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HCU Network America

Recipes from the Kitchen

Again, we'd like to thank Chef Amber Gibson for her amazing spread of low protein food at our patient/family conference! Not only does Amber make low protein food, but she also is the genius who comes up with the recipes.

We will be featuring several of the recipes from the conference and linking you to some videos she has made featuring some of the vendors' products. All items that are blue and underlined are hyperlinks to the product, video, or further information.

Breakfast

At breakfast, Amber's husband, Ben, had a low protein omelet station. Patients could choose a variety of low protein additions ranging from low protein cheese, onion, mushrooms, peppers and more! In this video Amber is using Cambrooke Eggz but at the conference she used Country Sunrise Universal Egg Mix. In this video Amber gives you step by step instructions on how to make the "eggs". Watch video

Also available at breakfast were:
Mini Bagels (by Cambrooke)
Cream Cheese (by Cambrooke)
Quick Breads (by Taste Connections)
Quick Breads (by Cambrooke)
Seasonal Fruit
Morningstar Farms Veggie Bacon (1 g protein per strip)
Yuca Tater Home Fries (by Cambrooke)
English Muffins (by Taste Connections)
Smoked Glazed Carrots (Recipe)

Lunch

Both days, there was an amazing spread of various sandwiches.

Saturday was a Corner Deli theme.

Bread (by Taste Connections)
Homestyle Bread (by Cambrooke)
Mock Tuna Salad
BBQ Jackfruit
Low Protein BLT's (using Morningstar Farms Veggie Bacon)
Yuca Tater Home Fries (by Cambrooke)
Tortilla Chips (by Cambrooke)
Wise Onion Rings (by Cambrooke)
Brownie Cookies (Recipe on Cookforlove.org)

Sunday was a BBQ theme

Garden Salad (hotel provided)

Coleslaw (hotel provided)

BBQ Jackfruit

Low Protein Sloppy Joes (Amber said to follow the Jackfruit Ragu recipe, but then add cumin, ketchup, chopped sautéed mushrooms and a little brown sugar)

Low Protein Corn Bread

Slider Buns (custom from Taste Connections)

Dinner

Saturday we held a reception for all attendees. Amber made a terrific Italian spread with 3 varieties of pasta, and 2 different desserts.

Mixed Greens Salad (hotel provided)

Vegetable Medley (hotel provided)

Jackfruit Ragu (recipe below)

Zucchini Lasagna (recipe below)

Penne Pasta with Cream Sauce (By Cambrooke) – Added Garlic and Follow Your Heart Parmesan Cheese

Focaccia Sticks (Cambrooke)

Garlic and Herb Breadsticks (by Taste Connections)

Key Lime Pie (Recipe on Cookforlove.org)

Pumpkin Panna Cotta Pie (Recipe on Cookforlove.org)

Pastry Dough Recipe for Pumpkin Panna Cotta Pie

Jackfruit Ragu

Yields 3 servings

Serving size: 0.5 cup

Protein per serving: 1.3 g per serving

Calories per serving: 124

1 TBSP Oil, Olive

1 TBSP Small Diced Carrots

2 TBSP Diced Onions

1 clove(s) Small Clove Garlic, Minced

2 tsp Tomato Paste

1/2 20-oz. can Jackfruit, Young in Brine, drained, seeds removed

1 1/2 tsp Sugar, White Granulated

1/2 c Wine, Red

5 fl.oz. Crushed Canned Tomatoes

1 tsp Thyme, fresh

2 tsp Bay Leaf, about one leaf 1 tsp Dijon Mustard

1/4 c Vegetable Broth

1/4 tsp Kitchen Bouquet Seasoning & Sauce

Heat the olive oil in a small saucepan over medium high heat. Add the carrots and onion and sauté until aromatic, about one to two minutes. Add the garlic and cook for another minute, stirring constantly to prevent burning the garlic. Next add the tomato paste and sauté together until heated through and nicely coated. Add the jackfruit and cook with the tomato mixture until a little browned.

Next combine all the rest of the ingredients into the small saucepan with the jackfruit. Bring to a boil, then reduce heat to medium low and cover. Slow cook until the jackfruit is tender enough to shred. Allow at least 30 minutes to 1 hour. The longer you let it cook, the more flavor will be infused into the jackfruit.

Remove the jackfruit from the saucepan and shred with two forks. Return the shredded jackfruit to the sauce. Season with salt and pepper, if desired. Serve with your choice of low protein pasta.

Kitchen Bouquet can be found in most grocery stores, sometimes near dressings and sauce mixes. You can omit or use coconut aminos in its place if desired.
**Total nutrition does not account for pasta used.

Zucchini Lasagna

155g Mushrooms

2 cloves garlic

2 tsp olive oil, divided

140g CBF Sausage Mix

1 ½ Tbsp Oil

1 cup water

1 Tbsp Italian Seasoning

1 3/4c tomato sauce

290g sliced Zucchini

10 oz nondairy cheese

Total Weight: 1375g
Serving size: 170g
3g protein per 170 grams serving

In a medium skillet, heat 1 tsp olive oil over medium heat. Sauté mushrooms and garlic together for about two minutes, then set aside.

To make the ground sausage mix, combine Cambrooke's sausage mix, 1 ½ Tbsp olive oil, 1 cup of water, and Italian seasoning in a medium bowl. Mix just until combined and can come together like a patty. Add the sautéed mushrooms and garlic and mix.

Heat 1 tsp olive oil in the medium skillet over medium heat. Add the sausage mixture and cook until lightly browned and can be crumbled. Remove from heat and set aside.

Preheat oven to 350 degrees. In a 9x13 pan, add sauce to just barely cover the bottom. Add a layer of sliced zucchini, top with ¼ cup sausage crumbles, more tomato sauce and then sprinkle cheese.

Repeat for two more layers, making sure to finish with the cheese. Bake for 30-40 minutes, until internal temperature reaches 145 degrees and the lasagna is fork tender.

$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!**

During the winter holiday's warm hearts and generosity can be felt near and wide. During this time, we ask that you share our appeal letter with your collegues, friends and family.

Amazon Smile

What is Amazon Smile?

Amazon Smile is a simple and automatic way for you to support HCU Network America every time you shop, at no cost to you. When you shop, you'll find the exact same low prices, vast selection and convenient shopping experience all with the added bonus that Amazon will donate a portion of the purchase price to us.

How do I set it up?

Simply, go to smile.amazon.com, the first time you enter the site it will ask you to designate an organization. Type in HCU Network America and select us from the list. It is important to note that in order for the donations to go to HCU Network America, you MUST check out from this url every time - see best practices below for some pointers on how to do this.

What if I'm already set up and would like to switch to HCU Network America?

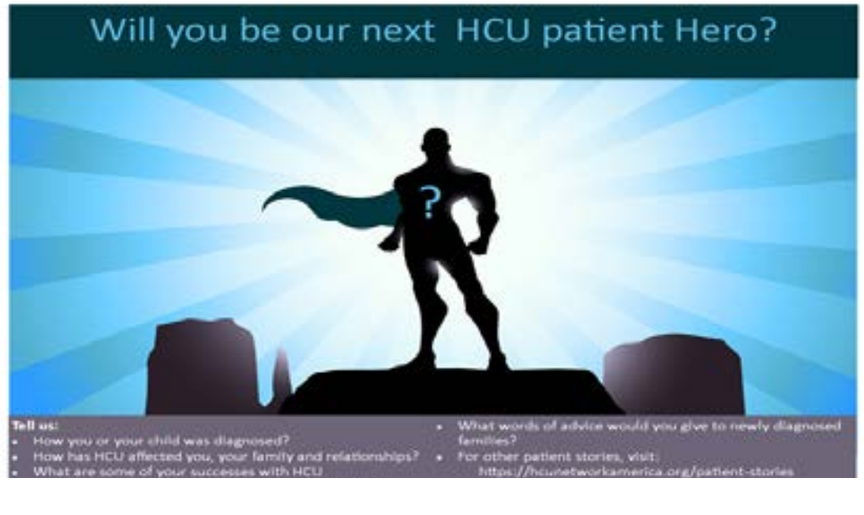
1) From your desktop, simply select "Your Account" from the navigation at the top of any page.

2) Then select the option to "Change your Charity". From your mobile browser, select "Change your Charity" from the options at the bottom of the page.

3. Type "HCU Network America" in the search bar and search for the charity.

4. Select HCU Network America charity to update your account

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

Danielle

From Florida

Hello! My name is Danielle and I was diagnosed with Classical Homocystinuria through the Newborn Screening Program in New York City. My parents remember receiving a call from the hospital saying that I needed to be brought back to the hospital or they would be reported to Children Services. Being that I am the last born in my family, this was certainly shocking information. When asking my mother about her reaction; she says she was numb since it was something she never heard of and could not figure out an instant fix. When asking my father about his reaction he remembers being in denial and angry due to the latency of the results. Being born in an advanced hospital and having both parents employed there definitely contributed to the indescribable medical care I immediately received. I became a patient of Dr. Selma Elenore Snyderman; an early pioneer of metabolic disorders. The support and care she provided has laid foundations, brought peace, and referrals to key contributors in the homocystinuria field for my past and present medical care. Presently, I live in Orlando, FL and travel to New Brunswick, NJ for medical care with Dr. Debra Day-Salvatore.

Having a strong medical team allowed my parents to provide care and transfer skills confidently. We were so confident that we moved to the Poconos in PA . The Poconos is made up of 4 small cities,1 state road and 1 highway; it was quite a change! We would commute back to NYC for medical care. My mother worked at the local hospital that had no idea of any metabolic disorder but given odds we always felt safe and had an emergency plan. I lived in the Poconos for over 20 years and only had 1 complication due to HCU – heart palpitations. I had them once as a child and twice as an adult. As a young adult my palpitations were due to non-compliance. That event was enough for me to overhaul my lifestyle.

While having HCU is all I know, I became deeply vested in my medical care when I was in the hospital on New Years Day for heart palpitations. I will never forget sitting in the hospital in the Poconos and everyone was uncomfortable to give care due to me having HCU. The medical consensus was to monitor and send me home once stabilized. From that day on I realized that I am my biggest advocate. While I have never stayed the night in a hospital or experienced grave complications attributed to HCU, this event motivated me to make it my mission to advocate for myself and the community.

Due to grace and quality care, HCU has never prevented me from anything I set my mind to accomplish. I had a highly active childhood (ballet, horseback riding, ice skating, and more). I proceeded to attend East Stroudsburg University of PA and received a Bachelor of Science, Bachelor of Arts, Master of Education and become a certified Spanish Translator.

I have an amazing support system: My parents – Frank & Francine, siblings (Dorothy, Vernette, Andre, Frederick), my husband (Irving) and 3 son's (Irving, Julian and Christian), and my extended sisters/best friends Avery and Sarah who all advocate for awareness and make HCU seem as normal as having 2 hands.

Originally, I was not comfortable with sharing my story as I thought it would be boring. After writing, I have to say that it is more of a blessing than bore. Having all these new treatments on the horizon makes it a vibrant time to be living with HCU. My advice to parents: Never stop transferring your amazing skills and care and for my HCU rare warriors; never stop advocating.....

Dear Methia

HCU and Sports, What's the Big Deal?

I'm really excited about joining my high school's indoor cross country team this winter. I love running and am pretty good at it, too! Plus, we get to travel for meets, which sounds like so much fun. My parents told me I should probably talk with my geneticist and metabolic dietitian before the season starts. Apparently, we might have to change some things about my HCU diet. I'm not really sure I understand why – what's the big deal about cross country? Does my diet really need to change?

Sincerely,

Ready to Run

Dear Ready to Run,

Kudos to you for taking this big step! Team sports are an excellent way to make new friends, teach time management skills, and stay healthy during the school year. It's important to acknowledge, though, that ALL kids who play sports have increased nutritional needs. While nutrition may be a little bit more straightforward for kids without HCU, your needs are a little bit more specific. Your parents' suggestion to talk with your geneticist and metabolic dietitian is spot on because they'll be able to help you optimize your diet for performance and overall health.

- **You will need more calories and more fluids**. Even if you hope to lose weight in your athletic endeavors, you will still need to make sure you are eating enough to prevent catabolism, or muscle breakdown. Catabolism in HCU can result in a release of amino acids, including methionine, into your bloodstream – the exact amino acid you are trying to restrict! Additionally, you will need to replace lost fluids with water and electrolytes before, during, and after activity to prevent dehydration, which can also affect your metabolic control. Your dietitian can work with you on a meal plan that will help you avoid catabolism, as well as help you to time your meals and snacks to perform your best during practices and track meets.

- **You might need more protein from medical food, and potentially more natural protein as well.** Increasing your medical food will help your body prevent catabolism, and give your body more of the amino acids, vitamins, and minerals it can utilize for recovery. If your body is building more lean muscle (we call this anabolism), you may need to increase your natural protein a little bit, too.

- **You may need more frequent labs.** If your weight begins to change drastically or if you're noticing changes in the way you feel and perform, your team might want you to be monitored more closely to make sure that your diet, formula, and medications are all optimized to support your activity.

The right prescription to meet your increased needs will be determined by working with your metabolic clinic, so make sure you stay connected with them throughout the season!

Sincerely,
Methia

HCU Awareness Recap

Over 100 patients, family members, vendors and healthcare professionals attended our 2 day conference in Indianapolis, Indiana where we had keynote speakers cover topics that included Updates from the Natural History Study, CBS Guidelines, Genetics of Homocystinuria and Screening for Family Members, Research Priorities and the Global Grants Program. This also included updates from two companies with therapies in the works, along with a panel and breakout session.

We will have a full conference report and recordings available later this month.

HCU Awareness Recap

Recordati Click Campaign

During the first week of October, Recordati Rare Diseases created a click campaign that benefited for the HCU community. For every "click" Recordati Rare Diseases donated up to $5 to HCU Network America. Thank you Recordati for partnering with us to raise awareness and funds for the homocystinuria community! This year we had 525 clicks – that's up 260% from last year!

Social Media Reach

Social Media is a powerful tool when you are using it to raise awareness. Not only does HCU Awareness Month bring attention to our organization and the actual disease, but it also draws attention to other issues related to homocystinuria. We see a lot of growth thanks to those who follow along with us and share. During the month of October we gained 26 Facebook followers and 16 Twitter followers. Over the course of the month, we reached thousands of people! We can't thank our community enough for participating in HCU Awareness month!

For the second year in a row, our most shared and viewed post was Day 13 of HCU Awareness Month: Real Cost of HCU: Grocery Cost Comparison. This year the infographic had over 1.6 thousand views and 17 shares. For this post this year, we also focused on the cost of formula and B12 injections – as they are just as crucial for the homocystinuria community. If our patients are going to be successful with their prescribed treatment, we need to urge legislators to

HCU Awareness Recap Cont.

A close second was Day 25 of HCU Awareness month with 1.3 thousand views and 12 shares.

This post emphasized the importance of newborn screening and how many patients are still missed.

HCU Awareness Fundraising Recap

Thank you to all the families who fundraised on behalf of HCU Awareness Month!
From Facebook donations alone, we have raised $6,151 !
Thank you to the:
The Bartke Family, Joanna Ball, Erika Narcio, The Sullivan Family, Saiorse Kelly, The Carter Family, The Mayes Family, The Lewis Family, The Karnes Family.

Open Enrollment

OPEN ENROLLMENT
Healthcare.gov premiums are dropping 4% for 2020 plans.

A note from Raenette Franco –
Certified Biller Coder Specialist/Consultant
Compassion Works Medical Food Reimbursement Specialists

Healthcare.gov premiums are dropping and are now more affordable. Also, open enrollment has already started for some health plans, but the actual start date for all plans is November 1, 2019 to December 15, 2019. Please make sure you and your family members or patients are aware.

There are a lot of different health plans and depending on which one you choose it could mean a whole lot for affordability and coverage for things such as premiums, co-insurance/co-pays and deductibles.

Keep in mind, medical foods/formula and solid low protein foods are typically under the Durable Medical Equipment (DME) medical benefits. So, when choosing a plan for yourself or your family member or patient that requires medical foods, search for the summary of DME benefits.

Next, once a health plan is chosen, go to their website and search for any policies in place for medical foods, enteral nutrition, and nutrition to get a better idea as to how the health plan covers medical foods (especially orally). Once you confirm coverage and affordability then choose the health plan. All plans purchased under the Healthcare.gov or directly from any health plan website are considered “fully-insured health plans”. All state mandates apply to any exclusions (if your state has a mandate).

As always, if you have any questions or need coverage support for yourself or your patients feel free to contact me. The service is free!

Support H.R. 2507/ S. 2158, the Newborn Screening Saves Lives Reauthorization Act

Legislation to reauthorize the Newborn Screening Saves Lives Act was introduced in the House of Representatives by Representative Lucille Roybal-Allard on May 2, 2019 and in the Senate by Senator Maggie Hassan on July 18, 2019. H.R. 2507/ S. 2158, the Newborn Screening Saves Lives Reauthorization Act, will continue critical federal programs that provide assistance to states to improve and expand their newborn screening programs, support parent and provider education, and ensure laboratory quality and surveillance for newborn screening. Without reauthorization, these programs will expire at the end of Fiscal Year 2019

As an advocate for patients with rare diseases you are a very important part of the legislative process. You can make the difference as you are the voices your legislators want, or in some cases do not want, but need to hear. Please click here to complete the online form to take action and contact your Members of Congress. This bill has been stalled in the Senate due to an amendment introduced that would stifle research – we need you to help us overcome this block.

After you take action your job is not done! The final step is to share the action alert with your family, friends, co-workers and any other people that might be interested in taking action on behalf of the rare disease community

Alternatively you can call 1-844-872-0234 and wait for the automated voice machine. Press "1" and enter your ZIP code XXXXX. This will connect you to your first senator.

Ask: Please cosponsor the Newborn Screening Saves Lives Reauthorization Act

Hi! My name is XXXX and I'm calling from [your city/town].

As a [patient or caregiver] in the rare disease community, I ask that you please cosponsor H.R. 2507, the Newborn Screening Saves Lives Reauthorization Act without the harmful informed consent amendment. This legislation will reauthorize critical federal programs that provide assistance to states to improve and expand their newborn screening programs, support parent and provider education, and ensure laboratory quality and surveillance for newborn screening. Without reauthorization, these programs will expire at the end of Fiscal Year 2019.

Newborn screening detects conditions that, if left untreated, can cause disabilities, developmental delays, illness or even death. If diagnosed early, many of these disorders can be managed successfullyand at a lower long-term cost. These public health programs were last reauthorized in 2014 with unanimous consent in both the House and Senate. Please stand with the 4 million babies born in the United States each year and cosponsor this legislation.

Please contact me at [your phone number] or [your email address] to let me know if you will support this effort.

Thank you for your service and for considering my request.

VMP, LLC
expanding genetic horizons...

Voice: 404.793.7800
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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

Mark Korson, MD
VMP Genetics
Director of Education

Jacob Athoe
Genetic Counseling Student
Boston University Genetic Counseling Program

VirtualMedicalPractice, llc
5579 Chamblee Dunwoody Rd, Suite 110, Atlanta, GA 30338

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/

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