

Falling into Wellness

This fall, we encourage patients and families to explore adaptive wellness opportunities throughout the Pittsburgh community.

Staying active and socially connected can support both physical and emotional health while building confidence and community.

One local organization making a difference is Three Rivers Adaptive Sports, which offers year-round adaptive recreation and fitness opportunities for individuals with physical disabilities. Programs focus on exercise, sports participation, and overall wellness in an inclusive environment. Visit: www.traspa.org to learn more.



Photo courtesy of TRAS

Can't make it out? Wellness does not always require a formal program. Small daily habits can make a meaningful impact, including:

- Gentle stretching or range-of-motion exercises
- Scheduling follow-up appointments
- Listening to music, journaling, or creative hobbies for stress relief
- Maintaining consistent sleep routines
- Practicing skin checks and hydration habits
- Spending time outdoors during cooler fall weather
- Staying socially connected through phone calls, virtual groups, or family activities
- Celebrating small victories and personal goals

As the seasons change, remember that wellness includes physical, emotional, and social health. Even small steps toward self-care can make a big difference. As always, our interdisciplinary team remains committed to supporting patients and families in reaching their goals and navigating barriers related to healthcare access, transportation, education, equipment, and overall quality of life. We are grateful to walk alongside our patients through every season.

Written by **Olivia Hughes**

Spina Bifida Clinical Care Meeting

Dr. Dicianno, Monica, Sara, and Cheyenne attended the Spina Bifida Clinical Care Meeting in Dallas in May, where healthcare professionals from across the country gathered to share best practices, discuss emerging research, and collaborate on strategies to improve care for individuals with spina bifida. The meeting provided valuable opportunities for learning and networking, helping our team stay at the forefront of multidisciplinary care and bring new insights back to the patients and families we serve.

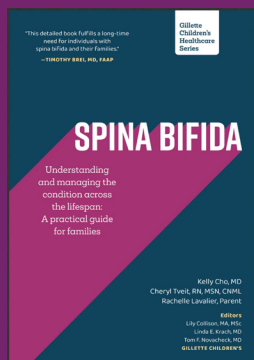
Written by **Brad Dicianno, MD**



New Book about Spina Bifida Care

Gillette Children's Healthcare Press and Mac Keith Press have published a new book, *Spina Bifida—Understanding and managing the condition across the lifespan: A practical guide for families*.

The book is meant for individuals navigating their own care, parents or family members supporting a loved one, and healthcare professionals looking for a broader perspective. It is available at [Mac Keith Press](#) and [Amazon](#).



Free Dental, Hearing, and Vision Care Event

The 2026 Mission of Mercy Pittsburgh ninth annual **FREE dental and hearing clinic will be held Oct. 16-17, 2026, at the David L. Lawrence Convention Center** in Downtown Pittsburgh. The clinic will again bring together dentists, clinicians, nurses, imaging technicians and general volunteers to support children and adults who lack access to—or cannot afford—dental and hearing care. Patients will have access to an array of dental procedures, including dental exams, cleanings, fillings, extractions and root canal treatments. Hearing evaluations, as well as free hearing aids, also are included.

New this year, patients will have expanded access to more comprehensive vision healthcare thanks to our enhanced partnership with the UPMC Vision Institute. Patients who check in to the October clinic with vision healthcare needs will be referred to the Vision Institute staff on-site, who will register them for an appointment at the Vision Institute's Community Vision Day sister event, scheduled for Oct. 18, 2026, at the UPMC Mercy Pavilion (1622 Locust Street, Uptown Pittsburgh).

Dr. Dicianno receives Distinguished Physician Advocate Award

Dr. Dicianno was selected as the Distinguished Physician Advocate Awardee for the 2nd Annual Access & Impact Awards by the UPMC Disabilities Resource Center, in celebration of the Americans with Disabilities Act 36th Anniversary. He was honored during a celebration at UPMC Mercy Pavilion on July 22.



(l-r): Ashli Molinero, Director Disabilities Resource Center, Dr. Dicianno, Chatón T. Turner, Senior Associate Counsel, Vice President, Civil Rights, Regulatory Affairs, Disability Resources, and External Relations (photo: John Dillard, UPMC)

Is Your Blood Pressure Monitor Accurate?

If you have high blood pressure, it's a good idea to monitor your blood pressure at home. But how do you know which blood pressure monitor to buy, or if the one you own is accurate? The American Medical Association has a free website [validatebp.org](https://www.validatebp.org). Every device on this list has been tested for accuracy. Monitors with an **upper-arm cuff** are generally recommended over wrist devices for most patients. Check that the cuff size matches your arm — the listing shows which sizes each device is tested for. If you are checking your blood pressure at home, accurate readings are important for getting the right medical advice and care.

Written by **Brad Dicianno, MD**



Sleeping Well

Getting a good night's sleep is something many people struggle with. For adults with spina bifida (SB), sleep problems are especially common.

Sleep matters more than most people realize. When we sleep well, our bodies recover and our mood stays more stable. A good night's sleep can make it easier to think clearly, stay organized, and manage daily tasks. When sleep is poor, everything else gets harder. You may have noticed this yourself: maybe pain feels worse after a bad night, or it's harder to stay motivated. Things that usually feel manageable can start to feel overwhelming. In previous newsletter articles, I have written about depression, anxiety, executive functioning, and chronic pain. Sleep plays a role in every one of those topics.

Adults with SB are more likely to experience sleep difficulties for several reasons. Back, joint, or nerve-related pain can make it difficult to get comfortable at night. Bladder and bowel routines may interrupt sleep. Some adults with SB also have sleep apnea, a condition where breathing repeatedly stops and starts during sleep, which can leave you feeling exhausted even after a full night in bed. Stress, worry, and low mood can also keep the mind racing at bedtime.

The good news is that there are effective treatments for sleep problems, and many of them do not involve medication.

One of the most well-supported treatments is cognitive-behavioral therapy for insomnia, often called CBT-I. This treatment involves working with a therapist to identify and change the habits and thought patterns

that keep sleep problems going. It typically involves learning strategies like keeping a consistent sleep and wake schedule, limiting time spent in bed while awake, and managing the racing thoughts that can show up at bedtime. Research consistently shows that CBT-I works as well as or better than sleep medication—and the improvements tend to last longer.

If sleep apnea is a concern, a sleep study can help determine whether treatment such as a CPAP machine is needed. This is a common topic of discussion with patients in the SB Clinic.

There are also simple things you can try on your own. Going to bed and waking up at the same time each day—even on weekends—helps set your body's internal clock. Avoiding screens for 30 minutes before bed can make it easier to wind down. Keeping your bedroom cool, dark, and quiet also helps. If pain is keeping you up, adjusting your sleeping position or using supportive pillows may make a difference. Limiting caffeine in the afternoon and evening can go a long way, too.

If sleep problems are affecting your daily life, please bring this up at your next visit to the SB Clinic. Your providers can help figure out what is going on and connect you with the right support—whether that is a referral for CBT-I, a sleep study, or other options. Sleep problems are common among adults with SB, but they do not have to be something you just live with. Better sleep is possible, and it can make a real difference in how you feel during the day.

Written by Ted Barrios, PhD

Tips on Moving

Moving can be an overwhelming and stressful experience for anyone, especially for individuals with disabilities. However, with adequate planning and support - transitioning to your new home can feel like a breeze.

Here are 4 tips to help navigate an accessible and accommodating move.

1

START EARLY: Moving out of your current home can feel daunting. To reduce fatigue and mental strain, begin organizing, labeling boxes, and decluttering as soon as possible, prioritizing essential items (such as medical supplies, mobility/sensory aids, documents, chargers...) and accessibility needs. The less you have, the easier it will be to delegate tasks and minimize both physical and mental stress.

2

SEEK OUT SUPPORT: Having moving assistance is essential – try reaching out to family or friends for help or consider hiring local movers experienced with accessible housing. Additionally, your local [Center for Independent Living](#) may be able to connect you with appropriate moving services and resources to suit your needs.

3

THINK AHEAD: Ensure you notify all necessary providers, such as utility and medical service companies of your upcoming move so there are no gaps in service, and you aren't left without essential supplies or support after move-in.

4

PACE YOURSELF: The process of moving can be physically and mentally demanding. Try to avoid overexerting yourself and take breaks as needed. Moving at your own pace and conserving your energy will help you stay safe and make the process more manageable.

*Written by **Cheyenne Hennen***





Is Organic Food Better for Health?

There is lots of information online about which foods are healthiest to eat. Folks often ask if they should be eating only organic produce, or if organic foods are healthier for them.

The short answer is: no, you do not have to eat only organic foods to eat a healthy diet.

Let's start with the definition of organic food. The USDA sets forth standards for organic foods. Farms must be certified to ensure they are following these practices. The USDA defines organic meat, poultry, eggs, and dairy as food items that come from animals that are not given antibiotics or growth hormones, who are fed organic feed, and have access to the outdoors. It defines organic plant foods as those made without using most conventional pesticides and synthetic fertilizers, bioengineering (such as GMOs), or ionizing radiation. Pesticides are still utilized in organic foods, but they are naturally sourced. Natural does not automatically mean safer. No matter what kind of produce you buy, it is still important to wash your fruits and vegetables before eating.

Current science does not show any differences nutritionally or in terms of safety between organic foods and conventional (non-organic) foods. Organic foods are often more expensive than conventionally farmed foods, and this can make them less accessible. If a person prefers to purchase organic foods for personal reasons (such as environmental or animal welfare concerns, taste preferences, etc.) and it fits their budget, this is perfectly fine to do. However, you can rest assured that conventional foods are safe to eat and are part of a healthy diet. The most important thing is that you are eating your fruits and vegetables – something many Americans do not get enough of!

Written by Jacquelyn Klunk, MS, RDN, LDN

What about the Dirty Dozen™ ?

Each year, the Environmental Working Group (EWG) publishes a list called the **Dirty Dozen™** and the **Clean Fifteen™**. These are meant to represent the twelve foods most contaminated with pesticides, and the fifteen least pesticide-containing foods. The EWG historically has counted pesticide contamination by number of different pesticides used – not by comparison to established safety levels. Even for Dirty Dozen™ foods, a person would have to eat huge amounts of the food items to exceed EPA and USDA thresholds for human safety. For example, spinach is at the top of the Dirty Dozen™ list. An adult male could eat 1,084 servings of spinach in a day without a negative impact on their health from pesticides. You can use this [online calculation tool](#) to see how many servings a person could consume of a food and not have negative effects from pesticide residues. At the end of the day, these lists lack nuance and context. It is most important to eat a balanced diet rich in fruits and vegetables that fits within your budget – regardless of whether or not the food is organic.



Photo: alexcorrie.com

Sample Strength Training Workout

3 sets, 10-15 reps, 1 minute rest between sets

- Seated Chest Press (resistance band)
- Horizontal Row (resistance band)
- Lateral Raise (dumbbell or household object with weight to it)
- Shoulder Press (resistance band or dumbbell or household object with weight to it)

Strengthening Body and Mind Through Seasonal Exercise

As the leaves change and the temperature drops, Fall offers a wonderful opportunity to focus on physical and mental wellness in preparation for the Winter months.

The feeling you get when you accomplish something difficult, especially when you don't feel like doing it, is a huge confidence boost and creates positive momentum for you in every aspect of your life that you might not even realize. When you achieve something difficult that you didn't want to or think you could do, this tells your brain that you can do difficult things and push yourself past what you originally thought you were capable of.

Physical Benefits of Exercise

Regular exercise helps build muscle strength, improve balance, and increase flexibility. Strength training has been shown to strengthen muscles (obviously) but also strengthens bones and ligaments in our bodies as well as our heart. These benefits are especially valuable for supporting mobility and maintaining independence. Even simple routines like stretching, resistance band workouts, or aquatic therapy can boost cardiovascular health and help prevent secondary complications.

Physical activity is not just good for the body—it's also a powerful tool for mental strengthening.

Mental Strengthening: Boosting Mood and Confidence

Physical activity is not just good for the body—it's also a powerful tool for mental strengthening. Exercise releases endorphins, which can elevate your mood and reduce stress. Throughout colder and more cloudy environments during the fall, we rarely get enough sunlight and vitamin D to help boost our mood. Eating food high in vitamin D along with engaging in movement during the fall months can help combat feelings of isolation by fueling your body in a healthy way, improving your sleep, and connecting you with nature or a community group. The sense of accomplishment from reaching fitness goals, no matter how small, builds self-confidence and resilience to tackle other life stressors outside of fitness.

Written by Dan McCoy, MS, CPT, PLY

Research Matters— And So Do You

I'm going to say this plainly: a lot of what we do in spina bifida care still isn't based on enough real evidence—especially for adults.

For a long time, people with spina bifida weren't included in research the way we should have been. And when you're not included, your needs don't get prioritized. Your outcomes don't get measured. Your life doesn't shape the system.

That's the problem research is trying to fix.

In clinic, we use research every single day—whether people realize it or not. The way we manage bladder programs, prevent wounds, think about mobility, even how we counsel patients—those decisions come from data. Good data leads to better care. Bad or missing data? That's when people fall through the cracks.

And I see that happen. Patients showing up after being lost to care. People traveling hours just to get something as basic as an accurate weight. Adults trying to manage complex bowel and bladder programs without support because no one ever studied what works long-term.

That's why research matters.

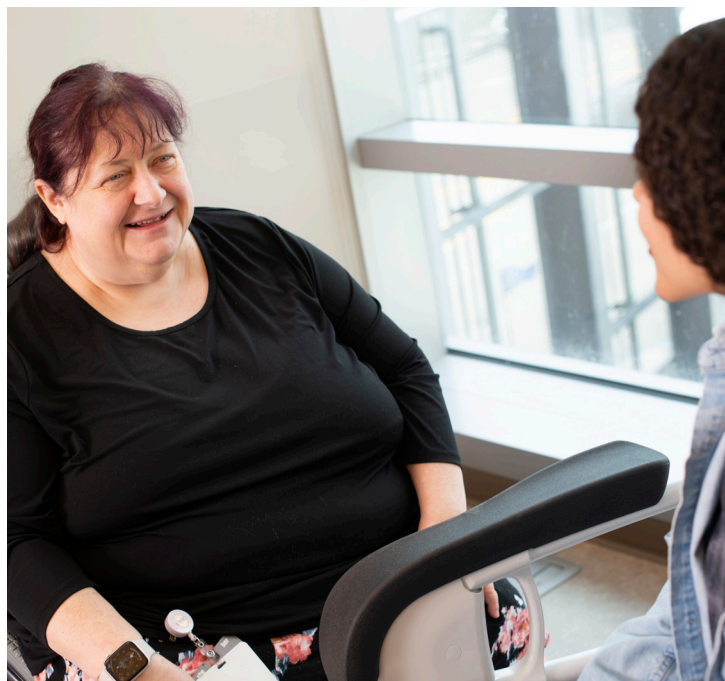
But here's the part people don't always say: research only works if people actually participate.

*What you're really doing is sharing
your experience so it can be turned into
something that improves care—for you
and for the next person.*

You are not a “guinea pig.” Most studies are not experimental in the way people fear. A lot of them are surveys, interviews, or tracking outcomes of care you're already receiving. What you're really doing is sharing your experience so it can be turned into something that improves care—for you and for the next person.

And right now, there are some important studies happening.

The **MOMS 3 Study** is following individuals who were part of the original MOMS trial, which looked at prenatal repair for spina bifida. We learned a lot from that first study—but MOMS 3 is where we start to understand the long game. What does life actually look like years down the road? Function. Independence. Real quality of life.



That's the information families deserve when they're making big decisions.

Then there's ongoing bowel research, **Bowel Continence Across the Lifespan in People With Spina Bifida (BCALS)**, funded by the Patient-Centered Outcomes Research Institute. And I'm going to be honest—this is one of the areas we have ignored for far too long. Bowel care is not minor. It's not optional. It impacts dignity, health, independence, and whether someone can fully participate in their life. These studies are asking the right question: what actually works in real life? Not in theory. Not in a textbook. In real, day-to-day living.

And importantly, PCORI research centers patient voice. That means your experience isn't an afterthought—it's the point.

I know people get hesitant about research. I get it. But if we don't show up, the data won't reflect us. And if the data doesn't reflect us, the system won't change.

Advocacy isn't just going to Harrisburg or telling your story (though that matters too). Sometimes advocacy looks like filling out a survey. Joining a study. Saying, “This is what my life is actually like.”

That's how we build better care.

That's how we stop being overlooked.

And that's how we make sure the next generation—and all of us aging with spina bifida—do better.

If you are interested in participating or learning more about the **BCALS study**, please contact our Clinical Coordinator: Sara Izzo at (412)-642-5494.

Written by Monica Albert Still, RN, BSN

Keeping an Eye on Your Shunt

Many people with Spina Bifida have shunts in their brains. These shunts help cerebral spinal fluid (CSF) drain more efficiently and prevent increased pressure in the brain (hydrocephalus).

About 70–85% of children with myelomeningocele develop hydrocephalus, requiring a shunt. Often, the shunt is put in very early in life, at the time of myelomeningocele repair. Sometimes one shunt lasts a lifetime. Sometimes a shunt malfunctions and needs to be adjusted or revised. Shunt revisions are significantly more common in childhood than adulthood. So how do you know when you need to consider getting a new shunt?



Symptoms of shunt malfunction can warn you that a shunt needs to be adjusted or replaced. If you are having symptoms such as new or changing headache, nausea, changes in your cognition and/or other neurological symptoms, you should seek medical attention right away.

Seeing the Spina Bifida Clinic every year can also help you track new or changing symptoms that could indicate a shunt malfunction. When you see us in the Spina Bifida Clinic, we are always asking questions about new or changing symptoms, and we do a thorough neurological exam every year to look for physical changes that could be warnings.

Getting an annual eye exam also helps you “keep an eye” on your shunt. An eye exam can detect shunt malfunction by identifying signs of elevated pressure in the brain that result from impaired CSF drainage. Rising pressure in the brain transmits directly to the eye and causes changes that an ophthalmologist can see on an eye exam. ***Have questions! Let us know!***

Written by Darcie Petrillo, MPAS, PA-C

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

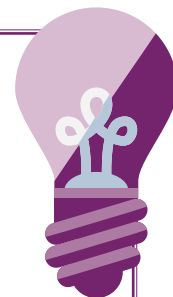
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Check out our other newsletters and clinic information at: UPMC.com/SpinaBifida



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Upcoming Events

September 26, 2026

Disability Pride Pittsburgh

Schenley Plaza, 4100 Forbes Avenue

[Learn more](#)

