



Happy 35th Birthday, ADA!

The landmark legislation that enshrined civil rights for disabled people turns 35 this July 26th.

Most of us know that the Americans with Disabilities Act passed by Congress and signed by President George Bush, Sr in 1990. Do you know the history of how we got to that signing ceremony? The road to the passage of the ADA began in the 1960's at a camp for disabled kids and young adults. Some of those attending were Jim Brecht, who has Spina Bifida, and Judy Heumann. They learned how to care for and advocate for themselves during their time at camp. I suggest watching the documentary "Crip Camp" if you want all the details. Fast forward to the 1970's and these young adults found themselves at UC Berkley.

In 1973 the Rehabilitation Act was passed. It is known as 504. It required that all buildings of organizations that receive federal funds ensure that the buildings were accessible. Unfortunately, this law was not being enforced. Disabled people gathered and held the longest sit in in American history with the help of the Black Panthers and each other. Disabled people around the country organized and protested. There were protests around the country calling attention to inaccessible transportation. As documented in pictures by Tom Olin disabled people laid down in front of buses and chained themselves to buses. The disability rights movement was moving forward.

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Unexpected Gardens

Big Panda and Tiny Dragon are characters in illustrated books by the author James Norbury. They embark on adventures together, exploring nature, their emotions, and finding beauty in uncertainty. In one scene as they sit next to a pagoda near the water, Tiny Dragon says, "This garden is beautiful." Big Panda nods and says, "And we only found it because we went the wrong way so many times." Life may present us with challenges to our health and function, but difficult journeys can lead us to wonderful, unexpected, and inspirational places. Take time this summer to think about a garden you found unexpectedly and imagine how many more are yet to be explored.

Written by Brad Dicianno, MD

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The result of all the voices being raised was the introduction in Congress of the Americans with Disabilities Act. It was moving through the legislature at a snail's pace until it was stuck. Again, disabled people mobilized and went to Washington, DC to protest. The Capitol Crawl occurred on March 12th, 1990. Sixty disabled activists crawled up the 83 Capitol steps to bring awareness to the need of the ADA. The Capitol Crawl is considered the event that sparked Congress into passage of the ADA.

UPMC is celebrating the passage of the ADA! UPMC is partnering with the Mid Atlantic ADA Center to celebrate here in Pittsburgh. The Disability Resource Office reports that all UPMC facilities are being encouraged to plan celebrations. Be on the lookout for your local events.

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

Farewell to Amy Kiska

Please join us in saying goodbye and congratulating Amy Kiska, BSW, our social worker, on her next life journey.

Amy says, "I will be ending my time at the Adult Spina Bifida Clinic at the end of May 2025. I will be transitioning into an exciting new role of becoming a full-time mother! I am thankful for the opportunity to work with the Adult Spina Bifida staff and patients, and I am grateful for the experience and knowledge gained during my time here."

We have hired a new social worker, and we will introduce you to her soon!



Staying Cool with Accessible Pools

Did you know we have several accessible swimming pools and spray parks in the surrounding Pittsburgh area? Allegheny County has wave pools in Boyce, Settlers Cabin, and South Parks, and the historic 2-million-gallon swimming pool at North Park. The three wave pools feature a water entry ramp at a one-inch depth that increases gradually to deeper water. The pool at North Park provides guests the option to enter the shallow end of the pool via a mechanical lift and includes access to the zero-depth baby pool and splash pad area, perfect for children and guests of all ages and abilities.

Make sure to visit the [spray parks](#) in Deer Lakes and Round Hill Parks for even more fun this summer. Follow [Allegheny County Parks on Facebook](#) for updates and information about county pools.

Boyce Park Wave Pool

200 Wave Pool Way, Monroeville, PA 15239
Phone: 724-325-4667

North Park Swimming Pool

9901 South Ridge Drive, McCandless, PA 15044
Phone: 724-935-3410

Settlers Cabin Wave Pool

600 Ridge Road, Robinson, PA 15205
Phone: 412-787-2668

South Park Wave Pool

280 Wave Pool Drive, Bethel Park, PA 15102
Phone: 412-831-0810

Allegheny County offers two spray park locations, in Deer Lakes and Round Hill Parks. Both facilities offer a fun and safe way to splash around! Swimming skills are not required to enjoy the spray parks, each facility is ADA accessible, and free and open to the public.

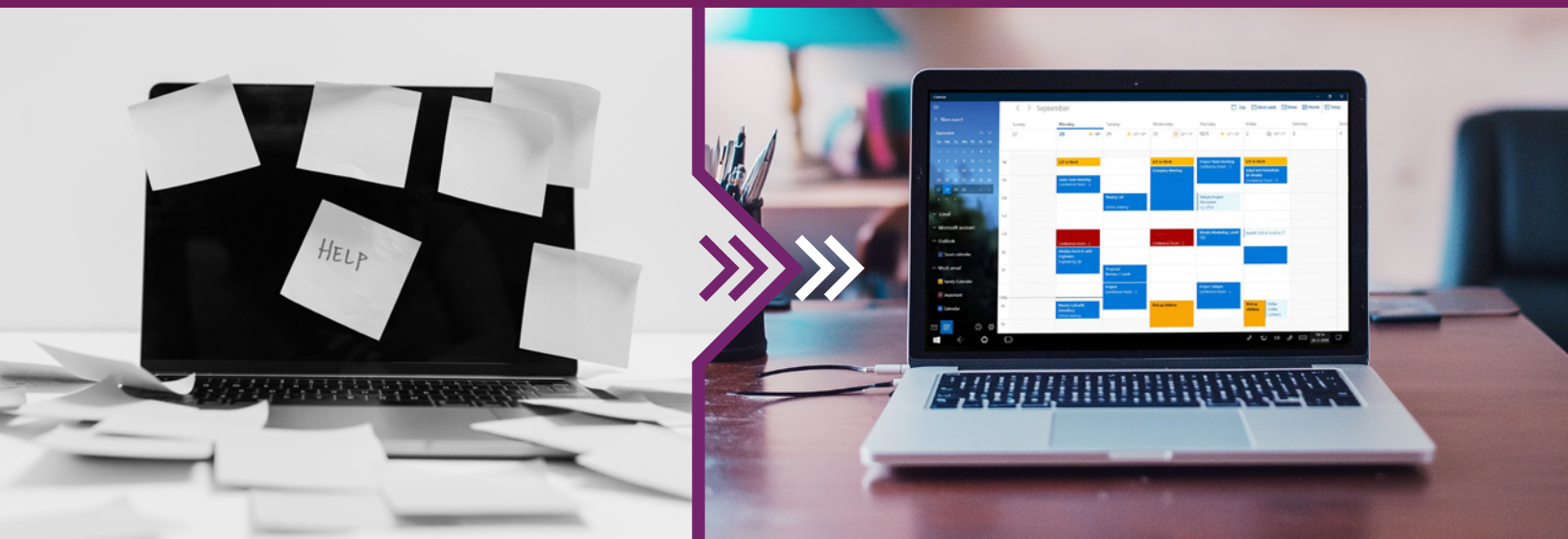
Deer Lakes Park Spray Park

Mahaffey Road, Tarentum, PA 15084

Round Hill Park Spray Park

351 Hereford Drive, Elizabeth, PA 15037

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



Understanding Executive Functions

Executive functions are important thinking skills for everyday life. Specific types of executive functioning include planning, organization, and multi-tasking.

These skills help us remember things, manage time, and solve problems. They also allow us to stay focused, control our feelings, and make good choices. When these abilities work well, it can be easier to handle changes, respond to roadblocks, finish tasks, and take care of daily needs. When people have difficulties with executive functioning, life can be harder.

Many adults with Spina Bifida have trouble with executive functions. This is because Spina Bifida can affect brain development, especially the parts of the brain that control attention, organization, multi-tasking, and problem-solving. When someone has challenges with executive functioning, we sometimes call that executive dysfunction. These difficulties, as you can imagine, sometimes make it hard to stay organized, keep track of time, and follow through with plans and responsibilities. Some people might forget appointments or take certain medications, have trouble paying bills on time, or struggle to finish work or other responsibilities. Others may find it hard to control their emotions when things do not go as planned. These challenges can affect friendships, family relationships, independence, as well as our stress, mood, and anxiety.

There are many different strategies, tools, and tricks, though, that can help people manage these challenges. Many of these strategies work by adding

structure and support to make daily tasks easier. Using tools like a planner, a calendar, or checklists can help people stay on top of their responsibilities and feel less frustrated. Creating habits and routines can also make it easier to remember important tasks without feeling overwhelmed. For example, making a to-do list every night before bed and then checking that to-do list the next morning during breakfast can, over time, become a habit. When something becomes a habit, it becomes much harder to forget.

Some people find it particularly helpful to use reminders, like on a cell phone or an alarm clock - When the reminder (or alarm) goes off, it can remind us to do something (like, take our medication or do a specific chore). Sticky notes can be another simple tool to help boost our memory for things we need to do. It can also be helpful to have a large, hard-to-miss calendar with important information and appointments in an easy-to-see, frequently visited part of the house (like, the kitchen). Keeping important things, like keys and wallets, in the same place every day can prevent losing them.

Another important skill is managing emotions. Deep breathing, taking breaks, or using calming exercises can help with stress or frustration. Having support from friends, family, or support groups can also make a big difference. Your team of providers in the Spina Bifida clinic can help connect you with other resources, like cognitive-behavioral (CBT), occupational (OT), or speech (SLP) therapy services. If you're interested in learning more about these resources, be sure to bring this up during your next SB Clinic visit – In the meantime, try using one of the tools mentioned in this article to help remind you to bring this up!

Written by Ted Barrios, PhD

Make Cooking Work for You: Kitchen Tips for Executive Dysfunction

Meal preparation and cooking can be intimidating. It can feel overwhelming and uses a lot of mental energy. Below are a few tips to help break down cooking into steps that may work better for you:

▶▶▶ *Use leftovers and no-cook meals to save time and reduce cooking days.*

This could be having leftovers in your freezer that go in the oven or microwave (use sharpie and masking tape as a label so you know how old it is and how to prepare it when you pull it out of the freezer. Example: “Lasagna 1/1/25; reheat in oven at 400 degrees for 30 minutes”) or no-cook meals (such as salad mix + shredded rotisserie chicken + an apple).

▶▶▶ *Some people find it is easier to read the whole recipe first and try to think about what you will do for each step. This helps you to make sure you understand the recipe before starting.*

If you are more of a visual or auditory learner, you can use a video recipe and pause as you go along.

▶▶▶ *As you actually go through the recipe, you can follow along with a highlighter. Highlight the steps as you read and perform them. If you lose your place, you can look at what you just highlighted.*

▶▶▶ *Clear a space and gather all the ingredients and kitchen tools you need for the recipe before starting. Try to put them in the order you will use them. Most ingredient lists are written in the order of which you will use the ingredients. This helps you not forget to add something to the recipe.*

▶▶▶ *Put dishes in the sink as you go to avoid clutter in your workspace.*

▶▶▶ *Put away leftover ingredients as you use them to reduce visual clutter.*

▶▶▶ *Use a simple, loud timer to avoid time blindness with recipes. An egg timer that you keep near the stove/oven is a good example.*

Keeping the timer visible on the counter is one way to help you remember to set the time.

You can also write the words “and start timer” next to any cook time in a recipe when you do your first read through.

Written by Jacquelyn Klunk, MS, RDN, LDN

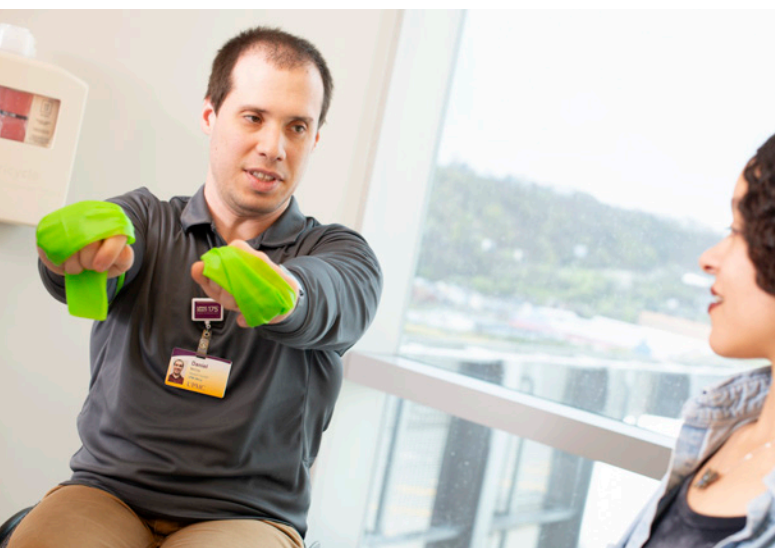


Bone Health and Spina Bifida

People with Spina Bifida have an increased risk of bone fractures. There are multiple factors that play into this increased risk. For one, people with Spina Bifida often are more likely to fall. They may also have a greater chance of developing osteoporosis, or low bone density. Sometimes, for a person with Spina Bifida, it can be more difficult to identify a broken bone because their fracture may present differently than it would in a person without Spina Bifida. For example, if the broken bone is in a place that the person cannot feel, they may not have pain that prompts them to seek medical attention.

So, what are some things that you can do to reduce your risk of bone fractures? Vitamin D and calcium are important in the process of bone building and bone strength. Adults who do not get 600 IU of Vitamin D per day from their diet should consider taking a vitamin D supplement. Vitamin D deficiency is very common in the general population, especially in northern climates and also more common among adults with Spina Bifida. Additionally, Chronic Kidney Disease can increase your risk of Vitamin D deficiency. Adult men should get 1,000 mg of Calcium from their diet every day, and women should aim to get 1,200 mg per day of Calcium. If you do not get this from your diet, you should consider supplementation, though getting calcium from food is preferred to supplementation when possible. Working on your transfer technique and keeping up your strength to ensure you can transfer safely could help prevent a fall and a possible fracture. Weight bearing exercises may help improve bone health in addition to reducing other complications. Need some help or guidance to make these bone health changes? Let us know! Our dietitian and personal trainer would be happy to help make a plan for you.

Written by Darcie Petrillo, MPAS, PA-C



Meet Yourself Where You Are, Then Aim Higher

In the current culture we live in, with social media especially, we tend to focus on the look we want our body to have for the summer, or the fitness level we want for summer and with that, we often compare ourselves to those around us, like friends, family, celebrities, or random people on social media. Comparisons can lead to a deflated sense of self-confidence if we do not meet ourselves in our current level of health and fitness, come to terms with that, then aim higher.

Contrary to what we may see on most social media, when we are talking about comparisons, I personally do not believe comparisons are a negative thing if we can learn to see the value in our own experiences and circumstances and learn from another person's experiences and circumstances. If we see someone achieving a goal we would like to achieve ourselves, we should realize that we can still achieve the same type of goal, just maybe not in the same way.

For example, if we see someone bicep curl 20lbs for 10 reps, but we can only bicep curl 10lbs for 5 reps, we can look at how long we have been training for, how long they have been training for, and realize we are in different points in the strength training journey, and use that situation as a motivator to reach a new level of health we haven't before. This type of thought process will not only allow us to focus on our own improvement but also allow us to see someone else's accomplishments as fuel to achieve our own goals and use our environment around us to challenge ourselves and build confidence.

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

Ableism in Medicine: Is Representation the Solution We Need?

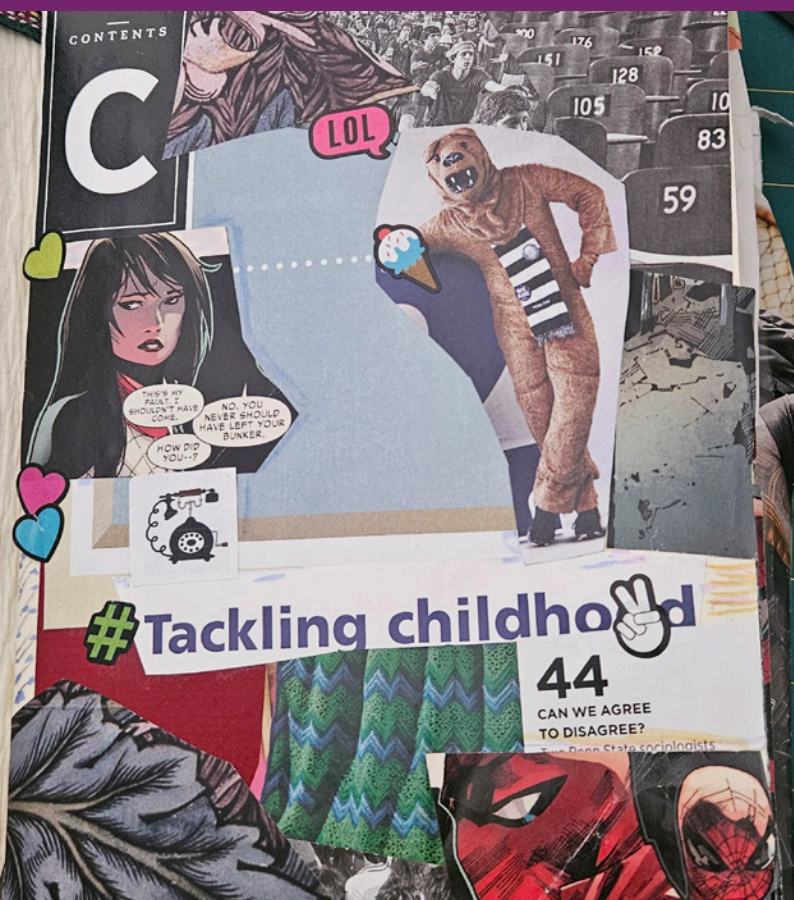
Some of the staff working at the UPMC Adult Spina Bifida Clinic are people living with Spina Bifida. This [video](#) by Access Mob Pittsburgh features our nurse coordinator Monica Albert Still, RN, BSN. She describes her experience as a healthcare professional living with Spina Bifida. She explains how increasing the number of healthcare providers who have disabilities could help build a more inclusive and equitable healthcare system.



Learn about Waiver Programs

Many of our patients have questions about waiver programs. They may want to know what services are available and whether they qualify. You may be interested in this [video](#) by Access Mob Pittsburgh, which explains everything you need to know about waiver programs in Pennsylvania.

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



Creative therapy and self-care: how to advocate for yourself through the arts

Taking care of ourselves is essential to our mental health and physical wellbeing.

During times of stress, prioritizing your self-care and finding time to reflect on your feelings allows you to align your thoughts, express your emotions and advocate for yourself in times of need.

Finding a creative outlet that you enjoy is the first step toward managing your self-care and advocating for yourself... Whether it's through crafting, journaling, music, drawing, painting, or other activities, there are no limits to how you express yourself.

Here are some practical ideas to help you get started on your self-advocacy art journey:

Optional art supplies

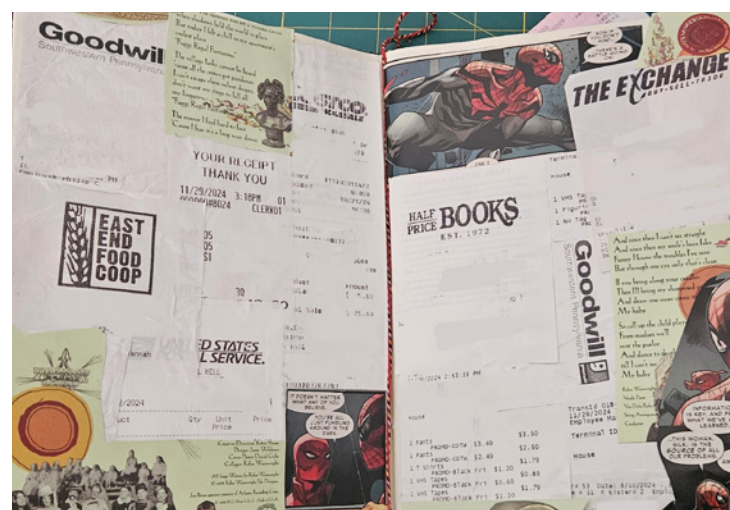
- Glue sticks or tape
- Paper of any kind (magazines, newspapers, etc.)
- Something to write with
- Your smartphone or tablet

Junk Journaling

What is junk journaling? The idea of a junk journal can vary from person to person, but in general, a junk journal consists of a variety of recycled materials that you have found or collected over time. For many of us, it can be challenging to keep track of what we did or how we felt throughout the week. Junk journaling is a practical and hands-on way to document your life and stimulate your senses. If you're someone who likes to hold on to miscellaneous things that you acquire from everyday errands such as, receipts, tags, coffee sleeves, business cards, etc. Then, a junk journal can be a great way to save space, spark creativity, and reflect on your life! In many ways, junk journaling can become a scrapbook filled with your daily habits, dreams, goals, feelings, and favorite things.

To start, all you need is a journal, tape or glue, and some of those random items you have hiding away in your kitchen drawer or wallet! As you create, be mindful of how you feel.

Here's an example of a collection of receipts and other scrap materials that I acquired throughout my daily adventures that were taking up space.



Remember: there are no rules to journaling, be creative and make it your own! Don't be afraid to experiment with different materials. By the end, you may surprise yourself and spark old memories and feelings.

Create a visual grocery shopping list

Do you ever feel overwhelmed while shopping at the grocery store? Creating a visual shopping list can be an accessible way to keep track of the items you need and want while running errands. Visual shopping aids are encouraged and supported by vocational/special education teachers to help students learn practical and

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engaging life skills. This tool can be adjusted to suit your own needs while also making the tedious task of shopping for groceries feel fun, accessible, and exciting.



To create your list, you can use images you find in daily coupon ads or newspapers you have around the house. First, think of the essential items you need. Then, make space for the items you want. You can also create a digital list using the notes app on your phone that you can save and easily access at any time. Think of it as your own personal map that you can take with you on every trip to the store!

Sensory Activities

At the end of a busy week, it can be helpful to take time out of your day to reflect on how you feel without distractions. You can do this in a variety of ways, such as; drawing, writing, or using your mobile device to record what you can see, hear, smell, and touch. Taking the time to actively listen to how you feel and observe your surroundings can bring a sense of calmness to your day. You can start by using the following phrases to describe yourself and how you feel

- I am...
- I feel...
- I see...

Furthermore, you can use [The Feeling Wheel](#) originally created by Dr. Gloria Willcox in the 1980s to identify your thoughts, reflect on your mood, and expand your ability to communicate your emotions. Communicating how you feel can oftentimes feel uncomfortable but be patient with yourself. Learning how you feel and what your needs are is the first step to advocating for yourself in your community. Remember to ask yourself:

1. "Why am I feeling this way?"
2. "What do I need to feel supported?"

Sensory activities can be adapted to suit your own needs but are a good way to stimulate your senses and provoke positive and negative emotions. You can also start by collecting household items and create a collage of all the things you can see and feel. Furthermore, finger painting, coloring or drawing with chalk are other sensory activities that allow you to be present, de-stress and focus on how you feel. Though these activities are centered towards younger aged children, it can be a fun way to release stress no matter your age. Don't be afraid to release your inner child and get messy!

Here are some examples of sensory art that my class created together when I taught ESL at Literacy Pittsburgh.



Using the iMHere app to manage your self-care

The iMHere app helps you manage issues related to your health and gives you a space to store your personal health information. After being prescribed the app by your physician, you can use the app as a helpful tool to keep track of your mood, nutrition, and physical activity. The app also allows you to schedule reminders to take your medications and track your bowel/bladder routines. Additionally, you can learn more about Spina Bifida and other educational topics prescribed to you. To learn more about the iMHere app or access tutorial videos; check out our [website](#) or contact Cheyenne Hennen: chh406@pitt.edu

There are no rules when it comes to being creative with your self-care. Just have fun!

Written by **Cheyenne Hennen**



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

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.



Refurbished Desktop Computer Give-Away Program

The "Computer Giveaways" Program awards free desktop computers to area residents who cannot afford a computer. The program refurbishes desktop computers sourced from donations from local schools and businesses and distributes them free of cost to people who qualify. For more information, visit [Computer Reach](#).



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

UPMC Mercy Pavilion

1622 Locust Street, 4th Floor PM&R Clinic

Pittsburgh, PA 15219

Phone: 412-232-8902

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



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