

Eat Well, Live Well.



CAMBROOKE™

# IVA Wellness Journal

**HEALTHY  
YOU**

**HEALTHY  
IVA**

Mental, Physical and Emotional  
Health on a Low Protein Diet

Your  
Mindfulness  
Journey

# Hi!

## 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 Isovaleric Acidemia (IVA).**

**This journal includes several personal stories from individuals with metabolic disorders. These views and opinions of metabolic contributors are not are not reflective of Ajinomoto Cambrooke.**

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

# Important Information

Name: \_\_\_\_\_

Email: \_\_\_\_\_ Telephone: \_\_\_\_\_

Hospital Name(s): \_\_\_\_\_

Dietitian Name(s): \_\_\_\_\_

\_\_\_\_\_ Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

Lab Address: \_\_\_\_\_

Primary Care Doctor: \_\_\_\_\_

Email: \_\_\_\_\_ Telephone: \_\_\_\_\_

Formula Supplier: \_\_\_\_\_

Email: \_\_\_\_\_

Details: \_\_\_\_\_ Telephone: \_\_\_\_\_

Specialty Pharmacy: \_\_\_\_\_

Email: \_\_\_\_\_ Telephone: \_\_\_\_\_

Details: \_\_\_\_\_

## Useful Links

SOCIAL MEDIA	WEBSITES 	APPS				
<ul style="list-style-type: none"><li>• Cook for Love</li><li>• How Much Phe</li><li>• Ajinomoto Cambrooke Metabolic Nutrition</li><li>• Low Protein in 15</li><li>• Canada: Canadian PKU and Allied Disorders (CanPKU)</li></ul>	<p><b>IVA Diet</b></p> <ul style="list-style-type: none"><li>• oaaanews.org</li><li>• cookforlove.org</li><li>• lowprorecipes.com</li><li>• golowpro.org</li><li>• rarediseases.org</li></ul> <p><b>Mental Health</b></p> <ul style="list-style-type: none"><li>• Adaa.org</li><li>• Mentalhealth.gov</li><li>• Nami.org</li><li>• Health.gov</li></ul>	<table><thead><tr><th>Physical Health</th><th>Mental Health</th></tr></thead><tbody><tr><td><ul style="list-style-type: none"><li>• My Fitness Pal</li><li>• Map My Run</li><li>• 30 Day Fitness at Home</li><li>• Fitness Buddy</li><li>• FitOn</li><li>• Fiit</li><li>• All Trails</li><li>• My Water</li><li>• Daily Yoga</li><li>• Pocket Yoga</li></ul></td><td><ul style="list-style-type: none"><li>• Reflectly</li><li>• Day On</li><li>• Headspace</li><li>• Calm</li><li>• The Breathing App</li><li>• Streaks</li><li>• Mediation by Soothing</li><li>• Affirmations-Daily Motivation!</li></ul></td></tr></tbody></table>	Physical Health	Mental Health	<ul style="list-style-type: none"><li>• My Fitness Pal</li><li>• Map My Run</li><li>• 30 Day Fitness at Home</li><li>• Fitness Buddy</li><li>• FitOn</li><li>• Fiit</li><li>• All Trails</li><li>• My Water</li><li>• Daily Yoga</li><li>• Pocket Yoga</li></ul>	<ul style="list-style-type: none"><li>• Reflectly</li><li>• Day On</li><li>• Headspace</li><li>• Calm</li><li>• The Breathing App</li><li>• Streaks</li><li>• Mediation by Soothing</li><li>• Affirmations-Daily Motivation!</li></ul>
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# The Feel Balanced. Feel Better. BLOG

## BE IN THE KNOW

- ✔ Low Protein Recipes
- ✔ Competitions
- ✔ Events
- ✔ And more...



Visit [Cambrooke.com/blog](https://Cambrooke.com/blog) to subscribe!





Feel balanced. Feel better.™

Available for download:

Android on Google Play

Apple App store

**Metabolic Balancer** is designed to help you manage a low protein 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 protein 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



Understanding how nutrition and neurotransmitters affect the body (those clever little things that regulate your mood) can help you to understand why you feel the way you do.


# 01. Inside Mental Health

GOOD NUTRITION HAS NO SIDE EFFECTS!<sup>TM</sup>





## Why is IVA formula important?

- ✔ 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 IVA treatment. If so, it is important to take daily and spread throughout the day to keep Leucine (Leu) levels stable.
- ✔ You also need vitamins and minerals if you are following a Leu or protein restriction. These are usually in your formula. If not, your Dietitian will recommend a supplement.
- ✔ 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 [Cambrooke.com](https://www.cambrooke.com) 







## Sleep

### Sleep is vital for mental and physical health.

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.

#### 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.

#### Try not to take afternoon naps

They make it harder to get to sleep at night.

#### 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.

# Lisa & Justin Hensley

## A bit about us!

Our son, Micah, is 12 years old. He had a metabolic crash at 5 days old. He was barely eating, mostly sleeping and cold. Miraculously, the doctor's office received the abnormal newborn screening during our appointment that day and sent us to the hospital. After transferring to two other hospitals and being told our son would likely die while he was in a coma and on life support, Micah started on dialysis and was eventually diagnosed with Isovaleric Acidemia.



*...there is always hope, ask for help and get connected to your metabolic community."*

We were at the hospital for 35 days. As young first-time parents, we had no choice but to just keep going. We were lucky to have family and friends support us day in and out. The scariest part was going home with no medical staff or machines to tell us he was ok. We now live in Virginia with Micah and his three younger brothers. We hope Micah's journey helps teach his siblings compassion and inclusion as they get older.

Micah has been on a low protein diet along with formula shortly after birth. Any deviation from his diet leads to increased irritability and eventually lethargy and a hospital visit. As Micah's parents, we manage his care. We have found sharing

responsibilities make us the best team. One of us takes on insurance, formula ordering and doctor's calls while the other focuses on school, IEP needs and teacher communications. We join forces on giving Micah formula and his low protein diet. We always try to talk to Micah about why we do what we do. We also encourage him to come ask about what he is eating and keep his preferred low protein foods around to give him options to choose from.

## Advocacy in the classroom and beyond

Micah has been diagnosed with autism which we believe was impacted by his high ammonia levels shortly after birth. He also struggles with high levels of anxiety and other associated mental disorders. When he was younger, our school system did not have the resources he needed so we home-schooled.

We made sure to start talking with his current school system as soon as we knew we were moving to help get services in place. We have found getting an official diagnosis of autism from an external provider instead of through the school system really goes a long way with an IEP. It is also very important to collaborate with everyone involved which includes our genetics team, teachers and psychologist. Dr. Burrow, our geneticist, wrote a recommendation letter to help us get additional mental health services in place. A physician's request for services seems to have more pull compared to a parent requesting help. He currently receives speech therapy, occupational therapy and works with a clinical psychologist. This has helped Micah learn coping techniques and

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how to help himself. Our ultimate goal is for Micah to become the best Micah he can be in this world, whatever that might look like for him both now and in the future.

## *My advice for anyone struggling*

When Micah was first diagnosed, the medical team brought us a stack of papers and said we think he has Isovaleric Acidemia and then walked away. We did not know about the metabolic community including the Organic Acidemia Association, Facebook groups associations, formula companies, etc. In that moment, we needed hope and support which never came. Any new metabolic diagnosis at Arkansas Children's gets the opportunity to talk with metabolic patients thanks to Dr. Burrow. So our advice would be...there is always hope, ask for help and get connected to your metabolic community.



Write down anything here that you think will help in your own journey!





Even five minutes a day will make a huge difference to your physical, mental and emotional wellbeing.

## Give yourself a Dopamine Lift!

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.

### 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)



# 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

# Danae Bartke

## A bit about me

Hi! My name is Danae Bartke, and I was diagnosed with Homocystinuria in 1995 at the age of 10. My younger brother, Garrett, had bumped his head on a table in school and complained he could not see. At the eye clinic, they discovered his lenses had detached from his retina. He had immediate eye surgery to remove the lenses in both of his eyes and was eventually diagnosed with Homocystinuria. The next step was for me and my six siblings to get tested. I was the only other one who tested positive for Homocystinuria. At the time, I just felt like I was being punished and had a lot of anger around my diagnosis.



*Get into good metabolic control, have your partner get carrier testing, make sure you have a supportive medical team including a dietitian, and enjoy your pregnancy. It is so worth it!*

## My early years

We tried a couple of treatments to see what we responded to. We found we needed B6, B12, baby aspirin, folic acid, formula and a low protein diet. After that we were on track... at

least for a bit. My brother and I gave my mother a very difficult time. We hated the food and medical formula and did not really follow the diet like we should. Our father had died a year prior to our diagnosis, so our mom did not have the time or energy to battle us every step of the way. Eventually, I did adhere to my treatment. I wasn't the best patient, but I tried my best.

## What changed?

In 2009, my attitude changed dramatically towards my diet and treatment. As a result of not following the diet as well as I should've, I developed a blood clot in my wrist. Dr. Wong advised me to go immediately to the Emergency Room. Being in hospital for a week gave me a lot of time to reflect. At first, I felt a lot of guilt for not taking better care of myself. I realized I could have died and felt helpless. I knew I needed more support to succeed. When I left, I had a completely new perspective on the hand I had been dealt. I realized how lucky I was to be alive and if I was going to have a healthy, productive long life, that I was going to have to take my diet seriously.

## Getting involved in the community

About two weeks after being released from the hospital, I received a letter from the PKU Organization of Illinois for a low protein cooking class. I did not know there were any other disorders

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out there following a low protein diet. I was so excited! I made great connections including Malathy from Taste Connections and learned of other HCU events. I eventually went on to be part of the board and then President of the PKU Organization of Illinois. In the course of a couple of years, we went from having no community to a huge and growing community that was just so helpful and kind. I realized others have even more restrictive diets than me and if they can do it, I can do it.

In 2016, I traveled to Prague for the first Homocystinuria Patient-Expert Meeting. I was able to meet with world-renowned researchers in the field, along with other patient organizations and families. It became very apparent we needed an organization in the US. Upon arriving back, Margie McGlynn and I began working on what is now HCU Network America!

## *Becoming a mom*

From as early as I can remember, I knew I always wanted to have my own family. Initially, I was told I'd never be able to have my own kids because of higher risks of blood clots. I got married in 2014. I started meeting with a maternal fetal medicine specialist and hematologist to discuss pregnancy with HCU. I became pregnant and had to increase my formula, adjust vitamins and increase calories. I also had a precautionary regimen of medications to avoid blood clots.

I was closely monitored during pregnancy and developed placenta previa and cholestasis of pregnancy which meant being induced at 37 weeks and more medication. After my daughter arrived, the placenta would not detach and I started hemorrhaging. We got through it. Dana, named after my dad, was healthy! I continue to follow a 20 g protein diet and drink formula. It was much harder than I anticipated with a baby, but it's doable. If you want to have children with a genetic condition, you can. Get into good metabolic control, have your partner get carrier testing, make sure you have a supportive medical team including a dietitian, and enjoy your pregnancy. It is so worth it!

## *My advice for anyone struggling*

It is going to be a grind and hard even though it looks easy. It is a struggle just like anyone trying to follow a diet. It does get easier and does become a routine. Just stick with it. One bad day does not define you. You can start again the next day...new day, fresh start.





# 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 IVA community. Interaction will help fight feelings of isolation and loneliness. There are lots of virtual and in-person events held throughout the year.

### Connect through social media

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

### 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.

### Be consistent with your low protein diet

Being in good metabolic control, allows you to stay healthy and clearly think through what you need.

### Discuss low mood with your clinic

Your Metabolic Team are experts in your treatment. Discuss how you are feeling.



# Self Reflection Mental Health and Wellbeing

How is your mental wellbeing?

Do you get enough sleep?

Do you suffer from symptoms of depression?

## Useful Links

### WEBSITES

[adaa.org](http://adaa.org)  
[thecalmzone.net](http://thecalmzone.net)  
[mentalhealth.gov](http://mentalhealth.gov)  
[ok2talk.org](http://ok2talk.org)

[rethink.org](http://rethink.org)  
[samaritans.org](http://samaritans.org)  
[nami.org](http://nami.org)  
[mhanational.org](http://mhanational.org)

[calmsage.com](http://calmsage.com)  
[verywellmind.com](http://verywellmind.com)  
Canada: [cmha.ca](http://cmha.ca)

# Sage Wang

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## A bit about me!

I'm 17 and was born in New Jersey in 2005. At 5 days old, I was diagnosed with MSUD. During my early years, it was hard to manage my leucine levels as it seemed to be triggered by anything and everything. I was getting blood tests every week until about 4 years old, which is when things started to calm down a bit. I continue my low protein diet every day, 365 days a year. I am looking forward to graduating high school and having a successful college experience too.



*...don't let MSUD or your disorder take over. Do everything other people do.."*

I have achieved a lot throughout my life so far. I've gotten good grades, volunteered in a workspace to deliver items to the homeless, been selected for the choir in my county and tried various hobbies like acting and singing. That said, I experienced my first panic attack when I felt I didn't have control over my body and all I could think about was

"how sick am I going to get?". I lost weight and I couldn't think straight and was tired. All I did was stay in bed. I felt useless and worn out.

## The impact my disorder has had on my mental health

I feel I am more anxious and emotional because of my disorder. I have a weekly session with my therapist to go over things that have happened during the week which has really helped me to talk about how I am feeling.

My parents also took me to multiple doctors after my first panic attack, and the doctors confirmed this was a result of high leucine levels. The tips and advice the team at Mount Sinai gave to me made a huge difference. I want to say a huge thank you to all the doctors and dietitians who helped me at the beginning and continue to support me on my journey.

## My advice for anyone struggling

My biggest piece of advice would be to make your formula on your own to be more independent. I also have learned to identify mood changes quickly so I can

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adjust my MSUD management as soon as possible.

Most of all, don't let MSUD or your disorder take over. Do everything other people do. Eating out can be difficult as 99% of the foods are high in protein, but I have found the best restaurants for me have a buffet option. You can eat the low protein foods you are allowed and avoid anything you don't want on your plate, instead of having to speak excessively to the staff about what you can and can't eat.



Write down anything here that you think will help in your own journey!



*Diet and physical, mental and emotional health go hand in hand.*



# 02. My Journal

“

It does get easier and  
does become a routine.  
Just stick with it.”

– Danae Bartke

# Diet and Nutrition



Current Blood Leu Levels: .....

Current Daily Protein or Leu: .....

Current Formula Intake: .....

Current Weight: .....

Current Daily Average Calorie Intake: .....



Target Blood Leu Levels: .....

Target Daily Protein or Leu Tolerance: .....

Target Formula Intake: .....

Target Weight: .....

Target Daily Average Calorie Intake: .....



What are your favorite Low Protein foods?

Light blue shaded area for writing favorite low protein foods.



What are your favorite healthy snacks?

Light blue shaded area for writing favorite healthy snacks.



What are your go-to healthy recipes?

Light purple shaded area for writing go-to healthy recipes.

# Exercise



Current Weekly Exercise: .....

Current Daily Steps: .....



Target Weekly Exercise: .....

Target Daily Steps: .....



What do you like about your body/physique?



What are your favorite exercises?



How does exercise make you feel?

*No exercise*



*After exercise*



How will you reach your exercise goals?

# Amanda and Jon Miller

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## A bit about me!

We are Amanda and Jon. We have a 13-year-old son, Evan. Evan was born in New Jersey in 2009. At 12 weeks old, he was in liver failure because his tyrosinemia was not caught on newborn screening! We were told he was going to die. It wasn't until after two hospital transfers and a massive effort by Children's Hospital of Philadelphia that our mystery was finally solved. They diagnosed him with Tyrosinemia type one. We felt so alone and betrayed by "the system." It took time to really understand what had happened and recover.



*...you can look for help or you can BE the help."*

As parents, we have found advocacy has become the treatment and therapy for the trauma our family went through. Jon founded N.O.T.A (The Network of Tyrosinemia Advocates) in 2014 with the goals of no one goes untreated, no newborn screening misses a diagnosis again, help parents recognize they are not alone in this struggle and they have the support they need.

## It's a family affair

Evan has a great family support team. All family members from parents, grandparents, aunts, uncles, his sister and cousins are willing to help. He is super close to his cousin, Jenna, who always watches out for him. We have made sure all family knows what is needed for Evan's tyrosinemia care, but as mom, I continue to be the one mostly in charge of making formula, calculating protein intake and making sure he takes his medication. Evan is in charge of easy things like making himself easy meals or snacks. Our entire family are vegetarians, but everyone still usually eats something different at mealtimes.

## Mealtime struggles

The biggest issues we face are Evan always being so hungry and weight gain. We originally found out Evan was sneaking food by finding food wrappers in his garbage and bed. We had a serious conversation with him regarding how important it is not sneak food and to let us know so we can account for it. After noticing it happening a few times, we encouraged Evan to make sure it was a low protein food option.

We recently were able to get Evan's insurance to cover low protein foods and now order low protein snacks to help him not be so hungry



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between meals. Evan is now a handsome young teenager and honestly, he is accepting of his situation. He does not view his metabolic disorder as a disability. None of us walk on eggshells when it comes to tyrosinemia, and we try to educate him at every healthy opportunity.

## *My advice for anyone struggling*

My best advice to anyone facing similar challenges would be to become your own champion. When faced with potential disaster, you can look for help, or you can BE the help. That is not something that comes easy, or without sacrifice. It is, however, the fuel that sends you on the path to success. Without passion, knowledge is useless.



Write down anything here that you think will help in your own journey!

# Relationships

Who are the most important people in your life?

How do they make your life better?

How do you make their lives better?

How will you continue to support these relationships?

# Work and Career

What are your school/career goals?

What do you need to reach your goals?

How will it make you feel when you achieve your goals?

How would it make you feel if you didn't achieve your goals?

# 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



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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 of the 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 took my 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!



Write down anything here that you think will help in your own journey!

# Hobbies



What are your favorite hobbies?

A large, empty rectangular area with a light orange background, intended for writing answers to the question above.

Are there any new hobbies you are interested in?

A large, empty rectangular area with a light green background, intended for writing answers to the question above.

How can you start to incorporate these new hobbies?

A large, empty rectangular area with a light teal background, intended for writing answers to the question above.

# 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 be 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 medical 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!***

# Today

date: \_\_\_\_\_

Fill in this page on Day 1 so you can track your progress.

**1 = Good, 3 = Medium, 5 = Bad**

My positivity level is:

1	2	3	4	5
---	---	---	---	---

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 with family and friends is:

1	2	3	4	5
---	---	---	---	---

My current Leu level is .....

My next blood Leu level date .....

My next clinic appointment is on .....

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

Monthly IVA goal .....

Monthly Non-IVA goal .....



# Monthly Summary

date: \_\_\_\_\_

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
---	---	---	---	---

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 with family and friends is:

1	2	3	4	5
---	---	---	---	---

My current Leu level is \_\_\_\_\_

My next blood Leu level date \_\_\_\_\_

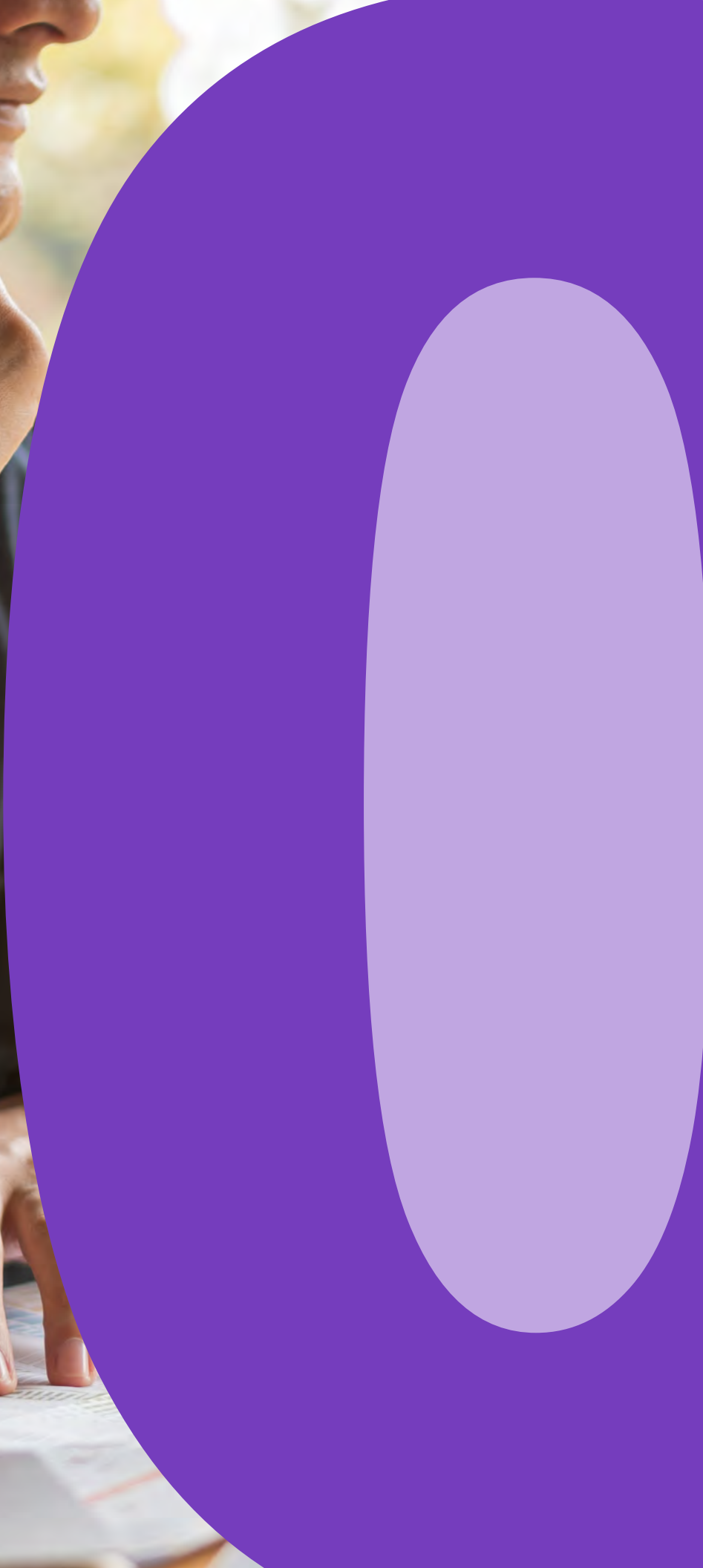
My next clinic appointment is on \_\_\_\_\_

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

Did you meet your monthly IVA goal \_\_\_\_\_

IVA goal \_\_\_\_\_

Monthly Non-Leu goal \_\_\_\_\_



# 04. Daily Journal

“

Become your own champion. When faced with potential disaster, you can look for help, or you can BE the help.”

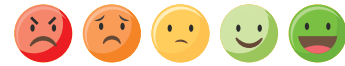
– Jon Miller

Fill in the following pages to track your progress.  
Begin your day with specific, measurable and achievable goals.  
Write down at least one thing you are grateful for to start your day off right.

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

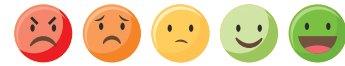
TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	



# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

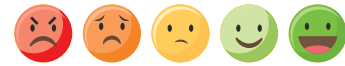
Steps/Exercise/Hydration:

TODAY'S GOALS		TODAY I'M GRATEFUL FOR	
---------------	--	------------------------	--

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

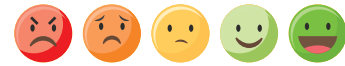
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

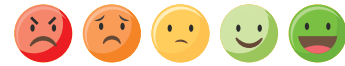
Steps/Exercise/Hydration:

TODAY'S GOALS		TODAY I'M GRATEFUL FOR	
---------------	--	------------------------	--

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

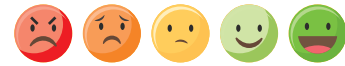
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING	AFTERNOON	EVENING
---------	-----------	---------



## Meals

BREAKFAST		amount	LUNCH		amount		
DINNER		amount	SNACKS		amount		
FORMULA	time	FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

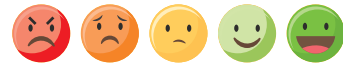
Steps/Exercise/Hydration:

TODAY'S GOALS		TODAY I'M GRATEFUL FOR	
---------------	--	------------------------	--

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	













# 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

FORMULA		LEU/PROTEIN		STEPS	
---------	--	-------------	--	-------	--

How do your averages compare to last week?

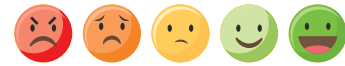
## Looking Forward

My goals for next week

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

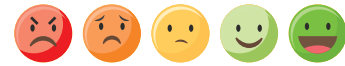
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

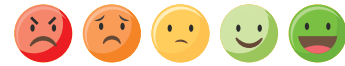
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

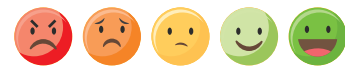
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS		TODAY I'M GRATEFUL FOR	
---------------	--	------------------------	--

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

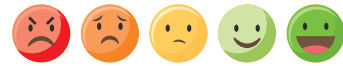
TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	



# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

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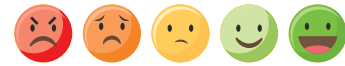
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	






# 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

FORMULA		LEU/PROTEIN		STEPS	
---------	--	-------------	--	-------	--

How do your averages compare to last week?

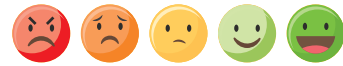
## Looking Forward

My goals for next week

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

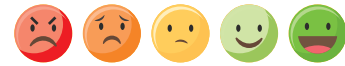
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS		TODAY I'M GRATEFUL FOR	
---------------	--	------------------------	--

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

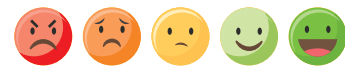
TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	



# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS		TODAY I'M GRATEFUL FOR	
---------------	--	------------------------	--

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

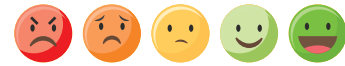
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

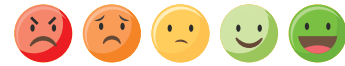
Steps/Exercise/Hydration:

TODAY'S GOALS		TODAY I'M GRATEFUL FOR	
---------------	--	------------------------	--

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	











# 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

FORMULA		LEU/PROTEIN		STEPS	
---------	--	-------------	--	-------	--

How do your averages compare to last week?

## Looking Forward

My goals for  
next week

# Daily Journal

date: \_\_\_\_\_

MORNING

AFTERNOON

EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	



# Daily Journal

date: \_\_\_\_\_

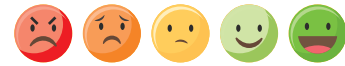
## MORNING



## AFTERNOON



## EVENING



### Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

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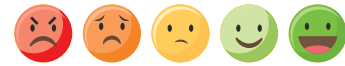
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

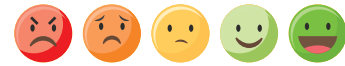
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

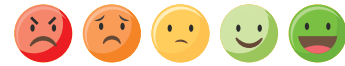
Steps/Exercise/Hydration:

TODAY'S GOALS		TODAY I'M GRATEFUL FOR	
---------------	--	------------------------	--

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

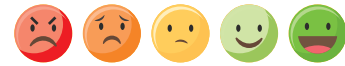
Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	

# Daily Journal

date: \_\_\_\_\_

MORNING AFTERNOON EVENING



## Meals

BREAKFAST		amount	LUNCH		amount
DINNER		amount	SNACKS		amount
FORMULA	time	FORMULA	time	FORMULA	time

Leu or protein target:

---

Steps/Exercise/Hydration:

TODAY'S GOALS	
TODAY I'M GRATEFUL FOR	











# 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

FORMULA		LEU/PROTEIN		STEPS	
---------	--	-------------	--	-------	--

How do your averages compare to last week?

## Looking Forward

My goals for next week

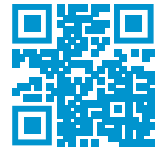




# 05. Useful Resources

# Other Resources

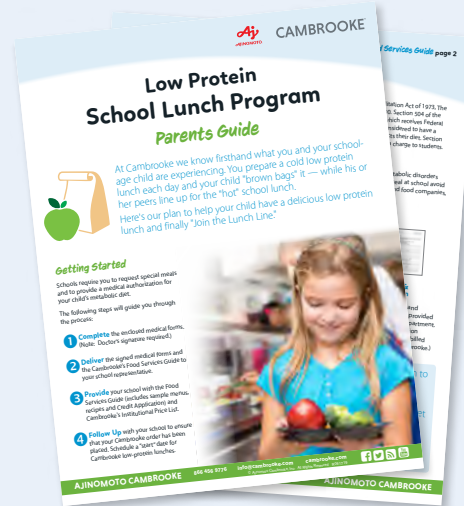
To request a copy, email [info@cambrooke.com](mailto:info@cambrooke.com) 



MORE  
RESOURCES

## National School Lunch Program

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



## 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 Paoella

# 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](http://Cambrooke.com) or call  
Customer Service at 866 456 9776, option 2



# a little dose of *sunshine* in every packet

We continue to innovate so you  
have more variety and choices.

*they're rare...we care!*

**15** ISOVACTIN™ AA  
**PE** LEUCINE FREE  
**Plus**  
POWDER



- ✔ Great Refreshing Flavor: **Lemon Lime**
- ✔ Flexible for all ages: **15g PE & 150 calories**
- ✔ Low Volume: **Mix with 5 oz water**
- ✔ Optimized Bone Health Profile
- ✔ Fiber: **2 g per packet**



REQUEST  
A SAMPLE



LEARN MORE



IVA



For people living with Isovaleric Acidemia,  
**Isovactin AA Plus Powder 15**  
is a low volume formula option.



Try these mixing tips to find what works best for you.

### **Adjust Flavor Intensity**

If you want a milder flavor, add an additional 1–2 fl. oz. (30–60 mL) of water until you find the right flavor balance for you.\*

### **Just Add “Milk”**

Give **Isovactin AA Plus Powder 15** a boost by mixing with your favorite nondairy milk alternative instead of water.\*\*

- ✔ Almond milk
- ✔ Coconut milk
- ✔ Oat milk
- ✔ Rice milk

### **Add Some Sparkle**

Mix one packet with 2 fl. oz. (60 mL) of water. Add 3–6 fl. oz. (90–180 mL) of flavored or unflavored sparkling water and mix. (Mix with a spoon, do not shake with carbonated beverage.)

### **Make Your Own Flavor**

Add a squirt or two of flavor drops to make your own unique flavor.

#### **Suggestions:**

- ✔ Cherry blackberry
- ✔ Orange tangerine
- ✔ Lemonade

*\* Standard mixing directions: add 1 packet to 5 fl. oz. (150 mL) water.*

*Mix with shaker bottle with mixing ball for best results.*

*\*\* Do not forget to count the methionine or protein from your nondairy milk alternative.*

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