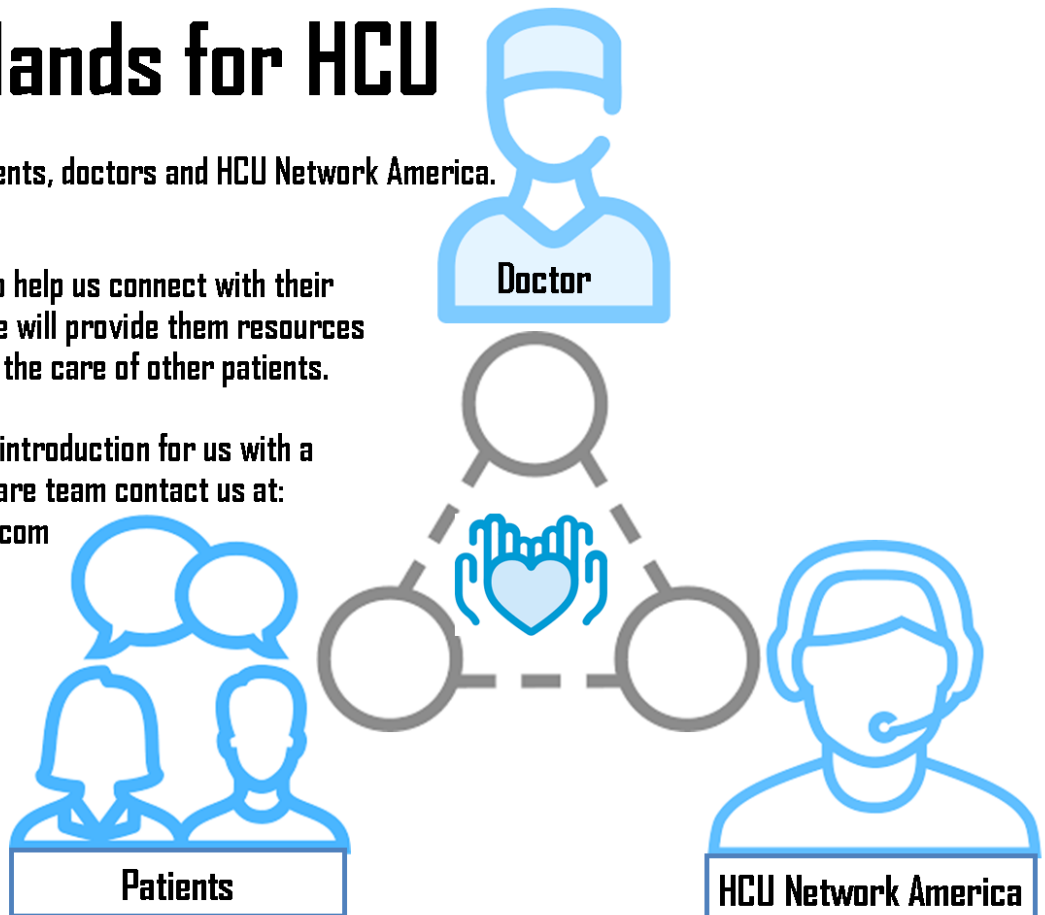
# Ways to Get Involved

## 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: Samantha from Indiana**

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

**GMDIR recap: Danae' Bartke**