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From The Desk Of *Roberta Kestenbaum*



We are happy to welcome back our nurse, Barbara Dombroff, RN, and announce the launch of our new program "[Health Conversations with Nurse Barbara](#)" - one-on-one discussions about your health and care. If you have questions about your or your family member's health, you can chat with Nurse Barbara about concerns or discuss potential options. Contact our office if you would like to plan a call.

To celebrate Spina Bifida Awareness month in October, we shared **Self-Care Tips** each day of the month. We also held our first online **Empowerment Auction**. Thanks to the generous donors and bidders, we raised over \$800. We would also like to give a special shout-out to Tom Kowal who raised over \$400 through fundraisers at **Rita's and Popcorn Nation** in honor of Spina Bifida Awareness.

Coming up in December, we will again be participating in the **Express Feedback for Good** campaign. This is a fun way to raise funds for SBRN but won't cost you a cent! All you have to do is give online feedback on products and services that you already use!

As the New Year approaches, we are thinking about and planning for **SBRN's 40 year anniversary**! Way back in 1982, we were founded as the Spina Bifida Coalition. To celebrate, throughout 2022, we will be commemorating this achievement through activities, opportunities and events. Stay tuned for details.

For those who celebrate, have a wonderful Thanksgiving!

OUR MISSION



*To provide educational resources,
social events and advocacy
programs that empower people
with disabilities and their allies
to challenge perceptions,
embrace interdependence and live
their best lives.*

OUR VISION

*A thriving community where
people with disabilities
have equitable access to
resources and opportunities
to optimize their wellness
and realize their
unlimited potential.*

URGENT! If Emergency Weather or Disaster Strikes, Are You PREPARED?

Recently it seems like we have been experiencing lots of different types of extreme weather and other disasters including hurricanes, tornadoes, massive flooding, fires, blizzards and earthquakes. Inclement weather and disasters are unpredictable and it can be difficult to make adequate plans in a short period of time when the stress level is already high. Everyone needs to be prepared for these situations, but it's even more important and complicated for those living with disabilities, chronic illnesses and mobility issues.



One size fits all emergency and evacuation plans don't necessarily work – everyone has different needs. Therefore, you will need to customize a plan for yourself and your family to ensure your safety and well-being when disaster strikes. Read on for tips and guidelines on how to prepare for emergencies in advance, while taking into consideration specific needs such as medications and mobility issues.

Start with a Plan

Inventory Your Personal Needs - The first thing you need to do is identify your needs. Consider both your day-to-day needs and your long term needs. Make lists! At minimum, include your medications and dosages, any special dietary needs, drug or other allergies, contact information for your doctors and all of your equipment with instructions. *Have both physical and digital copies of everything.* Also include phone numbers, websites and emails for where you can get up-to-date information about the current situation and who you can contact for assistance.

Establish an Emergency Personal Network – Choose *several* trusted people (family, friends, neighbors and co-workers) who would be able and willing to check in on you and assist you if needed. Share your plans, lists and contact information. Make sure you have their contact information on paper and digitally as well. Establish how you will get in touch with them and how they can check in on you. Keep in mind that phone lines may be down, so try to include someone who is near enough to come to your home. Provide your network with keys and security codes so that they can reach you. Go over with them how to use your devices and other special equipment and discuss transportation options with them.

Check Your Insurance – Have a list of your insurance plans, with all their contact information. Go over your plans in advance to see what is actually covered, including whether or how medical equipment is protected. Note that water or flood damage often isn't included in policies.

Create Emergency Kits

Put together emergency kits for your home, car and/or workplace that include relevant items for safety and well-being. Your home kit should include about a week's worth of supplies and it should be kept somewhere easily accessible – don't hide it away where you forget about it or it's difficult to get to! You should have basic needs (food, water) but also your own personal needs such as medications (see more below) and supplies such as catheters, sanitary needs, gloves, etc. Include extra chargers and batteries and label everything with your name and contact info in case you take it with you. It is essential that you periodically update your kits so that nothing has perished or expired.

Medication List

Your Name: _____ Pharmacy: _____
Date Updated: _____ Pharmacy #: _____

[illegible]

Organize Your Medications

If you take medications, planning in advance is critical. You should try to have three to four days worth at minimum; seven days or more would be better. (This can be difficult with prescriptions because many types of insurance do not allow you to get doses in advance. This may be worth speaking to your doctor about.) Medications should always be up-to-date and the current dosages. If you put medications in your emergency kit, periodically make sure that they have not expired.

You should also keep an up-to-date running list of your current medications (prescription and otc) including doses, frequency, doctor who prescribed and pharmacy. This list will be helpful to anyone who assists you in your home or if you have to evacuate.

Think Ahead About Mobility Issues

Keep Devices Nearby and Ready to Go – If bad weather is approaching, be sure to have your mobility devices nearby at all times, especially when sleeping. It should also be transport-ready, in case you need to leave quickly.

Label All Devices & Have Instructions – In advance, put labels on your equipment with your name, address and phone number. It's a good idea to keep simple instructions, as well as serial and model numbers, for all devices in waterproof cases, and have it ready to go with you if you have to leave. Show others, particularly those in your emergency network, how to use, disassemble and assemble your equipment.

Consider Alternatives – In some situations, it might help to have an alternative mobility aid. If you use a power wheelchair, it could be helpful to have a lightweight manual chair as well so that you don't have to worry about batteries, and it would be easier to transport. Also consider storing extra canes, braces or walkers if you use them. Store them in the car or by the door in case you need to leave quickly.

Plan for Backup Power Sources – Any devices that run on electricity will need backup power sources in case the power goes out. If you are able to purchase a generator for your home for emergency situations, that’s great, but they are expensive and can be difficult to use. You will need to create your own personal alternative source of power plan. You can start by reading equipment instructions and talking to equipment suppliers to see what they recommend. You may even want to talk to your power company to see if they have any suggestions.

For devices that rely on batteries, you should store extra batteries, and be sure to check on them periodically to see if they need recharging or replacing. It is helpful to know the working time of any of your batteries. You can also explore alternatives for recharging batteries when the electricity is out, such as connecting jumper cables to a vehicle battery or using a converter that plugs into the car's outlet (*but don't do this unless you know for sure that it is safe!!*)

When power has been restored, don't forget to check all of the settings on any devices since the settings sometimes revert to default mode or starter mode when the power goes out.

Tips for Specific Types of Disasters

Hurricanes & Heavy Rainstorms – Be sure to watch or listen to the weather reports because storms can rapidly change directions. Anticipate flooding and power outages and protect yourself and your equipment in your home. Keep equipment and supplies off of the ground or in waterproof containers if possible. Have a plan to move to higher ground if necessary. If evacuation is necessary, make sure you have your medications, devices and information ready to go. Prepare for alternate routes due to flooding.

Blizzards/Snow/Cold – Make sure you have what you need to keep warm if you lose power, including extra blankets, coats, hats and gloves. Be particularly attentive to areas of your body with paralysis or limited sensation since you might not be aware of the cold. In general, fingers, toes, ears, nose and cheeks are particularly prone to frostbite.

Earthquakes – When an earthquake occurs, the standard response is to “drop, cover and hold on.” This may not be possible if you are in a wheelchair, so instead lock your wheelchair and focus on protecting your head and neck, either with your arms or perhaps by holding something hard above you or against your neck. If you are in bed, use pillows and blankets to protect yourself from debris.

Tornadoes – If there is a tornado warning, get to a safe place immediately. If you are on a high floor, you may need assistance getting to a lower floor. Plan in advance how you will move if the power is out and you can’t rely on elevators or other devices. When you are in place, protect yourself by getting out of your wheelchair if you can and getting under a table or desk.

Don’t Forget Your Service Animal or Other Pets



If you have a service animal (or other pets!), be sure to include them in your emergency planning. Make a special kit for them and include food, bowls, leashes and waste collection supplies. You could also include favorite toys, blankets or treats to help reduce their stress. Copies of service animal certification, vaccination records and contact information for the veterinarian should be included as well. All animals should have proper identification with their contact information on them at all times. Microchipping is also beneficial in case your animal is separated from you or is lost.

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This information is presented for the purpose of education and is not meant as a substitute for medical advice or care from a physician or other healthcare providers. Contact your healthcare provider with questions about care.

OCTOBER was SPINA BIFIDA AWARENESS MONTH

Each day of October, SBRN posted Self-Care Tips on how to take care of yourself and live your best life.

#1 - Set some small easily achievable goals for yourself (like drinking a certain amount of water, going outside for 30 minutes, putting away your laundry) that once done, will help you feel accomplished.



#2 - Focus on getting enough sleep. Make your bedroom more comfortable and relaxing by removing clutter or getting new cozy bedding.

#3 - Practice mindfulness – spend some time focusing on the here and now, with no judgement.

#4 - Just as adults need mental health days or breaks, so do children. If your child appears stressed, take a break and find something fun and relaxing to do together like taking a walk, playing a game, doing a craft or cooking a special meal. Everyone will benefit from leisurely, carefree time together.

#5 - When you are faced with a new challenge, remember that as a person living with a disability, you already have problem-solving skills.

#6 - When you feel like you have no control, assess the situation. Break it down into smaller parts and determine what you can control (and then act on it) and what you can't (and then either let it go or seek assistance.)

#7 - Include different kinds of movement in your everyday life. Moderate or intensive exercise is great, but any kind of movement, including stretches, helps too. Moving can increase “feel-good” endorphins.

#8 - When you're feeling lost or overwhelmed with your life, it may help to develop some simple routines, which can make you feel like you're in control and provide comfort.



#9 - Help others in need. Helping someone else takes the focus off of yourself and benefits both of you. Lend an ear, fundraise, help make calls, donate funds or goods, advocate for someone or volunteer in some way.



#10 - Reach out to a counselor or therapist if you are struggling. If you can't go in person, online counseling is becoming much more prevalent now and it's easier to access.

#11 - Explore somewhere new. Plan something big like a trip to a new city, state or country. Or do something smaller: take a stroll or roll in a different neighborhood or park or try a new store or restaurant.

#12 - Find ways to make yourself laugh! Laughing relieves tension and can help you heal and feel better. Watch a funny movie or tv show, attend a comedy show (many are virtual) or get together with friends and share funny stories.

#13 - Going outside can change your mood entirely. Feel the sun on your face, or maybe the rain or snow if that's what you like. Breathe in the air and refresh yourself. Can't get outside? Open the curtains or open a window to let the light and air in.



#14 - Schedule pleasurable activities into your day or week. Write them down on your calendar or phone and set reminders.

#15 – Check your skin regularly for pressure sores or irritation. Use a mirror to help you see parts that are hard to see and where you have little or no feeling.

Spina Bifida Awareness Month *(continued)*

16 - Stretch out! Chair yoga and other gentle movement exercises can help you relax, increase your flexibility and improve spine health (but check with your doctor first.)

#17 - Focus on the positives. Use a notebook, computer or phone to write down any little or big thing that's positive in your life: something about you, your health, a friend, a family member, something funny that happened or a pleasant memory and then reflect on all this goodness and appreciate what you have.



#18 - Turn off, tune out. Shut down your screens an hour before bedtime, or at least stay away from what riles you up like social media or the news.

#19 - Embolden your future. Take an online class for career development and learn about new fields and skills such as writing, coding, business, technology, education, counseling and more.

#20 - Connect with others. Reach out to someone you haven't spoken to in a while. Join a virtual group like our Monday Afternoon Conversations or our Virtual Empowerment Speaker Series (VES). Join a virtual movie or book club. Even talking to someone at the grocery store can help you feel better, more connected.

#21 - Write down your achievements, big and small, every day. You'll be pleasantly surprised when you look back after a few weeks to see how much you really do.

#22 - Learn meditation and/or deep breathing to reduce stress and anxiety. Take the time to breathe slowly and deeply and empty your mind of negative thoughts.



#23 - Combine workouts with your social life. Find an online exercise class that fits your needs. It's more fun to exercise with others!

#24 - Decorate your home, your chair, yourself! Find something fun and sparkly or colorful or expressive to bring some brightness and cheer into your day.



#25 – For better bowel and bladder health, gradually increase your fiber intake. Naturally occurring sources of fiber include fruits and vegetables and whole grains.

#26 - Find your creative spark. It doesn't have to be great art – just have fun with it. Color in a book, doodle, learn to knit, sew or write. Create flower arrangements, make jewelry, write a poem or create with play-doh or Legos. The possibilities are endless.

#27 - Go green! Getting a nice houseplant or two can boost your mood, reduce stress and literally help clear the air. They may also help lower blood pressure and increase your productivity.



#28 - Clean up! Simplifying your space and de-cluttering can reduce stress and create a more calming environment. The act of cleaning is also good exercise and if you play music while you clean, it can further reduce your stress level.

#29 – Relish the cold autumn evenings and cuddle up with a cozy throw or blanket. Enjoy some tea, hot apple cider or hot chocolate and savor the warmth and the scents.

#30 – Do something out of the ordinary that makes you happy just for the fun of it. "Today you are you! That is truer than true! There is no one alive who is you-er than you!" – Dr. Seuss



#31 – Halloween Self-Care Tips: Eat a treat you love without feeling any guilt! Go for a stroll or a roll and take in the Fall colors and Halloween decorations! Host or attend a virtual Halloween game night or social event! Play some spooky or funny Halloween songs!



SBRN's Online Empowerment Auction

In October, we held our first online *Empowerment Auction*. We had over 25 items donated by generous diversified businesses. For several weeks, participants made their bids until the close of the auction determined the lucky winners!

Thank You to our Donors who made the event a success!

