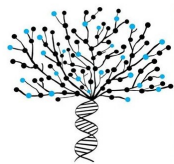


HCU Herald

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.**

**“Take the Lead” and be the first one to check out our agenda for
our 2018 conference!**



Heroes of HCU



Meet Colbie (7 years, 8 months) and Cayle (5 years 9 months) – brother and sister who both have HCU.

In June of 2012 shortly after Colbie's 3rd birthday she suffered a massive blot clot on her brain. She was flown from Montana to Seattle Children's Hospital to get treatment for the blood clot. The doctors were confounded as to what may have caused the blood clot and small strokes. After a week's stay and many tests they still didn't have an idea. They had chalked up the cause as chance or a freak incident. They allowed us to return home with follow up appointments scheduled 6 weeks out.

It wasn't until a month later, July 2012, when we were on the follow up visit that the doctors tested her blood for homocystine. Her levels were abnormally high and it alerted the doctors to what the cause of the blood clot may have been - her levels were so high that Colbie's blood had become toxic and prone to clot. The next day we got to sit down as a family and learn about Homocystinuria or HCU – a metabolic disorder so rare that we had never heard of it. We had an hour crash course on the metabolic disorder - we learned that our daughter didn't develop this disorder but was born with, natural protein in food is essentially poison to our daughter, and that she would have to go the rest of her life on a high amount of medication, lab formulated protein, and a strict vegan diet. It was a lot to absorb, Colbie's world was turned upside down – she had practically lived on dairy products up until then.

During our hour long crash course on HCU we also learned that HCU was hereditary and we should have our son tested for the disorder as well. Following the doctor's recommendations - we had Cayle, Colbie's younger brother Cayle for HCU – it came back positive. We took the diagnosis of our son pretty hard – such a rare disorder and we have two kids with HCU. The following weeks were filled with the thoughts and stresses of how the kids' lives would be affected since our society and social events in America are based so strongly around food. We blamed ourselves for not having a second heel prick test done on our kids (the state of Montana doesn't require a second state like some states do).

It is the simple things in life that people who don't live with HCU take for granted that remain at the forefront of our thoughts every day. If one of the kids' friends has a birthday party - we must supply a specially made treat. If the neighborhood ice cream truck comes through we must explain that they cannot have a treat from the truck but that they can have a different treat. If we attend a movie at the theater we must smuggle in diet friendly snacks. The overwhelming stress and anxiety of the holidays can only be understood by a small amount of the population.

Today with the help of their daily medication, lab formulated proteins, and very strict diets the kids are getting along well. Other than the clot/stroke that Colbie suffered we have not experienced any other of the side effects from this metabolic disorder.

HCU and You: Recipes from the Kitchen

Banana Bread by Bridgett Zaidi

Makes 13 slices—

12.7 mg Met. Per slice or 0.7 g protein per slice

Total Methionine = 165

Total Protein 9.1 g per loaf



Ingredients:

3 Ripe Bananas (253 grams)

1/3 cup melted butter

1 egg worth egg replacer

1 cup sugar

1 tsp vanilla

1 tsp baking soda

Pinch salt

1/2 cup flour

1 cup wheat starch

Directions:

Preheat oven to 350 degrees.

Mash bananas and add melted butter.

Mix sugar, “egg” and vanilla

Add salt and baking soda

Add wheat starch

Mix until combined

Pour into buttered loaf pan and bake for 45 minutes or until knife comes out clean

Fried Eggplant with Marinara by Bridgett Zaidi

Ingredients:

1 eggplant, peeled and sliced, about 1/2 inch thick

1/2 cup mocha mix

1 1/2 teaspoons of egg replacer powder

1/2 cup wheat starch

Marinara sauce for dipping

Oil for frying

Directions:

Heat oil in frying pan on medium-high heat.

Mix the non-dairy creamer with the egg replacer powder.

Dip the eggplant slices in the wet mix.

Then dip the wet eggplant into the wheat starch

Fry coated eggplant in skillet (this will not brown!)

It's done when the coating is crispy and hard to the touch

Top with Marinara



Protein per recipe—5.4 grams protein

Total protein doesn't include marinara sauce.

Do you have a recipe you'd like to share with the community? Please send it to: HCUNetworkamerica@gmail.com

In Case You Missed it!

**Congratulations to Margie McGlynn,
HCU Network America's President!**



Press Release

For Immediate Release

Contact:
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PM360 ANNOUNCES 2017 TRAILBLAZER AWARD FINALISTS

Top Companies, Marketers and Initiatives to be Honored on September 14th

NEW YORK, NY, August, 23, 2017--The finalists are in for the ninth-annual *PM360* Trailblazer Awards. *PM360*, a leading health-marketing industry trade magazine, will honor the pharmaceutical and medical device industries' most influential innovators. Established in 2009, the Trailblazer Awards are given to outstanding companies, marketers, marketing teams, brand managers, and initiatives representing the best the industry has to offer.

"The stature and size of our Trailblazer Awards continues to grow each year," says Anna Stashower, CEO and Publisher of *PM360*. "And we couldn't be more delighted! Not only did we receive more overall entries than ever before, but companies, in larger numbers than we have ever seen, entered this year's awards also. So as the competition becomes tougher and tighter, we can't thank our judges enough for choosing the most deserving entries as finalists."

The award finalists are selected by the *PM360* Editorial Advisory Board, which is comprised of some of the most forward-thinking leaders in their respective fields.

To reach the finalist phase, companies must show achievement in various areas including innovation, talent development, and social responsibility. Meanwhile, Brand Champions and Marketers of the Year are judged on their leadership, skill, dedication, impact, and effectiveness of their work. The Marketing Teams are assessed by the quality of their work together and the results they were able to deliver. And the Initiative entries are evaluated on their ability to overcome challenges; the skill, innovation, and quality of planning and execution; and the effectiveness of the work.

Finalists are acknowledged and winners will be honored during a special reception at Gotham Hall at 1356 Broadway in New York City on Thursday, September 14, 2017. Each year, the

Trailblazer Awards Gala attracts more attendees from the pharmaceutical industry than any other industry event. Profiles of all of the night's winners will appear in *PM360*'s October issue.

Emmy Award-winning actress and comedian Judy Gold will serve as the emcee for the event. Judy Gold has written and starred in two critically acclaimed, long-running Off-Broadway hit shows: *The Judy Show – My Life As A Sitcom*, (*New York Times* critic's pick) and *25 Questions for a Jewish Mother*, which won the 2007 GLAAD award for Outstanding New York Theater. Judy has also appeared as a guest star on several popular TV shows including "Louie," "30 Rock," "2 Broke Girls," "The Big C" and "Sex & The City."

Additionally, *PM360* is honored to announce that Margaret G. McGlynn, former President, Merck Vaccines, and currently Board Director at Vertex Pharmaceuticals, Amicus Therapeutics, Orphan Technologies and Air Products; and President, HCU Network America, will be the recipient of the prestigious Trailblazer Lifetime Achievement Award.

Tickets for the Trailblazer Awards Gala can be purchased by visiting www.pm360online.com/trailblazerawards2017/tickets. For more information about tickets, contact Kayla Walsh at 646-300-8117 or kayla.walsh@pm360online.com.

You can also follow the awards real-time on Twitter at www.twitter.com/pm360online.

About *PM360*

PM360 is the premier, must-read magazine for marketing decision makers in the pharmaceutical, biotech, and medical device industries. Published monthly, *PM360* is the only journal that focuses on delivering the full spectrum of practical information necessary for product managers and pharmaceutical marketing professionals to succeed in the complex and highly regulated healthcare environment.

The journal's targeted and insightful editorial focuses on issues that directly impact critical decision making, including: Planning and implementation of cutting edge strategies, trends, the latest technological advances, branding/marketing, advertising/promotion, patient/professional education, sales, market research, PR, and leadership. Additionally, the "360" in the title signifies the span of this critical, how-to info with personal and career insights for an enjoyable and thought-provoking read.

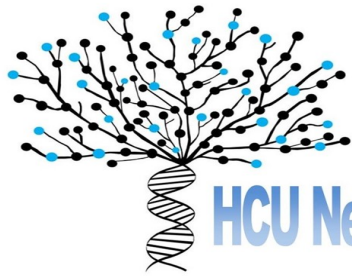
By providing the full circle of enriching content, *PM360* is truly an indispensable tool for busy and productive marketing professionals to stay at the top of their game.

To read the full press release, please visit:

<https://www.pm360online.com/pm360-announces-2017-trailblazer-award-finalists/>

Upcoming Events

Register today for our community call.
Get the inside scoop on all the exciting things that we have planned!
[Click here to register](#)



HCU Network America

Community Call



Find out what we have been up to and what we have planned!

Come join our call:

Tuesday, Sept. 19th, 2017
at 7pm Eastern

Register at: hcunetworkamerica.org/community-calls

GO BLUE FOR HCU

October is HCU Awareness Month

HCU Network America — Hcunetworkamerica.org — Hcunetworkamerica@gmail.com

Individual donations up to a total of \$20,000
made between October - December 31
will be matched by our anonymous donor!

Start planning your Homocystinuria Fundraiser now!
Have a fundraiser planned? Email us & we will help spread the word.

Need an idea? [Click here](#)
Need help? [Email us](#) - we will guide you through the process.

Are you an adult metabolic patient looking to network & socialize with other adult metabolic patients?

Are you always in search of quick and easy meals?

Well, we have the event for you!

Registration is required,
so don't hesitate head on over
and sign up today!

[Click here to register](#)

Cooking with Cambrooke: Quick and Easy Meals **An 18 and over event**

Sunday, October 1st, 2017, 1:00p.m.
Cambrooke Headquarters

Come meet other adults with metabolic disorders
(Homocystinuria, Galactosemia, MSUD, PKU, UCD and Others)
Significant others are welcome to attend
Tour the facility
Hands on Cooking Class
Learn more about homocystinuria and other metabolic disorders

Registration is Free!

Sign Up at: <http://hcnetworkamerica.org/cooking-with-cambrooke>
Or email: Cassandra.papaleo@childrens.harvard.edu

Co-hosted by Susan Waisbren of Boston Children's Hospital
Along with Cambrooke Foods, and HCU Network America



Taking the Lead for HCU

Save the Date ~ April 21 & 22, 2018

The first HCU Network America Conference

Westford, Massachusetts

Details to follow this fall at HCUNetworkAmerica.org

Taking the Lead for HCU



Friday Evening: Dinner Meet Up

There will be an informal dinner meet up for those who would like to attend and socialize at Clark's Pub at Westford Regency.

<u>Saturday</u>	<u>Topic and Speaker</u>
8:00-9:00 a.m.	Registration, Breakfast & Networking
9:00-9:30 a.m.	Introductions & Meeting Expectations
9:30-10:40 a.m.	CBS Guidelines Presented by Dr. Kimberly Chapman M.D., Ph.D., FAAP, FABIM, Children's National
10:40-10:50 a.m.	Intermission
10:50-12:00 a.m.	Dietary Best Practices Presented by—Krista Viau, PhD, RDN, CSP Boston Children's
12:00-1:30 p.m.	Lunch
1:30-3:15 p.m.	Transitioning to Adulthood Panel Presented by Next Steps Organization
3:15-3:30 p.m.	Intermission
3:30-4:30 p.m.	HCU and the Brain Presented by Ben Goodlett, PhD Boston Children's
5:00-8:00 p.m.	Cambrooke Tour and Reception





<u>Sunday</u>	<u>Topic and Speaker</u>
8:00-9:00 a.m.	Breakfast & Networking
9:00-9:15 a.m.	Vendor Acknowledgment
9:15-10:15 a.m.	Research Map & Strategy Presented by Margie McGlynn, President, HCU Network America
10:15-10:30 a.m.	Intermission
10:30-11:30 a.m.	Natural History Study Presented by Dr. Harvey Levy, MD Boston Children's
11:30-12:30 p.m.	Enzyme Replacement Therapy Presented by— Marcia Sellos-Moura, PhD Orphan Technologies
12:30-1:45 p.m.	Patient Panel: Keys to Success & Lunch
1:45-2:30 p.m.	Moving Forward: Input from the community Led by: Danae' Bartke Executive Director & Kristin Rapp, Vice President



The race does not always go to the swift, but to those who keep running—Anonymous

Fundraisers

❄️ Thirty-One Gifts Fundraiser ❄️ Supporting HCU Network America



Shop online October 1—October 15

All orders will directly support
HCU Network America.

Wherever you go, go in style. Pack up
for holiday travel and save over 60%
on one of three totes with every \$35
spent.

Shopping runs from
October 1 – October 15

If you want to support
HCU Network America
and shop for a cause

Email Danae' Bartke
for the direct ordering link
Danaeaustin@gmail.com

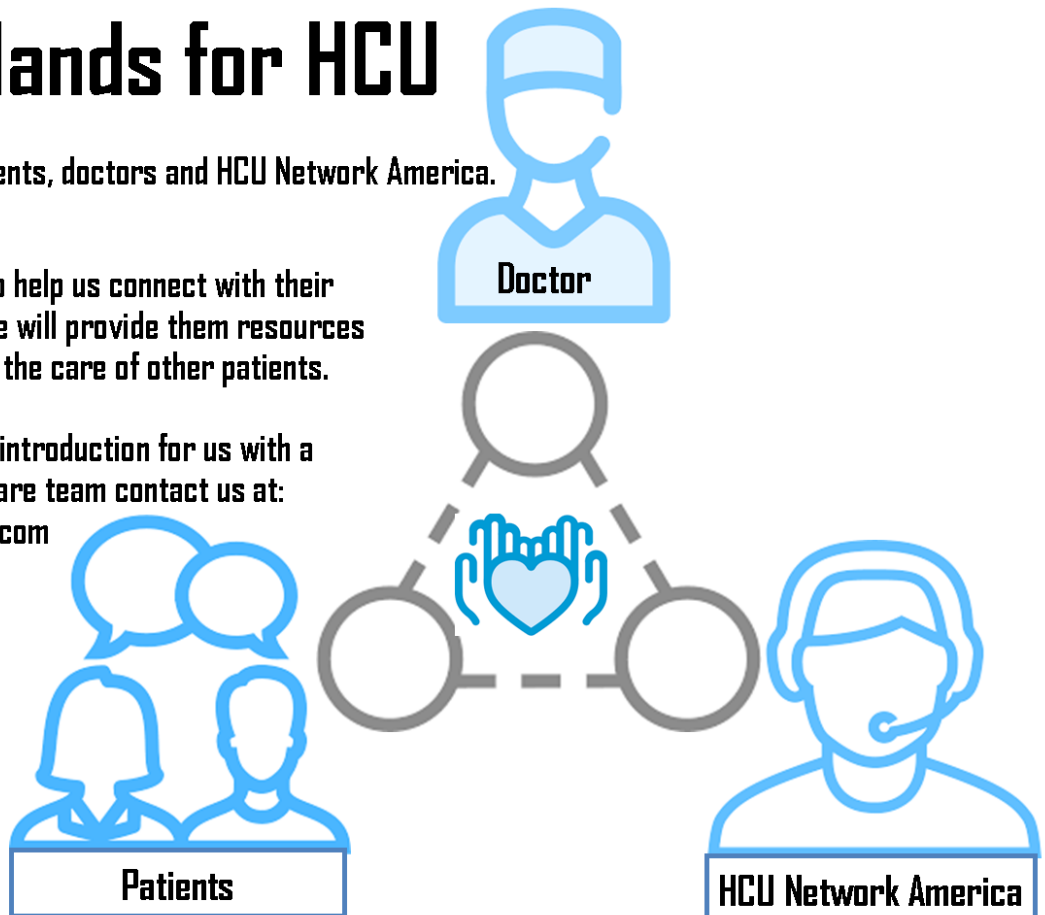
Ways to Get Involved

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



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

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HCU and You: *Recipes from the Kitchen*: Bridgett Zaidi

Fundraiser: Danae' Bartke