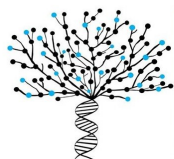


# HCU Herald

**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.**



## **Inside this issue:**

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# Heroes of HCU

## Bharatkumar from California

My name is Bharatkumar and I was born in Chennai, India. When I was 1 year old my family moved to London, UK., because of my father's higher education at the University of London.

When I was 2 years old I started having seizures. I was admitted in the hospital for the seizures but diagnosed with Homocystinuria (classical) which was the reason for them, due to high levels of homocysteine in my blood. Since the diagnosis I have been on the special diet of counted exchanges of restricted natural food, supplemented with amino acid formula that didn't contain Methionine and with low protein food products such as bread, etc. I have been on this diet ever since the diagnosis. Even though I've not liked the strong taste of my methionine free formula, I've always made sure I took it with every meal except when I was ill. It has helped me keep my Homocysteine levels in check. I was started on Cystadane or Betaine Powder in 1988 in England and my Homocysteine levels came down with its addition.



In 1989, my father started a new job in Los Angeles and so our family moved with him to the United States of America. Dr. Richard Koch became my Geneticist at the Children's Hospital of Los Angeles and he was a huge influence on how to manage my health condition without having to feel that it was a huge burden. He influenced my parents as well, especially my mother who created the company Taste Connections because of me and because of the encouragement from Dr. Koch who wanted her to do "something" with her experience in cooking low protein products. Over the years, even though on the special diet, I've struggled with recurring seizures due to my body not responding to seizure medications the same way as a person without Homocystinuria. Managing the diet and HCU has been easier than managing the seizures.



I have been able to get involved in various interests of mine including biology, history, space studies, etc. despite my health issues. After graduating high school, I started studying computer information systems, marine biology, history etc. classes at the local community college but recurring seizures prevented me from continuing to finish my degree. But I'm continuing to pursue my interest in animals, history, space studies and travel, and have created websites writing about these topics. Due to encouragement from my family and friends, I'm able to continue doing that.

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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/Bharatkumar-bio>

# HCU and You: Recipes from the Kitchen



Recipe by Amber Gibson

## Mock Tuna Salad

Makes about 2 cups

- 0.56g protein for ¼ cup serving,
- 1.12g protein for ½ cup serving

### Ingredients:

1 20oz can Jackfruit in brine, rinsed and drained (1.9g)

1 (40g) Stalk Celery (0.3g), finely chopped

1/4c finely chopped red onion (0.4g)

1 TBSP Finely chopped fresh Dill (0.07g)

3 TBSP Miracle Whip Dressing (0.3g)

½ to 1 tsp garlic powder (0.3 to 0.5g)

Salt and Pepper to Taste

### Recipe:

1. Drain and rinse the jackfruit and pulse in a food processor until it's shredded and resembles canned tuna. If you don't have a food processor you can chop it with a knife.
2. Put the jackfruit in a medium mixing bowl and add the celery, onion, dill, Miracle Whip, garlic powder, and salt and pepper and stir until it's fully combined. You can serve this with your favorite low protein crackers, on your choice of greens, or as a sandwich your bread of choice. Enjoy!



# Rare Disease Day 2018



## What is Rare Disease Day?

Rare Disease Day takes place on the last day of February each year. The goal is to raise awareness among the general public, researchers, drug companies and law-makers about rare diseases and the impact they have on patients' lives.

To find more information about Rare Disease Day, please click [here](#).

## How will HCU Network America Participate?

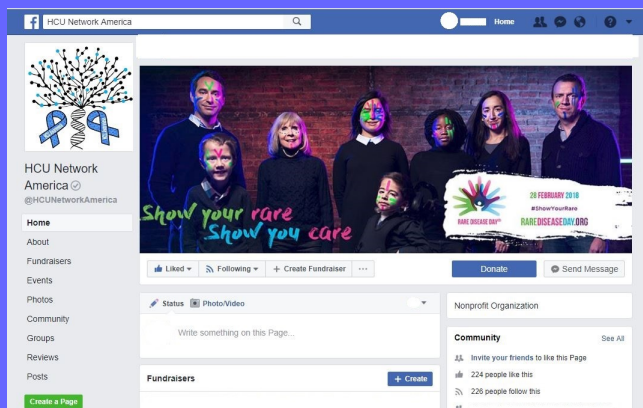
HCU Network America will change their cover photos on their social media pages.

HCU Network America has chosen to make Rare Disease Day a month long event! Each day during the month of February, HCU Network America will be sharing a fact about Homocystinuria via social media.

The last week of February, we will be asking our community to host a Facebook Fundraiser in honor of someone you know with Homocystinuria. The steps on how to set up the fundraiser are included below.

1) Head over to HCU Network America's Facebook page:  
<https://www.facebook.com/HCUNetworkAmerica/>

2) Click Create



3) Set your goal and end date (February 28, 2018).

4) Change the title of your fundraiser and explain why you are raising money.

Facebook will give you generic title and statement, but feel free to change the language.

Ex. Title – HCU Rare Disease Day Fundraiser  
Ex. Explanation: I am raising money for HCU Network America, because I am affected by Homocystinuria which is one of the 7,000 rare diseases this day represents. Homocystinuria affects 1 in 200,000 people and if left untreated can cause dislocated lenses, heart attacks and strokes, starting even in infancy.

5) Pick a cover photo. You can use the one on our Facebook page, or pick your own.

6) Click create.

# SAVE THE DATE

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7 PM EST

18

Register at: <https://hcunetworkamerica.org/clinical-guidelines-webinar>

## Cobalamin Webinar, Featuring Dr. James Weisfeld-Adams

Join us for an online webinar featuring Doctor James Weisfeld-Adams. Dr. Weisfeld-Adams was a member of the E-HOD Guidelines Committee that led to the *Guidelines for Diagnosis and Management of the Cobalamin-Related Remethylation Disorders cblC, cblD, cblE, cblF, cblG, cblJ and MTHFR Deficiency*.



To view Dr. Weisfeld-Adams biography click [here](#)

To view the guidelines that the webinar is based on, click [here](#)



# Upcoming Events



## Taking the Lead for HCU

Save the Date ~ April 21 & 22, 2018

**The first HCU Network America Conference**

Westford, Massachusetts

Haven't registered yet? [Register today](#)

## Attention: Volunteers Needed

For HCU Network America's Conference: *Taking the Lead for HCU*  
(An "educational meeting" for patients and families affected by homocystinuria, a rare genetic disease)

Westford Regency Inn and Conference Center | Westford, Massachusetts  
April 21-22, 2018



**We are now seeking a few adults to assist  
and help organize our children's program:**

- Arts & Crafts
- Educational Lessons
- Stories
- Games
- Hands on activities
- And more!!!
- Compensation available depending upon experience

Children's program will take place during the main  
session of the conference.  
(Saturday 8:00-5:00 and Sunday from 8:00-3:00)

Direct your contact with days and times of availability to:  
Danae Bartke, Executive Director at  
[hcunetworkamerica@gmail.com](mailto:hcunetworkamerica@gmail.com)

Do you have a friend or family member who might be interested to assist in part of our children's program?

Please send them our way!



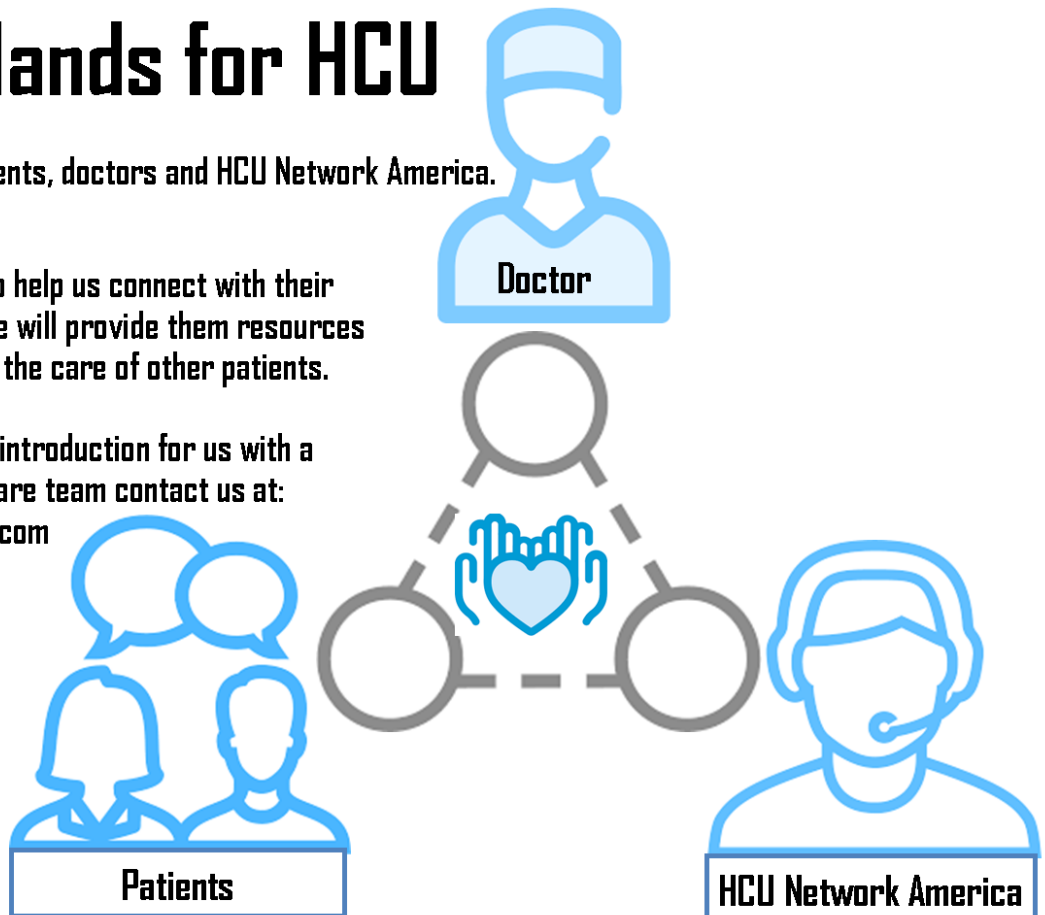
# Ways to Get Involved

## 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: Bharatkumar from California**

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