

## Introducing Two New Team Members and a Brand New Clinic Space!

The UPMC Adult Spina Bifida Clinic has moved to the new Mercy Pavilion.

The new Pavilion is groundbreaking because it houses cutting edge clinical and research programs all geared toward improving the lives and function of people with disabilities. It is embedded with innovative technologies and meaningful artwork and was designed to be an accessible and inclusive space. We are also proud to introduce two new members of our team.

The 410,000-square-foot, 10-story UPMC Mercy Pavilion is home to the UPMC Rehabilitation Institute, the UPMC Vision Institute, and several University of Pittsburgh research laboratories including the Rehabilitation and Neural Engineering Laboratory.

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*Amy*



*Monica*





The Rehabilitation Institute includes an innovative hybrid outpatient clinic and therapy gym, including a fully functional apartment and a healing garden on the rooftop terrace with various surfaces for learning wheelchair skills. The exam rooms are fully accessible with ceiling lifts and height adjustable examination tables. A wide, glass staircase with seating serves as a meeting space for clinicians and researchers and offers panoramic views. A glass elevator provides a similar experience for wheelchair users. The building has accessible parking and an outpatient laboratory for bloodwork and urinalysis. A bridge connects the Pavilion to the third floor of UPMC Mercy Hospital. The building was designed with input from one of the world's few blind architects. Art also plays a powerful role in the Pavilion through unique and commissioned pieces that focus on the senses, healing, culture, and empowerment. Read more about the [artists](#) and [artwork](#) featured in the Pavilion.



**LEFT:** A central gym with floor-to-ceiling windows with views of Mount Washington and the South Side Slopes.

**BELOW:** UPMC Mercy Pavilion rooftop garden.



*Monica & team*

### Amy Kiska, BSW

Amy is our new social worker. Amy obtained her Bachelor's degree in Social Work from Grove City College. Prior to living in Pittsburgh, she lived in New Jersey. She has experience in providing Supported Employment services to adults with disabilities which includes identifying jobs for people with little to no work history. Her primary role as a Social Worker for the Department of Physical Medicine and Rehabilitation Department is to collaborate with the healthcare team and provide relevant community resources by developing and implementing individualized plans of care.

### Monica Albert Still, RN, BSN

Monica is an adult with Spina Bifida who joins our team as our new Nurse. Monica spent most of her life in Connecticut and graduated Magna Cum Laude from Southern Connecticut University with her Bachelor's degree in Nursing. She has spent her nursing career helping people thrive in the community. Working her way from home care to starting two Home Health Care Agencies as the administrator, she decided to take on a new challenge. After 30 years in nursing, she has now turned her focus to the advocacy part of nursing

and serving her community on a broader level. She is involved in advocacy at the local, state, and national levels. Monica currently serves as a board member of Access Mob Pittsburgh. She is honored to serve as the secretary of the board for Disability Rights PA and the CT Health Law Project. She is on the planning committee for Disability Pride Pittsburgh. She graduated from the LEND program at the University of Pittsburgh. She has been involved with the UPMC Adult Spina Bifida Clinic as a leader in our peer navigator program and a member of our Spina Bifida Care Advisory Network. She is also a founding member of the Spina Bifida Association's (SBA) Adult Advisory Council and continues to serve this council and various other committees at SBA. When she began her nursing career she was in pediatrics. Her goal then was to become the nurse in a pediatric Spina Bifida Clinic. At the time, no adult clinics existed. Her career path took her in a different direction for a while. She is thrilled that it has landed her where she has always envisioned herself being. She plans on continuing research on adult care, advocacy, and improving the lives of everyone affected by Spina Bifida. Monica is the mom to two beautiful adult daughters and grandmother to one adorable girl.

*Written by Brad Dicianno, MD*



*"We can't change our world around us,  
until we change our mindset of the world  
around us."*

## Change Your Mindset, Change Your Life!

Have you ever tried to start a new health routine and wondered why it is so difficult to stick to it, even when you came up with the idea yourself? Well, me too!

I personally have struggled with consistency and accountability. We all know how difficult it can be to start a new routine and even more difficult to stick to it for the long term. What if I told you that you may be thinking about fitness and nutrition in the wrong way?

We often set too big of goals and neglect to set smaller goals first. We love the idea of the end result, but we dread the process of getting to that result. We want everything to be perfect, or near perfect at least, and we want to feel motivated and happy while striving toward our goals. Unfortunately, this is just not realistic. In fact, it is completely normal to feel like being consistent is difficult. If you ask one of your role models, they will most likely say that they take the small necessary steps to get things done, whether they felt like it or not. We can't change our world around us, until we change our mindset of the world around us. There could be a million different things going wrong in your life. But it is important to identify the controllable factors, like your nutrition and fitness routines, your sleep, and your

mindset (i.e., thinking about challenges as something to make you stronger and to help you, rather than hurt you and make you weaker). This won't make the problems of life go away, but it will make you more able to tackle life challenges whether you are motivated to do so or not. You will realize that nothing worth achieving in life happens easily, and it is always the difficulties that make the successes much more rewarding.

So, I recommend that you think of your challenges as things that will make you stronger and help you grow as a person. Each difficulty shapes you into the person you are meant to be. Set one ultimate goal for both fitness and nutrition, then break that goal up into smaller, more actionable goals and practice discipline and consistency. Tell yourself you are going to be accountable and stay accountable. Also think about how achieving your goals in life will help other people. This will give you an extra incentive and increase your personal discipline to achieve your own goals and dreams and those of others.

Remember that nothing meaningful is achieved without difficulties, discipline, perseverance, and integrity. We can improve our mindset and lifestyle for the better and live life to the fullest.

*Written by Dan McCoy, CPT, PLY*



## Let's Talk about Skin

Skin related issues are a major concern among people living with spina bifida

It is easier to prevent an open area from happening than trying to heal one. By improving skin care awareness and prevention skills, many serious complications can be avoided.

Many people with spina bifida have decreased sensation in parts of their bodies, meaning they have a diminished or absent sense of pain. Without the warning sign of pain, a person does not get that signal that the skin is being injured by pressure or some other insult.

You need to be aware of the potential damaging effects of **pressure and friction**. Friction is sometimes called "shear." Even soft surfaces and materials can cause dangerous pressure and friction. You should wear seamless socks that are clean and dry. Check your skin daily for areas of redness from clothes, especially where clothes fold, are tight, or have elastic bands. You also need to watch for skin damage from orthotics like AFOs, bandages, wraps, and equipment.

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*You should perform a pressure-relieving move every 15 minutes.*

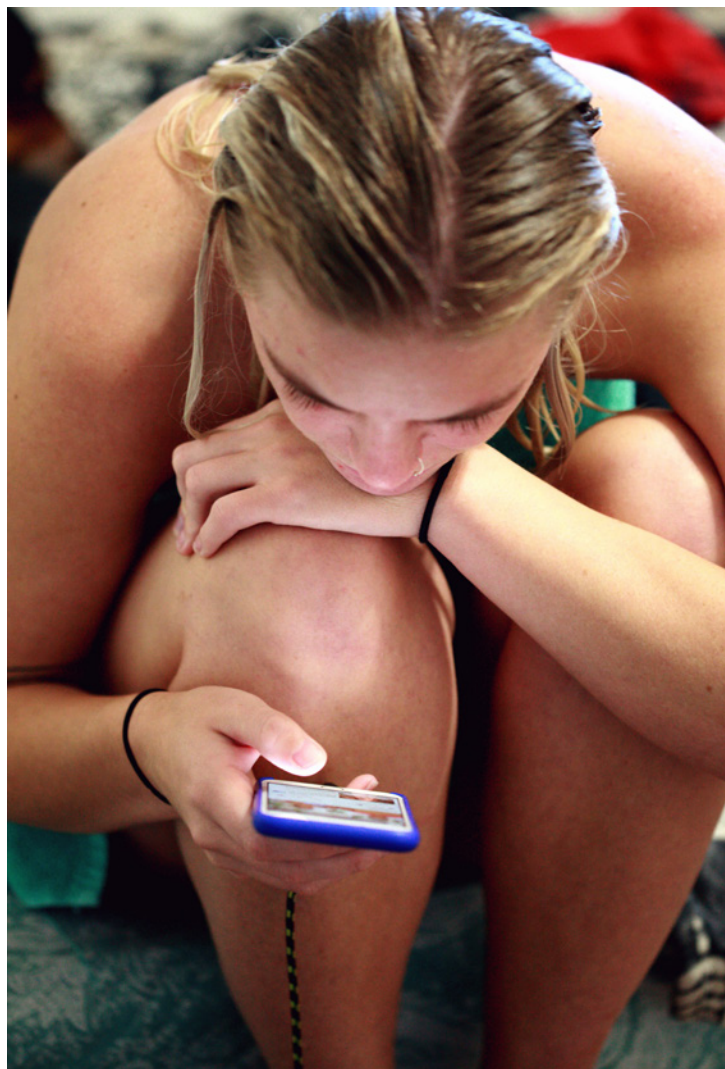
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Are you transfers safe? Sliding can harm your skin as you transfer. You should avoid friction to protect your skin. Consider consulting a physical therapist to improve or change your transfer technique. A common place to get friction during transfers is over wheelchair tires.

You should perform a pressure-relieving move every 15 minutes. You can do this in different ways. Lean forward in your chair, lean side to side, or perform a wheelchair push up. If you are seated in a power wheelchair with power features, use the tilt function. Yes, every 15 minutes! If you are not sure if what you are doing is enough, your clinic team would be happy to help you.

Pressure mapping is a great tool to assess whether your cushion and wheelchair are safe. We do pressure mapping at the [UPMC Center for Assistive Technology](#).

Many other surfaces can cause skin breakdown. This includes bath chairs, commodes, armrests, or backrests. Pressure relieving materials can be added to surfaces and your chair. Remember to check your cushions daily if they are made of gel or require inflation. Also, know that



cushions do not last as long as wheelchairs, and foam cushions should be replaced every year.

Think about **temperature** too! Be sure to check for hot surfaces that have been exposed to the sun such as car seats or bleachers. Also remember that sunscreen is necessary to protect exposed skin from getting burnt. It is important to check water temperature. Use a bath water thermometer to make sure your bath will be safe. Be careful around objects like space heaters, curling irons, laptop chargers, and microwaved dishes.

**Moist skin** is more susceptible to injury than dry skin. Incontinence and sweat can lead to excess moisture. To protect your skin, you should minimize bowel and bladder incontinence, wear breathable cotton underclothes and clothes, and use barrier creams that protect against dampness in moisture prone areas. You must keep all of your skin clean and dry. Remember, wet skin is weak skin!

**Poor circulation and swelling** can also result in an opening in the skin. Decreasing the amount of fluid in

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your leg by elevating your legs or wearing a special type of compressive garment can help prevent this type of injury. Keeping the fluid under control is important to get this kind of wound to heal.

**Nutrition** also has its role in proper skin care. Eating the right amount of protein, drinking enough water, and maintaining a healthy body weight can all help prevent pressure injuries. If you have questions, ask your clinic team about adequate hydration and proper nutrition for healthy skin. The next time you visit the clinic take a look at the pamphlet, **Did You Look?** It gives helpful tips and reminders to check your skin.

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*The absolute best situation is not get a wound in the first place...*

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**Perform daily skin checks!** Feeling with your hands is not enough. You cannot feel a red spot and that is when we want to catch a pressure injury, when the skin has not opened yet. You can use many different tools to inspect your skin: long handled mirrors, the camera on your phone, or a mirror positioned by your bed. A selfie stick can help you see the bottom of your feet with your cell phone camera. Taking a video on your phone will allow you to pause and closely examine the images of those hard to see places such as your ankles, the bottoms of your feet and the most elusive parts of your bottom. A change in skin color can be a sign that damage has already happened beneath the surface.

**Signs of trouble:** If you notice any of these, call your clinic team immediately.

- 1. A reddened area of the skin that does not fade after 15 minutes**
- 2. Unusual warmth or swelling that lasts longer than 15 minutes**
- 3. Blisters, open areas on the skin, scrapes, or draining wounds**
- 4. A purple or black area**
- 5. Equipment that needs repair (cushion, braces)**

The absolute best situation is not get a wound in the first place but if you do, getting the right care immediately can save you time, your independence, and sometimes even your life.

Written by **Darcie Petrillo, PA-C and Monica Still, RN, BSN**

**Some examples of tools to help you check the skin. Click on each picture to learn more.**

**Nutair Handheld Vanity Mirror with hanging hole in handle**



**NEZZOE Makeup Mirror Touch Screen Vanity Mirror with LED brightness**



**Mayhew Telescoping Inspection Mirror**



**Sammons Preston Flexible Inspection Mirror**



# Neurobehavioral Health Corner

by Lisa D Stanford, PhD, ABPP

Just like many other chronic conditions, Spina Bifida can affect one's thinking, socialization, emotions, and behavior in addition to physical health.

The mind-body connection is a strong one, as how we feel affects how we think, which in turn, affects how we act. For this reason, our clinic has added neuropsychology services (and me) to our team approach. We want to provide support for your mental, physical, and emotional well-being. This addition to our newsletter highlights the neurobehavioral health aspects of Spina Bifida care, as a place to answer your questions about these issues, and a place to offer you information.

For my inaugural article, I want to encourage you all to think about your emotions that occur in stressful or challenging situations, what that feels like in your body when you are worried, sad, or unsure about how

things are going or what is happening or might happen next. Checking in with how one is feeling and what any emotion "feels" like in our bodies is an important part of balancing the connection between our minds and bodies. Awareness that you are feeling something and how that affects your body can be the key to mindfulness or "being in the moment." This allows you to let go of the past and let go of what might happen before it has even happened, and to shift your focus to right where you are. Our brains lie to us all the time, and after a while, we start to believe that those things are true, even though they are just thoughts. Just thinking something doesn't make it true. So, find your

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*Everyone feels worried, anxious, sad,  
or stressed sometimes.*

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own mantra or "truth" that you want to say to your own brain, to stop it in the moment when it is lying to you. Then every time your brain tries to tell you something that isn't true, you can stop it and replace what you were thinking with your mantra to stop the other, less helpful thought. Examples of mantras might be: "I am doing everything I can do right now, and it's enough" or "I can focus on what is happening right now" or "I have everything I desire already within me" or "I am worthy of all of want for myself."

Everyone feels worried, anxious, sad, or stressed sometimes. If these feelings do not go away, and they interfere with daily life, then you can talk with other people, such as a family member or health care professional, about your feelings. It is helpful to have words for these emotions and feelings and to have someone that can help you understand them while creating a safe space for you to share them. If you've ever read Paulo Coelho's *The Alchemist*, then you know just how inspiring and motivating this book is. His enchanting novel follows the seemingly simple quest of an Andalusian shepherd boy in search of worldly possessions. However, the true story unravels as he starts to discover the priceless treasures that already exist within him. It's a story about life, love, meaning, and finding your true purpose. One of my favorite lines from *The Alchemist* is, "You will never be able to escape from your heart. So, it's better to listen to what it has to say."

Written by Lisa Stanford, PhD, ABPP





# Meals as Easy as...



While we know that eating healthy is important, sometimes we simply don't have the time or energy to cook a complicated meal.

The goal of this article is to help make healthy eating easy by breaking it down into simple steps. When we think about what makes a meal "balanced," we mean it has more than one food group. For example, broccoli is a healthy food but a plate full of only broccoli is not a balanced meal! Here are a few tips to make your meal balanced with the "Healthy Plate," as easy as 1-2-3.

## AT BREAKFAST, TRY TO INCLUDE:

- 1) A low-fat protein food +
- 2) fiber-full carbohydrate. For a bonus, add
- 3) a healthy (unsaturated) fat to make your meal even more filling and satisfying.

*Example: 1) 6 oz non-fat Greek yogurt (low-fat protein) + 2) ½ cup fresh or frozen blueberries (fiber-full carbohydrate) + 3) 2 tbsp. slivered almonds (healthy fat)*

## AT LUNCH AND DINNER:

- 1) Fill ½ of the plate with non-starchy vegetables +
- 2) ¼ of the plate with low-fat protein +
- 3) ¼ of the plate with fiber-full carbohydrates.

You can have fruit or low-fat dairy/dairy substitute on the side if they aren't a part of your plate already, but they don't have to show up at every meal if you're eating them regularly throughout the week.

*Example: Salad (lettuce, cucumber, tomato, carrots) topped with 2 tbsp vinaigrette dressing (½ plate vegetables) + 3-4 oz. Baked chicken (¼ plate protein) + 1 cup whole wheat pasta with tomato sauce (¼ plate carbohydrate).*

Check out the [table on the next page](#) for easy as 1-2-3 meal ideas with "convenience" foods that are still healthy.

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







*“Here are a few tips to make your meal balanced with the “Healthy Plate,” as easy as 1-2-3”*

NON-STARCHY  
VEGETABLE

LEAN  
PROTEIN

CARB  
WITH FIBER

FINAL MEAL

<p>Frozen mixed vegetables or frozen broccoli</p>	<p>1 can tuna</p>	<p>Plain microwave brown rice pouch</p>	<p><i>Follow package directions to cook the rice and the frozen vegetables in the microwave. Add canned tuna. Add a drizzle of olive oil, a pinch of herbs/spices (try garlic powder, onion powder, and Italian seasoning), and a sprinkle of cheese and stir. Makes 2-3 servings.</i></p>
<p>Frozen tri-color pepper and onion blend + 1 can no-salt-added diced tomatoes (with liquid)</p>	<p>1 can black beans (drained and rinsed)</p>	<p>1 cup uncooked quinoa</p>	<p><i>Sauté garlic + frozen peppers/onions in olive oil until cooked. Add quinoa, 1 cup water or low sodium broth, canned tomatoes, black beans, and 1 packet lower sodium taco seasoning. Bring to a boil, then cover and simmer for 15-20 minutes (stir occasionally) until the quinoa is done and most of the liquid is absorbed. If the liquid dries out too quickly, you can add more. Makes 4 servings.</i></p>
<p>16 oz frozen green beans + 2 cups (less if preferred) frozen diced onion</p>	<p>1 lb. chicken or turkey sausage (pick the lowest salt option available), cut into 1-inch pieces</p>	<p>1 cup frozen butternut squash or sweet potato cubes</p>	<p><i>Preheat oven to 450 degrees F. Line a baking tray with foil and grease with olive oil or oil spray. Add vegetables, sausage, and squash in one layer on the pan. Roast for 15 minutes on the middle rack of the oven. The sausage should be cooked to 165 degrees F. Mix 2 tbsp honey, 1 tbsp Dijon mustard, 1 tsp turmeric, and 1 tbsp olive or canola oil in a bowl; drizzle sauce over the pan once done cooking and stir to coat with the sauce. Makes about 2 servings.</i></p>



Recipe adapted from:

<https://www.dispatch.com/story/lifestyle/food/recipes/2020/09/23/sheet-pan-meals-easy-way-use-frozen-foods-dinner/5853756002/>



# ADULT SPINA BIFIDA PEER NAVIGATION

## GROUP SESSIONS

Summer 2023

### June Gender Identity Pride

**June 8<sup>th</sup> Elizabeth (Libby) Powers-** Issues Related to Gender Identity and Sexual Orientation while Having a Disability

**June 22<sup>nd</sup> Elizabeth (Libby) Powers** -Acceptance and Grief of Gender Identity While Disabled

### July Health and Wellness

**July 13<sup>th</sup> Dan McCoy-** Using Sports to Socialize While Getting Fit

**July 27<sup>th</sup> Dan McCoy** - How to Adapt to Your Fitness Routine with the Changing Seasons

### August Disability Pride

**August 10<sup>th</sup> Sara Izzo-** Barriers Keeping You from Feeling Pride About Your Disability

**August 24<sup>th</sup> Monica Still-** Discussing Pittsburgh Pride Celebration and How We Can Demonstrate Pride Daily

7:00 pm (Eastern Time)

Zoom Meeting ID: 937 3399 6022

<https://pitt.zoom.us/j/93733996022>

JOIN US!!!

Contact Sara Izzo for more information [sai20@pitt.edu](mailto:sai20@pitt.edu)

# SBA “Join the Conversation” Zoom Calls for adults with Spina Bifida

<https://fb.me/e/2gWe3dbFU>

<https://bit.ly/2SpBEom>

First and third Thursday of every month at 7pm ET

## Upcoming SBAWP Events

### 10th Annual Afternoon JamFest

June 25: 1:00 pm - 5:00 pm – Jergel’s

### Summer Camp-Staff training

June 27-30: Camp Guyasuta

### Adult Camp (ages 21+)

July 2-8: Camp Guyasuta

### 35th Annual John L. Moroney III Memorial Golf Classic

July 24: 8:00 am - 6:00 pm – Hickory Heights Golf Club

### 8th Annual Noll-Spratt Golf Scramble

Sept. 16: 12:00 pm - 8:00 pm – Beaver Valley Golf Club

### Adult Retreat

Sept. 22 - 24: All Day – Camp Guyasuta

300 23rd Street Extension, Sharpsburg, PA 15215

### 10th Annual Girlfriends for Good Purse Bash

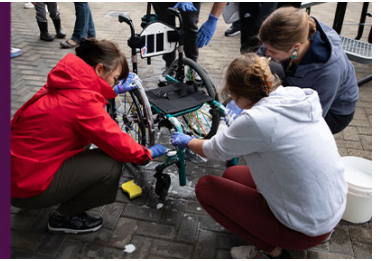
Nov. 11: 12:00 pm - 3:00 pm

St. Ferdinand’s Oldenski Hall

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



SAVE THE DATE  
UPMC Rehabilitation Institute  
**11th Annual  
Wheelchair  
Wash & Tune-Up**



Volunteers from [UPMC Rehabilitation Institute](#) and local vendors will be on-site to wash and perform minor repairs, as well as evaluate potential problems with the wheelchairs. Plus, enjoy an obstacle course, games, and fun!

### When

Friday, September 29, 2023

### Where

University of Pittsburgh Department of Physical Therapy  
School of Health and Rehabilitation Sciences  
Bridgeside Point 1  
100 Technology Drive, Suite 210  
Pittsburgh, PA 15219-3130

Stay tuned for more information and a link to register.



## 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

#### UPMC Adult Spina Bifida Clinic

UPMC Mercy Pavilion  
1622 Locust Street, 4th Floor PM&R Clinic  
Pittsburgh, PA 15219  
Phone: 412-232-8902

Check out our other newsletters and clinic information at: [UPMC.com/SpinaBifida](https://UPMC.com/SpinaBifida)

## SIGN UP HERE

to receive our Newsletter  
in your email.

