

Healthy Spring Comforts

We made it! It's Spring 2021 and I feel very hopeful for the New Year that is beginning. While we approach the anniversary of the country shutting down for the pandemic in 2020, I can't help but reflect and appreciate the strength and resilience of the many people around us. Spring is a season that we probably need most now. A chance to see a new beginning, a new beauty, and the possibility to learn how to appreciate the gift that time gives. Most of us have celebrated the New Year in January, but the earth sees the season of spring as life renewing.

I usually feel more compelled to make life changes in spring versus the New Year in January, the time when we make our new year's resolutions. Even though weight loss is a goal for many, we don't all have access to fitness centers and activities that would usually help us burn those extra calories. Food is the one thing I have the most control over. Cooking will always be the catalyst for how my day goes. If I can avoid ordering take-out, I have a better chance at managing my weight which helps me manage my issues associated with spina bifida. Having the energy to have an appropriate workout usually follows an appropriate meal. Most of all, making meals that fit my time and limit physical strain helps me stick to the lifestyle I hope to retain. I personally have struggled with this very topic, but I don't want to give up certain comfort foods. Italian is my all-time favorite type of food. I just love a good pasta dish, but many of us with spina bifida find that making a good pasta dish on our own is difficult. The recipe that I have made today is the perfect dish for spring because it is versatile. Since the spring weather is so unstable, I vary from wanting a cozy, hearty dish to a savory, light meal. This dish allows you to make it any which way you like. *Continued next page*

Spring Forward and Bounce Back

The word "spring" means "to leap forward" and also refers to a "resilient device that returns to its original shape when pushed or pulled." In this issue, we celebrate Spring with tips to propel you forward toward your goals and promote resiliency in your character when faced with life's challenges.





It's called slow cooker lasagna or lasagna soup depending on your mood. What's great about this particular meal is that it's loaded with vegetables, and you can choose to add meat or keep it as a hearty vegetarian dish. Today I used yellow squash, green pepper, yellow onion, minced garlic, and my favorite secret ingredient in red sauce, fresh carrots. Fresh carrots was a secret my mother-in-law gave me to help reduce the acidity often associated with tomato sauce. I always use 2-3 large carrots when cooking red sauce and I like to add them by shredding them or using a potato peeler to thinly slice them safely. You can also find shredded or matchstick carrots at your local grocery store along with other pre-diced veggies that are mentioned in the recipe. The natural sweetness in carrots also helps to balance the acidity so you don't need to add too much sugar if you like a sweeter sauce.

As I mentioned before, meat is optional. You can load your slow cooker with extra vegetables or use a meatless alternative like beefless ground or meatless meatballs. Today I made my own meatballs, and I will share my recipe with you, but my method does require you to partially cook the meatballs in either a pan or an oven. The reasoning for this step is because ground beef or pork, is higher in fat compared to a beef roast or chicken that is often slow

cooked. Cooking the fresh raw meatballs in the pan or oven renders the extra fat so they can then be added to the slow cooker to finish cooking. It is also important to choose ground beef that is marked 90%/10% or 96%/4%

fat. This means your ground beef is very lean and won't produce a lot of fat. If you are using a higher percent of fat, I suggest precooking them only just a little longer. However, if you like your sauce to have the flavor you can certainly use raw ground beef or meatballs in this recipe. The dish is cooked on high the entire time and you

can cook the sauce on high for 30 minutes before adding your raw meat just to ensure sauce is nice and hot before adding your meat.

To keep this meal as healthy as possible I suggest using whole wheat pasta. This recipe allows you to cook the pasta in the slow cooker too! Just adding a cup of water with your raw pasta, and cooking for an additional 15-20 minutes will complete your meal. I like using large shells or rigatoni, but the choice is yours. My only suggestion is that you may not want to use spaghetti noodles or pastas like linguine, you may need to stir the pasta quite often to prevent sticking. This entire meal can truly be cooked all together, and that is why it's truly one of my favorites.

Written by **Sara Izzo**

It's called slow cooker lasagna or lasagna soup depending on your mood. What's great about this particular meal is that it's loaded with vegetables, and you can choose to add meat or keep it as a hearty vegetarian dish.

Slow Cooked Lasagna / Lasagna Soup

Makes 4-5 servings | 15-35 minutes prep time; 6-7 hours cooking time

- 1 cup diced green pepper
- 1 cup diced yellow squash
- 2-3 carrots shredded (1 bag of matchstick carrots)
- ½ cup diced onion
- 3 Tbsp minced garlic
- 1 28 oz. can of plum or stewed tomatoes (diced tomatoes acceptable)
- 1 24 oz. jar of favorite good quality tomato sauce
- 3 cups beef broth (vegetable broth)
- 1 6 oz. can tomato paste
- 1 Tbsp dried rosemary
- 1 Tbsp dried thyme
- 1 Tbsp dried parsley
- ½ Tbsp dried basil
- 1 tsp black pepper
- ½ tsp sea salt
- 1 bag of frozen meatballs of your choice or meatless alternative (Optional)



Slow Cooked Vegetarian Lasagna

Place undrained plum or stewed tomatoes into the unplugged slow cooker and mash tomatoes with clean or gloved hands (if using diced tomatoes, no need to mash). Using a spoon, mix can of tomato paste into mashed tomatoes. Add all of the ingredients: diced and minced vegetables, seasoning, jar of tomato sauce, and broth. Turn slow cooker on High setting. Cook for 4-5 hours. Add 2 cups of uncooked wheat pasta, and cook for 15 minutes. Turn off slow cooker and let cook in its own heat for additional 5 minutes, check for preferred doneness. Serve with favorite cheese toppings! Parmesan cheese is an excellent thickener if you are seeking a thicker consistency.

Slow Cooked Lasagna with Meat

Follow vegetarian instructions and cook sauce for 1 hour; then add partially cooked, frozen meatballs or frozen meat-like substitute. Cook for 5-6 hours. Add 2 cups of uncooked wheat pasta and cook for 15 minutes. Turn off slow cooker and let cook in its own heat for additional 5 minutes, check for preferred doneness. Serve with favorite cheese toppings!



BONUS RECIPE >> Lasagna Soup

Add 1 cup of water to your slow cooked lasagna and then add the 2 cups of uncooked wheat pasta. Cook for additional 15 minutes. Turn off slow cooker and let cook in its own heat for additional 5 minutes, check for preferred doneness.

Fresh Meatball Recipe

Makes 4-5 servings | 25 minutes prep time; 5-20 minutes cooking time

- 1 lbs. lean ground beef
- 1 fresh egg
- 4 Tbsp minced onion
- 2 Tbsp minced garlic
- ¼ cup grated parmesan
- ¼ cup breadcrumbs
- ¼ cup chopped fresh basil
- ½ Tbsp oregano
- ½ Tbsp dried thyme
- ½ Tbsp dried rosemary
- 1 tsp black pepper
- ½ tsp sea salt
- ¼ tsp crushed red pepper (Optional)



Fresh Meatballs

While sauce cooks on high for the first hour, in a medium bowl, add all ingredients and combine using gloved hands. Continue to mold and fold the mixture until all seasonings and items are evenly distributed. Measure out 2 tablespoons of meat mixture and form into meatballs. Meatballs can be baked at 350° for 20 minutes or seared in a lightly oiled pan for 1-2 minutes on each side. After meatballs are partially cooked, add meatballs to sauce that has been slow cooking on high for 1 hour.



Don't hesitate to experiment with your favorite vegetables or different types of meatballs, like turkey! This dish is also great to switch up by substituting the jar of tomato sauce with your favorite salsa and substituting the Italian seasonings with your favorite low sodium taco seasoning. Be creative, it's your kitchen!! "The best things all come in good thyme."

Written by Sara Izzo



CREATE



Crafting and Sharing Your Personal Narrative

Sharing your personal narrative, no matter the size of the audience, can be intimidating and scary, but it can also be freeing, empowering.

American book author and storyteller Brene Brown, when discussing the significance of sharing one's personal narrative, explained that, "When we deny the story, it defines us, but when we own the story, we can write a brave new ending." I have spent many years crafting and sharing my own personal narrative as an individual living with Spina Bifida with audiences ranging from medical professionals to young children in the classroom environment.

Sharing your personal narrative is something that an individual has to be ready to do. If you are not ready or feel uncomfortable with sharing those intimate and deeply personal pieces of yourself with others that is perfectly alright. Sharing one's own personal narrative is a very conscious, independent choice that only that particular individual can make for themselves. No one should ever pressure you into sharing those intimate details about yourself with the rest of the world.

When beginning to write your personal narrative, you will want to use an attention getter such as a

famous quote, a personal anecdote, or something funny to grab and hold your audience's attention. Now that you have gotten your audience's attention, use factual information, but say it with vivid, descriptive language as if you are able to physically transport the audience back in time so as to be right there with you when and where the true story took place. Remember in this case, less is more. Don't use too much filler, fluff, and do not overexaggerate the details of your personal narrative too much because it's should already be a true-life story, and you want the audience to really believe that it happened to you because it did.

Lastly, you will want to end by telling your personal narrative with visual, expressive detail or a strong personal anecdote that will tug at the heart strings of your audience, and leave them wanting to know more. Sharing your personal narrative is a powerful tool that can motivate, encourage, and provide different perspectives of similar human experiences that can open doors to new opportunities, adventures, and can change the lives of others for the better. You may never know the true impact that sharing your personal story can have on the world, and to me that's the most exciting part.

Written by Libby Powers, MS.

Spring Forward with Nutrition

FACTS vs. FICTION

With so much information available today, it can be difficult know what is correct and what is misleading. Nutrition is no exception – whether at the click of a button online, by word of mouth, on television, or in books and magazines, nutrition often pops up in conversation.

While great information can be found about food online or in other media, many misconceptions can be found just as easily. Read on to separate some common nutrition facts from fiction.



Fiction #1: Skim (cow's) milk has less protein than whole milk.

WHAT ARE THE FACTS? Skim milk and whole milk have the same amount of protein: 8 grams of protein in 1 cup. The major difference between skim and whole milks is that fat is removed in skim milk products. This means that skim milk has little to no saturated fat. Why is that a good thing? Well, fats in general provide excess calories, which is important to consider if someone is watching their weight. But specifically, saturated fat can raise the LDL (low-density lipoprotein) or “bad” cholesterol levels in our blood. Over time, this can cause a build up of cholesterol in our blood vessels and increases risk for heart disease. What about vitamins and minerals like calcium, vitamin D, and vitamin A in the milk? The calcium content of both skim and whole milks remain similar around 300 mg calcium per cup. While it is true that vitamin D and vitamin A, which are fat-soluble vitamins, are lost when fat is removed from skim milk, there is no need to worry! Most manufacturers add vitamins A and D back into skim milk. Curious to compare? Pick up two cartons in your grocery store and take a look at the Nutrition Facts Label!



Fiction #2: Egg yolks are bad for you.

WHAT ARE THE FACTS? Eggs have gotten a bit of a confusing reputation over the years. Sometimes we hear that egg yolks are bad for heart health because of their cholesterol content and should be avoided, and other times we hear that eggs are perfectly fine. So, what's the truth? Egg yolks do have positive nutrition benefits. They contain vitamins, minerals, and antioxidants such as vitamin D, which is helpful in bone health and immunity; choline, which is used in neurological processes like memory and muscle control, and is also used in our cell membranes; and lutein and zeaxanthin, which have roles in eye health. Eggs are a convenient source of protein as well. One large egg contains 6 grams of protein – just a bit less than one ounce of meat. But what about the cholesterol? It is true that egg yolks are a significant source of cholesterol. However, more research is needed to clarify the relationship between the cholesterol in our diets to the levels of cholesterol in our blood. With the 2015-2020 edition of the Dietary Guidelines for Americans, a daily limit on cholesterol intake was removed due to lack of evidence for a specific number. That doesn't mean we should consume high cholesterol foods freely. A healthy dietary pattern lower in saturated fats (a type of fat which can raise the LDL or “bad” cholesterol levels in our blood) and cholesterol is still recommended. Often, foods that are higher in cholesterol are also higher in saturated fats (such as high-fat meats and whole milkfat dairy products), so focusing on a dietary pattern that lowers saturated fats can thus also help to lower cholesterol intake. Although eggs are high in cholesterol, they are not as high in saturated fat (though they do contain some). So where does that leave eggs? It is generally accepted to eat eggs in moderation as a part of a healthy diet. How you eat them also matters. For example, a hard-boiled egg paired with a fresh fruit cup and whole grain toast is a healthier choice than a fried egg with bacon and pancakes.



Fiction #3: Gluten-free foods are healthier.

WHAT ARE THE FACTS? Gluten is a protein found in wheat, barley, and rye. Gluten is not inherently unhealthy, nor does it cause weight gain; many people do not need to avoid it. However, there are cases when a gluten-free diet is medically necessary. For example, individuals who have a diagnosis of celiac disease must eat a gluten-free diet in order to avoid damage to their intestines. However, for people who do not have a medical need to avoid gluten, it is important to remember that just because a food is gluten-free does not automatically make it “healthy.” Gluten-free cookies are no healthier in terms of calories, fat, or sugar than a gluten-containing cookie. Healthy and unhealthy foods exist in both the gluten-free and gluten-containing food worlds, so making healthy and balanced choices is still important.



Fiction #4: Honey does not count as an added sugar.

WHAT ARE THE FACTS? Honey is still considered an added sugar. When consumed in large amounts it can quickly add calories to foods and beverages and can lead to weight gain over time. Micronutrient (vitamin or mineral) differences between honey and regular table sugar are not very significant when considering the

amount of honey typically consumed at a time. Honey may contain some antioxidants that sugar does not. However, it is still important to reduce your intake of added sugars overall – whether coming from honey, table sugar, brown sugar, molasses, or syrups! Think of sweet foods/drinks as a treat to be eaten in smaller amounts and less often, instead of as a daily staple. Note: Honey should never be given to children younger than 1 year of age due to risk of bacteria that causes infant botulism.



Fiction #5: Juice cleanses or detox diets are good for or refreshing for the body.

WHAT ARE THE FACTS? Our bodies do not need “juice cleanses” or “detox diets.” Our body can take care of “detoxing” on its own – our lungs, liver, intestines, and kidneys all work together to get rid of waste products the body does not need. Often these cleanse or detox diets are restrictive and lacking in various important nutrients; in some cases, they may even pose health risks. Instead of trying an extreme detox diet, focus on building an overall healthy eating pattern: aim to include a variety of food groups (such as fruits, vegetables, whole grains, lean proteins, and low-fat dairy) in balanced portion sizes, stay hydrated, and limit how often you eat foods with lots of added sugar, fats, and sodium.

BOTTOM LINE: With a plethora of nutrition information available online and in other media, it is important to take time to check if the information is correct or not. Registered dietitians/Registered dietitian-nutritionists (RD or RDN) are qualified professionals who can help provide accurate nutrition information. You can also make sure to visit dependable sources. Some examples of reliable websites to help you sort nutrition facts from fiction include The Academy of Nutrition and Dietetics www.eatright.org and My Plate www.choosemyplate.gov.

Written by Jacquelyn Klunk, MS, RDN, LDN



Medical PTSD

When we read the words “Post Traumatic Stress Disorder (PTSD),” we often think of veterans. We think of VA hospitals and clinics designed to help those affected return to civilian life.

However, as we gain knowledge about what trauma is and how it affects all of us, we are finding that it is more than just veterans who need assistance in learning coping skills and living with the after-effects of trauma.

Unfortunately, avoiding trauma is not always possible. Despite ours and other’s best efforts, we may have traumatic events occur in our lives. Receiving medical care, especially undergoing procedures, can be a source of anxiety, despite the clinician’s best efforts to minimize the impact and maximize healing.

I don’t remember most of my hospitalizations as a kid, or even those as an older child of 12. I recall bits and pieces. I remember learning how to make paper flowers and to play poker, and when the circus clowns came to visit me. I can tell you everything about how I “Trick or Treated” in the hospital when I was 9. But the rest is blank. As an adult, though, I began to have anxiety about medical procedures. For a very long time I was embarrassed by this. It never really occurred to be that I could have PTSD. A therapist helped me realize that there is no shame in having PTSD. I discussed with her what I could do to cope with these feelings when I had to have medical procedures done since my plan of avoiding them was not practical, feasible or safe. I learned mindfulness techniques such as breathing, meditation, distraction and creative visualization in order to decrease my anxiety. For a while, each of these approaches worked but ultimately as I needed more and more invasive procedures they simply were not enough. I found the help I needed by seeing a psychiatrist.

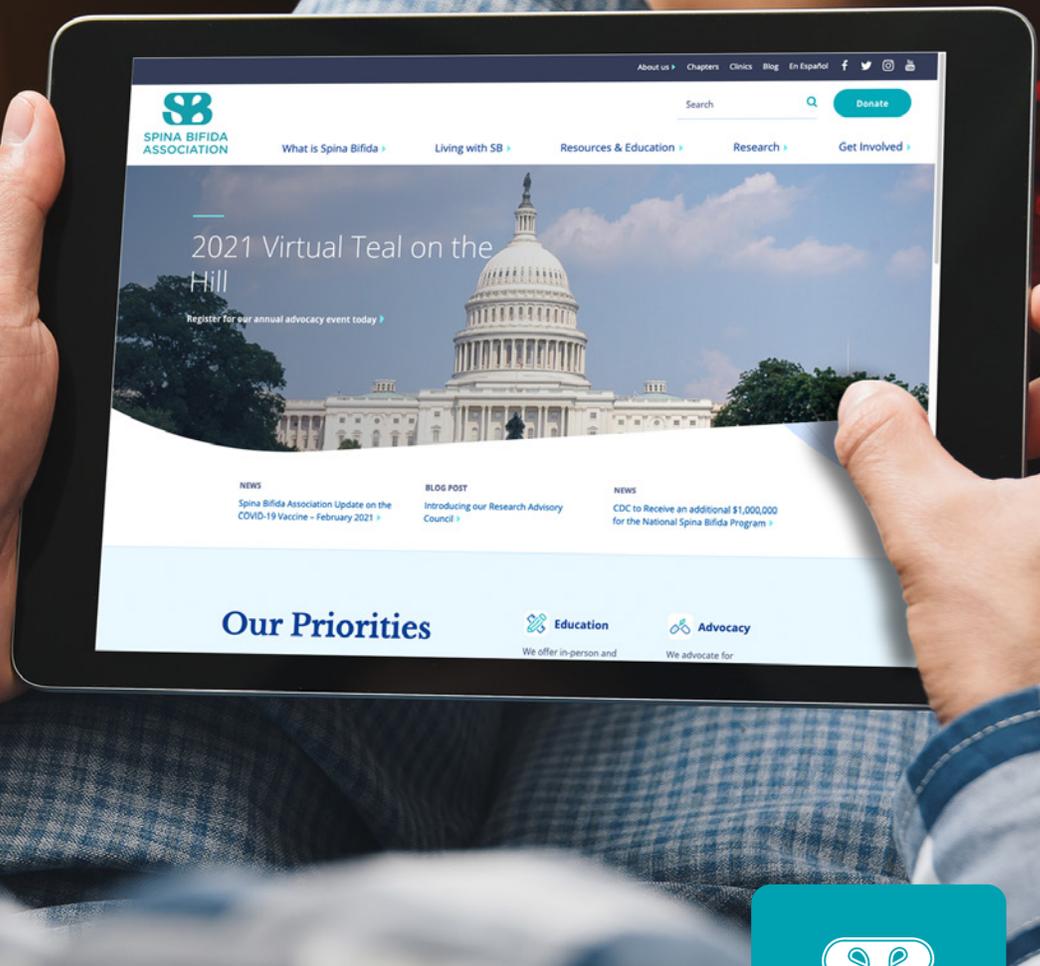
It was during this time when I heard about “trauma-informed care.” As a pediatric nurse, years ago, we often did things to try to minimize the trauma we thought the children were experiencing. We did not call it trauma informed care, though. It makes sense to recognize that adults need this type of help as well. This is especially true of adults living with spina bifida since we are more likely to have more medical procedures done than the average person.

I recently had a procedure and did not have a panic attack. I want to thank the UPMC Disabilities Resource Center for coordinating my care and ensuring that my needs were met. When you think of a disability resource center, you usually think of access or accommodations needed because of mobility or sensory issues. You rarely think of anxiety or trauma informed care. I hope this article changes that. As soon as I knew the date and location of my surgery I called them. I explained my past experiences, my anxiety, and my PTSD. They reassured me that they would have a plan for me and would speak to all who would be caring for me about my needs.

We should never be ashamed or afraid to ask for help in coping with how our life experiences have affected us. If you find yourself experiencing flashbacks, nightmares, anxiety, or uncontrollable thoughts about the medical procedures that you have experienced please contact your primary care physician, therapist, psychiatrist, or someone at the clinic to discuss what care you may need.

Written by Monica Albert Still, RN, BSN

If you are a person with a disability and would like more information, or need to request complex disability related accommodations for an upcoming scheduled procedure through the Let UPMC Help You (LUHU) program, please visit [UPMC.com/luhu](https://www.upmc.com/luhu) or call 412-605-1483.



Are you taking advantage of the many resources the Spina Bifida Association has to offer?

Established in 1973, the Spina Bifida Association (SBA) is a national voluntary health agency which works to improve the lives of people with Spina Bifida. In fact, the SBA is the only national group exclusively dedicated to those with Spina Bifida. Through research, advocacy, education, and support systems, the SBA promotes a better future for people affected by Spina Bifida. I wrote about their app in a previous newsletter. Today, I want to bring your attention to some other resources the SBA has available on their website.

There are many education resources available through the SBA. The “SB-YOU” program (available on the SBA website on the “Adults Living with Spina Bifida” page) is the SBA’s online education program. There are available webinar sessions which are free and can often be viewed live on the day of the session, or anytime by accessing the “SB-You” session archive. Webinar topics have included bowel routine, mental health, fitness, insurance coverage, and more.

You can also learn more about the research the SBA has been involved with on the SBA website. The SBA promotes research to improve the lives of people living with Spina Bifida. Their advocacy has yielded the National Spina Bifida Patient Registry (NSBPR) and the Urologic Protocol for Young Children with Spina Bifida. They also have brought to life the “Guidelines for People Living with Spina Bifida”. You can access this valuable resource on the SBA’s website, and also on their app.

You can learn about ways to get involved and join in the SBA’s advocacy efforts. Through the event Teal on the Hill, the SBA has completed 50 visits to Capitol Hill annually to lobby for continued Spina Bifida funding, research, insurance benefits, and more. The most recent Teal on the Hill event was on March 1-5, 2021.

There is so much to learn and many ways to get involved. Take a look yourself at www.spinabifidaassociation.org.

Written by Darcie Ilg, PA-C

WHEELCHAIR WORKOUT



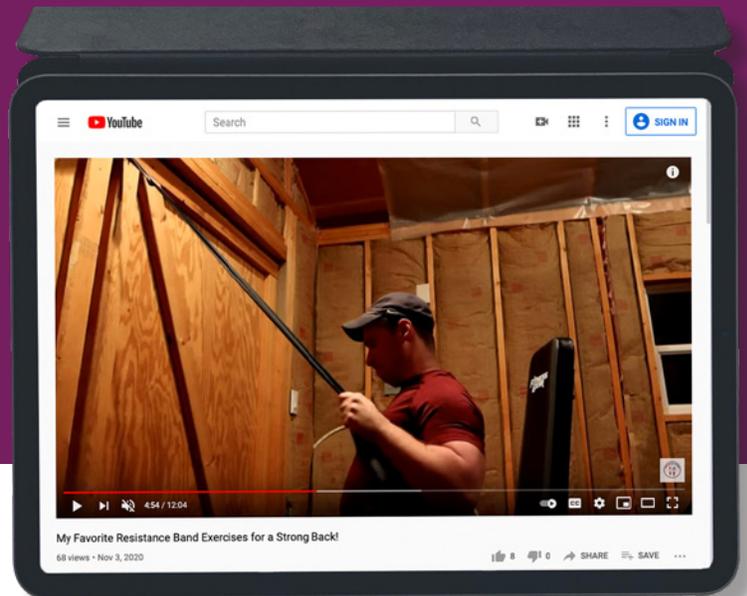
Building Back Strength and Stability

Building a strong and stable back is perhaps as important, if not more important, than a strong chest for individuals with Spina Bifida.

Each of the exercises below hits a different part of your back muscles in different ways in order to build the most stable and strong back possible. Personally, I like to do each of these exercises with resistance bands for 3 sets of up to 20 reps. Feel free to do more or less reps depending on your fitness level and personal goals. Breathe throughout the full range of motion of all exercises.

The **Lat Pulldown** hits your Latissimus Dorsi muscles which are the largest muscles on your back and are responsible for the primary strength in pulling movements. Start with a resistance band attached to a stable, stationary anchor point above eye level. This could be a coat hanger, doorknob (if you are sitting on the ground) or have a someone around you hold the resistance band over your head. The key to the set up is to make sure your arms are fully extended overhead with each end of the resistance band in each hand and an equal length of band on each side of the anchor point. Once you have the setup, simply pull your hands down toward your shoulders, leading with your elbows and finishing with your fists as close to shoulder level as possible. Try to hold your hands at the bottom of the motion for a second and pinch your shoulder blades together. This will allow for maximum contraction of your Lats. Return your arms to the start position completely locked out overhead.

The **High Row** primarily uses the Lats to perform the movement but with the added help of the posterior deltoids (shoulders) and biceps. Start with your arms straight in front of you; however, this movement requires the resistance band anchor point to be at chest level so your arms are in line with your shoulders. From this position, pull your elbows back so they are in line with your shoulders. If possible, try to bring your elbows past



your shoulders, while keeping your arms at shoulder level, to get more muscle contraction. Hold this position for one second and return to the start position.

The **Face Pull** works your posterior deltoids as well as your rotator cuff and biceps and gets its name because you pull your hands to and/or past your face. What makes this motion slightly more difficult is that you need to hold your elbows high in line with your shoulders throughout the full motion while pulling your hands back toward your face and up over your elbows. I personally like to use my thumbs as a guide for the movement and try to point them out to the side at the end of the motion. Do your best to keep your shoulders down and back to prevent any shrugging. This will engage the correct muscles while actively working to prevent any shoulder impingements or other injuries.

The **Horizontal Row** works your Lats, Rhomboids, Traps, and Biceps. Again, similar to each of the other movements, start with your arms straight out in front of you but slightly below chest level. From here, pull your elbows back to or past your sides until your hands touch just below your chest. Pause for a second and return to the start position. Again, breathe through the full range of motion.

The Spina Bifida Guidelines, which you can view [here](#), recommend that individuals looking to improve overall health and wellness spend at least 150 minutes per week of moderate intensity exercise, or 75 minutes per week of vigorous intensity exercise.

Click [here](#) for a video tutorial on each of the exercises described in this newsletter as well as other videos you can add into your resistance band workouts.

Written by Dan McCoy, ACE-CPT

Latex and Masks

The Spina Bifida Association has been made aware that there may be a risk of latex exposure in masks that have been commercially made. We don't know if that risk is due to masks being manufactured in facilities, or if there is latex in the components of the mask, such as the elastic ear loops. We believe this risk to people with Spina Bifida may be small, but may also be very real. What you can do:

- Make your own masks from recommended patterns on the internet, and make them with cloth ties rather than ear loops that use elastic (unless you know that the elastic doesn't include latex)
- If purchasing off the internet, purchase masks with cloth ties or check with the manufacturer as to whether the mask contains latex in any way or was manufactured at a site where there might have been a chance of latex contamination
- Many hospitals require patients to wear masks issued by the hospital for in-person clinic visits. If that is the case, check with your hospital or providers in advance of the visit to see if they can confirm that the mask you would be issued does not contain latex.



Do you know about our Financial Assistance Programs?

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. You can also find it at this [link](#) or at our website: [UPMC.com/SpinaBifida](https://upmc.com/SpinaBifida).

If 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.

Upcoming Events at SBAWP

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

Fundraising Events:

May 8	Highmark Walk
May 23	Shoot for SBAWP
June 13	Afternoon JamFest
July 26	John L. Moroney III Memorial Golf Classic
September 18	Noll-Spratt Golf Scramble
November 13	Girlfriends for Good Purse Bash

Camps & Retreats:

March 5-7	Youth and Teen Retreat
March 12-14	Adult Retreat
April 30-May 5	Adult Retreat
May 7-9	Youth and Teen Retreat
July 4-10	Adult Camp
July 11-16	Youth and Teen Retreat
October 22-24	Youth and Teen Retreat
November 5-7	Adult Retreat
December 3-5	Youth and Teen Retreat
December 10-12	Adult Retreat

For more information regarding events and/or camps and retreats, please visit our website at <https://sbawp.org/events> or call 724-934-9600.



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](https://upmc.com/SpinaBifida)