



## It's our 20th Anniversary: The History of the UPMC Adult Spina Bifida Clinic

There are over 160,000 people in the US living with Spina Bifida, and the majority of those individuals are adults.

We estimate that about 50% of adults with Spina Bifida live in an area of the country where there is no clinic dedicated to the care of adults. We are extremely fortunate to have resources at UPMC that have allowed us to provide care to adults with Spina Bifida for over 20 years. People often ask us how our clinic came to be, so we wanted to share some of the history.

The Spina Bifida Association of Western PA (SBAWP) was founded in 1969 by a group of parents. At that time, Dr. Donald Reigel (1937-2018) was a pediatric neurosurgeon at UPMC Children's Hospital of Pittsburgh. Through the advocacy efforts of SBAWP and Dr. Reigel's leadership, the first multidisciplinary spina bifida clinic in PA was established at Children's Hospital of Pittsburgh in 1974.

*(Continued on page 2)*



*"I must find the time to plant some  
trees in the meadow where the  
river flows. In time to come they'll  
make good shade... When winter  
comes, we're gonna fly away  
and find the sun."*

'Winter Bird/When Winter Comes' is the final track on Paul McCartney's 18th solo album. McCartney said that it was inspired by the months in the early 1970s when he retreated to his farm in Scotland. It reminds us that preparation today can benefit us tomorrow. This edition of our newsletter was designed to help you prepare for the year ahead.



Dr. Reigel eventually transitioned his practice to the West Penn Allegheny Health System and provided care to children and adults with Spina Bifida at different locations, including St. Francis Hospital and Allegheny General Hospital. Dr. Reigel retired from the Allegheny General Hospital in 1998, and Dr. Stephanie Schneck, an orthopedic surgeon, became the Director. At that same time, Marsha Park, RN, became the clinic's nurse coordinator and redeveloped the care coordination program. The SBAWP also established the Woodlands Foundation in 1998. The clinic at West Penn Allegheny Health System later closed in 2003. Many of the children receiving care at that clinic transitioned their care to Children's Hospital. Georgia Wiltsie-Tilford, RN served as the nurse coordinator of the pediatric clinic at Children's Hospital from 1992-2018.

Dr. Leland Albright, a neurosurgeon, treated patients at Children's Hospital from 1981- 2006. He later moved to Kenya to do medical missionary work.

Due to the large number of adults who had been receiving care in the Allegheny Health System, it was clear that a new adult model was needed. In 2003, the Department of Physical Medicine & Rehabilitation (PM&R) at the University of Pittsburgh School of Medicine applied for and received funding through the PA Department of Health Specialty Care Program to establish the UPMC Adult Spina Bifida Clinic. Marsha Park became the clinic's nurse coordinator and began to grow the program. The Dept. of PM&R was able to offer team-based, comprehensive care to focus on preventive care, aging, mobility, and function.

In its early years, the UPMC Adult Spina Bifida Clinic was housed in the Kaufmann Building in Oakland and was held twice per month. The PM&R physician in that clinic alternated among different faculty. At that time, Dr. Brad Dicianno was a resident in

(Continued on page 3)



*Left to Right: Kiara Nesbit (Nurse), Sara Izzo (Peer Counseling Program Coordinator), Dr. Brad Dicianno (Director), Darcie Petrillo (Physician Assistant), Dr. Lisa Stanford (Neuropsychologist), Jackie Klunk (Dietitian), Dan McCoy (Personal Trainer), Rajit Banerjee (Resident), Jamie Williams (Nurse), Carol Thomas-Smith (Patient Service Representative)*



*Front: Dr. Brad Dicianno (Director), Matt Berwick & Dr. Ashli Molinero (UPMC Disability Resource Center). Middle: Alissa Freese (Public Relations, CLASS), Jackie Klunk (Dietitian). Back: Shannon McCarty (Chief Development Officer, CLASS), Robin Wingard (Director of Development, SBAWP), Mallory Hudson (Outreach Coordinator, CLASS)*



*Left to Right: Dr. Lisa Stanford (Neuropsychologist), Aujahnea Tuner (Medical Assistant), Monica Still (Nurse), Darcie Petrillo (Physician Assistant), Dr. Brad Dicianno (Director), Carol Thomas-Smith (Patient Service Representative), Shannon McCarty (Chief Development Officer, CLASS), Robin Wingard (Director of Development, SBAWP)*

training in the PM&R program at UPMC. He had become interested in the field of PM&R through working as a summer camp counselor for individuals with disabilities. One of the summer camps where he worked was held at the Woodlands. Dr. Dicianno spent much of his elective time during residency seeing patients in the Adult Spina Bifida Clinic. Dr. Dicianno graduated from PM&R residency and became the Director of the UPMC Adult Spina Bifida Clinic in 2005. The clinic increased its operations to weekly.

In 2007, the UPMC Adult Spina Bifida Clinic moved to UPMC Southside Rehabilitation Hospital. Nancy Lewis, RN, was recruited to coordinate the clinic when Marsha Park transitioned to a new role. In 2009, the clinic moved to UPMC Mercy Hospital. Andrea Knapp, RN assumed the role of nurse coordinator when Nancy Lewis retired. The clinic then transitioned to the new UPMC Mercy Pavilion in 2023. Monica Albert Still, RN, BSN then assumed the role of nurse coordinator. In the last 20 years, we have provided care to over 600 adults with Spina Bifida.

On November 21, 2023 the clinic team and colleagues from CLASS, SBAWP, and the UPMC Disability Resource Center surprised Dr. Dicianno at the UPMC Mercy Pavilion with a party to celebrate the anniversary. We look forward to working with the community for many years to come.

*Written by **Brad Dicianno, MD** and **Marsha Park, RN***

## Celebrating Carol Thomas' Service to UPMC

Many of you have met our amazing Patient Service Representative, Carol Smith, who sits at our front desk and is usually the first smiling face to greet you. This year we are celebrating her 45 years of service to UPMC. Before coming to our clinic, she worked in our inpatient rehabilitation unit. Carol has a wonderful husband, three children, and 5 grandchildren. Carol says that the reason she has stayed so long with our department is because she loves working with her coworkers. Please congratulate Carol when you see her!



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



## Life in Motion Gym

The Life in Motion Gym is a gym run by physical therapists. We provide specialized fitness services that are accessible for all abilities, with a focus on neurological diagnoses and the aging population. We offer a gym membership, group classes, and personal training sessions. Our goal is to keep as many people in motion as possible in order to live their life to the fullest and achieve their goals. Some reasons to consider our gym: 1) you will be discharged from physical therapy soon, 2) you want to exercise but you are not sure where to go or how to start, 3) you find gyms intimidating or not appropriate or accessible, 4) you want a supportive and encouraging community. Contact us for a free consultation.

*Written by **Sarah Andrews DPT**, **Shannon Mathis DPT**, and **Jackie McMurray DPT***





# Sunshine in a Bottle: VITAMIN D

Did you know that lack of sunshine can cause more problems than a “blah” mood?

Sunlight is a major source of Vitamin D. Adequate Vitamin D levels are crucial for bone health, immune function, and overall well-being. People with Spina Bifida are at risk for not having enough vitamin D compared to the general population.



## Some things you should know about Vitamin D are:

- **Limited Sunlight Exposure:** Individuals with mobility challenges may spend more time indoors, reducing exposure to sunlight, which is a source of Vitamin D
- **Orthopedic Issues:** Vitamin D is crucial for calcium absorption and bone health, and deficiency can further make bone-related problems worse.
- **Limited Dietary Sources:** Few foods naturally contain significant amounts of vitamin D, and fortified foods may not be as accessible or consumed regularly.
- **Age:** older people are at risk of low Vitamin D levels.
- **Reduced Ability of your Body to Make Vitamin D:** Some individuals, especially those with darker skin, may make as much Vitamin D from sunlight.
- **Medications:** Some laxatives and seizure medications can reduce Vitamin D levels.
- **Absorption Problems:** Certain medical conditions may interfere with the absorption of Vitamin D from the diet, leading to deficiencies.



## Here are some things you can do to help prevent Vitamin D deficiency:

- **Dietary Sources:** While it may not be possible to get enough Vitamin D solely from food, try to eat foods high in Vitamin D, such as fortified dairy products, fortified cereals, and fatty fish.
- **Vitamin D Supplements:** Discuss taking Vitamin D supplements with your doctor.
- **Sunlight Exposure:** Try to get some sunlight exposure during the winter. Even brief periods of time outdoors, especially during sunny days at midday, can help the skin make Vitamin D.
- **Indoor Light Sources:** Exposure to specific types of indoor light that mimic natural sunlight (e.g., full-spectrum light) may help the body produce Vitamin D. However, it may not be as good as direct sunlight.
- **Regular Medical Check-ups:** Talk to your primary care doctor about regular medical check-ups, including blood tests to monitor Vitamin D levels.



Written by **Monica Albert Still, RN, BSN** and **Brad Dicianno, MD**

## Social Security Disability Resources

To be found eligible to receive Social Security Disability Insurance or Supplemental Security Income in Pittsburgh, PA, you'll need to show you've been disabled for a period of **one year** or longer and unable to hold a job due to either a long-term or permanent health condition. The Social Security Administration's guidelines measure the degree of disability to determine if you're eligible to receive Pittsburgh disability benefits.

Applying for Pittsburgh disability benefits is a complicated application process, and it can take several months to get through all the steps. Initially, only about 37% of applicants are approved for SSD. If you're denied benefits, you'll need to request a second review. If denied again, you will need to file an appeal, and your case will be scheduled for a hearing with an Administrative Law Judge.

To apply for Pittsburgh disability benefits, you should call the Social Security Administration (SSA) main phone line at **(800)-772-1213**, contact your Social Security offices in **Pennsylvania**, or use the forms available on the SSA's website. For help finding your local SSA office, call the number listed above, or visit the SSA's Office Locator webpage.

1. Go to [www.ssa.gov/benefits/disability](https://www.ssa.gov/benefits/disability) select **"Apply for Disability"**
2. Complete the Disability Benefit Application [Apply for Benefits, Social Security \(ssa.gov\)](https://www.ssa.gov/benefits/disability)
3. Complete the Medical Release Form
4. Mail or take the documents to your Social Security office.



- If you are deaf or hard of hearing, you can call **TTY 1-800-325-0778**.
- Call or visit your local Social Security office. If you want to apply in person, please call and make an appointment before you visit your local office.

SS offices in Pennsylvania:

[Pennsylvania Social Security Office Locations | Social Security Offices in Pennsylvania \(benefitsoffices.com\)](https://www.ssa.gov/benefits/disability)

Social Security office locator by zip code:

<https://secure.ssa.gov/ICON/main.jsp>

*Written by Amy Kiska, BSW*



## Adaptive Sports and Fitness Opportunities

Adaptive sports and online or in-person fitness programs can be a beneficial way to get or stay physically healthy, improve our mental health, and make new and lasting friendships along the way. Groups such as [Move United](#), [The Adaptive Training Foundation](#), [Adaptive Training Academy](#), and [Ability 360](#) all provide opportunities for adaptive sports, and online fitness opportunities including group classes or one-on-one training.

*Written by Dan McCoy MS, CPT, PLY*





## Nutrition Supplements

If you go down the supplement section of any grocery store, you'll see shelves nearly overflowing with vitamins and minerals. There is also a lot of marketing around us claiming that these products are necessary for health and that our food is not enough. So, what is the scoop on nutritional supplements?

### Who might benefit from supplements?

- People who can't absorb the nutrients they eat from food due to surgeries on their stomach or intestines, certain medical conditions that affect absorption (such as celiac disease or inflammatory bowel disease), or changes in absorption in aging (often seen with vitamin B12 and vitamin D).
- People with a nutrient deficiency that is confirmed by lab work.
- People who may need help to fill nutrient gaps if food intake is low for a period of time.
- Certain medical conditions that require increased nutrient intake. For example, women with spina bifida are at an increased risk of having children with spina bifida. Taking a folic acid supplement can decrease this risk. It is recommended that women with spina bifida take a daily oral supplement of 4 mg of folic acid for at least 1 month (but ideally 3 months) before conception and continuing for the first three months of the pregnancy. This is 10 times higher than the recommended amount of folic acid for women without spina bifida. This type of supplementation should be obtained by a prescription from your doctor – don't just take extra

prenatal vitamins for extra folic acid because you will get too much of the other vitamins/minerals and this can be dangerous.

### What are some concerns about supplements?

- Our bodies may use nutrients better when coming from whole foods. We always encourage nutrients from food first when possible, and then using supplements if needed. Supplements should "supplement" or "add to" your diet, not replace foods in your diet.
- Potential for interaction with medications or health conditions based on medical history.
- Potential for taking too much of a certain nutrient that can build up in the body to an unsafe level.
- Supplements are not regulated by the FDA. This means that some supplements do not contain the ingredients they claim to contain, may have ingredients in different amounts than what is on the label, or may contain ingredients that are not on the label.
- Choosing a supplement with a third-party verification (such as USP, NSF, or Consumer Labs) can be helpful. A third-party verification is a voluntary program that a manufacturer can choose to get to verify that what is on the label is actually in the product, that there are no contaminants in the product, and that the manufacturer is following safe manufacturing practices.

**In summary:** Getting your nutrition from food first in a balanced diet is the best choice when possible. There are times when nutrition supplements may be necessary, but you should discuss this with your healthcare provider first to make sure it is safe for you and how much you should take.

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





## Do you Qualify for Rent or Tax Rebates?

**The PA Property Tax and Rent Rebate Program** benefits eligible Pennsylvanians aged 65 and older; widows and widowers age 50 and older; and people with disabilities age 18 and older. The income limit is \$35,000 a year for homeowners and \$15,000 annually for renters, and half of Social Security income is excluded. Spouses, personal representatives or estates may also file rebate claims on behalf of claimants who lived at least one day in the claim year and meet all other eligibility criteria. Even more individuals will likely qualify in 2024 when the income limit will likely be raised for both homeowners and renters.

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

## Parking Reminder

If you are parking in the UPMC Mercy Pavilion garage, we recommend parking on the rooftop, which is Level 8 (P8). This level has abundant accessible parking spaces. Also, if you enter the building from the garage on that level, you will be on the 4th floor and will immediately see the waiting room for our clinic. The first two hours of parking in the garage are free. Valet parking is also available in the front of the building.

## 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*

## Education & Outreach Events

On November 11, 2023, Dr. Dicianno was the keynote speaker on the topic of Adult Health and Aging Well with Spina Bifida at the Spina Bifida Coalition’s Looking Forward: A Midwest Spina Bifida Conference.

He also spoke on the same topic for the Spina Bifida Association on December 5, 2023 which will be followed by an Ask the Expert Session on January 11. Watch the SBA’s website for details.

He will be giving a Grand Rounds presentation at Cleveland Clinic Childrens in April.

## Save the Date to Advocate!

The Teal on the Hill Advoacy event will take place virtually on Feb. 25-27. Registration opens on Feb. 9. Go to [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org) for more information.



## 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](http://UPMC.com/SpinaBifida)



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