

Emergency Preparedness Supplies for PHENYLKETONURIA (PKU)

- Metabolic geneticist name and contact information _____
- Dietitian name and contact information _____
- Primary care provider or pediatrician name and contact information _____
- Local hospital/emergency room name and contact information _____
- Pharmacy name and contact information _____
- Formula manufacturer name and contact information _____
- Formula prescription _____
- Medication manufacturer name and contact information _____
- Medication prescription _____

- Emergency letter with diagnosis and treatment plan from genetics clinic
- 7-10 day supply of metabolic food/formula
- 7-10 day supply of low-protein food
- Food scale with extra batteries
- Calculator and preferred method for tracking daily phe intake
- Container for mixing metabolic food/formula
- Preferred container for consuming metabolic food/formula
- Purified or bottled water
- Low protein food list and/or list of phe content of foods in your emergency kit
- Supplements (tyrosine, vitamins, etc.)
- Daily medications (i.e. Kuvan)
- Medication/formula supplies: syringes, scoops, measuring spoons
- Supplies for doing home finger sticks and/or standing orders for blood draw at lab
- Solar-powered chargers
- Adapters for car chargers
- Hand-powered radio

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