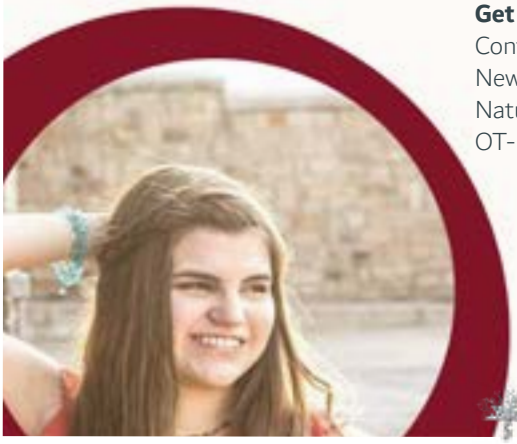
Connecting for a cure. There have been great things happening for the HCU Community and HCUNA. We strive to keep you informed and connected.

The HCU Herald

In This Issue



Recipes from the Kitchen

Trick or Treat Snack Mix

Ingredients
60 g Pumpkin Spice Cheerios Cereal
50 g Vanilla Almond Bark, broken in small chunks
35 g Pretzel Sticks, Broken in half
80 g Candy Corn
60 g Cranberries, dried, sweetened (such as "Craisins")

Directions

1. Combine all ingredients in a large bowl and toss to mix. Store in a sealed container.

Notes:
Yields: 15 Servings
Serving Size: ¼ cup
Protein per Serving: 0.4 g
Calories per Serving: 74

Apple Pie Blondies

Ingredients

275 g Cambrooke All Purpose Baking Mix
2 tsp Baking Powder
1 tsp Cinnamon, ground
1/2 tsp Salt, Table
50 g Vanilla Pudding, dry mix only
8 TBSP Butter, regular or unsalted, softened
3/4 c Sugar, Brown, packed
3/4 c Sugar, White Granulated
1 banana(s) Banana, fresh, peeled, medium, mashed
1 egg(s) Egg, whole, large (without shell), lightly mixed
1 tsp Vanilla Extract
1 c Peeled, Diced Apples

Directions

1. Preheat the oven to 350 degrees. Spray a 9x13 pan with baking spray and line bottom of pan with parchment paper. Set aside.
2. Combine the baking mix, baking powder, cinnamon, salt, and vanilla pudding mix in a medium bowl and lightly whisk to combine. Set aside.
3. In the bowl of a stand mixer add the softened butter and sugars and mix until light and fluffy. Add the egg, banana, and vanilla and mix just until combined. Scrape bowl. Next add the dry ingredients to the wet ingredients and mix just until combined. Fold in the apples. The batter will be thick but it works.
4. Pour batter into prepared 9x13 pan and spread evenly over bottom of pan. Bake in preheated oven for 40 minutes, until a toothpick inserted comes out clean. Allow to cool in pan before cutting.

Notes: These can be served with whipped topping of choice or a la mode!
Yields: 12 servings
Serving Size: 1 piece
Protein per Serving: 0.8 g
Calories per Serving: 299

HC and You: Dear PheBea – an article by Methia's sister

Occasionally Methia's sister, PheBea will fill in for her. PheBea helps Phenylketonuria (PKU) patients. In the article, if you see the word PHE, substitute it with the word methionine or protein and you should be set.

Printed with permission from the PKU Organization of Illinois

Click Campaign

Get your mouse ready and be prepared to click!

For one week only (October 1-7th) Recordati Rare Diseases will donate $5 (up to $5,000) to HCU Network America for every click. You can click multiple times a day, every day.

Click here to get started – and don't forget to share: http://bit.ly/HCUClick19

RECORDATI RARE DISEASES GROUP
Focused on the Few

HCU Awareness T-Shirts are back!
Get your official 2019 HCU Awareness T-Shirts. All proceeds benefit HCU Network America!

Buy me now:
bonfire.com/hope-connects-us-letter-tiles
Pick me, Pick me!
bonfire.com/hope-connects-us-hands-together

HCU Awareness and You

$20,000 donor match is back!

Thanks to an anonymous donor, any **funds** you help raise from October through December 31, 2019 **will be matched up to $20,000!**

We are asking every patient and family to help us raise funds for homocystinuria. Set up a Facebook Fundraiser or host your own alternative fundraising event and invite your family and friends to participate. Alternatively, they can donate directly to HCU Network America.

Have an idea for a fundraiser, but not sure how to get started? Let our fundraising committee help you get started!

Email info@hcunetworkamerica.org and we will connect you!

15,000 Companies Match Gifts....

Does Yours?

Need information to complete your match?
Visit: https://hcunetworkamerica.org/company-matching/

Be a HCU HERO !

A Hero is an ordinary individual who finds the strength to preserve and endure in spite of overwhelming obstacles.
-Christopher Reeve

HCU Heroes

Sienna

From Texas

My beautiful daughter Sienna was born in 1998 with a metabolic disease called MMA-CblC, unbeknownst to me. Texas did not have newborn screening for MMA at that time. I had a relatively uneventful pregnancy except for pockets of air inside my placenta and the fact that she stopped growing towards the end. She arrived on October 28th weighing 4 lbs 15 oz and 17.75 inches. She was a little jaundiced, and I could not get her to breastfeed. I was able to take her home 48 hours later with the condition that she sees the pediatrician within the next few days. The pediatrician said she looked good, and she was only mildly jaundiced. I noticed that she seemed to sleep more than most newborns and had a hard time latching on to feed. She vomited a lot and was on 13 different formulas before diagnosis. I had a feeling that she had reflux due to all the vomiting. Her doctor ordered an Upper GI test, and it was confi[illegible]. Medications were not helping, and I had a mother's instinct that something was wrong.

On Valentine's Day in 1999, I took her to the pediatrician again. The nurse practitioner took one look at her, saw how pale she was and sent us to the lab to have blood drawn. Thirty minutes later she called me back and said the labs needed to be redrawn because somehow the test got messed up. After having blood drawn again, the results were exactly the same. Her hemoglobin was at 6 and a low normal is 10. We were immediately sent to a hematologist. The doctor thought that maybe it was leukemia. She was admitted into the hospital, and the next day her hemoglobin dropped to a 5. She was given her first of many blood transfusions over the next two weeks. She had so many tests, such as bone marrow extraction and a sweat test, to try to determine what was wrong.

Over the next two weeks her health continued to deteriorate. The gastroenterologist thought it was a metabolic disease but said there were so many that it would be hard to find out which one. On March 1st she was intubated as she could no longer breath on her own. Her organs were shutting down and her red blood cells were fragmenting. She had a couple of blood exchanges with little improvement. I was told she would not make it through the night and to call family and friends to come say goodbye. We were devastated. I prayed to God to please spare my daughter's life, and I would take her however He saw fit, disabled or not, and I meant it. While waiting for our parents to arrive, the gastroenterologist asked if an autopsy could be performed if she died. That night was the longest night of my life. My strong girlie fought so hard and made it through the night.

The very next day we were told that they finally had a diagnosis. I knew it was not good when the Chaplin followed us into the room to discuss it. We were told it was a very rare metabolic disease and that the outcome was not good. Fort Worth did not have any metabolic specialists, so we were care flighted to San Antonio. We were 5 hours away from home and family while staying at a Ronald McDonald house. We arrived at 2 a.m. and the very next day we met the metabolic specialists. She said that there were only 19 cases within the US and that most had died in infancy. We were told she would not live to see her 1st birthday. She was immediately started on cyanocobalamin injections and Cystadane. She also had a nissen wrap and g-tube due to her reflux. She slowly improved and almost 3 months later we were finally able to go home. We followed up with a metabolic specialist in Dallas. Although we were told that she would be in and out of the hospital, she continued to thrive. We had a huge celebration on her 1st birthday. At age 2, she was diagnosed with severe vision impairment and uses a cane. She can't see text, so she reads Braille instead.

The next 13 years were smooth sailing until she went into puberty. Her homocysteine levels started rising, and she was hospitalized a couple of times due to complications. In 2014 we went to NIH to be included in a study on her disease. After many tests, we found out she was diagnosed with a heart condition called non-compaction. Unfortunately, we had to see 3 cardiologists before I could get one to listen to me. She started heart medications, and it really helped. About that same time, she started having debilitating migraines. She also was hospitalized about 3 or 4 times due to heat exhaustion, dehydration and migraines.

She will be 21 next month and is relatively healthy. We are still trying to manage her migraines better as well as her neuropathy in her hands, feet and legs. She gets fatigued easily, and we have to be careful during the summer (TX heat) because she does not sweat very much and gets heat exhaustion easily. She is happy, outgoing and always has a smile on her face. Despite her many challenges she remains positive. I thank God every day for her life

Megan

From Ohio

My name is Megan and for much of my life I grew up not knowing anything about Homocystinuria or even knowing such a thing existed.

Growing up, I was always the tall, thin girl in class. For class pictures I always knew I was going to be in the middle back row. From an early age I loved school but struggled to process information that I was being taught. I had to work hard to understand concepts and remember them. What took my peers ten minutes to do often took me a half hour and often a lot of repetition to fully comprehend. It was as if the information would go in one ear and out the other. My parents were always very supportive and with their help, the help of my teachers and my friends, I developed a love of learning that pushed me to always want to do and try my best. I was blessed by many wonderful teachers who inspired me to want to be a teacher, help children reach their full potential, and teach them skills on how to overcome their difficulties.

In 2014, I got married, moved to the Toledo area from Cleveland (in Ohio), and switched jobs. Everything happened pretty quickly and at the time, was a little stressful. During this time, I had met my deductible on my insurance, so I decided to do something my cardiologist and family doctor had been asking me to do for a while, get a genetic test done to rule out Marfan Syndrome. Silly me, I thought this would be a one and done kind of test. Being newly married, my husband and I really wanted kids, so I wanted to be careful and go into pregnancy safely. Little did I know it would take a total of three genetic tests and a year and a half before I would find out that I did not have Marfan Syndrome.

I still remember getting the call on my way home from work. I remember pulling over at a convenient store and the nurse telling me nothing on my test came back positive for Marfan Syndrome. What the test did show was that I had something called Homocystinuria. She then proceeded to tell me that she was going to connect me with a doctor from University Hospital (UH) in Cleveland that traveled to Toledo once a month so he could speak with me more about Homocystinuria. I am sure she said more, but all I remember was thinking oh great, this is not what I wanted to hear. I wanted to move on with my life and have a baby.

HCU Hero: Megan

The day I met the doctor, my mom and I went to Big Boys for Lunch, and I got one of my favorite feel good meals at the time. This was a Big Boy with extra tartar sauce and fries (I have since found out the burger itself is 34 grams of protein, I clearly didn't know anything about limiting my protein). Needless to say, my protein levels for my first blood draw were extremely high, and my doctor had me meet with a dietitian and start drinking formula. Knowing that my husband and I had been wanting to have children, my doctor recommended either continuing my care in Cleveland or Michigan. Since both my husband and I are originally from the Cleveland area the choice to move back and have the support of family was not even a question.

Within a few months, I was fortunate enough to find a wonderful job teaching kindergarten at a small private school in the Cleveland area. The staff and principal have been beyond understanding and supportive of my condition. However, once I moved to the Cleveland area my insurance changed and the medications I was easily getting from compounds no longer were covered by my new insurance. I also felt my doctor, who encouraged me to move to the Cleveland area and knew we really wanted to start a family, became stricter about getting my levels under control before having a baby. He needed me to prove I could lower my levels. This condition I had only recently found out about had turned my life upside down and became a big stumbling block to where I wanted to be. I started wondering if I was ever going to be able to have children and watched as many of my friends started having families of their own. In addition to being stricter, my doctor at the time, also refused to work with my doctors at the Cleveland Clinic. I felt trapped. I loved my doctors at the Clinic and already had relationships with them. I trusted them, and they never once made me feel bad like this doctor was starting to make me feel. Even now I feel terrible going into this part of my story, because I really wish this wasn't the case.

Around this time, as I was feeling children were not going to be an option for me because the life changes were so drastic and seemed almost unattainable is when my mom told me about HCU Awareness and support groups on Facebook. Shortly after I joined, Danae had asked members to share which clinics they went to so she could send out information about the group to doctors' offices. I saw that one of the members went to the Cleveland Clinic, which I inquired more about. (When I first came back to Cleveland I was told that there wasn't a doctor I could see at the Clinic.) I found out that there was, in fact, a very knowledgeable Genetic Specialist that worked at the Clinic, and for the first time since moving back, my husband and I felt hopeful. I wouldn't have to change all my doctors to move to UH (just to be clear, I have nothing against UH, I just always went to Cleveland Clinic and it was where I was comfortable).

To make a long story short, my husband and I decided to put things in God's hands, and I left my doctor at UH and started to see my Genetic Specialist at the Cleveland Clinic, who graciously decided to take me on around the time I got pregnant with our son. During the whole process I prayed every day and got weekly blood draws to monitor my levels. My new doctor is so thorough, and I am beyond blessed to have him as my physician. He went above and beyond to make sure I had a healthy pregnancy and was in constant communication with my other doctors. There are truly no words for how grateful I am that God put him in my family's life!

HCU Hero: Megan

On September 25th of this year it will be a whole year since we had our son. He was born weighing 6 lbs. and 14 oz, just perfect. The process to have him was by no means easy, and after having him I had to be in the hospital for a week to monitor my levels, which skyrocketed at first, but I had no serious complications with the pregnancy otherwise.

I would love to tell you that since the pregnancy I have my levels under control and that life is perfect, but reality is it's still a struggle every day. I hate the formula and though my doctor wants me to have three a day, I can only usually tolerate two. In addition, in December, I went to pick up my three month old son and felt a pop in my back. I had a lot of pain afterwards. My primary doctor ordered x-rays, which showed low bone density and fractures in my spine. My Genetic Specialist ordered a bone density scan, and I found out that I have very low bone density and osteoporosis. I spent much of my summer in Physical Therapy, and I am still waiting for insurance to approve medication to rebuild my bone, which has been denied twice now, because I am not in the targeted age range for the medication.

Once again, I would love to say that life is good, but it's a daily struggle. I am not going to try to sugarcoat it. I've never been good at faking that. All I can do is thank God for my blessings. I am blessed to have a Mom who comes to many of my appointments when my husband can't get away from work. She helps with my son and is always trying to find recipe alternatives I can have so I can feel full. She is my biggest supporter by far, and I don't know what I would do without her. I am thankful for my husband that even as I am writing this is taking care of my son and making sure I take my shakes and occasionally makes them for me. He was my rock while I was in the hospital after having my son and through the recovery process, putting my needs above his own and making sure I had everything I needed. I am also thankful for my sister and dad, who love both my son and I, and are our biggest fans and supporters. Lastly, I am thankful for my coworkers and principal as they support me through my good days and bad. They always offer understanding and support when it comes to the challenges with my health and what I need to do to remain healthy. I truly feel blessed and thankful to have a healthy baby boy that I get to watch grow each day. Being a mom is truly a gift from God and the answer to my prayers. It inspires me to learning to live as a person with homocystinuria.

HCU Awareness Calendar

Want to do more to raise awareness for HCU? Check out our fun online activities you can take part in to help those understand more about HCU.

Confused about one of the activities?
Find examples and resources on our website: https://hcunetworkamerica.org/hcu-awareness-month/
Follow us on Facebook, Twitter and Instagram during the month for examples and additional activities!
Help spread awareness, share your participation on social media and your Facebook Fundraising page

October 2019

Sun	Mon	Tue	Wed	Thu	Fri	Sat
		1 Change your Social Media picture to the HCU Awareness Ribbon	2 Start your HCU Facebook Fundraiser and Invite your friends	3 Share the Classical HCU infographic OR Cbl pathway and share there are 10 types of Cobalamin defects!	4 Share a HCU patient story! Videos: http://bit.ly/PatientStoriesVideos Text: http://bit.ly/HCUHeroes	5 Share your diagnosis story!
6 Challenge your friends to eat 10 g of protein and a normal protein shake 3 times a day. #ToastToHCU	7 Share a pic of an item that has the same amount of protein you can have	8 Share your daily diet record - completed	9 Share a low protein meme	10 Share your favorite low protein recipe! Bonus if you cook it and share a pic.	11 Dining out, low protein style	12 Share a pic of what your grocery store "haul" looks like
13 Real Coast of HCU: Grocery Cost Comparison #MedicalNutritionEquityAct OR Some patients with HCU require injectable B12. B12 on average is $300-400 a month and most insurance companies don't cover it!	14 Share a picture or video capturing all the medication, or of you taking your medication for the day (this includes formula for those who need it).	15 Share a pic of your first pair of glasses - or a device that helps you navigate or communicate due to lack of vision	16 Share something you wish people would understand about HCU	17 #HaikuforHCU Write and share a Haiku describing life with HCU	18 Wear jeans for your rare genes	19 Wear your HCU Shirt and share a pic online
20 #GoBlueForHCU	21 #HCUAwareness post in a public place	22 Share with stranger what HCU is and why it's important to you	23 #Create4Cure create a work of art that brings awareness for HCU	24 #High5forHCU List 5 ways HCU makes you a stronger, better person	25 All states test for Classical HCU, but many patients are still missed	26 Share a picture of you and a HCU buddy! Or tag a friend who is a great support!
27 #FacesOfHCU Share a picture of you saying - I am one of the estimated 1 in 200,000 people with HCU	28 #Hope4HCU Share 4 things that give you hope and encouragement	29 Share the HCU timeline - if you know other facts, let us know!	30 Cutting Edge of HCU: Share about a therapy that is in the works!	31 Your message to the world about HCU!		

print-a-calendar.com

Last Chance toRegister

Join us in Indy for HCU Network America's 2nd Homocystinuria conference, Accelerating Towards a Cure. Join the 100+ attendees from 22 states.
Registration closes Friday, October 4, 2019

Open Enrollment Health Insurance

November Marks Beginning of Open Enrollment for Health Insurance

Do you find your insurance coverage inadequate for low protein foods, formula, betaine, or supplements? Don't fret—November marks the beginning of open enrollment for new health insurance policies. Feeling overwhelmed? Not sure what policies cover your doctors and your medications? Don't worry, we can assist you with that!

Raenette Franco of Compassion Works Medical is able to assist you with your needs. Raenette can help you find a policy that works for you, or work with your current policy to help you get low-protein foods, medical formula, betaine and "supplements" covered.

There is no fee to work with Raenette, but we do urge you to contact her immediately if you do need a new policy. Open enrollment for 2019 ends December 15, 2019.

You may contact Raenette:
raenettef@compassionworksmrs.com
(973) 832-4736

Want to get more involved, but don't qualify for the Enzyme Replacement Therapy Trial – Drive research by joining the Natural History Study!

Current sites include: Atlanta, Boston, Denver, Indianapolis and Philadelphia. 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.

Click here to learn more

VMP, LLC
expanding genetic horizons...

Voice: 404.793.7800
Fax: 866.744.5665
www.vmpgenetics.com

HELP US TEACH PHYSICIANS ABOUT HOMOCYSTINURIA

FACT! Teaching about metabolic diseases in medical school and residency programs is poor.
FACT! Most patients live and die without a diagnosis being made, especially when the disease presents in adulthood.
FACT! Patients cannot access effective therapies unless a proper diagnosis is made.
FACT! The sooner a diagnosis is made and treatment begun, the better the outcome.

WE NEED YOUR HELP!

We at VMP Genetics believe in the power of "patient-teaching" and are bringing patients and families into lectures and presentations - at conferences and in the classroom around the country. While doctors teach facts, patients tell stories. Story-telling is a more compelling teaching method with better recall over time than didactic lecturing. We also believe that doctors are more likely to make a diagnosis if they have already seen a patient and heard her/his story. Story-telling can be live or taped...

WE ARE LOOKING FOR...

- ***Patients and/or family members who are interested in telling their stories in local medical classroom settings...*** We are developing a Patient Teacher Registry. If a medical school faculty member is looking to introduce the patient story in a teaching session, the Registry can tell him/her if there are patient-speakers in the area and what diagnoses they have.
- ***Patients and/or family members who are interested in having their stories videotaped...*** As we secure funding, we are interested in recording stories that reflect the broader patient experience. The more variety in the stories, the richer the learning potential.
- ***Videos of patients and families telling their stories...*** A 5-or 10-minute clip can be downloaded into a lecture about that disease or relevant biochemistry to enhance the learning potential of the session.

Please help us in our efforts to raise awareness about Homocystinuria through this innovative educational outreach to the medical community. To Volunteer or participate, or for more information about this project... please contact Jacob Athoe at PatientTeacherRegistry@vmpgenetics.com

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OT-58, Enzyme Replacement Therapy Clinical Trial Recruitment

Orphan Technologies has initiated a first in human (Phase 1) clinical trial of OT-58, an enzyme replacement therapy that addresses the underlying enzyme defect for patients living with classical homocystinuria. The goal of this trial is to evaluate the safety and efficacy of OT-58 in patients with classical homocystinuria and identify the appropriate dose. Patients between the ages of 12 and 65 years of age with classical homocystinuria may be eligible to join. For additional information on criteria for eligibility, please go to:
https://clinicaltrials.gov/ct2/show/NCT03406611?cond=Homocystinuria&rank=1
There are four sites in the US currently participating in the trial:
• Children's Hospital of Philadelphia – open to patient enrollment
• Boston Children's Hospital – open to patient enrollment
• Indiana University – open to patient enrollment
• Children's Hospital Colorado - open to patient enrollment
Payment for time and travel may be available to patients who participate in this trial.
To inquire about participation into the trial, please email: info@orphantechnologies.com

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. The information you provide helps us succeed in our mission, plan events, develop resources and educational tools, and ensure everything is being done to support 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/
https://hcunetworkamerica.org/contact-register/

We'd like to thank the following content contributors:
Editor in Chief: Danae' Bartke
Heroes of HCU: Gabbi from Massachusetts
HCU and You: Recipes from the *Kitchen:* Amber Gibson

Newborn Screening Survey for Classical Homocystinuria

But we have newborn screening for HCU...

According to recent statistics, approximately 25-50% of patients are missed by newborn screening for Homocystinuria. There are multiple factors that can play into these numbers. Currently it is federal mandate that all states screen for Homocystinuria through the newborn screening test, but there are no set standards. Meaning, every state or region can set their own methionine cut offs. A handful of states also do tier two testing—meaning they have a second round of newborn screening, making it more likely for homocystinuria to be picked up. Another factor that plays into the effectiveness of the test, is how elevated the patients levels are at the time of the test. Patients who are pyridoxine (B6) responsive, or have more functioning CBS enzyme, are less likely to be picked up by the newborn screening

So how can you help?
Talk to your geneticist about the newborn screening survey and urge them to complete it! This will help us build support for changes to the process to increase the likelihood that HCU patients will be diagnosed at birth.

Here is the letter portion we would ask you to give to your clinic, followed by the survey form:

The Letter:
To Whom this may concern,

I would appreciate your support in answering a brief survey to help support efforts to improve newborn screening for classical homocystinuria.

I have been working with HCU Network America, a patient advocacy and support group for Homocystinuria (HCU), for whom I serve as a medical advisor. One of their key goals is to improve newborn screening for HCU, as it is estimated that over half of patients are missed by the current screening process and often are not diagnosed until they have developed serious clinical symptoms. To build support for an improved process, we are collecting information on patients missed by the current screening process, which we intend to then publish in a consolidated case report.

Could you please support our efforts by completing the attached brief questionnaire, and sending it to me viae-mail at:
FICICIOGLU@email.chop.edu

Sincerely,
Can Ficicioglu, M.D., Ph. D.
Director of Newborn Metabolic Screening Program, Children's Hospital of Philadelphia

Survey on Classical Homocystinuria (HCU) Patients Missed by Newborn Screening

Do you have any patients with classical HCU missed by NBS and diagnosed later based on symptoms?
( ) Yes ( ) No

If yes, at what age were the patients diagnosed, and what year were they born and in what state?

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Age at diagnosis (mos.) ____ Year of birth _____ State born_____

Would you be willing to provide information to contribute to a "Case Report" we plan to publish on patients missed by Newborn Screening?

What is the name and address of your clinic and the best contact person for further information:
Clinic Name
Clinic address
Contact Person:

- Name
- E-mail
- Phone

Please send completed survey to Dr. Can Ficicioglu at ficicioglu@email.chop.edu