

SCENARIO PREPAREDNESS

KEY CONSIDERATIONS

- » EMERGENCY SERVICES1
- » EMERGENCY NUMBERS1 »
- GENERAL SUPPLIES2 »
- COOLERS FOR TRAVELING AND SHORT-TERM POWER OUTAGES2
- » PORTABLE REFRIGERATORS FOR TRAVELING AND POWER OUTAGES3
- » GENERATORS3 »
- REMOTE THERMOMETER MONITORING4
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EMERGENCY SERVICES

- Call local pharmacy, hospital, or fire station to ask if they have space to refrigerate medications during power outages.
- Be prepared for adverse weather events by looking at FEMA, National Weather Service, and NOAA websites. Sign up for weather alerts to prepare for power outages and flooding.
- Sign up for power outage alerts to receive updates when you are not home. It is especially helpful when traveling to have a plan of action with a neighbor to properly store medication during an outage.
- Inquire with your local utility company about whether a power restoration priority list is available for people with medical needs. Services may vary with each company.

EMERGENCY NUMBERS

- Alexion's OneSource Patient Support Program provides personalized help with health insurance navigation, disease information, ongoing support, and community connections. Phone: 1.888.765.4747. Email: OneSource@alexion.com.
- Call PANTHERx Rare Pharmacy support hotline, 855.726.8479 or 412.246.9858, to request medication be sent in advance of a storm to avoid medication delays. Call PANTHERx Rare if medication gets wet, if medication is left in direct sunlight or if medicine was left out in the 34-36° F range.
- Keep your doctor's number handy to discuss the implications of missing a dose.
- NORD's Hurricane and Natural Disaster Emergency Relief Fund provides financial assistance to those who are diagnosed with a rare disease and are impacted by natural disasters. Covered expenses may include physician-prescribed medical devices and/or emergency repairs on medical devices. Phone: 877.291.8082. Email: hurricane@rarediseases.org.

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GENERAL SUPPLIES

1. Medication (STRENSIQ), syringes, and alcohol wipes.
2. Refrigeration, frozen solid ice packs with cooler, and dry bags.
3. Remote thermometer.

Have a list of all medications the patient takes, including the dosages and frequency.

COOLERS FOR TRAVELING AND SHORT-TERM POWER OUTAGES

- Consider family or friends in contingency planning for storage of additional ice packs and other supplies.
- For brief transportation, use insulated travel cases.

According to PANTHERx Rare, the VIP or Vacuum Insulated Panel Cooler your STRENSIQ® medication is shipped in is designed to keep the medication cold under optimal conditions. Since conditions may vary, it is crucial to continuously monitor the temperature with a remote thermometer. Buying additional ice packs can be useful to give to friends and family to store for you. In cold weather power outages, the ice packs can be frozen outside. Keep cooler out of sunlight and heated areas. Medicine should be monitored using a remote thermometer to make sure outdoor temperature and cooler temperature are stable.

The time a refrigerator will stay cold when power is lost depends on the brand and model and the condition of the door seals. Time can vary from 2–6 hours without opening the doors. After the power goes out, think of your refrigerator as a large picnic cooler.

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PORTABLE REFRIGERATORS FOR TRAVELING AND POWER OUTAGES

Using a portable refrigerator is useful for transporting medication. You can run a portable fridge from your car battery for about 18 hours – varying based on car battery, fridge model and length of time car is run. For a 1- or 2-day trip while running your fridge, run your engine for at least 30-60 minutes each day to replace the charge you have used. *Run car in open outside area to avoid carbon monoxide poisoning*

Consider a deep cycle battery, inverter-generator and camping power banks to charge a portable fridge without draining the car's battery. A car solar charger provides an additional source to charge a portable fridge.

Additional tips: Keep cooler or portable fridge properly shut to ensure cooler temperatures remain in the proper range. This also helps to keep the power source from draining because the fridge will use less power to maintain a consistent temperature. Compressor portable fridges are more reliable than thermoelectric because compressors have AC while thermoelectric only pushes heat out.

GENERATORS

Home generators (full or partial) are two options for keeping medication at the proper temperature during power outages.

Standby generators can be connected to the home and provide immediate power once the critical circuits experience a power outage. Portable generators, or backup generators, provide temporary energy through plugging devices directly into the machine and some have a twist-lock plug that can provide up to 240 volts and be used to power circuits in a home via a manual transfer switch. There are laws that vary from town to town on the use of generators depending on their size and type.

"A generator purchased for medical needs is tax deductible as a medical expense, provided you have a letter from your doctor to submit along with your tax return."

The cost of a portable back-up generator may be subsidized under NORD's HPP Emergency Relief Program. To find out if you are eligible reach out to the HPP ERF Program at 866.828.8902.

All generators should be kept outside or out of enclosed spaces to avoid carbon monoxide poisoning

A refrigerator battery backup is like a generator, but it is smaller and would only power the refrigerator. Solar panels are an option for homeowners if the roof of the house is not blocked by trees or tall buildings.

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GENERATORS (cont'd)

FEMA provides generator reimbursement for a generator purchased during an adverse weather event by the applicant to power medically required equipment after a utility outage. The application process must be accepted to receive reimbursement, which may vary per location and storm. A search of the storm declaration list can lead you to local and/or government assistance based on storm severity.

The Red Cross and Salvation Army may provide generators on loan. Purchase and reimbursement options may be available at some local chapters depending on funding, or these organizations can direct you to other local services. Call your state's Red Cross or Salvation Army for more information.

REMOTE THERMOMETER MONITORING

Remote thermometers that use Wi-Fi or Bluetooth are an excellent way to monitor that medication is kept in the acceptable temperature range whether storing in a fridge, cooler, or using a backup power source. Some remote thermometers that have an app to monitor temperature include *MedAngel* and *Brifit*. A Bluetooth option for close range monitoring includes *Govee*. Two remote thermometer options that also include a humidity sensor to make sure the medication is in a dry environment include *Ubibot* and *Proteus*. Since keeping cell phones charged can be problematic, when power is lost, it is a good idea to have a traditional thermometer on hand as well.

FLOOD SUPPLIES

Having a sealable container or dry bag (airtight) is useful for flooding, general storage, or travel to keep medication dry. Three dry bag options that vary in size and bag style are made by Earth Pak, OtterBox and the SealLine Bulkhead Tapered Dry Bag. Storage containers such as double zipper Ziploc bags and Ziploc Twist 'n Loc, Rubbermaid Brilliance Pantry Organization & Food Storage Containers with Airtight Lids, Click Clack Cubes, and Pyrex Snapware Airtight & Leakproof Glass Food Keeper Set are useful for travel.

EVACUATION PREPAREDNESS

- Have a list of all medications, and their dosage frequency. Include the name and number of the doctor who prescribed them.
- Keep an emergency health information card with the patient during travel that has the patient's name and how to handle a medical emergency with a list of contacts.
- The OneSource Patient Assistance Support may be able to assist you with arranging alternate medication delivery options while traveling. Call in advance to coordinate travel delivery and/or plans for emergencies. 1.888.765.4747

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EVACUATION PREPAREDNESS (cont'd)

- Use a car refrigerator to keep medicine cool while traveling.
- Insulated travel cases are useful to keep medication protected and cold. If flying, keep STRENSIQ® in cabin, do not check with luggage.
- Monitor medication storage with Wi-Fi thermometer while traveling.

Call the local pharmacy, hospital, or fire station of the town you are evacuating to and ask if they can refrigerate medication. Or bring a generator to power a portable fridge used to store medication but research local laws on the use of generators in the locations you are evacuating to.

Action Plans

Have you considered what to do when...	Plan
It floods	
There is a power outage during warm weather for less than 24 hours	
There is a power outage during warm weather for a few days	
There is a power outage during warm weather for at least a week	
There is a power outage during cold weather for less than 24 hours	
There is a power outage during cold weather for a few days	

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Action Plans (cont'd)

Have you considered what to do when...

Plan

There is a power outage during cold weather for at least a week

There is a hurricane

There is a blizzard

Trees, snow, power lines, or debris block roads after storm

There is adverse weather in the location you are staying while traveling

The power goes out at your home while you are away for the day

The power goes out at your home while you are away for a few days

The power goes out at your home while you are away for at least a week

You are forced to evacuate your home

For more information, please contact the Soft Bones Foundation.

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(866) 827-9937 – Toll Free • www.SoftBones.org