

UPMC Adult Spina Bifida Clinic Summer 2021 Newsletter

My Pain Management: Medications and Meditation

The sun is shining. My garden needs tending. However, I cannot care for my tomatoes because, right now, I hurt. Like many people with Spina Bifida, I am often in pain.

Sometimes that pain doesn't let me do what I want to do. I am both frustrated and saddened by this. My doctor knows about my pain. I go to a pain management clinic. We have discussed what medications I can take to make my pain more tolerable so that I can live my life. While I take my medications exactly how my doctor prescribed them, I have found some ways that help me lessen my pain even more and allow me to live my life.

Rest

When you are tired and worn out you feel pain more. Resting may help. Pain is your body's way of saying,



"Stop"! You can end up injuring yourself if you ignore your pain and don't rest.

Changing Position

You know the really old joke about the patient and the doctor? The patient says, "Doctor, doctor! It hurts when I move my arm like this". The doctor says, "So, don't move your arm like that"! The joke is funny because it contains a grain of truth. If you know sitting or moving a certain way will cause you to hurt, try to avoid it as much as possible. Sometimes, how you are positioned can affect how much pain that you feel. Changing position can help lessen the

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Resilience

Resilience is toughness — the capacity to recover quickly from difficulties. A recent study in the Journal of Health Psychology showed that young adults with spina bifida may be quite resilient. The researchers examined perceptions of over 300 young adults about what living with spina bifida taught them. The study participants noted that having spina bifida made them more patient and stronger as a person, more accepting and understanding that all people need love, more sensitive to family issues and closer to their family, more focused on life priorities, and more successful with friendships. They also reported more emotional and spiritual growth as a result of having spina bifida. You can read more about the study at this link. This summer newsletter will focus on resilience and how to find the silver lining when life is difficult.

pain. Always remember to check to see if something is pressing against your skin. Since people with Spina Bifida have poor sensation, you may not know if something is causing pressure until you look.

Distraction

People tend to have more pain when they don't have other things to think about. It's part of why pain tends to bother people more at night when they are trying to sleep. There are many ways that you can try to keep your mind busy and help decrease the amount of pain that you feel. Playing games, doing puzzles or crafts, coloring, watching movies are examples of things that can distract you from pain. But these things won't help if you are trying to sleep. Meditation can help you relax and fall asleep. You can find videos online or apps for guided meditations. Some are for sleep and some are specifically for pain. You have to be careful of the apps because some are not free. If you don't want to try a guided meditation you can always try to do it yourself. You can start by thinking of a place that is very special to you. You can imagine that place in detail from the clouds floating across a clear blue sky to a sparkling drop of dew hanging from a red flower petal. You can have people, animals, or anything you can dream up.

Breathing

Some people have anxiety along with their pain. Being anxious only makes the pain feel much worse. Taking deep slow breaths can help calm you making you feel more comfortable. Concentrating on how you are breathing is a way to distract you from anxiety, pain, or both. You can also take a deep breath in through your nose and blow it out from your mouth all the while imagining that you are blowing the pain away. You can find online examples of breathing exercises. If you have any kind of breathing problems be sure to check with your doctor to see if performing breathing exercise is right for you.

Heat and Cold

Applying either heat or cold can help decrease your pain. Since people with Spina Bifida usually have poor sensation you have to be very careful if you are going to try this. I would ask your doctor beforehand if this type of pain relief is right for you. Be certain to check your skin both before and after you put either heat or cold on the area causing you pain. Make sure that there are no open areas, bruising, or redness on your skin. Never place either the heat or cold pack directly on your skin or in areas where you have numbness. Have a piece of cloth like a towel between your skin and the source of heat or cold. Avoid electrical heating pads which may not shut off









and get too hot. Do not apply the heat or cold for more than 15 minutes at a time. If you notice that you are more uncomfortable while using heat or cold, stop immediately and check the area for any changes in your skin. Call your doctor if you find anything that you are concerned about.

Exercise

Routine exercise may help you hurt less. Discuss with your doctor what kind of exercise program can be best to help your pain. Your doctor may order different types of therapy or a personal trainer consult to find an exercise regime that is best for you.

Weight Loss

Excess weight puts more wear and tear on your body, making you feel the pain even more. Talk to your doctor or diettian about the healthiest weight for you and how to reach that goal. Do not use food as a way of making yourself feel better about having pain.

These are just a few of the things that you can do to help decrease your pain. If none of these ways gives you any relief, discuss with your doctor what your other options may be. Never try any kind of pain relief without talking to your doctor.

I hope that you find that some of these methods help you be able to live your life while living with pain. Have a happy sunshine filled summer!

Written by Monica Albert Still, RN, BSN



Finding the Right Mental Health Therapist for You

Finding the right type of mental health support can be intimidating at first, but it does get easier over time because as you continue to grow and develop as an individual, you will begin to understand what will work for you and what will not work for you.

Personally, as an individual with Spina Bifida, who has struggled with her physical, emotional, and mental well-being in various chapters of my life, I have sought out and received both peer and professional mental health supports.

Until very recently, I struggled tremendously to find the right type of mental health professional, whom I felt could effectively and appropriately meet my personal needs. Psychological research has shown that it typically takes up to 6 to 8 weekly one-hour sessions with a mental health professional to truly know if the working relationship between the two of you is an overall good match. This time is also needed to know if you will gain more insight into who you are as an individual, learn healthier coping mechanisms, and obtain beneficial resources to help you to continue your progress well after your working relationship with your mental health therapist ends.

During those first 6 to 8 weekly sessions with your therapist, ask them questions about the various therapeutic methods that they use in their mental health practice and what tools may be the most beneficial to you. If at first you do not find the right therapist, do not be discouraged. It is all a part of the overall therapeutic journey. It just might take a little more time and effort on your part to search and find the right one. Remember that it is not the therapist's job to solve all of your life's

problems, but it is their job to carefully listen to you and to provide their most honest feedback and suggestions as to how you could work through those more problematic scenarios in your life. You may not always agree on everything. As with all relationships, your relationship with your mental health professional is a two-way street. You have to be ready and willing to be brutally honest with yourself and with them for therapy to truly work, and as a mental health therapist they have to be willing and able to listen to you and to use their best professional judgment and guidance.

There are many resources available to help you find a mental health therapist located near you. You can ask your spina bifida providers or your primary care physician for a referral. You can find your own mental health therapist using the **Psychology Today** website. You can also call the behavioral health line that is typically listed on the back of your health insurance card to ask them for names and phone numbers of therapists located in your area. If you feel comfortable doing so, you can also ask your trusted friends or loved ones for their recommendations.

It is never too early or late to work on improving your overall health and well-being from the inside out. Help is out there and needing mental or behavioral health support is nothing to be ashamed of. Breaking longstanding societal stigma that surrounds individuals seeking professional mental and behavioral health supports can start and end with you by using your own voice, using your own lived experiences, and becoming the best self-advocate you can be. In the end, we are all only human, we each experience our own feelings and emotions, and we all could use a little extra love, compassion, care, and support from those who surround us daily.

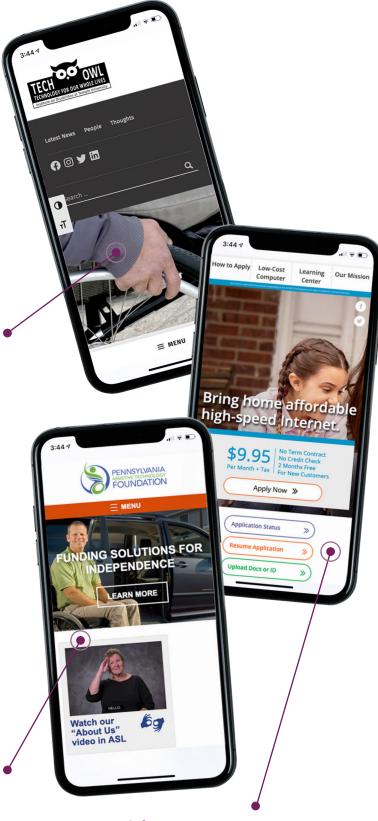
Written by Libby Powers

Technology: Let's Talk About TechOWL, PATF, and Internet Essentials

In the last year we have seen a drastic increase in the number of ways we rely on technology for all aspects of our lives. Many of us have been using our commuters and phones to attend telemedicine appointments, do our grocery shopping, and meet with colleagues and friends. Three programs have come to my attention that have the shared goal of providing people with disabilities access to the technology that is essential to perform these necessary tasks.

TechOWL (Technology for Our Whole Lives) is a part of the Institute on Disabilities at Temple University. They partner with Pennsylvania's Initiative on Assistive Technology to ensure people with disabilities in Pennsylvania have access to assistive technology programs and projects. They provide many services. I suggest you look at their website to see all the resources they provide. TechOWL has a technology lending program for Pennsylvanian seniors or people with disabilities. Through TechOWL's lending library, a person can borrow an iPad, computer or other assistive technology for up to 4 weeks. A loan period can be extended to 6 weeks in some cases. To borrow a device, go to their website and select the tab labeled "Borrow". You will then be able to select "Go To The New Library" on the center of the page. From there, you can create an account, browse inventory and track your loan requests. All loaned devices will be shipped to the borrower's home with a prepaid return label. Remember to keep the original box that you receive the device in so that you can use it later to return the borrowed technology.

The Pennsylvania Assistive Technology Foundation (PATF) is also launching an effort to increase people with disabilities' access to assistive technology. On January 18th, they started a pilot program offering interest-free financial loans between \$100 and \$7,000 to Pennsylvanians with disabilities and older adults for the purchase of needed assistive technology devices and services. More information about this program can be found on the PATF's website.



Internet Essentials is a program offered by Comcast that provides low cost internet service at \$9.95 per month plus tax for those meeting financial eligiblilty requirements and living in areas served by Comcast. For more information, refer to this **website**.

Written by Darcie Illg, PA-C

WHEELCHAIR WORKOUT

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Lower Body Strength and Flexibility



No Equipment Needed!

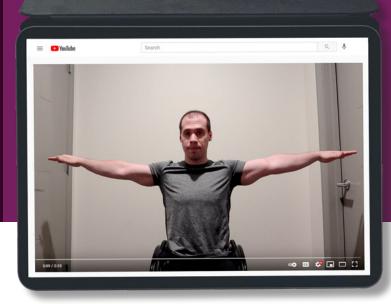
It can be easy to overlook exercising or even *stretching* our lower bodies. Fortunately, there are several different movements that we can perform that are both safe and beneficial.

The **figure 4 stretch** is a commonly used in physical therapy to alleviate hip pain and stretch out the muscles of the hips and low back. Perform this stretch by bending your knee and placing the side of your calf on the opposite thigh so the bottom of your bent leg is facing away from your body. I usually hold this stretch for 15-20 seconds on each side while applying slight pressure to the bent knee. Depending on your level of fitness and Spina Bifida, I recommend completing 1-3 sets of 15-20 seconds at a time with one minute rest between sets. Remember to sit up as straight as possible and do your best to engage your core muscles.

The **knee to chest hold** can be performed either one leg at a time for beginners or those with higher levels of Spina Bifida or both legs for those with lower levels of Spina Bifida. If you perform this movement with one leg at a time, you have the added benefit of more stability during the movement. If you perform this movement with two legs at a time, you will be able to build stability and strength in your core. I usually perform this one for 15-20 seconds at a time with 1 minute rest between sets.

To perform the **knee to chest with reps**, follow the instructions for the knee to chest hold, but instead of holding the knees in place, hold only briefly and repeat the movements. Repet for 15-20 reps or until fatigued, for 3 sets with a minute rest between sets.

For those who walk, the knees can cave inward toward each other, which is called "valgus." This can cause injury



to the tendons and ligaments in the knees. Two exercises can strengthen the muscles around the knee. One option for those who walk is the **bodyweight squat**. Stand and lower yourself into a squatting position, trying to keep your knees outward as you plant your feet on the ground and through the full range of motion. If you cannot walk or are not able to complete this movement due to stability or weight bearing issues, another option is to perform **seated leg extensions** by sitting on a stable surface like a chair and extending your leg from the knee so that the sole of your foot goes from facing the floor to facing the wall in front of you. Repeat the motions for 15-20 reps or until fatigued for 3 sets with 1 minute rest in between.

The Spina Bifida Association "Guidelines for the Care of People with Spina Bifida" released last year state that it is recommended that adults with Spina Bifida should engage in *at least* 150 minutes (2 hours 30 minutes) per week of aerobic activity that is moderate-intensity, 75 minutes (1 hour 15 minutes) of vigorous intensity aerobic activity, or an equivalent combination of the two. While these guidelines will most certainly get you on the right track to achieving fitness goals, there are increased benefits to engaging in further activity beyond this.

If you are looking to increase muscle mass and strength, it is recommended that you engage in *at least* 2 days of resistance training (muscle strengthening) activity per week as well. Added benefits can be seen by engaging in more frequent exercise. I recommend anywhere from 3-6 days per week of some type of exercise for at least 30 minutes at a time.

Click <u>here</u> for a link to other videos you may find helpful in achieving your fitness goals!

Written by Dan McCoy, ACE-CPT

When Summer gives you Lemons...

For me, fruit is one of the best things about summer. In one of my early articles titled "Healthy Tips for those with Bladder Incontinence" from our 2019 winter newsletter, I mentioned removing the 5 C's in our diet. The first "C" mentioned is for Citrus. Citrus is often associated with oranges, grapefruit, lemons, and limes. For those with an overactive bladder, this can cause urgency if consumed frequently in large amounts. However, without overindulging, these fruits have an overwhelming number of nutritional benefits. There are many benefits of citrus fruits used in many different cultures. During hot summer days, I like to hydrate by drinking a cold glass of coconut water. I am not too fond of the taste of coconut water but love the nutritional benefits it provides. Squeezing a wedge of lemon freshens the glass with a bright flavor that also adds antioxidants. Lemonade and desserts featuring our citrus favorites really remind me that summer is near and here! I want to share with you my favorite pink limeade recipe sweetened only with honey and frozen raspberries, and my absolute favorite indulgence is an almond cake that is only slightly brightened by the zest of lemon. What I love most about this dessert is that the almond flour is what flavors the cake, and it is naturally gluten free. It is also a very light dessert that is perfect for the summertime.

Written by **Sara Izzo**



"There is no sincerer love than the love of food."

George Bernard Shaw

If you are interested in reading about the health benefits of citrus fruits, please check out this **reference**.

Pink Limeade

Makes 1 serving | 2-3 minutes prep time

10 oz cold filtered water

2-3 spoons of frozen raspberries

1-2 Tbsp honey (sweeten to taste)

1 fresh lime (juice 1 half at a time)

In a tall glass, spoon in your frozen raspberries and add the juice of 1 half of your lime. Then add 1 tbsp of honey and your water. Mix with a spoon and taste your limeade, adding more lime or honey to your liking.



Summer Almond Cake

Makes 4-6 servings | 10-15-minute prep time; 25-30 baking time

- 1 1/2 almond flour
- **4 eggs** (separated; see below)
- ½ cup granulated sugar
- 14 cup sliced almonds
- 1 lemon

Powdered sugar for decoration (optional)

How to separate eggs: Take 1 small mixing bowl, 1 regular sized mixing bowl and 1 grocery bag, for the eggshells, ready on your counter. Using clean hands, crack an egg and drop it in the small mixing bowl and throw away your shell. Using a serving spoon, or your hand, scoop the yellow yolk carefully letting the white part of the egg slip away and separate from the yolk. Take your separated yolk and carefully place it in the large mixing bowl. Repeat this process for all 4 eggs.



Pre Heat Oven at 350°

In your mixing bowl with your egg yolks, add your ½ cup of granulated sugar and beat with a hand mixer for about 3 minutes until creamy and light. Using a zester or grater, zest 1 lemon right into your mixing bowl and add your almond flour. Use a spatula or mixing spoon and fold the flour and zest into the sugar and egg yolk batter. Set aside.

Rinse off the whisks to your hand mixer and dry them with a towel. With your clean mixer, take your egg whites in the small mixing bowl and beat on high for 2 minutes until you see peaks form. Take one giant spoonful of the egg whites and add them to your batter by folding them in. Just fold until the egg whites are mixed in, do not over mix. Add one spoon at a time until you have used up all the egg whites. Grease a 9 inch cake pan and pour batter into the pan using a spatula. Sprinkle the ¼ cup sliced almonds on top and bake 350° for 30 minutes checking for doneness around 25 minutes.

Let cake cool for 45 minutes, sprinkle with powdered sugar if you desire. Enjoy!

Written by Sara Izzo



Master the **FACTS** about the Mediterranean Diet

What is the Mediterranean Diet?

Though not new, the Mediterranean-style diet has continued to make waves over the years. For the fourth year in a row, U.S. News & World Report has listed the Mediterranean diet as their "No. 1 Best Diet Overall" in 2021. It is also included in the 2020-2025 Dietary Guidelines for Americans as a healthy eating pattern for wellbeing and to prevent the risk of chronic disease. But what makes this eating pattern unique? A key point of the Mediterranean diet is there is no single "diet." The phrase "Mediterranean diet" is a broad term that refers to dietary patterns often seen in countries bordering the Mediterranean Sea. Instead of a strict set of rules, there is a focus on including plant-based foods such as whole grains, fruits, vegetables, beans, and unsaturated fats (such as nuts, seeds, and olive oil) throughout the day. Herbs and spices add flavor to liven up meals. Dairy, eggs,

lean meat, and seafood are eaten in moderation. The diet limits red meat, added sugar, saturated fat, and highly processed foods. Let's take a closer look at the main foods that make up a Mediterranean-style diet!

✓ CHOOSE: Fruits and Vegetables

Fruits and vegetables provide vitamins and minerals that our bodies need for good health. They also contain fiber, which helps keep us feeling full and promotes regular bowel movements. In addition to these functions, a specific kind of fiber called "soluble fiber" also helps lower low-density lipoprotein (LDL) cholesterol levels. LDL cholesterol is known as "bad" cholesterol because when levels are too high, it contributes to fat deposits in the blood vessels, which increases the risk of heart disease and stroke. Soluble fiber helps bind to cholesterol, so you absorb less of it. A few examples of fruits and vegetables higher in soluble fiber are oranges, Brussels sprouts, and asparagus. Beans and oats are also sources of soluble fiber. The other form of fiber found in fruits, vegetables,

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beans, and whole grains is called "insoluble fiber," which encourages regular bowel movements and thus helps with constipation. Many foods contain both types of fiber. In addition to their nutritional value, fruits and vegetables brighten up our plates with colors and textures. Variety is important, so pick rich reds, bright oranges, dark greens, and deep blues to include a rainbow of produce in your diet! As summer begins, it is a great time to include more fruits and vegetables into your day. Add orange slices and pomegranate onto a salad for a burst of flavor, toss tomatoes and cucumber with basil and olive oil for a refreshing side dish, or grill colorful vegetable kebabs.



✓ CHOOSE: Fish, Lean Protein, and Beans

In the Mediterranean diet, fish and seafood are encouraged at least two times per week. Fatty fish like tuna and salmon provide heart-healthy omega-3 fatty acids. Eggs, lean poultry, and low-fat dairy are also incorporated in moderation during the week. Red meat is not eliminated but is consumed less often - such as a few times per month. Legumes, which include beans, peas, and lentils, are another staple in the Mediterranean diet. They are a plant-based protein source that is low in saturated fat (the type of fat that raises your LDL cholesterol) and provide both soluble and insoluble fiber. They also provide vitamins and minerals such as iron, magnesium, and potassium. Interested but unsure how to add more legumes to your diet? Try dipping vegetables like carrots, peppers, or celery into hummus for a snack. Or, add beans into soups or salads. Lentils can be used as a substitute for ground meat in recipes like tacos or pasta sauce. Experiment with recipes and you may find a new favorite!

✓ CHOOSE: Whole Grains

What is a whole grain versus a refined grain? A whole grain is made up of three parts: the bran, germ, and (continued on next page)



Mediterranean Chicken and White Bean Salad

Makes 4 servings | 20 minutes prep time

1 cup cooked chicken (diced into 1/2-inch pieces)

1 can (15.5 ounce) **low-sodium white beans** (drained and rinsed with cold water)

1 cucumber

(peeled and diced into 1/2-inch pieces)

% red or white onion (peeled and chopped into 1/2-inch pieces)

1/2 cup chopped fresh tomatoes

2 Tbsp vegetable oil (or olive oil)

¼ cup lemon juice

1 Tbsp dried basil or parsley leaves

¼ tsp salt

¼ tsp black pepper

Put all ingredients in a bowl and gently toss to combine. Serve right away, or cover and refrigerate up to 2 days.

Notes

- 2 (5-ounce) cans of tuna in water can be used instead of chicken.
- Great Northern, chickpeas, cannellini, or navy beans can be used.

Source: <u>USDA Center for Nutrition Policy and Promotion</u>

endosperm. To process whole grains into refined grains, the bran and germ are removed, leaving the starchy endosperm behind. However, the bran and germ contain nutrients such as fiber, iron, and B vitamins. Therefore, whole grains naturally contain more of these nutrients than refined grains. How can you add more whole grains into your day? Pick whole wheat pasta (or mix half and half with regular pasta), choose whole wheat bread, and pick brown rice instead of white rice. Feeling more adventurous? Try whole grains you may not have heard of before, such as guinoa, farro, barley, or bulgur!



✓ CHOOSE: Unsaturated Fats Instead of Saturated Fats

Fat is part of a balanced diet, but certain types of fat are healthier than others. What's the difference? Saturated fat intake is associated with higher LDL cholesterol levels. High LDL levels can increase the risk of heart disease and stroke. Saturated fats are found mostly in animal products, such as meat (think marbled steaks or the skin on poultry), high fat dairy products, palm and coconut oils, and butter. Saturated fats should be limited. Trans fats (or hydrogenated oils) also increase LDL cholesterol levels. Trans fats are found in processed baked goods or snack foods and in stick margarine. Try to avoid trans fats. Unsaturated fats, when eaten instead of saturated fats, can help lower LDL cholesterol levels and may reduce the risk of heart disease. Unsaturated fats are found in fatty fish like salmon, nuts/seeds, and plant oils such as olive or canola oil. Omega-3 fatty acids are a type of unsaturated fat found in foods such as salmon and tuna, walnuts, and ground flax seed. Intake of omega-3 fatty acids may lower triglyceride levels, which is also helpful for heart heath. Foods rich in unsaturated such as nuts, seeds, fish, and olive oil are plentiful within the Mediterranean eating style. To add sources of unsaturated fat into your diet, try cooking with olive oil instead of butter, add chopped nuts into salads, or pair avocado with whole wheat toast. Swap saturated fats out for unsaturated fats when possible when making food choices. Remember that all fat is still high in calories, so portion size is important.



✓ CHOOSE: Herbs and Spices

The Mediterranean diet utilizes herbs and spices to flavor foods, rather than excess salt intake. Experiment with basil, garlic, pepper, parsley, oregano, or other herbs and spices that appeal to you to add extra flavor to your dishes.

✓ LIMIT: Added Sugar and Refined Foods

Sweets and beverages with added sugars are limited in the Mediterranean diet. Highly refined processed foods are also eaten less frequently, such as white rice and white pasta.

WHAT'S THE BOTTOM LINE?

The Mediterranean-style diet is more of an eating pattern than a strict diet. It does not focus on eliminating food groups. Instead, it emphasizes plant-based foods such as fruits, vegetables, whole grains, nuts, seeds, and legumes, paired with moderate intake of fish, chicken, dairy, and healthy fats. It is a flexible eating pattern and can be tailored to an individual's tastes, budget, and lifestyle.

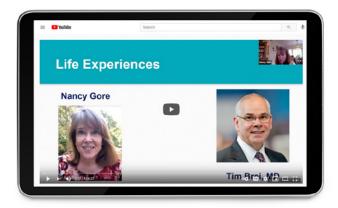
Written by Jacquelyn Klunk, MS, RDN, LDN

Article References:

- 1. US News article
- 2. <u>U.S. Department of Agriculture and U.S. Department of Health and Human Services dietary guidelines for Americans</u>
- 3. heart article 1
- 4. eatrightpro article
- 5. heart article 2

Webinar: Your Health After Forty

Dr. Dicianno recently participated in a webinar that discusses health issues of people with spina bifida age 40 years and up. This webinar explores aging well in body and mind, caring for aging parents, considerations to minimize wear and tear on your joints, and changes in mobility. You can watch the webinar <a href="https://example.com/here/health/people.com/health/pe





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**.

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:

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:

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.

Access Kaleidoscope (SBAWP's newsletter) here.



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: <u>UPMC.com/SpinaBifida</u>