

GOALS FOR OPTIMAL PKU MANAGEMENT

Adolescence Through Adult Years

PKU requires a lot of planning and effort. Although all these goals may be hard to achieve all at once, start to think about what is possible for you. These are just some ideas to help you become an independent adult with PKU.

Adolescence (13-18 years)

- ▶ PKU formula awareness:
 - ▶ Prepares and takes formula without reminders
- ▶ PKU food knowledge:
 - ▶ Responsible for managing daily phe or protein intake
 - ▶ Cooks/prepares simple low protein recipes
 - ▶ Can count phe or protein accurately and keeps food records
 - ▶ Knows how to order low protein food and where it comes from
- ▶ Independent PKU management skills:
 - ▶ Takes blood samples independently
 - ▶ Understands PKU and treatment. Females are aware of maternal PKU risks with high blood phe levels.
 - ▶ Starts to seek support with PKU care and is responsible for communication with dietitian for lab results, formula needs, or nutrition questions
 - ▶ Knows how to order formula
 - ▶ Thinks about how to maintain PKU care when no longer living with parents



Adult

- ▶ Basic Adult Medical Management:
 - ▶ Considers additional medical needs such as obtaining a primary care physician, dentist, or gynecologist for women
 - ▶ Takes charge of overall health
- ▶ PKU food knowledge:
 - ▶ Feels confident eating out or preparing meals for work or school
- ▶ PKU management skills
 - ▶ Identifies the consequences of high blood phe levels
 - ▶ Aware of all PKU treatment options including diet and medication options
 - ▶ Females are aware of necessary treatments to prevent Maternal PKU Syndrome with pregnancy
 - ▶ Continues to stay connected with PKU clinic for at least yearly visits



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