

The HCU *Herald*



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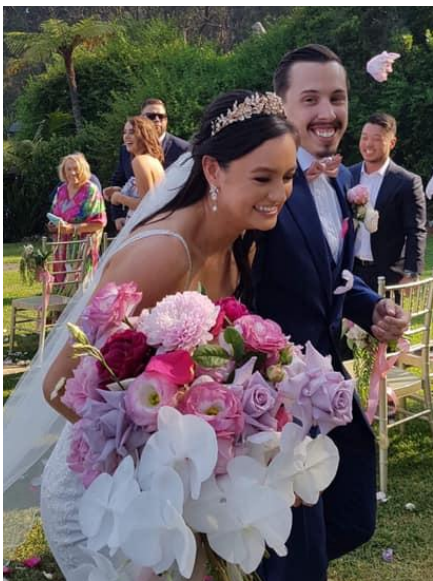
HCU HERO: JAKE FROM MELBOURNE, AUSTRALIA

My son, Jake, was born in 1991 and within 8 weeks he was so sick they put him in hospital. We found out his hemoglobin was 6 instead of 12; then the journey of testing started. Finally diagnosed at 3 months of age with Cobalamin E Disorder, I was told he was only one of five in the world, all of whom were in a vegetative state. He would never walk, talk, feed or toilet himself. We were put on the cycle of 3x per week of B12 injections (this baby was skin and bone) and daily pills and powders. I tried so hard to contact people. I joined many online groups. I was put in touch with two siblings who were severely affected, but they never responded. I'm in Australia and there were no other Cobalamin E patients here. His skin sample was sent to Canada, and they wrote of him in journals and used his case in university exams.



Jake looked at me one day in those first few months and I could see the recognition and intelligence. I knew he was going to be better than they said. He was slow to pass his milestones, but he did. We had almost full-time therapies for his first four years and by the time he started school he was walking, toilet trained and saying a few words. Jake struggled at school, mainly as he was very immature, but he still learned to read and write and gradually spoke more. He had a teacher's aide most days, and this helped with his focus. Jake repeated a grade, but he was almost normal from the outside. The doctors were amazed! I still could not find any other families.

When he was 13 they diagnosed him with autism. We did not know if it was related to the deficiency or separate. This explained most of his behaviors. He matured quickly all of a sudden and although he still required help, he finished year 10. He loved music and played guitar, self-taught as he didn't want to go to lessons.



My son was an almost normal teenager and grappled with the medication he needed. He learned to do it himself eventually. He went to TAFE (Technical and Further Education – Australia's largest vocational education and training provider) and studied fitness right up to diploma with minimal help. He is now in his final year of a degree in body science. He married a nurse in November. I'd say the only thing you'd notice about him is his behavior with his mild Autism/Asperger's. He's a bit particular about things sometimes. He has no symptoms of the deficiency except tingling of fingers and toes sometimes. He's a miracle!

Dear Methia,

How in the world do you balance pre-diabetes and HCU?

I just had my annual follow-up with my genetics team. In addition to my homocysteine and plasma amino acid levels, they also checked a few other routine labs. One of those labs included a glucose level, which was 104 mg/dL. I hadn't eaten anything yet that day, so a normal level would be under 100 mg/dL. Since this level is a little high, my geneticist said it's possible that I have something called "insulin resistance," which might mean prediabetes. She said the fact that I have gained 20 pounds in the past year, and am now a little overweight, makes her even more suspicious. They are going to check more labs, but I'm really nervous about this! Even though my wife and kids are really supportive of all of my dietary needs, my diet is already so hard. Does this mean I can't have sugar anymore either? That's all I eat!

Sincerely,
Carb King

Dear Carb King,

Kudos to you for being on top of your routine follow-up and taking care of yourself. Unfortunately, diabetes is much more common than you might think, with about 10% of the U.S. population carrying this diagnosis. This doesn't include the thousands of people diagnosed with prediabetes, or people who do not receive routine medical care and remain undiagnosed! Although further research must be done, there also may be a genetic predisposition to developing diabetes if you have an inborn error of metabolism.

Simply, if you have prediabetes, the cells in your body don't respond normally to insulin. This causes your blood sugar to rise, but technically not high enough to meet criteria for type 2 diabetes. It does, however, place you at higher risk for developing type 2 diabetes down the road. If you have in depth questions about what diabetes is, and what the possible complications are, it's important to speak with your doctor. The good thing, though, is that some diet and lifestyle changes can decrease your risk – and no, you don't have to ditch carbohydrates (in fact, you really shouldn't)! Here are some tips:

1. **If you need to, lose weight.** Weight loss, if you are overweight, can lower your risk for developing type 2 diabetes. However, fad diets and rapid weight loss can result in catabolism for patients with homocystinuria. Weight loss of a half a pound to two pounds per week, depending on your gender and current weight, is typically recommended. This could be as simple as substituting that Coca Cola for water at lunch every day!
2. **Increase your physical activity.** Exercise can increase your body's sensitivity to insulin and lower your blood sugar. As with everything else, exercise in moderation is recommended, with 150 minutes (two and a half hours) of activity per week being a realistic goal. This can include swimming, brisk walking/jogging, or cycling if you are looking for independent activities in the COVID-19 pandemic. Many gyms and facilities are also offering outdoor, socially distanced fitness classes right now, too (drink plenty of water!).
3. **Increase your intake of complex carbohydrates.** To optimize blood glucose control, most dietitians would NEVER tell you to stop eating all carbs! Rather, they would encourage you to choose your carbs wisely. Decrease your intake of "concentrated sweets," which includes cookies, cakes, and candy, and opt for a piece of fruit instead. Fruit contains sugar, but is also full of vitamins, minerals, and fiber – which is a key for controlling blood glucose levels and slowing the rate at which it rises. Also, re-think your morning juice or sugary soda with lunch or dinner, which always results in a rapid glucose spike. Whole grains tend to be higher in protein than refined (white) grains, but if you can fit them in your HCU diet, they are also higher in fiber and a better choice.

Your dietitian at your metabolic clinic has, more than likely, helped at least one metabolic patient to navigate the complexities of a (pre) diabetes diagnosis. They are your best resource if you need help achieving a healthy weight and improving the quality of your diet. They can also connect you with other patients. Remember, you have a support system, and within that support system there is almost always a solution!

Sincerely,
Methia

Looking for more information on this topic? Read: *Metabolic Pathways at the crossroad of diabetes and inborn errors*:
<https://pubmed.ncbi.nlm.nih.gov/28952033/>

RECIPE SNEAK PEEKS WITH COOK FOR LOVE

This month we are switching things up a little bit, and with permission, we are borrowing a couple of low protein recipes from the wonderful PKU Chef Brenda Winarski! These will not be added to our website. These are great recipes for school or for work!

Super Soft Flatbread Wrap

Makes 10 servings

Ingredients:

Starter

- 1/4 c (30g) Flour, Yes, regular all-purpose flour
- 1 tsp (4g) Active Dry Yeast
- 1/4 c (60g) Water

Dry Ingredients

- 1 3/4 c (230g) Wheat Starch
- 2/3 c (80g) Tapioca starch
- 2 TBSP (24g) Metamucil Coarse Milled Original
- 2 1/4 tsp (7g) Xanthan Gum
- 1 1/2 tsp (9g) Salt

Wet Ingredients

- 1/3 c (50g) Boiled Potato, put through ricer
- 1 c (240g) Water, from boiled potato
- 2 TBSP (28g) Butter, melted
- 1 TBSP (21g) Honey



Nutritional Information

- Serving size: 1 flatbread
- Protein per serving: 0.6 g
- Calories per serving: 146

Find the directions at: <https://cookforlove.org/recipes/detail/88891>



This wrap has more substance than a tortilla -- more Gordita, pita like. It is super soft and crazy steady. Best of all it freezes beautifully and is still pliable when it defrosts. It is a great one to bring in your bag stored in a Ziplock placed in a folder (thanks Sarah Foster for this tip) when you are getting a salad to make it more substantial. Minor modifications and it is delicious naan bread!

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Buffalo Pinwheels

Makes 1 servings

Ingredients:

Buffalo Cauliflower

- 3/4 c (81g) Raw Cauliflower, broken into small pieces
- 1 tsp (5g) Olive Oil
- 1 tsp (5g) Brown Sugar
- 2 tsp (10g) Frank's Hot Sauce

- 2 TBSP (30g) Violife Just Like Cream Cheese Original
- 1 TBSP (15g) Daiya Ranch Dressing, or Blue Cheese
- 2 tsp (7g) Red Onions, minced
- 2 tsp (4g) Raw Celery, minced
- 2 TBSP (16g) Raw Carrots, shredded
- 1/4 c (15g) Iceberg Lettuce

- 1 flatbread Super Soft Flatbread Wrap (ingredients above)



Nutritional Information

- Serving size: 8 pinwheels
- Protein per serving: 2.9 g
- Calories per serving: 372

Find the directions at: <https://cookforlove.org/recipes/detail/88893>



We all get in a lunch rut. Pinwheels are the way out! You can make them the night before and then slice and place in your lunch box. There are loads of different fillings -- and leftovers are our favorite -- but buffalo cauliflower is our go to! (I will often make extra roasted cauliflower at dinner and set it aside for the wrap).

Want more wrap, pinwheel and sandwich ideas- head to the end of our newsletter!

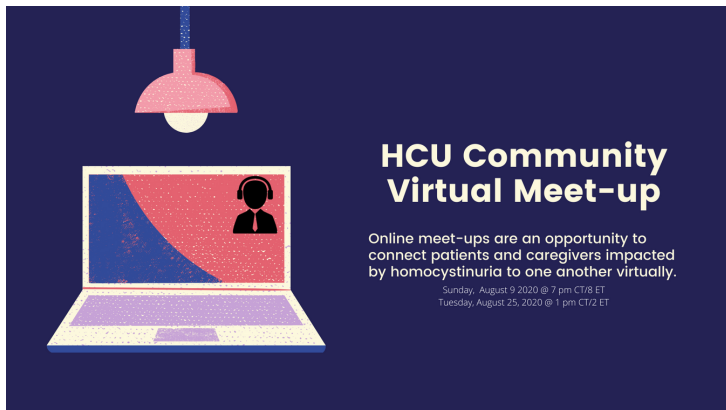
EVENTS

Come check out our Virtual Homocystinuria Meet-ups!

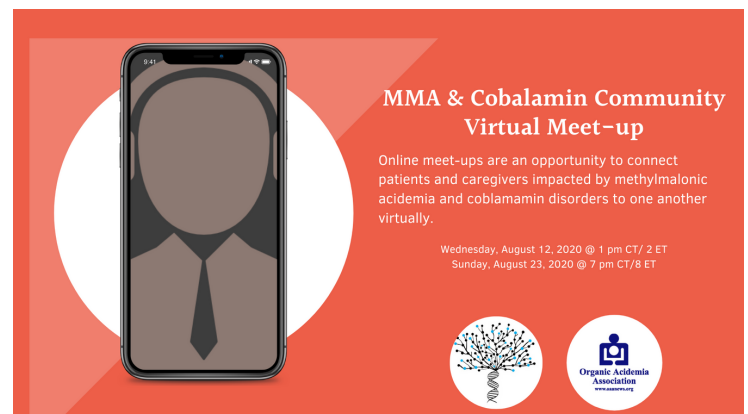
Join our virtual meet-up for a chance to meet, connect, and learn from other patients and caregivers who are facing similar challenges. Whether it's navigating adherence issues, insurance, clinic visit, or life transitions, you are not alone.

Register now at: <https://www.eventbrite.com/o/hcu-network-america-30163980100>

For Classical Homocystinuria



For MMA+HCU patients and caregivers - CblE and CblG families welcome (different than Classical HCU)



For Kids with Classical HCU ages 7 and up: TBD



Special Feature: [Click here to register](#)

College Planning Young Adult Virtual Meet Up

JOIN FELLOW YOUNG ADULTS (18-35) IMPACTED

BY RARE OR CHRONIC CONDITIONS

AUGUST 13, 2020 5PM EST



**OUR
ODYSSEY**

SPECIAL EVENTS

College Planning Young Adult Virtual Meet Up

JOIN FELLOW YOUNG ADULTS (18-35) IMPACTED
BY RARE OR CHRONIC CONDITIONS
AUGUST 13, 2020 5PM EST



**OUR
ODYSSEY**

Join Our Odyssey for their second topic-specific meet-up discussing college planning as a young adult living with a rare or chronic condition. [Click here to register](#)

Host: Danae Bartke
Executive Director
HCU Network America
Adult with Homocystinuria

Host: Sarah Chamberlin
Executive Director, PKU News
Parent of child with PKU

Benjamin Goodlett, PhD
Clinical Psychologist
Cognitive and Social aspects in Education

Pamela Kowalczyk
Special Education Teacher
Adult with PKU
Mother of child with PKU
504 and IEP Accommodations

Jennifer Beazer, RDN, LN
Metabolic Dietitian
How Much Phe
Diet Management in School

Lynn Paoletta
Mom of 2 adults with PKU
Founder of Cambrooke Foods
School Lunch Program

Brenda Winlarski
Mom of college student with PKU
Founder of Cook for Love
Brown Baggin it, Low Pro Lunches

BACK TO SCHOOL
Low Protein Community Virtual Chat
August 19, 2020
7 pm CT

HCU Network America
PKU News
HOW MUCH PHE?

Starting school can create a lot of anxiety, not just for students, but also for parents of children who require a low protein diet. We may ask ourselves "how will they get their formula in?", "how will we manage the low protein diet?", "My child has learning issues related to their disorder, how will the school manage?", "Is it even safe for my child to attend school with COVID?"

"Relax, you are not alone – HCU Network America and PKU News would like to invite you to a Back to School: Low Protein Community Chat lead by a panel of experts! Click here to register: https://zoom.us/webinar/register/WN_fNf3ypE1R-K-vmO9fozbFQ

COME FUNDRAISE AND RAISE AWARENESS WITH US!



GO THE EXTRA MILE FOR HCU

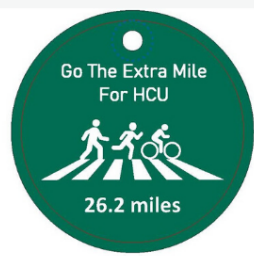
VIRTUAL RACE BENEFITING HCU NETWORK AMERICA

WALK, RUN, RIDE | SEPTEMBER 2020

Per individual: \$25

Per Family (up to 4): \$40

Register at: <https://runsignup.com/Race/IL/Batavia/GoTheExtraMileforHCU>



FRONT



BACK



GO THE EXTRA MILE FOR HCU
WALK, RUN, RIDE | MAY 1 - 31, 2020

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info@hcunetworkamerica.org | <https://hcunetworkamerica.org> | 630-360-2087

COME FUNDRAISE AND RAISE AWARENESS WITH US!



GO THE EXTRA MILE FOR HCU

VIRTUAL RACE BENEFITING HCU NETWORK AMERICA

WALK, RUN, RIDE | SEPTEMBER 2020

What is a virtual race?

A virtual race is a race that can be walked, ran, or biked from any location you choose. You can participate on the road, on the trail, on the treadmill (or stationary bike), at the gym or on the track (or even at another race). You get to run your own race, at your own pace, and time it yourself. You do not have to complete the miles all at once, in one day, or even a week. You can use the entire month to complete the race.

How do my miles translate to money raised?

After a racer is registered, they are set up with their own personal donation page. You can direct those who would like to donate to your race link.

How do you know how many miles I completed?

- We rely on the honor system. You don't have to use a device to prove your miles.
- If you'd prefer to use an app to track your miles, we recommend Strava. You can join the HCU Network America Club.
- Please use intentional miles – this means no step counting
- Please log all your miles by 11:59 pm EST September, 30, 2020.

Learn more or register at <https://runsignup.com/Race/IL/Batavia/GoTheExtraMileforHCU>



info@hcunetworkamerica.org | <https://hcunetworkamerica.org> | 630-360-2087

CELEBRATE YOUR BIRTHDAY WITH A FACEBOOK FUNDRAISER!

Did you know that July through September have the overall highest birthrates with August or September typically having the highest number of births?



BIRTHDAYS

AUGUST BIRTHDAY?

Create a
BIRTHDAY FUNDRAISER
to help homocystinuria patients



Create your own birthday fundraiser to raise money for HCU Network America. Go to
<https://www.facebook.com/fund/HCUNetworkAmerica/>

Penny Wars

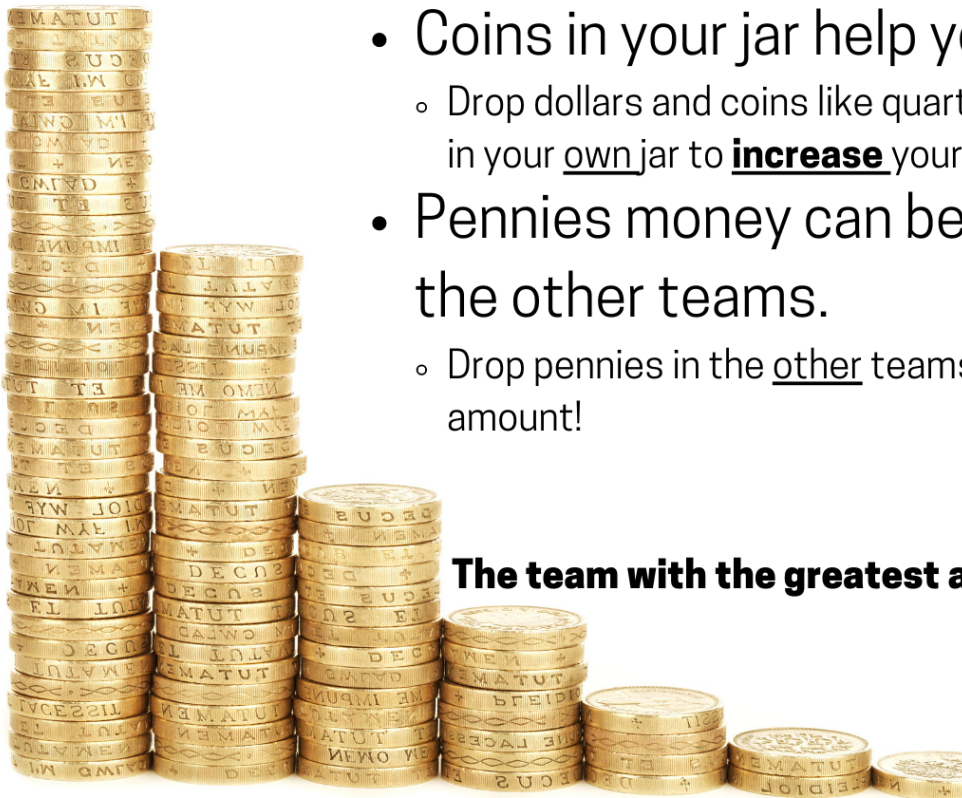


1. Decide dates for your school wide Change War (work with school administration in advance)
2. Create flyer with dates and rules, distribute to students and teachers
3. Distribute containers to classrooms (or in a common area if you are going to do one per grade).
4. Encourage kids with announcements or charts
5. Count the donations and reward the winning class.

Change Wars Rules

- Coins in your jar help your team win!
 - Drop dollars and coins like quarters, dimes, and nickels in your own jar to **increase** your total amount
- Pennies money can be used against the other teams.
 - Drop pennies in the other teams jars to **decrease** their amount!

The team with the greatest amount of money wins!



NAVIGATING YOUR CAREER WITH HCU

Teacher, Lawyer, Veterinarian, Accountant – How do you decide what you want to be? Choosing a career is difficult; there are so many things to take into consideration: what are my interests, how many years at a college and or university will it be, how much will it cost, will I be able to find a job after I graduate? These are just a few complications young adults and adults face when trying to decide on a career path, but when they are faced with a rare disease, such as Homocystinuria, narrowing down the field can be a bit more complicated. While navigating your career with Homocystinuria may seem complicated, it's not impossible – let's get you started.

Part 1: Choosing a career path

Step 1) Evaluate your skills, abilities, and interest

This may seem like a no brainer to most; however these things don't always add up to things you want to do every day for long periods of time. The saying "Do something you love and you'll never work a day in your life" is far from true. Even doing the things you love takes a lot of time, commitment, and effort and over time those wear on you and can create burn out. While a career doesn't have to be forever, it's important you can see yourself doing it for a long period of time at a pace that is realistic.

If you find an area you think you'd like to focus on, find a mentor in the field of interest. Having a mentor gives you someone to talk to about your interest. They can provide guidance, emotional support, help set goals, develop contacts and identify resources. Mentors can help you hone your area of interest in a more real world way.

If you don't have an area of focus, we highly suggest volunteering. There is a wide array of volunteer opportunities available for young adults and adults. Do you think you'd be interested in construction, architecture or engineering? Volunteer for organizations such as Habitat for Humanity. Interested in Education? Volunteer in school after school programs or volunteer during the day at a school. There are a wide variety of volunteer programs available. Volunteering helps you define what you want to do (and don't want to do), as well as, build important skills that are beneficial to the workforce. Additionally, volunteering is looked upon in a positive manner when building a resume.

Step 2) Know yourself

"To thine own self be true" – Hamlet.

We all need to hear this once in a while, but especially when we are picking a career and are navigating a rare disease and the obstacles it can throw at us. The first part of this is to know your strengths and limitations. With having a rare disease, it's easy to get stuck and fixate on the things that may be setbacks or obstacles; "I can't see well, my levels cause me to be anxious and depressed". While it's good

to be realistic, also focus on your strengths ; “I am more compassionate because I understand what it’s like to struggle”, “I have a plethora of nutrition information because of the low protein diet”. If you are struggling with finding your strengths or weaknesses, ask your closest friends/family and don’t be afraid to consult professionals or professional resources on how they view them. Also ask them what they see you doing long term.

Step 3) Engage in trial and error

“There is no better (teacher) than adversity. Every defeat, every heartbreak, every loss, contains its own seed, its own lesson on how to improve your performance next time.” – Malcom X

As rare disease patients, we have likely encountered some form of trauma. Use it as a teacher. Trauma teaches us about what we want from others, from life, and from ourselves. Using trauma as a teacher allows us to learn, adapt and change so we don’t land back in the same circumstances we once were in. The process of trial and error is not easy and will take time and energy – be patient with yourself. Part of learning from trial and error though, is practicing self-acceptance and knowing when you have reached your limit.

“To be of service, you need to be fit for service. You can’t be fit for service if you aren’t tending to your needs. You can’t tend to your needs if you don’t know what they are.”– Francie Fitzgerald

If Homocystinuria seems to be the setback, ask for realistic accommodations. As you engage in trial and error, remember to frequently pause and reevaluate what you think you want in a job.

Part 2: Navigating your Career with Homocystinuria

1. Disclosing Homocystinuria

- a. If you are using a career recruiter to find a job, let them know you have Homocystinuria and what accommodations at your job you might need.
- b. Do not bring Homocystinuria up in your interview.
 - i. A potential employer may not ask you medical questions or ask you to have a medical exam before extending a job offer. They cannot ask if you have a disability.
- c. When you get the job, make an appointment with Human Resources to discuss your needs.
 - i. Extra time for doctor appointments/lab work

2. Put your health first

- a. Know what is expected of you
- b. Set goals and boundaries
- c. Meal plan and prep so you can stay on diet at work
- d. Find a space you feel comfortable taking your formula while at work (it will help provide you the energy and focus you need to get through your day).

Additional Resources:

- U.S. Equal Employment Opportunity Commission:
 - <https://www.eeoc.gov/disability-discrimination>
- Information and Technical Assistance on the Americans with Disabilities Act:
 - <https://www.ada.gov/employment.htm>
- U.S Department of Labor: Wage and Hour Division: Family Medical Leave Act
 - <https://www.dol.gov/agencies/whd/fmla>

NAVIGATING YOUR CAREER WITH HCU

A Personal Experience Story

by Danae' Bartke

Ever since I was a little girl I dreamed of being a teacher. I'd line up my dolls and stuffed animals and reteach them what I had been learning in preschool and school. My great-grandma, grandma, my mom, and my aunt were all teachers, so to me it always seemed like a no brainer – I was going to be a teacher.

Although it wasn't necessary, when I attended our local community college, I declared my major as Early Childhood Special Education. When it came time to transfer to a four-year university, I chose a school close to home (30 minutes away), so I could continue the job I had as a nanny. When I met with their admissions office, the advisor convinced me there were no jobs in Early Childhood Special Education, and I really should switch my major over to Elementary Education. So out of practicality I did. Throughout my college experience, I always worked full time as a nanny. For the majority of the time it was for the same family. I split my days up; Monday and Wednesday were my classes and then Tuesday, Thursday, Friday I worked 12-hour days. I had an additional job on the weekends getting groceries and cooking meals for the week for another family. I loved being busy with school and work, and I figured the experience as a nanny was a good choice for my resume.

I graduated college in December 2007 and decided I'd use that time to buckle down and start subbing and applying for teaching jobs for the following school year. The Spring came and went with no job offers and very few sub jobs. It was discouraging, but I was not about to give up. I thought I'd go a different route and started looking at daycare centers that offered preschool and kindergarten. In June 2008 I started working at a daycare center teaching preschool, it seemed like the perfect fit. I loved the enthusiasm and excitement the kids had for learning and loved watching them blossom in their academics and social skills. However, in September 2009, I had a blood clot due to Homocystinuria and the time in the hospital gave me time to think about my life. At the time of my blood clot, I was working splits, so I'd open and close and have an extended lunch. Long days made me exhausted and gave me little time to make sure I had time for healthy lunches that worked for HCU. It didn't allow me time to exercise, and because my regular prep time (their nap time) had been removed, I ended up planning at night. I knew I couldn't keep myself going at that pace and needed to take better care of myself and hopefully find a job too that had health insurance. So, I made the hard decision to quit my job and really pursue teaching, or subbing – something that would get me into the classroom.

This time around I was very busy with substitute teacher jobs. I was able to work full time and got to know many teachers and administrators in many schools. I learned a lot about teaching from subbing and used the time to hone my skills in the classroom. In 2010 I was offered a full-time job as a paraprofessional. It wasn't my dream job, but it got me in the door at a school and many of their para's eventually became teachers. With the encouragement of my aunt (who was a teacher), in 2011 I went

back to school while still working as a para to get an endorsement in English as a Second Language (ESL). In 2012 I completed my ESL endorsement and was offered a part time ESL position in the school I worked as a para. The other part of my day they kept me on as a para – I finally felt I was moving in the right direction. When the 2013-2014 year came to a close though, our district decided to restructure and move their ESL students to one school and my position was eliminated. They offered me a position as a full-time para, but I decided I needed to move on. Being a para I functioned in many ways as a teacher, but without the benefits – I had no planning time, no health benefits and the pay was alright at best.

At the same time that I started originally working as a substitute teacher, I started getting involved in the PKU Organization of Illinois (PKU IL). Initially it started at just attending their low protein cooking classes, then their social events, then their educational workshops (it was more than just information on PKU). In 2013 I joined the PKU IL board as their Newsletter Coordinator. I was in charge of coordinating with various people in the community to find patient stories, diet advice columns, low protein recipes, events, and more. Despite having never done anything like this, I was told it was easy and I'd do great. Well, the first PKU Press I sent to the printing company was laughable at best. The printer emailed me back asking – is this really what you want to print? They offered to “fix it”. All the content was there, but not in the format they were used to. Embarrassed for myself, I replied I'd be glad to accept the help, but was determined to do better next time. So, I quickly threw myself into learning how to format newsletters and doing better graphic design for event flyers. It turned out that I loved it. Growing up I had 10 years of private art lessons, and this gave me a great creative outlet. I continued in this role until the end of 2015.

In January 2016, I was elected the PKU IL President. I was determined to clean things up for the organization, both figuratively and literally. The first thing I did was clean up the storage unit they had – we pitched over 80 gallons worth of outdated material and garbage. We organized the remainder so we didn't end up rebuying things we already had for future events. I also went through and restructured how events were done. Initially, each event was running start to finish by 1 person – it didn't make sense since all 11 board members were volunteers. I was determined to have everyone pull their weight! I created a Chair, a list of positions and jobs for each event. I created the rule that everyone needed to participate in so many events, that way it wasn't so stressful for the chair person. As the president, I also functioned as the National PKU Alliance Rep for Illinois and organized our annual meeting. I officially rolled off the PKU IL board in December 2017 after my term was up.

In July 2014 I did something I told myself I'd never do, I went to work for my mom. My mom runs a violin shop that my dad started in 1981. My mom had always asked me to work in the shop, and I always said I never would. This time though, her offer sounded good, but I told myself it would be temporary until I figured out my next move. At her shop, I was initially hired as a secretary. Quickly I added book keeper, inventory manager, route coordinator and office manager to my titles. My love for organization was key in these roles, but even with my obsession of organization, it was not meant to be. Working in a family business presents a lot of its own issues ,and I will leave it at that.

While working in my mom's shop and running PKU IL, I started another adventure. In 2015, Margie McGlynn (now HCU Network America's President and co-founder) reached out to me about possibly starting a non-profit with her for the Homocystinuria community. I was apprehensive because my plate

was so full between my job and PKU IL, but I also knew that this was finally my opportunity to do something for the Homocystinuria community – something I very badly wanted to do. In February 2016 in Prague, Czech Republic, I attended the first Homocystinuria Patient-Expert Meeting hosted by HCU Network Australia and European Network and Registry for Homocystinurias and Methylation Defects (E-HOD). At the end of this meeting, they had a session on starting other HCU organizations since there were families from the US, UK, Brazil and other European countries. It was pretty much at that moment when I made the decision to be 100% in.

“People are always blaming their circumstances for what they are. I don’t believe in circumstances. The people who get on in this world are the people who get up and look for the circumstance they want, and if they can’t find them, make them”

– George Bernard Shaw

After coming back from Prague, Margie started the necessary paperwork to get HCU Network America established. At record speed, by June 2016 HCU Network America was incorporated. Then just as fast as HCU Network America was incorporated, in October 2016 HCU Network America received their 501c3 status from the IRS. The first few months were extremely exciting (it still is almost 4 years later). In March 2017, I was hired part time to continue building upon HCU Network America’s mission on a daily basis. This truly is my dream job, and I feel honored to have it.

If someone would have told 10-year-old me (the year I was diagnosed), or even 20-year-old me I would one day co-found a non-profit for HCU, and it would become my full-time job I would have laughed. If someone told me at 16 I would one day work for my mom, I also would have said no way on earth. The point being life takes you to unexpected places and your path to the place you settle down isn’t always a straight line. The steps outlined in the previous part of the article (evaluate your skills, interest and abilities, know yourself, engage in trial and error) were all part of my process to get where I am now. Was it easy? No way! Was it worth it? Definitely! With determination and creativity you can find a job that makes you feel fulfilled too.

Meet Patient Parent Advisory Committee Member – Ruth Kelly!



Ruth is a wife to Dan and mother to four children. They live in Cincinnati. Ruth & Dan's third child, Josie, has HCU. She was diagnosed while in kindergarten. While initially shocked, Ruth diligently read every medical article she could on HCU and listened to every available lecture. Ruth & Dan manage their daughter's diagnosis by tracking every gram of protein and her medication on a spreadsheet every day. Through the metabolic clinic in the genetics division of Cincinnati Children's Hospital, Ruth was referred to HCU Network America. By serving and supporting HCU Network America, Ruth hopes to help other parents navigate the many aspects of the diagnosis of their child. She also supports efforts for more accurate newborn screening. In addition, Ruth is an adoption attorney and advocates for foster children and adoption in general.



HCU NETWORK AMERICA

IS LOOKING FOR STATE AMBASSADORS

Looking for active and outgoing members of the HCU community

What does an ambassador do?

Ambassadors...

- *Connect with local HCU families*
- *Share their story*
- *Advocate and raise awareness for HCU*
- *Amplify and support our mission*
- *Help fund-raise*

Get involved today! Contact Danae'
dbartke@hcunetworkamerica.org

**BECOME A
STATE AMBASSADOR
FOR HCU NETWORK AMERICA**



PURSUE YOUR DREAMS THROUGH THE #RAREIS SCHOLARSHIP FUND



I want to be
a veterinarian

What's your dream?

#RAREis
Scholarship Fund
Powered by the EveryLife Foundation

MAKE IT HAPPEN

Living with a rare disease means managing unique challenges, including frequent doctor visits, rigorous treatment regimens and hospitalizations, and exposure risks. While quality and duration of life continues to improve thanks to improved diagnosis and treatment approaches, individuals living with rare diseases still face disparities in achieving traditional life milestones.

That's why The EveryLife Foundation for Rare Diseases established the #RAREis Scholarship Fund – to enrich the lives of adults living with rare diseases by providing support for their educational pursuits. Thanks to the support of Horizon Therapeutics RAREis, one-time awards of \$5,000 each will be granted to up to 32 recipients for the Spring 2021 semester.

Deadline for application is August 28th, 2020 at 3:00 p.m. CDT

Learn more and apply here: <https://everylifefoundation.org/rare-scholarship/>



RECORDATI RARE DISEASES

Focused on the Few™

At Recordati, we focus on the few - those affected by rare diseases. They are our top priority and at the core of everything we do. Our mission is to reduce the impact of extremely rare and devastating diseases by providing urgently needed therapies. We work side-by-side with rare disease communities to increase awareness, improve diagnosis and expand availability of treatments for people with rare diseases.

Recordati Rare Diseases is proud to support HCU Network America in their commitment to people living with HCU.



www.recordatirarediseases.com/us
@RecordatiRare
NP-RRD-US-0162

Other lunch ideas from Brenda!

If you follow Brenda, you know she loves kitchen gadgets! Brenda highly recommends a sandwich grill press (they have many names, so we included a picture). What she likes about this sandwich press is it seals the edges – which make transporting them less of a mess!

You can use whatever bread you prefer, but Cook for Love is preferred. Here are some ideas for you:

“MonteCristo”

Ingredients:

- Violife cream cheese
- Berries or jelly of choice
- Cook for love French toast

<https://cookforlove.org/recipes/detail/75625> (make wet mixture only)

Directions:

- Spread Violife cream cheese on insides of bread
- Top with berry or jelly of choice
- Close sandwich and dip in Cook for Love French Toast mixture
- Cook in sandwich press
- Sprinkle with Cinnamon



Fancy Grilled Cheese

Ingredients:

- Fig spread
- Smoked Gouda cheese (Follow Your Heart brand)
- Caramelized Onions
- Sautéed Swiss Chard

Directions:

- Smear fig spread on inside of bread
- Top with smoked gouda, caramelized onions and sautéed Swiss chard
- Spray grill and cook

“Grilled Pizza Sandwich

Ingredients:

- Violife cheese mozzarella shreds
- Fresh basil, chopped
- Salt
- Marinara,
- Garlic butter

Directions:

- Spread garlic butter on outsides of sandwich
- Top inside with cheese, fresh basil, salt and marinara
- Spray and cook

COOK
FOR LOVE
LOW PROTEIN RECIPES

The logo for 'Cook for Love' features the words 'COOK' and 'FOR LOVE' in a bold, sans-serif font. Below 'FOR LOVE' is the phrase 'LOW PROTEIN RECIPES' in a smaller, all-caps font. To the right of the text is a stylized illustration of a whisk.

More pinwheel recipes – each pinwheel recipe uses 1 wrap

Rainbow Pinwheel

Ingredients:

- 1 Tbs. Alouette Garlic and Herb cheese spread
- 15 g mini diced tomato
- 15 g mini slivered carrots
- 15 g bell yellow/banana/or pepperoncini peppers
- 15 g avocado
- 15 g red onion, sliced thin
- 15 g pickled beets

Directions:

- Spread Alouette cheese on wrap
- Layer rest of ingredients
- Tightly roll wrap
- Wrap in Saran Wrap
- Refrigerate for 2 hours then slice and serve

Italian Pinwheels

Ingredients:

- Zucchini, thinly sliced length wise (mandolin works best for this)
- Eggplant, thinly sliced length wise (mandolin works best for this)
- Olive oil
- Minced Garlic
- Balsamic Vinegar
- 30 g Violife Feta Cheese
- Minced Banana peppers
- Sun dried tomatoes, minced

Directions:

- Preheat grill and spray
- Grill zucchini and eggplant on hot grill until grill marks are light brown
- Remove from grill and toss with olive oil, garlic, and balsamic vinegar
- Allow veggies to get cold in the fridge
- Mix violife feta cheese, banana peppers and sundried tomatoes
- Spread cheese mixture on wrap,
- Layer with cold zucchini and eggplant mixture
- Roll tightly and wrap in Saran Wrap
- Let refrigerate for 2 hours then slice and serve

Want to see a video of any of the recipes from this months HCU Herald? Brenda did a Facebook live event with them, and it's been archived for your viewing pleasure:

<https://www.facebook.com/events/1182697118749218/>

For more delicious lunch ideas at treats, visit

<https://cookforlove.org>



Why Do Families Need Navigate Newborn Screening?

Newborn screening (NBS) is a health screen that checks for serious conditions at birth. NBS is a life-saving service, available to the nearly 4 million babies born in the United States each year. To better understand family preferences for NBS education, Expecting Health surveyed **819 participants** made up of parents, expecting parents, individuals with NBS conditions, or family members of individuals with NBS conditions.

LIMITED NEWBORN SCREENING AWARENESS



2 out of 3 participants
are aware of NBS.



1 out of 3 participants
aware of NBS can correctly
identify a definition of NBS.

DISPARITIES IN NEWBORN SCREENING EDUCATION

Participants living in HRSA-defined medically underserved areas (MUA) may experience disparities in NBS education compared to those living in other areas.

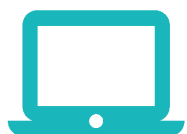


55% of participants in an MUA
were previously aware of NBS
compared to **67%** of those living in
other areas.



50% of participants in an MUA
learned about NBS before birth -
the optimal time - compared to
61% of those in other areas.

FAMILY LEARNING PREFERENCES



An **online module** was the
preferred format compared to
other educational formats.



Family stories were considered
very helpful to learn about
NBS.



Participants use **social media** to
connect with others about NBS
and other health topics.

Informed by this data, Expecting Health developed ***Navigate Newborn Screening***, a free online learning module that helps families just learning about newborn screening and provides opportunities to become leaders in the newborn screening system.

Sign up today:

https://expectinghealth.myabsorb.com/?KeyName=NavigateNBS_HCUNA

Have questions? Contact **Annie Evans** at aevans@geneticalliance.org

Navigate Newborn Screening

An Expecting Health Program

WHAT IS NAVIGATE NEWBORN SCREENING?

Navigate Newborn Screening is a free, learning opportunity that gives families information on one of the most common tests newborns get - newborn screening. The module can help families just learning about screening as well as those looking to be leaders in this system.

In this module, you will learn about:

- The newborn screening process
- Newborn screening results
- Types of conditions detected
- Questions to ask your healthcare provider
- How to tell your newborn screening story
- Additional newborn screening resources

WHY LEARN ABOUT NEWBORN SCREENING?

- Newborn screening is a **state-run public health service** that ensures all babies are screened for certain conditions that can cause serious health problems.
- Newborn screening usually happens when your baby is between **24 and 48 hours**.
- In the U.S, all states require newborn screening, but **not every state screens for the same conditions**.
- **Only 1 in 3 people** can correctly identify the definition of newborn screening.

BENEFITS OF PARTICIPATING



Learn about the most common screening test



Gain leadership and advocacy skills



Options to attend national conferences or meetings

Sign up today

https://expectinghealth.myabsorb.com?KeyName=NavigateNBS_HCUNA

Interested but have more questions? Contact **Annie Evans** at aevans@geneticalliance.org