



# **EMERGENCY** **Preparedness** **TOOLKIT**

**for Genetic-Based Inherited Metabolic Disorders**



**PRESENTED BY**

Southeast Regional Genetics Network (SERN)

Consumer Alliance Emergency Preparedness Workgroup

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# INTRODUCTION

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Included in this document are disorder-specific lists of supplies needed in case of emergency, as well as a general list of basic emergency preparedness supplies.

The information and recommendations provided in this document are not intended to be a substitute for consulting with your medical professional. This information is only intended to provide suggested practical supports to help you and your family as you prepare in advance for possible emergencies.

**CARE PROVIDERS:** Simply print the page(s) of this document that apply to your patient and provide at his or her next clinic appointment or at your earliest convenience.

This document is brought to you by the Southeast Regional Genetics Network (SERN) Consumer Alliance Emergency Preparedness Workgroup.

We welcome any input or suggestions to keeping this toolkit up to date and accurate. Please feel free to contact us at: [southeastgenetics.org/contact.php](https://southeastgenetics.org/contact.php)

# PLANNING FOR EMERGENCIES

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Planning for emergencies is important for any family, especially so when a loved one with a disability, chronic medical condition, or complex care need is involved. There are many resources available from the federal government, state and local agencies, and non-profit and health-related organizations to help you plan and prepare for emergencies.

Every family is unique and planning is based on a variety of factors – where they live, the climate, availability of local resources, local provisions for emergency, safety oversight and shelters, as well as specific health care needs. However, all families have similar baseline planning needs. The

first section of this document covers those basic action plans.

The remaining sections of this document are devoted to specific planning ideas and supply lists based on a particular medical condition. The information provided is to help those families with low incidence complex care needs within the realm of specific, genetic-based metabolic or blood-related disorders. If you do not find the specific condition you or your loved one may have, please see the final page of this first section for other resources that may be of service.

Preparing today increases how well your family will handle an emergency.

## START UP: Develop a Plan

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Planning together is important so everyone in the family is aware of all that must be done in the event of a natural disaster, fire, or other unplanned emergencies. Even children need to be a part of the planning discussions so they will know what to do during

different situations that might occur.

As children grow in ability and understanding of this type of planning and preparation, they will be better equipped for their personal emergency planning in the future.

# PLANNING STEPS

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- ➔ Consider a typical day and week in the life of your family, and **what is required for your basic life and care needs**. Make a list of those specific, personal needs – from food, water, clothing, medicine, and equipment (see a suggested basic list under “NEXT STEP” within this section)
- ➔ **Create a family communication plan** – how you will contact each other during an emergency? Also, which specific person(s) outside the family and away from your area will you set as your family point-of-contact? Having an out-of-town contact is recommended as they may live away from the impacted area. Many times phone lines are down, and even cell phones may not work for making calls. However, you may find that text messages or emails can still be sent and received.
- ➔ **Determine a family “meet-up” plan** – where you will all go to gather in case you are in different parts of the house or immediate vicinity when a disaster occurs? If everyone is at home, determine a place outside the home and far enough away for safety purposes – the front sidewalk, the back corner of your yard, etc. If various members are not at home, select a relative’s or neighbor’s home to meet up.
- ➔ Depending on the emergency situation and your personal circumstance, **discuss how you will make the decision of whether your family should stay at your home or should evacuate**. Make a plan for how you will monitor television, radio or social media coverage for news and official instructions, especially during a power outage.
- ➔ **Recommendations of where to go and what to do differ for natural events** such as tornado or hurricanes, versus extreme cold weather, or extended power outages. Consider each possibility that might occur in your particular locale.
- ➔ If the emergency is such that it is better for you to stay home, **decide where you will gather within the house, and possibly store your pre-packed emergency items to this space**. For example, in the event of a tornado, you will likely be safest in a basement or an interior room on

the lowest level away from corners, windows, doors, and outside walls. Figure out which space or room that is in your home.

- ➔ If special medical equipment is a part of the household, make sure those who will likely be with you know how to use the device(s) to support your loved one.
- ➔ Other options during a disaster or emergency include **sheltering in place away from home, mass local shelters, or special need/medical shelters** if one is approved and requires this type of medical oversight during an emergency. Check with your local Emergency Management Office or Agency to see if your state has a registry.
- ➔ Prepare in advance for the **possibility of sheltering in place away from home**. Learn about your workplace emergency plans and let appropriate personnel know if you might need special assistance. Check with your child's school or daycare about emergency plans and related information, and ensure they know the specific needs of your child in case of such emergencies.
- ➔ If there is a need to evacuate to a

mass shelter in your community, **search for open shelters** by texting "SHELTER" and your zip code to 43362 (4FEMA). Example: Shelter 01234

- ➔ **Don't forget to plan for your pets and service animals!** Place stickers on your entry doors alerting emergency personnel there are pets in the home. Add the basic needs of your pet to your emergency packing list. Remember to take your pet with you to the safe area in your home or to wherever you may need to evacuate. Make sure you have your pet micro-chipped and that they have an I.D. collar.
- ➔ Once you have discussed and determined the specific plans and list of needs for your family, **create a written document**. Make sure each member of your family has a copy of the plan and that it is easily accessible in other forms. Also store a copy in your emergency kit. Share your plan and contact information with appropriate people – relatives, neighbors, friends, and/or co-workers – so they know how to contact you and provide support.
- ➔ Finally – Review/practice your plan with your family on an annual basis.

# NEXT STEP: Build an Emergency Supplies Container and Medical Kit

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Once you have the list of basic items for your family's needs, the next step is to gather all the items in one place. Clear plastic bins with lids are good containers that can be easily labeled as to the contents in each.

If possible, once the container(s) is filled, store it in the area of your home where you will gather in times of emergencies. If it is not practical to store the container in your designated emergency area, try to store it in a safe, cool dry place where it can quickly and easily be retrieved.

Also, depending on the specific needs of your family, you may want to consider making duplicate emergency supply containers to store away from

your home. Some may need to keep a kit at their workplace or their child's school. Others may feel it is important to keep a duplicate container at a distant relative or friend's home or in a separate storage facility. This may be especially important in flood prone or earthquake prone areas where one may not be able to access their stored items, or in case of a home fire that may destroy emergency items.

Finally, if you anticipate a time or need for a quick evacuation, you may want to consider creating a smaller, duplicate set of "grab-and-go" bags/containers that you either store in your vehicle or at an easily accessible site close to a home exit area.

# Basic Emergency Preparedness Supply List

- ➔ 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
- Bottled water (one gallon a day per person for drinking and sanitation)
- Gatorade and/or Pedialyte
- Non-perishable foods, can opener, and infant formula (a three-day supply – be sure to plan for each member's likes/dislikes)
- Mess kits, or plastic utensil and paper goods for eating and drinking
- Cooler and ice packs
- Flashlights
- Radio
- Batteries
- First-aid kit and first-aid booklet
- Toiletry items: Soap and/or liquid sanitizer; wet wipes; toothbrushes and paste; powdered hair cleaner; hairbrush; feminine protection items, deodorant, etc.
- Diapers – as needed for infants or others with incontinence concerns
- Paper towels, toilet paper, wet wipes
- Ziploc bags and garbage bags to dispose of personal sanitation items



- Small comfort and entertainment items for each of your children (let them be a part of deciding what they might like in the container, and perhaps add an extra surprise item or two).
- Extras of personal medications and medical equipment supplies (see specific recommendations in the remaining sections of this document)
- Emergency health information in a waterproof container: Copies of medical insurance card and/or Medicaid/Medicare cards; contact information of doctors; a health history for each member of the family that includes necessary and pertinent health history/information (allergies, medications, copies of current prescriptions, etc.)
- Copies of other important family documents in a waterproof container: Insurance policies; identification papers; social security cards; driver's license; bank account records; deed of your home/properties
- Extra credit card, cash, traveler's checks, and/or change
- Paper and pen/pencil
- Dust masks and old cotton t-shirt (helps filter air if needed)
- Plastic sheeting and duct tape (to create further barriers, if needed)
- Fire extinguisher
- A whistle (to signal for help)
- One extra change of clothing for each family member (appropriate clothing should be considered based on the climate in your area, and the possibility of power outage)
- Jacket/coat and hat/gloves for each family member, if needed for your area
- Rain poncho for each member
- Sturdy pair of shoes for each member
- Warm blanket or sleeping bag for each member
- Pet meal and water bowls
- Water and pet food for three days
- Pet medications
- Leash
- Pet chews and toys
- Pet bedding/blanket
- Necessary items for pet elimination and cleanliness, as well as items for clearing/disposing

## SPECIAL CONSIDERATIONS

Along with the specific information provided in each section of this document, you may want to consider the following:

- ➔ **MEDICATIONS:** Those with private insurance or who are Medicaid/Medicare will want to check with their providers on what to do to ensure you have enough medication in case of a disaster or emergency.

If time does not allow for you to get to your regular pharmacy in the event of an emergency, you will want to discuss how and where you can secure necessary medication with your provider.

➔ **MEDICAL DEVICES:** Plan accordingly with your insurance and Durable Medical Equipment supplier as to how to gain extra supplies for emergency preparation kits. Be certain to have contact information and knowledge as to where to go

and what to do to get more supplies during emergency situations.

➔ **COMMUNICATION:** If a loved one has a disability that impacts their ability to communicate, you may want to have extra communication tools stored in your emergency supplies. Temple University's Institute on Disabilities also has a free, downloadable emergency communication tool, found at: [disabilities.temple.edu/programs/eprep/](https://disabilities.temple.edu/programs/eprep/)

# ONGOING: Review/Renew and Keep Up-To-Date

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## REVIEW/RENEW

It is recommended you check the status of your emergency supply containers every six months. Put a reminder on your calendar to perform a quick “check and re-stock” on May 1st (just prior to start of hurricane season, and other types of common summer storms) and December 1st (before the height of winter weather for many parts of the country).

Consider changing out items that are near or have passed their expiration dates. If items have become damp or mildewed, change them out for new items and store them in more individualized, waterproof containers, if possible (i.e. paper goods, or each set of clothing in separate Ziploc bags that are then stored in lidded plastic containers). Also remember to change out items that are too small or no longer necessary for your various family members. If you have added a member to your immediate family, be sure to add all necessary items for that newest member.

Make sure flashlights, the radio, and any other stored equipment are still operable. Exchange the extra batteries for new ones. Paperwork, insurance cards, and other related items may need to be updated and changed out.

If the health status and needs of a loved one has changed, be sure to make the necessary additions or exchanges to their specific medical supplies, equipment and paperwork.

Finally, use this six month review/renew time to double-check the status of your home’s emergency equipment such as smoke alarms, fire extinguishers, and any alert systems installed at your home. It can also be the reminder to update your overall family emergency plan and review/practice the plans with the family.

## KEEP UP-TO-DATE

State and local emergency management agencies use various emergency alert systems to inform the public of pending disasters. You may want to set up your mobile device or other

technologies available to you and your family members to receive such alerts. You can do so through your local television or radio stations, the National Weather Service’s wireless emergency alerts, or other state entities managed by the Federal Communications Commission (FCC).

You might also go to the Integrated Public Alert and Warning System Authorities website to learn what emergency alert services are available in your area.

Stay updated with work and school emergency policies and procedures, especially if you have a change of work or educational sites. In the event you move to a new locale, be sure to update all supplies, plans and paperwork accordingly.

## OTHER RESOURCES

We encourage you to “read more about it!” Websites are always being updated, and local situations are ever changing. Also, your family circumstance may require more knowledge about emergency preparedness than offered here, especially as changes occur within your family. For further helpful information and support, please check out the following resources.

To learn more about general emergency preparedness, go to:

- Federal Emergency Management Agency (FEMA): [fema.gov/faq-details/Preparing-for-a-disaster-1370032124282](https://www.fema.gov/faq-details/Preparing-for-a-disaster-1370032124282)
- FEMA’s Preparedness-Specific Resource Site: [Ready.gov](https://www.ready.gov)
- The American Red Cross – Be “Red Cross Ready”: [redcross.org/get-help](https://www.redcross.org/get-help)
- Centers for Disease Control: [emergency.cdc.gov](https://www.emergency.cdc.gov)
- Centers for Disease Control: [cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html](https://www.cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html)

To learn more about emergency planning and procedures in case of evacuation, go to:

- Ready.gov: [ready.gov/evacuating-yourself-and-your-family](https://www.ready.gov/evacuating-yourself-and-your-family)
- The National Association of Realtors “HouseLogic”: [houselogic.com/finances-taxes/home-insurance/home-evacuation-checklist/](https://www.houselogic.com/finances-taxes/home-insurance/home-evacuation-checklist/)
- Centers for Disease Control: [cdc.gov/childrenindisasters/checklists/index.html](https://www.cdc.gov/childrenindisasters/checklists/index.html)

If you don't find the specific medical condition you or your loved one may have within this document, you may find further help specific to your needs at:

- The American Red Cross's guide on "Preparing for Disaster for People with Disabilities: [redcross.org/prepare/location/home-family/disabilities](https://www.redcross.org/prepare/location/home-family/disabilities)
- The National Fire Protection Association: [nfpa.org/public-education/by-topic/people-at-risk/people-with-disabilities](https://www.nfpa.org/public-education/by-topic/people-at-risk/people-with-disabilities)
- Easter Seals' "Safety First" initiative: [easterseals.com/explore-resources/making-life-accessible/safety-first.html](https://www.easterseals.com/explore-resources/making-life-accessible/safety-first.html)
- Temple University's Institute on Disabilities: [disabilities.temple.edu/programs/eprep/](https://disabilities.temple.edu/programs/eprep/)
- A couple of organizations provide a large selection of links on preparation and readiness that are disability-related or condition-specific, such as: Deaf/Hard of Hearing; Visual impairments; Mobility disability; Psychiatric disability; Speech/Language/Communication disabilities; Alzheimer's disease; and other chronic health conditions

- [cdc.gov/disasters/chronic.html](https://www.cdc.gov/disasters/chronic.html)
- [sis.nlm.nih.gov/outreach/specialpopulationsanddisasters.html](https://sis.nlm.nih.gov/outreach/specialpopulationsanddisasters.html)

- The Association of University Centers on Disability also provide a large selection of resources at their website regarding a variety of different disability and medical conditions: [aucd.org/template/page.cfm?id=544](https://aucd.org/template/page.cfm?id=544)

For further help in regards to pets and service animals:

- American Society for the Prevention of the Cruelty of Animals: [aspca.org/pet-care/general-pet-care/disaster-preparedness](https://www.aspca.org/pet-care/general-pet-care/disaster-preparedness)
- FEMA: [fema.gov/helping-pets](https://www.fema.gov/helping-pets)
- Ready.gov has several toolkits, including the "Community Pet Preparedness Toolkit": [ready.gov/toolkits](https://www.ready.gov/toolkits)
- The American Red Cross: [redcross.org/prepare/location/home-family/pets](https://www.redcross.org/prepare/location/home-family/pets)

# 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

→ THIS LIST WAS LAST UPDATED ON:

# Emergency Preparedness Supplies for **GLUTARIC ACIDEMIA/ACIDURIA** Type 1 (GA-1)

- ➔ 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 \_\_\_\_\_

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|--|--|
| <ul style="list-style-type: none"><li><input type="checkbox"/> Emergency letter with diagnosis and treatment plan from genetics clinic</li><li><input type="checkbox"/> 7-10 day supply of metabolic food/formula</li><li><input type="checkbox"/> 7-10 day supply of low-protein food</li><li><input type="checkbox"/> Food scale with extra batteries</li><li><input type="checkbox"/> Set of household measuring cups and spoons</li><li><input type="checkbox"/> Calculator and preferred method for tracking daily lysine levels</li><li><input type="checkbox"/> Preferred container for consuming</li></ul> | <ul style="list-style-type: none"><li>metabolic food/formula</li><li><input type="checkbox"/> Purified or bottled water (plenty to prevent dehydration)</li><li><input type="checkbox"/> Low protein food list and/or list of Lysine and Protein content of foods in your emergency kit</li><li><input type="checkbox"/> Supplements (i.e. L-carnitine, Arginine, vitamins, etc.)</li><li><input type="checkbox"/> Daily medications with dosage cups and syringes</li><li><input type="checkbox"/> Thermometer and fever reducers</li></ul> |
|--|--|

(i.e. ibuprofen, acetaminophen)

- Glucose tablets, glucose meter, lancets, test strips, alcohol wipes
- Feeding tube supplies and pump
- Standing orders for blood draw at lab
- Well Day and Sick Day at Home Management Protocol
- Emergency Protocol Letter
- Medical notebook/records
- Solar-powered chargers
- Adapters for car chargers
- Hand-powered radio

→ THIS LIST WAS LAST UPDATED ON:



# Emergency Preparedness Supplies for ORNITHINE TRANSCARBAMYLASE DEFICIENCY (OTC)

- 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, high carbohydrate food and drink
- 7-10 day supply of all medications
- Food scale with extra batteries
- Preferred container for consuming metabolic food/formula
- Cooler with instant cold packs to refrigerate metabolic formula
- Purified or bottled water (plenty to prevent dehydration, mix with metabolic formula, or wash supplies/materials)
- Standard orders for blood draw at lab
- Oral syringe and supplies (barrel, plunger, adapter caps, syringe caps)
- G-tube supplies for management, cleaning, and preparation (syringes, liquid foods, measuring cups, clean

food containers, pole/wall hooks to hang food containers during feedings, soap for hand washing, water for washing and tube flushing, dishwashing liquid to wash the container, cotton swabs to clean around the stoma site, washcloths, gauze, antibiotic ointment)

- Solar-powered chargers
- Adapters for car chargers
- Hand-powered radio

→ THIS LIST WAS LAST UPDATED ON:

# Emergency Preparedness Supplies for **MEDIUM-CHAIN ACYL-CoA DEHYDROGENASE DEFICIENCY (MCADD)**

- 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 \_\_\_\_\_

- |  |  |
|--|--|
| <input type="checkbox"/> Emergency letter with diagnosis and treatment plan from genetics clinic | <input type="checkbox"/> Argo cornstarch                                   |
| <input type="checkbox"/> Carnitine   | <input type="checkbox"/> Container for mixing with water, syringes or cups |
| <input type="checkbox"/> High carbohydrate food  | <input type="checkbox"/> Solar-powered chargers                            |
| <input type="checkbox"/> Drinks containing sugar (Gatorade, Koolaid, etc.)                       | <input type="checkbox"/> Adapters for car chargers                         |
|  | <input type="checkbox"/> Hand-powered radio                                |

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# 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)*

→ THIS LIST WAS LAST UPDATED ON:

# Emergency Preparedness Supplies for LONG-CHAIN HYDROXYACYL- CoA DEHYDROGENASE DEFICIENCY (LCHADD)

- 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 non-perishable low fat food (i.e. pretzels, crackers, dried fruit, fruit strips, applesauce, tuna packets, cans of beans, low-fat muesli, PB2)
- 7-10 day supply of all medications (i.e including Zophran if administered)
- 1 Bottle MCT oil or MCT Pro-Cal (tsp to measure)
- 1 Container Corn Starch
- 1 Container Powdered Gatorade
- 4 packets Gatorade chews
- 4 32 ounce containers coconut water

- Food scale with extra batteries
- Battery-operated heater or air conditioner depending on weather conditions
- Preferred container for consuming metabolic food/formula
- Cooler with instant cold packs to refrigerate metabolic formula
- Purified or bottled water (plenty to prevent dehydration, mix with metabolic formula, or wash supplies/materials)
- Standard orders for blood draw at lab
- G-tube supplies for management, cleaning, and preparation (syringes,

liquid foods, measuring cups, clean food containers, pole/wall hooks to hang food containers during feedings, soap for hand washing, water for washing and tube flushing, dishwashing liquid to wash the container, cotton swabs to clean around the stoma site, washcloths, gauze, antibiotic ointment)

- First Aide Kit
- Flashlight
- Solar-powered chargers
- Adapters for car chargers
- Hand-powered radio

→ THIS LIST WAS LAST UPDATED ON:

# Emergency Preparedness Supplies for PROPIONIC ACIDEMIA (PPA)

- 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 “sick” formula items (extra Prophree or SolCarb)
- 7-10 day supply of non-perishable low-protein foods (low-pro tortilla chips, pretzels, crackers)
- 7-10 day supply of all medications
- Nausea medications
- Shelf-stable high carbohydrate foods and drinks
- Food scale with extra batteries
- Preferred container for consuming metabolic food/formula
- Cooler with instant cold packs to refrigerate metabolic formula
- Purified or bottled water (plenty to prevent dehydration, mix with metabolic formula, or wash supplies/materials)
- Standard orders for blood draw at lab
- Oral syringe and supplies (barrel, plunger, adapter caps, syringe caps)
- G-tube supplies for management,

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cleaning, and preparation (syringes, liquid foods, measuring cups, clean food containers, pole/wall hooks to hang food containers during feedings, soap for hand washing, water for washing and tube flushing, dishwashing liquid to wash the container, cotton swabs to clean around the stoma site, washcloths, gauze, antibiotic ointment)

- Back-up g-tube
- Battery-operated heater or air conditioner depending on weather conditions
- Solar-powered chargers
- Adapters for car chargers
- Hand-powered radio
- Flash light
- First Aide kit

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