Living with PKU

The diet for PKU can be managed during all the activities your child and family choose to participate in:

Birthday parties

Vacations

Sports

Dining Out

Childcare

HOW CAN I HELP MY CHILD ENJOY HAVING AND GOING TO BIRTHDAY PARTIES?

With a little planning, your child 's birthday party can be a success. There are plenty of low Phe options. Or you can shift the focus of the party to a game or activity and start a new birthday tradition.

Bake a low protein cake

Top cake with frosting (usually a free food)

Serve low protein party foods (Fresh fruit skewers, veggie platter, low pro pretzels or low pro pizza)

Pack a low protein cupcake for your child to take to a friend's birthday or other celebration

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It is helpful to have food your child can eat readily available. This will empower your child to make appropriate food choices.

At home:

- Create a low protein food zone in your kitchen

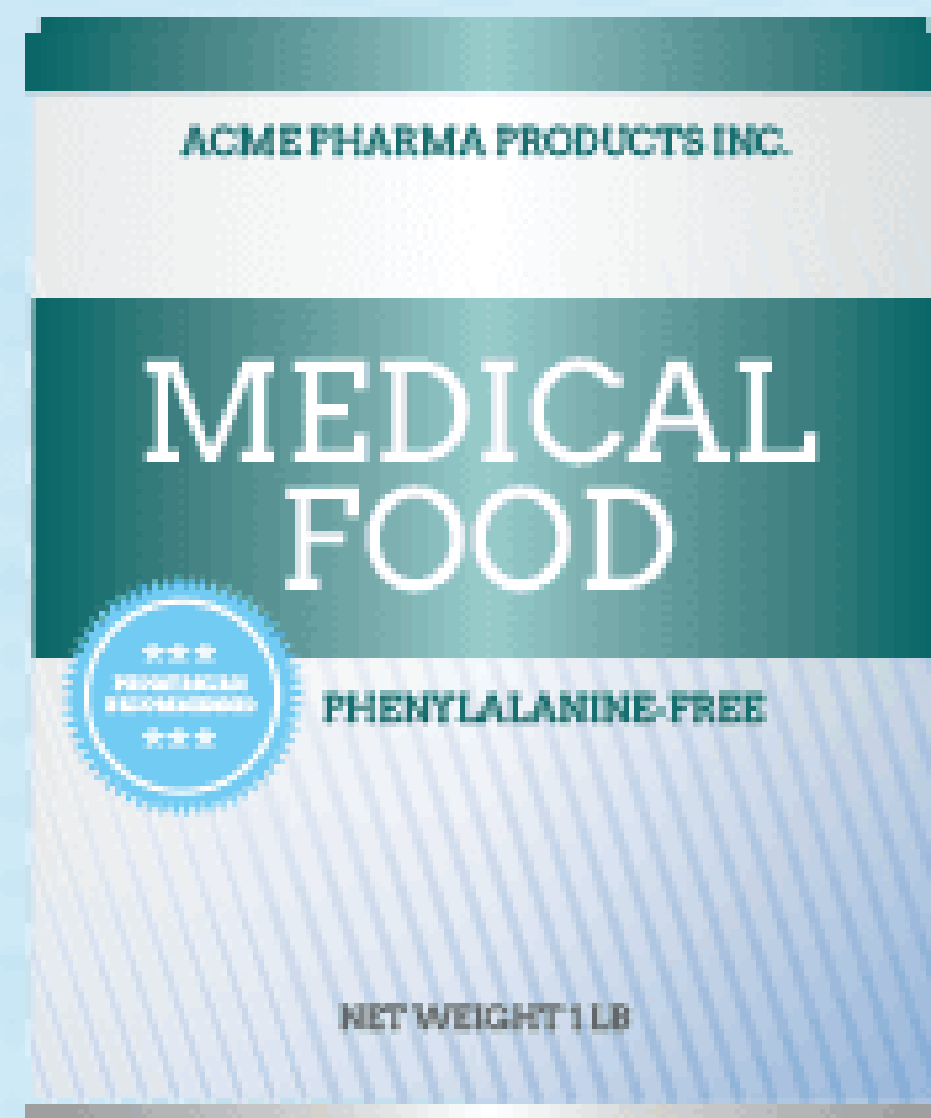- Keep low protein meals in the refrigerator for a babysitter to heat up and serve

At daycare:

- Send your child to daycare with a lunch and snacks

- Keep a low protein treat on hand in case of a special event

- Share your food diary with your care providers. Let them record the foods and amount eaten and you can do the math later.

Note to Babysitter
Low Protein Snacks for Suzy

FOOD RECORD DATE:

BREAKFAST
Time:

SNACK
Time:

LUNCH
Time:

Suzy Johnson's Lunch

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HOW CAN I KEEP MY CHILD ENERGIZED FOR SPORTS AND EXERCISE?

Staying active is healthy for everyone. With the right diet, children with PKU can play sports, exercise, and participate in all physical activities.

ACME PHARMA PRODUCTS INC.

MEDICAL FOOD

PHENYLALANINE-FREE

NET WEIGHT 1 LB

BOTTLED SPRING WATER

SPORTS DRINK
LEMON/LIME

Have your medical food before exercise. It contains the protein used to build muscle, strength and stamina.
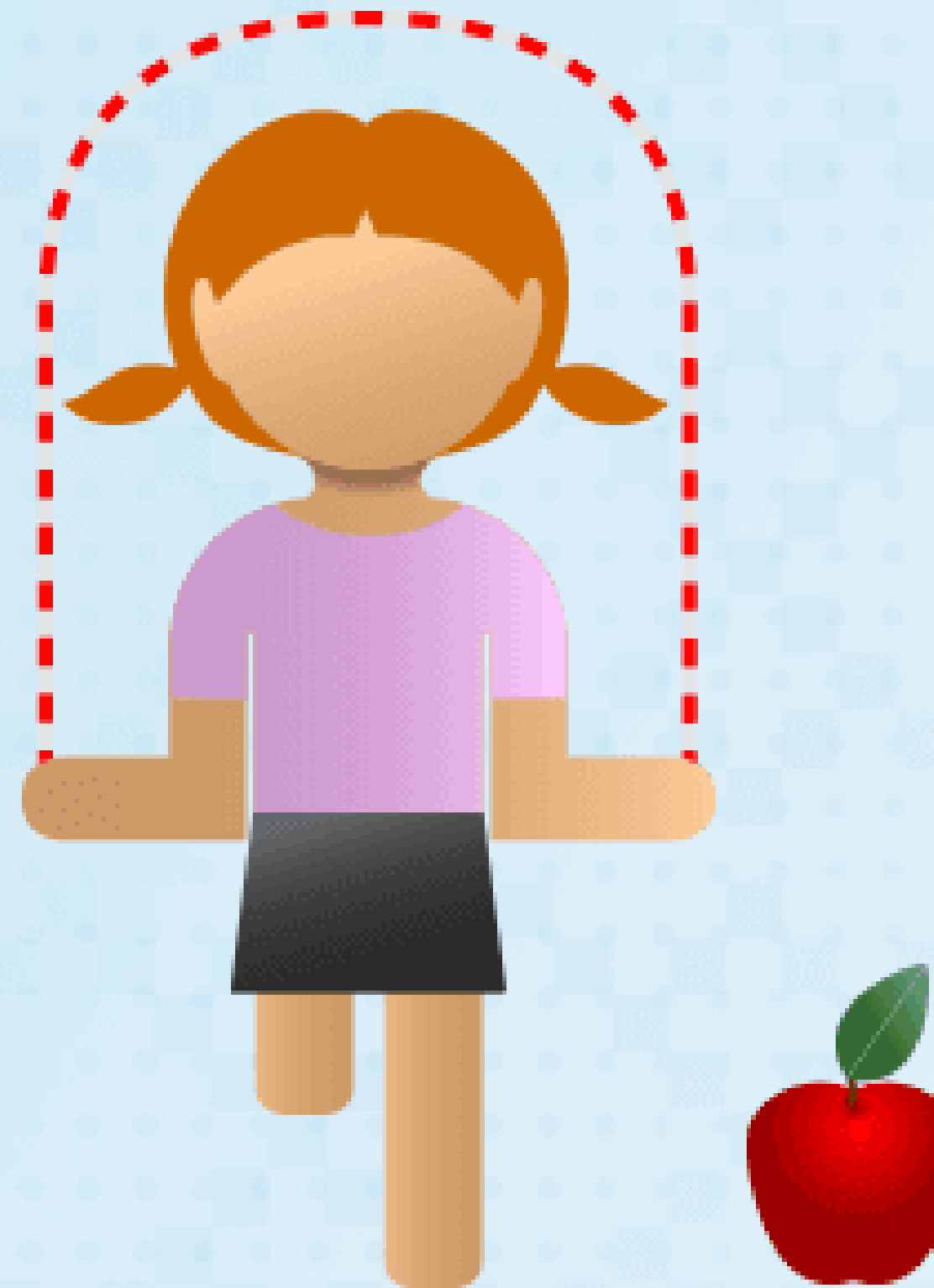
Bring snacks to provide energy. Extra calories are needed during exercise. Too few calories can increase blood Phe.

Drink plenty of fluid (water, juice or sports drinks).

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HOW CAN MY CHILD STAY ON HIS DIET WHEN WE GO OUT TO EAT?

Going out to eat can be a challenge with any child. Here are a few tips to make a little bit easier for your child with PKU:

Serve PKU formula and a low phe snack before going to the restaurant to curb your child's appetite

- Look at menus and the nutritional information of foods served at the restaurant online.

- Find restaurants with vegetarian options

- Save enough of the allowed daily Phe for the restaurant meal

- Ask for menu modifications. Explain that your child is on a special diet and ask if they will prepare low protein food if you supply the ingredients

- Bring medical food with you. This will provide nourishment and satiety to your child

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Making sure you have a fun vacation takes planning.

- Pack the items you will need: medical food, low protein food, scales or measuring utensils, and a mixing container

- Check for vacation destinations that welcome people on special diets

- Network with other families to find restaurants that offer options for a low protein diet

- Consider staying at places with access to a refrigerator and/or a kitchen

- Consider sending your child to a PKU camp or event where they will form friendships with other kids with PKU, gain a sense of independence, and become confident in managing their diet.

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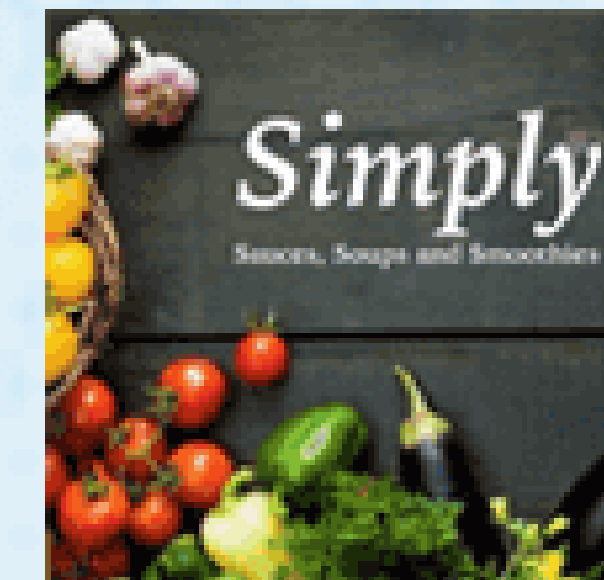# FOR MORE INFORMATION
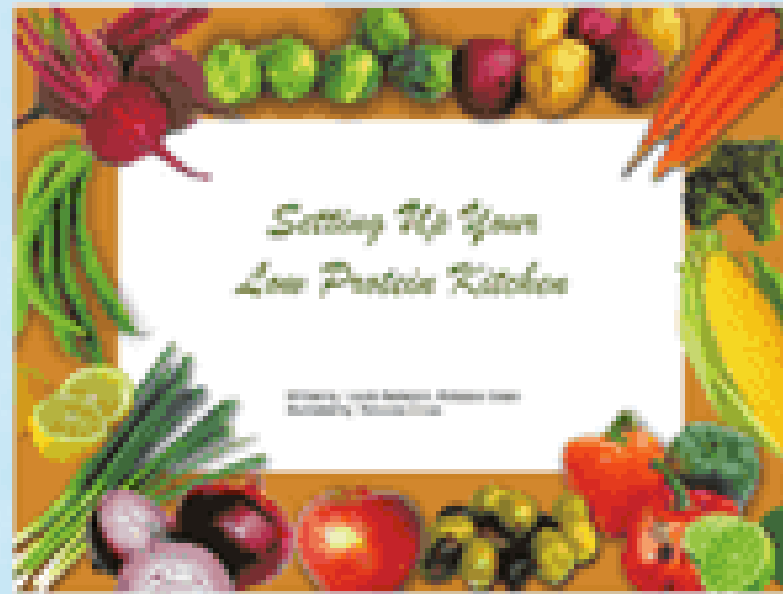
Setting Up Your Low
Protein Kitchen
by Laurie Bernstein
http://www.amazon.com/Sett
ing-Your-Low-Protein-Kitchen/
dp/1481752499

Lo Pro Network (Offers low protein
cooking classes and education
about diets)
http://lopronetwork.weebly.com

Simply Soups, sauces,
and Smoothies
http://df79136e-0030-4f0c-b0
46-91602ed69317.mobapp.at/
landing/Desktop#.VgCm_WR
Viko

Phe content of foods: How Much Phe?
https://howmuchphe.org/

New England Consortium of Metabolic Programs
Connecting professionals to provide the best patient care

Diet for Life PKU Toolkit
http://newenglandconsortium.org/toolkit/

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