Birth to Five Years

Galactosemia Foundation

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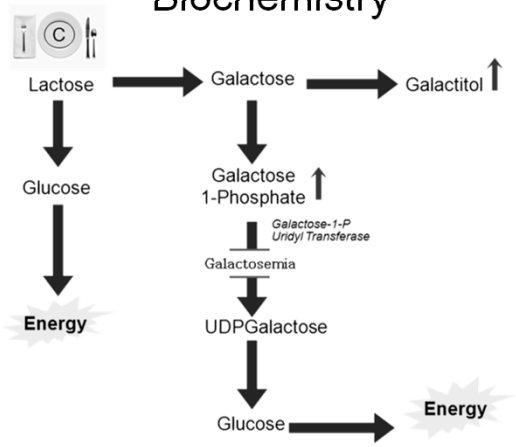
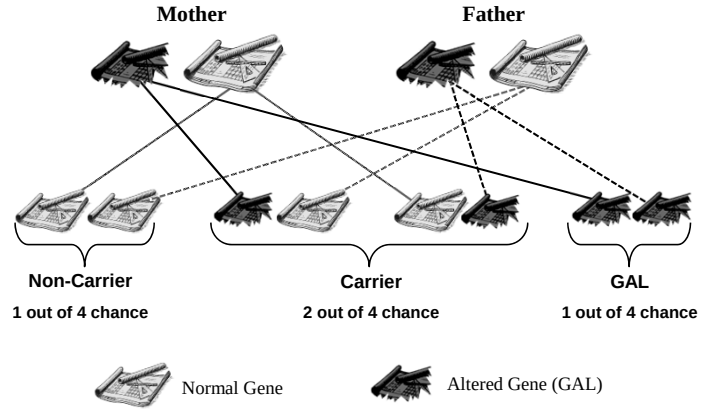
Do You Understand?

- Biochemistry
- Autosomal recessive disorder
- Recurrence risk
- Outcome

Biochemistry

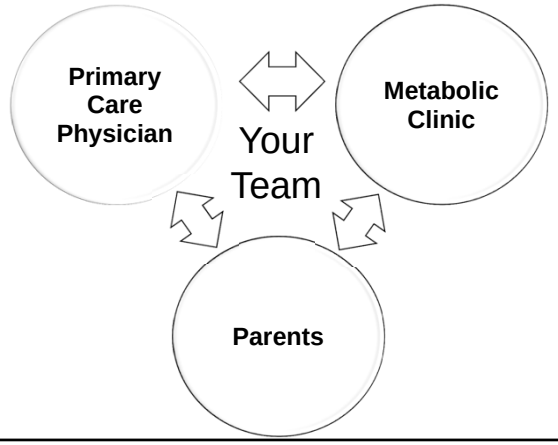


Autosomal Recessive Inheritance



Emotional Responses to Diagnosis of Chronic Metabolic Disease

- Denial
- Fear
- Anger
- Guilt
- Over involvement
- Sorrow/sadness



Nutrition Intervention Birth to 4 months

- Bottle feeding only
- Preparing for solid foods
  - Accessing development – when is my baby ready to begin solids?
  - Acceptable vs Unacceptable Foods and Ingredients
  - Label reading
- Nutrition education – family members, babysitters

Why Soy Formula

- Very low in galactose, allowing for gal-1-P to decrease in blood
- Gal-1-P level will decrease slowly – can take months
- ? Use of elemental formulas to decrease level faster
- Let your baby dictate the amount of formula he takes
- Continue use of soy formula at least until age 1

Starting solids

- 4 to 6 months of age
- Progression:
  - Rice Cereal
  - Fruits and Vegetables
- 6 to 8 months of age
  - Table foods ok to start
  - Begin cup-drinking of formula
  - Finger foods
- Increase variety, but formula remains primary source of calories

Appropriate Feeding Practices

- ☑ Feed solids only when an infant is sitting up in a high chair or being held upright.
- ☑ Solids should be fed from a spoon, Promotes the proper development of tongue muscles
- ☑ Introduce solids one at a time with approximately 3-5 days in between each new item.
- ☑ Wash baby food jars before opening. Listen for a popping sound when opening. If the "bubble" on top of the jar has already popped up - DO NOT use this jar.
- ☑ New foods that are rejected should be offered at another time. Acceptance of new foods can be encouraged by a positive attitude.

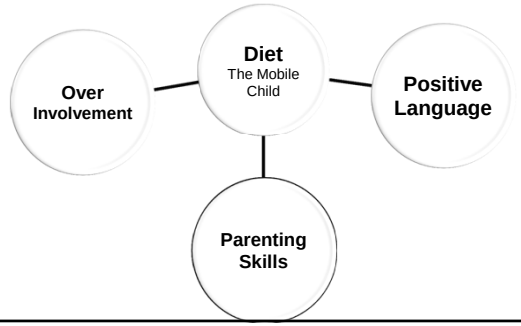
Inappropriate Feeding Practices

- ⊘ Solid foods should not be fed from a bottle.
- ⊘ Infants do not need salt, sweeteners, and seasonings. Do not offer honey or corn syrup; they may contain botulinum spores.
- ⊘ At about 6 months, babies begin to hold their own bottles. Do not put babies to bed with a bottle.
- ⊘ Do not feed the baby directly from the baby food jar to avoid contamination
- ⊘ Do not use the microwave to warm foods or bottles.

What to learn during the first year

- Unacceptable Ingredients
- Label-reading
- Brands that are ok
- Cookbooks
  - First Birthday Cake
- Honor the feeding relationship
  - ☑ Allow your baby to set the pace for feeding.
  - ☑ It is not necessary for an infant to finish a bottle or solids. The baby is usually the best judge of how much to

Nutrition Intervention
One to 5 years



Nutrition Intervention: 1 to 5 years

- When to transition from soy formula to soy milk?
  - Can use soy "toddler" formulas
  - Calcium and Vitamin D of most concern
- Education
  - Babysitters, day care, family members, grandparents
  - Your child
    - "Yes" and "No" foods
    - "I can't have that unless I ask my Mom or Dad"

Calcium - Requirements

Age Range	Calcium (mg/day)
0 to 6 mo.	200
7 to 12 mo	260
1 to 3 years	700
4 to 8 years	1000
9 to 18 years	1300
Adults	1000 (> 70 yrs = 1200)

Vitamin D - Requirements

Age	Vitamin D µg/day
Infants	10 (400 IU)
1-3 years	15 (600 IU)
4-8 years	15 (600 IU)
9-18 years	15 (600 IU)
19-70 years	15 (600 IU)
> 70 years	20 (800 IU)

- Requirements for vitamin D were increased in 2010 by the National Research Council
- Vitamin D levels in Infant formulas, supplements and fortified foods are being adjusted to meet new standards

Bridging the Gap

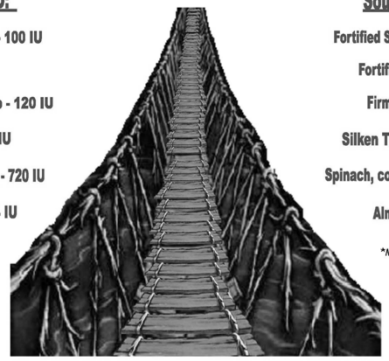
Sources of Vitamin D:

- Fortified Rice Milk - 8 oz - 100 IU
- Firm Tofu - 3 oz - 120 IU
- Fortified Soy Milk - 1 cup - 120 IU
- Fortified O.J. - 8 oz - 100 IU
- Salmon, farm raised - 3 oz - 720 IU
- Salmon, wild - 3 oz - 2964 IU
- Shrimp - 3 oz - 130 IU

Sources of Calcium:

- Fortified Soy Milk - 1 c - 400 mg
- Fortified O.J. - 1 c - 300 mg
- Firm Tofu* - 1/2 c - 200 mg
- Silken Tofu* - 1/2 c - 140 mg
- Spinach, cooked - 1/2 c - 130 mg
- Almonds - 2 oz. - 150 mg

*Made with calcium sulfate



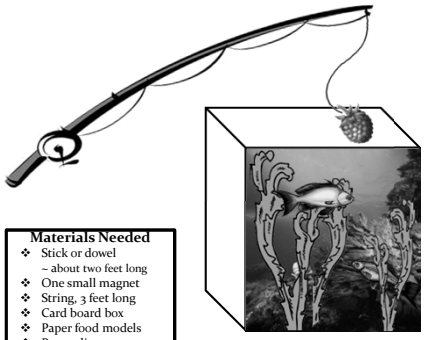
Restricting the lactose and galactose-containing dairy products from your diet may make it hard to get all of the Calcium and Vitamin D you need for growth and development.

Nutrition Education

- Fishing for Galactose
- Clinic Supermarket
- Role Playing
- Red Light!! Green Light!!
- Ways We Are Alike and Ways We Are Different

Fishing For Galactose

Objective: To learn the names of a variety of foods and to recognize them as "*Yes*" and "*No*" foods.



Materials Needed

- Stick or dowel ~ about two feet long
- One small magnet
- String, 3 feet long
- Card board box
- Paper food models
- Paper clips ~ one for each food model

How It's Done

Create a fishing pole:

Attach the magnet to one end of the string, and to the other end of the string, to the stick.

Create an ocean or lake:

- Cover a cardboard box with blue paper.
- Draw fish, seaweed, or anything you find in the sea or a lake on the paper.
- Fill the box with paper food models and attach a paper clip to each model.

Go Fishing!

Clinic Supermarket

Objective: To learn the names of a variety of foods and to recognize them as "*Yes*" and "*No*" foods.

CLINIC SUPERMARKET

Materials Needed

- Posterboard
- Markers, crayons, or paints
- Magazines and newspapers
- Paper or plastic food models
- Basket or paper bag

How It's Done

Create a sign for your store:

Develop a sign that clearly states "Clinic Supermarket" and decorate the sign with pictures of food. Coupons and magazine clippings are an easy, inexpensive, and colorful approach to decorating.

Create a shopping environment:

- Place food models on a table and allow each child to shop for "yes" foods.
- The container for shopping can be a paper bag, shopping basket, or a mini shopping cart.
- This concept can be expanded upon based on the age of the children.

Role Playing

Objective: To rehearse when and how to say "Yes" or "No" when confronted with food choices.

Lights…

Camera…

Action

How It's Done

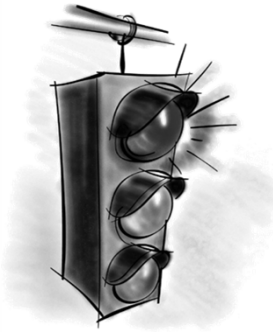
Create an interactive environment:

- Using food models, have the clinic professional or parent offer a "yes" or a "no" food to the child.
- Have the child identify the food either as a "yes" or a "no" food and then ask the child if they would like a little taste.
- Reinforce appropriate answers and modify inappropriate responses.

Materials Needed
- Paper or plastic food models

Red Light!! Green Light!!

Objective: To reinforce "Yes" and "No" food choices.



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 and red for "no" foods.
- Develop more game pieces as the group matures (i.e.: yellow is for foods that are "yes" but need to check labels to decide if "yes" or "no").
- Use felt backed food models and let the children place them in the appropriate section.
- A positive reward system is used with all of these programs.
  - Stickers
  - Buttons
  - Applause
  - Verbal affirmation
  - Safe treats

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

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.

How It's Done

- Discuss the terms "alike" and "different" and use these terms in relation to physical characteristics.
- Compare your physical traits to those of others in the room, pointing out ways you are alike and ways you are different.
- Identify a feature in yourself that is different than that seen in other individuals in the room. Point out how this makes you unique and special.
- Compare physical characteristics of other individuals present.
- Have all individuals with GAL 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.

No Materials Needed

Allergy Kids.com

- The goal of AllergyKids is to create universal awareness of children with life threatening food allergies.
- AllergyKids offers a simple symbol for children with serious food allergies so that they can be easily and quickly identified.

Thank you…

- Laurie Bernstein MS, RD, FADA
- Children's Hospital Colorado Metabolic Team