

## Guidelines for the Care of People with Spina Bifida: What You Need to Know about Sleep Apnea

Sleep apnea in adults with spina bifida is a common but very serious condition. Sleep apnea occurs when a person stops breathing or has slow or shallow breathing during sleep and is often associated with excessive sleepiness or headaches during the day. Sometimes apnea can sound like snoring, gasping or choking.

Why does sleep apnea occur? Obesity and Chiari II malformations can cause sleep apnea. Being overweight can prevent normal breathing during sleep. Many people with the myelomeningocele type of spina bifida have a Chiari II malformation, which is an abnormality of the back part of the brain. This abnormality can cause problems in the way the brain controls breathing during sleep. Some people with spina bifida have scoliosis, or a curvature of their spine. Scoliosis can make sleep apnea worse because the lungs can't move normally.



What are the long-term effects of sleep apnea? If sleep apnea is not treated, it can cause problems with thinking, metabolism, the immune system, and the heart and circulatory system. This is not a health problem you should ignore or wait to treat.

What can you do about it? If you think that you may have sleep apnea, talk to your doctor. At the UPMC Adult Spina Bifida Clinic, we ask questions about sleep apnea. We may refer you to a sleep specialist who can do testing to determine whether you do have sleep apnea. If you are found to have sleep apnea, you will be offered a treatment to help your body breathe better at night. By understanding sleep apnea, identifying it, and getting early treatment, you may be able to sleep better and prevent long term risks associated with this condition.

*Written by Brad Dicianno, MD*



## Winter Hibernation

*We tend to want to hibernate in the winter, and we often think of it as an inactive or dormant state. But animals use hibernation to get needed rest and recharge their bodies. This issue will give you tips to “hibernate” your way through winter in a healthy way.*

## Tips on How to Cope and Manage Everyday Life with an Executive Functioning Disorder

Benjamin Franklin once said, “Tell me and I forget. Teach me and I remember. Involve me and I learn.” Individuals with Spina Bifida often experience the physical barriers of their disability and must learn to adapt to and manage varying degrees of learning disabilities.

Learning disabilities may arise early in education and may continue to affect an individual’s life, spanning social skills, interpersonal relationships, and acquiring and mastering the basic life skills that everyone needs to survive and thrive.

Typically an individual is diagnosed with a learning disability through a series of tests given by a professionally trained neuropsychologist, whose primary role is to first assess the individual and identify their strengths and weaknesses and give recommendations about coping and managing these specific learning challenges out in the real world.

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*...there are many supportive strategies that an individual with problems with executive function can use to help them complete tasks in a timely manner and engage in effective communication and relationships with others.*

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Individuals with Spina Bifida such as myself often have problems with executive function. The executive functioning capabilities of a person’s brain help them to manage time, pay attention, plan and organize, identify the main ideas or recall specific details in a story, and multitask. These problems are often due to hydrocephalus, which is increased pressure in the brain. Hydrocephalus is treated with the surgical placement of a shunt, but problems with executive function may persist even if a person has a shunt.

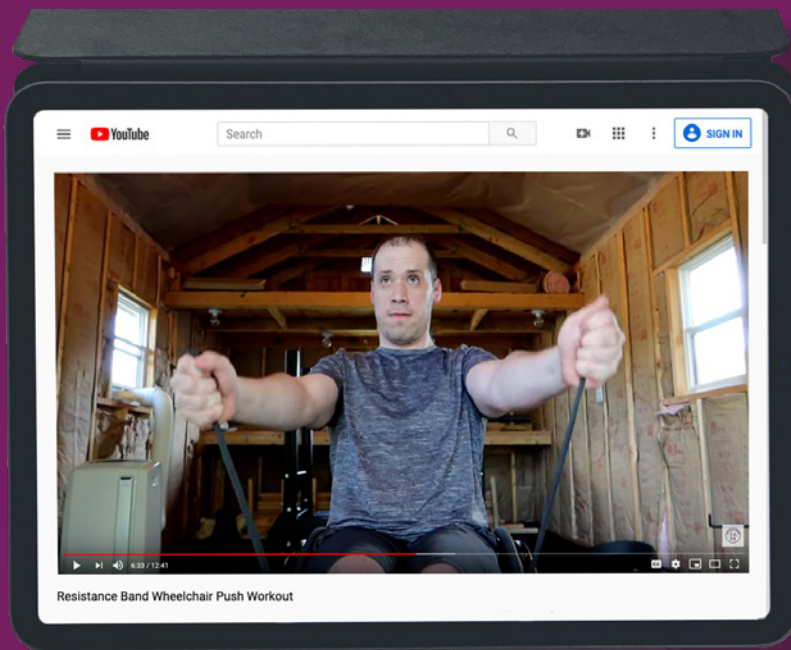
Nevertheless, there are many supportive strategies that an individual with problems with executive function can use to help them complete tasks in a timely manner and engage in effective communication and relationships



with others. Color coding information in large documents can help you organize ideas and understand the content. It might also be helpful to “chunk” large portions of written information, which means to break down the amount of information into much smaller parts to help reduce the amount of information you are reading and processing at one time. Another helpful strategy is to institute a “scaffolding” approach, which means having extra support and guidance when learning new, complex tasks and slowly withdrawing the support when you begin to master the task. I have also personally begun to use a daily planner and a dry erase board to help me visually map out my daily schedule and daily tasks. Lastly, I have also found it helpful to ask people for a simple list of directions, outlining the steps I will need to take in chronological order to efficiently be able to complete a task.

Never be afraid to ask for help, whether that means asking more clarifying questions if you don’t understand something, rereading the list of steps given to you as many times that you need, or using other external tools available to you for guidance and support. For example, using the internet or YouTube to help you learn more as you go. Everyone has something to give. All it takes is for someone to ask you to join, to have faith in you, and to give you a chance.

*Written by Libby Powers, MS*



## WHEELCHAIR WORKOUT



### The “Push” workout

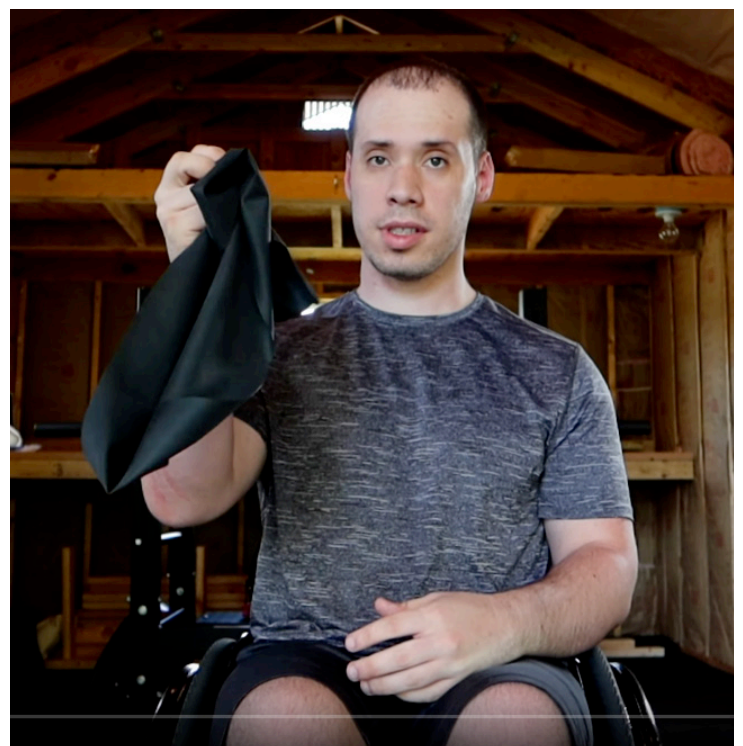
*This consists of strengthening your pushing muscles, which are your chest, shoulders, and triceps.*

## Push Your Way to a Stronger Body!

As individuals with Spina Bifida, having a strong, healthy body is extremely important for overall health both physically and mentally. For wheelchair users, our upper bodies are our way of mobility. For those of us who do not use wheelchairs, keeping a strong upper body is still just as important for mobility and overall health and wellness.

One of my favorite workouts to do for my upper body strength is a “Push” workout. This consists of strengthening your pushing muscles, which are your chest, shoulders, and triceps. When I am exercising these muscles, I always do at least two exercises per muscle group. Completing at least two exercises per muscle group has been shown to increase muscular strength and endurance in the targeted muscles more effectively than one exercise per muscle group.

Now let’s talk about sets, reps, and rest times. I usually like to go with 3 sets for each exercise (15 reps in the 1st set, 12 reps in the 2nd set, and 10 reps in the 3rd set). Rest periods should range anywhere from 30 seconds to 2 minutes, with 1 minute being my preferred rest period. As with any exercise, it is important to perform the exercise with correct form, which includes



proper technique and full range of motion.

[Click here](#) to watch a video breakdown of each exercise with proper technique. Stay tuned for the next Spina Bifida newsletter to find out my favorite “Pull” workout to strengthen your back and biceps! Follow me on social media [@danmccoyfitness](#) and let me know what videos you want to see next!

*Written by Dan McCoy, ACE-CPT*

# Slow Cooking Your Way to Health

Winter has returned!!

I just love the look of snow covering our Allegheny Mountains and beautiful evergreen trees. The glowing, twinkly lights that are exhibited in our friendly neighborhoods and the sweet smells of holiday baking that fills the air of our favorite grocery store and warm homes. Unfortunately, many of us with spina bifida have a love-hate relationship with the winter months. It is the most beautiful time of year to me, from the inside of my home! The freezing temperatures are not very forgiving to my aches and pains, and the cold winds accompanied by dry air do not add much reprieve to my already troubled skin.

Food is my personal source of “feeling-good” source, and my biggest issue during the winter holidays is loving foods that do not love me back. On a yearly basis, our physicians and dietitians have expressed the importance of a balanced diet for reasons that are not just limited to weight loss and management.

Skin breakdown is one of the biggest issues our spina bifida community faces and it is important to understand that nutrition has a big impact on a preventable problem. Protein is just one of the multiple suggestions that we encourage to prevent skin breakdown.

Sometimes, having a high protein diet can give us issues with elimination and can cause constipation. Protein in meats can become an issue if we are not drinking enough water and having a balanced amount of dietary fiber that includes fruits and vegetables.

Now when I used to think of fiber, I thought of bran cereal and whole wheat, but I have learned that there are many types of fibrous foods that are both delicious, beneficial, and are filled with healthy carbs. Oat milk is a new form of dairy free milk which is my new favorite

milk substitute. It has protein as well as fiber, and oats are naturally gluten free. However, if you do have a gluten allergy, be sure your brand states that it is gluten free. Although it does not contain gluten, it may have gluten contaminates due to its manufacturing. Oat milk can give your favorite cereal a nutritional boost or a nice addition to your favorite healthy smoothie. Fruits that are not latex reactive that contain fiber are raspberries, blackberries and blueberries, and can be found in your freezer section at your local grocery store during the winter. My favorite leafy and green vegetables that can be enjoyed cooked or

raw are also rich in fiber. Spinach, broccoli, peppers and swiss chard are delicious in a salad but can be digested more easily if steamed or cooked lightly. My ultimate favorite fiber rich-food is beans, especially in chili or my favorite Mexican dish.

The recipe I want to share with you addresses a few issues that I have run into as a woman with spina bifida. I often find myself not reaching my daily requirement for fiber and the right source of protein. This dish is rich in protein and fiber and loaded with the feel-good warmth that is heavily needed on a cold winter day. It is made with raw beans that must be soaked overnight for ultimate healthy digestion. This recipe also includes a Mexican seasoning recipe. Seasoning packets found in grocery stores are convenient, but may be too high in sodium. If you do not already have these seasonings, you will find that they are

beneficial beyond this single recipe. Having your own collection of unique spices is one of the biggest necessities to have complete control of your ingredients and it makes you feel like a real chef. As a great Marilyn Monroe film is titled, “Some like it Hot”, you can make this dish as hot or as mild as you like. You are in control! Spicy foods have been known to irritate some bladders so pay attention to your body and adjust the seasonings to your preference and personal needs.

Written by **Sara Izzo**



*“Winter is the time for comfort,  
good food and warmth”*

*Edith Sitwell*

# Slow Cooked Latin Chuck Steak and Pinto Beans

Makes: 2-3 servings | 10-15 minutes prep time; 10 hours cooking time

**1 lbs. Beef chuck steak**

**½ lbs. raw pinto beans**

*(half of a 1 lb. bag, save the rest in a ziploc)*

**1 diced green pepper** *(pre-cut optional and convenient)*

**1 diced onion** *(pre-cut optional and convenient)*

**1 Tbsp minced garlic**

**1 can chipotle pepper** *(these are mild 1 or 2 are enough but use the juice from the can for flavor)*

**1 Tbsp cumin powder** *(non spicy)*

**1 Tbsp chili powder** *(mild spice)*

**½ Tbsp Hungarian smoked paprika** *(also comes in mild or hot paprika if you want a spicier taste)*

**1 tsp dried or fresh cilantro**

**½ tsp oregano**

**½ tsp garlic powder**

**½ tsp onion powder**

**1 bay leaf**

**3 cups low sodium beef broth**

*(or 3 cups water and 3 tsp. powdered beef broth base)*

**Sea salt to taste**

*(no more than 1/4 tsp. add at the end of cooking)*



**THIS IS HOW YOUR DISH SHOULD LOOK RIGHT BEFORE TURNING THE SLOW COOKER ON.**



**THE FINISHED PRODUCT!  
IF EXTRA BROTH IS LEFT OVER,  
YOU CAN MASH THE BEANS  
FOR A REFRIED BEAN TEXTURE.**

**Night Before: Bean Soaking Instructions** *The night before making this dish, soak ½ lb. raw pinto beans in 4 cups of cold water, and let them soak for at least 8 hours. You will see the beans open up, and this will help break the beans down during cooking. **If you forget this step or want to make this in one day — Stove top:** Cover the beans in water and bring to a boil. Once brought to a boil, turn the heat off and cover the pot and let soak for an hour. **Microwave:** Add 1 ½ cups of water and microwave on high for 15 minutes, cover and let soak for 1 hour.*

**Slow Cooker Instructions** *Drain and add your pre-soaked beans to your slow cooker along with your diced peppers, onions, garlic, canned chipotle peppers and the sauce from the peppers. Add all of your measured seasonings, and do not forget your bay leaf. Then add your low sodium beef broth. After you have handled all of your fresh vegetables and seasonings, with clean hands, add your chuck beef steak to your crock pot. You can add the same seasonings you added to your crock pot to your steak if you would like extra flavor added to your protein. Plug your slow cooker in and set on low for 10 hours. If desired, ladle your meat on to a plate and remove extra broth by taking a ladle and spoon it into a bowl. This allowed me to take a masher and mash half of the beans like refried beans. Add back the amount of broth to your desired thickness. When the dish is done you can use two forks to shred the tender meat, and it should fall apart nicely. Serve this with tortilla chips or over rice with your favorite toppings. My favorite is Gluten free Multi Grain Tortilla chips. Before eating a meal high in protein/fiber, drink a glass of water to help aid digestion. Protein and fiber already help with feeling full so adding water to your daily habit before meals can help with over eating and digestion!*

***Felices Fiestas!!! Happy Holiday!!!***

Written by **Sara Izzo**



## Only Winter Blues?

Anyone who lives in Western Pennsylvania is familiar with how the lack of sunshine, greenery, and the constant grayness of every day can take its toll on your mental health.

Once the excitement of the holidays is over (and for some people the holidays are more challenging than exciting), it can all seem very “blah”. There is even a name for this: Seasonal Affective Disorder (SAD). Talking with your clinician is the best way to diagnose and treat SAD.

But what happens if spring comes and you still feel the same way? Or what if you simply feel this way all of the time? It’s possible that you might have depression. Depression is so much more than just feeling sad. It can affect your appetite, energy level, concentration, sleep, and interaction with the people around you. Your physician can screen for depression. Answering a few simple questions is all that it takes. If you do have depression, your physician can make a referral to a therapist and/or a psychiatrist.

Treatment sometimes involves talking to someone or it can involve medication or both. Be aware that most medications take a few weeks to work, and sometimes it takes a few tries to find the right medication. If you do get put on medication make sure you call your doctor and report any changes in your mood (if you feel worse)

and any physical side effects, or if you are planning on stopping the medication. There are many antidepressant medications that you cannot just stop taking. You need to be weaned off of them or you might have some serious symptoms occur. There is no shame in taking medications for your mental health. I take antidepressants. It simply is another way to take care of my health.

Unfortunately, depression can lead to suicidal thoughts and attempts. If you feel suicidal please reach out to friends, family members, or anyone you trust. If you feel that you can’t talk to anyone you know or know someone who feels this way, get help immediately. You can contact the National Suicide Prevention Lifeline. The lifeline is available 24 hours a day, 365 days a year. They have both English and Spanish speakers. The number is 1-800-273-8255.

Your mental healthcare is as important as your physical healthcare. There is no difference between needing help for a medical issue or a psychiatric one. Every part of your body interacts with every other part, whether it’s physical or mental. Make a resolution this upcoming year to treat your whole self, no matter the season.

May the upcoming year bring you prosperity, joy, and health!

*Written by **Monica Albert Still, RN, BSN***

## 'Tis the Season: Try Winter's Seasonal Produce

Even when the weather gets cold and snowy, there are still plenty of in-season produce items that you can enjoy.

This winter, add variety into your meals by including seasonal fruits and vegetables in your diet. In-season produce may also cost less, which can be helpful when following a budget. Remember, fruits and vegetables provide vitamins and minerals that keep our body working its best, fiber to keep us full and help promote regular bowel movements, and a variety of color and texture to our plates. Read on for information about a few (but definitely not all!) of the fruits and vegetables that are in season during winter. Try a new produce item you have never eaten before or find a new recipe for an old favorite!

Check out the recipes on the following page, which feature a few of winter's in-season fruits and vegetables included in this article. While it's great to take advantage of fresh produce that is currently in-season, don't forget that there are still plenty of ways to enjoy many different fruits and vegetables year-round. Frozen vegetables and fruit (plain, without sauces, gravies, or sugar), canned produce (pick low-sodium or no-added-salt vegetables and fruits canned in 100% juice instead of syrup), and dried fruit are all ways to add variety and nutrition to your plate. And remember — the produce items listed are only a few of the many winter seasonal fruits and vegetables. To learn more, visit:

<https://snaped.fns.usda.gov/seasonal-produce-guide>.

*Written by Jacquelyn Klunk, MS, RDN, LDN*

**Apples** are a great way to add fiber into your day (especially if you leave the peel on). Enjoy them as a quick snack with nut butter or low-fat cheese, toss on a salad, or enjoy cooked into various recipes. When selecting apples at the grocery store, choose smooth apples without blemishes or bruises and with intact stems. Apples can be stored in a plastic bag in the crisper of the fridge, usually for about three weeks; however, store them away from other produce items as apples can make them ripen or spoil faster. Make sure to wash your apples with cool running water before cutting or eating.



**Oranges** are often touted as a good source of vitamin C, a vitamin which helps the body with wound healing, immune system functioning, and even helps absorb iron from the foods we eat. Oranges also contain folate, potassium, and fiber. Pick the whole fruit instead of fruit juice to get more nutrients and fiber. For example, toss oranges on a salad for a tart but sweet burst of flavor, top yogurt or oatmeal with a few wedges for a filling breakfast, or make it savory by serving with a fish or meat entrée. When purchasing oranges, pick a fruit that is firm and heavy for its size. Oranges can usually be stored for a few days at room temperature. However, storing in the refrigerator extends shelf life; oranges can typically be stored in the refrigerator for up to 2-3 weeks. Just like other produce items with tough skins, make sure to wash your oranges in cool running water before peeling and enjoying!



**Sweet potatoes** are a tasty and versatile starchy vegetable. They are a good source of vitamin A, which plays a role in our immune system, vision (particularly how your eyes adjust to see better when you enter a dark room), and cell growth. They, like many fruits and vegetables, also provide fiber. In the store, select firm sweet potatoes with smooth skin without blemishes, soft spots, or any open areas. Store in a cool dry place and use within 1-2 weeks (though if properly stored, they may last up to 1 month). Sweet potatoes are great roasted, mashed, or added into simple recipes such as soup, chili, or even quesadillas. They can even be worked into sweeter recipes such as muffins or pancakes as a treat. Wash sweet potatoes immediately before using them (they will go bad quickly if washed in advance and stored), using running water and scrub to remove excess dirt.



**Brussels sprouts** contain folate, vitamin K, fiber, vitamin A, and vitamin C. Choose Brussels sprouts that are bright green and firm. Buying them still attached to the stalk will lengthen shelf life, but if you are buying individual sprouts in a bag, they will usually last about 1 week in the fridge. Do not wash Brussels sprouts before storing in the fridge, as they will go bad faster (but you should wash them before cooking). Brussels sprouts' flavors are great when roasted. Try them roasted on their own, tossed in olive oil, pepper, and a dash of salt. Or, pair them with other winter favorites such as apples and squash for a delicious seasonal dish.



## Roasted Brussels Sprouts with Apples

Makes: 2 servings

- ½ cup fresh apples, chopped
- 8 oz fresh Brussels sprouts, trimmed and quartered
- 2 Tbsp apple cider vinegar
- 2 tsp extra-virgin olive oil
- 1 tsp fresh thyme, minced (or ½ tsp dried thyme)
- ¼ tsp salt
- ⅛ tsp black pepper



**Directions:** Preheat oven to 375 degrees Fahrenheit. Combine chopped apples and Brussels sprouts in an 11 x 17-inch baking dish. Add apple cider, olive oil, thyme, salt and pepper. Toss well. Bake at 375 degrees for 25 minutes or until sprouts are tender.

Recipe Source: Credit: Texas A & M AgriLife Extension <https://fruitsandveggies.org/recipes/roasted-brussels-sprouts-with-apples/>

## Asparagus and Mandarin Orange with Chicken and Rice

Makes: 4 servings



**Directions:** In a small bowl, whisk vinaigrette ingredients, set aside. Cook rice according to package directions. Place whole trimmed asparagus in a large skillet with 1 ½ inches of water. Bring to a boil, reduce heat and simmer, uncovered, for 2-5 minutes. Rinse with cool water and cut into 1-inch pieces. (If you are using frozen asparagus, cook it according to package instructions. Cut into 1-inch pieces after cooking if needed.) In a medium size bowl, toss all ingredients.

Recipe Source: Credit: Produce for Better Health Foundation  
<https://www.choosemyplate.gov/recipes/myplate-cnpp/asparagus-mandarin-orange-chicken-and-rice>

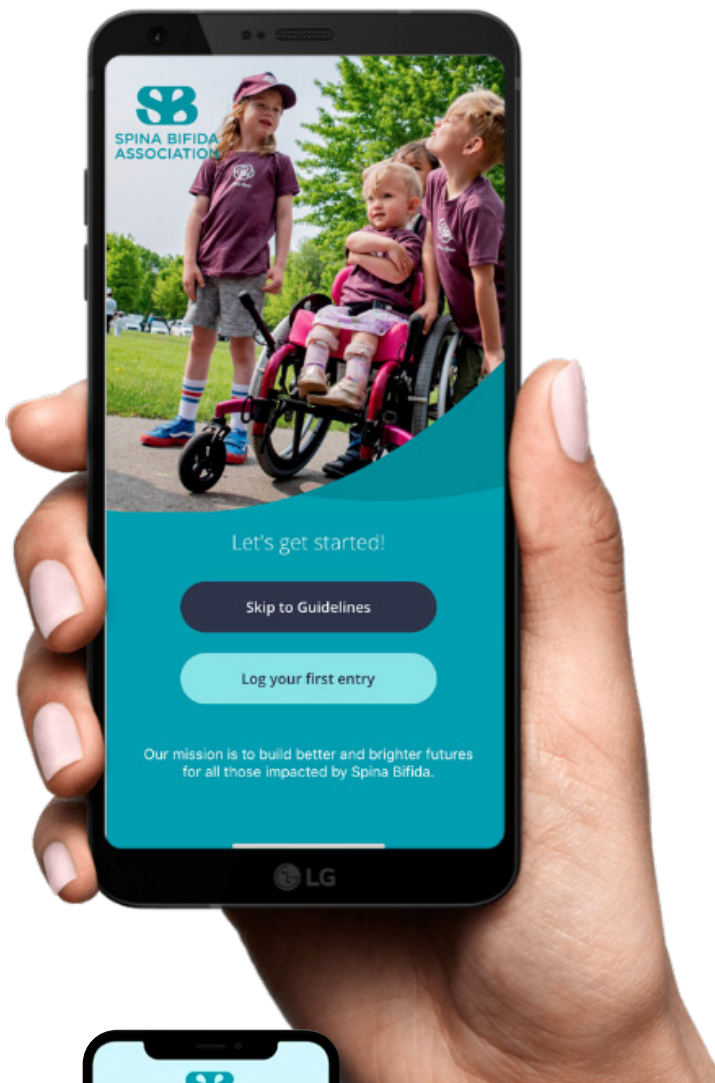
### For the Vinaigrette:

- 2 Tbsp extra virgin olive oil
- 2 Tbsp rice vinegar
- 3 Tbsp orange juice  
(if using canned oranges, used the reserved juice)
- 1 Tbsp lower sodium soy sauce

### For the Salad:

- 3 ⅓ cups fresh asparagus (trimmed)  
You can also use frozen asparagus!
- 2 cans (11 oz cans) mandarin oranges  
(drained, reserve juice)
- NOTE: Want to take advantage of in-season citrus?  
Use about 3 cups fresh orange wedges!
- 12 oz cooked chicken breast (cut into chunks)
- 3 cups cooked instant brown rice





## Want a More Active Role in Your Health Care? *There's an App for That!*

The Spina Bifida Association (SBA) App for Apple and Android devices is now available.

It is a free App that serves two important purposes. It is both a source of spina bifida related knowledge and a tool to track health issues.

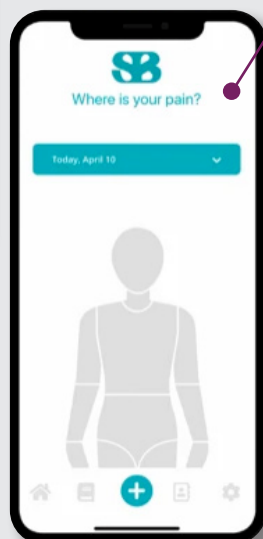
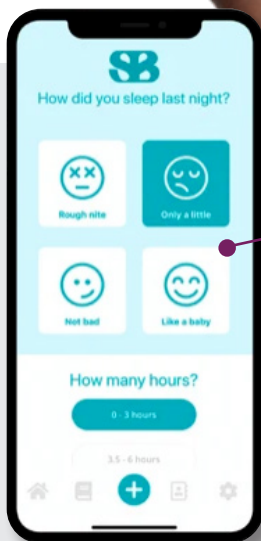
The App provides easy access to the guidelines for the care of people with Spina Bifida, right from your cell phone. These guidelines are valuable to healthcare providers and people with spina bifida. Using the App, you can search the 24 Guidelines by age and by topic, making it easy for you to find evidence-based medical expert guidance for people with Spina Bifida from birth through adulthood.

The App also provides a very useful healthcare tracking tool for people with spina bifida. It has a symptoms tracker that allows you to record and follow varying health issues including skin integrity, pain, issues with sleep, and physical activity. The App is designed to help you better follow medication recommendations, bowel management plans, and catheter routines. The tracker also allows you to add personal notes specific to your situation. This information can then be shared with your physicians at an upcoming appointment.

By using this App to track your symptoms regularly, it is possible for you to witness changes that takes place and hopefully develop a more active role in your own health care and treatment.

*Development of this application was supported by the Rehabilitation Engineering Research Center for Community Living, Health and Function (LiveWell RERC) funded by a grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) in the U.S. Department of Health and Human Services under (grant no. 90RE5028)*

Written by **Darcie Ilg, PA-C**



 [www.spinabifidaassociation.org/mobile-application](http://www.spinabifidaassociation.org/mobile-application)

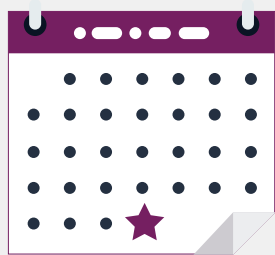
## Upcoming Events at SBAWP

Some of the upcoming events for adults at the Spina Bifida Association of Western PA (SBAWP) include:

**Youth and Teen Fall Retreats**  
*December 4-6, 2020*

**Adult Fall Retreats**  
*November 13-15, 2020*  
*December 11-13, 2020*

Dates are subject to change.  
For more information,  
please visit the website at  
[www.sbawp.org](http://www.sbawp.org).



## MyUPMC Patient Portal

In order to serve you better and improve communication, we are asking that you join MyUPMC. MyUPMC is a free, secure online portal that allows you to communicate with our office, view test results, refill prescriptions, and manage your overall health. To sign up, go to [MyUPMC.com](http://MyUPMC.com) and create an account. If you have any questions, please ask our front desk or give us a call at 412-232-8901.

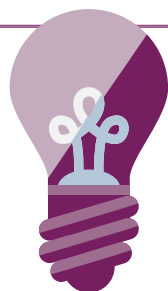


## Patient Assistance Fund Program

Patient Assistance Funds are available for Pennsylvania residents with Spina Bifida who qualify. To determine your eligibility, you will need to complete and submit an Income Attestation form, which we will provide annually and upon request. If you are approved to use the Patient Assistance Funds, we can reimburse you for purchases and expenses related to your health and well-being. After approval, you can submit receipts for reimbursement via mail:

**Darcie Ilg, PA-C**  
**UPMC Mercy, Dept of Phys Med and Rehab**  
**1400 Locust St, suite G103**  
**Pittsburgh, PA 15219**

Message Darcie Ilg via MyUPMC or call 412-232-8909 for more details and any questions.



## Do you have ideas for our Newsletter?

If you have particular topics you'd like to see in our newsletter, please reach out and let us know.

**Contact us**  
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Check out our other newsletters and clinic information at: [UPMC.com/SpinaBifida](http://UPMC.com/SpinaBifida)