

# The Diet for Phenylketonuria (PKU)



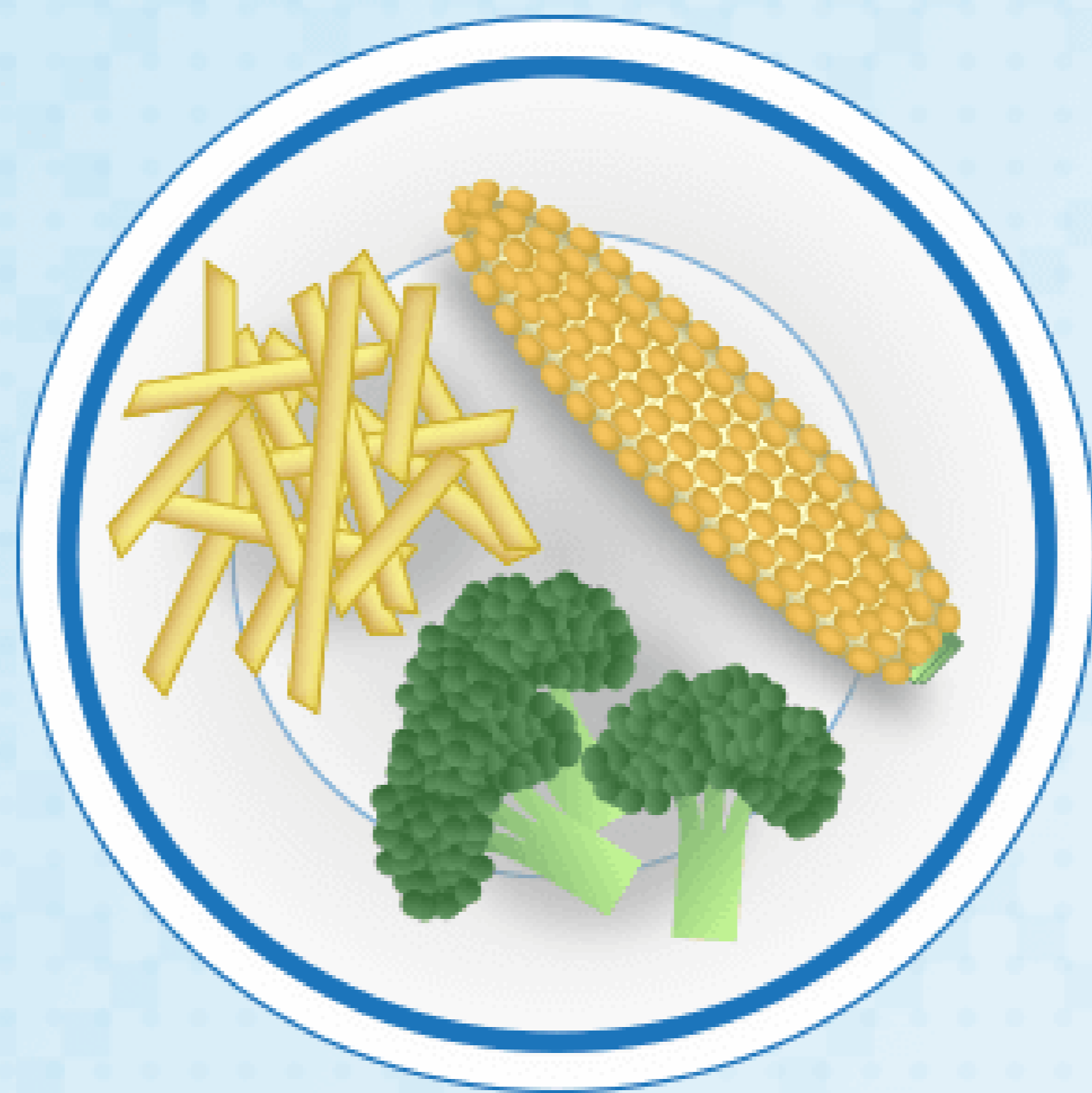
# INTRODUCTION: WHAT IS THE DIET FOR PKU?

People with phenylketonuria (PKU) are not able to properly breakdown the amino acid called phenylalanine (Phe) into tyrosine. As a result, too much Phe can build up and is unhealthy for the brain. Phe levels can be controlled within a treatment range by eating the prescribed amount of Phe.

**Your dietitian will explain more about allowed foods and the special formula.**

**There are two parts to the PKU diet:**

- 1. Limiting foods containing Phe to the amount needed for normal growth and development.**
- 2. Including a special medical food that provides other parts of protein (amino acids) without Phe.**



# WHAT FOODS SHOULD BE AVOIDED?

Foods that are high in protein are avoided. These are sometimes called “No” foods and include:

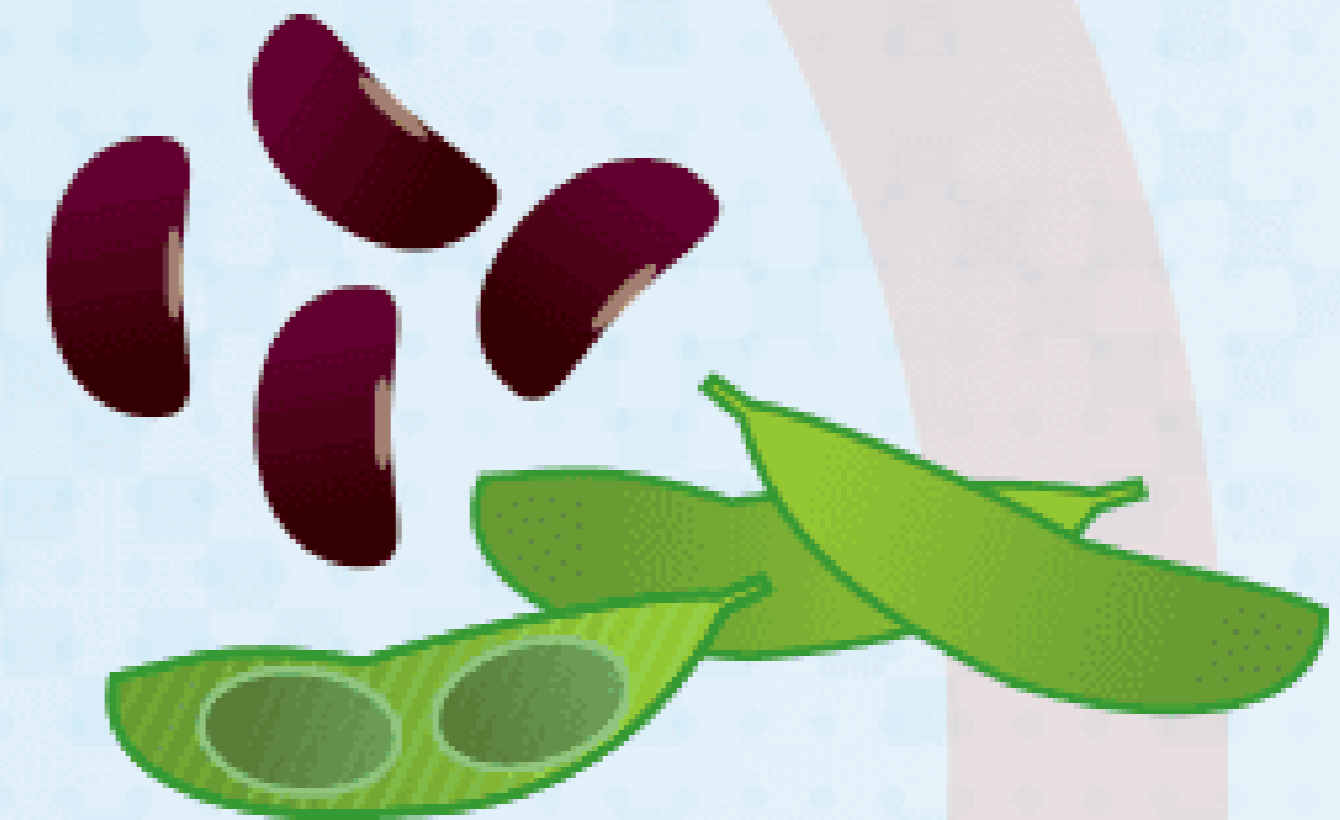
**MEAT, FISH, POULTRY**



**MILK & DAIRY PRODUCTS**



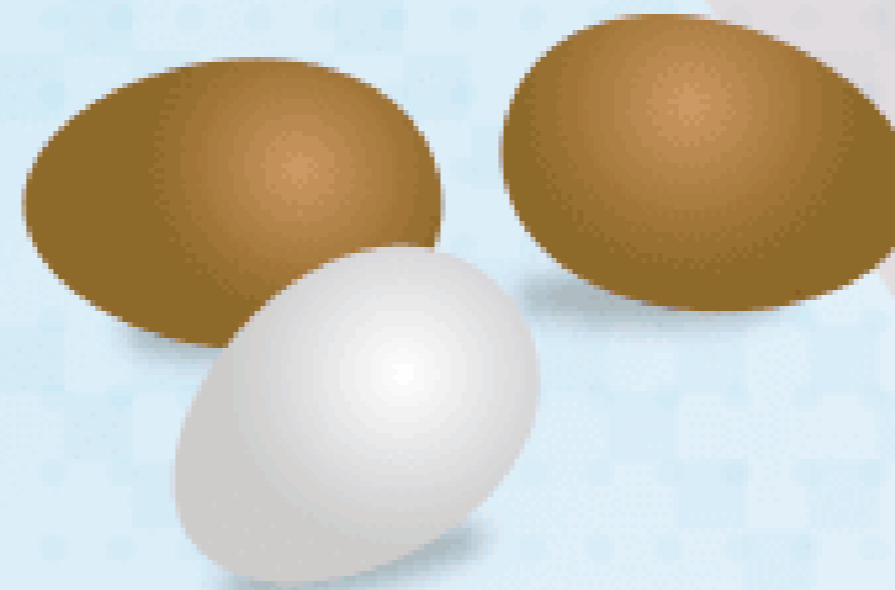
**LEGUMES  
(SOYBEANS, KIDNEY BEANS, ETC.)**



**ASPARTAME**



**EGGS**



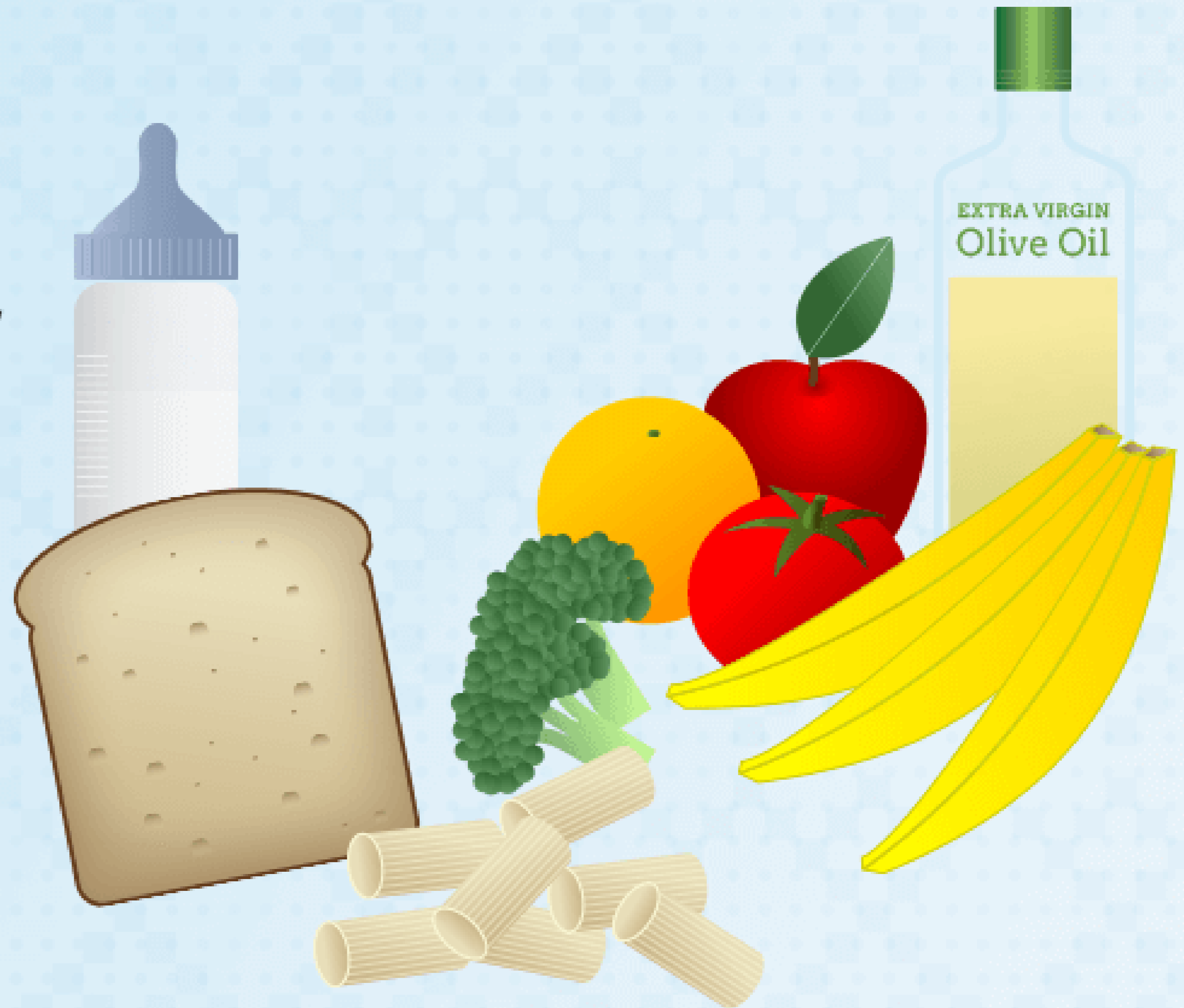
**NUTS**



## WHAT FOODS ARE OK?

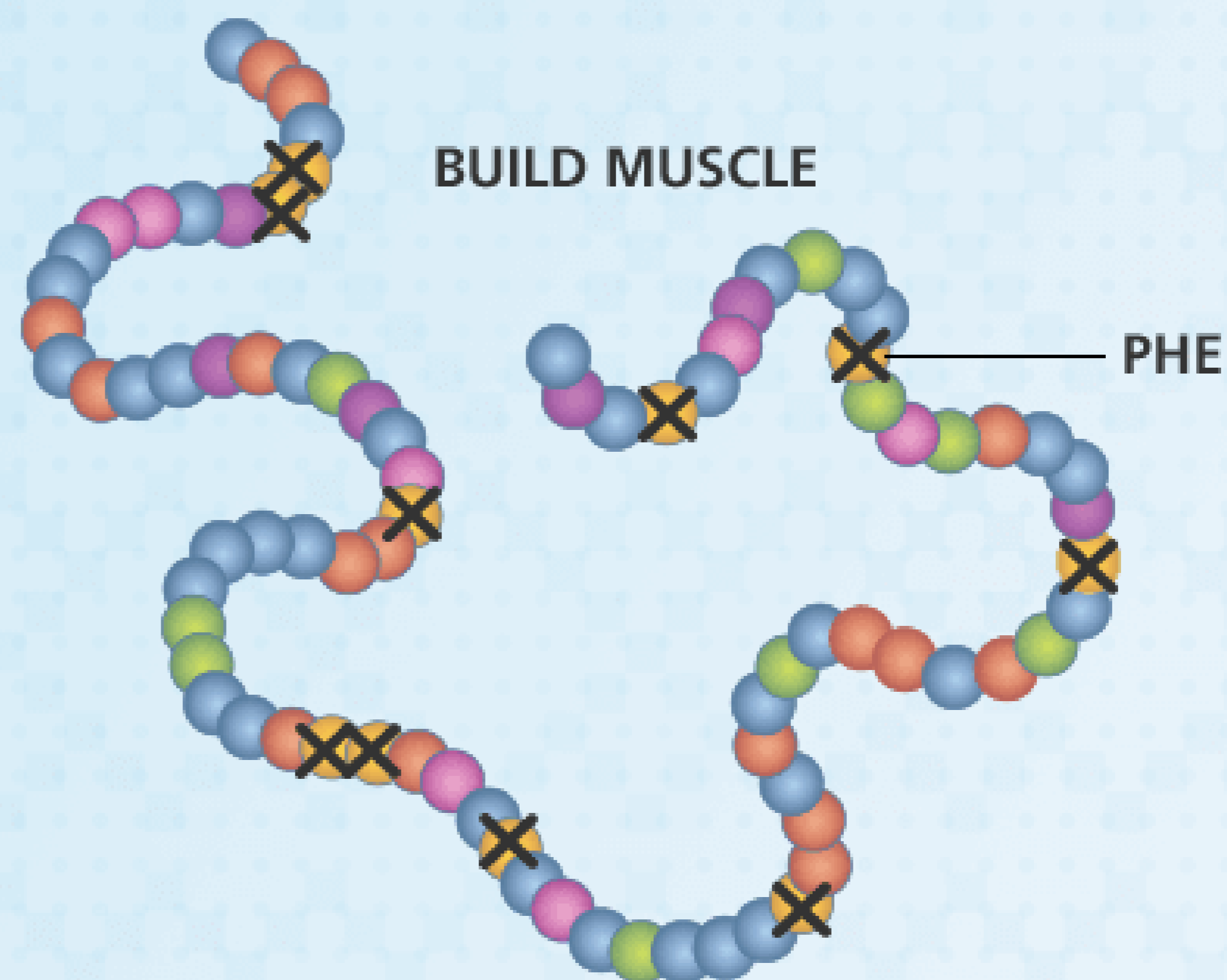
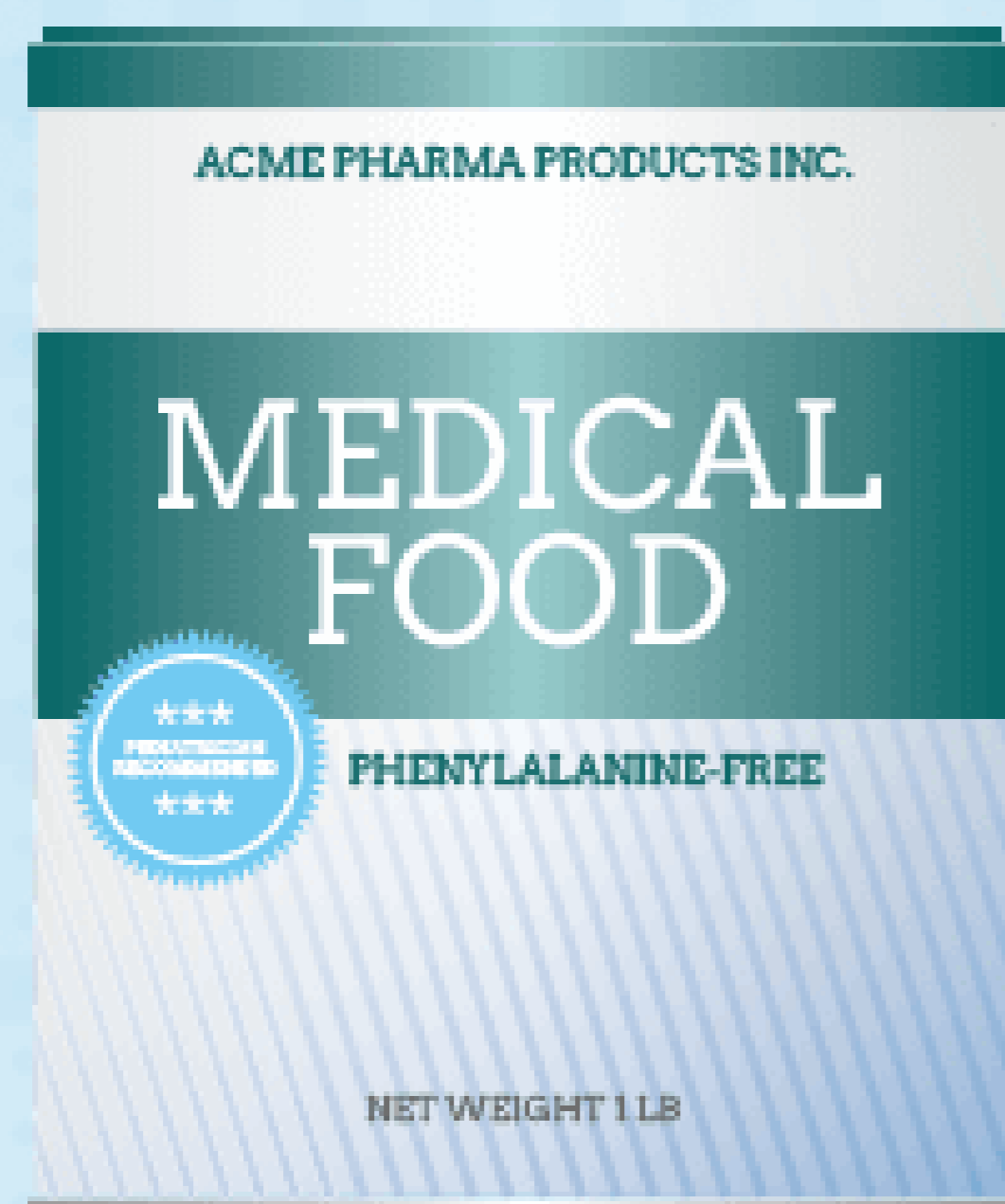
Foods that are included in the diet for PKU are often referred to as “allowed” or “yes” foods.

- Limited amounts of breast milk or regular infant formula (for infants)
- A wide variety of fruits, fruit juices, and vegetables
- Special low protein foods, such as low protein breads, pastas, flours, and baked items
- Oils, sugars, spices
- Starchy vegetables and some cereals may be allowed, but in measured amounts



# WHAT ARE MEDICAL FOODS?

The amount of protein that comes from the allowed foods on the PKU diet is not enough to support normal growth and development. So it is important to consume a special formula, or medical food, which will be your child's main source of nutrition. Medical foods also contain carbohydrates, fats, vitamins, and minerals—all the nutrients needed to grow well.



Medical foods contain the amino acids (without Phe).

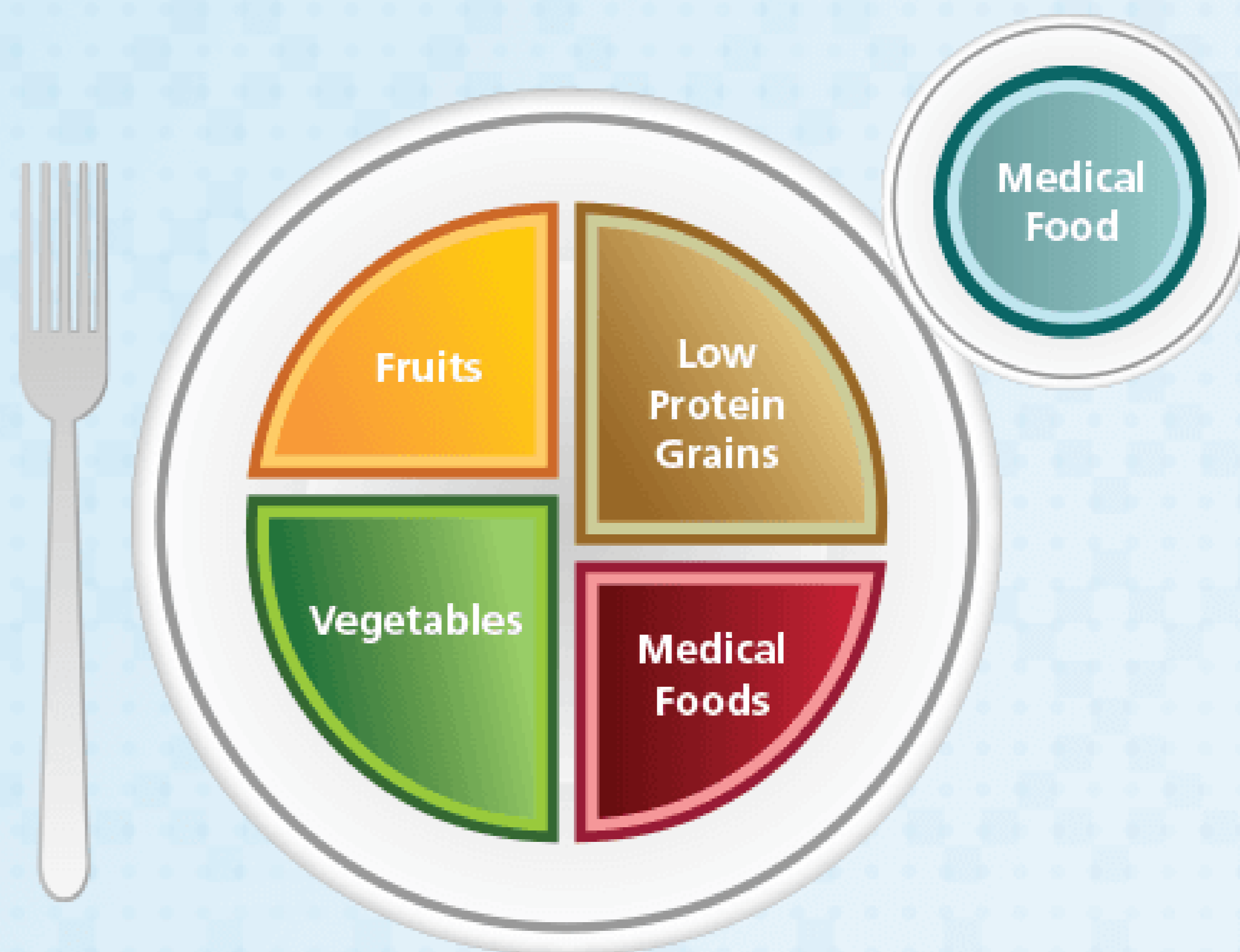
# WILL MY CHILD GET ENOUGH TO EAT?

**Yes! Your child will be well nourished.**

The PKU diet reduces Phe, not calories, the energy that comes from foods and that gives the body the fuel it needs. Your child needs the same calories, vitamins, and minerals as a child who does not have PKU.

Without enough calories, your child's body may break down its body muscle to get the energy it needs. This is called catabolism and it can lead to high blood Phe levels.

There is some variation in what children will eat from day to day and there are strategies that you will learn for when a child wants more or less than the allowed amounts of Phe. Listening to your child's hunger cues is important in building a healthy attitude about food and eating.



## HOW MUCH PHE IS RIGHT FOR MY CHILD?

Each child needs a different amount of Phe. This is because of growth, health and genetic factors.

- If blood Phe is too high (more than 360  $\mu\text{mol/L}$  or 6 mg/dL), or too low (less than 120  $\mu\text{mol/L}$  or 2 mg/dL), your dietitian will adjust the diet.

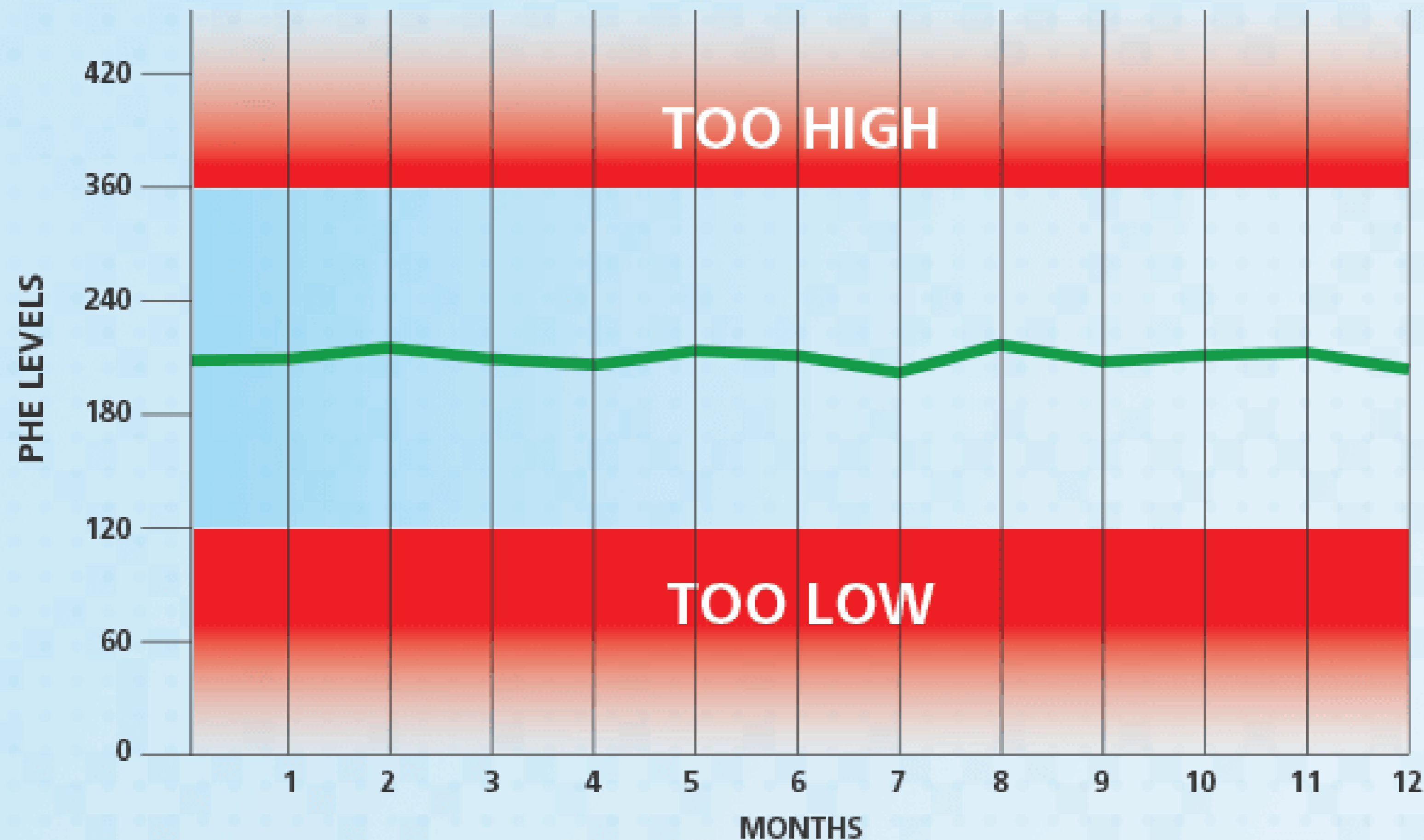


By monitoring your child's blood Phe, we will know if your child is getting the right amount of Phe.



# WHAT HAPPENS IF BLOOD PHE LEVELS GO TOO HIGH OR TOO LOW?

The goal of the PKU diet is to keep Phe levels consistently within treatment range over time. An isolated case of a high or low level is not a concern.



Remember, the problems seen in PKU occur when blood Phe is high or low over a period of time.

- High blood Phe in infants and children affects brain development and leads to intellectual disability. In older children and adults, high blood Phe can cause problems with memory and processing speed and can lead to anxiety and/or depression.
- Low blood Phe in infants and children may lead to poor growth.



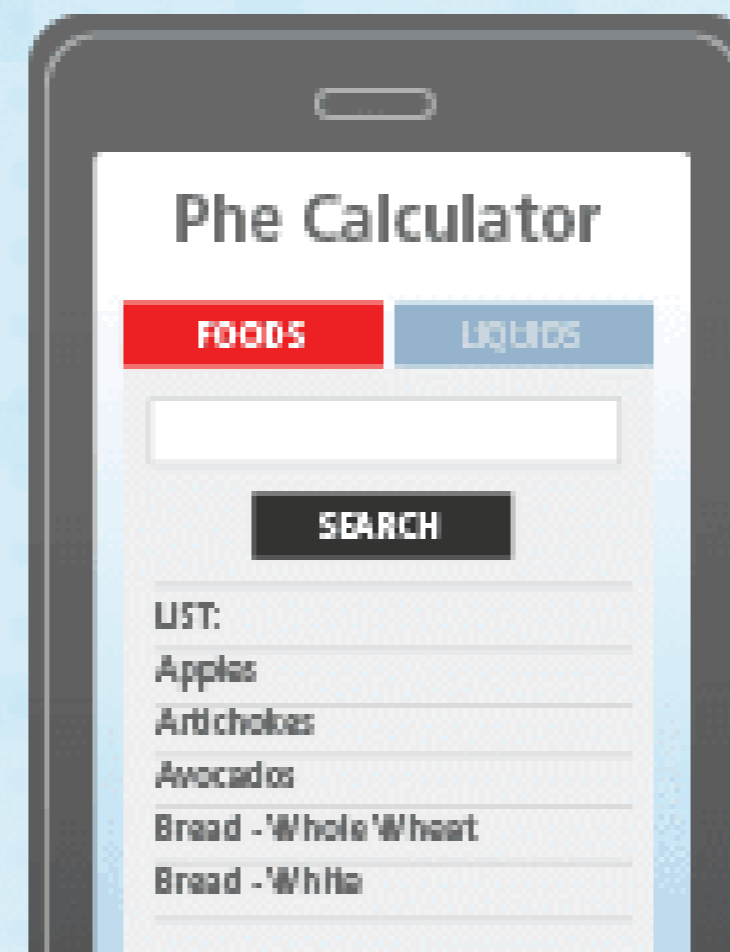
# YOU CAN DO IT!

There are many tools and resources you can use to help make following this diet easier.

## TALK TO YOUR DOCTOR OR DIETITIAN



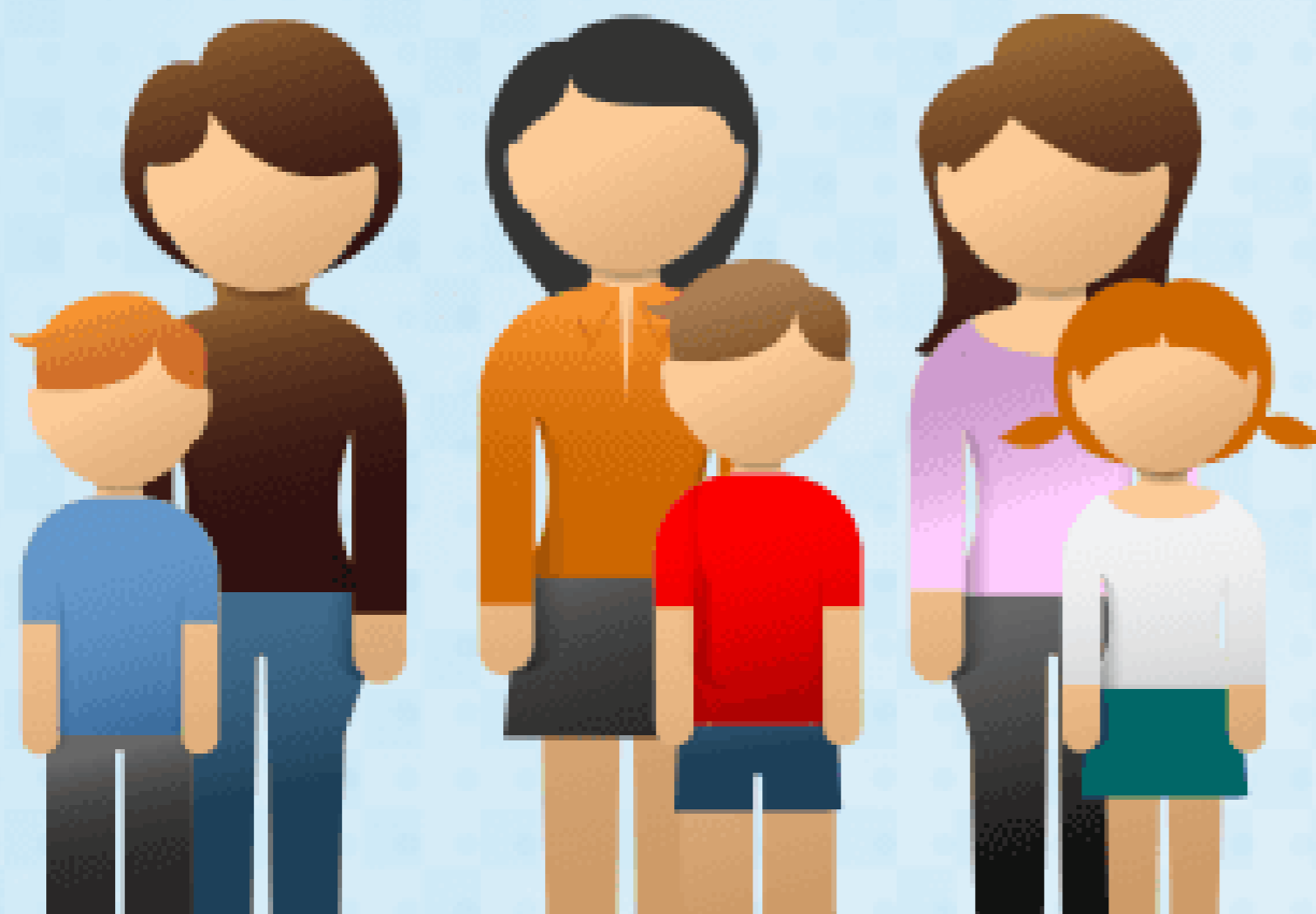
## PHE CALCULATOR



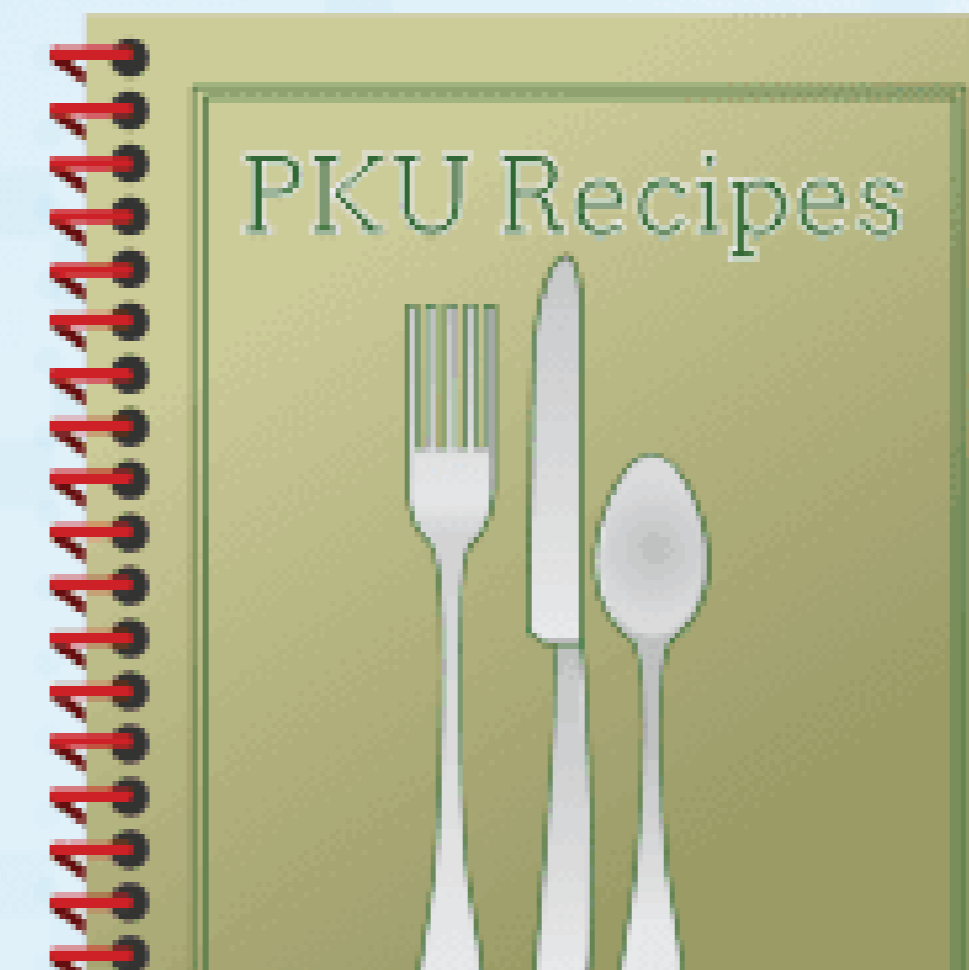
## SHOPPING FOR LOW PROTEIN FOOD IDEAS



## SUPPORT GROUP - SHARING OF IDEAS



## RECIPE CARDS AND COOKBOOKS FOR PKU



# DIET INSTRUCTIONS

## Diet Prescription

Medical food to be used

Source of Phe to be used

To prepare formula

## Check blood phe

## Next clinic appointment

## Food record

## For further information:



National PKU Alliance  
(family support group):  
[www.npkua.org/](http://www.npkua.org/)



How Much Phe?  
<https://howmuchphe.org/>

# DISCLAIMER

This presentation is for informational purposes only and is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified healthcare professional with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this presentation.

