



NEW YEAR, NEW OPPORTUNITIES

Happy New Year! In late 2019, our committees met up to discuss their priorities for 2020. We are excited to hit the ground running and start sharing our priorities and new resources for the year. This year you will see some fresh takes on some old items, but you will also see some new events and many new resources as well.

Some of our plans for 2020 include a webinar on how all the Homocystinuria's are connected, a Cobalamin Emergency Guide, local HCU meetups and much, much more!



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New OT-58 site!

HCU HERO: HALLIE FROM THE UK

Hallie was diagnosed at age 6 after 2 years of investigations following a rapid decline in her sight. It was discovered that she had dislocated lenses and had 2 lensectomy operations. We were under the impression that she had Marfan syndrome which has similar physical characteristics to HCU and samples were sent off for genetic testing which would apparently take months. Just days later we got the call that Hallie had Homocystinuria. That phone call and subsequent first meeting was beyond overwhelming. We're getting told our daughter, who was an amazing eater, all of a sudden will be going on a stricter than vegan diet, will be on medication for life, will need to undergo regular tests and is at risk of blood clots and strokes. In hindsight, the blind panic is unnecessary. You will adapt and so will your child. It's a lot to digest but you will work it out.



"You will adapt and so will your child. It's a lot to digest but you will work it out."

Our biggest HCU success is down to our little hero herself. From that first sip of her amino acid drink she gave us a big thumbs up and carried on. We had been prepared for this to be a daunting task after hearing they're so unpalatable and they don't go down too well. From that moment on, she's taken everything in her stride and adjusted accordingly. No it isn't fair; yes it's heartbreaking denying her something such as food, but she is an amazing, resilient girl and makes all our worrying seem ridiculous. My advice to families facing a new diagnosis is positive breeds positive. Make sure you have weighing scales, a note book and bear in mind that this will soon become second nature to you. 5 years on and I could probably tell you the protein allowance on half of the supermarket shelves. You can do this!

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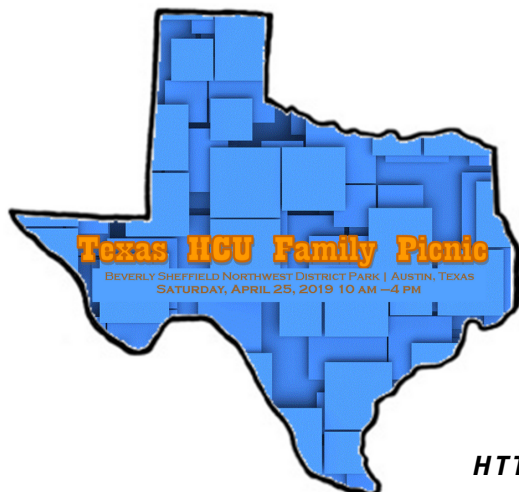
LET'S CONNECT

Will you be our next HCU patient Hero?



Tell us:

- How you or your child was diagnosed?
- How has HCU affected you, your family and relationships?
- What are some of your successes with HCU?
- What are some of your challenges you have faced?
 - How have you overcome them?
- What words of advice would you give to newly diagnosed families?
- For other patient stories, visit:
<https://hcunetworkamerica.org/patient-stories>
- Email your story to: info@hcunetworkamerica.org



HCU Family Picnic

Come Meet Up With Us!

25, APRIL 2020 - 10:00-AM 4:00 PM
BEVERLY SHEFFIELD PARK, AUSTIN, TX

REGISTRATION REQUIRED

[HTTPS://HCUNETWORKAMERICA.ORG/TEXAS-FAMILY-PICNIC/](https://hcunetworkamerica.org/texas-family-picnic/)

RECIPES FROM THE KITCHEN: CHINESE NEW YEAR EDITION!



Pho is a traditional Vietnamese soup made up of broth, rice noodles, herbs and meat (you won't miss it though in this recipe). Pho is a popular street food in Vietnam and served in restaurants around the world.

Pho Broth

Makes 4 servings

Ingredients:

- 1 TBSP Butter, regular or unsalted
- 60 g Mushrooms, white or brown (Crimini), sliced
- 85 g Half of one onion, skin removed
- 1 TBSP Oil, Canola
- 2 1/2 c. Vegetable Broth
- 1/2 c. Coconut Aminos
- 2 tsp Minced Ginger Root
- 1 tsp Minced Lemongrass
- 1 g One Cinnamon Stick
- 1/8 tsp Cloves, ground
- 1/2 tsp Cardamom, ground

Directions:

1. In a medium sauce pan over medium heat, melt the butter. Saute the sliced mushrooms just until browned. Remove from pan and set aside.
2. In the same pan add the canola oil and heat over medium heat. Add the onion, cut side down, and cook until caramelized. Flip and caramelize the other side.
3. Add the vegetable broth, coconut aminos, sauteed mushrooms, minced ginger, and minced lemongrass to the sauce pan with the onion. Bring to a simmer over medium heat. Cover with a lid and continue to simmer for at least 30 minutes.
4. Remove lid and add the cinnamon stick, cloves, and cardamom. Cover and simmer another 15 to 30 minutes. Remove the cinnamon stick and serve with your choice of noodles and vegetables for your own Pho.

Notes: You can add low protein spaghetti, rice noodles, glass noodles, sweet potato noodles, rice cakes bok choy, cilantro, bean sprouts, jalapeños, shredded carrot, siracha, spinach, watercress, onion, green onion, lime, mint, tomatoes – and much more! Just make sure to adjust the protein for these items!

Nutritional Information

- Serving size: 6 oz.
- Protein per serving: 1 g
- Calories per serving: 108

RECIPES FROM THE KITCHEN: CHINESE NEW YEAR EDITION!



Vegetable Green Curry

Makes 6 servings

Ingredients:

- 3 TBSP Olive Oil
- 50 g Slivered Onions
- 2 clove(s) Garlic, minced
- 100 g Diced Celery
- 100 g Sliced Carrots
- 114 g Sliced Bell Peppers
- 3 TBSP Thai Green Curry Seasoning, dry (pictured below)
- 230 g Red Potatoes, large diced
- 13 fl. oz. Coconut Milk, canned
- 2 1/2 c Vegetable Broth, ready-to-serve
- 150 g Zucchini, sliced and quartered
- Optional: Rice (not included in nutritional info.)

Notes: If you need to reduce the protein, reduce the amount of potatoes in the recipe or you can omit them altogether. If you do not use potatoes add the zucchini with the broth and coconut milk and simmer for five minutes then serve.

Nutritional Information

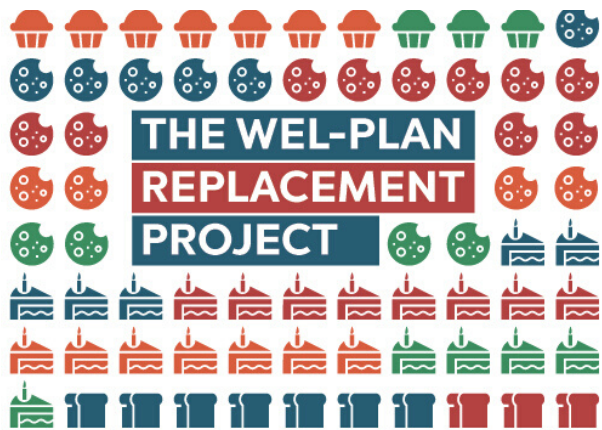
- Serving size: 204 g
- Protein per serving: 2.7 g
- Calories per serving: 217



Directions:

1. In a large sauce pot over medium heat, heat the olive oil. Add the onions and garlic and sauté for two minutes, stirring frequently to avoid burning. Add the celery, carrots, and peppers to the onions and sauté for five minutes. Add additional oil if vegetables begin to stick. Next add the curry seasoning to the sautéed vegetables and cook for one minute.
2. Turn heat up to medium high and add the potatoes, coconut milk, and vegetable broth. Bring to a boil, then reduce heat to medium and allow to simmer until potatoes are fork tender, about 30 minutes. Now add the zucchini and simmer for an additional 5 minutes. Serve with your choice of rice.

NEWS YOU SHOULD KNOW



The Wel-Plan Replacement Project Results!

In October 2018, Nutricia North America confirmed that they would no longer be importing and distributing Wel-Plan, the low-protein baking mix on which so many families had relied for decades. Shortly thereafter, Cook for Love undertook a semi scientific project to try to determine the best replacement for Wel-Plan: A baking mix that was accessible, affordable, and versatile enough to work in all the recipes Wel-Plan had worked in. Cook for Love received a grant from Nutricia to support the project, and donations of mixes from the following companies: Cambrooke Foods, Cook for Love, Flavis, Nutricia, Promin, and Taste Connections. We'd like to thank these sponsors for making this project possible, and also thank the volunteers who gave their time & taste buds to help us narrow down the competition. The results are in, and they are definitive (sort of). Read the results here: <https://pkunews.org/welplan/>

New OT-58 Clinical Trial Site Added

Orphan Technologies is excited to announce a new clinical trial site at **University of Miami** for a prospective enzyme replacement therapy drug, OT-58.

Sites now include:

- Children's Hospital of Colorado
- Boston Children's Hospital
- Indiana University
- University of Miami
- Children's Hospital of Philadelphia

To learn more, visit:

<https://clinicaltrials.gov/ct2/show/NCT03406611?cond=Homocystinuria>

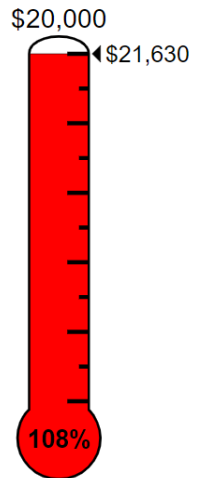
Or email: info@orphantechnologies.com



2019 ANNUAL APPEAL HIGHLIGHTS

Thank you to everyone who donated and helped fund-raise!

Our annual appeal started in October with HCU Awareness month. We had a good start to the month with several fundraisers hosted on behalf of HCU Network America. In October we raised \$3,278 thanks to the 10 families who set up fundraisers on behalf of the organization and to the many others for their individual donations.



HCU Awareness Month
Fundraiser Participants

In November we had another wonderful opportunity to raise awareness and funds for HCU Network America with Thanksgiving and a late Giving Tuesday. We also sent an email with an appeal letter that those in the community could share with their family, friends, co-workers and others. By the first part of December we were at more than half way to our goal. Thank you to those who set up #GivingTuesday fundraisers.



#GIVINGTUESDAY™

Giving Tuesday Fundraiser Participants

By mid-December, as our annual appeal was about to come to a close, we sent out a couple more emails recapping our accomplishments of the past year. Because of our successful campaign we were able to accomplish a lot in 2019! With these emails we were able to take in \$9,788 to continue our mission in 2020, and we will receive a match for the \$20,000 from our anonymous donor.

We are very thankful for our generous donations from our supporters! This was our second year that we not only met our goal, but surpassed it! We couldn't have had a successful 2019 without you and know this will be true for 2020 as well!

FUNDRAISING ALL-STARS: THE HAWKINS



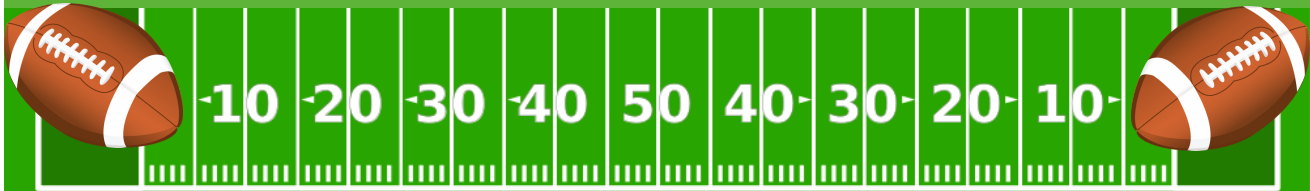
Chicago Bears v. Green Bay Packers Squares Fundraiser



Some rivalries turn out to be great opportunities for fundraisers. The Hawkins Family used the longstanding rivalry between the Chicago Bears and Green Bay Packers to host a squares fundraiser for HCU Network America in December. They did not just filled up one squares board, but two and raised over \$1,600 in the process. Way to go Kristen, Tom, Virgil and Annie!

JANUARY FUNDRAISING EVENT: SUPER BOWL SQUARES

Touch Down!



Big Sporting events are a great way to not just show your team spirit, but they are a fantastic way to raise funds for your charity of choice - HCU Network America!

How it works:

The cost is \$5 or \$10 donation per square. The purchaser writes his or her name in the square, and then the seller will randomly pick numbers 0-9 from each team in the game, and assign that number to a particular row or column (the grey shaded columns). These numbers represent the last numbers in the score of each team at the end of the game. In other words, if the final score is Giants 17 - Dolphins 14, then the winning square is the one with a Giants number 7 and a Dolphins number of 4. Since no one knows what numbers each square will represent, the odds are the same for everyone. So good luck and have fun!



Winner Breakdown:

If you sell 100 squares (you must sell all squares to host the fundraiser) at \$10 each, the funds raised are \$1,000. You can chose to split the pot evenly and the winner will get \$500 or get a large item donated for the winner and keep all funds raised toward your fundraising effort. (You can also decide to split the prize money and give some at half time or the end of each quarter.

For further instructions and templates:

<https://www.printyourbrackets.com/nflweekly100squares.html>

For online tools, check out:

<http://footballsquaresonline.com>

<https://www.runyourpool.com/nfl-football-pools.cfm>