

PKU Wellness Journal

HEALTHY YOU HEALTHY PKU

Mental, Physical and Emotional Health on a Low Protein Diet

Windkribes

How are you?

We're so excited you have decided to start on this journey with us, so you can take the first of many steps to achieving optimum physical, mental and emotional health on a low protein diet.

We hope your journey will be one of both discovery and courage.

Discovery, as you will be given the tools you need to monitor your diet, symptoms and progress over the coming weeks and months and **courage**, as you put your action plan into practice, developing habits that will last a lifetime.

Please note: This journal is for people living with Phenylketonuria (PKU).

The personal experiences shared throughout this journal are not those held by Ajinomoto Cambrooke.

Always consult your metabolic dietitian before making any changes to your diet.

Important Information

| Name: | | |
|----------------------|------------|--|
| | Telephone: | |
| Hospital Name(s): | | |
| | | |
| Dietitian Name(s): | | |
| | Telephone: | |
| Email: | | |
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| | | |
| | | |
| Primary Care Doctor: | | |
| | Telephone: | |
| Formula Supplier: | | |
| Email: | | |
| Details: | Telephone: | |
| | | |
| Specialty Pharmacy: | | |
| Email: | | |
| Details: | | |
| | | |

Useful Links

SOCIAL MEDIA

- National PKU Alliance (NPKUA)
- Cook for Love
- How Much Phe
- Phenylketonuria World Wide Support Group!
- PKU Friendly
- PKU Strong
- Ajinomoto Cambrooke **Metabolic Nutrition**
- Low Protein in 15
- Canada: Canadian **PKU** and Allied Disorders (CanPKU)

WEBSITES ☑

PKU Diet

- nPKUa.org
- canPKU.org
- PKUnews.org
- howmuchphe.org
- cookforlove.org
- lowprorecipes.com
- golowpro.org
- rarediseases.org

Mental Health

- Adaa.org
- Mentalhealth.gov
- Nami.org
- Health.gov

Physical Health

- My Fitness Pal
 - Map My Run
- 30 Day Fitness at Home
- Fitness Buddy
- FitOn
- Fiit
- All Trails
- My Water
- Daily Yoga
- Pocket Yoga

APPS

Mental Health

- Reflectly
- Day On
- Headspace
- Calm
- The Breathing
 - App
- Streaks
- Mediation by Soothing
- Affirmations-Daily Motivation!





Feel balanced. Feel better.™

Available for download:

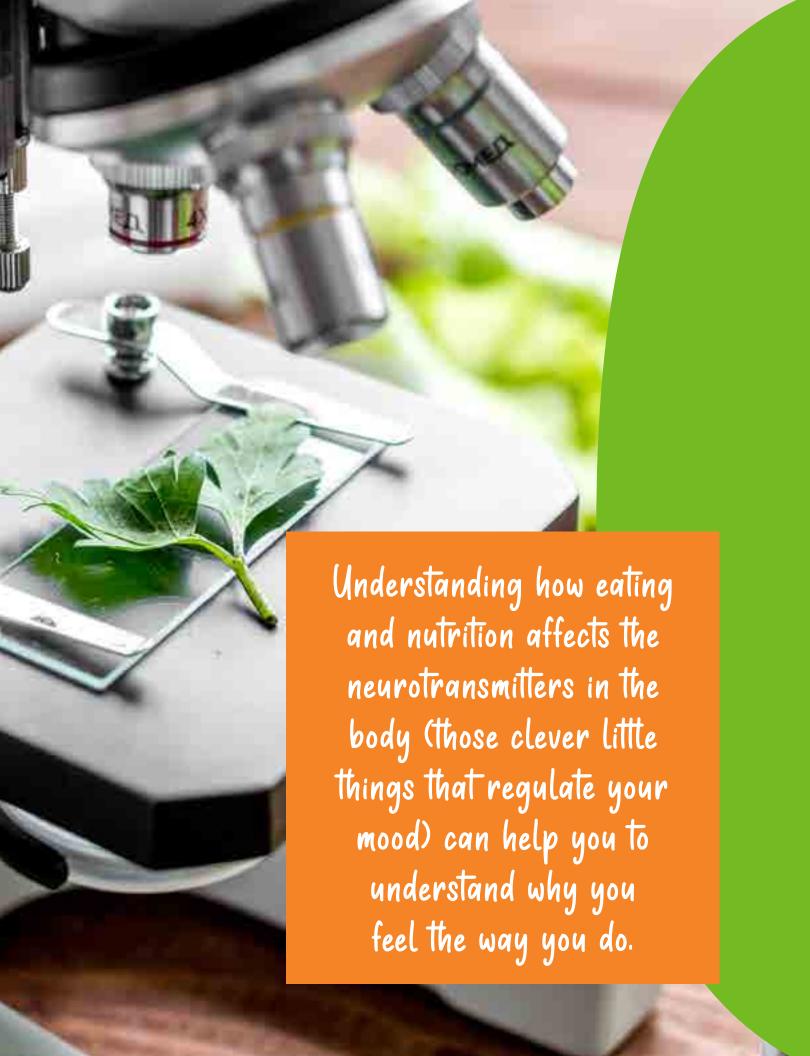
Android on Google Play
Apple App store

Metabolic Balancer is designed to help you manage your PKU diet.

This app guides you through your meals, snacks, and formula intake.

Use Metabolic Balancer to:

- Discover dietary information for over 7,500 low protein foods and formulas
- Search and learn the Phe content of your food
- Track your blood levels
- Print or email your diet log before clinic visits
- Record your food over time to make connections between what you eat and feeling well
- Track your Kuvan intake



01. The Science



GOOD NUTRITION HAS NO SIDE EFFECTS!

Why is PKU formula important?

"Thankfully formulas have come a long way and I was able to choose one that was tasty, low volume and that I could easily take to work with me."

- Debbie Colyer, Classical PKU

- What you eat and drink affects your energy level and how you feel.
- Your body needs protein. It helps to build, repair and maintain your skin, muscles, organs, blood and even bones.
- Formula may be part of your PKU treatment. If so, it is important to take daily and spread throughout the day to keep Phe levels stable. There are many different formulas e.g. ready-to-drink liquids, powders, bars and tablets.
- You also need vitamins and minerals if you are following a Phe or protein restriction. These are usually in your formula. If not, your Dietitian will recommend a supplement.



Mix-ins



Ready-to-drink cartons



Milklike powders



Bars

- ✔ It is important to try different formulas and find the right ones for you. Speak to your Dietitian about getting samples.
- ▼ To find out more about Cambrooke formulas, visit <u>Cambrooke.com</u>

Jack Domnick

A bit about me

My name is Jack Domnick, I am 25 years old, and I have Classical PKU. I am from Wichita, Kansas where we have beautiful sunsets and that's about it. I graduated from Kansas State University in December 2019, with a Bachelor's Degree in Social Sciences (with an emphasis on Business), and am currently working in a private clinic with children with special needs.

My PKU journey

Growing up in Kansas with PKU in the early 2000s was no easy task. I didn't know anyone else who had PKU (or anything like it) and there weren't nearly as many readily available foods as there are now. My parents felt like the clinics near me weren't the best fit, so when I was two, we made the trek to The Children's Hospital in Colorado for treatment – and I still go there today. I've been on diet all my life – okay, I've cheated here and there, more

I've cheated here and there, more than what I'd like to admit, but when I am off diet, I feel so sluggish and it is hard to get out of bed.

I feel like I'm watching myself do the things I am doing, like my head is in a fog and I'm walking through a forest in the early morning where you can hardly see where you are going, but you are still moving.

When off diet, I find it hard to keep my

emotions in check. I hate the feeling I have

PATIENT

when my levels are off, so I'm motivated to stay on track. When my levels are steady, the fog is lifted and I feel more normal. When it comes to food, which I'm not a huge fan of personally, I mainly eat low protein pasta, bread, all varieties of potatoes and lots of sugary foods.

Staying on diet has helped me reach my full potential. I played football, basketball, and tennis in high school.

I participated in intramurals in college, and currently enjoy weightlifting, running and biking. PKU will never

hold me back or stand in the way of me doing what I want to do.



Stop and notice the beautiful things that can happen through having PKU"

Mental health and PKU

Having PKU has been both a blessing and a curse. I feel like I was left out of a lot of things because my friends didn't want to eat in front of me. Also, I didn't know all the cool restaurants to take dates to because I rarely ate out and my parents always stuck to their favorite eateries. Not knowing other kids with PKU growing up made me feel lonely with no one to talk

to. But having PKU has also blessed me with amazing lifelong friends and priceless memories. I've been able to travel to Boston, New York, Montana, Utah, and Colorado, all because I have PKU. I've been able to ride in the Courage Classic bike ride and got to ski for the first time because of people I met through having PKU. Although my life is different than most, and I have to make specific choices every day, it's like everything in life - it all depends on your perspective. If you only see the negatives of PKU, then your whole life will only be about negatives, but if you stop and notice the beautiful things that can happen through having PKU, then it can help make life great.



Your body and PKU

Brain

High blood Phe levels can affect how you think and feel. Keeping blood Phe levels in range helps to balance your neurotransmitters in the brain.

> Neurotransmitters control many things in the body like sleep and digestion. Examples of neurotransmitters are Dopamine and Serotonin.

- **Dopamine:** releases during enjoyable activities and is important for learning, memory, muscle movement, and more.
- Serotonin: Helps regulate your mood, sleep, appetite, digestion, learning ability, and memory.

Heart

Eating foods high in calories, sodium, and saturated fat can lead to clogged arteries. Fruits and vegetables are an important part of a healthy PKU lifestyle. They are high in nutrients such as vitamins and fiber that are essential for heart health. Eating a variety of fruits and vegetables and maintaining a healthy weight are key to lowering your risk of heart disease.

Liver

This is the organ that breaks down Phe using an enzyme called phenylalanine hydroxylase (PAH). This enzyme is not working so Phe builds up and does not allow your body to make tyrosine, an essential amino acid in PKU.

Symptoms of high blood Phe levels:

- ▼ Feeling "foggy" or slow processing of information
- Problems with memory









- Anxiety, depression or irritability
- Difficulty in decision making, problem solving, and planning
- Unable to pay attention

Paul Bremer

A bit about me

Hello, I am Paul Bremer and I was born in Connecticut in 1965. When I was a child I was quiet, reserved and had a lot of blonde hair, fair skin and blue eyes when the rest of my family had dark hair and dark skin. My clinic at Yale was a scary place as a child! I was the one patient all the doctors knew of. I remember having four physicians caring for me. I was good at giving blood and I remember I was on television for a news report on PKU.

Coming off diet

I was on diet from diagnosis to age 8 (1973) and have struggled with this my entire life. There were very little choices back then, for formula, food or clinic services. As a child I could not handle formula, it was too thick, the smell was disgusting, and it had no flavor!

I remember gagging it up. At one point, we tried to make it into a salad dressing. It didn't work.
I thought I was a bad kid because I could not get it down. I know my mom was really struggling to find ways to get me to drink it.

Anything to help boost dopamine and serotonin is a good thing!"

Then at age 8, I was told with my mom that I could discontinue the diet, and the clinic would still follow me. That was the big mistake I have never recovered from to this day! When I was 13, I was told to consider going back on diet. I refused. There were still no choices for formula, and no alternative foods.

My mental health on and off diet

PKU definitely affects your mental health and how you feel about yourself. It also affects your surroundings and how you relate to others. I try and push myself every day. There are lots of methods that can be used to help. You just have to find the right one for you. Anything to help boost dopamine and serotonin is a good thing!

As a young kid, I didn't feel a huge difference. It was great eating a hamburger and french fries, but it eventually faded and problems began to set in. Guilt, sadness, lack of concentration, memory loss, how I felt about myself, body odor and anger, were all emerging. What was happening to me? It has been such a subtle decline over many years.

On diet, or when I have access to formula, I feel so much better. But this is short lived if you don't have access to continuous support. My energy improved, my concentration improved, how I related to people improved and that is especially important in a work setting or at home. I remember losing many jobs because of PKU symptoms and its effects on my concentration.

Sleepiness, irritability, memory, motor skills, many physical aspects of life, are

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all impacted by high Phe levels! I know, I am still dealing with them today. Especially as I get older.

Advice for others managing their mental health

I try to eat what I should and although it is almost impossible to stick completely to the diet, you have to find the right balance for you. I think that is true in every aspect of life.

I have found poor finances can restrict your choices too so you have to find a compromise. I try to find any wellness services that I can take part in, until I get better coverage. These include walks, music, movies, eating healthy green foods, organic foods, teas and more. You must push yourself to do better because that accomplishment is great for your wellbeing!

Travel is another way to boost your wellbeing, and meeting others from many countries around the world is simply amazing and it helps you become a more well-rounded person. The internet also helps in connecting you with others from around the world and learning of their PKU journey.





Give yourself a Dopamine Lift!

Some ideas...

- ☐ Go for a walk, bike ride or run. Exercise is also good for heart health!
- ☐ Go to the movies with a friend
- ☐ Learn a new skill: knitting, painting, a card trick
- ☐ Baking, make low protein cookies or cupcakes
- ☐ Learn a language
- ☐ Call a friend that you haven't talked to in a while
- ☐ Watch a funny show or movie
- ☐ Mindfulness and meditation practices (see the next page to get some ideas)

My goals...

Mental Health and Wellbeing

Physical and mental wellbeing go hand in hand. Good mental wellbeing doesn't mean you're always happy or unaffected by what happens to you day to day. But poor mental wellbeing can make it more difficult to deal with daily life. There are lots of things we can do to take care of ourselves.

We asked yoga, meditation and mindfulness coach Lillian Mirsafavi to share the benefits of mindfulness and how you can incorporate it into your routine.

Mindfulness

Mindfulness is really simple. It means being fully present in each moment, and even five minutes a day will make a huge difference to your physical, mental and emotional well-being.

It's especially important to practice mindfulness when managing your own health or caring for others. The busier life is, the more important it is to take small moments through the day to pause.

5 minute morning activity: Morning journaling

This can be done before getting out of bed, or once you have made a cup of coffee. Take a notebook, turn to a blank page, grab a pen and write! Journaling is an amazing way to start the morning. You can "free write" whatever comes to mind, writing out thoughts and worries so these are left on the page before you start your day.

Another quick and easy way to journal is by writing three things you are grateful for.

The journal is just for you, you don't have to show it to anyone so write away!

5 minute lunchtime activity: 5 senses check-in

This can be done while sitting at your desk, sitting in a quiet space or while walking.

- See: Start with sight, look for five things you can see, focus on each one by one.
- ✔ Hear: Next listen for five sounds, even if you think there is "silence," try to pick out five different sounds from it.
- Smell: Then notice any smells? What are they? What do they make you think of?
- Taste: Notice the taste on your tongue.
- ▼ Touch: Lastly, feel your clothes against your skin, feel the surface you are sitting, standing or walking on.

Tune into each sense one by one and really connect with the information you are receiving.

15 minute evening activity: Belly breathing

Belly breathing is an amazing way to destress and prepare for a good night's sleep. Throughout the day we tend to breathe only into our upper chests and our breath can become shallow during times of stress.

Lie on your back, placing your right hand on your belly and your left hand on your heart. Breathe deeply in through your nose, feeling your belly rising up to the ceiling. Pause for a moment and then slowly breathe out through the mouth, feeling your belly softly falling. Try to breathe in for a count of four, and out for a count of four.

-Lillian



Sleep

Sleep is vital for mental and physical health.

A Dutch study found 48% of men with PKU had symptoms of a sleep disorder, compared to just 19% of their close relatives.

If you have problems sleeping, there are techniques recommended by the National Sleep Foundation and Mayo Clinic that can help you learn how to sleep through the night:

Stick to a sleep schedule

Go to bed and wake up at the same time every day – even on weekends.

Make your bedroom ready for rest

Keep the light low, and don't look at screens in your bedroom – the light from a TV, laptop, or phone can keep you awake.

Try not to take afternoon naps

They make it harder to get to sleep at night.

Get exercise

It sounds funny, but moving more during the day can make it easier to rest at night.

Good habits before bedtime

Caffeine, alcohol, nicotine, and even a heavy meal close to bedtime can interfere with sleep.

Stop taking your worries to bed with you

Racing thoughts and anxieties can keep you up at night. Find a way to manage stress, and it will help you to sleep easy.

Do your best to track what you eat and take your formula on schedule if this is part of your PKU management. Getting the nutrition you need can help reduce symptoms of anxiety and depression that make sleep a struggle.

Read more: https://www.cambrooke.com/blog/2018/03/getting-enough-sleep-with-PKU/

Kevin Alexander

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A bit about me

Hi! My name is Kevin Alexander and I'm an adult living with Phenylketonuria. I didn't know anyone else with PKU until I was in my early 30s. This was long before social media. All that changed shortly before my 31st birthday. I'm a professional videographer and I made a film called "My PKU Life" and shared it on YouTube. I never imagined anyone would actually see it. Before long, it had been shared across the world, I was invited to speak at numerous newborn screening and PKU events, and most importantly, I became friends with countless others who also have PKU.

My relationship with PKU diet

I never came completely off diet, but I did struggle in my teens. I grew up in the 80s and 90s before the advice on 'diet for life' was published and so I tried new foods just to see what they were like. That experimentation led to me becoming more relaxed. From the age of 16, I was eating a basic vegetarian diet, but definitely not low enough in protein. I also wasn't drinking formula anymore. I didn't realize it at the time but looking back I can see how much of an impact that had on me. When off diet it is very hard for me to concentrate for long periods of time, so I struggled in high school and college. I could understand material, but I didn't have the motivation to get good grades. Looking back, I can also see that it caused depression during those years. When I was in my early twenties, I started working in television news as a news videographer. The hours were long, the

work was physically demanding and since I wasn't diligent with my diet, it took a

physical toll on me. My wife noticed the

impact that it was having on my health and recommended that I reestablish contact with my PKU clinic.
I resumed my diligent approach to the diet and started drinking formula again. Shortly thereafter I noticed a huge difference.
I was better able to be focused and maintain physical strength while at work.

Connecting the dots

Connecting the dots between your diet and your health is often difficult. The symptoms of unmanaged PKU impacts the way you think and perceive the world around you. In my case, I thought everything was fine. I knew that I was tired all the time, but I convinced myself that it wasn't related to PKU. I also couldn't see the negative impact it was having on my mental health. Thankfully, I had someone close to me who could see it, who loved me, and who made the suggestion that I visit my PKU clinic. I'm very glad I did because looking back all these years later, it changed the course of my life. I believe PKU influences the way I perceive everything. It is the filter through which I

I believe PKU influences the way I perceive everything. It is the filter through which I see the world. After I began to meet others with PKU, life became much easier. Even if the people around me didn't understand my challenges, I knew I wasn't alone anymore. I had friends across the world who did understand... and that was okay.



I believe hobbies aren't a luxury, they are a necessity."

Steps I took to improve my mental health

Number one for me is following the PKU diet, but I also read, write in my journal, play music and enjoy yoga. I believe hobbies aren't a luxury, they are a necessity. For me, it's always been music. I've played guitar for over 25 years and I am currently learning how to play piano properly. Over the past year I have been learning how to compose music. I think having an outlet is so important to relieve the pressures and stresses of life. When my schedule allows, I also try to get in some physical exercise.

My biggest piece of advice

Know that you aren't on your own. It's much easier to cope with PKU when you have friends to talk to about it. Surround yourself with like-minded people with a positive outlook. I have made friends through the NPKUA conferences who have become like brothers to me. It's so nice to hang with people that just 'get it'. I would also advise anybody to ensure they have a supportive partner. My greatest champion is my wife, Mara. She has always encouraged me to make my PKU lifestyle a priority.



Kristi Smith

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Our family

Our family is somewhat unique. My name is Kristi and I was born in Arizona in the 1980's. After some confusion with a pediatrician who didn't know PKU well, my parents were finally put in touch with a great doctor who helped my parents a lot. He taught us from the beginning 'diet for life' was going to be our approach. It wasn't until late elementary school that I began disliking and forgetting to drink my formula. My levels snuck up to about 13 mg/dL (790 mcmol/L) on a regular basis.

Finding life hacks is instrumental in managing all of the avenues of PKU!"

A few years later, I met a few adults in an online PKU chatroom who were a bit older and who had returned to diet despite 'diet for life' being a relatively new concept. They didn't realize it at the time, but those women sharing their stories gave me the inspiration to think about my own future goals. I wanted to go to college and didn't want PKU to impact that. I began to track my diet more closely, drink my formula consistently, and my levels dropped as a result. I graduated high school with honors and an academic scholarship to a 4-year college. I completed 2 bachelor degrees with honors. I now work as a school nurse. I also married an amazing guy who jumped in with both feet the day he learned about my PKU. We also decided to adopt a child with

PKU, which turned into two, three, and ultimately four. Yes, we have adopted four boys with PKU! Including me, we have five PKU diets to track, five PKU formulas to prepare, five people lined up on blood test day, and if we accidentally eat something that has more Phe than we realize, potentially five emotional people with high levels for my husband to deal with at once!!!

Who supports you with managing your PKU?

My parents were very supportive and had

My parents were very supportive and had a "everybody has something" view and a "let's do what we can to fix it and move on" approach. PKU is simply what makes me different. It affects my diet, and how well I do with that affects other things in my life. When I'm having a down day or week, I can make some tweaks to help lower my levels again, celebrate the small improvements, and start fresh each day. We try to teach this mindset to our boys too.

My husband has been supportive since the beginning. He makes PKU meals, helps prepare my formula, encourages me to make "low" protein choices, and talks with other patients and families. His family, my in-laws, bought PKU cookbooks, ordered low protein foods, and have let us take over their kitchens on our visits with food scales, formula, and low protein specialty foods so we can continue our day-to-day PKU maintenance.

What parts of the diet do you struggle with?

We all know PKU life is a juggling act. Staying well stocked of PKU formula, low protein food and other medications is crucial.

PKU takes a lot of self-discipline. I will tell my friends, "I've had all of my Phe. Please move these fries" and they understand. I have my Kuvan strategically placed next to my toothbrush so I don't forget to take it. I set my blender bottles out so when I come into the kitchen first thing in the morning, I remember to make the family's formulas. I have alarms set on my phone to remind us to take our PKU medications. Finding "life hacks" is instrumental in managing all the avenues of PKU!

Biggest piece of advice for someone living with PKU?

Some nuggets of advice from me and my closest friends in the community:

- "Connect with other PKU friends. Even if you don't get together to talk about PKU, just knowing they are doing the PKU life like you really does help!" - PKU adult & mom of PKU kids
- "Make it fun! Race the clock to drink your PKU formula!" – 8 y.o.
- I didn't like my PKU milk at first but I drank a new PKU milk that I liked better. You should try a new one if you don't like yours." 17 y.o.
- "Find someone who will love you and support you." - 8 y.o.
- "If you're bored with your food, try a new recipe or change the taste!" - 12 y.o.





Depression

What is depression?

Most people go through periods of feeling down, but depression is when you feel persistently sad for weeks or months, rather than just a few days. Depression is a real illness with real symptoms. It isn't a sign of weakness or something you can "snap out of" by "pulling yourself together".

How to tell if you have depression?

Depression affects people in different ways and can cause a wide variety of symptoms including, but not limited to:

- Lasting feelings of unhappiness and hopelessness
- Losing interest in the things you used to enjoy
- Feeling like you are going to cry
- Constant anxiety
- Constant tiredness
- Poor sleeping pattern
- Having no appetite
- Various aches and pains

What can help relieve the symptoms of mild to moderate depression?

Socialize with others

Socialize with others as well as with family and friends outside of the PKU community.

Interaction will help fight feelings of isolation and loneliness. There are lots of virtual and inperson events held throughout the year, as well as the NPKUA's biennial conference.

Connect through social media

You might be the only PKU person you know, but there is a huge network out there!
Connect to national and local support networks such as NECPAD or MACPAD

Be consistent with your low protein diet

The higher your levels are, the higher the risk of constant tiredness, sadness and low mood.

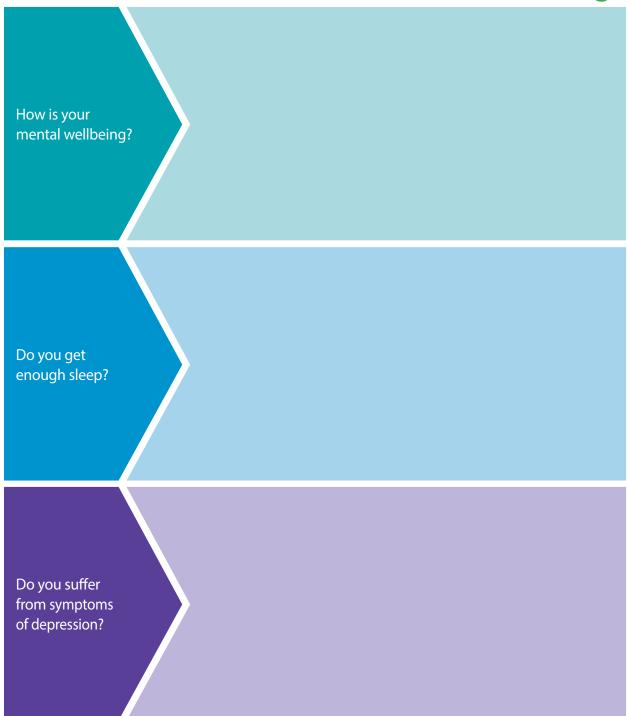
Get moving

Exercise can have a big impact on how you view yourself and how you feel mentally. Just moving every day will make a huge difference.

Discuss low mood with your PKU clinic

Your Metabolic Dietitian is the expert in your treatment. Discuss how you are feeling.

Self Reflection Mental Health and Wellbeing



Useful Links

| | WEBSITES ♂ | |
|--|--|---|
| adaa.org thecalmzone.net mentalhealth.gov ok2talk.org | rethink.org samaritans.org nami.org mhanational.org | calmsage.com verywellmind.com Canada: cmha.ca |

Michelle Hays

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A bit about me

My name is Michelle and I have a teenage daughter, Katy, who was diagnosed late with PKU. At the time of Katy's birth my husband (Isaac) and I were living in Monterrey, Mexico. Although some basic health screening was performed, specific metabolic testing, such as PKU, was not mandatory. We had never even heard of it! Three days after Katy was born, we took her home, completely unsuspecting of the imminent storms that we were about to face.

"

I have found that laughter really does heal I try to find humor every day."

The impact PKU had on Katy's emotional and mental health

The late PKU diagnosis had a severe, negative impact on Katy. At the time of her diagnosis, she was unable to walk, crawl or even just hold her body up to sit. She did not understand spoken words and much less produce them. Katy suffered about five to six seizures daily, each lasting between ten and fifteen minutes. Since PKU

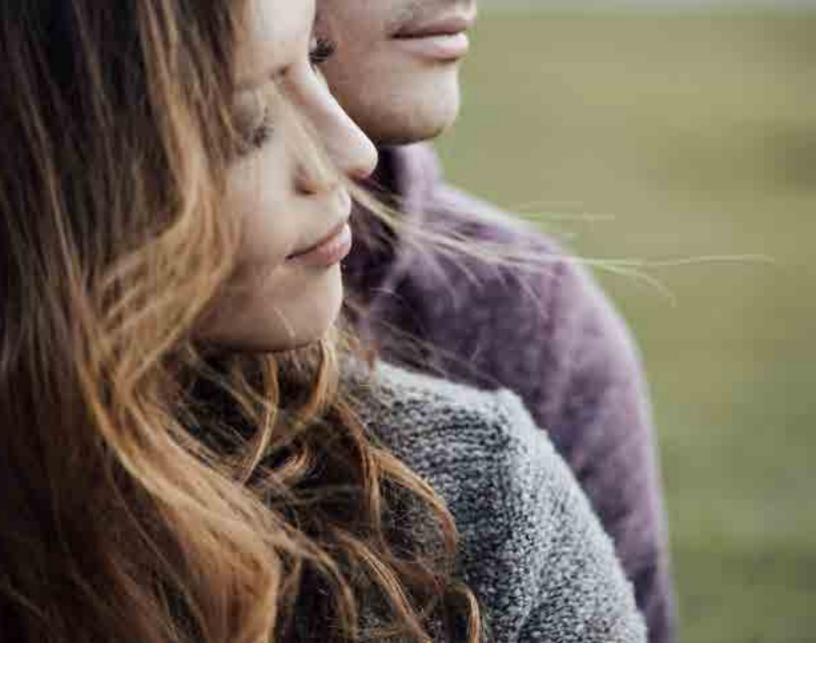
was hardly diagnosed in Mexico, it was impossible to find adequate treatment for her in the country.

Once she started PKU treatments it was like a haze had come off her eyes! She looked around with great wonder, as if taking the world in for the first time. Her desire to explore things gave her the motivation to learn to move her body. She began to sit up, crawl and finally, at the age of two, take her first steps!

Navigating my mental health as a Mom and Caregiver

Taking care of Katy's needs can be a lot. We are both working parents and can often find ourselves running out of steam. It can seem like I never really hit that perfect (PKU) parent mark. Nevertheless, I have to remind myself not to be my own worst critic. In focusing on what I have not been able to accomplish, I can overlook all of the amazing things I have been able to do. Keeping a record of all that I have done right for Katy can often put things back into perspective. It's usually a lot more than I give myself credit for! I also remind myself that I am a parent (and wife) first and employee second. A replacement for me can easily be found in the workplace, whereas in the home, there is only one me. Having this mentality helps me set my priorities. Mostly, I have found that people at work are more empathetic and understanding than I expected. I am often met by grace and understanding and not seldom, I gain a friend or two. Lastly, I have found that laughter really does heal. I try to find humor every day. I listen to a funny podcast or a stand-up comedy. I put on happy music while I work. I watch a funny movie. I act silly and playful with those around me. This helps me recharge my soul, fills me with wonder and helps me bond with the people I love. Laughter really is the best medicine and it keeps my engine going!





Preconception & Pregnancy

High Phe levels during pregnancy can affect the development of an unborn baby since Phe crosses the placenta. The damage is permanent and can lead to problems such as learning difficulties, microcephaly (small head syndrome), heart defects and a low birth weight.

If you are thinking of having a baby, tell your dietitian. Your PKU team will help you lower your Phe levels and let you know when it is safe for you to try to conceive. Close monitoring and stable Phe levels are crucial during pregnancy. Lean on your clinic for support.



Alyssa Augusto

A bit about me

Hi! I'm 27 and have Classical PKU. When I was about 19 years old I went off diet because I was a teenager who wanted to rebel and I did not surround myself with very good people. The people I called my friends at the time were not supportive of me or my diet, in fact, there was a particular person involved in my life at the time who convinced me that I was improperly diagnosed. Looking back I feel so stupid for believing it but that is exactly what happens when you are off diet; you allow fiction to become fact and will do anything to be "normal".



PKU doesn't need to define you but it will always be a part of you so own it and THRIVE!"

My mental health off diet

The longer I was off diet the more I adjusted to feeling horrible with high levels. At the time I was so stubborn and I didn't realize it was high levels causing my anxiety and depression. Looking back it was a huge contributing factor. I have always been on the smaller side and being off diet caused me to lose even more weight. I remember being so sad and angry all the time. I have a vivid memory of my mother and I standing in the kitchen of my childhood home and she could see how depressed I was. She said to me, "Alyssa, you just need to do something that makes

you happy. What makes you happy?". My response to her with tears in my eyes was, "Nothing makes me happy anymore". Looking back now, if I had been fully on my PKU diet, that should have been a red flag that I needed to make a change right then and there. But I continued to stay off diet for a couple years until I was about 21. I wanted to go back on diet but I couldn't find any resources to help. I started to take formula here and there but I was so used to just being off diet that my PKU diet seemed more of a hassle than anything.

Turning my life around

It wasn't until around age 22 I made the decision to jump back into my PKU diet 100%. I had finally reached a point where I just couldn't stand to live like I was anymore. My clinic sent me an invitation for a low protein cooking class led by NECPAD (New England Connection for PKU and Allied Disorders). I went and I have been a proud Board Member ever since. NECPAD has helped me so much with my PKU journey. I was in college at the time and joining NECPAD lit a fire in me. I wanted to achieve so much, I wanted to get back on diet, I wanted to feel better. I set a goal for myself to graduate college with honors. I truly believe it is so important to surround yourself with people who "get it". Being around the PKU community has allowed me to meet PKUers just like me not only in my home state but across the country. When you are struggling with insurance headaches, can't figure out what to eat, or have a random crazy high level, your PKU friends are the ones who are going to "get it". I am so thankful to be in the place I am mentally, physically, and emotionally with my PKU journey. PKU can be so hard and isolating and when I

PATIENT STORIES

was off diet all I wanted was to know that I wasn't alone in my struggles.

My advice for others

If anyone is struggling, don't give up. Find your way into your own little PKU community (social media is a great tool!), and surround yourself with people who support you for YOU, not just for who they want you to be. My family, my husband, and my friends are so supportive of me and my PKU. I made the decision to return to my PKU diet not only for my health but for the health of my future children. I finally made the decision to walk away from the toxic friends. I started dating my now husband and I knew that one day I wanted to marry him and have children. Having a baby with PKU is very possible but it requires full control ofthe PKU diet. I wanted to make sure I got ahead of it years in advance. Here I am almost 6 years later and I have complete control of my PKU. I tookmy life back! I graduated college with High Honors, I have an amazing PKU community, beautiful friendships, a loving husband and family, and I am expecting my first baby this year. If I can do it, so can you! PKU doesn't need to define you but it will always be a part of you so own it and THRIVE!





02. My Journal

Make yourself a priority, practice gratitude, value yourself."

- Amanda Cosburn

Diet and Nutrition

| Current Blood Phe Levels: | |
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| Current Daily Protein or Phe: | |
| Current Formula Intake: | |
| Current Weight: | |
| Current Daily Average Calorie Intake: | |
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| Target Blood Phe Levels: | |
| Target Daily Protein or Phe Tolerance: | |
| Target Formula Intake: | |
| Target Weight: | |
| Target Daily Average Calorie Intake: | |
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| What are your favorite Low Protein foods? | |
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| What are your favorite healthy snacks? | |
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| What are your go-to healthy recipes? | |
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Exercise

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| Current Daily Steps: | |
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| Target Weekly Exercise: | |
| Target Daily Steps: | |
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| What do you like about your body/physique? | |
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| What are your favorite exercises? | |
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| How does exercise make you feel? | |
| No exercise | After exercise |
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| How will you reach your exercise goals? | |
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Debbie Colyer

A bit about me

Hi! I'm Debbie and I was born in 1958 in Australia. While initially a healthy baby, I was slower to reach my developmental milestones during the first two years of my life. My mother tirelessly searched for answers, but doctors just told her that I would grow out of it. Eventually after lots of testing, PKU was diagnosed by a wet diaper test. I was the first person in Australia to be diagnosed with PKU and to this day, thousands more have been diagnosed because of my mother's tenacity. I followed in my family's footsteps and am an avid PKU awareness campaigner. I have been part of the PKU Association of New South Wales for over 22 years. My mother and I have also been awarded an Order of Australia Medal (OAM), an award recognizing exceptional achievement by

PKU and me

PKU didn't take over our lives, it just became a part of it. Mum and I would count up how many protein

Queen Elizabeth and the government, for our work the PKU community.



Now I am just focused on being the healthiest version of myself that I can be.."

equivalents I could have each day (method of counting Phe back then) and we would go for regular blood tests. I do remember feeling like I was going to die when my mum and the dietitian would speak privately. I guess I always wanted to know what they were saying about me.

As a child I was bullied so much because of having to take lofenalac, one of the first PKU formulas, to school. I also got bullied when I drank my formula, but I stuck it under the kids noses and the torment stopped.

When I was 16, my doctor told me I

When I was 16, my doctor told me I could come off diet as that was the advice at the time. Being 16 and wanting to fit in with everyone else, as well as being depressed about all the formula I was taking, it was an easy decision. I lived off diet for the next 18 years.

Mental and physical impacts of being off diet

The symptoms were minimal at first but then as time went by, I experienced headaches, fatigue, stomach issues and constipation. Then the moods started. I would have uncontrollable outbursts at work, I would get eczema everywhere, tremors with eye twitching, brain fog and that was just the start of it.

I knew something had to change, so I returned to my clinic and requested to go back on diet. It was such a hard decision, mainly because I dreaded taking my formula again, but thankfully formulas have come a

PATIENT STORIES

long way and I was able to choose one that was tasty, low volume and that I could easily take to work with me.

When I went back on diet I started to feel great, gained a lot more energy, could focus on tasks a lot better, the brain fog lifted, eczema and tremors disappeared. My mood and my relationships with people improved at work and in my personal life. I was happy.

My weight and mental health

My adult PKU clinic has drawn attention to my weight for as long as I can remember. It caused me a lot of mental distress over the years, but now I am just focusing on being the healthiest version of myself that I can be. As well as staying healthy, I have been working hard to achieve my career goals. I will graduate with a Diploma of Nutrition this year and then I will start my Master of Nutrition straight after.

Tips for staying mentally healthy

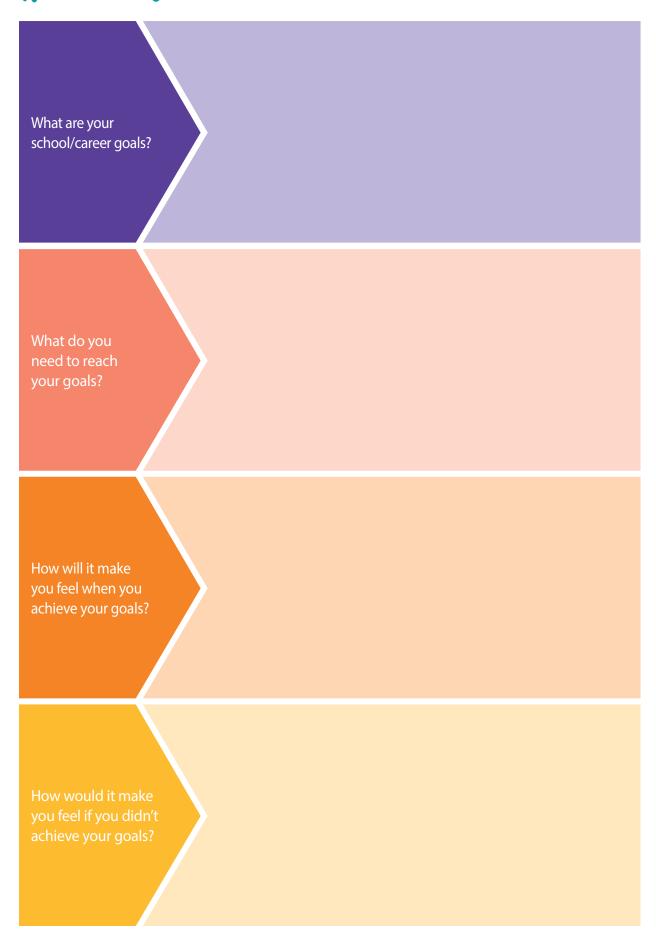
- Focus on your diet and nutrition
- Meditation
- Set achievable goals
- Enjoy every day



Relationships

your life better? How do you make their lives better? How will you continue to support these relationships?

Work and Career



Amanda Cosburn

A bit about me

Hello! My name is Amanda and I am an adult living with PKU in Canada. I live with my husband Cole and our beautiful daughters Madelyn (age 5) and Amelia (age 2).

I have been a long-time advocate and voice in the PKU community, especially for adults and maternal PKU patients. I am the creator of the PKU Strong Blog and Facebook page. I am a past board member of the Canadian PKU and Allied Disorders Inc. I also recently started a podcast called "Voices of PKU".

My PKU diet struggles

If I am being honest, I have always struggled with my diet and PKU treatment. I'd say it began when I was 13. I was not properly supported, educated or aware of the disadvantages of noncompliance. Sure, we had it drilled in our heads from parents and medical professionals, but not having the network that I do now, not knowing anyone else with PKU growing up and feeling like I was the only one, really affected me.

It started small, I'd sneak a bigger portion or add a little extra pasta to my plate when no one was looking, but it eventually spiraled to not drinking my formula, trying foods I'd never had before and trading my food or throwing it away at school.

I have never really been considered fully "off diet". I have never tried any meat or eggs or dairy. I mostly "cheated" with grains, rice, potatoes and higher Phe foods that I was already allowed small amounts of. It has resulted in a lifelong

struggle with my low protein diet and constant ups and downs, highs and lows.

Now as an adult, I always take my formula but I don't weigh or track my Phe intake unless I am pregnant. I do my blood dots monthly and I eyeball my portions or use measuring cups. I love minute rice, avocado sushi, yam sushi, potatoes, corn, mushrooms, bread, chips, etc. I have an all or nothing mentality so if one thing goes out the window, or one day is wrecked then the rest are too. I find the time needed to stick to the diet (with tracking, measuring, prepping, weighing, meal planning, precooking, or baking ahead) doesn't work for my busy schedule. It feels like a full-time job.

It's the easiest thing to let go of when you have a lot going on (family, running a household, raising kids, working, running my daycare business, living through the pandemic).

How I feel when my levels are elevated

When my Phe levels are high, I struggle with forming thoughts, thinking, planning, implementing. I have trouble finding words, articulating myself and retaining information. I also really struggle with motivation and self-esteem. I get very overwhelmed, sensory overloaded, my anxiety increases and I get sensitive and emotional. I also get headaches, fatigue and stomach aches.

I think the thing I notice the most is the mental fog. You can't really see it at first, you're almost blinded to it but when you have a couple good days, and your levels

PATIENT STORIES

drop you get hit with this realization that you have been in the fog again and it's like waking up from a bad dream.

How I feel when my levels are stable?

When my levels are stable, I am more creative, patient, social, happy, and able to laugh. I am a better friend, more dependable, a better advocate, a better public speaker, more passionate, driven and outgoing. I am more successful and way more ambitious.

PKU and my mental health

Though I don't feel that PKU is a direct cause of my mental health struggles, it certainly has a large impact on it and I know it directly affects my anxiety. Previously I have been diagnosed with chronic major depression, general anxiety and panic disorders with PTSD and I still very much struggle with anxiety and panic attacks. In my life I have suffered abuse, trauma, accidents, chronic pain and have been in counseling now for a year and a half. I also did cognitive therapy for my depression.

Regular activities to manage my mental health include:

- Weekly counseling over zoom
- Yoga and meditation
- Journaling
- Bubble baths
- Regular walks, swimming
- Jewelry making



Make yourself a priority, practice gratitude, value yourself."

My advice for others

If I can offer anyone advice, try not to feel like you're 'failing' all the time. I know it sounds easy but this journey you are on is demanding. Don't give up and do reach out and ask for help. I bet anyone you talk to is struggling in some capacity. When you speak to someone who understands, it's so much better. Also, if you're a child, youth or teen who has not strayed from diet – don't! Once you start it is so much harder to stop. Keep going and do your best. You are not alone. Make yourself a priority, practice gratitude, value yourself enough to do the hard work and make it less hard on yourself by being with people who get it!



Hobbies

| What are your favorite hobbies? | |
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03. Monthly Check In

Your Monthly Check In!

This section is really important and is a great way to see how much progress you have made each month!

Quite often you take steps forward each day that might seem small, but over the course of a month, huge progress can been made.

The most important thing is to be totally **honest** with yourself about how you are **feeling** so you can judge if you are making progress or need extra help and guidance from your PKU team.

On the page titled 'Today', fill in the page according to how you are feeling right now. After one month, fill in 'Month 1', then 'Month 2' and so on.

Happy filling in!

date:

Today

Fill in this page on Day 1 so you can track your **Healthy You Healthy PKU** progress.

1 = Good, 3 = Medium, 5 = Bad

My positivity level is:

| 1 | 2 | 3 | 4 | 5 |
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| My concentration | is: | | | |
| 1 | 2 | 3 | 4 | 5 |
| My mood is: | | | | |
| 1 | 2 | 3 | 4 | 5 |
| My frustration is: | | | | |
| 1 | 2 | 3 | 4 | 5 |
| My relationship wi | th family and friends | is: | | |

My current Phe level is

My next blood Phe level date

My next clinic appointment is on

My formula and/or low protein food delivery will arrive on

2

Monthly PKU goal

Monthly Non-PKU goal

date:

Month 1 Summary

Fill in the following pages on a monthly basis to track your progress.

1= Good, 3 = Medium, 5 = Bad

My positivity level is:

| 1 | 2 | 3 | 4 | 5 |
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| My concentration | is: | | | |
| 1 | 2 | 3 | 4 | 5 |
| My mood is: | | | | |
| 1 | 2 | 3 | 4 | 5 |
| My frustration is: | | | | |
| 1 | 2 | 3 | 4 | 5 |
| My relationship wi | th family and friends | s is: | | |

My current Phe level is

My next blood Phe level date

My next clinic appointment is or

My formula and/or low protein food delivery will arrive on

Did you meet your monthly PKU goal

PKU goal

Monthly Non-PKU goal



04. Daily Journal

When I'm having a down day or week, I can make some tweaks to help lower my levels again, celebrate the small improvements, and start fresh each day."

- Kristi Smith

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Weekly Review Mood Tracker Average this week

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Averages



How do your averages compare to last week?

Looking Forward

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Daily Journal

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How have you felt this week?
What have you achieved this week?

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Mood Tracker Average

Count up your mood levels throughout the week to see how you did!

previous week











this week











Averages



PHE/PROTEIN



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How do your averages compare to last week?

Looking Forward

My goals for next week

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Daily Journal

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Weekly Review

date: _____

How have you felt this week?

What have you achieved this week

Mood Tracker Average

Count up your mood levels throughout the week to see how you did!

previous week











this week











Averages



PHE/PROTEIN



STEPS

How do your averages compare to last week?

Looking Forward

My goals foi next week

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Daily Journal

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Mood Tracker Average

Count up your mood levels throughout the week to see how you did!

previous week











this week











Averages









How do your averages compare to last week?

Looking Forward

My goals for next week



05. Useful Resources

Finding life hacks is instrumental in managing all of the avenues of PKU."

- Kristi Smith

Other Resources

To request a copy, email info@cambrooke.com





National School Lunch Program

- Eating/Feeding Evaluation & Information Card
- Food Services Guide
- Institutional Price & Account Application for your School Service Department



THRIVE in 5

Looking to make a positive change to your health and fitness? Not sure where to start?

- 5 day healthy meal plan
- 5 day exercise program
- Customizable wellness planner





Live Love Learn Series

Resources created by Lynn to support families with practical tips, tools, and recipes.

"I bring my LIVE LOVE LEARN way of life to you. My family's approach to LIVING every day is to eat healthy foods, to LOVE life's abundance of acceptable foods (vs what you cannot eat) and to LEARN eating nutritious foods while staying physically active will help you maintain or improve how you feel." - Lynn Paolella

Cambrooke's Low Protein Foods

are designed by a PKU mom who understands your needs

Delicious · Quality Ingredients · Easy & Convenient



Place an order 24-7 visit **Cambrooke.com** or call **Customer Service at 866 456 9776, option 2**

Not all GMP is created equal.

Cambrooke continues to stay a step ahead with the lowest Phe GMP. GMP formulas typically have 1.8 mg Phe per gram of protein. GMPure is the lowest Phe GMP available with only 1 mg Phe per gram of protein. This is at least 35% less Phe than other PKU GMP formulas!





Speak to your dietitian to request a prescription or call **Customer Service at 866 456 9776, option #2,** for assistance

Ready for different GLYTACTIN options?

Don't worry we have you covered ...



BetterMilk - NEW & IMPROVED

160 calories, 15 g PE, 15 mg Phe

- Low volume
- Good option for all ages
- ♥ Flavors: Original, Strawberry Creme, Orange Creme



BUILD 20/20 Flavors

110 calories, 20 g PE, 20 mg Phe

- Low volume & low calorie powder
- Ideal for school age and up
- ♥ Flavors: Vanilla, Chocolate, Smooth, Raspberry Lemonade



BUILD 10 & 20/20

50 calories, 10 g PE, 10 mg Phe 100 calories, 20 g PE, 20 mg Phe

- Versatile powder you can add to formula/food or flavor however you like
- No sugar or artificial sweeteners
- Flavors: Neutral



RTD Lite 15

120 calories, 15 g PE, 15 mg Phe

- 40% less calories than RTD 15
- No added sugar
- Flavors: Vanilla, Coffee Mocha



RTD 15 ... coming soon with GMPure

200 calories, 15 g PE, 27 mg Phe

- Ready-to-Drink liquid
- Great for school & work
- Flavors: Original, Chocolate





RTD 10 ... coming soon with GMPure

153 calories, 10 g PE, 18 mg Phe

- Ready-to-Drink liquid
- Ideal for younger children
- Flavors: Original, Chocolate





You've got this!



CAMBROOKE

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