

PKU ages >18years

Clinic Visits:

- Yearly

Phe levels:

- Monthly
- Recommended treatment ranges:
 - >12 years 6-10 mg/dL (120-360 umol/L)
 - Females planning pregnancy
 - Phe levels 2-6 mg/dL 3 months prior to conception and throughout pregnancy
 - levels at least weekly during pregnancy

Other Labs: Yearly

- Prealbumin/albumin
- Plasma ferritin, transferrin, or iron studies
- Quantitative tyrosine level or possible quantitative plasma amino acids
- Folate and Vitamin B12
- Possible nutrition labs: zinc, selenium, vitamin D, essential fatty acids, and lipid profile)
- Possible CBC, hemoglobin, and hematocrit

Other Evaluations:

- Neuropsychological evaluation at age 18 years old
- Consider psychiatric evaluation
- Spine DEXA at age 18 years old

Topics:

- Review of PKU, biochemistry, and genetics
- Diet/management
 - Phe restricted diet as per metabolic dietitian
 - Kuvan® (Sapropterin) if possible
- Females: continued education about Maternal PKU

Please make sure you schedule clinic visits and have levels done on time. Call the metabolic clinic at _____ to make an appointment, schedule a blood draw, or with any other questions.

Thank You,
Your Metabolic Team

