UPMC
LIFE CHANGING MEDICINE

UPMC Adult Spina Bifida Clinic Summer 2026 Newsletter

Living With Trans Anal Irrigation: Challenges I Navigate—and What Helps

Trans anal irrigation (TAI) is a bowel management method that helps empty the bowel in a planned, controlled way.

In simple terms, it involves gently introducing water into the rectum using a medical system, which stimulates a bowel movement. The goal is to fully empty the bowel at a chosen time, reducing unplanned accidents and urgency later. Many people with neurological or mobility-related disabilities use TAI as part of their routine healthcare.

I use TAI as part of my bowel management routine. It works well for me, but like many aspects of disability-related care, it comes with challenges that show up most clearly in social life. Over time, I've learned practical ways to navigate those challenges so I can participate more fully and confidently in the world around me.

Time and Scheduling

TAI takes time, and that time has to be planned. Early on, I struggled with how it fit into workdays, appointments, and social plans. What helped was building a consistent schedule and protecting that time as non-negotiable healthcare. Once I stopped trying to squeeze it in "wherever it fit" and instead planned my day around it, my stress level dropped, and my reliability in social and professional settings improved.

Access to Private, Accessible Bathrooms

TAI requires privacy and an accessible space, which isn't always available outside my home. This can affect travel, long days out, or events with limited facilities. I've learned to plan ahead, advocate for accommodations when needed, and be realistic about what environments will work for me. These strategies don't eliminate the challenge, but they make it manageable and predictable.

Social Stigma and Silence

Talking about bowel care is still uncomfortable for many people, which can make using TAI feel isolating.

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Summer is Here

Walt Whitman wrote, "Happiness, not in another place but this place… not for another hour, but this hour." This is a reminder that emotional and physical well-being aren't something to put off, but something we should focus on right now. Take advantage of the longer daylight hours by enjoying time outdoors, spending time with loved ones, staying active, and trying new healthy, fresh foods. The time and effort you invest today will pay off in health and well-being for the days ahead.

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

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I've found that being open—when and where it's safe to do so—has been empowering. Naming TAI as routine medical care helps normalize it, and connecting with other disabled people who use similar systems reminds me I'm not alone or unusual.

Acknowledging the challenges—and sharing the strategies that help—makes it easier to live a full life without letting bowel care define or limit it.

Confidence at Social and Community Events

One of the clearest examples of how TAI supports my social life was using it before Disability Pride Pittsburgh. Knowing I had completed my routine ahead of time gave me real confidence. I was able to focus on the event, the people, and the joy of being in community, rather than worrying about whether an accident might happen. That sense of predictability made it easier to be present and fully engaged.

Emotional Energy and Sustainability

Managing any long-term care routine takes emotional energy. When TAI feels harder, I check in with myself and my clinicians about small adjustments rather than pushing through. I also lean on peer support, where shared experiences and humor make a real difference.

For me, TAI is a tool that supports participation, confidence, and connection. Acknowledging the challenges—and sharing the strategies that help—makes it easier to live a full life without letting bowel care define or limit it.

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

Participate in Research on Bowel Continence

We are looking for individuals with myelomeningocele who are starting new enema or trans anal irrigation (TAI) programs to participate in a research project. The BCALS (Bowel Continence Across the Lifespan) study was funded by the Patient-Centered Outcomes Research Institute (PCORI). We are studying the effectiveness of enema programs. The study involves periodic surveys and an interview. ***If you are interested in participating or learning more about the study, please contact our Clinical Coordinator: Sara Izzo at (412)-642-5494.***

Learn a New Term: *Tethered Cord* vs. *Tethered Cord Syndrome*

A ***tethered cord*** refers to a spinal cord that is attached within the spinal canal. This is often seen on imaging like an MRI. Many people with Spina Bifida have a tethered cord, and this doesn't necessarily mean any treatment is needed. But if the tethered cord stretches, like when a child grows or with certain activity in adults, it can then cause symptoms like back pain, leg weakness, numbness, or changes in bladder or bowel function. When symptoms occur, this is called ***tethered cord syndrome*** and may require treatment. Recognizing and understanding these terms can help you spot potential warning signs early and discuss treatment options with our clinic team.

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

Challenge leads to Change

Why do we do certain things that don't benefit us and avoid the very things that ***could*** benefit us if we just push through some discomfort? There are many reasons for this, but I believe some of the main reasons are to fit in or fear of failure.

Think of the most influential things to ever be accomplished by humans. Did any of those things come with ***no*** difficulties? People who have accomplished anything big have always done so by overcoming major obstacles and by being stronger for it.

Now, imagine this on a smaller scale, but related to our health. Accomplishing a goal of losing fat, gaining muscle, improving mobility, or just being able to move more comfortably all starts with setting small, challenging, but achievable goals and consistently working toward them over time. This summer is a perfect time to set goals and challenge yourself to get outside of your comfort zone, setting goals that ***do*** make you a bit nervous. But with hard work and consistent discipline it will be worth it. Breaking a barrier that you once thought you couldn't achieve will naturally give you the confidence you needed to continue to tackle life's biggest challenges!

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

Stay Cool & Save This Summer

Summer heat can be especially challenging for individuals and families living with spina bifida. Mobility equipment, medical devices, and increased sensitivity to heat can make keeping your home cool not just about comfort—but about health and safety.

The good news is that a few simple adjustments can help you stay comfortable while also lowering energy costs. Here are some practical tips to help you beat the heat:

- In hot, humid summer months, set your thermostat at 78 degrees when you are home and 85 degrees or off when you are away.
- Keep drapes closed and shades drawn. The amount of energy required to cool your home will be considerably less.
- Replace filters monthly for maximum benefit and check air and return vents on a regular basis to keep circulation air paths clear.
- Request a "home energy audit" from your local utility to identify any areas where energy is being lost and to find out ways to save on your heating and cooling bills.
- Use only lights and appliances you really need. Even a basic light bulb can add heat to a room.
- Clothes dryers and dishwashers produce a lot of heat. Use them in the early morning or late evening, not in the heat of the day.
- Use a microwave oven instead of a conventional range or oven.
- Wash full loads of clothes in cold water whenever possible and avoid over-drying.
- Relax in rooms that do not receive direct sunlight or stay on the lowest floor of your home.
- Air leaks waste energy dollars year-round. Caulking and weather-stripping will help keep cool air in.

Important Reminder: *Older adults and people with chronic health problems should stay indoors during a heat wave and remain in the coolest available place.*

Taking small steps now can make a meaningful difference in both comfort and cost throughout the summer months. As always, our clinic team is here to support you—please reach out if you have questions or need additional resources to stay safe and well this season.

Written by ***Olivia Hughes***

Keto Craze
What Should You Know?

Advertisements and social media posts encourage following a lot of different diets. One diet that has gained a lot of attention in the past few years is the ketogenic ("keto") diet.

A keto diet is a low carbohydrate, high fat/protein diet. By cutting down severely on carbohydrates, the body starts to break down fat for fuel instead of using carbohydrates (the body's preferred energy source). The goal of this diet is usually weight loss and better metabolic outcomes like blood sugar control. But is this a safe diet to follow?

There is not evidence to recommend a keto diet for most people. Current studies do not show greater benefit of following a keto diet versus a standard balanced diet for weight loss when people eat the same number of calories. We also don't have enough information on long-term effects of the diet.

There are also potential risks, such as:

- Vitamin/mineral deficiencies due to cutting out major food groups
- Higher intake of saturated fat, which can increase LDL ("bad") cholesterol levels which is not good for heart health
- Mental health impacts of a restrictive diet, including disordered eating patterns
- Lack of sustainability (that is, it is hard to keep up with the changes in the long term). This can lead to starting and stopping the diet, which can lead to a cycle of weight loss and regain. This weight cycling has negative impacts on metabolism, physical health, and mental health.
- Constipation, increased risk of kidney stones, and increased risk of osteoporosis – these are particularly relevant to folks with spina bifida. Many people with spina bifida already experience constipation. Kidney health is closely monitored in people with spina bifida, and preventing kidney stones is helpful to protect kidney health. People with spina bifida can also be at risk of osteoporosis due to changes in mobility and ability to do weight-bearing activities.

A keto diet is typically not recommended for the general population based on current evidence, and given the potential risk factors of the diet, it is less appropriate for folks with spina bifida. A balanced diet including fruits, vegetables, whole grains, beans, nuts/seeds with a moderate intake of lean proteins and low-fat dairy products (or dairy alternatives) remains the most evidence-based eating pattern for health. All foods fit in moderation!

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

Fresh, Simple, and Accessible: Summer Cooking for Everybody

Summer is a season of enjoying the best that Spring has to offer. It is the perfect time to incorporate eating habits that make it easier to manage our health overall– especially for those of us with spina bifida. Healthy cooking does not need to be complicated or time-consuming, but it does have to be delicious. One of my favorite dishes that requires minimal effort is Vegetarian Taco Salad. What I love most about this recipe is that it is naturally gluten and dairy-free and made with fresh ingredients packed with nutrition. The 5 grams of plant-based protein, and the whopping 8 grams of fiber make a filling snack, or meal for lunch and dinner. This dish is paired perfectly with your favorite tortilla chips, and you can pump up the protein by adding chicken or ground turkey using my favorite Taco Seasoning Recipe *(on the following page)* made from scratch.

*Written by **Sara Izzo***

Vegetarian Taco Salad

Servings 3-4 | 15-20 minute prep time; 15 minutes marinating

INGREDIENTS

- **4 cups romaine lettuce, chopped**
- **1 cup corn** *(fresh or canned)*
- **1 can of black beans** *(rinsed and drained)*
- **2 avocados, diced**
- **½ Tbsp cumin**
- **1 tsp smoked paprika**
- **¼ cup fresh cilantro, chopped**
- **1 lime (Tbsp Lime juice)**
- **Salt and pepper to taste**
- **¼ cup salsa**

INSTRUCTIONS

- *Wash and dry all vegetables and lime- drain and rinse canned beans and corn*
- *Cut and chop each vegetable into your desired size and place in a large bowl*
- *Roll the lime on the counter, applying pressure to make the lime softer to squeeze. Cut in half and squeeze over vegetables.*
- *In the large bowl add corn, beans, and diced avocado and drizzle ¼ cup of salsa (or more) over the top and gently mix everything together until well combined.*
- *Finish by sprinkling fresh cilantro and an extra squeeze of lime on top for a burst of flavor.*
- *Serve with Chips and remaining salsa. Pairs great with plant-based or animal protein of choice.*

*Written by **Sara Izzo***

Navigating distressing media and protecting your mental health

Sudden changes in society can leave individuals feeling a sense of uncertainty for the future.

Exposure to distressing news content can impact your emotions in a variety of ways, making it harder to focus, engage socially, and connect meaningfully with others. You may find yourself feeling anxious, frustrated, or burned out from daily media coverage. However, it is important to remember that your feelings are valid. During challenging times, it is essential to protect your mental health and take care of those around you.

Here are **3 TIPS** to help you navigate media burnout:

PRACTICE MINDFULNESS

- Take time to disconnect, unplug from social media, and set healthy boundaries. Reflect on how consuming current news makes you feel throughout the day. If you find yourself feeling overwhelmed, try shifting your focus toward art, journaling, music, or nature to help clear your mind and provide a sense of clarity and balance moving forward.

CONNECT WITH YOUR COMMUNITY

- Unsettling events can leave individuals feeling disconnected and isolated from their communities. Finding a safe space among family, friends, or peers to share thoughts and lived experiences can help restore a sense of comfort, support, and connection. Wherever you find a community, don't be afraid to ask for help and check-in on those around you.

TAKE CARE OF YOUR BODY

- Viewing graphic media can overstimulate the nervous system and lead to lingering feelings of stress or agitation. Stress not only impacts your mind but can eventually affect your body. Calming practices such as meditation, stretching, deep breathing, or gentle movement after watching the news or engaging in overwhelming dialogue can help regulate emotions and promote a sense of peace and grounding throughout the day.

No matter how you choose to take care of your mental health and wellbeing, remember that you are not alone. If you find that your circumstances feel overwhelming or beyond your control, consider seeking additional support from trusted medical professionals who can help you navigate ongoing stress while offering resources, hope, and a range of helpful perspectives. Contact Resolve Crisis Services for help: **1-888-796-8226**.

*Written by **Cheyenne Hennen***

Spina Bifida and Chronic Pain

Chronic pain is something that many adults with spina bifida (SB) experience. If you deal with pain on a regular basis, you are not alone.

Pain is the body's way of telling us that something needs attention. But when pain lasts for months or longer (even after an injury has healed or without a clear reason) it becomes what is called chronic pain. Chronic pain can be tiring, frustrating, and hard to explain to others.

Adults with SB are more likely to experience chronic pain than adults without SB. Pain can show up in different ways. Some people feel it mostly in their back, hips, or joints. Others feel burning, tingling, or numbness. For some, pain is fairly constant, while for others it comes and goes. Pain can also be affected by things like stress, mood, sleep, and how active you are. Because of this, two people with SB can have very different pain experiences.

Living with chronic pain can affect more than just the body. It can make it harder to sleep, stay active, spend time with others, or keep up with daily tasks. Over time, pain can also lead to feelings of frustration, sadness, or worry. That is why it is important to address pain early and to know that there are helpful treatments available, many of which do not involve medication or surgery.

For example, physical therapy (PT) is one of the most common non-medication treatments for chronic pain. A physical therapist can work with you on stretching, strengthening, and movement exercises to help reduce pain and make it easier to get through your day. PT can also help you learn how to stay active without overdoing it. Many adults with SB find that PT helps them feel more comfortable and more in control of their pain.

Another helpful treatment is cognitive-behavioral therapy (CBT). You may recognize CBT from previous newsletter articles on depression and anxiety. CBT for chronic pain helps people understand how their thoughts, feelings, and actions can affect how they experience pain. Through CBT, people learn skills to manage stress, challenge unhelpful thinking patterns, and get back to doing things they enjoy even when pain is present. Acceptance-and-commitment therapy (ACT) is a closely related treatment that is also helpful for chronic pain. ACT similarly focuses on managing the thoughts and feelings brought up by pain, so you stay connected with the people and things that matter most to you.

If you are interested in trying either CBT or ACT for chronic pain, one option is the Pain Management Program at the University of Pittsburgh Clinical Psychology Center. This clinic is located on Pitt's campus in Oakland and offers therapy at reduced fees. Their pain program is designed to work alongside the medical treatment you are already getting, with the goal of helping pain get in the way less. **You can reach them by calling 412-624-8822**. If interested in finding a provider who offers these services in the community, consider checking out *PsychologyToday* or asking to speak with the SB Clinic social worker for resources.

Remember, chronic pain is common among people with SB, but it does not have to control your life. With the right help, it can be managed.

There are also simple things you can try on your own. Gentle movement and stretching, even on tough days, can help prevent stiffness. Deep breathing can calm both the body and mind during painful moments. Keeping a regular sleep schedule and staying connected with people you care about can also make a big difference.

If chronic pain is getting in the way of your life, please bring this up during your next visit to the SB Clinic. Your providers can help connect you with the right support, including physical therapy and/or CBT. Remember, chronic pain is common among people with SB, but it does not have to control your life. With the right help, it can be managed. This is not something you have to deal with on your own.

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

JUST ICE IT 2026

UPMC SLED HOCKEY CHALLENGE

The UPMC Just Ice It sled hockey fundraiser for the Mighty Penguins returned this year on Saturday, March 14, 2026 at the UPMC Lemieux Sports Complex in Cranberry Township. The participation (whether volunteering, cheering in the stands or competing on the ice) helped to show some incredible support for the Mighty Penguins Sled Hockey team while raising over $21,000! First the residents took on the UPMC Attendings/Staff and won in double overtime, then team UPMC took on the Mighty Penguins themselves and scored a 2-1 victory!

Upcoming Events

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.

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