

# 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 \_\_\_\_\_

- 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
- Set of household measuring cups and spoons
- Calculator and preferred method for tracking phe or protein 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 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](http://pediatricnursing.net/ce/2016/article40026190.pdf)*

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