

Emergency Preparedness Supplies for TYROSINEMIA TYPE 1/ HEREDITARY TYROSINEMIA TYPE 1 (TT1/HT1)

- 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 _____

- | | |
|--|---|
| <ul style="list-style-type: none"><input type="checkbox"/> Emergency letter with diagnosis and treatment plan from genetics clinic<input type="checkbox"/> 7-10 day supply of metabolic food/formula<input type="checkbox"/> 7-10 day supply of low-protein food<input type="checkbox"/> Food scale with extra batteries<input type="checkbox"/> Set of household measuring cups and spoons<input type="checkbox"/> Calculator and preferred method for | <ul style="list-style-type: none">tracking phe or protein intake<input type="checkbox"/> Container for mixing metabolic food/formula<input type="checkbox"/> Preferred container for consuming metabolic food/formula<input type="checkbox"/> Purified or bottled water<input type="checkbox"/> Low protein food list and/or list of protein content of foods in your emergency kit |
|--|---|

- Supplements (prescribed vitamins, etc.)
- Daily medications (nitisinone)-syringes
- Standing orders for blood draw at lab
- Urine ketone testing strips
- Written emergency information form (see “Other Resources”, this document)
- Solar-powered chargers
- Adapters for car chargers
- Hand-powered radio

***A journal article about the nursing care of children with Tyrosinemia Type 1 is useful when accessing emergency care. You can access it for free at: pediatricnursing.net/ce/2016/article40026190.pdf*

→ THIS LIST WAS LAST UPDATED ON: