UPMC
LIFE CHANGING MEDICINE

UPMC Adult Spina Bifida Clinic Spring 2026 Newsletter

It is often said that springtime marks the true new near – a season rooted in renewal, fresh energy, and new beginnings. Nature wakes up and energy returns. This season, we invite you to celebrate your strength and take steps toward wellness. Whether you're focused on health goals, education, employment, or connection, remember that growth happens when we nurture ourselves. Below are some community events to support your journey:

2026 Disability & Mental Health Summit Resource Fair

Date: Thursday, May 7, 2026 (11:00 AM - 2:00 PM)
Location: CCAC Allegheny Campus, Pittsburgh, PA
Register here

Access Mob Pittsburgh 2026 Lecture Series (online only)

"Thinking Outside of the Box: Employment and Persons with Disabilities"
Date: Monday, March 30, 2026 (6:00 PM - 7:30 PM)
Register here

"More Than Words: Empowering Nonverbal Youth Through Multimodal Communication Access"
Date: Monday, May 18, 2026 (6:00 PM – 7:30 PM)
Register here

Written by ***Olivia Hughes***

Anxiety and Spina Bifida

Anxiety is a common experience for many adults living with spina bifida (SB). It can show up in different ways: sometimes as a feeling of nervousness before a medical appointment, other times as a sense of worry about trying something new or facing changes in routine. For some, anxiety is a constant companion, while for others, it comes and goes depending on life's circumstances.

If you have ever felt tense, restless, or found yourself thinking about worst-case scenarios, you are certainly not alone. Anxiety is a normal human emotion, and it serves an important purpose by helping us respond to danger or uncertainty. However, when anxiety becomes persistent, overwhelming, or starts to interfere with daily life, it can be difficult to manage without support.

People experience anxiety in different ways. Some notice physical symptoms, such as a racing heart, tightness in the chest, upset stomach, or trouble sleeping. Others find that anxiety shows up more in their thoughts, possibly as a constant worry, fear of making mistakes, or a sense that something bad is about

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"It is important to remember that anxiety does not define you. It is something you experience, not who you are. "

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to happen. Anxiety can also influence behavior, leading people to avoid certain places, people, or activities that feel stressful or unpredictable. For adults with SB, anxiety may be connected to medical challenges, social situations, or uncertainty about the future. It might arise before a procedure, when meeting new people, or when routines are disrupted. Sometimes, anxiety appears without any clear reason at all.

It is important to remember that anxiety does not define you. It is something you experience, not who you are. With the right team and approach, anxiety can be managed, and you can continue to live a fulfilling life. There are many approaches to managing anxiety, and what works best can vary from person to person. Some people find that talking about their worries with trusted friends, family members, or support groups helps them feel less alone. Others might benefit from either medication-based or non-medication-based anxiety treatment.

To this second point, acceptance-and-commitment therapy (ACT) and cognitive-behavioral therapies (CBT) are two non-medication therapies for anxiety that have been found to be highly effective. These approaches differ slightly, but both focus on learning how to live a meaningful life consistent with your values even when feeling anxious. Over time, this approach results in the "volume being turned down" on the anxiety. Certain medications, like selective-serotonin reuptake inhibitors—or SSRIs—have also been found to be effective in treating anxiety.

In addition to professional help, there are everyday strategies that can make a difference. Simple routines, like keeping a regular schedule or breaking tasks into smaller steps, can help reduce uncertainty and make life feel more manageable. Paying attention to your senses—what you see, hear, touch, smell, and taste—can help you stay present and grounded during stressful moments. Taking deep, slow, steady breaths can calm both body and mind. Reaching out for support, whether through friends, family, or your healthcare team, is always encouraged.

If anxiety is making it hard to enjoy life, maintain relationships, or take care of your health, consider discussing this with the team during your next visit to the SB Clinic. Your providers can help connect you with resources and support tailored to your needs, values, and goals. Remember, anxiety is a part of life for many people, but with understanding and the right tools, it can be managed. You are not alone, and help is available.

*Written by **Ted Barrios, PhD***

Accessible Gaming: Opening Play to Everyone

Accessible gaming ensures people of all abilities can enjoy video games by using thoughtful design and adaptive technology.

Pittsburgh's Leadership in Inclusive Gaming

The **United Spinal Association of Pittsburgh** is helping make gaming accessible across the region through its Tech Access Initiative. In partnership with UPMC, the chapter supports **Empowered Esports**, a program that brings people with mobility disabilities together to play, connect, and compete.

What the Program Offers

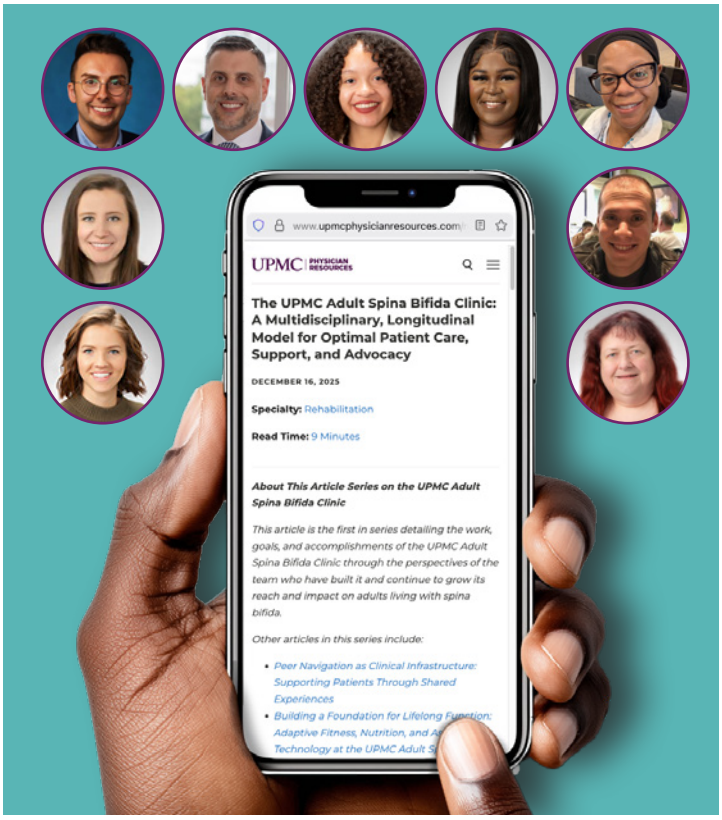
- Monthly Community Gaming Nights featuring Xbox, PlayStation, Switch, PC, and VR. Meeting at UPMC Mercy Pavillion
- Adaptive Gaming Equipment available onsite for anyone who needs alternative controls.
- Free Adaptive Gaming Evaluations with clinicians who help participants find the best setup—and sometimes even secure equipment at no cost.

Pittsburgh is proving that gaming truly is for everyone. Learn more at: **unitedspinalpgh.org**.

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

Education, Awards, and Outreach

Dr. Dicianno was featured on Sirius XM Doctor Radio on December 8, 2025 to speak about Spina Bifida and Assistive Technology. He will also be receiving the Outstanding Service Award at the Association of Academic Physiatrists meeting in Feburary, 2026 for "exceptional efforts by an AAP member to improve and benefit the field of PM&R through significant contributions to council programs, initiatives, and activities." Monica will be involved in advocacy at the Spina Bifida Association's Teal on the Hill event in March 2026.



UPMC Physician Resources Highlights our Clinic

UPMC Physician Resources recently published a series of articles about the UPMC Adult Spina Bifida Clinic and various programs we offer. The series also highlight the lived experiences of four of our staff members who are adults with Spina Bifida, all of whom contribute to this newsletter. We welcome you to read more about us and our programs.

Written by ***Brad Dicianno, MD***

Spina Bifida Advocacy with NASCAR

Richard Jenkins, a longtime NASCAR fan, has been raising awareness for Spina Bifida. He and his family traveled to Martinsville Virginia for a race, and he was able to make a connection with NASCAR leadership. He later received a call from them, and they surprised him with an experience of a lifetime – a chance to be an honorary Pit Crew member and to promote Spina Bifida Awareness during the race. You can watch the video of his call on X **here**. Richard noted, "I have been working for years to make this happen and to see it finally come through makes me happy. Just wanted to let you know, Spina Bifida is now known to THOUSANDS of more people."

Crafting and Community

Spring is the season for self-reflection and fostering a community. Crafting can help uplift your mood and create a sense of belonging.

Through art and creativity, individuals are able to create and strengthen bonds with those around them. The holiday season is often a time when many look forward to seeing friends and family; it can also be a difficult period for others who feel isolated or disconnected from their peers. However, spring welcomes room for change and new energy. When people are given the ability to express themselves through art—whether it's drawing, painting, sewing, or any other creative outlet—they can turn their emotions into tangible expressions that manifest into the world around them. Frida Kahlo, a Mexican painter, explored cultural identity, pain, and inner struggles which were displayed in several self-portraits, including "The Broken Column" (1944). Despite physical barriers, she used art to express her lived experiences as an individual living with chronic pain and disability.

"I don't paint dreams or nightmares.
I paint my own reality"

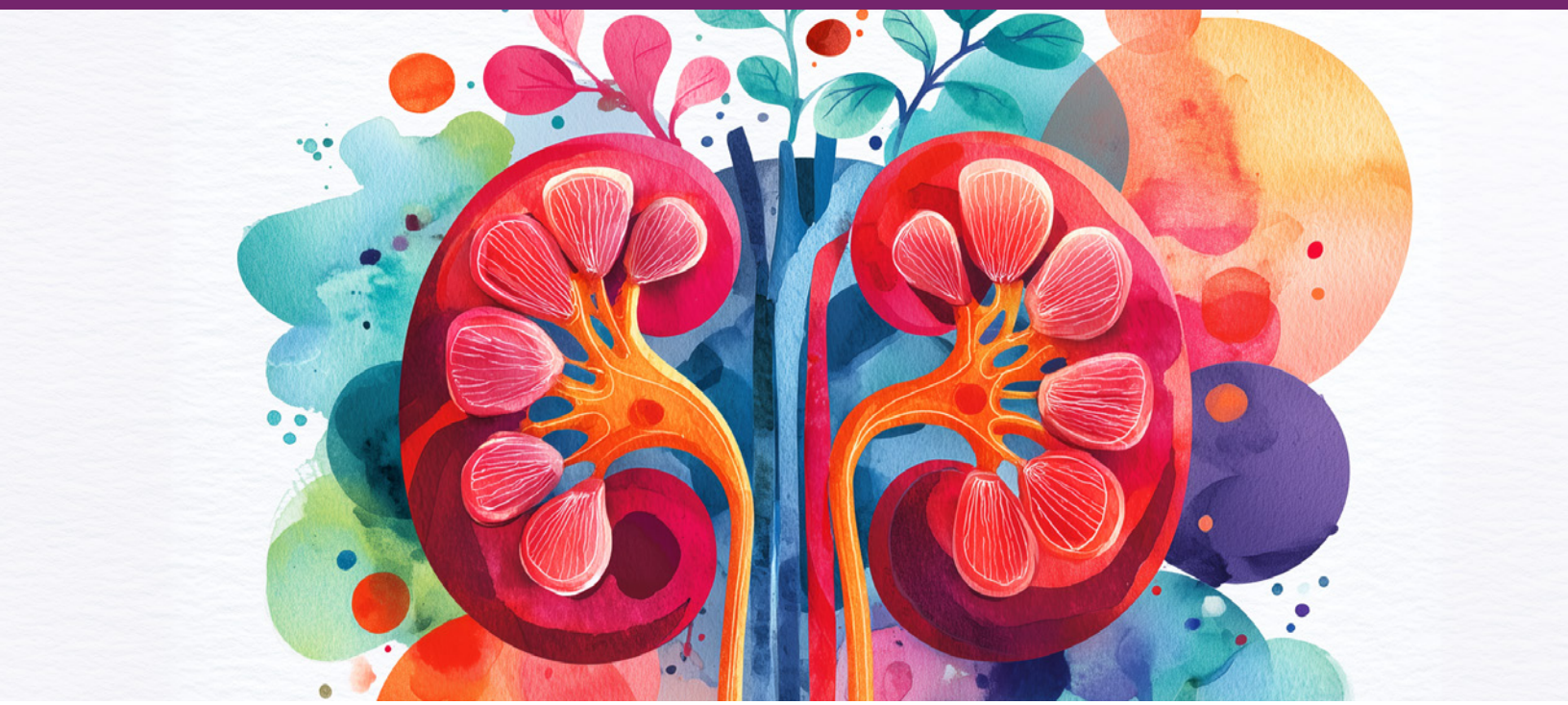
— Frida Kahlo —

This spring, reflect on what you feel and are looking forward to accomplishing this season. Here are 3 craft ideas to get you started:

1. **REFLECTION COLLAGE** – Create a collage using a small journal or calendar with scrapbook, magazine, and mixed-media materials to highlight a collection of images, words, and colors that reflect your memories and emotions.
2. **BLOOM BOARD** – Create a seasonal-themed collage using paper or natural materials. On each petal, reflect on what you've learned about yourself; your achievements, growth, and the challenges you hope to overcome in the months ahead. Let the center of the flower symbolize a core value, mission, or intention you hope to nurture this season.
3. **GRATITUDE LETTER** – Take a moment to reflect on what you've accomplished and what you hope to achieve. Write a letter to yourself, then tuck it away to revisit later as a gentle reminder of self-acceptance, growth, and gratitude.

No matter what style of art you choose to express yourself with this season, remember to reflect on your strengths and personal identity as you continue on your creative journey.

*Written by **Cheyenne Hennen***



Understanding Yearly Kidney Checks

At your annual visits, we order an ultrasound of your kidneys and bladder, blood tests called Creatinine and Cystatin C, and a urine test called Albumin Creatinine Ratio. We use these tests to measure kidney function. The ultrasounds allow us to see whether there are stones in your bladder or kidneys or whether the kidneys are experiencing too much pressure. You may already be familiar with Creatinine because many physicians order it. When Creatinine is elevated, it means that the kidneys are not functioning as well as they should be to clear this substance out of the body. However, a person's Creatinine level depends on how much muscle is on their body. And because some people with Spina Bifida have a lower amount of muscle, Creatinine can remain low even when the kidneys are starting to have problems. Cystatin C, on the other hand, does not depend on muscle mass. Recently our team published a scientific article demonstrating that Cystatin C is a more stable measure of kidney function in people with Spina Bifida compared to Creatinine, especially those who have higher spinal lesions and in those who have myelomeningocele. It may allow us to detect kidney problems earlier. The Albumin Creatinine Ratio measures how much protein is in the urine, and when it is elevated it means that the kidneys might be having problems. The combination of these tests allows us to determine your risk of developing kidney problems in the future and whether a consultation with our kidney doctor (nephrologist) is needed. We now have the ability to consult our nephrologist electronically, which means he doesn't need to see you at first and can review your labwork and provide recommendations for how often we should check labs, whether any follow up with him is needed, and whether any treatments are needed to protect the kidneys. In some people who have had surgeries that have affected the small bowel, like bladder reconstructive surgeries, we also check your B12 level. The small bowel is where you absorb this vitamin, and those with prior surgery can sometimes have difficulty absorbing it, leading to a vitamin deficiency.

The good news is that these tests can help us detect and address kidney problems long before they become major problems.

The good news is that these tests can help us detect and address kidney problems long before they become major problems. The tests need to be completed at least once a year (and sometimes more often if you have kidney problems already). Those who have had bladder surgeries should also see a urologist because you may need a periodic scope to take a look at your bladder. If you have any questions about your kidney studies, please ask us at your appointments and be sure to follow up regularly for your testing.

Written by ***Brad Dicianno, MD***

Caffeine Craze

Caffeine is in a lot of foods and drinks – whether naturally found in the food or added later. Many people choose to drink caffeine to help them feel more awake during the day. But how much caffeine is safe?

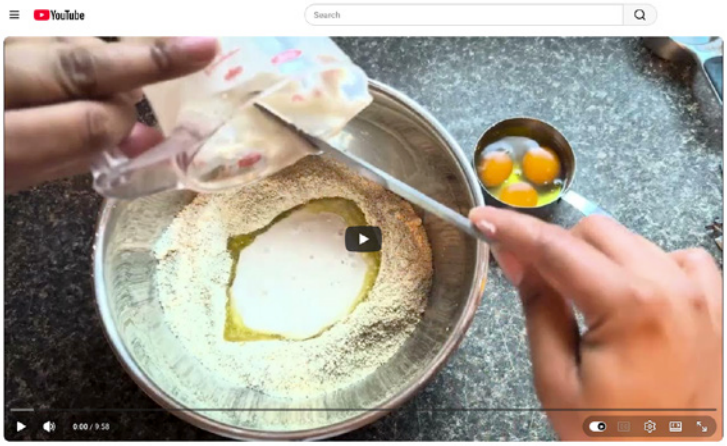
For many adults, some caffeine can be a part of a healthy eating pattern. The FDA recommends consuming no more than 400 mg of caffeine daily to avoid negative effects of too much caffeine. This is the same as about two or three 12-ounce mugs of coffee. To help stay under this limit, it is important to read labels on foods/drinks with added caffeine (like energy drinks) because they often contain large amounts of caffeine in each serving. For some people, it is easy to let caffeinated drinks take the place of water, which can lead to dehydration – so don't forget to drink water throughout the day too!

Some adults have medical reasons (such as some heart conditions) that require them to reduce or avoid caffeine intake. Pregnant or breastfeeding people should also consume less caffeine. Some people also find that they are individually more sensitive to caffeine. "Decaffeinated" drinks do often contain small amounts of caffeine (up to about 15 mg), so if a person is very sensitive to caffeine, they may need to also avoid decaf drinks. If you are unsure, it is important to talk with your healthcare provider about whether you should restrict your caffeine intake.

For people with spina bifida with neurogenic bladder, it can be helpful to pay attention to caffeine intake as it can irritate the bladder and increase the urge or frequency of urination. Caffeine can also cause some people to have stomach upset like heartburn or diarrhea; however, because it can help encourage a bowel movement, some people find caffeine helpful for constipation *(tip: a warm drink with caffeine in the morning can stimulate some of our natural reflexes to tell the body to have a bowel movement. If you can't tolerate caffeine, a warm drink in the morning can still be helpful for this even without caffeine).* Too much caffeine or drinking it too late in the day can also affect our sleep cycles and make falling/staying asleep more difficult. Try limiting your caffeine intake about 6 hours before bed to prevent it from altering your sleep.

If you are looking to cut down on your caffeine intake, doing so slowly over a few weeks can reduce the chance of getting headaches from caffeine withdrawal. While caffeine withdrawal is not dangerous, it can be uncomfortable.

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



Baking Without Barriers: Spring into Accessible Cooking

Cooking is a personal joy for me and as an adult with Spina Bifida, I think that baking is something everyone can enjoy.

This is a favorite recipe of mine that is easy for any person, especially for those who may be limited in movement or feel uneasy about using a hot oven. We will be covering the important tips and tricks used for baking with a slow cooker and covering other basics of baking any cake. I hope you get the chance to enjoy this delicious, Spring recipe video, **Almond Pound Cake**. I will be using a traditional pound cake recipe that's baked in a bread pan – the twist is baking with my trusted family sized slow-cooker and applying some tips that will allow you to adapt this technique to nearly any cake recipe you like.

THE BASICS IN BAKING MATERIAL

Using the right baking pan for your slow cooker starts with knowing your materials. Metal baking pans such as steel or aluminum are the most reliable and available baking pans to date. According to cooking experts from ***Bon Appétit***, metal pans hold heat wonderfully (great heat conductors) providing your baked goods with moist centers and crispy edges when desired (Jampel, 2020). Metal is also a safer option than glass bakeware due to the material in glass having a tendency to crack with sudden changes in temperature. Silicone and ceramic are also baking options, but they take longer to warm up and may not have the same desired texture that you would traditionally get from using metal bakeware. This makes metal perfect for your oven or in this case, our slow cookers!

TIPS USING A SLOW-COOKER FOR BAKING

Shape and Size: Now that we have the perfect pan in mind, let's talk about using the right size and shape metal pan. Slow cookers come in many sizes and shapes and are traditionally round or oval, making round metal cake pans for round slow cookers and rectangle bread pans for oval cookers, the perfect type for our use.

To bake one 8' inch cake or one regular sized bread pan (9x5x3), you will need a slow cooker that's **6-quart round** or **5-quart oval in size or larger**. An 8-quart slow cooker is highly suggested because it allows enough space for you to take out your pan easily with oven safe gloves; however, using a cake pan smaller than 8' inches will help you avoid this problem if 5 or 6 quarts is all you have. No need to buy a bigger slow cooker!

THE PERFECT BAKE

A Foil Rack: Creating a rack for your slow cooker allows your cake to rest in an elevated position, mimicking the same type of air circulation that's used in an oven. You will do this by taking about 13 inches of aluminum foil and folding it longways until you have a thick long strip of foil. You will fold the ends together making a ring big enough for your pan to rest on and small enough to fit in your slow cooker. To ensure the size fits, test this before baking by placing your rack in the slow cooker after forming and then put the pan on top, adding pressure to ensure it is level. After your test, make sure you are pouring your cake batter safely into your cake pan while it's still on the counter. **Do not pour your cake pan while the pan is in the slow cooker!**

Hot Water for Preparing the Slow Cooker: Once you have your aluminum foil rack in the slow cooker and you have prepared your cake batter recipe, safely heat up 2-3 cups of water in your microwave. Pour your hot water over your foil rack and safely place your batter filled cake pan on top.

Cover the slow cooker with a dry clean towel. This important step ensures condensation doesn't drip moisture on your cake making it soggy. After placing a clean towel that covers the top of the slow cooker, add the lid and fold over the corners and secure around the handle with a hair tie (you can use a rubber band as long as you are NOT allergic to latex)

Toothpick Check: Stick a toothpick in the center of your cake. If it comes out clean with no wet marks, it's done!

My Slow Cooker Almond Cake is the perfect recipe for trying these tips. The lightness that comes from the almonds pair beautifully with your favorite Spring fruit and whipped topping. I hope these tips encourage you to tap into your baking skills and the power that comes with independence.

*Written by **Sara Izzo***

Slow Cooker Almond Pound Cake

Servings 2-4 | 15-minute prep time; Cook 1.5 hours; Total 1hr 45 min

EQUIPMENT

- **6–8-quart slow cooker**
- **Mixing Bowl**
- **Spatula**
- **Hand Mixer**
- **Measuring Cups and Spoons**
- **Clean Towel and Hair Tie for Lid**

DRY INGREDIENTS

- **2 cups Almond Flour**
- **½ cups All-Purpose**
  (can use Gluten Free All-Purpose)
- **½ cup sugar**
  (I used a mix of cane and coconut sugar for a caramelized texture)
- **½ tsp baking soda**
- **½ tsp baking powder**
- **½ tsp salt**

WET INGREDIENTS

- **¼ cup melted butter or neutral oil**
  (canola, vegetable, or coconut)
- **½ cup plain yogurt (can use dairy free or regular sour cream/Greek yogurt)**
- **¼ cup milk** *(I used Almond Milk for dairy free)*
- **2 tsp vanilla extract**
- **3 large eggs**

Watch on YouTube!

INSTRUCTIONS

1. *Prepare your slow cooker using the foil rack instructions above.*
2. *If using butter instead of oil, melt butter in a microwave and set aside to cool*
3. *In one large bowl, combine dry ingredients: Both flours, sugar, baking powder, baking soda, and salt and whisk together. Press out any lumps to avoid clumps in your batter. Form a pit in your dry ingredients like a well.*
4. *Add wet ingredients to your well in the bowl: Butter/oil, milk, yogurt, and eggs*
   a. *If you have a liquid measuring cup, you can measure the ¼ cup milk and scoop out your ½ cup yogurt and mix this in with your milk. Adding your vanilla to this mixture makes it easier to poor all wet ingredients together.*
   b. *Add eggs in the batter one at a time by cracking each into the measuring cup first to avoid cracked egg shells*
5. *Mix all ingredients together using a hand mixer. Scrape sides after 1 minute and mix again for 30 seconds.*
6. *Pour batter into a bread pan and use the hot water preparation tip above. (safely heat up 2-3 cups of water in your microwave and pour hot water over your foil rack and safely place your batter filled cake pan on top)*
7. ***Cover the slow cooker with a dry, clean towel** and add the lid. Fold over the corners and secure around the handle with a hair tie. Set Slow Cooker on High and bake for 1.5 hours. Use toothpick check for doneness.*
8. *Remove from cooker and cool for 15 minutes. Turn pan over and let cake finish cooling before decorating.*

*Written by **Sara Izzo***

Embrace Spring:

Opportunities for Adaptive Exercise

As the days grow longer and the weather becomes warmer, spring presents an excellent opportunity to become more active, both indoors and outdoors.

For adults with Spina Bifida, exercise is not only about building bigger and stronger muscles—though that is certainly a major benefit—but also about seeking enjoyment, fostering independence, and building a sense of community.

The Importance of Exercise

Regular physical activity offers a wide range of benefits, such as enhanced enjoyment, improved independence, and meaningful opportunities to connect with others in the community. By joining adaptive sports and fitness programs, individuals can improve their health, nurture friendships, and become more involved with those around them. Spring is an especially favorable season to begin new activities and strengthen these connections, making exercise a vital part of a healthy and satisfying lifestyle.

Spring Workout Options

- **Resistance Band Home Workouts:** Enjoy low-impact strength training that can be performed from a wheelchair or seated position.
- **Outdoor Workouts:** Take advantage of the pleasant weather to work out outside.
- **Going for a Walk or Roll:** Spend time outdoors, whether walking or rolling to get fresh air and exercise.
- **Traditional Gym Workouts:** Access equipment and facilities for a comprehensive fitness routine.
- **Virtual Trainings:** Participate in one-on-one sessions or group workouts online for ease of access and social interaction.

Tips for Success

Experiment with different activities to discover what you enjoy most. Invite friends or join a group to stay motivated and foster social connections. Remember to set realistic goals for yourself and take the time to celebrate each small achievement along the way!

*Written by **Dan McCoy, MS, CPT***

Spina Bifida and Sensation

Many people with Spina Bifida have decreased sensation, or a decreased ability to feel pressure, pain, and temperature. Have you ever wondered why that is?

To answer, you first need to understand how your spine and nerves are involved in sensation. Your spinal cord serves as the central communication system between your brain and body parts. Branching off your spinal cord are spinal nerves. These nerves communicate between your spinal cord and the rest of your body. In your brain, when you think about what you want to do, your brain tells a muscle to move by sending a signal through your spinal cord to the nerves that talk to that muscle. Signals can also come back the other way; when you feel something with your fingertips, this signal is sent through nerves to your spinal cord, then up to your brain. Your brain recognizes this signal ,and that is how you can feel sensation such as pressure or pain on your fingers.

The term "Spina bifida" means "open or split spine". While there are several types of Spina Bifida, most types cause damage to the spinal cord or to the spinal nerves or both. This means that the nerve communication pathway is interrupted at the level of the Spina Bifida, and sometimes at nearby levels too. Because many people with Spina Bifida cannot feel parts of their lower body, they do not have that warning sign of pain when their skin is hurt by trauma, a burn, or pressure. It is very important for people with decreased sensation to perform skin checks; looking at the parts of the body where they can't feel for signs of injury.

Written by ***Darcie Petrillo, MPAS, PA-C***

Upcoming Events

March 14, 2026
April 11, 2026
May 9th, 2026
Empowered Esports — Gaming Readapted | The Adaptive Gaming Resource
2pm–5pm

March 30, 2026
AccessMob PGH Lecture Series — Thinking Outside of the Box: Employment and Persons with Disabilities

May 7, 2026
13th Annual Disability & Mental Health Summit

September 26, 2026
Disability Pride Pittsburgh
More info to come

For information regarding events and/or camps and retreats with the Spina Bifida Association of Western Pennsylvania, 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**

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