

# PKU AND PREGNANCY

---

*A very special time in life*



# Preconception

Congratulations on taking the first step to having a baby.

The journey to motherhood begins with your metabolic clinic. It is essential to work with your clinic before, during and even after pregnancy. Only your clinic can provide the best guidance to ensure the best outcome for you and your baby. They will work with you to ensure well-controlled blood phenylalanine (PHE) levels prior to pregnancy and throughout pregnancy.

Studies in maternal PKU (MPKU) have shown uncontrolled blood PHE levels during pregnancy can cause the following outcomes for the baby:

- Microcephaly (small head size)
- Intellectual disability
- Behavioral issues
- Congenital heart defects (CHD)
- Low birth weight and reduced length for age

Keeping your PHE levels within recommended range will help protect your baby from these risks.

Speak with your metabolic healthcare professional regarding recommended PHE levels during pregnancy.

*This booklet provides tips for your entire pregnancy. However, always follow your clinic's guidance first.*

## Steps to getting PHE levels in the recommended range:

### Re-commit yourself to the low PHE diet

- Find low-PHE recipes at [NutriciaMetabolics.com/Recipes](https://www.nutricia.com/metabolics/recipes).
- Explore vegan recipes, however skip the plant-based protein ingredients such as legumes, soy, tofu, etc.
- Change regular bread, rice and pasta to low protein versions.

### Find a PKU formula you enjoy

- Nutricia offers the widest range of PKU formula options. You are sure to find one that meets your personal taste and needs (see page 15).
- Form a plan and stick to it. This will help to make sure you take all your prescribed formula each day.

### Make a new routine

- Regular blood samples (blood spots) will let you know when your PHE levels are in the safe range for pregnancy. Set a reminder on your calendar or cellphone to send your blood spots to your clinic.
- Meal planning will help make food shopping and new dining habits easier.

### Get connected

- Join an online Maternal PKU group to share, talk and get to know other women with PKU who are pregnant, planning to become pregnant or have tips to share from their past pregnancy.

# 1<sup>st</sup> trimester

In this trimester, you will gain anywhere from 0.5-2.3 kilos (1-5 pounds). Your baby will grow from the size of a tiny poppy seed to a lemon.

Some women report feeling nauseous during their 1st trimester and having difficulty keeping food down. Despite these challenges it is extremely important to drink your formula as it provides PKU-friendly protein and nutrition, which is essential for you and your baby.

## If nausea and vomiting strikes, here are some tips to help:

- Try eating just the foods you enjoy
- Remember that cold foods are sometimes better tolerated than hot foods
- Avoid an empty stomach
  - Try small frequent snacks every 2 hours during the day
- Ask your metabolic dietitian if a lower volume PKU formula is appropriate
- Divide current PKU formula into small frequent portions throughout the day
- Ask your metabolic dietitian if you can try a PKU formula with less of a smell
  - You can also drink your current PKU formula through a straw from a container with a cover to prevent smelling PKU formula while drinking
- Avoid taking any vitamin/mineral supplement on an empty stomach

## Some women also report constipation in their 1st trimester. Here are some tips to help:

- Focus on fruits and vegetables that are high in fiber and low in PHE
- Be sure you are drinking enough fluid

**DO NOT WAIT.** Make your clinic aware if nausea, vomiting or constipation does not improve.





## 2<sup>nd</sup> trimester

Depending on your pre-pregnancy weight, you will now start gaining about 0.23-0.45 kilos (0.5-1 pound) per week. In the 2nd trimester your baby will grow from the size of a peach to an acorn squash.

During this time period, you may notice the return of your appetite and a desire to eat more. It is still extremely important to keep your PHE levels in check, so be sure to work with your metabolic dietitian and have a meal plan in place.

**If hunger strikes go for your formula first. You may also benefit from preparing portioned out low-PHE snacks for the week:**

- Make single-serving bags of low protein pretzels, popcorn and cereal
  - Consider gluten-free\* items
- Fruit leathers or fresh fruit
- Sliced vegetables such as cucumbers, peppers, zucchini, etc.
- Portioned out cherry or grape tomatoes or baby carrots
- Prepare ahead and freeze bulk items such as low protein breads, biscuits, muffins, cookies and soups

### Get Ready!

During this stage you may have an increase in your daily PHE tolerance, which means increased food options. Your dietitian will work closely with you and monitor your blood PHE, but remember PKU formula is still your main source of PKU-friendly protein for both you and your rapidly growing baby.

\*Be sure to read labels and check serving sizes when planning a snack. PHE content varies by brand. Not all gluten-free foods are low in protein. For more information on finding the PHE content in common foods, check out [www.HowMuchPHE.org](http://www.HowMuchPHE.org) (English) or [TyrophED.com](http://TyrophED.com) (French Canadian).

# 3<sup>rd</sup> trimester

Depending on your pre-pregnancy weight, you will have gained roughly 5-18 kilos (11-40 pounds) by the end of your pregnancy. In your 3rd trimester your baby will grow from the size of a large butternut squash to a small watermelon.

Now you are getting closer to the exciting day. As your baby grows you may experience reflux, heartburn or feel full quickly.

## If heartburn strikes, here are some tips to help:

- Avoid caffeine, peppermint or spearmint, sodas, spicy foods and acidic foods
- Avoid large meals
  - Try small frequent meals spread throughout the day
- Limit meals close to bedtime
- Sleep with your head at elevated angle
- Consider ginger candy or tea

You have been working really hard on your diet. Set a plan to help you stay on diet once the baby arrives. **Here are some suggestions:**

- Teach your significant other, family and friends how to prepare your formula so they can help in the first few weeks.
- Share your favorite recipes with family and friends so they can prepare some meals for you.
- As you begin “nesting” cook some meals low in protein in advance and freeze for easy reheating.

**Almost there! Keep sending in your blood spots.**



# Now your baby is here!

You now have your new wonderful bundle of joy. You worked really hard on your diet to get to this point. Don't give up, you have another person to take care of now, and being your best means staying on diet.

As you know, going off diet could mean an increase in your PHE and a decrease in your tyrosine (TYR) blood levels.

## **PHE buildup (high levels) can cause:**

- Difficulty concentrating
- Feeling tired, moody or in a fog
- Tremors in hands, fingers, feet or legs
- Poor memory, short term recall or general forgetfulness
- Trouble focusing at work or school
- Difficulty following directions and problem solving
- Anxiety, phobias or depression

## **Taking care of a newborn is tough work. Be sure to keep formula as part of your daily routine. Here are some tips:**

- Set an alarm for several times each day to drink your formula
- Have your significant other, family or friends be in-charge of preparing 24 hour batches of your formula
- Make feeding time an opportunity for both of you to have your formula (or feeding)
- Turn your formula into a fruit smoothie to start your day



**Staying on diet is important for both you and your baby!**

Please seek help from a healthcare professional if you start to feel down or overwhelmed.



# Breastfeeding

You can breastfeed your baby just like any other mother. For every nursing mom, calories play an important role in the ability to produce breastmilk. Your dietitian will review how your PHE intake and your diet overall may change with breastfeeding.

## Here are some tips to help when more calories are needed:

- Mix oil or non-dairy margarine into low protein pasta or rice
- If your dietitian feels it's appropriate, change from a low calorie PKU formula to a higher calorie PKU formula containing fat
- Dip low protein bread in olive oil
- Add avocado to salads or sandwiches
- Add sweets to teas, coffees, muffins and smoothies
  - Maple syrup, honey, agave nectar, sugar

**Be sure to continue checking your blood levels regularly!**

# Low protein cooking

Planning ahead, making grocery lists and exploring vegetable-based recipes will help you keep control of your PHE levels.

Here are two quick and delicious recipes low in protein.

## Zucchini Pizza Bites

1 XL zucchini (400 g)  
1 tsp salt  
Olive oil spray  
¼ cup tomato sauce  
½ cup low protein cheese

### Directions:

1. Preheat oven to 450° F (230° C)
2. Cut zucchini into 1.3 cm (½”) slices
3. Grease baking sheet with olive oil and place zucchini slices on sheet
4. Bake for 8 minutes on each side or until lightly browned
5. Spoon tomato sauce onto each slice
6. Top each slice with low protein cheese
7. Return to oven for an additional 2 minutes

1 pizza bite (70 g)

Protein **0.8 g** PHE **30 mg**

## Jicama Fries

1 jicama (1 lb or 0.45 kg), peeled, cut into 1.3 cm (½”) thick fries  
1 tbsp olive oil  
½ tsp coarse salt  
½ tsp garlic powder  
½ tsp paprika  
¼ tsp ground black pepper

### Directions:

1. Preheat oven to 400° F (205° C)
2. Line a cookie sheet with foil and fit it with a cooling rack
3. Bring water to a boil in medium saucepan on medium heat
4. Add jicama and cook for 8 minutes until jicama is less crunchy
5. Drain water, using a colander
6. In a large bowl, toss the jicama fries with the olive oil and the spices
7. Arrange on the cooling/booking rack
8. Bake 45 minutes, until browned. Serve immediately

**Prep Tip:** To microwave instead of boiling on stove-top, place the jicama strips in a microwave-safe bowl. Add 2 tbsp of water. Cover and microwave for 15 minutes, stopping once to gently stir.

**Tip:** Blend with your personal favorite flavours, herbs and spices for variety.

Makes 2 servings (170 g)

Protein **1 g** PHE **29 mg**



Find more recipes at [NutriciaMetabolics.com](https://NutriciaMetabolics.com)

# Nutricia products

## Find the Right PKU Product for You

Every person is different and has different needs, especially during pregnancy. Taste, smell and volume may be a challenge at times. Nutricia provides an extensive selection of PKU formulas to help during this critical time.

All PKU formulas should be used only under medical supervision and managed by a healthcare professional. Always speak to your metabolic healthcare professional prior to making any changes in your PKU diet plan.






Request samples from your dietitian, by calling **1-877-636-2283** or by sending an email at [Canada.CustomerService@nutricia.com](mailto:Canada.CustomerService@nutricia.com).







All products shown are food for special dietary use from Nutricia North America for proven phenylketonuria (PKU) and must be used under medical supervision.

Visit [NutriciaMetabolics.com](https://www.nutricia.com/metabolics) for more information.



## Looking for a higher calorie PKU formula?

	Product Name	Description
	PhenylAde® GMP READY	<ul style="list-style-type: none"> <li>• Plain flavour</li> <li>• GMP-based</li> <li>• Ready-to-drink</li> <li>• Added DHA and EPA</li> <li>• 10 g PE (18 mg PHE)/110 kcal (per 250 mL, 8.5 fl oz container)</li> </ul>
	PhenylAde® GMP Drink Mix	<ul style="list-style-type: none"> <li>• 2 flavours (Original and Vanilla)</li> <li>• GMP-based</li> <li>• Added DHA</li> <li>• 10 g PE (15.3 mg PHE)/132 kcal (180 mL, 6 fl oz)</li> </ul>
	PhenylAde® Essential Drink Mix	<ul style="list-style-type: none"> <li>• 5 flavours (Unflavoured, Vanilla, Chocolate, Orange Creme and Strawberry)</li> <li>• 10 g PE/157 kcal (240 mL, 8 fl oz)</li> </ul>
	Periflex® LQ	<ul style="list-style-type: none"> <li>• 2 flavours (Orange Crème and Berry Crème)</li> <li>• Ready-to-drink</li> <li>• 10 g PE/107 kcal (15 g PE &amp; 160 kcal per 250 mL, 8.5 fl oz container)</li> </ul>
	Periflex® Advance	<ul style="list-style-type: none"> <li>• 2 flavours (Unflavoured and Orange)</li> <li>• 10 g PE/110 kcal (120 mL, 4 fl oz)</li> </ul>

## Looking for a lower volume PKU formula?

	Product Name	Description
	PhenylAde® GMP ULTRA	<ul style="list-style-type: none"> <li>• 2 flavours (Lemonade and Vanilla)</li> <li>• GMP-based</li> <li>• 10 g PE (18 mg PHE)/49 kcal (20 g PE &amp; 98 kcal per pouch)</li> </ul>
	PhenylAde® 60 Drink Mix	<ul style="list-style-type: none"> <li>• 2 flavours (Unflavoured and Vanilla)</li> <li>• 10 g PE/49 kcal (90 mL, 3 fl oz)</li> </ul>
	Lophlex® LQ	<ul style="list-style-type: none"> <li>• 3 flavours (Juicy Orange, Mixed Berry Blast and Juicy Tropical)</li> <li>• Juice-based</li> <li>• Ready-to-drink</li> <li>• Added DHA</li> <li>• 10 g PE/60 kcal (20 g PE &amp; 120 kcal per 125 mL, 4.2 fl oz pouch)</li> </ul>
	PKU Maxamum®	<ul style="list-style-type: none"> <li>• 2 flavours (Unflavoured and Orange)</li> <li>• 10 g PE/76 kcal (120 mL, 4 fl oz)</li> </ul>

Is the smell or taste of the PKU formula a problem?

	Product Name	Description
	PhenylAde® GMP Mix-In	<ul style="list-style-type: none"><li>• Mix into any liquid or semi-solid food without significant flavour change</li><li>• GMP-based</li><li>• 10 g PE (15.3 mg PHE)/42 kcal†</li></ul>
	PhenylAde® MTE Amino Acid Blend	<ul style="list-style-type: none"><li>• Mixes into any flavoured liquid (except plain water)</li><li>• 10 g PE/40 kcal†</li></ul>

Please note when using these products sufficient fat and energy intake from other sources are essential; these products must be combined with an appropriate vitamin and mineral supplement when taken as the sole source of PKU formula.

†For the product on its own; flavoured liquid added to product may alter caloric and PHE content



WANT TO TRY  
SOMETHING NEW?

3 EASY WAYS TO REQUEST A SAMPLE

1. Talk to your metabolic clinic
2. Send us an email at [Canada.CustomerService@nutricia.com](mailto:Canada.CustomerService@nutricia.com)
3. Call Nutricia at 1-877-636-2283



## *Who's who (contact details)*

### **My dietitian**

Name: .....

Phone #: .....

Email: .....

### **My nurse**

Name: .....

Phone #: .....

Email: .....

### **My doctor**

Name: .....

Phone #: .....

Email: .....

# Notes

---

---

---

---

---

---

---

---

---

---

# Notes

---

---

---

---

---

---

---

---

---

---

# Your family journey is about to begin... Nutricia is here to support you along the way.

“This is the hardest and most rewarding journey in a PKU woman’s life and worth every second of all the hard work we put into our pregnancies.”

**Lisa Marie , Classical PKU, Age 36, Northern NJ**

“Finally gave birth to my beautiful and healthy baby girl Claire Marie (7 lbs 2 oz). I am so proud of myself and what I’ve accomplished with my diet and pregnancy. Now time to enjoy this little lucky charm of mine! – feeling blessed.”

**Leann, Classical PKU, Age 28, Tampa, FL**

