Guide to HCU
(Homocystinuria)

Grandparents

What is HCU?

HCU is short for Homocystinuria (ho-mo-sis-tin-ur-ee-a). It is a serious metabolic disorder that some people are born with. To stay healthy, many people with HCU have to take a special HCU formula, consume a diet that is low in whole protein and methionine, as well as take certain medications.

What is Methionine?

Amino acids are the building blocks of proteins. Methionine (MET) is an amino acid. A person with HCU lacks the enzyme needed to convert methionine to a substance called cystathionine.

What happens?

HCU is not a food allergy with an immediate reaction when the wrong foods are eaten. Eating too much protein causes an unhealthy buildup of methione and homocysteine (HCY). Poorly controlled HCU can lead to intellectual disabilities, blood clots and other medical conditions.

High HCY levels may cause:

- Lack of attention or focus
- Learning disabilities
- An overall tiredness or lack of energy
- Behavior problems
- Anxious feelings
- And more…

HCU formula, a low protein diet and medications will help keep your grandchild healthy. Help your grandchild by providing foods low in protein in proper portions and make sure all formula is consumed and medications taken when scheduled.

What is a low protein diet?

In order to limit the amount of methionine (MET) that your grandchild eats, he/she must follow a diet low in whole protein. The HCU diet mostly consists of fruits, vegetables and special low protein foods. Your grandchild must avoid high protein foods such as meat, poultry, fish, eggs, nuts, seeds, peanut butter, milk, yogurt, cheese and other dairy products. Regular bread, pasta, rice and cereal also contain whole protein and are restricted.

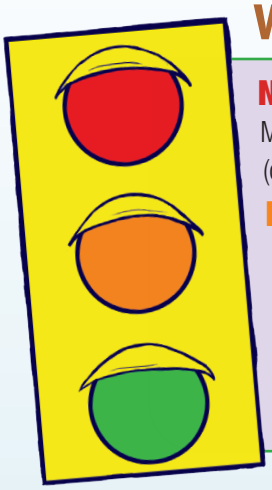
HCU formula provides the special protein your grandchild needs to grow and stay healthy.

Many Individuals with HCU must drink a special ***formula*** *to supply the body with the necessary protein requirements for growth and maintenance.*

Available at **NutriciaMetabolics.com**

The HCU diet must be followed strictly throughout life.

What can I feed my grandchild?*



NOT PERMITTED

Meat, poultry, fish, eggs, nuts, peanut butter, seeds, regular bread, pasta, rice, grains, beans, milk, yogurt, cheese (other dairy) and soy/pea protein-based meat alternatives.

PERMITTED IN LIMITED AND MEASURED AMOUNTS

Fruit juice, rice milk, butter, starchy vegetables such as peas, corn and potatoes.

PERMITTED LOW PROTEIN FOODS

Special foods made to be low in protein, such as low protein breads, pastas and baking mixes. Many fruits and vegetables, dairy-free margarine, cooking oils and many sugar-based sweets (such as lollipops and jelly beans).

*This is not a complete list. Permitted foods and quantities will vary. Always consult the metabolic clinic prior to making any changes to the HCU diet plan. To find out the protein content of food, visit HowMuchPHE.org or MetabolicDietApp.org

Bake low protein with your grandchild!

What can I do?

Support your grandchild's parents in teaching the child that following the HCU diet is important.

Respect the wishes of the parents and only provide food permitted on the low protein diet.

Learn to cook low protein. There are many great recipes available. Your grandchild will love when there is always something good to eat at your house.

Things to remember:

- Always encourage diet adherence. "Just a taste" can set a bad example that not following the diet is an acceptable behavior.
- Your grandchild is in many ways not different from any other child. Enjoy the normal things grandparents do with their grandkids and support your grandchild's formula, diet and medications needs.
- You are not to blame. HCU is a genetic disorder and is no one's fault. Each time two people who carry the HCU gene have a child, there is a 1 in 4 (25%) chance the baby will have HCU.

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This HCU educational handout is brought to you by Nutricia Metabolics, maker of Anamix®, Maxamum® and Lophlex® brand formulas for HCU. For more information visit NutriciaMetabolics.com