



## **PKU and the Self-Management Timeline**

An important part of parenting a child with PKU is helping first yourself and then your child to manage PKU effectively.

The PKU Self-Management Timeline is included to provide a long-term view of the expected developmental progress as your child gains in skills and self-management competence. This guideline suggests incremental self-management goals for you and your child.

A timeline is a flexible guideline that will help you look forward as you begin to parent your child with PKU.

Initially, you are in charge of the information about PKU and management of PKU. Fairly quickly as your child gains in language skills and is interested in his environment, it is time for him to have a role in his own PKU management. One of the parents in our clinic has said, 'You talk to him all day long about shapes, colors, and names of things; it is logical to label foods YES foods or No foods during this on-going conversation.'

By responding to the developmental cues that your child offers, you are on your way to implementing the PKU Timeline. And, amazing as it may seem, on the way to the development of a competent, knowledgeable, young adult who effectively manages his own PKU.

There is, of course, a step or two of educational effort and management between the infant and the adult. The process of one-step-at-a-time is appropriate and necessary. Think of the process as a 'dance'; you and your child are partners moving together, changing momentum and direction as needed for advancement. Acknowledge the difference between your child 'having' a specific self-management skill' and performing the skill independently at all times. It is important that parents 'be present' for the entire process of development and maturation of their child.



## PKU Self-Management Timeline

Age of Child	Tasks for Children and Parents
0-6 months	Parents learn about and adjust to PKU
6 months	Start low-protein solid foods
6-7 months	Introduce cup with water Introduce cup with formula
8-9 months	Introduce finger foods
10-15 months	Consider final weaning from bottle (discuss transition with clinic staff)
2-3 years	Learn the concept of "formula first" Learn to distinguish "yes" and "no" foods
4-5 years	Begin to learn to count foods - "how many" Begin to use scale - "how much"
5-6 years	Assist in formula preparation Teach children how to deal with other children's curiosity about PKU
7-10 years	Prepare formula with decreasing supervision Choose after school snack Learn to pack school lunch Begin to list foods on food record Begin weighing food regularly on scale
10-12 years	Begin to prepare and consume formula independently each day (with parental monitoring) Prepare simple entrees independently Know what blood levels are ideal
13-14 years	Increasing self-monitoring (with continued parent support) in formula preparation and consumption Independently manage total phe intake for the day Learn menu planning Responsible for food records
15-17 years	Competent to perform and primarily responsible for all aspects of self-management with continued parent support Able to perform own Guthrie blood draw or schedule blood draw Able to explain the basics of PKU - "What is it?" Responsible for remembering recent blood levels
18 years	Transition to adult-based clinic care Ready to live independently, including: --formula preparation and consumption --food preparation and records --monthly serum phe --setting and keeping own appointments on regular basis Parents act as consultants