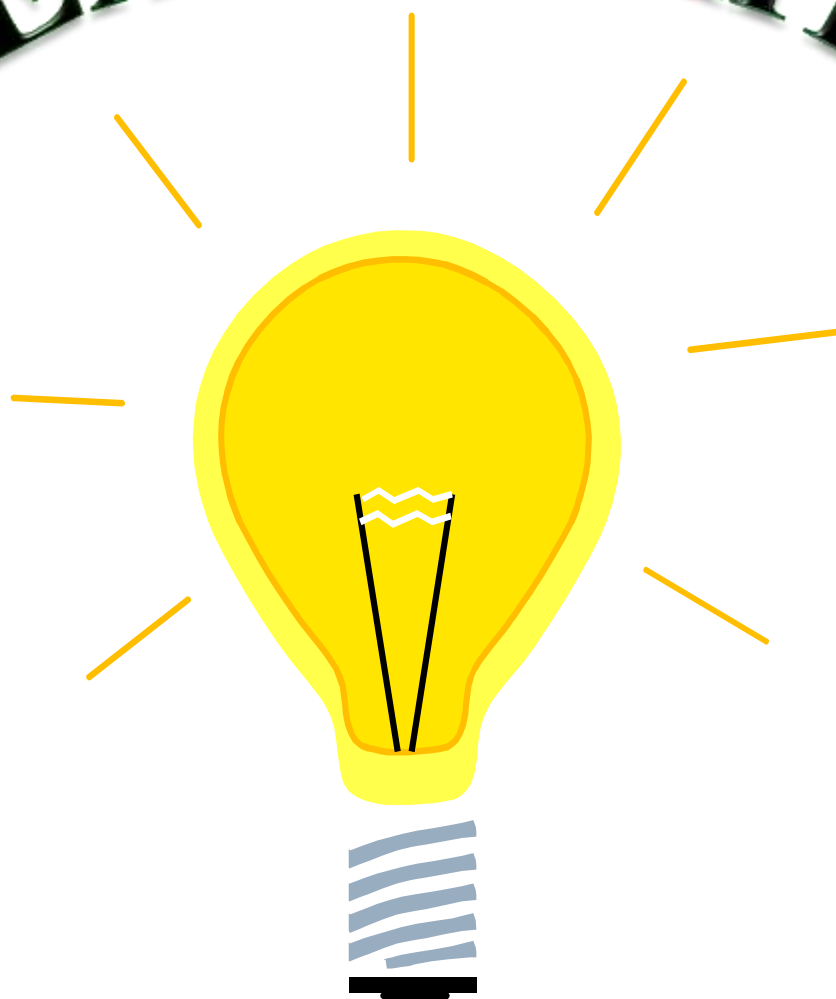


EAT RIGHT



STAY BRIGHT™

Guide For Hyperphenylalaninemia



The Children's Hospital

Affiliated with
University of Colorado Denver

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CHAPTER TWO



The Elementary School Years

INTRODUCTION

The Inherited Metabolic Clinic at The Children's Hospital in Aurora, CO serves the Rocky Mountain Plains Region and at least 130 individuals with hyperphenylalaninemia (PKU). Children and families require a great deal of complex information, most often new and alien to their experience, in order to establish and maintain consistent and effective treatment. Our experience with the process of sharing such information with families motivated us develop this anticipatory guidance book with teaching aids. We also found it useful to develop a checklist to be certain our delivery of service is consistent and thorough. We hope that this guide will prove to be a useful tool for you in your clinic.

THIS EDUCATIONAL TOOL IS DIVIDED INTO FOUR CHAPTERS:

1. Birth to Five Years

2. The Elementary School Years

3. Adolescent Years

4. Maternal PKU

EACH CHAPTER IS SUBDIVIDED INTO FOUR SECTIONS:

Clinic Encounter Check Lists

Contains forms to be utilized during each clinic appointment in an effort to ensure that appropriate key issues are discussed at each clinic visit.

Experience and Thoughts

We share insights from our experience. This section can be read independently, however, superscript items on the clinic encounter checklists refer to specific topics.

Teaching Aids and Handouts

Find the materials designed to assist in counseling and teaching.

Resources

Other useful and generally available teaching aids and information on acquiring those publications.

Keep in mind that all chapters have been developed as an anticipatory guidance tool with patient education and improved patient compliance as its main goal. We urge you to copy, individualize, and add to any and all of the sections. Whatever your approach, we hope this educational tool assists you in your clinic setting. New innovative methods are always helpful in our roles as health care providers.

This book has been developed with contributions from many professionals and students within The IMD clinic. There are some teaching aids that are available in one or more variations; we hope this complements your teaching style and facilitates the learning of new information.

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CHECKLIST: Introduction

Children of school age should be active participants in their health care. To successfully involve the children, strategies should be oriented to their physical, cognitive, emotional, social and psychological development. In each of these areas there is progression during the elementary school years, and a solid base of knowledge about these parameters is useful. This is a critical time for children with metabolic disorders to adapt successfully to their disorder. Children who feel good about themselves are better equipped to withstand peer pressure.

Children need both the freedom of personal expression and the structure of expectations and guidelines so that they can accept and begin to participate responsibly in the management of their disorder. Developing an understanding of their metabolic disease can be facilitated by acquiring an age appropriate knowledge in areas of anatomy, physiology, biochemistry and genetics, as they relate to hyperphenylalaninemia. We continuously work to promote age appropriate independence by encouraging developmentally appropriate decision-making. We hope that some of the following suggestions help health professionals, families and the child to work together to foster their emerging independence.

We have created three separate checklists that address the unique issues of each role:

❖ **Parents**

Parents remain the front line providers of care during the elementary school years.

❖ **Children**

With the child's increasing age and cognitive abilities, he also becomes an integral player in management, and the health professional should speak directly with the child.

❖ **Professionals**

A professional checklist has been developed to remind us that the care of chronic diseases requires a sensitive and creative approach.

CHECKLIST: Parents

Planning For The Future

- ☐ Genetics
 - Future pregnancies
- ☐ Carrier testing for extended family
- ☐ Diet for life
- ☐ Adverse effects of elevated levels
 - MRI findings
 - Neurological findings
 - Personality changes
 - School and social performance
- ☐ Maternal PKU

Phe Levels, Growth Charts, Interim History

- ☐ Interim levels
 - Phenylalanine (Phe)
 - Tyrosine (Tyr)
- ☐ Intercurrent illness
- ☐ Growth

Daily Living Routine¹

- ☐ Weighing, measuring, and preparing formula
- ☐ Cooking/recipes
- ☐ Diet records² (see teaching aids/handout)
- ☐ Blood draws (including time of draw in relation to food/formula intake)
- ☐ Family integration

Superscript numbers throughout the Clinic Encounter
Checklists refer to the Experience and Thoughts section.



CHECKLIST: Parents

Psychosocial Issues

- ☐ School
- ☐ Peers
- ☐ Siblings
- ☐ Manipulation/power struggles
- ☐ Over-commitment/martyrdom
- ☐ Overprotection
- ☐ Family communication
- ☐ Parental attitudes
- ☐ Self-esteem
- ☐ Finances³
- ☐ Impact of diet on family life⁴
- ☐ Realistic expectations

Nutrition Intervention

- ☐ Use of the following items
 - Low protein foods
 - Low protein recipe books (V. Schuett)
 - Gram scale, bread machine, etc.
 - Low protein food lists
- ☐ Childcare/school/aftercare (see teaching aids/handouts)
 - Yearly education of school staff and childcare providers
 - Variety at home and school
 - Formula intake schedule at home and school⁵



CHECKLIST: Children⁶

Age Appropriate Continuing Education

- ☐ Anatomy
- ☐ Biology
- ☐ Biochemistry
- ☐ Genetics

Phe Levels, Growth Charts

- ☐ Phenylalanine levels
- ☐ Tyrosine levels
- ☐ Heights and weights

Daily Living Routine

- ☐ Weighing, measuring, and preparing formula⁷
- ☐ Cooking/recipes⁸
- ☐ Diet records⁹ (see teaching aids/handout)

Psychosocial Issues (see teaching aids/handout)

- ☐ Self esteem
- ☐ Siblings
- ☐ School¹⁰
- ☐ Peers
- ☐ Family dynamics and communication¹¹
- ☐ Power struggles
- ☐ Sports/hobbies

Diet For Life

- ☐ Adverse effects of elevated levels (see teaching aids/handout)
- ☐ Attitude



CHECKLIST: Professionals

Sound Educational Strategies ¹²

- ☐ Passive - handouts, posters, videos, etc.
One on one and/or peer supported group
- ☐ Interactive - activity sheets, role play
One on one and/or peer supported group

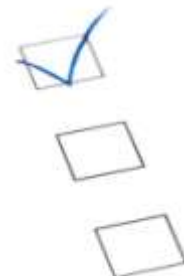
Sound counseling ¹³

- ☐ Empathy
- ☐ Genuineness
- ☐ Unconditional positive regard

Positive focus

- ☐ Feedback¹⁴

Empower parents ¹⁵

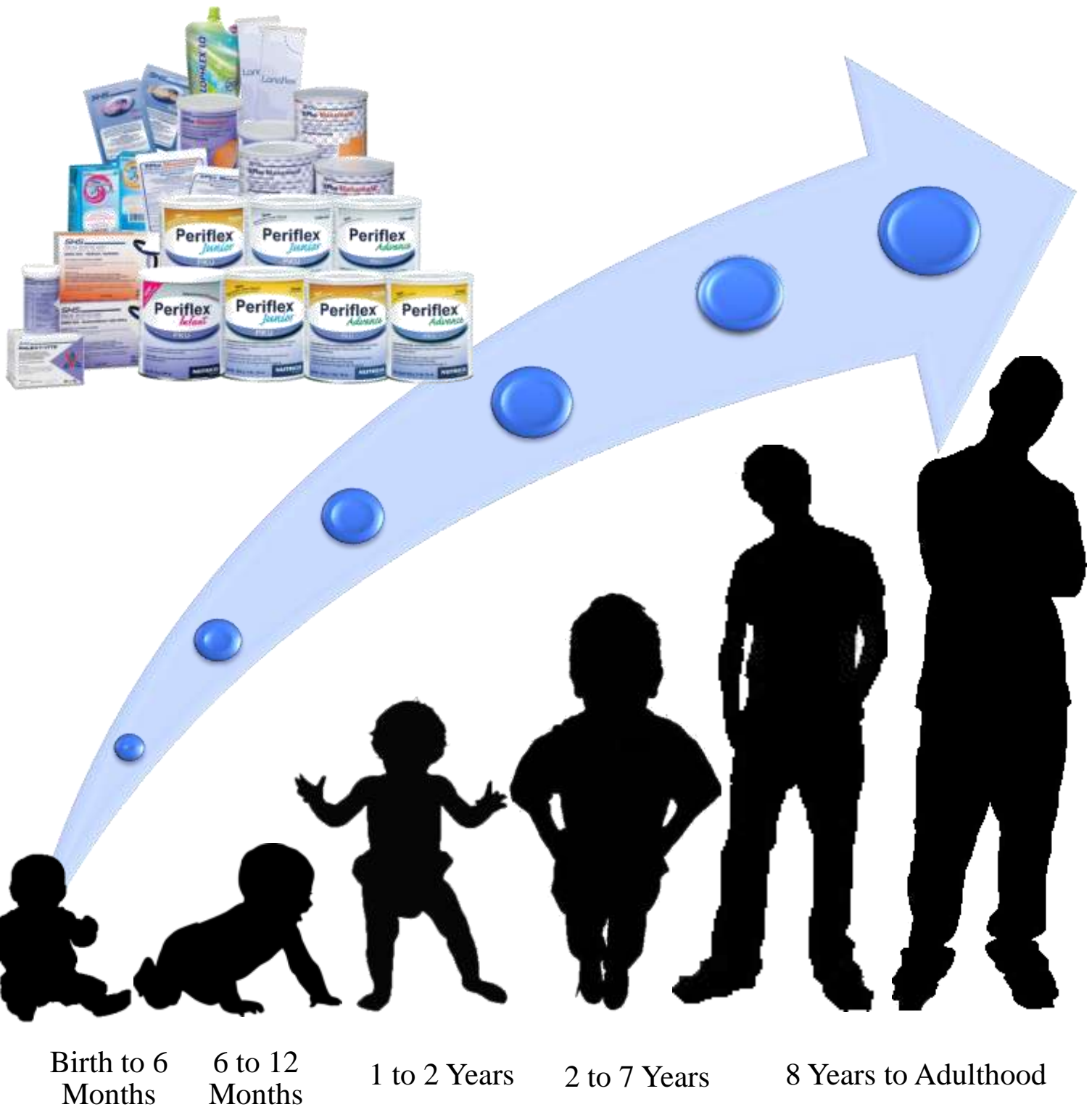


EXPERIENCE & THOUGHTS

1. As the child grows and matures, the daily living routines should reflect increased participation in and responsibility for management of PKU.
2. Delineation of roles becomes an important factor for good compliance. Structure facilitates responsibility and accountability. As early as Kindergarten, the parent can encourage the child to participate in diet record keeping.
3. Depending on the state and on the insurance provider, the cost of formula, low protein foods, and laboratory tests may impact the family dynamics.
4. Has the family returned to or achieved its full potential? Has there been traveling, camping, parental trips without children? Are all family members' needs being met; not just the child who is on the diet?
5. It has been our experience that children often finish the formula in the morning "to get it over with" or, conversely, delay intake until the evening. Without questioning the specific formula schedule this pattern would not be identified.
6. To achieve free flowing dialogue between staff and children, use age appropriate terminology. The use of fun phrases can break the ice and the generation gap.
7. How much is the child participating in weighing, measuring, and preparing formula? As age increases so should the expectations (i.e.: add the ingredients, pushing the blender button).
8. Safety in the kitchen is a major consideration. Level of participation is age and ability dependent. A good starting point is with reading the recipes and measuring the ingredients. Then move on to greater responsibility in the kitchen.
9. Diet records are very important in understanding the diet prescription. A child's participation in record keeping should start as early as Kindergarten. Encourage finding a middle ground. For example during the school year, let them be responsible for record keeping on Saturdays, Sundays and holidays. During the summer months, responsibility could be shifted to 2 days a week. These responsibilities should increase with age.
10. Begin and maintain discussions about peer pressure, feeling different, and self esteem.
11. The family is the child's primary support system. Always encourage communication. Invite all people involved to clinic.
12. Using a variety of approaches to teaching biochemistry, genetics and nutrition are vital to achieving success.
13. The psychologist, Carl Rogers, lists these three qualities in the effective counselor.
14. Provide the family with feedback relating to observations made during clinic appointments. This feedback can be based on your expectations for the child's age. Solicit feedback from family regarding clinic experience as well.
15. Empower parents by keeping them informed on resources that are available to their child. Ensuring their understanding in all areas of their child's disease creates an independence and makes interaction with the clinic more valuable. This places responsibility back into the hands of the family.

PRINCIPLES OF DIET PRESCRIPTION

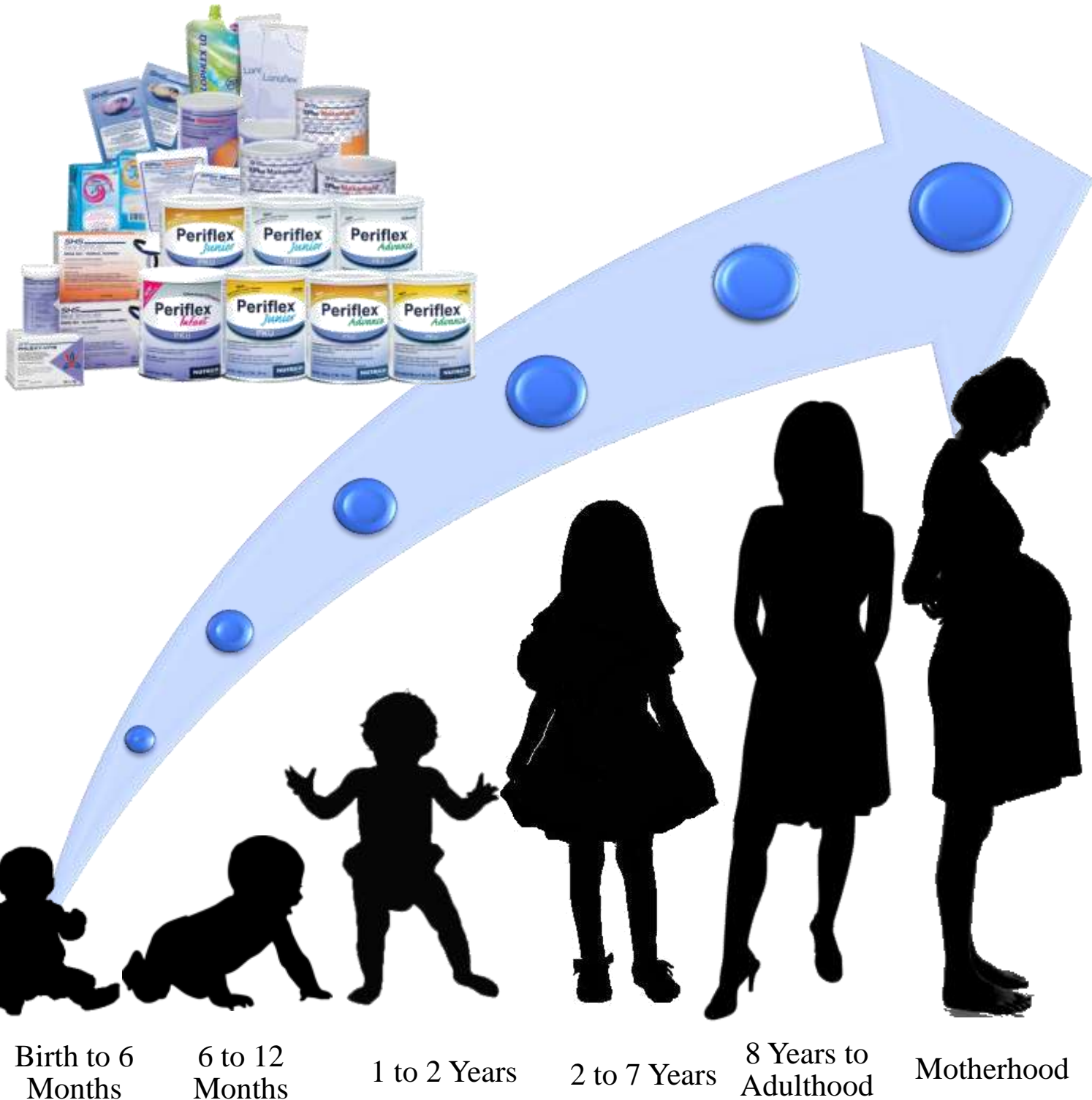
Throughout a Lifecycle



At Every Age, Medical Food Is An Important Part Of Your Daily Nutrition!

PRINCIPLES OF DIET PRESCRIPTION

Throughout a Lifecycle



At Every Age, Medical Food Is An Important Part Of Your Daily Nutrition!

PRINCIPLES OF DIET PRESCRIPTION

Elementary School Years



If an infant or child eats only what is allowed on a low phenylalanine diet without medical food , they would be malnourished in protein, calories, essential vitamins and minerals. The **medical food** provides most of the protein needs and daily requirements of essential vitamins and minerals.

DAILY DIET PRESCRIPTION

2 to 7 Years Old



+



+



=



Complete Nutrition

Phe, Amino Acids, Vitamins, Minerals & Calories

Name: _____ DOB: _____

Medical Food/Formula:

Step 1: Measure Medical Food/Formula:

_____ grams of _____. Add to hand shaker.
of grams Medical Food

_____ grams of _____. Add to hand shaker.
of grams Medical Food

Step 2: Measure out _____ grams of _____. Add to hand shaker.
of grams Milk Source

Step 3: Add water to make a total volume of _____ ounces or _____ ml

Step 4: Shake vigorously for 10-15 seconds.

Step 5: Refrigerate, complete within 24 hours.

Regular and Low Protein Food:

mg Phe gm Protein # Exchanges

Circle One

Medical food may provide complete nutrition without any Phe.

Formula with a milk source, in addition to low protein and other solid foods provide additional amino acids, vitamins, minerals, and calories.

DAILY DIET PRESCRIPTION

8 Years Old Through Adulthood



Complete Nutrition

Phe, Amino Acids, Vitamins, Minerals & Calories

Name: _____ DOB: _____

Medical Food/Formula:

Step 1: Measure Medical Food/Formula:

_____ grams of _____. Add to hand shaker.
of grams Medical Food

_____ grams of _____. Add to hand shaker.
of grams Medical Food

Step 2: Measure out _____ grams of _____. Add to hand shaker.
of grams Milk Source

Step 3: Add water to make a total volume of _____ ounces or _____ ml

Step 4: Shake vigorously for 10-15 seconds.

Step 5: Refrigerate, complete within 24 hours.

Regular and Low Protein Food:

mg Phe gm Protein # Exchanges

Circle One

Medical food may provide complete nutrition without any Phe.

Solid and low protein foods provide additional amino acids, vitamins, minerals, and calories.

24 HOUR DIET DIARY

Name: _____

Dates Covered: _____

Date of Birth: _____

Age: _____

Weight/Height: _____

Medical Food/Formula	Amount

Kuvan:
Tyrosine:
Multivitamin:
Other:

Add water to make _____ ml (_____ fl. oz.)

Before obtaining a blood specimen, please record the food eaten for 3 consecutive days.

Date	Time	Foods or Liquid Eaten	Amount Eaten	Phe (mg)	Energy (kcal)
Totals					

Patient was ill today: ___ No ___ Yes, describe: _____

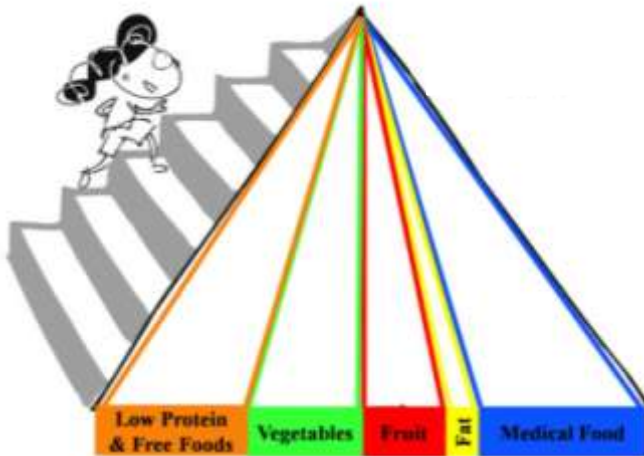
Medication Required? ___ No ___ Yes (Name and amount of prescription): _____

Additional Notes:

TEACHING AID

Modified Food Pyramid

Objective: To provide individuals on diet with an understanding of how their formula plays a role in their diet.



How It's Done

Present the standard food pyramid

- ❖ Discuss the importance of various food groups.
- ❖ Incorporate formula as an essential nutritional component.
- ❖ Discuss how their formula becomes a large portion of their pyramid, replacing high protein foods such as the traditional milk and meat sections on the pyramid (light blue and purple).

Create a pyramid:

Have the children fill in their own pyramid, drawing their favorite foods in each food group and their formula in the medical food section.



Materials Needed

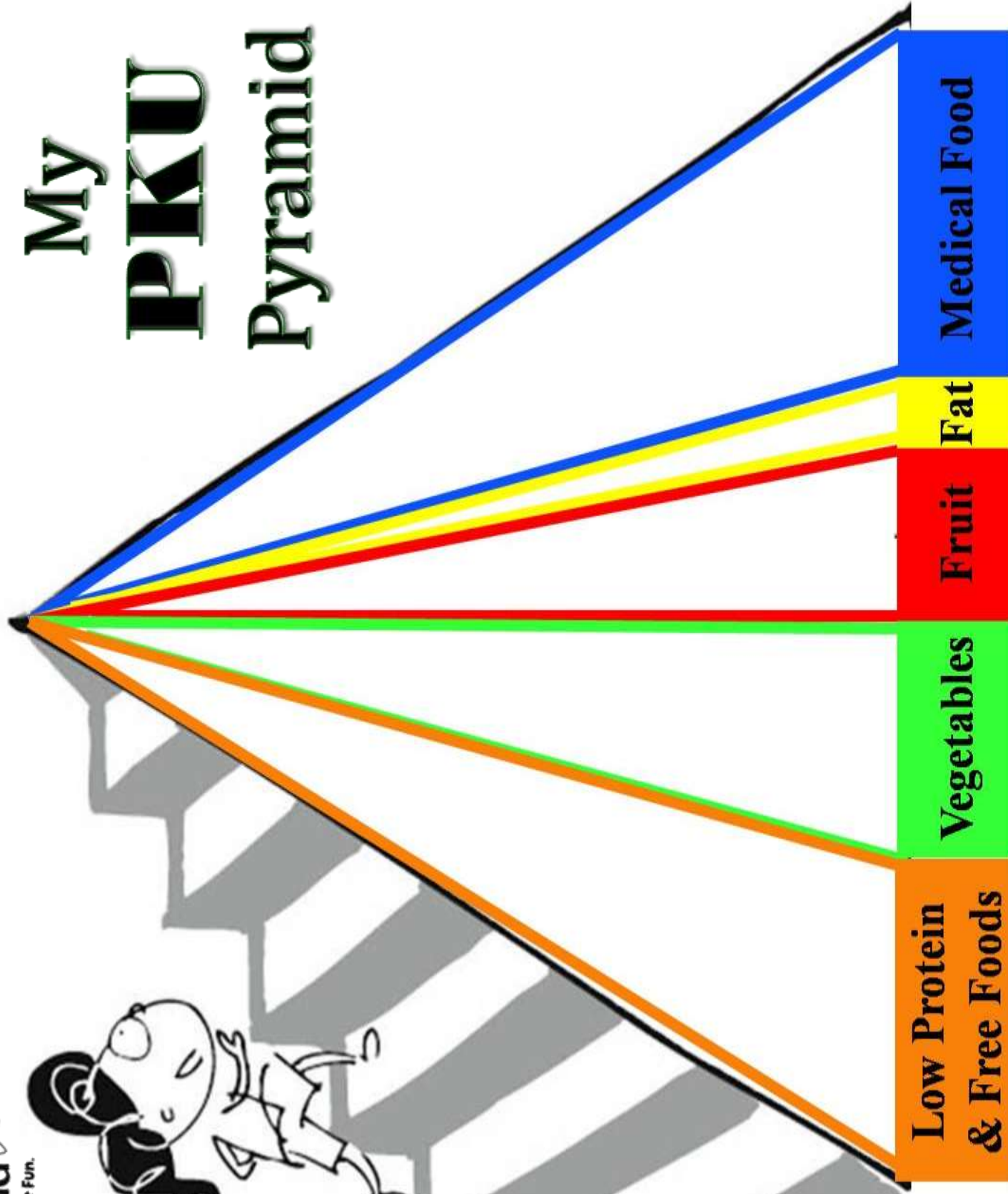
- ❖ Crayons, Colored Pencils, or Markers.

Handouts:

My Pyramid For Kids
PKU Pyramid Coloring Page



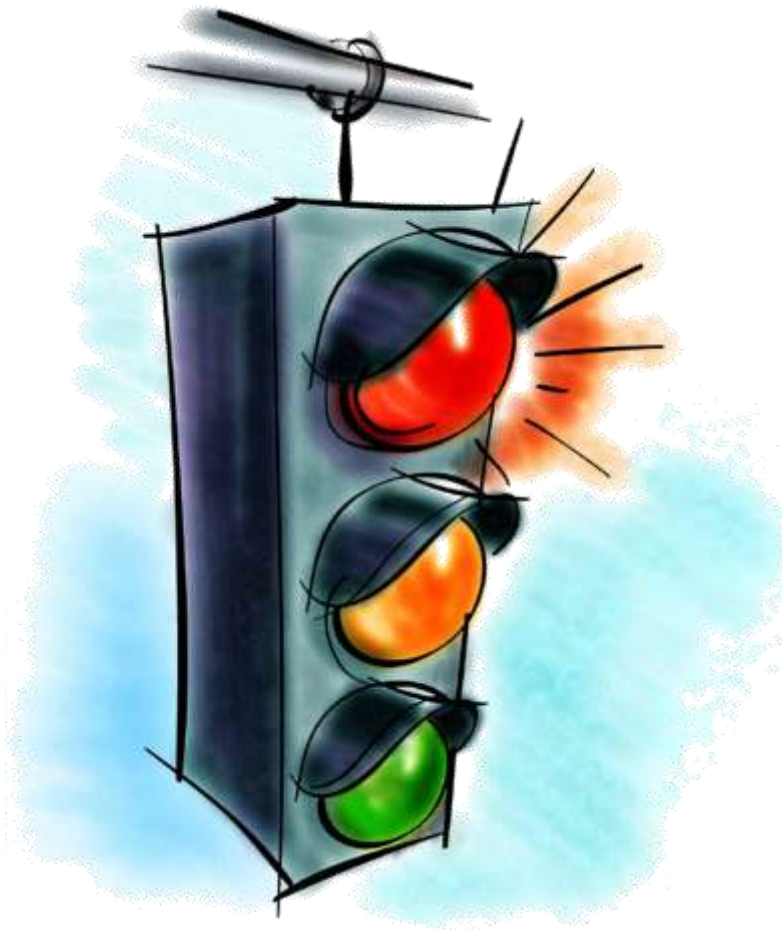
My PKU Pyramid



TEACHING AID

Red Light!!! Yellow Light!! Green Light!

Objective: To reinforce “Yes”, “Sometimes”, and “No” foods.



How It's Done

Create a board:

- ❖ Make a felt board that is in the shape of a traffic light.
- ❖ Attach food models to separate pieces of felt to use as game pieces.

Create a shopping environment:

- ❖ Use green for “Yes” foods, yellow for “Sometimes” foods, and red for “No” foods.
- ❖ Use felt backed food models and let the children place them in the appropriate section.
- ❖ This activity can also be reversed by having individuals identify foods already placed within the red, yellow or green circles as being misplaced or appropriate.
- ❖ A positive reward system is used with all of these programs:

Materials Needed

- ❖ Posterboard
- ❖ Felt for board and game pieces
- ❖ Paper food models
- ❖ Glue or staples

- ❖ Stickers
- ❖ Buttons
- ❖ Verbal affirmation
- ❖ Low protein treats

TEACHING AID

Clinic Supermarket

Objective: To increase the child's involvement in their diet.



Materials Needed

- ❖ “Clinic Supermarket” sign
- ❖ Pens or pencils
- ❖ Calculators (optional)

Handout:

Supermarket Shopping List

How It's Done

Create a supermarket environment:

- ❖ Set up supermarket sign and food models like a grocery store.
- ❖ Each child will write a shopping list for a single meal (breakfast, lunch, or dinner) or a one day diet.
- ❖ Help each child to look up the Phe content of the foods they selected. Provide pen, paper, and calculator (optional) for Phe and protein calculations.
- ❖ Compare this information with their diet prescription and discuss the results with the child.
- ❖ This concept can be expanded upon based on age to include buying foods for a recipe, etc.

Supermarket Shopping List

What meal are you making? *Circle One*

Breakfast Lunch Dinner Snack

What is on the menu?

What ingredients do you need? How much do you need?

Example: Low Protein Cheese 1 slice 19 gm 20 mg Phe 0.4 gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

_____ gm _____ mg Phe _____ gm Pro.

Total: _____ mg Phe _____ gm Pro.

Does this menu fit your diet prescription?

YES or NO



TEACHING AID

Dramatic Play: Restaurant Setting

Objective: To increase the child's involvement in their diet.

How It's Done

Set up a restaurant-like situation

- ❖ Have all participating individuals play a role: customer, waiter or waitress, chef or cashier.
- ❖ All individuals should have the opportunity to play various roles

The Customer orders the food from a menu on which the Phe content is listed.

The Waiter or Waitress takes the order and serves the food.

The Chef prepares the order by selecting models of the food ordered and placing them on a plate or tray.

The Cashier rings up the amount of Phe and Protein ordered.

- ❖ Use this opportunity to begin a discussion about the Phe content of the foods, ordering in a restaurant, and monitoring daily intake of Phe .

Chef's Low Protein Specials



- ❖ Wel-Plan Tortilla Chips**
- ❖ Dietary Specialties
Nacho Cheese Dip
- ❖ Low Protein Pasta with
Alfredo Sauce
- ❖ Crispy Apple Coleslaw
with Add-Ins*
- ❖ Chocolate Cake*



Materials Needed

- ❖ Paper or plastic food models
- ❖ Pens or pencils
- ❖ Order/note pad for waiter
- ❖ Calculator
- ❖ Apron/chef's hat

Handouts:

Menu Template
Menu Ideas
Food Models

* Nutricia North America -- Low Protein Products - www.shsna.com/pages/loprofin.htm

** **Mile High, Low Protein Cookbook.** Low Protein Food Store, IMD Clinic, The Children's Hospital, Aurora, CO.

Menu Ideas

	Low Phe	High Phe
Breakfast	Fruit LP Cereals LP Pancakes LP Toast Juice Formula Coffee/Tea	Egg Dishes Yogurt Milk
Lunch	Salads LP Soups LP Sandwiches Juice Soda Formula Coffee/Tea	Salads Soups Sandwiches Milk
Dinner	Salad French Fries LP Pasta LP Tacos Juice Formula Coffee/Tea	Salads Pizza Burger Milk
Dessert	Fruit LP Cookies LP Cake LP Ice Cream	Ice Cream Pie Cake

LP = Low Protein



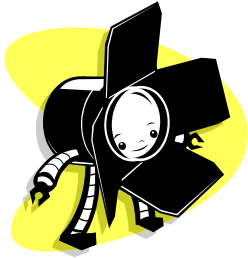
Chef's Low Protein Menu



TEACHING AID

Role Playing

Objective: To increase the child's involvement in their diet.



Lights...

Camera...



Action



How It's Done

Set up a school lunchroom situation

- ❖ Have each child line up, walk along side the table, and receive/choose a lunch.
- ❖ Continue the role play by sitting at a table together while “eating lunch”.
- ❖ This activity may be modified by having the children bring their lunch box or providing them with a paper bag to fill with models of food representing a typical lunch they might bring to school.
- ❖ Facilitate discussion about their food choices and how it relates to their diet prescription.
- ❖ Also address the idea of trading food with their classmates.

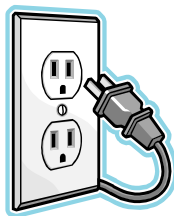
Materials Needed

- ❖ Paper or plastic food models

TEACHING AID

Energy Sources

Objective: To introduce food and formula as essential forms of energy for use by the body.



How It's Done

Use the handout “Energy Source Matching”

- ❖ The children are presented with two groups of pictures:
 - ❖ One group of pictures representing different kinds of fuel.
 - ❖ The second group representing users of the fuel.

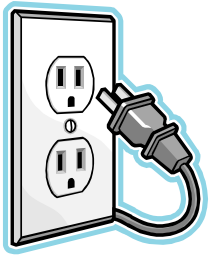
For example:

- Gasoline for a car
 - Carrots for a rabbit
 - Battery for flashlight
 - **Formula for children with PKU**
- ❖ Ask them to match the fuel with the user and discuss why and how each uses the source for energy.

Handout Needed
Energy Source Matching

Energy Source Matching

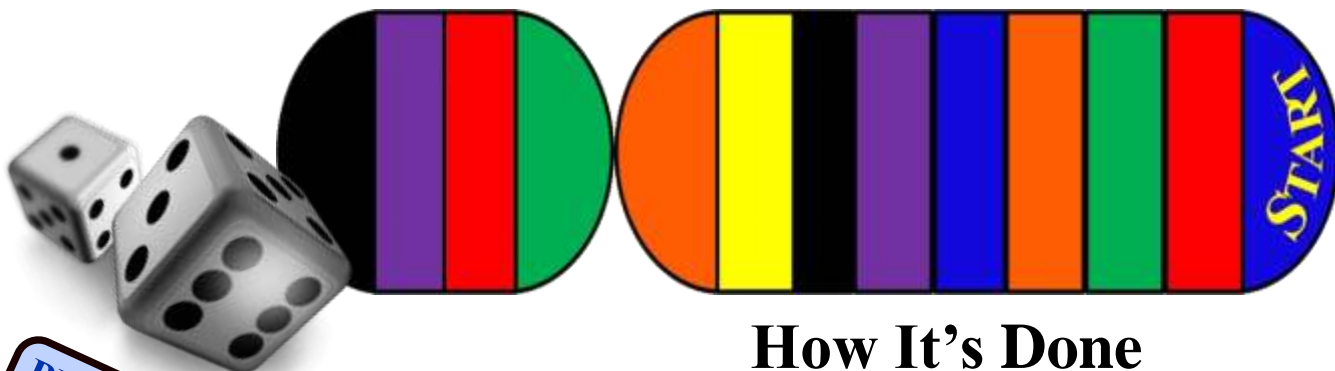
Draw a Line to Connect the Energy Source to its User



TEACHING AID

PKU Adventure Game

Objective: To assess the Hyperphenylalaninemia knowledge base while providing a fun learning environment.



How It's Done

Set up a board game

- ❖ Use an existing game board, create one, or purchase a ready to use **PKU Adventure Game***
- ❖ Create question cards, or use those provided with the PKU Adventure Game, that are appropriate to the children's age and level of understanding. PKU Nutrition Cards ** are another great option for question cards.
- ❖ Provide a game piece for each child.
- ❖ Each child will role the dice at the beginning of their turn.
- ❖ A question card is drawn and the questions is asked.
 - ❖ A correct answer allows the player to move their game piece ahead the number of spaces determined by the number they rolled on the dice.
 - ❖ An incorrect answer results in no movement of the game piece.

PKU Question Card
What is the name of your formula?

PKU Question Card
What does PKU stand for?

PKU Question Card
How much Phe do you get from food each day?

Materials Needed

- ❖ PKU Adventure Game
- ❖ PKU Question Cards
- ❖ Dice
- ❖ Playing pieces

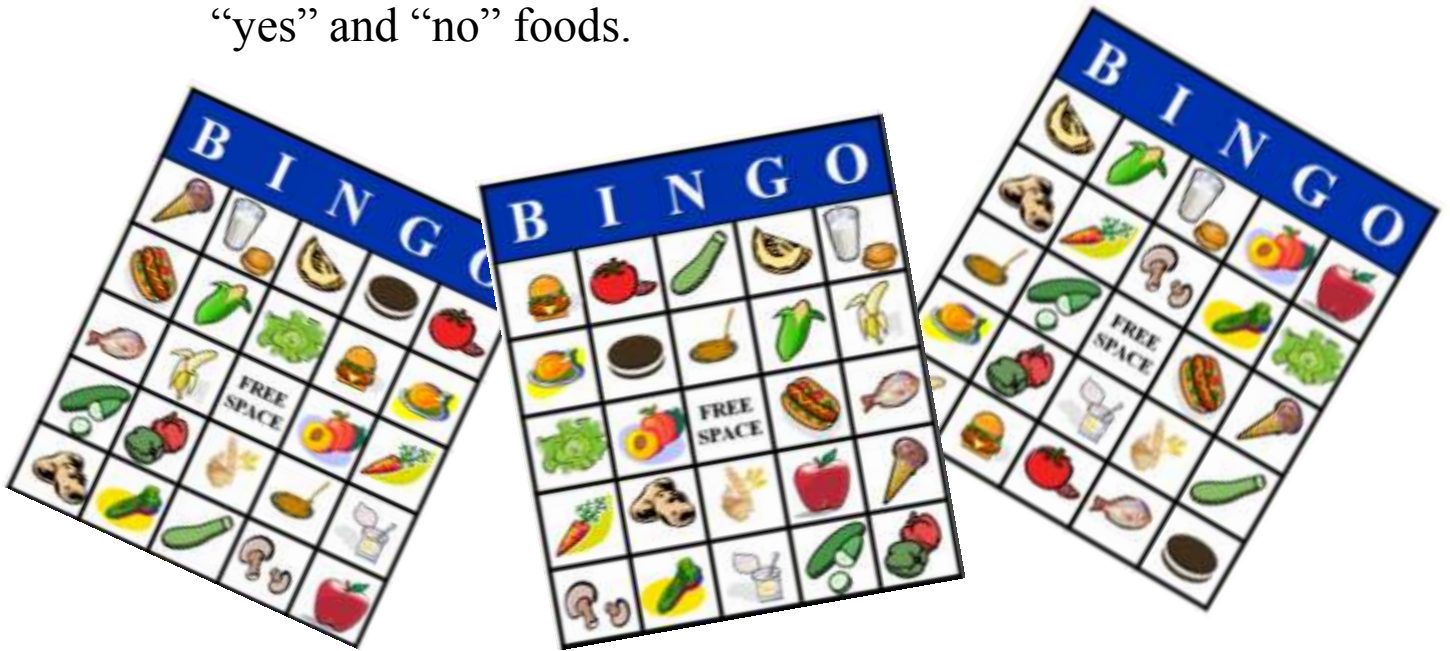
* **PKU Adventure Game.** Available through the Low Protein Food Store, IMD Clinic, The Children's Hospital, Aurora, CO.

** **PKU Nutrition Cards.** Available through Nutricia North America Web. <<http://www.shsna.com/>>.

TEACHING AIDS

“Yes” “No” BINGO

Objective: To increase participants understanding of their diet by recognizing “yes” and “no” foods.



How It's Done

This game can be as simple or complex as you decide to make it. For younger participants, limit discussion to “yes”, “no”, and “sometimes” foods. If participants are older, lead discussion to include topics such as serving size, cooking method, etc.

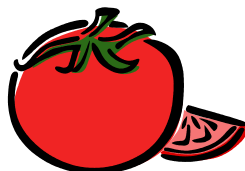
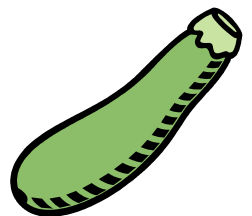
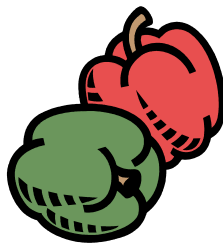
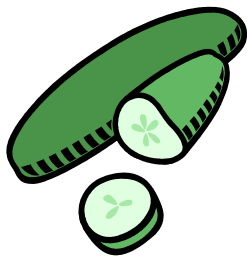
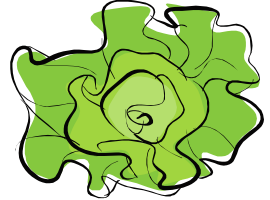
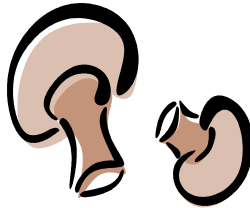
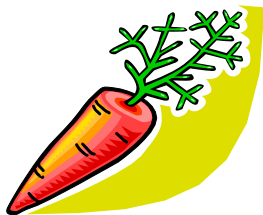
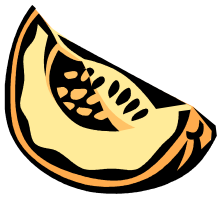
- ❖ Using the cut out game pieces mixed in an envelope, draw one square and call the name of the food out loud. Have participants mark the appropriate square with a piece of candy, and have the participants say if it is a yes, no, or sometimes food (for older participant, begin to discuss what a typical serving size is and how much Phe is in one serving).
- ❖ Once a participant has five in a row (in any direction) they should shout “BINGO”. To prove they have a BINGO they will need to read off the foods that make up their BINGO, and say if the food is a yes, no, or sometimes food.
- ❖ Game boards can be shuffled or traded between participants and all game pieces put back into the envelope, this game can be played until all the foods have been discussed.

Materials Needed

- ❖ Bingo Game Pieces
- ❖ Bingo Game Boards
- ❖ Candy (as markers)

BINGO GAME PIECES

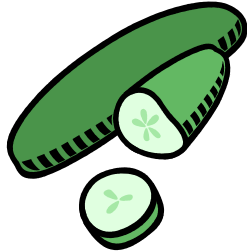
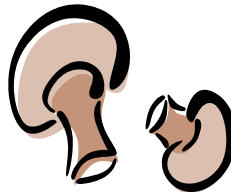
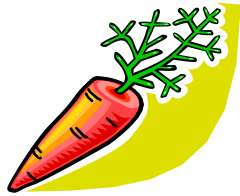
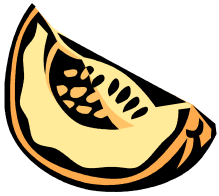
Cut out these pictures, mix them in an envelope.



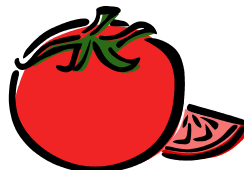
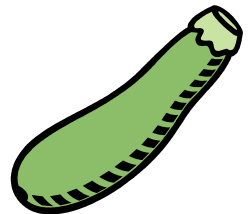
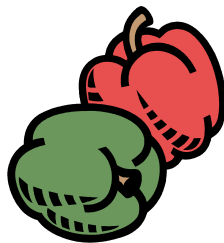
BINGO GAME BOARD

Place candy on the appropriate square and discuss each food until you get five in a row.

B I N G O



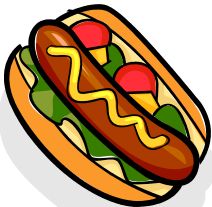
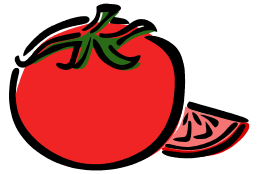
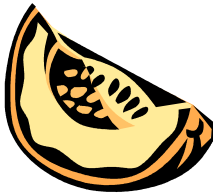
**FREE
SPACE**



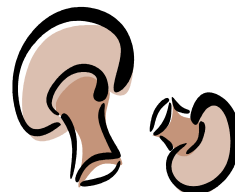
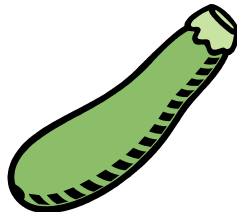
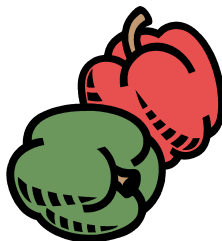
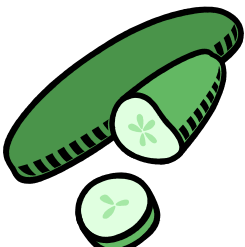
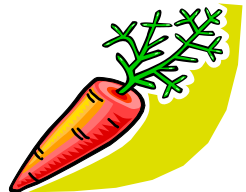
BINGO GAME BOARD

Place candy on the appropriate square and discuss each food until you get five in a row.

B I N G O



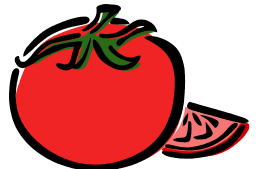
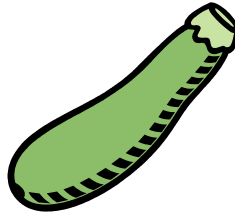
**FREE
SPACE**



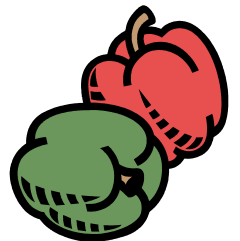
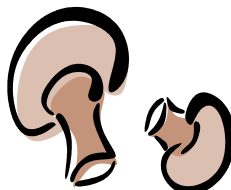
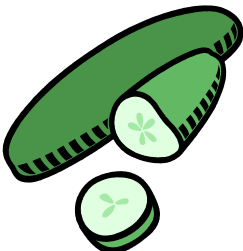
BINGO GAME BOARD

Place candy on the appropriate square and discuss each food until you get five in a row.

B I N G O



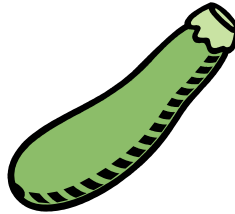
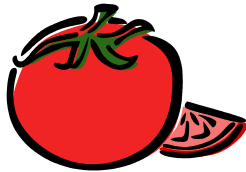
**FREE
SPACE**



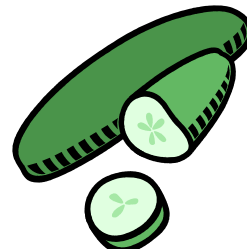
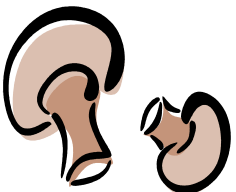
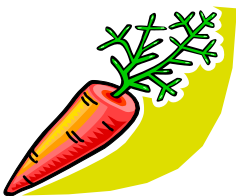
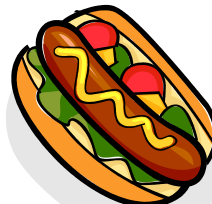
BINGO GAME BOARD

Place candy on the appropriate square and discuss each food until you get five in a row.

B I N G O



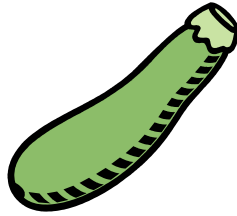
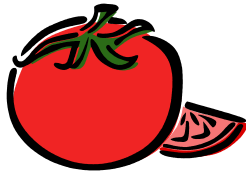
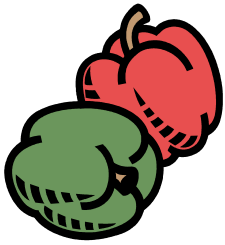
**FREE
SPACE**



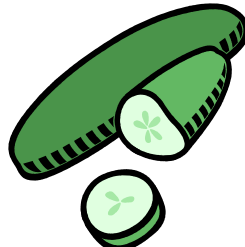
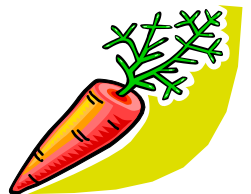
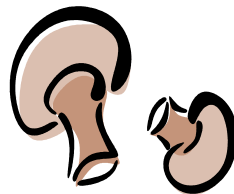
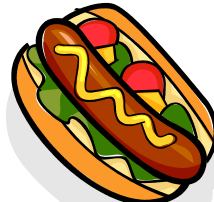
BINGO GAME BOARD

Place candy on the appropriate square and discuss each food until you get five in a row.

B I N G O



**FREE
SPACE**



TEACHING AID

Recipe Preparation

Objective: To introduce the use of recipes and increase the child's level of responsibility.

How It's Done

Each handout is designed to increase the level of responsibility

❖ **“It's a Mix-up”**

Discuss the importance of each step and the obvious missing step of weighing the ingredients.

❖ **“Mix and Match”**

Help the child to become familiar with the ingredients and identify what it takes to create a meal.

❖ **“Grocery Shopping is a Must!”**

Participants identify “Yes” foods beginning with a specific letter that can be used for meals, recipes or as snacks. Enhance this exercise by visiting the kitchen in your hospital or clinic.

❖ **“Have Snacks that Slither!”**

Actually make the recipe! Identify and gather ingredients, weigh/measure, follow directions, count Phe and enjoying the finished product.

❖ This can be done using recipes from the **Mile High Low Protein Cookbook®**



Materials Needed

Recipes:

Snacks that Slither
Spooky Snacks

Handouts:

It's A Mix-up
Mix and Match
Grocery Shopping Is A Must!
Answer Keys

It's A Mix-up



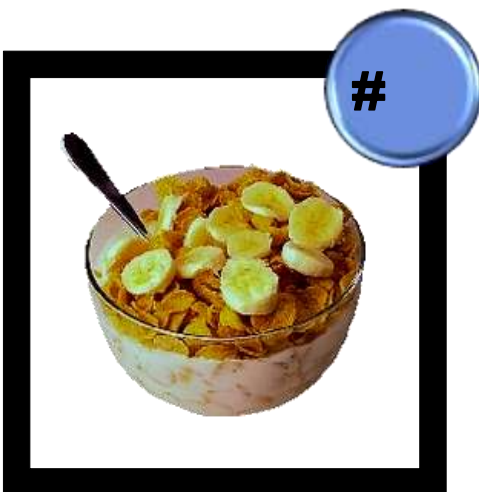
Cut out the images
&
organize them into
the correct order.



It's A Mix-up



Number the
images so
they are in
the correct
order.

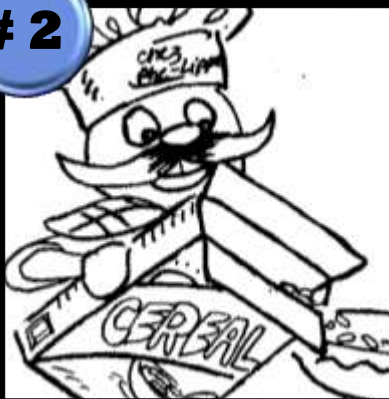


ANSWER KEY: It's A Mix-up

1



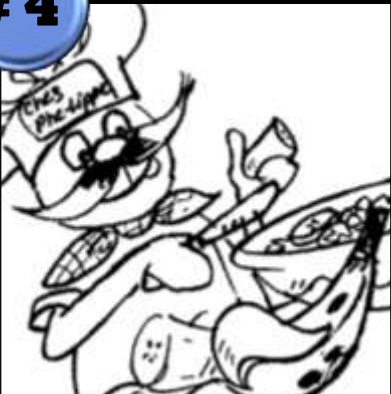
2



3



4



5



6



7



8



Mix & Match

What should the Chef serve for dinner?

Draw a line between each dish and the ingredients needed to make it.

Dish:	Recipe	Serves:
	<i>LP Cheese</i>	
	<i>LP Lasagna Noodles</i>	
	<i>Tomatoes</i>	
	<i>Mushrooms</i>	



Dish:	Recipe	Serves:
	<i>LP Pizza Dough</i>	
	<i>LP Cheese</i>	
	<i>Mushrooms</i>	
	<i>Tomato Sauce</i>	



Dish:	Recipe	Serves:
	<i>LP Taco</i>	
	<i>Taco Shell</i>	
	<i>Lettuce</i>	
	<i>Tomato</i>	
	<i>LP Cheese</i>	



Grocery Shopping's A Must

The Chef was in a hurry to get to the store. He only wrote down the first letter of each food item, and now he can't remember what to buy!

**Help by listing several foods allowed in your diet
that begins with the letter provided.**

Pizza Toppings

B _____
P _____
M _____
G _____
S _____

Colorful Fruits

B _____
P _____
M _____
G _____
S _____

Breakfast Foods

B _____
P _____
M _____
F _____
C _____



ANSWER KEY: Grocery Shopping's A Must

This is not an all inclusive list, just suggestions for foods that could work as answers. Encourage the children to think of their own favorite foods.

Pizza Toppings

Bell peppers, broccoli, black olives

Pineapple, peppers

Mushrooms, mozzarella*

Garlic, green olives, green peppers

Sauce, spinach

Colorful Fruits

Bananas, berries, blackberries, blueberries

Peaches, pineapple, pears, plums, prunes

Mango, melon

Grapefruit, grapes

Star fruit, strawberries

Breakfast Foods

Banana, bagels*

Peaches, pineapple, pancakes*

Melon, muffins*

Formula

Cereal*



*** Indicates a LOW PROTEIN food choice**

RECIPES: Snacks That Slither

A SUPER SILLY SNAKE SANDWICH

Yields: 1 Serving

Phe: 28mg **Protein:** 0.56 g

Ingredients:

19g (1 slice)	Low Protein Cheese
31g (5 each)	Loprofin Crackers*
64g (5 slices)	Apple slices
5g (2 each)	Grapes



Directions:

1. Cut the cheese into 4 pieces.
2. Lay down a cracker, a piece of cheese and an apple slices
3. Repeat the pattern until you use up all the cheese, crackers and apples.
4. Add a grape for the head and the tail.

DYNAMITE DIRT PUDDING

Yield: 1 Serving

Phe: 23 mg **Protein:** 0.6g

Ingredients:

½ cup	Butterscotch Pudding
57g	Banana, <i>sliced</i>
2 each (31g)	Loprofin Chocolate Wafers*
2 or 3	Gummy Worms

Directions:

1. Put pudding into a cup.
2. Add banana slices.
3. Fill with more pudding.
4. Put a few “Gummy Worms” into the pudding.
5. Top with cracker crumbs.



RECIPES: Spooky Snacks

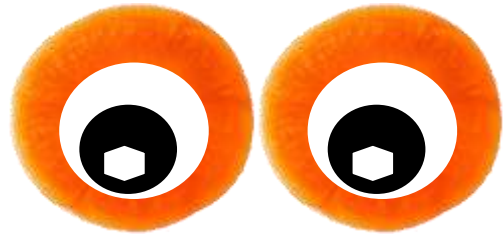
SCARY EYEBALLS

Yields: 1 Serving

Phe: 34 mg **Protein:** 0.8 g

Ingredients:

- | | |
|----------|--------------------------|
| 1 medium | Carrot |
| 2 Tbsp | Low protein cream cheese |
| 3 each | Black olives, pitted |



Directions:

1. Chop carrots into bit size chunks.
2. Top each with a blob of cream cheese.
3. Place halved olives on top of cream.

SPOOKY GHOST

Yields: 1 Serving

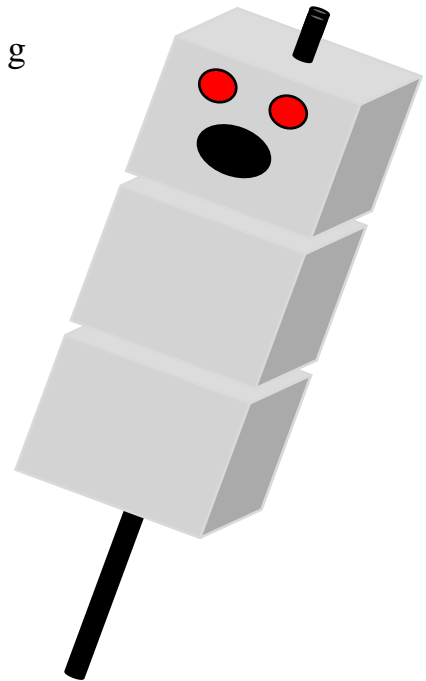
Phe: 20 mg **Protein:** 0.49 g

Ingredients:

- | | |
|----------|----------------------|
| 3 each | Marshmallows |
| 2 each | Cinnamon “Red Hots” |
| 1 square | White almond bark |
| 1 tub | Black decorating gel |
| 1 each | Wooden skewer |

Directions:

1. Place marshmallows on skewers.
2. Melt almond bark and cover
3. Place Red Hots as eyes.
4. Make a mouth with decorating gel.



TEACHING AID

ABC's

Objective: To be able to identify and spell the name if their metabolic disease.



How It's Done

Use the "ABC Cutouts" Handout

- ❖ Have the children pick out the name of their metabolic disorder from a large list.
- ❖ You may choose to point out other metabolic diseases that are managed by diet.
- ❖ Using jumbled cut-out letters, ask each child to spell their disorder. This can be done as a group on a felt or black board or individually.
- ❖ Use a word find activity including the name of the disease and low Phe foods. Practice writing the disease name.

Materials Needed

- ❖ List of metabolic disorders
- ❖ Cut-out letters

ABC Cutouts

A

B

C

D

E

F

G

H

I

J

K

L

M

N

O

P

Q

R

S

T

U

V

W

X

Y

Z

PKU Word Find

Find the words below.

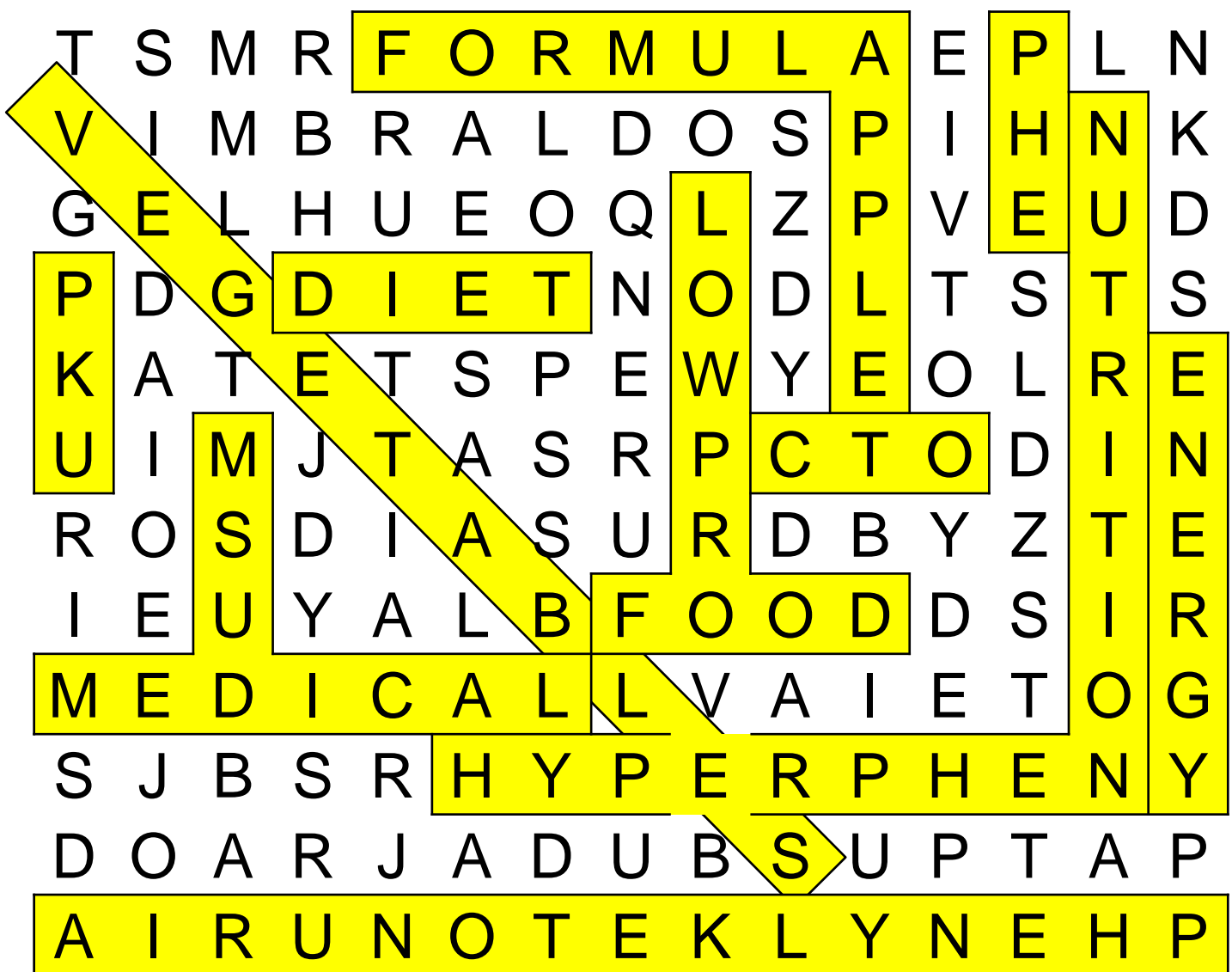
Words can be horizontal, vertical, diagonal, and even backwards!

T	S	M	R	F	O	R	M	U	L	A	E	P	L	N
V	I	M	B	R	A	L	D	O	S	P	I	H	N	K
G	E	L	H	U	E	O	Q	L	Z	P	V	E	U	D
P	D	G	D	I	E	T	N	O	D	L	T	S	T	S
K	A	T	E	T	S	P	E	W	Y	E	O	L	R	E
U	I	M	J	T	A	S	R	P	C	T	O	D	I	N
R	O	S	D	I	A	S	U	R	D	B	Y	Z	T	E
I	E	U	Y	A	L	B	F	O	O	D	D	S	I	R
M	E	D	I	C	A	L	L	V	A	I	E	T	O	G
S	J	B	S	R	H	Y	P	E	R	P	H	E	N	Y
D	O	A	R	J	A	D	U	B	S	U	P	T	A	P
A	I	R	U	N	O	T	E	K	L	Y	N	E	H	P

APPLE
DIET
ENERGY
FOOD
FORMULA
FRUIT
HYPERPHE
LOWPRO

MEDICAL
MSUD
NUTRITION
OTC
PHE
PHENYLKETONURIA
PKU
VEGETABLES

ANSWER KEY: PKU Word Find



APPLE
DIET
ENERGY
FOOD
FORMULA
FRUIT
HYPERPHE
LOWPRO

MEDICAL
MSUD
NUTRITION
OTC
PHE
PHENYLKETONURIA
PKU
VEGETABLES

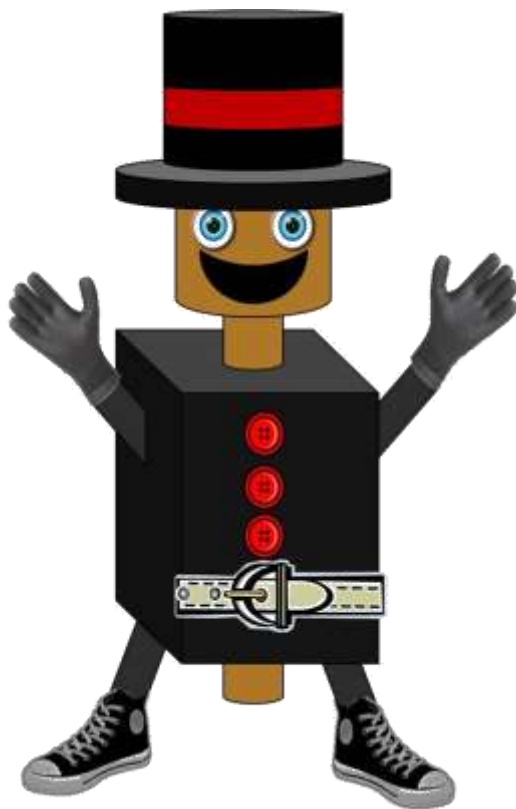
TEACHING AID

Herman The Human Pathway

Objective: To introduce the idea of a metabolic pathway.



Low Phe vs. High Phe



Materials Needed

- ❖ Cardboard box
- ❖ Large tub
- ❖ Decorations
- ❖ Glue, scissors, etc.
- ❖ Small candies or food models
- ❖ Large food models

How It's Done

This is an excellent way to teach children what their bodies can and cannot use, and how a block in that pathway can cause unwanted substances to build up and have negative consequences on the body.

Make Herman.

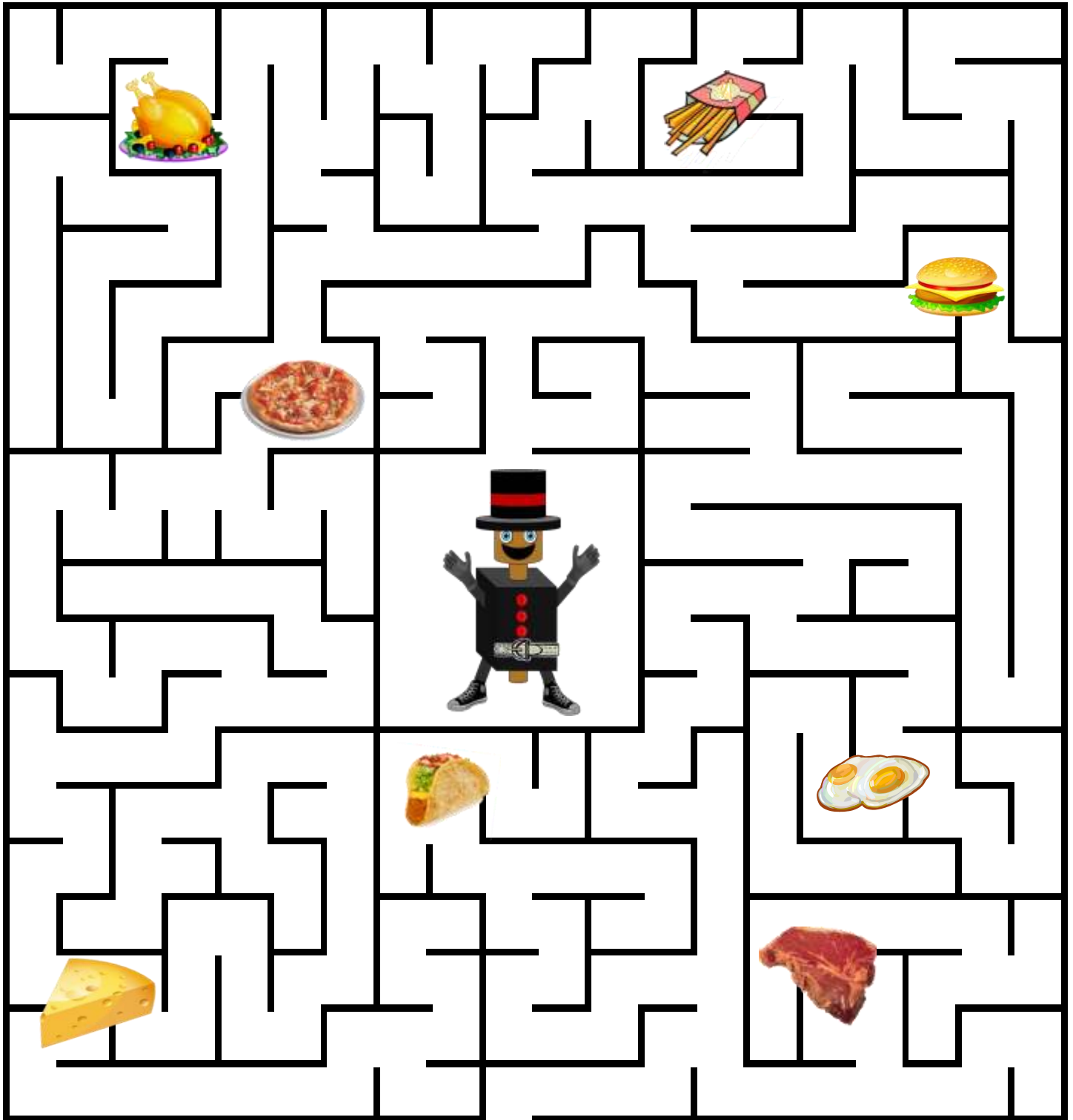
- ❖ His torso is made from a box that contains a tube that runs from top to bottom.
- ❖ Within the tube is a cross-section of cardboard that has a specific size hole in it. This cardboard restricts the size of food items that can pass all the way through the tube. Food items that are too large will collect within the tube.

Feed Herman

- ❖ Have the children feed Herman jelly beans or small candies that will fit through the tube to represent low protein foods. Then have them feed Herman larger, high protein foods that will not fit down his tube.
- ❖ Herman's blocked "digestive tube" makes an analogy for a blocked metabolic pathway.

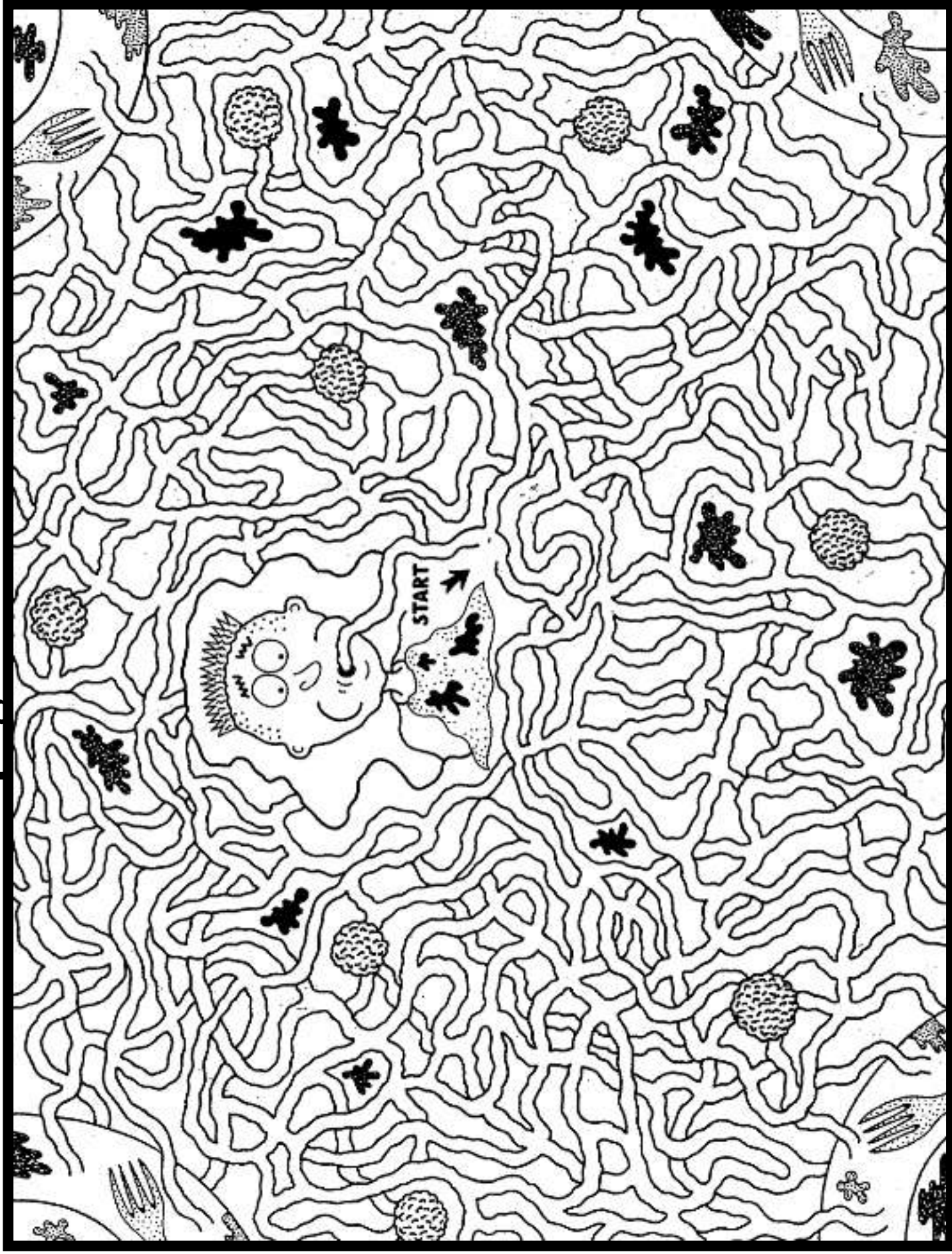
Herman's Maze

Herman is stuck in the middle of a maze.
Help him escape without running into high Phe foods!



You Win!

Spaghetti Maze



Spaghetti Maze Key



TEACHING AID

The Stuff Between Your Ears

Objective: To introduce brain anatomy and biochemistry.



How It's Done

Make a comparison

- ❖ A visual aid, such as cauliflower, is a good way to introduce the parts of the brain.
- ❖ It is important to discuss:
 - The location and function of both white matter and gray matter.
 - Providing our brains with good nutrition throughout our entire life.
 - What the effects of not following their special diet will be.
- ❖ Just as cauliflower requires nutrients and energy to grow, so does our brain. Toxic levels of fertilizer can damage the cauliflower just as excessively high Phe levels can damage the human brain.
- ❖ Showing a typical and an atypical cranial MRI may be interesting for older children.



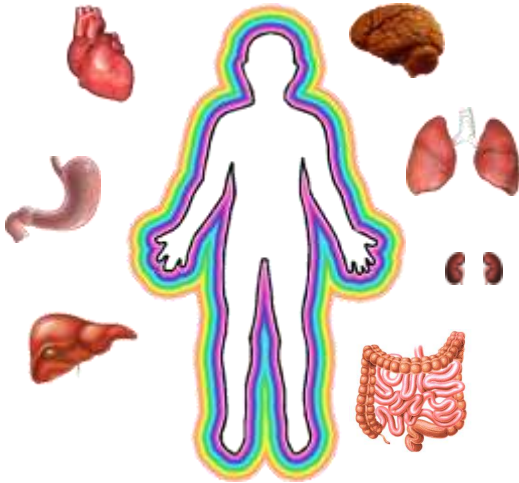
Materials Needed

- ❖ Paper or plastic food models

TEACHING AID

Body Parts

Objective: To describe the essential functions of the organs in our body, and to introduce the concept of how they are involved in Hyperphenylalaninemia.



Materials Needed

- ❖ Butcher or drawing paper
- ❖ Markers
- ❖ Glue

How It's Done

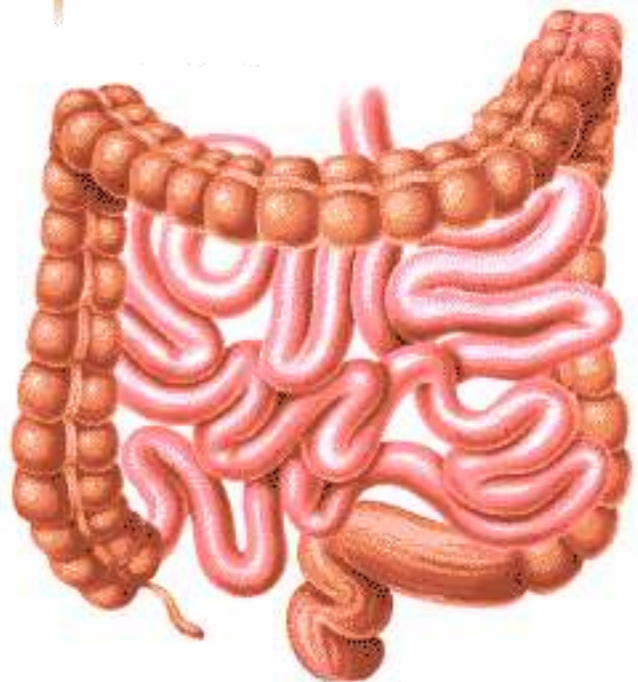
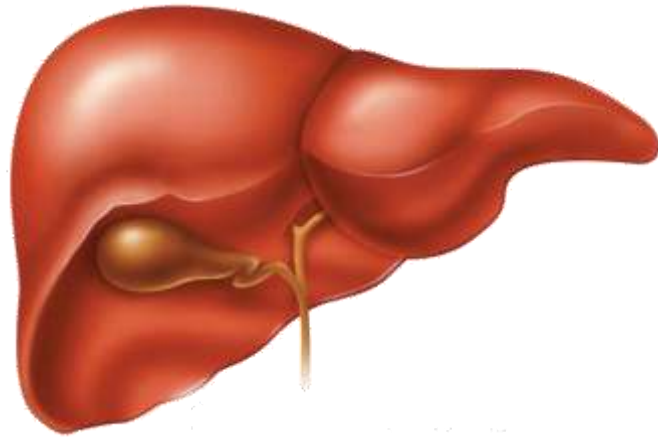
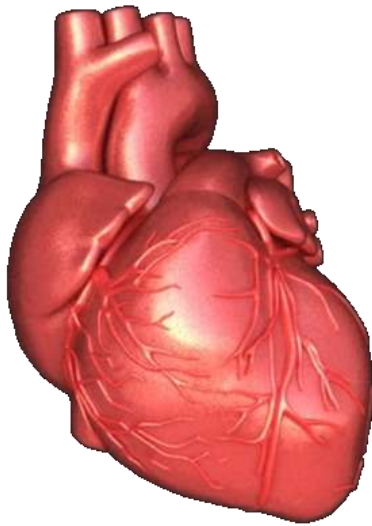
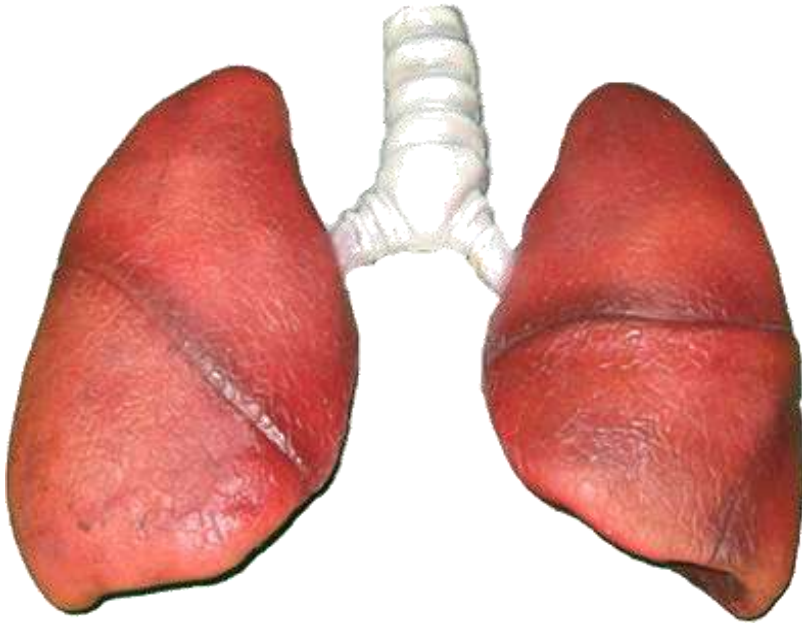
This activity can be adapted to a variety of models. There are two main options:

1. Have the participating individuals trace each other's body onto a piece of paper and draw their organs in the appropriate locations.

OR

2. Draw a tracing of a body on a board or easel of paper and have the children either draw in the organs or attach pre-made cut-outs of the heart and the liver.
- ❖ Use this as an opportunity to discuss the functions of the heart, liver, lungs, stomach, brain etc. and how they are or are not impacted by Hyperphenylalaninemia.
 - ❖ It may also be useful for the older children to see a fresh liver. These can usually be obtained through a local slaughter house.

BODY PARTS



TEACHING AID

We Are Alike & Different

Objective: To engage preschool and early elementary children in discussion about how everyone has ways they are alike and ways they are different, and how that is good.



How It's Done

Begin a discussion:

- ❖ Use the handout “We Are Alike & Different” to introduce the terms “alike” and “different.”
- ❖ Once all the children have completed the instructions on the handout, have them discuss their own traits and characteristics.
- ❖ Ask all participants with brown hair to raise their hand. Count the number of hands, write the number on the board. Repeat this using other colors of hair and traits.
- ❖ Discuss that there are some traits that we can not see, give examples (PKU).
- ❖ Have all individuals with PKU raise their hand. Make it “cool” to have PKU.
- ❖ Emphasize that both differences and similarities are good.

Additional Activity 1: Read the book We're Different, We're The Same.

Additional Activity 2: Ask the participants why they think they have a nose, hair, and other traits discussed. Introduce the concept of a gene being a recipe or a set of instructions to make something. Discuss that there are many recipes or genes inside our body (that we can not see). For example, a recipe or instructions to make our eyes, ears, hair color. Introduce the concept of a gene or recipe for PKU. Ask the participants if they can list any other recipes they have.

Handouts Needed

We Are Alike & Different

Adapted from March of Dimes Activity Master 2

We Are Alike & Different

Draw a circle around all the children who have curly hair.

Draw a square around all the children who have rosy cheeks.

Draw a triangle around all the children who have freckles.



We Are All Alike, Yet Different



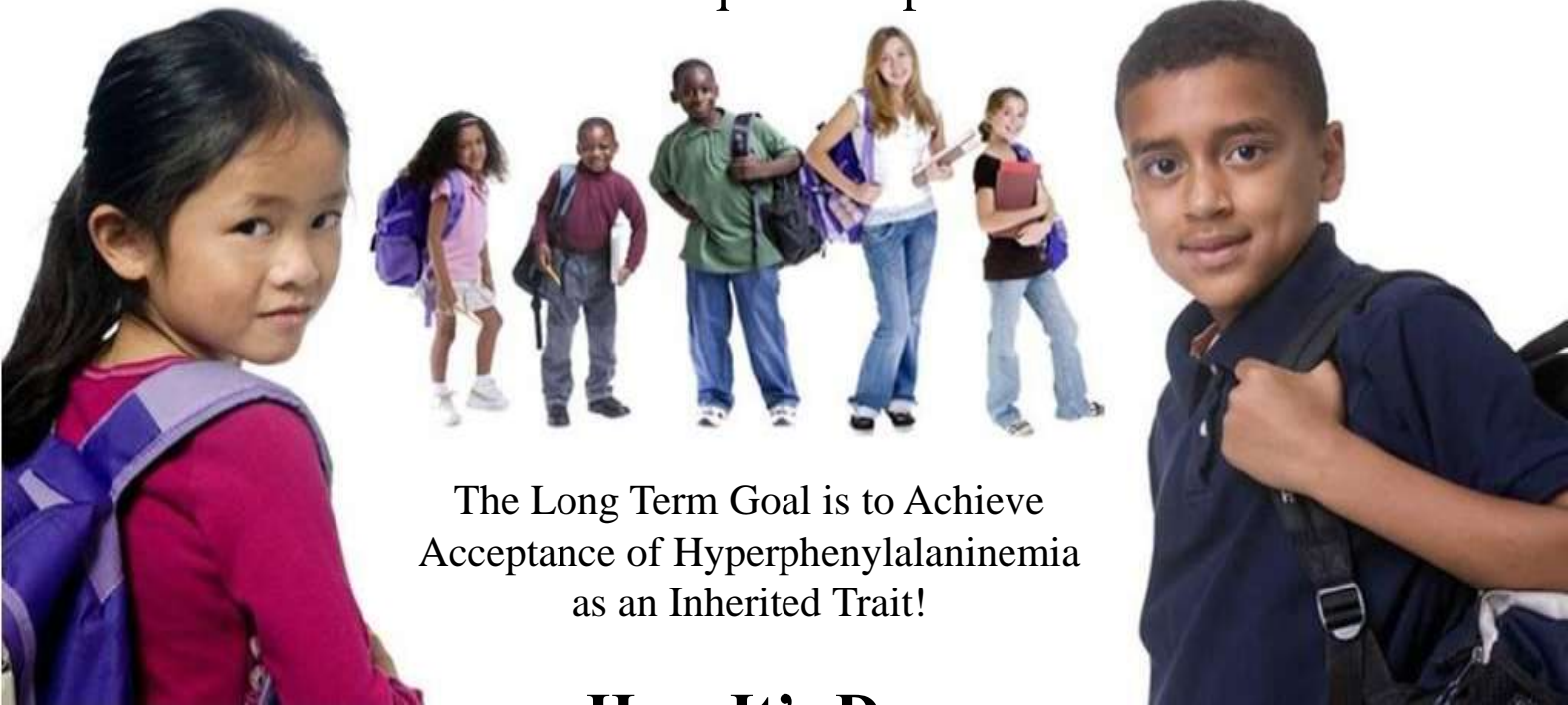
Can You Find The Differences?



TEACHING AID

Ways We Are Alike & Ways We Are Different

Objective: To introduce the concept of genetic variability and to achieve an understanding that variability is what makes each individual unique and special.



The Long Term Goal is to Achieve
Acceptance of Hyperphenylalaninemia
as an Inherited Trait!

How It's Done

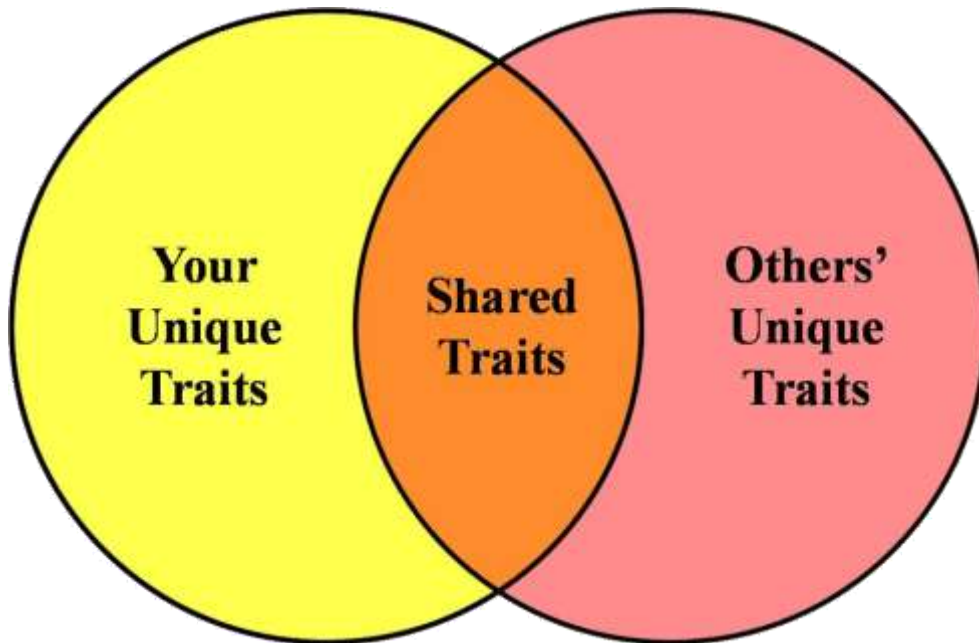
- ❖ Discuss the terms “alike” and “different” and use these terms in relation to physical characteristics and other distinguishing traits.
- ❖ Compare physical traits of individuals in the room, pointing out ways participants are alike and different.
- ❖ Talk about other personal characteristics such as food preferences and or sports skills.
- ❖ Have all individuals with PKU in the room raise their hand. Acknowledge this as a trait that is either shared with other people in the room or as a trait that is unique and special.
- ❖ Use the Venn Diagram teaching aid to continue discussing ways participants are alike and different.
- ❖ Talk about how some traits are genetic, some environmental, and some are a combination of the two.
- ❖ Ask participants to discuss the benefits of variation.

Handouts Needed
Venn Diagram

TEACHING AID

Venn Diagram

Objective: To teach the concept of characteristics and traits being unique or shared with others.



How It's Done

This activity works well with 2 or more children

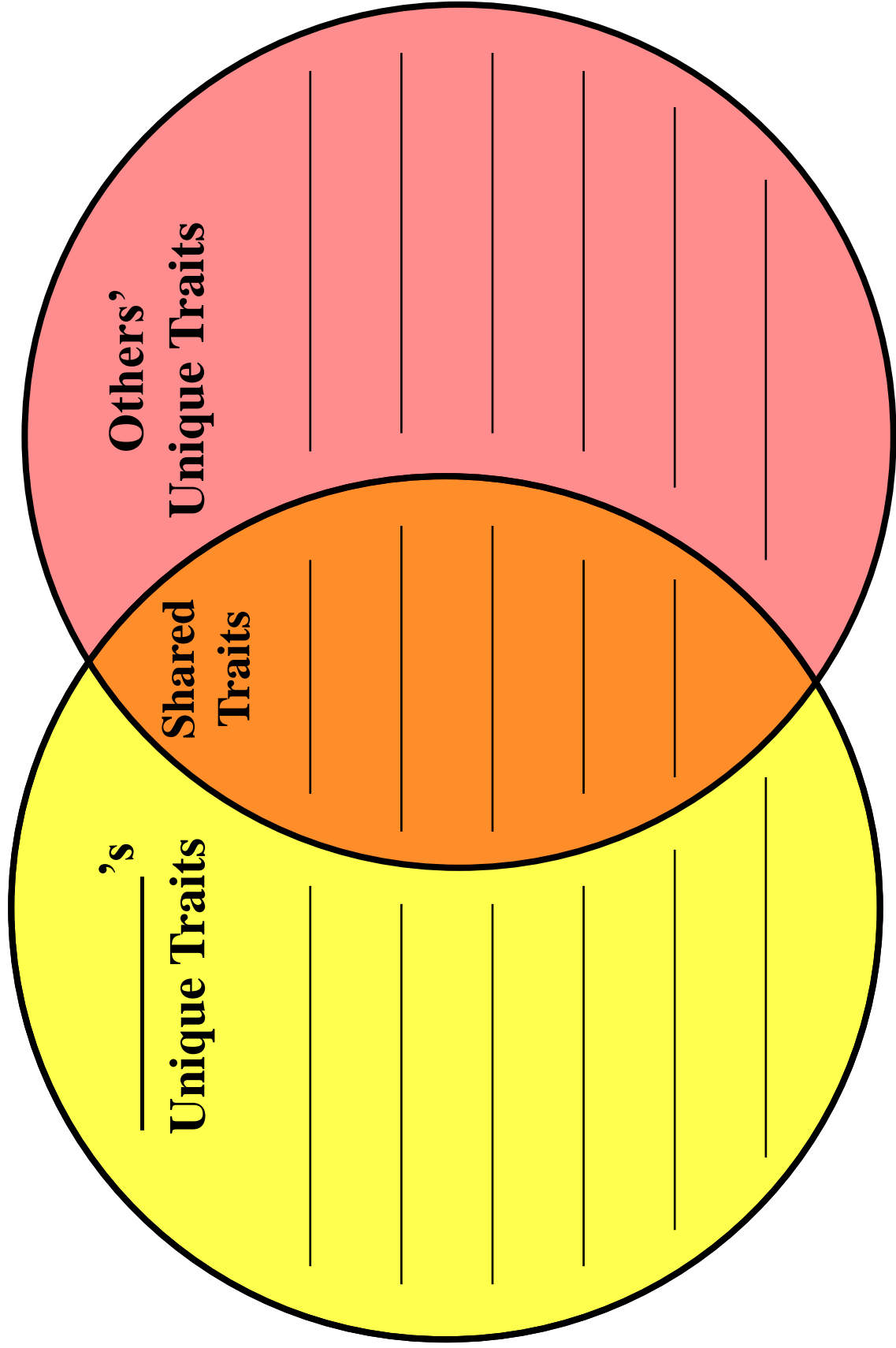
Using the Venn Diagram handout:

- ❖ In the **yellow** circle, have each child write down some of their unique characteristics. Discuss how some of their traits are theirs only, no one else has that trait, that is what makes them unique.
- ❖ In the **red** circle, have each child write some of characteristics that are unique to others in the room.
- ❖ In the **orange** area in the middle, have each child write the characteristics they share with the others. One shared trait could be their metabolic disorder.
- ❖ Discuss the value of having unique traits and characteristics as well as having characteristics that are shared.

Handout Needed

Venn Diagram

Venn Diagram



Adapted from "Alike or Different?" Scholastic Inc. 2006

Chapter Two Handout: VENN DIAGRAM

TEACHING AID

Comparing Apples To Apples

Objective: To introduce the concept of genes and genetic uniqueness.



How It's Done

- ❖ Bring an assortment of apples to clinic. Start by discussing how the apples are similar. Then note how the apples differ.
- ❖ Discuss how there may be other similarities or differences that are not readily visible, such as taste.
- ❖ If sufficient time is available, cut up the apples and have the participants taste them. Compare the different tastes.
- ❖ Follow with a discussion about members of the group. Talk about similarities and differences that are both visible and non-visible (i.e. PKU)
- ❖ Review with the group that our similarities and differences are a result of genes. Tailor the level of discussion to the participant's age and previous exposure to the topic. For example, for younger children one could discuss (or review) that genes function as recipes to make things. A red skinned apple will have a gene to make the color red. A green skinned apple will have a gene to make the color green. People have genes for skin, hair and eye color. They also have genes that impact how the body works. For example some people have genes for PKU and others don't. For older children, you may elect to discuss that we have genes (i.e. recipes) to make enzymes such as PAH. Discuss what happens if an individuals genes to make PAH have been altered such that no PAH is made.
- ❖ End by emphasizing that may of our similarities and differences are a result of genes. Stress that the differences we have make us unique and special!

Materials Needed

5 different apples

TEACHING AID

It's In The Code

Objective: To facilitate the introduction and discussion of genetic concepts.

How It's Done

The following is a suggested progression, incorporating the several handouts that can be used to talk about genetics at different levels. Remember to incorporate the children's metabolic disorder and positively reinforce uniqueness as often as possible

It's In The Code

- ❖ Compare the similarities and differences between people, animals, and plants: physical features, sources of energy or food, locomotion, and intelligence.
- ❖ Discuss these traits as being determined by genetic material called genes. Then ask the children what features might be comparable in people, animals, and plants: fur to hair, stem to legs, sounds to speech, walking to hopping.
- ❖ Introduce the concept that the parents of every species contribute the genetic make-up of their offspring, half from the mother and half from the father. Be sure to discuss that parents do not have control over which genes they pass on and which genes they do not. Tracing traits from one generation to the next is a fun activity. Use their own families or make-believe ones. *Be sensitive to variations in family structure.*
- ❖ Discuss that genes are contained within chromosomes in nearly every cell of living things. Show a Karyotype and discuss where the gene for **PAH** is located.

Jean's Genes

This is a teaching aid designed to introduce the concept of genes and inherited traits.

Recipes and Genes

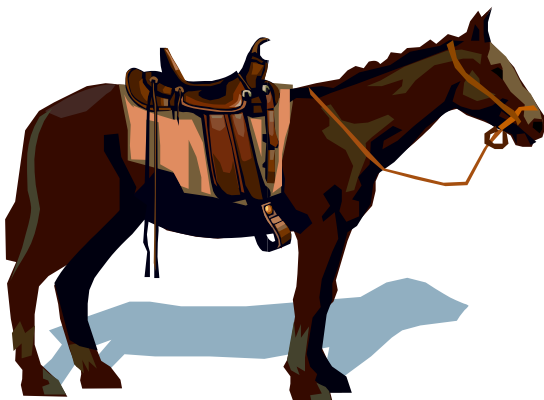
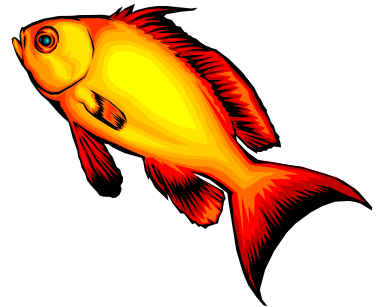
This is a teaching aid designed to introduce the concept that a gene is like a recipe, a set of instructions. A change to those instructions can affect the end product.

Handouts Needed

It's In The Code
Jean's Genes
Recipes and Genes

It's In The Code

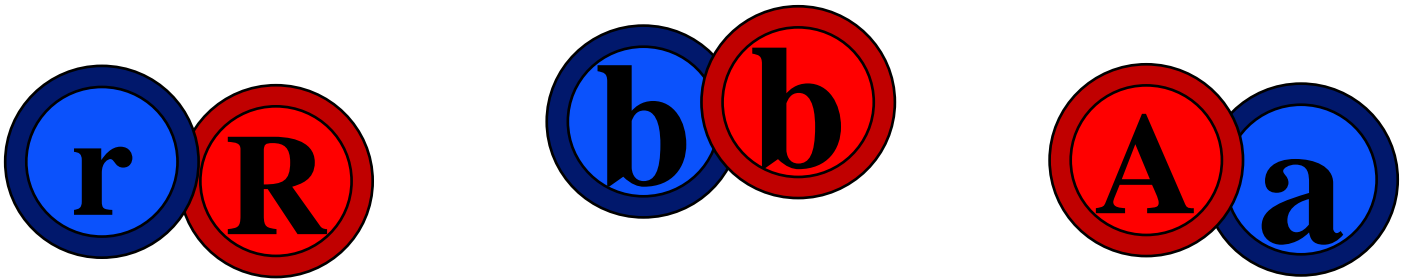
What is similar and what is different
Between the objects below?



TEACHING AID

Jean's Genes

Objective: To reinforce the concept of genes and uniqueness.**



How It's Done

Preparation:

Label poker chips to represent the genes utilized in this activity (see genotype worksheet handout). Use one color of chips to represent the genes inherited from Dad and another color to represent the genes inherited from Mom. Create random sets (each set to contain one gene for face shape, one gene, for hair color, one gene for eye color, etc.) of maternal and paternal genes, placing them in envelopes labeled according.

Activity:

Discuss the concepts of genes and how they determine individual traits. Provide each participant with an envelope containing a set of paternal genes and an envelope containing a set of maternal gene. Note that these are Jean's genes; the genes she inherited from parents. Instruct the participants to open the envelopes and organize the genes into pairs. Start by finding the gene for face shape inherited from Dad. Line it up with the gene for face shape inherited from Mom. Have the participant record the inherited genotype on the genotype worksheet. Next, have the participant circle the resultant phenotype based on the genotype. After this is done for all the genes, have the participants draw a portrait of Jean based on her inherited traits. Introduce the terms "genotype" and "phenotype" referring back to the appropriate worksheets.

Materials Needed

- ❖ Red and blue poker chips
- ❖ Markers or colored pencils

Handouts:

Genotype Worksheet

Genotype Worksheet

FACE SHAPE: _____

- ☐ RR = Round
- ☐ Rr = round
- ☐ rr = oblong

HAIR COLOR: _____

- ☐ DD = Black
- ☐ Dd = Brown
- ☐ dd = Blond

EYE COLOR: _____

- ☐ BB = brown eyes
- ☐ Bb = brown eyes
- ☐ bb = blue eyes

NOSE SIZE: _____

- ☐ NN = large nose
- ☐ Nn = medium nose
- ☐ nn = small nose

EAR LOBES: _____

- ☐ EE = hang free, not attached
- ☐ Ee = hang free, not attached
- ☐ ee = attached,
do not hang free

LIPS: _____

- ☐ LL = full lips
- ☐ Ll = full lips
- ☐ ll = thin lips

FRECKLES: _____

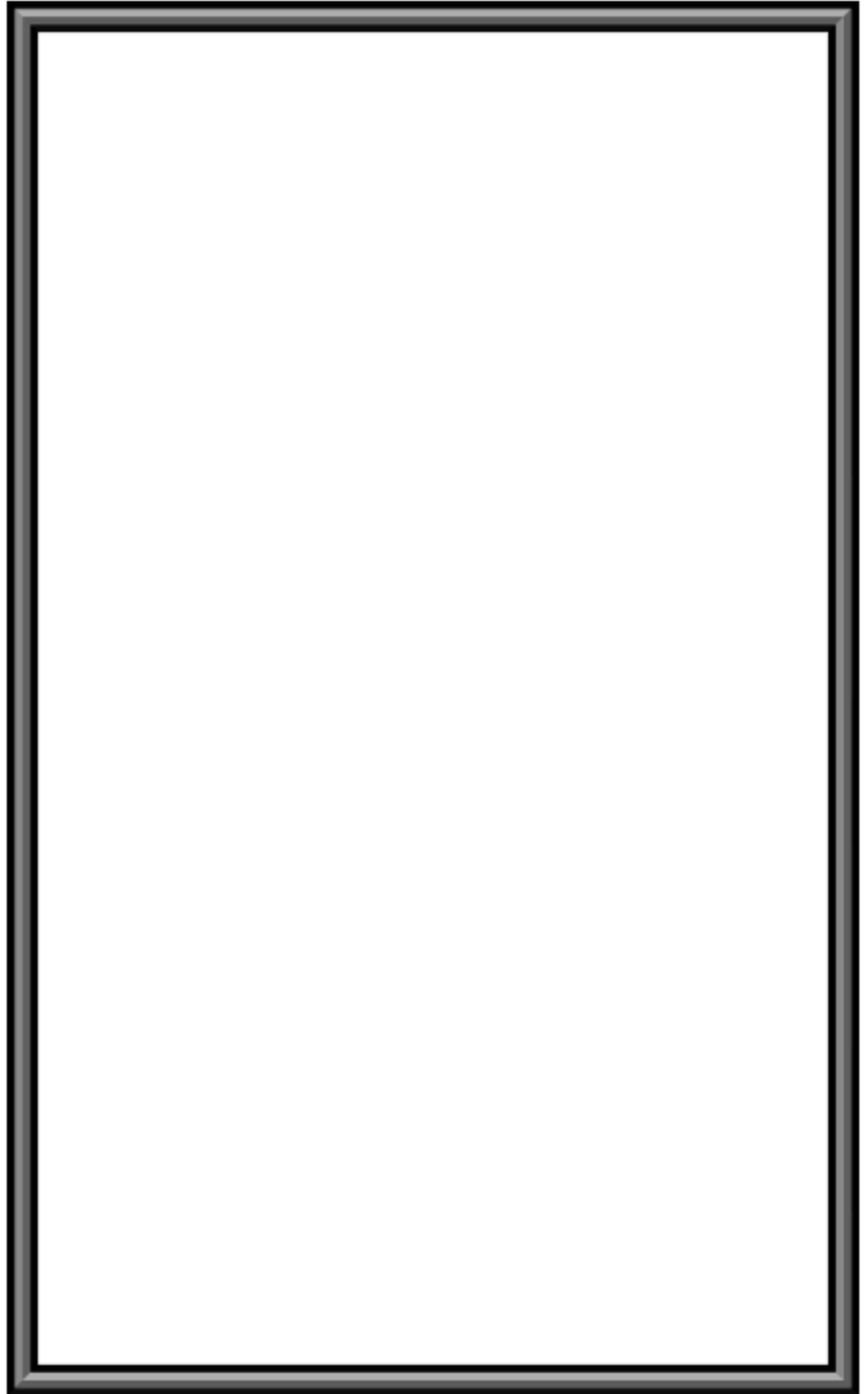
- ☐ FF = no freckles
- ☐ Ff = no freckles
- ☐ ff = freckles

PKU: _____

- ☐ AA = does not have PKU
- ☐ Aa = does not have PKU
- ☐ aa = does have PKU

HFI: _____

- ☐ HH = does not have PKU
- ☐ Hh = does not have PKU
- ☐ hh = does have PKU



Jean's Portrait

Using the results from the
worksheet, draw what
Jean will look like.

TEACHING AID

Recipes & Genes

Objective: To introduce the concept that a gene is like a recipe, a set of instructions. A change to those instructions can affect the end product.



How It's Done

- ❖ Discuss that genes carry instruction to make PAH and other substances in our body.
- ❖ Relate this to a recipe that instructs on how to make waffles or cookies.
- ❖ Have the participant's speculate what might happen to the waffle or cookie if the recipe was changed. For example, speculate on what would happen if the changed recipe called for one teaspoon of salt rather than two teaspoons of salt. What would happen if it called for two cup of salt rather ant two teaspoons of salt?

Discussed how some changes can results in a waffle or cookie that may not be “perfect” but is still edible (hence functional). Other changes will result in a waffle or cookie that you cannot eat and would not be functional.

- ❖ Relate this to a changes in the gene for PAH and resultant changes in PAH activity or functionality.
- ❖ Make products using a recipe provide in the handout. Change the amount of a particular ingredient. Discuss the outcome and how the change in the recipe impacted the end product.



Materials Needed

- ❖ Baking ingredients

Handout:

Recipes & Genes

Holiday Cookies

Low Protein Waffles

RECIPES & GENES



HOLIDAY COOKIES

RECIPE FROM WWW.MYSPECIALDIET.COM

Yields: 20 Servings

Per Cookie: Phe: 5 mg Protein: 0.12 g



Ingredients:

4 oz	Butter, room temperature	½ oz	Butterscotch Instant Pudding (powder)
2 oz	Sugar	¾ tsp	Milupa lp Drink
6 ½ oz	Loprofin Low Protein Baking Mix*		

Directions:

1. Place the butter and sugar in a mixing bowl and beat well, until light in color and texture.
2. Stir in the Loprofin and pudding powder. Using one hand, stir and squeeze the mixture until it comes together, adding sufficient Milupa lp Drink to give manageable dough. Transfer to a surface lightly dusted with Loprofin Baking Mix and knead the dough for about until smooth.
3. Roll out the dough to about ¼ inch thickness, on a surface lightly dusted with Loprofin.
4. Cut out shapes. Re-roll the trimmings and continue cutting out the shapes, until all dough is used.
5. Transfer the cookies to lightly greased non-stick baking trays and bake in pre-heated oven for 15 minutes, until a pale golden color.
6. Allow the cookies to cool slightly on the baking trays, carefully remove from the trays and complete cooling on a wire rack.

LOW PROTEIN WAFFLES

RECIPE FROM PKU COOKERY, VIRGINIA SHCUETT

Yield: 5 waffles (4 squares per waffle)

Phe: 14 mg Phe (per ¼ waffle – 1 square)



Ingredients:

330 g (3cups)	Wel-Plan Baking Mix*	¼ tsp	Vanilla
110 g (1 cup)	Wheat Starch	29 g	Egg White (1 Tbls + 1 tsp)
2/3 cup	Vegetable Oil	4 tsp	Baking Powder
1 1/3 cup	Rich's Coffee Rich	½ tsp	Salt
1 ¼ cup	Water	¼ cup	Sugar

Directions:

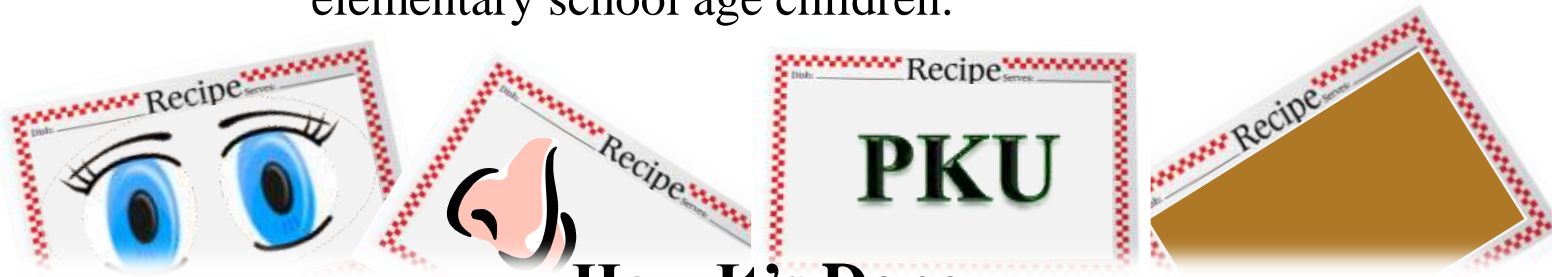
1. In a large mixing bowl, mix Wel-plan baking mix, wheat starch, baking powder, salt, and sugar.
2. Combine oil, Coffee Rich, water and vanilla in a large liquid measuring cup or small bowl.
3. Add to dry ingredients, mixing until smooth.
4. Put egg white in a small bowl and beat with an electric mixer until stiff but not dry. The total volume will be about ¾ cup.
5. Gently mix beaten egg white into waffle batter. Thin batter with a little water if batter is too thick to spread on waffle iron.
6. Brush vegetable oil lightly on top and bottom of a hot waffle iron to prevent any sticking. Use a 1 cup measuring cup to scoop the batter, scraping out quickly onto hot iron (1 cup of batter will make a nice, full 4-square waffle).
7. Bake 3 to 5 minutes. Lid should open easily when done. Open iron and remove waffle carefully.
8. Serve immediately, or cool completely on a wire rack and freeze.

* Nutricia North America -- Low Protein Products - www.shsna.com/pages/loprofin.htm

TEACHING AID

My Genetic Recipe Book

Objective: Introduce the concept of a gene to kindergarten and early elementary school age children.



How It's Done

Introduce or review the concept of a gene being a recipe

- ❖ Discuss the term “recipe” and how it is a set of instructions to make something. Introduce the term “gene” and discuss how it is like a recipe.
- ❖ Dependent upon participants writing skills, have participant’s write the word “gene” on a piece of paper or white board. Discuss that inside our bodies, there are thousands of genes or recipes.

For example: There are genes (i.e. recipes) to make our eyes and genes (i.e. recipes) to make our fingers. There are genes for hair color; individuals with brown hair have a gene to make their hair brown. There are genes that result in PKU.

Use the My Genetic Recipe Book Handout.

- ❖ Have participants write their names on the top of the handout. Ask them to feel their hair and determine if it is curly or straight. If their hair is curly, they should circle the “curly recipe gene”; if straight, they should circle the “straight recipe gene”. Next talk about hair color. Have them circle the “hair color recipe gene” that is appropriate for them. Note, on the hand out sheet, you will need to add colors to the blank boxes (such as back, brown, blond and red) as these were left blank due to the high likelihood that a color printer or copier would not be used when generating the hand out.
- ❖ Ask participants if they have eyes. Since they do, they need to circle the “recipe gene for eyes”. Repeat this for all traits. Finally ask the participants if they have PKU or HFI. Describe HFI, noting that people with this disorder cannot eat fruit. Have them circle the appropriate recipe gene.
- ❖ End by celebrating that they have just made a recipe gene book specific for them!! How cool is that!!

Handout Needed

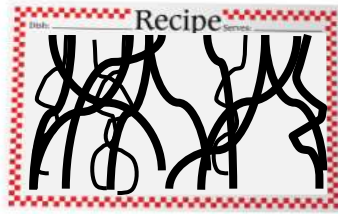
My Recipe Gene Book

My Recipe Gene Book

Name _____

Each box represents a gene or recipe to make important parts of your body. Circle the genes (or recipes) that you have. For example, if you have curly hair, circle the curly hair gene. If you have straight hair, circle the straight hair gene. *Note for instructor:* The hair color genes need to be colored in (such as black, brown, blond, and red).

Gene For Hair Texture



Gene For Hair Color



Gene For Eyes



Gene For Nose



Gene For PKU



Gene For HFI



TEACHING AID

I'm Thumb-body Special

Objective: To introduce the concept of genetic differences between people.



How It's Done

Fingerprints are a fun way to demonstrate the subtle differences between people

- ❖ Have the participants first examine their thumbs and fingers closely and notices the fine lines that make up the thumb/finger print.
- ❖ Explain that, like snowflakes, no two fingerprints are alike. Discuss that every person in the world has a unique thumb print.
- ❖ Help the participants make their own thumb print on the “I’m Thumb-body Special” handout.
- ❖ Use as magnifying glass to look closely at the pattern created.
- ❖ Compare prints and note the differences. Discuss that these differences are, in general, caused by our genes. Discuss that our genes make each individual special.
- ❖ Have the participants to turn their thumb print into a “thumb-body”. Ask them to think of the print as a face. Have them use markers to add hair, eyes, nose, etc. Demonstrate this process using your thumb print.
- ❖ Encourage them to make additional thumb-buddies. Dependent upon how much time is available, recommend they draw different types of faces (happy, mad, etc.) to reflect how they feel right now, how they feel when they have to have their blood draw, how they feel when they eating lunch with their friends, etc.. Explore, discuss, and validate these feelings.
- ❖ End by reviewing that each participant, is unique. Have them list several things that are special about themselves. Ask if they would like to share with other, items that they have listed. Discuss if the participants listed their metabolic disorder (or not), and why.

Materials Needed

- ❖ Ink Pad
- ❖ Markers

Handout:

I'm Thumb-body Special

I'm Thumb-body Special

Name: _____

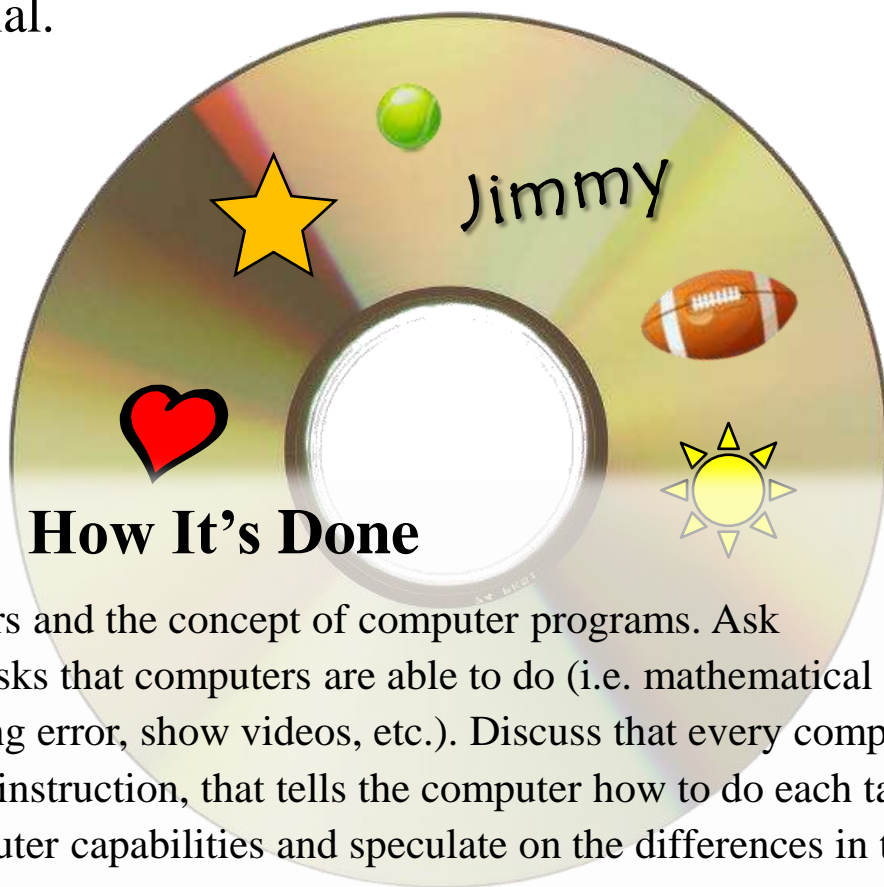
Special Things About Me:



TEACHING AID

Personalized CD

Objective: To emphasize uniqueness and to introduce the concept of genetic material.



- ❖ Start by discussing computers and the concept of computer programs. Ask participants make a list of tasks that computers are able to do (i.e. mathematical calculation, check for spelling error, show videos, etc.). Discuss that every computer must have a program, or set instruction, that tells the computer how to do each task. Discuss differences in computer capabilities and speculate on the differences in their computer programs.
- ❖ Relate a computer's set of "programs" to an individual's set of "genes".
- ❖ Give each individual a blank CD that is to be personalized with programs (i.e. genes) that make them special and unique. Start by having them write their name on the CD. To further personalize it, have them write, draw pictures, or add stickers that represent how they look and or things they like to do. If they have added PKU to their CD, explore why they chose to do so. Do the same if they have not added PKU. Discuss that either way is okay; it is an individual feeling (than may vary from day to day and situation to situation).
- ❖ Have each participant share with the group their personalized CD. Discuss similarities and differences between the CDs.

Materials Needed

- ❖ Blank CD or Personalized CD Handout
- ❖ Markers or color pencils
- ❖ Stickers

PERSONALIZED CD



TEACHING AID

The Gene Song

Objective: To use music as a medium for learning about genetic inheritance.



How It's Done

Use the handout “The Gene Song”

- ❖ Sing the words provided in the handout to the tune of:
“*Head, Shoulders, Knees and Toes*”.
- ❖ Ask each participant to sing a verse of the song, maybe even add their own lyrics.
- ❖ Add hand gestures and dance moves.
- ❖ Practice your creation. Stage a production for families or staff, or videotape the performance.
- ❖ Have fun! Be crazy!

Handout Needed
The Gene Song

The Gene Song



To the tune of “Head, Shoulders, Knees and Toes”

Genes come from mom and dad (mom and dad!)
Genes come from mom and dad (mom and dad!)
They make us short or make us tall
Genes make us who we are (who we are!)

Genes come from mom and dad (mom and dad!)
Genes come from mom and dad (mom and dad!)
They make our nose big or make our nose small
Genes make us who we are (who we are!)

Genes come from mom and dad (mom and dad!)
Genes come from mom and dad (mom and dad!)
They change things that cannot be seen
Genes make us who we are (who we are!)

Genes come from mom and dad (mom and dad!)
Genes come from mom and dad (mom and dad!)
Mine can't use phenylalanine
Genes give me PKU (PKU!)

TEACHING AID

A Kid's Life

Objective: To dialogue on how various parts of a child's lifestyle make that a child whole.

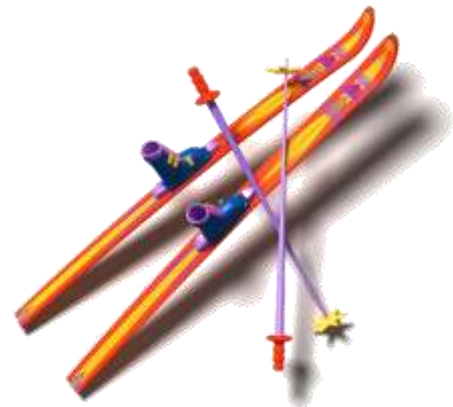


How It's Done

- ❖ Utilize the handout as a means to help the child identify important aspects of their daily life.
- ❖ Create an opportunity for discussion about how each part of their lifestyle contributes to who they are.
- ❖ Emphasize the role of diet as a key factor in being able to achieve wholeness.

Handout Needed
A Kid's Life

A Kid's Life



REFERENCES

"Alike or Different?" Reproducibles & Quizzes Archive. Scholastic Inc., Sept. 2006. Web. 22 Apr. 2010. <<http://http://storyworks.scholastic.com/reproducible-archive/past-issues#sep06>>.

"Holiday Cookie Recipe." Nutricia North America. Web. 26 Apr. 2010. <<http://www.myspecialdiet.com/Information/Doc.aspx?t=3&a=409>>.

Low Protein Cookery for Phenylketonuria (PKU). Virginia E. Schuett, University of Wisconsin Press; 3 edition. ISBN: 0299153843

Mile High, Low Protein Cookbook Available through the Low Protein Food Store, IMD Clinic, The Children's Hospital, Aurora, CO. 303-724-2338

Nutricia Advanced Medical Nutrition - Nutricia.com. Web. <<http://www.nutricia.com/>>.

Nutricia North America - Advanced Medical Nutrition. Web. <<http://www.shsna.com/>>.

Nutricia North America -- Low Protein Products Nutricia - Advanced Medical Nutrition. <<http://www.shsna.com/pages/loprofin.htm>>.

"Printable Coloring Pages, Free Coloring Drawing for Kids." Free Coloring Pages for Kids, Printable Coloring Book Pages. Web. 29 Mar. 2010. <<http://www.freecoloring.org/animals/turtle-coloring-pages.htm>>.

"USDA's MyPyramid - Graphics." *MyPyramid.gov - United States Department of Agriculture - Home.* Web. 01 Mar. 2010. <http://www.mypyramid.gov/global_nav/media_resources.html>.

RESOURCES

Amazing Schemes Within Your Genes. Fran Balkwill, Lerner Publishing Group, 1994. ISBN: 0876146353

The Brain Box: Making sense of science. S. Rose and A. Lichtenfels, Portland Press, London, 1997. ISBN: 9781855780965

Cells Are Us. Fran Balkwill, Lerner Publishing Group, 1994. ISBN: 0876146361

DNA Is Here To Stay. Fran Balkwill M.D., Lerner Publishing Group, 1994. ISBN: 0876146388

Denny the Dragon and his Magic Milk. N. Beiman, M. Rosetti and H. Wolf, SHS North America. Available online at the Texas Department of State Health Services website:
<<http://www.dshs.state.tx.us/kids/colorbook/denny/denny1.shtm>>

Everyone Has Something. Margaret Domnick. Bloomington, Indiana: Author House, 2004. Print. ISBN: 1420800507

Great Thumbprint Drawing Book. Ed Emberley, Little, Brown and Company, Boston, 1977. ISBN: 0316236136

The Incredible Human Body: A Book of Discovery & Learning. Frances R. Balkwill, Lerner Publishing Group, 1994. ISBN: 0806961252

Low Protein Cookery for Phenylketonuria (PKU). Virginia E. Schuett, University of Wisconsin Press; 3 edition. ISBN: 0299153843

Mile High, Low Protein Cookbook Available through the Low Protein Food Store, IMD Clinic, The Children's Hospital, Aurora, CO. 303-724-2338

More Phe, More Choices: Think Healthy! Laurie Bernstein, Sommer Meyers, Kelly Parker, and Kelly Tice. IMD Clinic, The Children's Hospital, Aurora, CO. 303-724-2338

More Phe, More Choices: Think Healthy! Generation X,Y,and Z. Laurie Bernstein, Sommer Meyers, Casey Burns, Kathryn Bloxsom, Janine Gessner, and Catherine Long. IMD Clinic, The Children's Hospital, Aurora, CO. 303-724-2338

Nutricia Advanced Medical Nutrition - Nutricia.com. Web.
<<http://www.nutricia.com/>>.

Nutricia North America - Advanced Medical Nutrition. Web.
<<http://www.shsna.com/>>.

Nutricia North America -- Low Protein Products Nutricia - Advanced Medical Nutrition. <<http://www.shsna.com/pages/loprofin.htm>>.



RESOURCES

PKU Adventure Game. Available through the Low Protein Food Store, IMD Clinic, The Children's Hospital, Aurora, CO. 303-724-2338

PKU Nutrition Cards. Available through Nutricia North America Web.
<<http://www.shsna.com/>>.

A Teacher's Guide to PKU. M. Kaufman and M. Nardella, Office of Nutrition Services, Crippled Children's Services, Arizona Department of Health Services, Phoenix, AZ, 1985. Mimi Kaufman, M.P.H., R.D. and Maria Nardella, M.A., R.D. Available online at the Texas Department of State Health Services website:
<http://www.ub.edu.ar/centros_de_estudio/ceegmd/documentos/TeachersGuide.pdf>

We're Different, We're The Same. Kates, Bobbi Jane., and Joseph Mathieu. New York: Random House, 1992. Print.. ISBN: 9780679832270

Why Can't I Eat That? Helping Kids Obey Medical Diets. John F. Taylor, Sharon R. Latta. Ultramarine Publishing Company; Rev 2nd edition. Available from Ross. ISBN: 0882479814

