

UPMC Adult Spina Bifida Clinic in the News!

Recent News and Updates – In our Fall 2018 newsletter, we announced that the new “[Guidelines for the Care of People with Spina Bifida](#)” were published online at SpinaBifidaAssociation.org/Guidelines. As soon as these were published, the website ended up crashing because of the high amount of people trying to view them all at the same time! Below are a few articles published about the new guidelines and the UPMC Adult Spina Bifida Clinic in the Pittsburgh Post-Gazette:

- [Article 1](#)
- [Article 2](#)

If you are interested in learning more about the “*Guidelines for the Care of People with Spina Bifida*,” please watch [this video](#). *Written by Brad Dicianno, MD, Director*

Healthy Tips for those with Bladder Incontinence

As we begin to settle in the New Year after much holiday indulgence, it’s a great time to continue the momentum of our New Year’s resolutions. Daily routines and lifestyles can be different for all patients with spina bifida. Many of us have used a regimen that hasn’t changed much since young adulthood, even though our metabolism has slowed with age. Food has a very powerful influence in our lives, and we don’t always know the impact it can have on our daily routines. We discovered that removing 5 items commonly found in foods and drinks have helped relieve some patients of mild incontinence.

Removing the 5 C’s

- 1. Citrus** – This includes sour fruits such as oranges, lemons, grapefruit and their juices. These do not need to be eliminated, but you will need to pay attention to how they affect your system. If citrus fruits are used to flavor water, try crushed berries or sliced apples and pears for flavoring. You can make a large pitcher and refill water bottles for drinking on the go.
- 2. Chocolate** – Eating and drinking a lot of products that have chocolate can cause problems. Occasional treats are fine, but pay attention to the effect on your system. Carob is a chocolate alternative that does not have caffeine. You can use this as a substitute for chocolate milk and other recipes.
- 3. Caffeine** – In general, it is better to limit or eliminate caffeine. Colas and energy drinks are very high in caffeine. Do your best to avoid these items. Drinking plenty of filtered water in the morning can help with fatigue and avoids dehydration that can lead to headaches when weaning off of caffeine.
- 4. Carbonation** – Any carbonated drinks, including those without caffeine, need to be monitored. These can irritate the bladder.
- 5. Coloring** – Any drink that has dyes and coloring can irritate the bladder. Some colors are known to be more irritating than others, such as red and blue dyes that are commonly found in powdered drink mixes, punches and sports drinks.

You should be aware of how your body responds to certain foods. Next time one of these items is consumed, make note of how your bladder responds. If you try to remove some of these items and see your body's reaction, you might be pleasantly surprised to find relief over time. You may find it hard to remove some of these items from your diet, but drinking 8 oz. of water before and after consuming them can help get rid of some irritations. Trying new ways of doing things is never easy. The first step is changing your perspective and seeing this as a new food adventure. American author William Feathers once said, "One way to get the most out of life is to look upon it as an adventure." You never know what you may discover. *Written by Sara Izzo*

Your Fitness Journey Starts Here

Being Active with Spina Bifida – Starting your fitness journey can be quite intimidating if you don't know where to start. It can be especially intimidating for someone with spina bifida. Our goal is to show you that you can be healthy and physically active while living with spina bifida. Each of our newsletters will have a different movement and/or exercise routine with a video that shows some exercises that you can try out for yourself. Click [here](#) to watch an introductory video. More videos will be posted with some of our recommended exercises. If you have any questions about your fitness journey, please feel free to contact us. *Written by Dan McCoy, ACE-CPT*

Healthy Living to Support Immunity

The Connection Between Nutrition and Fighting Illnesses – Flu season is one of the top reasons for unplanned doctor visits and call-offs from work. In response, there tends to be an overwhelming number of articles and ads that push different types of remedies for boosting immunity and fighting illness during flu season, but what can we actually believe? Most researchers and health care professionals recognize that there is a connection between nutrition and immunity.

While there is little evidence that one particular food or nutrient can help to improve immune function, research shows that the best defense for cold and flu season is to maintain a healthy lifestyle during the winter months. The best way to do this is to eat a diet packed with fruits and vegetables of various colors, whole grains and lean protein items. The natural antioxidants, vitamins, minerals and protein found in these foods can support your overall health and well-being. When you are putting together your next meal, keep in mind that variety is key and try to include fresh sources of all the different food groups. Take the time needed for yourself and your family to prepare balanced meals, exercise regularly, and get enough sleep so that your body is strong enough to fight off unwanted illnesses. *Written by Sabrina Palmieri, RD, LDN*

Monica Still's Spina Bifida Story

Advocating for Yourself – The most important life lesson that my mother taught me was how to advocate for myself with health care professionals and those who cover the costs my care. From when I was very young, my mother always made sure to include me in my health care decisions. I was able to sit in on all discussions with my doctors and she helped to explain what needed to be done to get my needs met and paid for.

At every appointment, my mother made sure to ask the doctors many questions and got answers before we went home. She kept notebook of questions with her and wrote down the answers so she could remember what was said later. Now, as an adult aging with spina bifida, I am doing the same thing. I have found that writing my questions down in a notebook beforehand and bringing it with me to appointments helps me to better discuss my care needs. I also try to bring a friend or family member with me whenever possible. Having someone there helps me to remember what I wanted to talk about with my doctor and/or what was discussed after my appointment. Not so long ago, most children born with spina bifida did not live long enough to have the health problems that go along with aging. It's no surprise that you are able to find many doctors who are experts in their specialty, but do not have much experience with spina bifida. For years I have struggled to explain how my spina bifida affects all of my health issues. Now, with the "[Guidelines for the Care of People with Spina Bifida](#)," I have a link that I can share with my doctors that better explains spina bifida and the health problems associated with it.

Figuring out how to get the services and treatments you need paid for can be one of the hardest things to do when you are your own advocate. It's important to educate yourself on what requirements the payer source has. Always ask what the rules are and what you need to do to follow them. Sometimes, the answer is no. When this happens, make sure to ask what you can do to appeal the decision. It helps to be aware of deadlines and write everything down, including who you speak to. When in doubt, ask for help from your doctor, the payer source, or an outside advocate. The more advocate for yourself, the more confidence you will have in discussing and handling your care needs. Ultimately, you will find that being an active participant in your care has many untold benefits. *Written by Monica Still, RN, BSN*

Talking about Transition

There are many parts of transition that we will discuss in your upcoming appointments. This winter season is a great time to talk about the importance of finding a primary care doctor (PCP). This would be a doctor that you could go to for your yearly exams, immunization updates, sick visits, and any other health care needs specific to you. Now that we are well into the new year, it is a great time to be sure you are scheduled for your annual visit with your PCP. At this visit, we encourage you to discuss if certain vaccinations such as the flu, pneumonia, and Tdap booster are right for you. If you do not have a PCP, please contact our clinic so that we can help you find one. Remember to wash your hands often during cold and flu season and stay warm! *Written by Rachel Young, CRNP*

What's Happening at SBAWP

Upcoming Events – The Spina Bifida Association of Western PA (SBAWP) was founded by parents and is a nonprofit committed to improving the quality of life for people with spina bifida and their families. Some of the SBAWP upcoming events include:

- Adult Weekend Retreats: February 22-24 and March 22-24, 2019
- Afternoon Jamfest Fundraiser at Jergel's Rhythm Grille: March 3, 2019
- Noll Spratt Golf Outing Fundraiser: June 8, 2019
- Adult Summer Camp: June 30 – July 6, 2019



For more information, please visit the website at www.sbawp.org.

Tools for Techies and Gadget Lovers

Be Present, Be Happy – Our brains are working all the time; thinking, planning, wondering, and reacting. Our minds are often occupied by thoughts of things that have already passed and plans that may happen in the future. All this reflecting and planning can be quite stressful! Mindfulness is the act of being present in the moment without judgement or emotion. You can practice being mindful in countless ways. For example, you can be mindful while focusing on drinking a hot cup of tea, or by taking slow, deep breaths while focusing on the air filling your lungs as you breathe in and then escaping your lungs as you breathe out.

Practicing mindfulness regularly can help you learn to be less reactive and more intentional with your thoughts and actions. It also can be used to calm your mind in stressful situations. Living mindfully is not as easy as it sounds. Mindfulness is a skill that requires practice to improve. Anxious thoughts and worries will still come to mind, but you can choose to let them go.

You can start being mindful right now! Take a few seconds to close your eyes, shut out what's going on around you, and be present in your body in the current moment. Decide to let negative feelings go and choose to be happy right now.

There is a mobile app for smart phones available called "HEADSPACE" that leads guided meditations to help users practice being mindful. You can find it by going to Headspace.com. Written by **Darcie Ilg, PA-C**





UPMC Adult Spina Bifida Clinic Winter 2019 Newsletter

MyUPMC Patient Portal

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

UPMC Financial Assistance Program

If you qualify for the UPMC Financial Assistance program, you may receive help with medical expenses such as reduced copays. The general financial aid program is available regardless of where you live. If you live in Pennsylvania, you may also qualify for additional refunds for medical expenses through our Adult Spina Bifida Clinic grant. Apply by going to [UPMC.com/FinancialAssistance](https://www.upmc.com/FinancialAssistance) or ask someone in our office for an application. If you apply, please let us know so we can track your application and let you know if you are approved. We also ask that you save a copy of your medical receipts and expenses.

Contact Us

UPMC Adult Spina Bifida Clinic
1400 Locust Street
Building D, Suite G-103
Pittsburgh, PA 15219

Phone: **412-232-8901**
[UPMC.com/SpinaBifida](https://www.upmc.com/SpinaBifida)