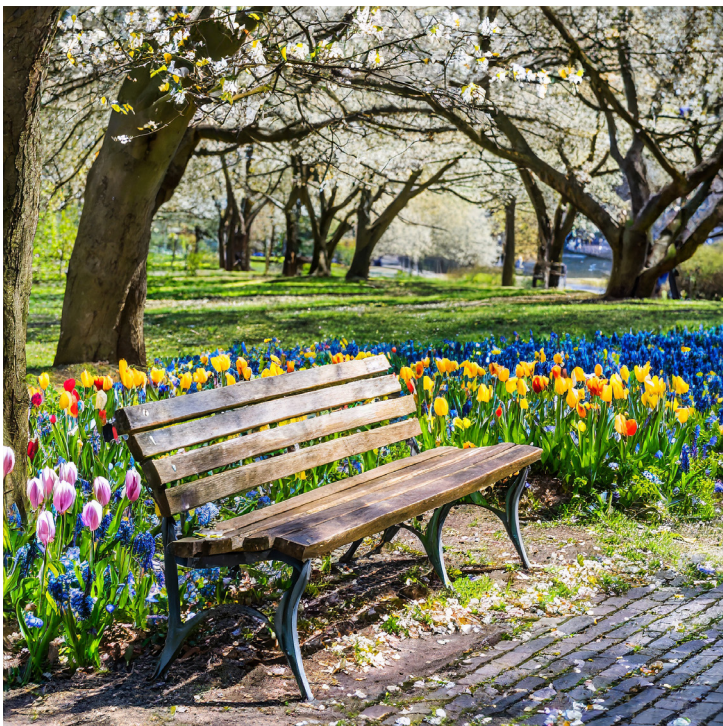


New Spina Bifida Program Manager

Darcie Petrillo, PA-C

We are very pleased to announce that Darcie Petrillo, PA-C has assumed the role of Spina Bifida Program Manager of the UPMC Adult Spina Bifida Clinic. Darcie will assist Dr. Dicianno by overseeing clinics operations and management of the agreement with the PA Department of Health. Darcie has worked as a Physician Assistant in the field of Physical Medicine and Rehabilitation for 7 years. Darcie said, "My last 5 years have been with the UPMC Department of Physical Medicine and Rehabilitation where I have specialized in Neuro Rehab and serve in both the Children's and Adult Spina Bifida Clinics. I have learned so much from our amazing teams and all the people I get to know each day. I can honestly say I love my job more with each passing year."

Written by Brad Dicianno, MD



**"Every flower blooms
at its own pace."**

This is a simple and yet elegant quote by Suzy Kassem, an American writer and poet. The rate at which a flower blooms depends on many factors, including the temperature, soil, sunshine, and water. Similarly, our growth as people depends on how we nourish our bodies and minds and on our environment. Ms. Kassem's quote reminds us that life is not a competition and that everyone reaches goals at different rates. This edition of our newsletter provides tools and information to help you bloom at your own pace.

Written by Brad Dicianno, MD

Understanding Neurogenic Bowel

There are so many reasons why adults with Spina Bifida have not yet found a strategy that works for them to manage their bowels. For one, it takes a lot of time and discussion to learn what a person has tried before and to understand why different strategies do not work for them in particular.

While signs and symptoms of neurogenic bowel dysfunction can vary, the underlying cause is the same: damage to the central nervous system's control of the bowel. This results in slow movement of stool, which increases the risk of chronic constipation and bowel incontinence.

The colon is a long (1.5 meter long!) muscular tube. Think of it as a winding highway. In neurogenic bowel, due to impaired muscle movement and sensory function, traffic is slowed, and a traffic jam is very likely if things don't keep moving.

The primary goal of a "bowel program" is to establish a routine that results in a complete bowel movement on a set schedule, ideally every day. By **emptying the bowel regularly**, it is less likely that a person will become constipated. Keeping on a schedule also reduces the risk of an accident. If a person can take control of their bowels, then they no longer have to allow their bowels to control their life.

The foundation of a bowel routine is diet and lifestyle. While lifestyle changes are often not enough to get control of a neurogenic bowel, they still are important.

Fiber plays a big role in bowel regularity. It adds bulk to the stool and also brings water into the stool. This bulk and extra water helps the stool move along. There are two types of fiber: insoluble and soluble fiber.



Insoluble fiber does not break down in water. This type of fiber is what we may think of as "roughage" that "cleans the pipes." Insoluble fiber adds bulk to the stool, but it does not become "gel-like." Instead, it tells the body to move water into the colon and speeds up how quickly stool moves through the intestines. Insoluble fiber can help constipation. Food sources of insoluble fiber are the skins of many fruits and vegetables, nuts, seeds, and beans.

Soluble fiber pulls water into the stool and makes it more formed and "gel-like." Soluble fiber can help diarrhea and constipation. It helps diarrhea because it makes the stool more formed. It helps constipation because it keeps the stool moist which helps it move along. Plus, some soluble fibers are fuel for the good bacteria that live in the colon. Some foods higher in soluble fiber are oats, beans, barley, Brussels sprouts, and oranges.

When increasing the fiber in your diet, do so SLOWLY – not all at the same time. Fluid helps your body work with fiber, especially soluble fiber. If you don't drink enough water, adding more fiber can make constipation worse. It is important to drink at least 64-80 ounces (8-10 cups) of non-caffeinated fluid each day.

Exercise is also an important part of managing neurogenic bowels. While exercise is good for health in many ways, it may help stool to move through, which may improve constipation. Adults should try to do at least 150 minutes (2.5 hours) of exercise per week.

If you think you might like help getting control of neurogenic bowel dysfunction, please reach out! Your team at the Spina bifida Clinic is here to help you!

Written by Darcie Petrillo, PA-C





Understanding Packaged Foods

Are all packaged or processed foods unhealthy? Not necessarily. Foods that come from a box or a bag can help make cooking a simpler and faster task – and that can make us more likely to follow through with doing it! But we do need to pay attention to make better choices when picking up these foods at the grocery store.

Tips

Read Food Labels

- Choose foods with **LESS** saturated fat, trans fat, sodium, and added sugar.
- Choose foods with **MORE** dietary fiber and protein
- Easy rule of thumb: On the Nutrition Facts label, 5% is a little, 20% is a lot.

Aim for More Plain Foods

- Less added sauces, dressings, gravies, flavorings
- Season food at home with herbs/spices, vinegar, lemon juice, etc.

Keep it Simple

- As a rule of thumb, a shorter ingredient list is better. But sometimes an ingredient list is longer because vitamins/minerals have been added back into the food.

Quick & Healthy Pantry and Freezer Staples

- Canned beans (reduced sodium)
- Canned vegetables & tomatoes (no salt added)
- Canned tuna or salmon
- Whole grains (plain instant microwave brown or wild rice, quinoa, oats, whole grain pasta)
- Dried or canned lentils
- Dried fruit (no added sugar)
- Canned fruit in 100% juice or water
- Nuts and seeds (unsalted)
- Nut butter
- Olive oil or other vegetable oils, or cooking spray
- Dried herbs/spices
- Frozen vegetables (plain, no sauce)
- Frozen edamame
- Frozen fruits (no added sugar)
- Frozen turkey, chicken, fish (plain)
- Veggie burgers with at least 10 gm protein and less than 3 gm saturated fat
- Plain frozen brown rice or quinoa
- Frozen dinners with <800 mg sodium, <5 gm saturated fat, and include protein and vegetables

Written by Jacquelyn Klunk, MS, RDN, LDN



Spring Training

With each new year comes new challenges and experiences. Below are some strategies you may find helpful for healthy living and exercise this spring and beyond:

- Try to drink as much **water** as you can throughout each day.
- Work on getting to **sleep** at least 6-8 hours per night.
- **Workouts before or after meals** can help digestion.
- **Strength training** at least 2-3 times per week (Resistance bands, Bodyweight exercises, Dumbbells, Machines).
- **Cardiovascular training** 1-2 times per week (Treadmill, Wheelchair Propelling, Handcycle, Adaptive Sports, Stationary Arm Bike).
- **Stretching** daily (upper and lower body where able)
- Shoot for **150 minutes of moderate intensity exercise** weekly, or **75 minutes of vigorous intensity exercise** weekly.

Using as many of these strategies as possible will help us to lead the most consistently healthy lives we can!

Written by Dan McCoy, MS, CPT, PLY



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

<https://fb.me/e/2gWe3dbFU> & <https://bit.ly/2SpBEom>

First and third Thursday of every month at 7pm ET



Our Catheter Closet

Did you know that there are hundreds of different catheters available for you to use? A catheter is unique to the person who is using it. What that means is that as your body changes over time, the type of catheter you need may also change. You may remember that the type of catheter that you used as a child changed as you grew. Did you know that the type of catheter that you use as an adult may need to be changed as well based on how your body ages?

Catheter technology has also changed over the years. Some catheters come pre-lubricated, some are made of material that makes them slide in easier, and others are antibacterial.

With all these choices how will you choose? The good news is that the clinic is here to help. We have many samples of catheters that you can try out to see which works best for you. We can talk to you about each catheter and help you decide. Once you find the right catheter, we can send your medical equipment company an order for the catheter of your choice to be delivered to your home. You can do this during your annual visit or set up an appointment with me to discuss your changing catheter needs.

Written by Monica Albert Still, RN, BSN



**SPINA BIFIDA
ASSOCIATION**

2024 Spina Bifida Clinical Care Meeting

May 31 - Jun 1, 2024, Sacramento, CA

The Spina Bifida Clinical Care Meeting is a unique forum that focuses on new and evolving aspects of medical care for people with Spina Bifida. This year it will be held in conjunction with UC Davis Health. The UPMC Adult Spina Bifida Clinic team will be attending and presenting on our unique model of care delivery that integrates peers as part of the care team. For more information about the meeting, visit: <https://www.eventcreate.com/e/2024ccm>.

Written by Brad Dicianno, MD

SBAWP Events

Mar 1-3, 2024

[Adult Retreat - Camp Guyasuta](#)

Apr 12-14, 2024

[Adult Retreat - Camp Guyasuta](#)

May 16, 2024

[7th Annual Shoot for SBAWP](#)

Hunting Hills Shooting Preserve, Dilliner, PA

Jun 23, 2024

[11th Annual Afternoon JamFest](#)

Jergel's Rhythm Grille

Jun 30-Jul 6, 2024

[Adult Camp - Camp Guyasuta](#)

Jul 29, 2024

[36th Annual John L. Moroney III Memorial Golf Classic](#)

Hickory Heights Golf Club

Sep 21, 2024

[9th Annual Noll-Spratt Golf Scramble](#)

Beaver Valley Golf Club

Sep 27-28, 2024

[Adult Retreat - Camp Guyasuta](#)

Nov 9, 2024

[11th Annual Girlfriends for Good Purse Bash](#)

Divine Parish – St. Ferdinand's Oldenski Hall, Cranberry Twp

Dec 6-8, 2024

[Adult Retreat Dec 6-8 - Camp Guyasuta](#)

For more information, visit

<https://sbawp.org/events/>

Adult Spina is Common

The majority of people with Spina Bifida are **adults**. A **study** by Briggs in 2020, supported by the Centers for Disease Control and Prevention, found that 2/3 of people living with Spina Bifida were between 30-80 years old.



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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Phone: 412-232-8902

Check out our other newsletters and clinic information at: UPMC.com/SpinaBifida

SIGN UP HERE

to receive our Newsletter in your email.

