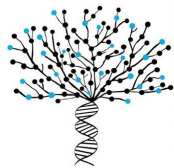


HCU Herald

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.**

Low Protein Food and Formula Reimbursement Support is now Available



Heroes of HCU

Pam P. from Nevada

"I often questioned why this happened to me since I had been following a healthy lifestyle "



I am Pam and I was diagnosed with Classic Homocystinuria in April of 2011 at the age of 54. Growing up, I had always thought I had Marfan Syndrome, a connective tissue disorder. This was because at the age of two, my parents were told I had dislocated lenses in my eyes. This was something that doesn't show up in many conditions, and at that time, no one knew about Homocystinuria.

When I was 46, I suffered a stroke. Luckily, it was very mild, but obviously very scary. I often questioned why this happened to me since I had been following a healthy lifestyle for quite sometime. After that I resigned from my teaching job, and made an appointment at Stanford Hospital's Marfan's clinic. Although I didn't totally fit the criteria, they too thought I probably had Marfan's.

A few years later, I was hospitalized with blood clots in my lungs. I was put on Coumadin for six months. Two weeks after stopping the Coumadin, I again was hospitalized with more blood clots in my lungs. An ultrasound also revealed many blood clots in the deep veins of my legs. After I was released from the hospital, I started doing some investigating online. I started looking at the Marfan's website which I had looked at several times before. This time under the related disorder section, I saw something new. Homocystinuria was listed there. As I started reading about how it can cause strokes and blood clots, I became very interested. I called Stanford again and told them what I had read. They told me what blood work to have done, and to report back to them with the results. As soon as I reported my numbers to them, they immediately scheduled an appointment for me to be seen by one of their geneticists. This time I had genetic testing done which confirmed my diagnosis.

As others have said, I was put on high doses of B vitamins but I was found to be non responsive to that therapy. I then began taking Betaine and a special metabolic formula which supplies all the amino acids my body needs, except the one I can't process. I also began a very strict low protein diet. That has probably been the toughest part for me. I grew up eating anything and everything I wanted. My Mom was a gourmet cook, and I was used to going out to nice restaurants and eating whatever I chose. As hard as it is, I know it is something I will have to do for the rest of my life. I have already experienced some of the more scary aspects of this condition, but somehow I have been given a second chance and want to do everything I can to stay healthy. I have done very well on the diet and my numbers are now in the mid 20s. A far cry from where I started out at over 400!

I hope that by sharing my story, it will help spread awareness and inspire others who are dealing with this condition. There is hope!

HCU and You: Connecting the Dots

Talking about Homocystinuria Isn't Always Easy

Everyone has things we worry about or that cause us stress. Sometimes we cope with stressful things by addressing them and coming up with solutions, but sometimes we use avoidance to escape thoughts, feelings, or situations that are stressful. Avoidance can feel like a good (temporary) solution. This could involve avoiding people or places associated with medical care, or this could involve avoiding thoughts or reminders of Homocystinuria. Avoidance can be a purposeful decision or often it's a less conscious strategy.

Thinking about and taking care of Homocystinuria isn't always easy. Not talking about it, always forgetting or putting off clinic appointments, and trying not to worry about following a diet are likely signs of avoiding.

How can you avoid *avoidance*?

Insight. Ask yourself, what do you keep “putting off” until later? Recognize that there is often an inner conflict for anything about your health. Part of you wants to change or do the “right thing,” while another part of you wants to escape or avoid. Attend to and realize what your inner voices are saying.

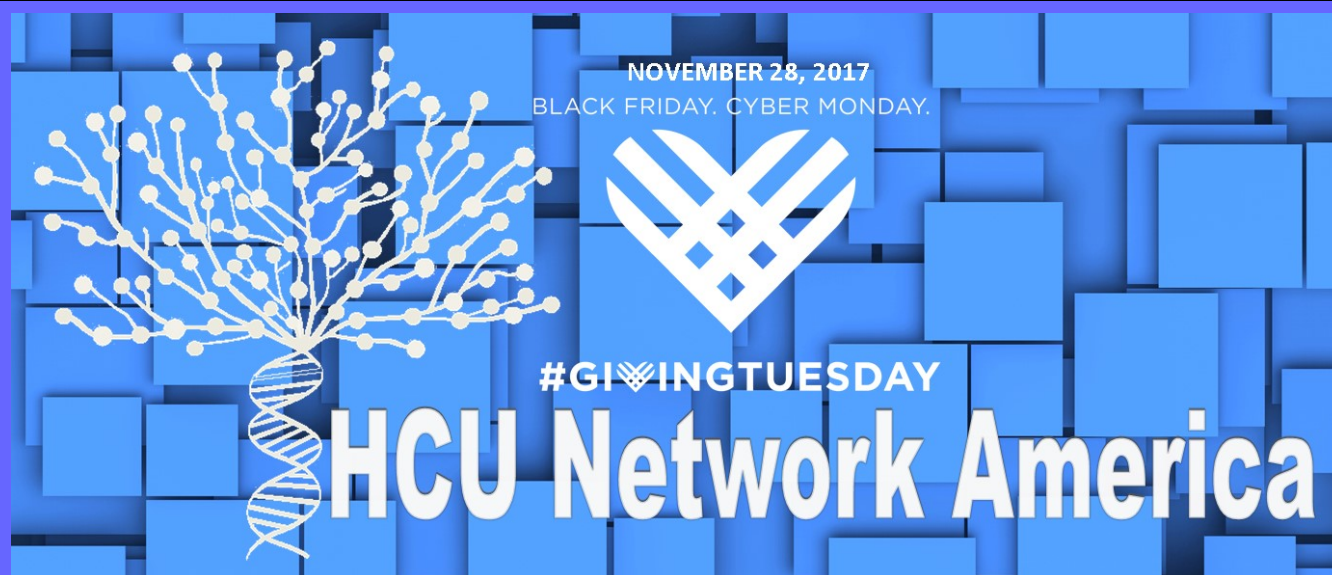
Self-Compassion. Treat yourself the way you would treat another person. Recognize that imperfection is part of being human, and it is okay to have part of you that wishes Homocystinuria would just go away. Everyone has something that they want to change about their health or their behavior.

Connect Values and Behaviors. We all have goals for our lives and for our health. Take a step back. In your heart, what really matters to you? What matters to you in the big picture? How can you include Homocystinuria as part of who you are and what your goals are? Getting “back to care” or “back on diet” is a common topic and a common source of stress for people on low protein diets. It is okay to be stressed about diet adherence. Compassionately listen to your inner voices – those that say *change* and those that say *avoid* because those voices are a part of you.

Sincerely,
Ben

Connecting the Dots is part of a series of articles with a focus on how Homocystinuria affects daily life. Benjamin D Goodlett, PhD is a psychologist who works with children and families affected by metabolic disorders.

#GivingTuesday Fundraising Highlights



This year #GivingTuesday fell on Tuesday, November 28th.

What is #GivingTuesday?

According to the official #GivingTuesday website, #GivingTuesday is “Celebrated on the Tuesday following Thanksgiving (in the U.S.) and the widely recognized shopping events like Black Friday and Cyber Monday, #GivingTuesday kicks off the charitable season when many focus on their holiday and end-of-year giving. Since its inaugural year in 2012, #GivingTuesday has become a movement that celebrates and supports giving and philanthropy with events throughout the year and a growing catalog of resources.”

#GivingTuesday 2017 incentives

This year on #GivingTuesday Facebook has agreed to waive all transaction fees for donations made through their platform. In addition to this, the Bill and Melinda Gates Foundation agreed to match up to \$50,000 per non profit with a max of \$1,000 per fundraiser until the \$2 million in matching funds runs out. By 9 AM EST all the matching funds had been depleted!

In addition to the generous matching opportunity through the Gates foundation, our anonymous donor offered to match any Facebook fundraiser for the day. They have also extended this offer through December 31st—so you still have lots of time!

#GivingTuesday Participants

This year we had four #GivingTuesday Participants: Danae’ Bartke, Margie McGlynn, Lori Parish and Kristin Rapp. Each of them held fundraisers for \$1,000 and almost all of them were met! This means at minimum we will have almost \$4,000 to put towards new educational resources, tools and our 2018 conference.

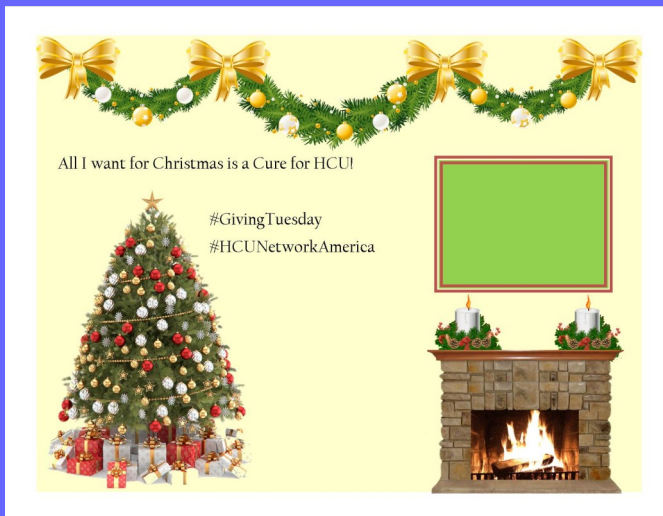
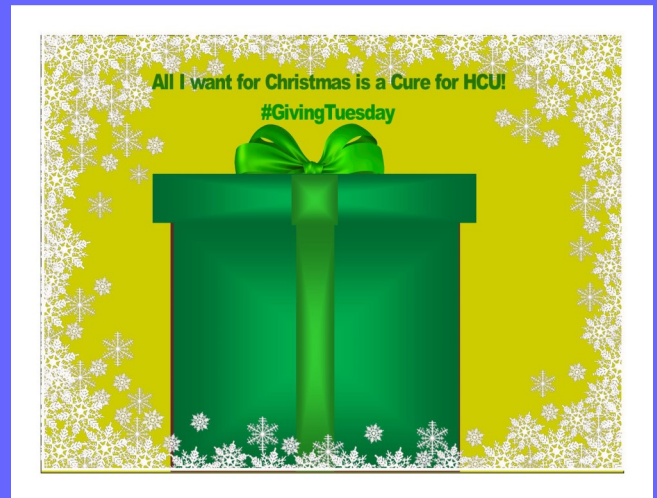
Still confused on how to set up a Facebook Fundraiser?

If you would still like to set up a Facebook fundraiser benefiting HCU Network America, there is still time! If you are having trouble figuring out the how to, please email us at HCUNetworkAmerica@gmail.com or message us on Facebook and we will gladly walk you through the steps!

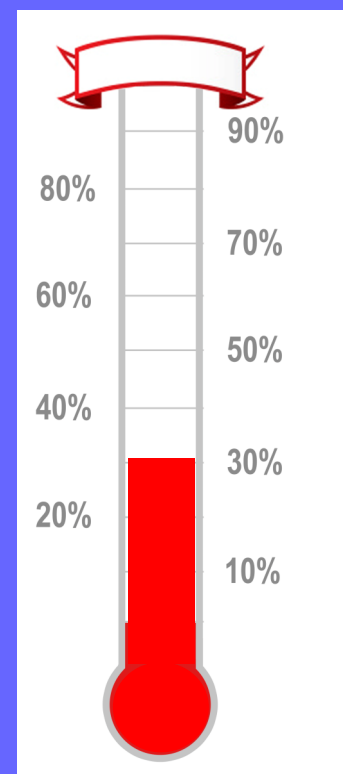
Fundraising

Help us meeting our \$20,000 goal! Right now after our #GivingTuesday fundraiser we are about 31% of the way there. All proceeds go to creating new educational re-sources tools and our 2018 conference.

Give the gift of hope this holiday season and change your profile picture to one of our holiday banners.



Instructions can be found at [here](#).



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

We are excited to announce we have our first official sponsors for our conference:

Recordati Rare Disease and Vitaflo, USA.

We currently have 35 registrants, representing 14 families!

We anticipate about 100 attendees!

Do you plan on attending? Add yourself to the count and [register today](#)

We'd like to welcome:



Raenette Franco of Compassion Works Medical, LLC.

Part of our mission as HCU Network America is to increase access for treatments and supplements for Homocystinuria patients. In order to fulfill this part of our mission, we have been in contact with Raenette Franco of Compassion Works Medical, LLC to help us fulfill this part of our goals.

A native New Yorker, Raenette Franco came to New Jersey in 2001 and landed a career as Medical Biller Insurance Specialist/Consultant. Her background consists of hospice and palliative care, bariatric surgery, and other medical specialties geared around insurance coverage. Raenette landed a job within the medical food arena in 2011 as a medical food insurance specialist that captured her heart. Inspired by helping others, Raenette expanded her career as founder of Compassion Works Medical. Raenette received her Certification as a Certified Biller Coder Specialist (CBCS), from the NCCA Accreditation, NJ. Her big heart and deep passion is dedicated to helping patients, dietitians, and physicians avoid the difficult tasks of insurance coverage and reimbursement issues for medical foods/enteral nutrition. Raenette's specialty is working directly with Medical Food coverage for both formula and low protein foods.

Mission

Compassion Works Medical has a special mission to change the lives of the rare genetic disease community by supporting a genuine helping hand with insurance coverage challenges. Over the past years at Compassion Works Medical, a blessing in disguise had come across my path – I have expanded my support to all kinds of special diseases that require medical foods and enteral nutrition, including cancer, ALS, TBI, etc. It is truly rewarding and my inspiration grows stronger and stronger to help those people find a way to afford and stay on diet.

"We don't take NO for an answer along with compassion that makes all of us successful!"

How to get in touch with Raenette

Email: raenettef@compassionworksmrs.com

Phone: (973) 832-4736

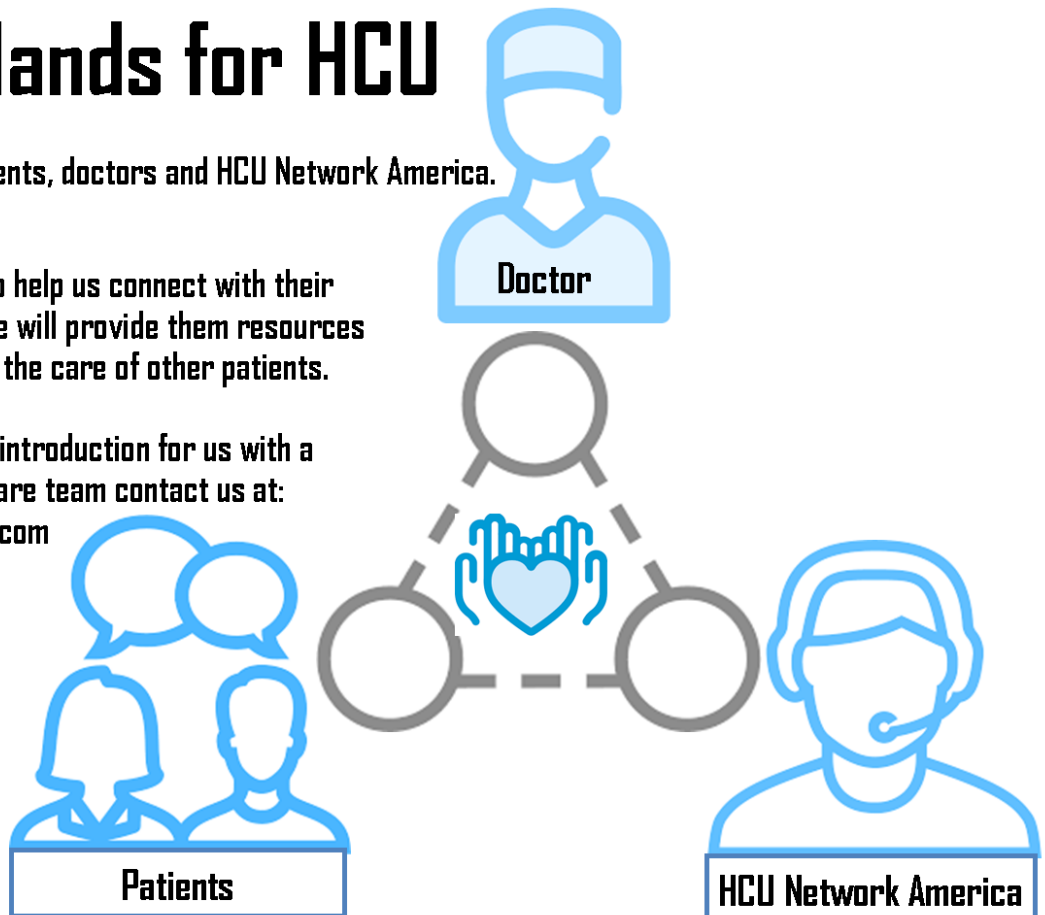
Ways to Get Involved

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



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: Pam P. from Nevada

HCU and You: *Connecting the Dots*: Ben Goodlet