UPMC
LIFE CHANGING MEDICINE

UPMC Adult Spina Bifida Clinic Spring 2025 Newsletter

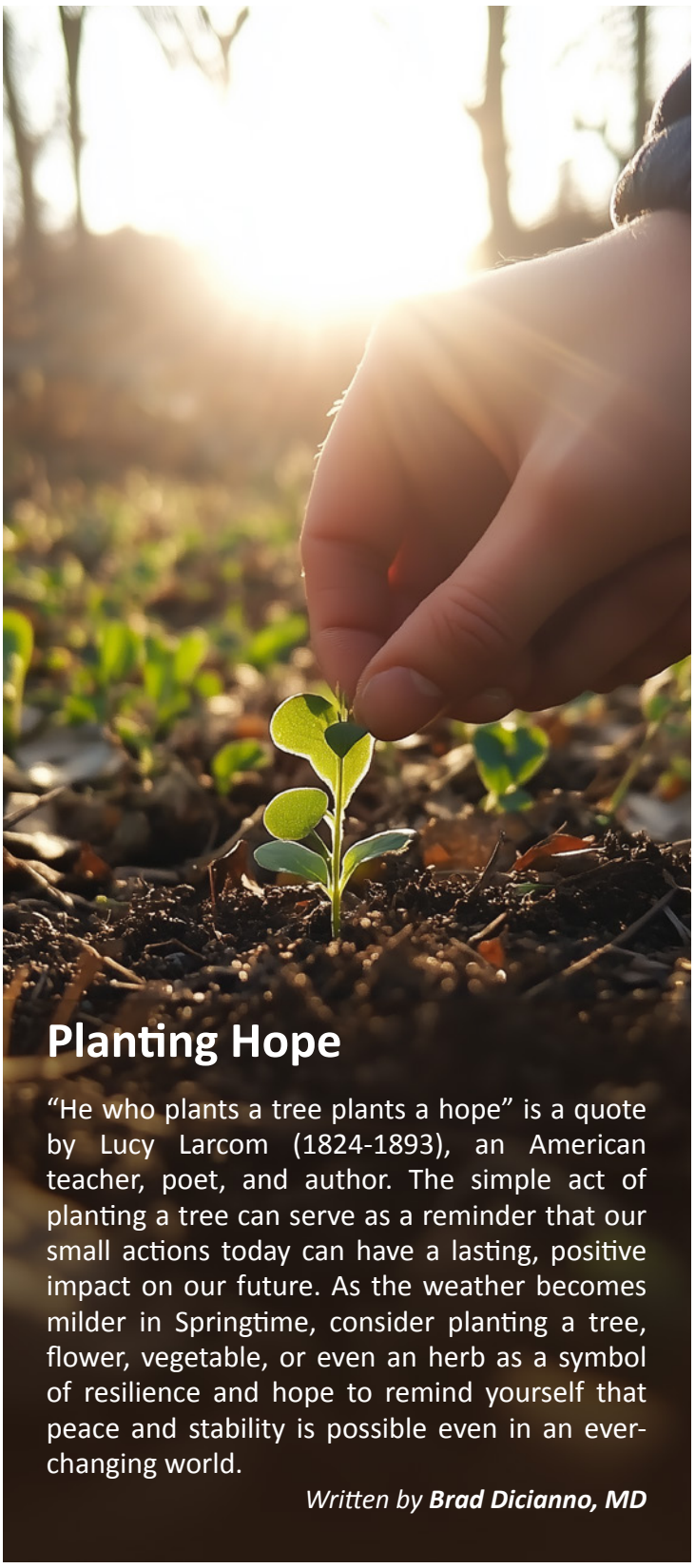
Looking for New SB-CAN members: Your Voice is Needed!

We are looking to add new members to the **Spina Bifida Care Advisory Network of Western Pennsylvania**, abbreviated as SB-CAN.

We need your voice; the voice of people living with Spina Bifida and their family members. SB-CAN virtual-meetings are held every quarter. SB-CAN meetings allow us to engage people with Spina Bifida and their families to share goals and objectives and identify shared barriers to care so that we can improve our care system. During our meetings, we discuss how to best implement the Guidelines for the Care of People with Spina Bifida as outlined by the National Spina Bifida Association, discuss current practices and resources, learn about pertinent events and research opportunities and have meaningful conversations that lead to change. SB-CAN discussions have helped us to recognize where we need to build relationships with other specialists, improve resource access, better support people through the transition from pediatric to adult services and much more. We encourage panel participant selection to promote diversity across the spectrum of Spina Bifida. Please reach out to Sara Izzo (izzos@upmc.edu) or Monica Albert Still (stillm2@upmc.edu) if you are interested in joining or want to learn more.

Spina Bifida Care Advisory Network of Western PA

Written by ***Darcie Petrillo, MPAS, PA-C***



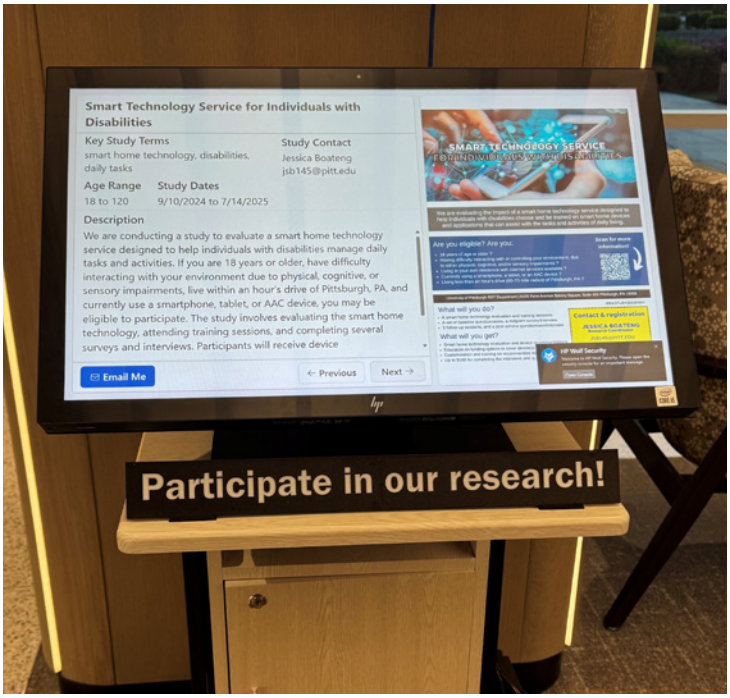
Planting Hope

"He who plants a tree plants a hope" is a quote by Lucy Larcom (1824-1893), an American teacher, poet, and author. The simple act of planting a tree can serve as a reminder that our small actions today can have a lasting, positive impact on our future. As the weather becomes milder in Springtime, consider planting a tree, flower, vegetable, or even an herb as a symbol of resilience and hope to remind yourself that peace and stability is possible even in an ever-changing world.

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

Our New Research Kiosk

Check out our new research kiosk in the clinic waiting room. On the kiosk you will find information about exciting research studies at the University of Pittsburgh. You can scroll through flyers and request information be emailed to you. Adults living with Spina Bifida are usually eligible for many of our active studies. Please browse through the opportunities and see if there is a study right for you!



Adults 55 and up can Save 5% on Vehicle Insurance

Under Pennsylvania law, drivers 55 years of age and older are eligible to receive a 5 percent discount on their vehicle insurance by completing the Basic Mature Driver Improvement Course. In order to maintain the discount, individuals would have to take the Refresher Mature Driver Improvement Course every three years. Individuals should check with their insurance carrier for specifics of their program. For more information and to find organizations that offer the course, visit the **PA DMV website**.

Meet Dr. Ted Allaire Barrios

Dr. Ted Allaire Barrios is a clinical neuropsychologist and the newest member of our UPMC Adult Spina Bifida Clinic team. Dr. Barrios is an expert in conducting rehabilitation-oriented neuropsychological evaluations; managing conditions like depression, anxiety, "brain fog," and post-traumatic stress, all of which can occur following a major medical event or diagnosis. He is a behaviorist and licensed psychologist who specializes in the application of cognitive behavioral therapy (CBT) and third-wave behavior therapies (e.g., acceptance-and-commitment therapy; ACT) across medical settings and populations. He transitioned to UPMC from the Rehabilitation Institute of Michigan where he led several research projects funded by multiple federal agencies. He has received multiple awards for his rehabilitation research, including the Nancy M. Crewe Award from the Foundation for Rehabilitation Psychology and the Sunil K. Sengupta Award from the VA Office of Rehabilitation Research and Development. Please join us in welcoming Dr. Barrios to our Spina Bifida community!

PEER SPOTLIGHT

AJ VAZQUEZ, 23

"Anything you put your mind to...do it," AJ Vazquez remarks during our afternoon zoom call. AJ's passionate nature and positive outlook on life has allowed him to navigate the world as an individual with spina bifida. "Just because you do something differently, doesn't mean you can't do it..."

On Oct 23, I had the pleasure of interviewing AJ Vazquez, 23, of Beaver County, who is an active member of the Adult Spina Bifida Peer Navigation Program (PNP) who shares his experience growing up as an individual with Spina Bifida and finding himself through family, community support, and self-determination. These are some of the highlights of our conversation.

Q: What inspires you?

A: My family and friends have always treated me like everyone else. Just having the idea in mind that doing anything is not impossible even if you are disabled. I never really thought I would play sports until I saw sled hockey. Immediately, I was like "I want to do this." Unfortunately, I'm not doing it anymore – but I knew this is something I enjoy doing and it gave me an outlet that allowed me to go out and be who I am in a whole different way aspect of what I would be doing at the time. I would see all of these able-bodied athletes and then go to sled hockey practice or games and do the same exact thing...just doing it a little bit differently.

Anything you put your mind to...do it.

Q: What does your support system look like?

A: My family has been there for me 100%. I have really good friends. My parents have come a long way...even though it hasn't been the easiest at times. It has taught us how to handle certain things and really communicate on a different level...and just being able to understand the difference between normal everyday struggles and struggles in the medical world. We've really come to terms on how to balance it all.

Q: At times when you don't feel supported, how do you express yourself?

A: Even though I know I can go to anyone in my family or certain friends, there are some topics you don't feel comfortable talking to them about. So, you really have to know yourself, learn how to work through things, know what you need, and learn how you feel both physically and mentally to gain new experiences. Groups like the Adult Spina Bifida Peer Navigator Program (PNP) and Spina Bifida Camp have helped me find a community of people to talk to that can relate to certain aspects of things that my family or friends may not know about.

Q: For the future – what change (if any) do you want to see in our world regarding misconceptions related to individuals with disabilities?

A: I feel like the most common misconceptions with people is that they think that all disabled people are the same. Everyone in the disability community is different and unique. Even just based off Spina Bifida itself – it's very rare to find someone with the same type as you. Just because you're in a wheelchair or seen in one, people assume you can't walk. People act the most shocked when I tell them I can walk...or when they see me in my chair and the next day I'm walking with my crutches or without them. Just having that misconception that all disabled people are the same is not true.

Q: Disability does not mean inability.

A: Vazquez goes on to express, "Throughout life, a lot of people may think you are incapable of achieving because of your disability" Furthermore, Vazquez says, "Right at the beginning of my life – people were thinking I would not be able to achieve what I have achieved...I can proudly sit here today and say I've been in this world 23 years later." No matter how you identify or navigate the world – we are all human.

As our zoom call came to an end, leaving us with a sense of hope and possibility for the future of the disability community. Vazquez encourages peers with Spina Bifida who are navigating the world to never let anything hold you back from doing the things you want to do or from being the person you want to be. Thank you to AJ Vazquez for taking the time to speak with me and engage in an insightful conversation. To get involved in the discussion; reach out at **hennencs@upmc.edu**;

Written by: ***Cheyenne Hennen***

Congressional Appropriations for the Spina Bifida Program: Advocacy and Action

The National Spina Bifida Program, housed within the Centers for Disease Control and Prevention (CDC), has seen varying levels of funding over the years. Recently, the House Appropriations Committee approved a $2 million increase, bringing the total funding to $8 million. Consistent and increased funding is essential for the National Spina Bifida Program to continue its vital work.

The funding for the National Spina Bifida Program is used for several critical initiatives aimed at improving the lives of individuals with Spina Bifida.

Here are some key areas where the funding is allocated:

1. Research and Data Collection: The program supports the National Spina Bifida Patient Registry, which collects data from various clinics to improve the quality of care. This data helps identify best practices and areas needing improvement.

2. Clinical Care: Funding is used to develop, update, and implement clinical care guidelines. These guidelines help healthcare providers offer the best possible care for individuals with Spina Bifida, addressing issues such as urologic health, mobility, and overall well-being.

3. Education and Resources: The program provides educational materials and resources for individuals with Spina Bifida, their families, and healthcare providers. This includes information on managing the condition, navigating healthcare systems, and accessing support services, especially for adults with Spina Bifida.

4. Support Services: Funding helps support services that improve the quality of life for individuals with Spina Bifida. This includes programs that assist with transitioning from pediatric to adult care, as well as initiatives aimed at preventing complications like sudden unexplained death and sepsis.

5. Advocacy and Awareness: Part of the funding is used to raise awareness about Spina Bifida and advocate for policies that support the community. This includes efforts to increase public understanding and reduce stigma associated with the condition.

Here are some examples on how you can advocate for continued and increased funding for the Spina Bifida Program:

1. Stay Informed: Keep up-to-date with the latest news on congressional appropriations and the status of funding for the Spina Bifida Program. For example, the Spina Bifida Association website provides information about advocacy events and ways you can help.

2. Contact Your Representatives: Reach out to your local and state representatives to express the importance of funding for the Spina Bifida Program. Personal stories and data on how the program have impacted lives can be very persuasive. Compose letters and emails to your representatives. Be clear about the need for increased funding and provide specific examples of how the program benefits the community.

3. Join Advocacy Groups and Participate in Advocacy Events: Become a member of advocacy groups such as the Teal on the Hill event, sponsored by the Spina Bifida Association and held every February. Organizations supporting advocacy often have coordinated efforts and campaigns that you can participate in to amplify your voice.

4. Utilize Social Media: Use platforms like X, Facebook, and Instagram to raise awareness about the importance of funding for the Spina Bifida Program. Tag your representatives and use relevant hashtags to increase visibility.

By being an advocate, you can help to enhance the health and quality of life for those affected by Spina Bifida.

*Written by **Amy Kiska, BSW***

Spring Ahead with Consistency and Momentum!

When starting a new health and wellness journey, many people think they need to be 100% consistent, workout 7 days per week, be perfect on nutrition, and get 8+ hours of sleep, or they've failed on their goals.

This can lead to overtraining and an unmanageable increase in stress. Exercising 2-3 days per week can help us make wellness a top priority, without letting it take over our lives. The key to fitness and nutrition "consistency" is not to aim for perfection, but rather to aim for discipline. This is much easier said than done, especially with life pressures, whether we have a disability or not. With Spina Bifida, and all the pressures that come along with it, it can be difficult for us to develop a routine, build discipline, and cultivate a habit of consistency. We build mental and physical strength best when we are challenged. Whether you want to gain muscle, lose fat, or improve your sleep, achieving a goal is much more manageable when we focus on consistent action each day, keep pushing through difficulties, and recognize our wins along the way.

See the following sample workout programs to start or continue to build consistency and discipline:

3 Day Exercise Program

2-3 sets, 10-20 reps, 1–2-minute Rest between Sets

Day 1:

- Chest, Back, Biceps
- Chest Press, Horizontal Row, Biceps Curls

Day 2:

- Shoulders, Triceps, Core (if applicable)
- External Rotations, Shoulder Press, Lateral Raise, Triceps Extension, Core Press

Day 3:

- Legs, Core (If applicable)
- Leg Extensions, Bodyweight Squats, Leg Curls, Figure 4 Stretch, Z stretch (on the floor)

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

SPINA BIFIDA ASSOCIATION

2025 Spina Bifida Clinical Care Meeting
Jun 6 - Jun 7, 2025, Birmingham, AL

The Spina Bifida Clinical Care Meeting (SBCCM) is a unique forum where you can access all that's new, evolving, challenging, and successful in the care of individuals with Spina Bifida, and is an unparalleled opportunity to meet, network and collaborate with thought leaders and other experts in Spina Bifida care. It will be held at Children's of Alabama in Birmingham, AL, on June 6 and 7, 2025. Click here to register.

Upcoming SBAWP Events

Spina Bifida Association of Western Pennsylvania

May 15, 2025
8th Annual Shoot for SBAWP
Hunting Hills Shooting Preserve

June 8, 2025
Afternoon Jamfest
Jergel's

July 28, 2025
John L Moroney III Memorial Golf Classic
Hickory Heights Golf Club

Sept 20, 2025
Noll-Spratt Golf Scramble
Beaver Valley Golf Club

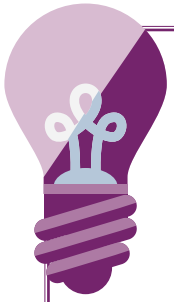
Nov 15, 2025
Girlfriends for Good Purse Bash
Divine Parish – St. Ferdinand's Oldenski Hall in Cranberry Twp

For more information regarding events and/or camps and retreats, please visit our website at https://sbawp.org/events or call 724-934-9600.

Job Training Opportunities:

Carnegie Library of Pittsburgh has several classes focused on resume building and job assistance workshops throughout the month. Visit their calendar to view specific events.

Schedule a time to meet with a career counselor from the Jewish Family and Community Services (JFCS) Career Development Center to discuss your job search strategies, self-marketing, and employment barriers. Call 412-622-3133 to make an appointment.



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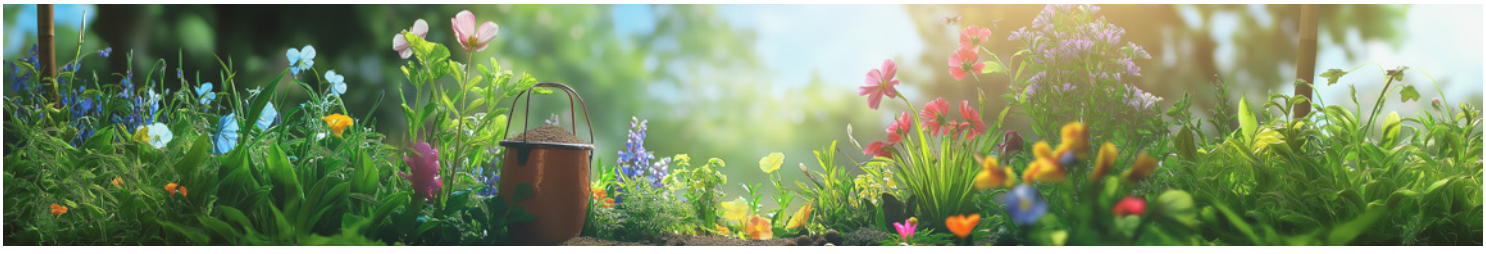
Check out our other newsletters and clinic information at: UPMC.com/SpinaBifida

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