

# THINGS TO DO

- Call the PKU Clinic if you have any questions or concerns about your child or your appointment. Make note of the place, clinic appointment times, transportation possibilities, etc.
- Read the PKU Clinic Management Guidelines see the “Clinic Information” section of this notebook.
- Provide insurance information to the PKU Clinic (Contact Vicki Frasher, Program Coordinator, at 206-685-3015 and Sheila Neier, Newborn Screening Coordinator, at 206-361-2840.)
- Keep a record of formula given to your infant and what your infant actually takes. For instructions on how to do this and for tracking sheets, see the “Food & Formula” section of this notebook.
- Subscribe to the National PKU Newsletter. For information and an order form, see the “Clinic Information” section of this notebook.
- Order the Low Protein Food List for PKU. For information and an order form, see the “Clinic Information” section of this notebook.
- Read information provided on PKU (the “Clinic Information” section of this notebook).

## IMPORTANT THINGS TO REMEMBER

- ✓ When there is a change in address or insurance contact Vicki Frasher at (206) 685-3015 and Newborn Screening at (206) 361-2840. Cascade Billing 1-800-682-2037 should also be contacted with any insurance changes.
- ✓ If you would like to speak with other families who have children with PKU notify the clinic and they will give you the names and numbers of parents who have volunteered to share information with others.
- ✓ If you are unable to attend the clinic, call Vicki Frasher (206) 685-3015 to cancel your appointment. You may be asked to send blood samples to Children’s Hospital and Regional Medical Center so your child’s blood phenylalanine level can be measured. (For information on how to do this and where to send it see the “Records” section.)
- ✓ Make sure your infant is immunized. (See the immunization schedule in the “Records” section of your notebook.)



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