

UPMC Adult Spina Bifida Clinic Winter 2026 Newsletter

Using AI and The Internet to Research your Medical Diagnoses

There is an unbelievable amount of information right at our fingertips. This is a wonderful thing because it allows us to learn endlessly and be more informed about our health.

However, an abundance of information can also be overwhelming and can potentially even cause problems if it is not used cautiously. Al, and the internet in general, are great as supportive educational tools to help make more informed medical decisions but should not be used to replace professional medical advice. A few key points to remember:

Use AI for general education only. You can use AI to help you understand medical terminology, explain test results in simple language, and provide an overview of conditions. It is best to use AI to get background knowledge that you can use to help you come up with questions for your healthcare provider, rather than using AI as your only source to answer your medical questions.

Use only trusted sources. Whenever you use AI to get information, you should cross-check the information by also checking a couple other reliable sources as well to confirm accuracy and avoid getting misinformation. You can also ask AI for the source of the information it is providing.



Never depend on Al for a diagnosis. Information from Al can have gaps and mistakes. Be sure to consult a healthcare professional as part of your medical work-up. Beware of Al limitations and biases. Al's recommendations are only as good as the sources it uses and how well it was trained. Out-of-date or incomplete data or biased training can cause there to be errors, especially for rare or complicated symptoms.

Do not forget that you have the Spina Bifida Clinic on your team! We are happy to answer any questions you may have about your health.

It is good to ask questions and to always be learning on your own. Al can be a great tool to help you expand your knowledge. Be sure to use your own tools and knowledge in addition to the knowledge of your medical team!

Written by Darcie Petrillo, MPAS, PA-C



As we journey through the winter months, it's a time to reflect on our health and well-being. Consider the lyrics from the song "The Sound of Silence" by Simon & Garfunkel: "Hello darkness, my old friend, I've come to talk with you again." Let this winter be a time to revisit goals, embrace solitude and introspection, and nurture both body and spirit. Engage in mindful activities, savor nourishing meals, and prioritize goal-setting for the new year. In the silence of the winter months, find the strength to cultivate a season of health and inner peace.

Written by Brad Dicianno, MD

Dr. Dicianno Honored with a Community Heroes Award

Dr. Brad Dicianno was honored Community Living and Support Services (CLASS) with a Community Heroes Award. The organization recognized him for the work he does to address the medical/community needs of people living with spina bifida to ensure they have inclusive lives in their communities. He was recognized with the award at the annual CLASS Community Heroes Awards Dinner on Oct. 28. Here is a link to watch the tribute **video**.



Educational Outreach

Dr. Dicianno has been educating and advocating for care of adults with Spina Bifida through several different venues. He was an invited speaker at Disability Pride in Pittsburgh in September. In addition, he gave 2 talks about using assistive technology to prevent and treat skin breakdown at Spina Bifida Days hosted by Skåne University Hospital and Lund University for Sweden and Norway, and at the UPMC Wound & Hyperbaric Center Educational Series. He gave a talk about transitioning individuals with spinal cord conditions from pediatric to adult care for AAPM&R. He also gave a talk about how to build adult Spina Bifida programs at the Spina Bifida Clinical Care Meeting in. Birmingham, AL.

Building Careers, Building Confidence: Employment Options

Finding a job is about more than earning a paycheck it's about independence and purpose. Pittsburgh



Mercy's Employment Services program is dedicated to helping people with intellectual and developmental disabilities achieve those goals.

Through personalized support, job coaching, and skill development, the program matches individuals with employment opportunities that fit their strengths. Once on the job, participants receive ongoing support to ensure long-term success. This approach benefits those seeking employment and diversifies workplaces and communities.

Pittsburgh Mercy's mission is rooted in compassion and inclusion—making sure that everyone has the chance to showcase their talents and reach their full potential. They are creating pathways to brighter futures by breaking down barriers and focusing on one's abilities.

<u>Learn more</u> about Pittsburgh Mercy's Employment Services and how they're making a difference.

Written by Olivia Hughes

UPMC Financial Assistance

Did you know that in addition to the client assistance funds available to patients with spina bifida in our clinic, UPMC also offers financial assistance to any patient who qualifies? You can apply for assistance to cover fees related to medical care provided by UPMC facilities and UPMC affiliated physicians. Based on your financial need, either reduced payments or free care may be available. Learn more and apply here.

Grants to Help with Gas Bills

Dollar Energy Fund grants are now available to Peoples Gas customers in Pennsylvania. To find out if you qualify, visit this <u>link</u>.





In 2022, members of the Spina Bifida Association's Adult Advisory Council at UPMC Mercy, developed a peer navigation program that allows patients from the clinic to have one on one sessions with one of our many talented mentors.

Our mentors use their life experiences to connect with members of our community to promote self-advocacy, empowerment, and inclusion. We welcome all adults with spina bifida to our Peer Navigation Group Sessions 18 years and up. Our mentors are excited to introduce a new feature and schedule to our group session programs. We are now holding age specific virtual group sessions with 18–39-year-olds meeting on the 4th Wednesday of each month and 40 years and up meetings on the 2nd Wednesday of each month. Our team has also grown, featuring our new team member, Abby McCormick. Let me introduce you to our updated team!

Hello! My name is Abby McCormick.

I am a 25-year-old woman living with Spina Bifida and I am so excited to be a mentor. I was interested in becoming a mentor because I feel it is so important to surround yourself with supportive people, especially those who can relate to daily challenges you

face. As a mentor, I'd like to provide a safe space for other individuals living with SB and inspire them to express how they feel, share their story if comfortable, and most importantly—advocate for themselves. I graduated with a bachelor's degree in music therapy from Seton Hill

University in 2022. As a mentor, I'd also love to utilize my music therapy skills for those who are interested. I currently live in Midland, PA with my boyfriend and our two cats, Koda & Cora. My favorite hobbies include playing sled hockey, rowing, going to the gym, coloring, cuddling with my cats, and watching cooking shows and paranormal shows with my boyfriend.

Monica Still is a 60-year-old adult with Spina Bifida who works as a registered nurse at the UPMC Adult Spina Bifida Clinic. She also spends her time volunteering at the Spina Bifida Association, as the Board Secretary of Directors of Disability Rights PA, Chair of the Mental Health Advisory Committee,

board member of CT Health Law Project, and planning committee of Disability Pride PGH as well as many other advocacy groups. In her free time, Monica enjoys several hobbies including gardening, cooking, embroidering, reading, and playing with her cats. Monica also leads great discussions in our Peer Navigation Group Sessions, helping those of us to self-advocate and to network within our community.

Sara Izzo is a 40-year-old adult with spina bifida who has been a research and project coordinator at the University of Pittsburgh for the past 10 years. Her primary focus has been on the Spina Bifida population as well as providing other rehabilitative

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services at UPMC Mercy's Adult Spina Bifida Clinic. She has a bachelor's degree in psychology and is currently a master's in counseling student at Chatham University. Sara spends her free time cooking from scratch and making recipes that are more adaptable to the spina bifida community. She also enjoys watching films, collecting specialty board games, and spending time with her husband and two cats named Jean Grey and Mila Kunis.

Dan McCoy is a Paralympic Gold Medalist in Ice Sled Hockey with an MS in Human Performance as well as a Certified Personal Trainer through the American Council on Exercise. In addition to his services as a fitness trainer at the UPMC Adult Spina Bifida Clinic, Dan's interests include

all things related to health and nutrition. His passion for Spina Bifida comes not only from having it himself but also finding ways to maximize our physical and mental potential with Spina Bifida.

Chevenne Hennen is a research coordinator at the University of Pittsburgh who works on several projects concerning people with spina bifida and other disabilities within Physical Medicine & Rehabilitation. She is an International-Global Studies and Korean Asian Studies

graduate from Penn State University, and she enjoys getting involved in the community by participating in international advocacy groups. She was interested in joining the peer navigation program because as an individual who has experienced the challenges of having a physical disability, she believes having representation and direct support is essential in the community. Her goal is to be an advocate for other disabled individuals and to provide them with the support and guidance they need.

Written by **Sara Izzo**

Check out our flyer on the next page to join our sessions!



Navigating Grief

Losing a loved one can be an overwhelming experience. Having support and a compassionate community to help you navigate grief after a traumatic loss is essential to healing. There is no right or wrong way to grieve; everyone experiences grief

your emotions, seeking support when needed, and taking care of your physical and emotional well-being are essential steps in managing the impact of loss. Here are a few healthy tips to help you navigate grief:

differently — but acknowledging

Be patient with yourself

- Listen to your emotions, take breaks when needed, and remember — grief is not a weakness, but a natural human response to loss.
- Don't hesitate to ask for additional support at work, school, or within your community whenever you need it.
- Remember to breathe; some days will be better than others. It's okay to cry or step away when things feel overwhelming.

Seek Support

- Having a healthy emotional outlet is an important part of the healing process. Consider speaking with trusted friends, family members, colleagues, clinicians, or mental health professionals to help process and express your emotions in a safe space.
- If you're not ready to talk, consider journaling, listening to music, engaging in creative activities, or using art as a way to express your emotions. Creating art to honor and celebrate your loved one who passed away, can feel both therapeutic and meaningful.

Prioritize self-care

- Grief is exhausting. Remember to rest, stay active, hydrated, and eat.
- Connect with nature a local park or recreational space is a great place to explore, relax, and mentally recharge after a stressful day.

No matter how you choose to grieve, remember that you are not alone — and it's okay to take things slowly and ask for support.

Written by Cheyenne Hennen

Adult Spina Bifida Peer Navigation Program



Are you an adult with Spina Bifida and a patient at the UPMC Adult Spina Bifida Clinic?

- Want to learn different methods for navigating spina bifida from others like you?
- Find new ways to socialize with people with similar life experiences?
- Do you need someone to just listen?

Then you may be interested in joining our Peer Navigation Program (PNP)!

If you are interested in participating in group sessions or one-on-ones, please contact Sara Izzo at sai20@pitt.edu and Monica Still at moa128@pitt.edu.

PNP Group sessions are now designed just for you in mind! If you are an adult who identifies with the life of someone

40 years and up, join us every 2nd Wednesday at 7:00 pm EST with Monica Still. Scan QR Code or click here.



Meeting ID: 825 9445 6995 Passcode: 08231

For those who identify as an adult **between the ages of 18-39**, join us every

4th Wednesday of the month 7:00 PM EST with Abby McCormick and Sara Izzo. Scan QR Code or click here.



Meeting ID: 960 6836 0136



Understanding Anxiety

Anxiety is something that many adults with Spina Bifida experience. If you've ever felt nervous, worried, or on edge, you're not alone.

Anxiety is a normal human emotion that helps us respond to danger or uncertainty. But when anxiety sticks around too long, shows up too often, or feels too intense, it can start to interfere with daily life.

Like depression, anxiety can look different from person-to-person. Some people feel it mostly in their bodies—like a racing heart, tight chest, upset stomach, or trouble sleeping. Others notice it more in their thoughts—like constant worry, fear of making mistakes, or feeling like something bad is about to happen. Anxiety can also show up in behaviors, such as avoiding certain places, people, or tasks that feel overwhelming.

For adults with Spina Bifida, anxiety may be linked to medical challenges, social situations, or changes in routine. It might show up before a doctor's appointment, when trying something new, or when facing uncertainty about the future. And sometimes, anxiety just shows up without a clear reason at all.

The good news? Anxiety is treatable. You don't have to "just deal with it" or go through it alone. If you think you might be experiencing anxiety, please mention it during your next visit to the UPMC Adult Spina Bifida Clinic, so we can help connect you with resources.

For example, one of the most effective treatments for anxiety is acceptance-and-commitment therapy (ACT). ACT focuses on helping people notice and accept difficult thoughts and feelings, like anxiety, instead of trying to change them. In other words, people learn how to step back from unhelpful thoughts—a process called cognitive defusion—so those thoughts feel less powerful or overwhelming. ACT also encourages people to identify what matters most to them (their values) and take small, meaningful steps toward those things, even when anxiety is present. ACT also emphasizes slowly facing fears and doing things that are hard in ways that feel manageable. This approach also emphasizes the role of mindfulness and grounding exercises as a means of remaining present and calm during stressful moments.

Some people also benefit from **medication-based treatments**, which can be used alone or alongside therapy. If you're curious about this option, bring it up during your next Spina Bifida Clinic visit or talk with your primary care provider. Cognitive-behavioral therapy (CBT) is another effective anxiety treatment similar to ACT that is another good fit for many people.

There are also simple tools you can try right away:

- Deep breathing: Try inhaling slowly for 4 seconds, holding for 4 seconds, and exhaling for 4 seconds.
- Grounding techniques: Focus on your senses what you can see, hear, touch, smell, and taste to stay present.
- Routine and structure: Having a predictable schedule can reduce uncertainty and help you feel more in control.

Remember: anxiety doesn't define you. It's something you experience—not who you are. And with the right support, you can learn to manage it and feel more confident, calm, and connected.

Written by Ted Barrios, PhD

SEED OILS:

Good or Bad?

Seed oils have been getting a lot of attention in the media recently. So, what is the verdict – are seed oils safe?

What are seed oils?

Seed oils refer to oils extracted from seeds. Examples include sunflower oil, canola oil, flaxseed oil, or corn oil.

What is the concern?

There are claims being made that seed oils are harmful, inflammatory, and toxic.

What is the truth?

Seed oils are a safe and accessible option to use in cooking. They can be a good fat choice for heart health. They contain mostly unsaturated fats. Unsaturated fats are healthier for the heart compared to saturated fats. Common sources of saturated fat are butter, ghee, fatty meat, full-fat dairy, and coconut oil. Saturated fats can raise bad (LDL) cholesterol levels and increase the risk for heart disease when eaten in excess. Replacing saturated fat intake with moderate amounts of unsaturated fat in the diet can help support lower cholesterol levels and heart health. That being said, even healthy fats are high in calories, so portion size is still important.

Claims about inflammation:

"Inflammation" is a normal response to an injury or infection and is a way that your body protects itself so it can heal. But long-term inflammation can contribute to some diseases.

People may claim that seed oils are inflammatory because they contain more omega-6 fatty acids than omega-3 fatty acids. The concern is that an omega-6 fatty acid called linoleic acid can become arachidonic acid in the body. Arachidonic acid is used in many inflammatory processes in the body. But:

1) A lot of the research that led to claims about linoleic acid being inflammatory were done in rats. But rats and humans do not respond the same to everything in their diets! Right now, research is lacking to show that omega-6 fatty acids cause inflammation in humans. So far, several studies in humans show that dietary omega-6 fatty acids, particularly linoleic acid, do not worsen inflammation.^{2,3}

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2) Omega-6 fatty acids are still an essential fatty acid that our body needs and cannot make on its own.

Claims about harm and toxicity:

Some claims state that seed oils are dangerous due to a chemical called hexane used to extract oil from the seeds in processing to make the oil more shelf-stable. Hexane is removed during the refining process and is present in only minimal amounts that are not harmful (well below established safety limits) in the final oil product.

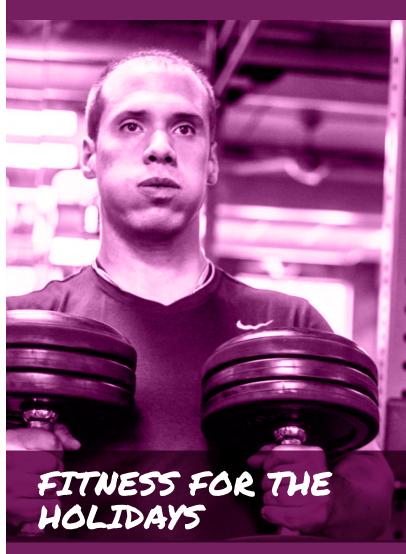
Concern has also been expressed that seed oils oxidize in the body and make free radicals that can damage cells or cause inflammation. A major way that seed oils oxidize is when they are heated too much – hotter than would be achieved by typical home cooking. One place where this could be a true concern though, is fried food at restaurants or fast-food locations, as oil is reheated to very high temperatures multiple times in a row.

It is easy to want one food group or item to blame for multiple health issues. Ultimately, health is a complex issue affected by many factors – environment, socioeconomic status, lifestyle, health systems, available resources, and more. Fear around foods goes farther faster – both in terms of profit and virality. At the end of the day, overall eating patterns will make a bigger difference to health and wellbeing than one single food item will. For many people, seed oils are an affordable, heart-healthy, accessible option to use in healthy cooking with lean proteins, whole grains, and colorful vegetables.

Written by Jacquelyn Klunk, MS, RDN, LDN

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The best parts of the holidays include the family, friends and, of course, the food. We often think of food as fuel. While that can be a true, food is much more than just fuel. Food can be comfort, a bonding experience with loved ones, and many other things. It is important during the holidays to view food as both fuel and enjoyment. During the holidays, there may not necessarily be a good balance of foods that taste good and also have all important nutrients. That's okay! Prioritize protein when you can. Another thing you can do is prioritize movement. Start moving 10-15 minutes before and after each meal. This can have a significant impact on digestion and how we feel after we eat. Overall, the holidays are only a few days of the total year, so they will not completely destroy your strength and wellness plan as long as we get right back on track after we fall off. Adding extra movement will allow you to enjoy some of your typical holiday meals and not miss out on making memories with loved ones. Happy Holidays!

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



"I have found great benefits by exploring different types of flour that's easier on my digestive system..."

Winter Baking with Ease

Baking is my favorite hobby, and Winter allows me to break out all my tricks of the trade when it comes to convenient cooking. This winter, I want to share with you a new favorite recipe of mine, Slow-Cooker Pumpkin Delight Cake.

This tasty pumpkin recipe is not only accessible and easy to make but it also allows you to utilize alternative flours that may be easier on your tummy during the holidays. As an adult with spina bifida, my body has changed over the years and has required me to pay more attention to my diet. I have found great benefits by exploring different types of flour that's easier on my digestive system and also wonderful for baking, such as a low gluten wheat called einkorn, rice, and casava flour.

Einkorn is an ancient wheat crop scientifically classified as Triticum monococcum (Antognoni, Mandrioli, Bordoni, et al., 2017). That long tounge twister is sometimes referred to as "man's first wheat" due its cultural traditions in artisnal baking. Einkorn is a wheat that contains gluten; however, the smaller grains do not contain the D genome that often triggers those who are gluten sensitive (not to be used for those with gluten intolerance or celiac disease) (Axe, 2023). Einkorn wheat has a higher protein profile compared to other flours, with 5.25 grams in a quarter cup as well as lower polyunsaturated fatty acids (Antognoni, Mandrioli, Bordoni, et al., 2017). It is often used for baking bread with other flour alternatives for its lower gluten content and ease on the digestive system. It must be noted again, einkorn is not suited for individuals with a gluten intolerance or celiac disease due to the flour being a wheat grain with some gluten content.

Rice is one of the most consumed grains in the world and is often an ingredient in gluten free foods (*Park & Kim, 2023*). Rice flour is a processed form of rice used in a variety of products, including bread, noodles, and even beer uses rice as a partial replacement for barley or wheat. Brown rice flour provides a more nutritious profile than white rice— containing over 37 grams of bran in 1 quarter cup, and 3 grams of protein— which is the same compared to traditional wheat.

Cassava flour is defined as a processed item made from the fermentation of moist starch extracted from the cassava root, often called yuca or yuca root (Levy, 2019). Yuca root is commonly used in African, Asian, and Latin American foods for various baked goods and snacks (Bhattacharya, 2023). It is a gluten-free ingredient; however, cassava is a root vegetable- therefor it is not only gluten free and nut free, but it's also grain free which I personally find to be easier to digest. Cassava flour contains a similar nutritional profile as brown rice flour with 3 grams of protein in a quarter cup. Although it has lower protein compared to einkorn, cassava has lower fat and higher water content compared to wheat, rice, and other gluten free flours (Levy, 2019). Cassava is also has a high amount of Vitamin C, providing nearly 17% of your daily recommended dose.

Trying these new flours one at a time is easy to do if you swap out half of your regular all-purpose flour in any recipe. Don't worry if you don't have any of the flours discussed in this article. This pumpkin cake can still be made with regular all-purpose flour!

This wonderful winter dessert (next page) is easy to make from an accessible counter and can be easily made in a deep oven safe pan for traditional baking! Enjoy!

Written by Sara Izzo

Slow-Cooker Pumpkin Delight Cake

Servings 4-8 | 10-minute prep time; Cook 2 hours; Total 2hrs 10 min

EQUIPMENT

4 quart slow cooker

2 mixing bowls

Electric Mixer or Mixing spoon

Measuring cups and spoons

INGREDIENTS

- 2 cups all-purpose flour (any alternative flour can be used)
- 2 tsp baking powder
- 1 tsp baking soda
- ½ tsp salt
- 1 tsp pumpkin pie spice or ground cinnamon
- 1 tsp vanilla extract
- 1 cup light brown sugar (coconut brown sugar alternative)
- 1/3 cup white granulated sugar
- 1 cup butter, softened
- 4 eggs, at room temperature
- 15 oz solid packed pumpkin, 1 can

INSTRUCTIONS

- 1. Coat slow cooker with butter
- 2. Plug in slow cooker and turn to "high."
- 3. Combine flour, baking powder, baking soda, salt, and pumpkin pie spice in mixing bowl.
- 4. In another mixing bowl beat sugar and butter with electric mixer for about 3 minutes, until light.
- 5. Add eggs, one at a time, mixing well after each one.
- 6. Add packed pumpkin and vanilla, blend until well mixed.
- 7. Gradually add flour mixture and beat at low speed for a minute or so until smooth.
- 8. Carefully spread evenly in slow cooker and cover. (cover with foil before lid if air can escape).
- 9. Cook on high setting 2 hours or until centerinserted tooth pick comes out clean. Let cake stand, uncovered 10 minutes before cutting. Enjoy!

Written by Sara Izzo





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Winter Weather Safety

Mobility aid safety on snow and ice is crucial to prevent slips, falls, and injury.

No one wants to spend time in the hospital over the holidays. Whether using a cane, walker, crutches, or wheelchair, winter conditions pose unique challenges. Here's a practical guide to staying safe:

General Tips for All Mobility Aids

- **Footwear:** Wear boots with non-slip soles and good insulation.
- Take Small Steps: Move slowly and deliberately to maintain balance.
- Check the Weather: Avoid going out in icy conditions if possible.

For Canes and Crutches

- Ice Grippers: Attach an ice grip or ice tip to the bottom for extra traction (retractable spikes are ideal for indoor/outdoor transitions).
- **Rubber Tips:** Make sure rubber tips are not worn down; replace if smooth or cracked.
- Weight Bearing: Shift your weight cautiously to avoid slipping while placing the cane.

For Walkers

- All-Terrain Walker Tips or Skis: Use larger, textured tips or walker skis made for outdoor use.
- Tennis Balls Warning: Avoid using tennis balls in snow; they get wet and freeze, losing grip.
- Front-Wheel Walkers: Offer better mobility outdoors, but ensure the wheels have traction treads or ice grips.

For Wheelchair Users

- Winter Tires: Use pneumatic tires or install snow grips for better control on ice.
- Gloves: Wear waterproof insulated gloves for pushing.
- Wheel Maintenance: Keep wheels clean and dry to avoid rust and slipping.
- Assistance: On icy paths or inclines, have someone assist whenever possible.

Safety Add-Ons

- Cleats or Ice Grips for Shoes: Yaktrax or micro spikes can prevent slips.
- **Reflective Gear:** Days are shorter in winter; use reflective strips and lights to stay visible.
- Carry a Phone: Always have a way to call for help in case of a fall.

At Home: Prevention Starts at the Door

- Use Ice Melt or Sand: Keep walkways clear and gritted.
- Handrails: Install or check handrails along stairs and ramps.
- Mats: Use absorbent, non-slip mats indoors to prevent wet floors.

Written by Monica Albert Still, RN, BSN



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



EMPOWERED ESPORTS

Accessible Community Gaming for Connection and Growth

The University of Pittsburgh Medical Center invites individuals with physical disabilities to join our monthly community video gaming nights!

GAMING NIGHTS INCLUDE



Gaming stations set up with PlayStation, Xbox, Switch, and PC consoles for multiplayer gaming



Standard and accessible video gaming controllers available to use



Organized video gaming competitions with prizes



Free adaptive gaming evaluations by clinicians and the opportunity to receive adaptive gaming equipment at no cost

SIGN UP!



www.gamingreadapted.com/
empowered-esports

Use the QR code or website link to sign up and to learn more about events, find parking information, and sign up for adaptive gaming evaluations.

WHO CAN PARTICIPATE?

ANYONE IN THE COMMUNITY LIVING WITH A PHYSICAL DISABILITY

WHERE ARE EVENTS?

UPMC MERCY PAVILION
1622 LOCUST ST, PITTSBURGH, PA 15219

WHEN ARE EVENTS?

MONTHLY, PLEASE SEE THE LINK ABOVE FOR EXACT DATES.

Please email redepenningd@upmc.edu with questions.





