

The HCU *Herald*



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HCU HERO: VIRGIL AND ANNIE FROM ILLINOIS



My HCU heroes are of course my kids, Virgil and Annie, who were diagnosed in 2016 and 2019 with HCU. Our third child, our son Charlie, was born in 2020 and doesn't have HCU.

When Virgil was born in 2016, the newborn screening at the hospital (or "PKU test") returned one abnormally high result. Our doctor ordered a re-test. Then we had to take him to ACL labs to get another blood test. Additionally, they also wanted a urine sample; we had to adhere a plastic bag around our baby boy, and once nature called, we had to drive it to a hospital an hour away to get it tested.

After about two weeks, the diagnosis was official: Virgil had Homocystinuria, a rare metabolic disease. Like any new parent we freaked out, and then when we visited Google MD we freaked out some more. Most sites describing the effects of Homocystinuria mention high risk of eye lens dislocation, delayed brain development, and an increased risk of stroke and blood clots. None of the sites contain the caveat, "these risks are close to zero if treated properly through diet."

Our doctors reassured us though: with a special metabolic formula and following a rigid "low protein" diet, he would develop normally and lead a happy, healthy life. Four years later that has come to pass.

Luckily, Virgil has been a rock star, and has always been fully compliant in drinking his metabolic formula. He doesn't fully understand yet that he is on a special diet, but he happily drinks his "milk" each day (HCU Next, about 25oz per day), and we keep his protein from foods (with the help of our amazing dietician at UIC Chicago and meticulous tracking) to 6g per day.

At the moment with our picky toddler, his meals mainly consist of gluten-free bread/toast, dairy-free cheese, LOTS of fruit pouches and some veggies pouches, and chips.

To say Kristen & I were overwhelmed – and scared, worried, sad – after the diagnosis was an understatement. But, we were able to figure it out together. As part of the low-protein regimen, Kristen had to alternate feedings, one breastfeeding, one special formula. Virgil took to this well and was growing and thriving. His blood levels quickly dropped to a good place. Alternating feedings was difficult, as were the extra pumping sessions for Kristen, bottle feedings, and tracking of what he

consumed each day. Luckily I had a generous paternity leave so was off of work, and we were able to figure it out together.

Fast forward to 2019. As we were awaiting our second baby, we knew that as carriers for Homocystinuria, baby #2 had a 25% chance of having the condition as well. But surely that wouldn't happen, right? Annie was born on a Friday afternoon in April. They did her blood test Saturday afternoon and told us we would have results by Sunday. Given we had a newborn, we slept a few spotty hours that night. I woke up Sunday morning a bit delirious, with our pediatrician already in our hospital room doing her newborn check-up. After going through vitals and blood pressure, she checked the computer for blood test results: her homocysteine level was 60, and the typical range is 0-10. EXPLETIVE. Annie was also diagnosed with Homocystinuria.

The second time around it stung less, and we were able to process it all faster. Having been through it once, we already had a deep understanding of the condition and treatment. We already had a pantry full of formula for Virgil that we could begin providing to Annie. Yet, though we were more prepared, it was extremely helpful to be off of work as we dealt with it (extra doctor appointments, delivering blood samples, etc.).

A lot of people said to us after Annie was diagnosed with HCU: "Isn't it better that Annie has it too, so Virgil doesn't have to watch his sibling eat things he can't?" While it's a silver lining that they will have each other to relate to, you would never want your child to have a chronic health condition.

Annie is now almost two years old, and she makes us laugh every day. She is currently limited to 3g of protein per day (both kids are non-B6 responsive), but she is also great about drinking her formula each day (25-30oz per day). Having heard parents' stories of kids that were diagnosed when they were older, we feel extremely lucky that both kids were diagnosed from the newborn screening, so they could start drinking the formula from birth.

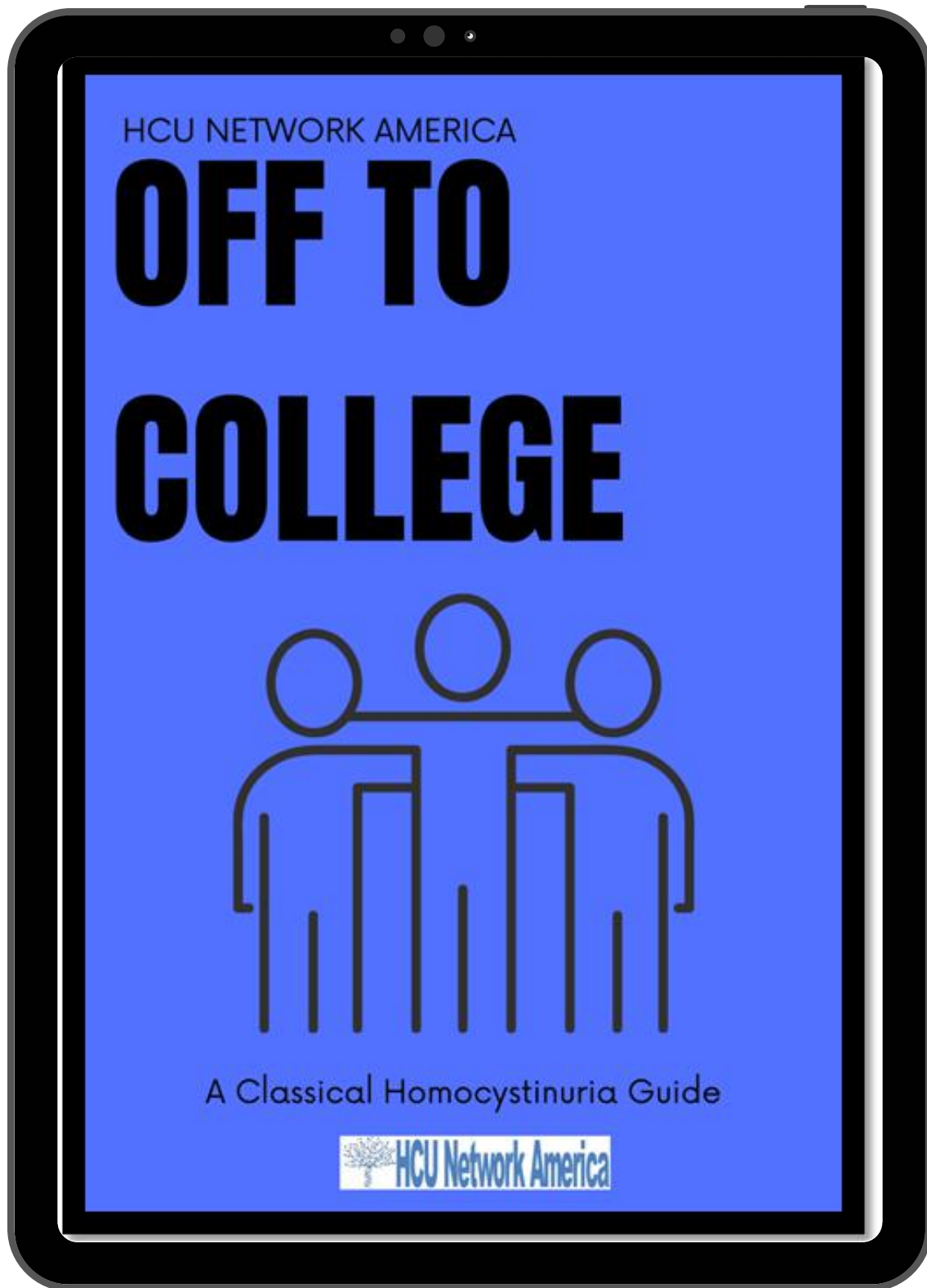
Some things that have worked well for us have been making games at the dinner table. When Virgil started on Cystadane (age 2 or 2.5?) it was really hard to get him to finish all of his water during dinner, like the doctor asked. So we did a lot of "cheers" and we did "water drinking races", etc., to get him to finish. We also watch a lot of TV in our house - and we've found that if one of the kids is low on their formula intake for the day, when we put a show on they mellow out and drink 5-10 ounces when we plop them on the couch.

Having been in the HCU community for almost 5 years now and hearing about older kids rebelling against formula, or growing to dislike the taste, makes me very worried about the future. We also know that Virgil, who is almost 5, is a very stubborn and willful child - so is there a risk he grows older and becomes stubborn and willful about staying compliant with his diet? We've also noticed that Annie has taken more of an interest in her parents' food and wanting to grab items from our plate - so she may be a handful as well.

But as of now they are both doing well and are growing and thriving. Here's hoping in a few years time there will be a cure!

Tom Hawkins | tmmyhkw09@gmail.com

NEW RESOURCE



Check out this resource to help Classical HCU patients and their parents plan for this big transition at:
<https://hcunetworkamerica.org/toolkits-and-checklist/>

February 2021: HCU and You: *Ask Methia*

Dear Methia,

I Don't Know What to Eat!

Plain and simple: I don't know what to eat! Many nights, I find myself standing in front of the fridge, trying to put together a compliant dinner. If I can't find anything, I either get frustrated and don't eat anything, or I order take-out (which, of course, is typically whatever I'm craving with no attention to compliance). I feel like I am probably just not planning out my weeks very well. Can you give me some suggestions?

Sincerely,
Refridgerator Warrior

Dear Warrior,

A very common phrase that dietitians use when trying to encourage change is, "If you fail to plan, you plan to fail." I don't really like using the term "fail," but the truth in this statement is that not planning ahead of time certainly does not help you achieve your goals.

There are certainly ways to become better prepared to make compliant weekly meals. Here are some ideas:

1. **It all starts with writing it down!** Before you go grocery shopping, think about your meals for the next week. Use some cookbooks or websites to find a new recipe you'd like to try to make it fun, and stick to a few that you already know and love. Think about recipes that make multiple servings so it takes the pressure off finding something for another meal. Make a menu for all seven days for breakfast, lunch, dinner, and some snacks if that's something you enjoy.
2. **Write down all of the items you will need on your grocery list.** I can't tell you how many times I plan out my own weekly menu, come home from grocery shopping, and realize I forgot ONE ITEM! Talk about frustrating. This often results in me either dragging my feet back to the store for that one thing, or just putting off the recipe for the following week (this is the most common!). To avoid this from happening, double (or even triple!) check your list before leaving for the store.
3. **Read food labels while you shop to make sure you are purchasing the correct ones.** Manufacturers change the ingredients in their foods constantly. This is especially important for you if an ingredient change affects the protein content, of course. A food item you may have loved years ago may now be higher or lower in protein than you remember, and blindly purchasing an item before checking the protein content per serving might affect meal plan compliance. Also, never assume that two different brands' version of the same product (for example, gluten free pasta) are the same in protein content! They can differ drastically and sometimes recipes that use specific brands utilize that brand for a reason.

Even if you don't think you could put together an entire week's worth of meals, start with a few days! The more you expand your menu and find new recipes, the better equipped you'll be to fill up your week with delicious meals. Your metabolic dietitian would likely be more than happy to review your menu and even offer suggestions. Remember, you have a support system, and within that support system there is almost always a solution!

Sincerely,
Methia

THIS WEEK'S MENU

M

Breakfast: Waffles & Peaches

Lunch: Asian Stir Fry Pasta

Dinner: Burger & Pretzels

T

Breakfast: Pancakes & Strawberries

Lunch: Tacos

Dinner: Veggie Pasta

W

Breakfast: Oatmeal, Strawberries & Bananas

Lunch: Broccoli Soup & Salad

Dinner: Pizza

T

Breakfast: Yogurt, Granola & Blueberries

Lunch: Pasta Marinara & Broccoli

Dinner: Quesadillas

F

Breakfast: Avocado Toast

Lunch: Mac & Cheese, & Green Beans

Dinner: Shepards Pie

For HCU Network America, 2021 is all about Back to Care. We know it's easy to stray away, but as patients age, they realize the importance of keeping in contact with their clinic, following their diet, and keeping themselves all around healthy! As part of this initiative we will be bringing to you a weekly meal plan every other month. We are hoping that this will make the transition of Back to Care just a little bit easier! Be on the lookout for more helpful resources this year to help guide you Back to Care!

Each day has meals for <10 of protein day, 20-30 of protein day, and 30-40 of protein day.

Shopping List

Click each day to view the week long menu!

Disclaimer: This meal plan is intended to be a foundation or guide to what meals could look like on a low protein diet. It does not take into account individual caloric, protein and formula requirements, which are all patient-specific. Please consult with your metabolic geneticist and dietitian prior to making any significant dietary changes or following any meal plans of which you are unsure.

HCU COMMUNITY COOKBOOK

Mardi Gras

Cheesy Vegetable Etouffee



Makes 6 servings

Ingredients:

- 4 TBSP Butter, regular or unsalted
- 55 g Diced Onion
- 45 g Diced Celery
- 2 clove(s) Garlic, fresh cloves, chopped, minced
- 85 g Diced Bell Peppers
- 130 g Canned Diced Tomatoes
- 2 TBSP Wheat Starch
- 6 fl. oz. Vegetable Broth, ready-to-serve
- ¼ c Rice milk
- 150 g Chopped Zucchini
- 60 g Chopped Mushrooms
- 1 tsp Bay Leaf
- 2 TBSP Parsley, dried
- 1/2 tsp Thyme, ground
- 3/4 tsp Pepper, black
- 1 tsp Salt, Table
- 10 g Cheddar Cheese Savory "Shakes"
- Serve with low protein rice of choice (not included in nutritional information).

My husband and I enjoy going to a Creole restaurant called Yats and my daughter always wants to try it. I came up with this recipe to be similar to the chili cheese etouffee that is popular there. I made this with vegetable broth, but if you want a more authentic flavor and you diet allows it, you can use a seafood broth in its place.

Directions:

1. In a large skillet over medium heat melt the butter. Once the butter is heated add the onions, celery, garlic, and peppers. Cook for 5 minutes, stirring often.
2. Add the diced tomatoes to the skillet and stir. Now add the wheat starch to the skillet and cook until the starch has thickened and absorbed the liquid. Slowly pour in the broth while stirring. Cook for 1 minute. Add the zucchini, mushrooms, bay leaf, parsley, thyme, salt, and pepper. Cook over medium heat for 20 minutes, or until the etouffee has thickened and vegetables are tender.
3. Now sprinkle in the powdered cheese and stir. Serve hot over rice of your choice.

Nutritional Information: Serving size: 116 g | Protein per serving: 1.5 g | Calories per serving: 112

Happy Chinese New Year!

February 12!

Vietnamese Spring Rolls

Serving per recipe	12
Serving size	1 roll
Protein per serving	2.28 g
Calories per serving	55

Low Protein Fried Rice

Serving per recipe	12
Serving size	
Protein per serving	2.22 g
Calories per serving	280

Sticky Jackfruit Wings

Serving per recipe	6
Serving size	166 g
Protein per serving	1 g
Calories per serving	220



UPCOMING 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.

Note our new registration page: <https://hcunetworkamerica.org/virtual-meet-ups/>



HCU Community Virtual Meet-up

Online meet-ups are an opportunity to connect patients and caregivers impacted by homocystinuria to one another virtually.



MMA & Cobalamin Community Virtual Meet-up

Online meet-ups are an opportunity to connect patients and caregivers impacted by methylmalonic acidemia and cobalamin disorders to one another virtually.



- Sun., February 7 @ 7 pm CST
- Mon., February 22 th @ 1 pm CST | 7 pm UTC

- Sun., February 21 @ 7 pm CST

NAVIGATING RELATIONSHIPS
A PATIENT PANEL PERSPECTIVE

LOW PROTEIN COMMUNITY CHAT

SATURDAY, FEBRUARY 27, 2021 | 10 AM CST
FREE | REGISTER AT [HTTP://BIT.LY/NAVIGATINGRELATIONSHIPSLPCHAT](http://bit.ly/NAVIGATINGRELATIONSHIPSLPCHAT)

Logos at the bottom: HCU Network America, MSUD Family Support Group, Organic Acidemia Association, PKU News, and PHE.

Please join us for a one-hour panel discussion on Saturday, February 27th at 10 am CST featuring young adults and adults with various low protein disorders, including Homocystinuria (HCU), Maple Syrup Urine Disease (MSUD), Methylmalonic Aciduria Mut(0) and Phenylketonuria (PKU). During this discussion, our moderator will explore questions of how the diet has impacted their relationships with family members, friends, co-workers, roommates, significant others, and spouses.

Patients, Parents, Caregivers, Medical Professionals and Industry from various communities are all encouraged to attend. Register now: <http://bit.ly/NAVIGATINGRELATIONSHIPSLPCHAT>

SHOW YOUR STRIPES®

ON RARE DISEASE DAY®
FEBRUARY 28TH

#ShowYourStripes on #RareDiseaseDay



NORD's **#ShowYourStripes** campaign takes its cue from the majestic zebra, the unofficial symbol of rare diseases in the United States. Showing your stripes means embracing your uniqueness and expressing support for people living with rare diseases. To raise awareness around rare disease issues, we are asking the world to show its stripes leading up to and on Rare Disease Day. Here are three ways to get involved!



Share Your Story

Sharing your experience helps others understand what it is like to live with or care for someone with a rare disease.

Download NORD's resources for tips on how to share your personal story with your local media outlets or online, and submit it for the NORD site [here](#).



Join the Movement!

Get involved with the Rare Action Network (RAN) in your state and participate in virtual statehouse events to drive change in your community!

Sign-up to make a difference with RAN: rareaction.org



Join the Movement!

There are many ways you can still Show Your Stripes and make this day impactful and celebratory as we endure the ongoing COVID-19 pandemic. Embrace your stripes by [sharing a message](#) using **#ShowYourStripes** and **#RareDiseaseDay** in your social media posts, or help your rare community [light up buildings and landmarks](#) in your area on or around February 28.

SHOW YOUR STRIPES®

ON RARE DISEASE DAY®
FEBRUARY 28TH

#ShowYourStripes on #RareDiseaseDay



Shine a Light on HCU During Rare Disease Day!

Get your T-Shirt: <https://www.bonfire.com/rare-disease-day-hcu/>



What does RARE mean to you?

During February, leading up to Rare Disease Day, we challenge you to write an Acrostic Poem about what Rare means to you.

An acrostic poem is a poem where certain letters in each line spell out a word or phrase. Typically, the first letters of each line are used to spell the message, but they can appear anywhere.

Remember to use the hashtags
#ShowYourStripes , #RareDiseaseDay
#ItsInMyGenes #GoBlueforHCU
Here is our example:



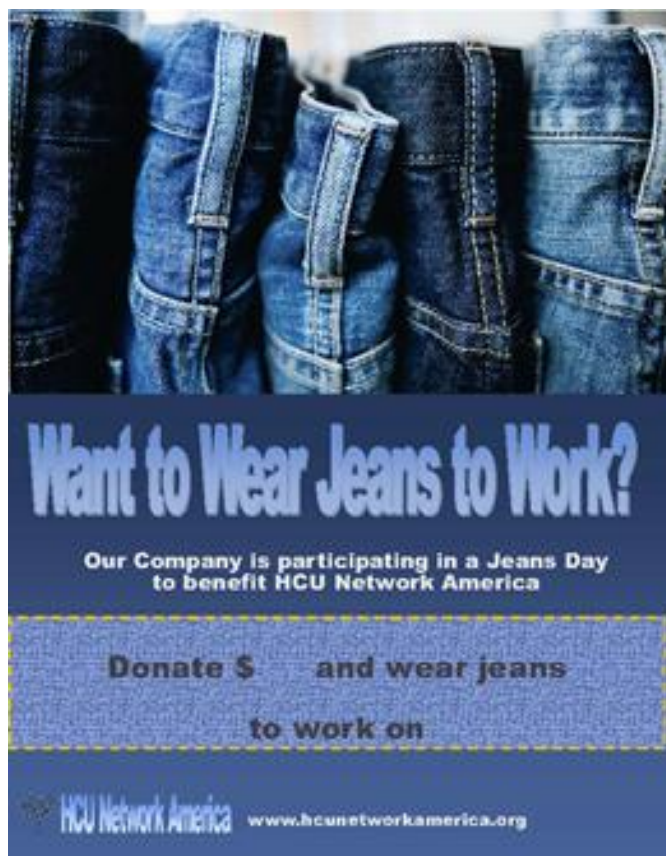
FEBRUARY FUNDRAISING EVENT: CASUAL FOR A CAUSE



Itching to forgo the traditional slacks and skirts for a more relaxed look at the office?

Take the lead in your company to sponsor a Casual Cause: Jeans Day to **raise funding for the resources and tools HCU Network America** provides to the Homocystinuria community!

Encourage employees to dress down for a day or even an entire week by requesting donations in exchange for a day in their casual best.



Not sure where to start? No problem! We've created several "Team Captain" materials to help you on your way toward sponsoring a successful fundraiser. Take a look at our customizable flyers, stock emails to inspire participation, tracking sheets and more! View resources at:

<https://hcunetworkamerica.org/casual-for-a-cause/>

NEED HELP HOSTING A FUNDRAISER? EMAIL US - INFO@HCUNETWORKAMERICA.ORG

LAND OF THE FREE, HOME OF THE BRAVE

June 26-27, 2021 | Bethesda, Maryland



To learn more or register, visit: <https://hcunetworkamerica.org/2021-conference>

GET INVOLVED WITH HCU NETWORK AMERICA

JOIN OUR FUNDRAISING TEAM

We are looking for new community members to join our fundraising team!

Help create, organize and support new and existing fundraising ideas.

These vital funds help support our outreach, programs and research!



Email us:
dbartke@hcunetworkamerica.org



COBALAMIN STEERING COMMITTEE

Representing Cbl C, F, G - with hopes of E, J and X to join us!

JOIN US!

HELP DRIVE THE FUTURE OF
COBALAMIN DISORDERS



LEARN MORE ABOUT THE COMMITTEE AT:
[HTTP://BIT.LY/HCUNACBLSC](http://bit.ly/hcunacblsc)
OR EMAIL: BPARK.HCUAMERICA@GMAIL.COM



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**



HCU Network America

ADVOCATE FROM HOME!

REGISTRATION IS NOW OPEN
RAREACROSSAMERICA.ORG



#HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR
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YARR

Leadership Academy

The next step in your advocacy journey starts here.

HEARUSYARR.ORG



March 23, 2021: Virtual Webinar

May 1, 2021: Las Vegas

May 15, 2021: Miami

May 22, 2021: Chicago

#RAREOnTheRoad

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.

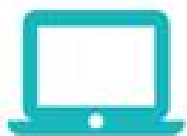


55% of participants in an MUA were previously aware of NBS compared to **67%** of those living in other areas.



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](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