

Peer Navigation Program, for Us by Us

Living with spina bifida is such a unique experience. Only someone like you could understand the barriers and emotional toll that occurs every single day. It's a journey that can be easier with a listening ear and a support system.

This is why members of the Spina Bifida Care Advisory Network of Western Pennsylvania developed a Peer Navigation Program (PNP). The PNP allows patients from the clinic to have one-on-one sessions with one of our many talented mentors to help reach self-directed goals. Our mentors use their life experiences to connect with members of our community to promote self-advocacy, empowerment, and inclusion. We also welcome all adults with spina bifida to our Peer Navigation Group Sessions which are held every 2nd and 4th Thursday of the month at 7:00 pm (Eastern Time), except for major holidays. Come meet our mentors!!

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Soar Higher in Spring

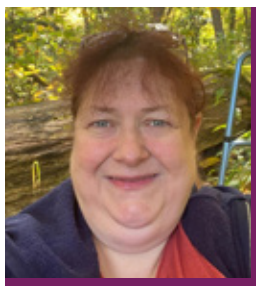
Oprah Winfrey once said, "Surround yourself with only people who are going to lift you higher." Including the right people in our lives can make us stronger and remind us that we are not alone in our journeys. This edition of our newsletter provides suggestions for including friends or family as supports to help you prepare for the future, to motivate you to exercise, or to keep your healthy eating on track. We are also excited to introduce our peer support program, which we hope will lift you higher and help you soar.

Written by Brad Dicianno, MD

Peer Navigation Program Mentors

Monica Still

is a 56-year-old adult with Spina Bifida. She is a retired registered nurse and now spends her time volunteering at the Spina Bifida Association, as a member of the Board of Directors of Disability Rights PA, and advocating for disability justice. 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.



Elizabeth (Libby) Powers

is an independent adult living with Spina Bifida. She graduated from Duquesne University with a Master of Science in Leadership and Professional Advancement and has been a Research Assistant since 2018. She has worked within the Pittsburgh area nonprofit sector for the past 25 years serving multiple healthcare and cross-disability organizations such as the Spina Bifida Association of Western PA, The Woodlands Foundation, and Children’s Hospital of Pittsburgh. She is currently pursuing her second Masters in Social Work to better help serve others with disabilities.



Sara Izzo

is a 38-year-old adult with spina bifida who has been a Research Associate for the past 8 years working on a series of studies focused on the spina bifida population, as well as providing other rehabilitative services at UPMC Mercy’s Adult Spina Bifida Clinic. She is an adult learner, studying psychology to better the mental health of all persons with visible and non-visible disabilities. Sara spends her free time cooking from scratch, watching films, collecting specialty board games, and spending time with her husband and two cats named Jean Grey and Mila Kunis.



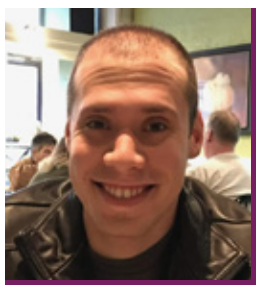
Deidre LaSalvia

is a 50-year-old with Spina Bifida who lives with her border collie, Shelby, who is her world! She has an above knee amputation due to a femur fracture and is a wheelchair user. Deidre worked in the medical profession as a medical receptionist/transcriptionist for 25 years. She loves to shop and decorate for the changing holidays and seasons and she enjoys spending time with friends, family, and her boyfriend.



Dan McCoy

is a Paralympic Gold Medalist in Ice Sled Hockey and is also a Certified Personal Trainer through the American Council on Exercise. In addition to his services as a personal 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.



Cheyenne Hennen

is an International-Global Studies and Korean-Asian Studies graduate from Penn State University. She enjoys getting involved in the community by participating in international advocacy groups as well as creating projects within her university to make spaces on campus more accessible. 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.



If you or someone you know is looking to connect one-on-one with another adult with spina bifida, please reach out to Sara Izzo – Peer Navigation Program Coordinator – at 412-328-1773, or join us every 2nd and 4th Thursday of the month for a peer lead group discussion.

Written by **Sara Izzo**

“It’s easier to be brave when you’re not alone” – Amy Poehler

Sip into Spring: Infused Water

Drinking enough water is important to health. Being well hydrated helps keep our body functioning the way it should, makes sure nutrients are delivered to our cells, keeps our joints moving smoothly, impacts our immune system, and helps our body stay at a normal temperature.



Water can be especially for patients with neurogenic bowel. This is because with neurogenic bowel, stool tends to sit in the intestines for longer. This extra time in the intestines allows extra water to be absorbed from the stool into the body, making the stool dry and harder to push out. Staying well hydrated acts as one factor (of many) to help keep stool moving along for a bowel movement. While fluid needs are different for each person, a general starting point is 8-10 cups of fluid per day.

So, we know water is important. But many people struggle to drink enough, or simply don't love the taste of plain water. Making infused water with fruit and herbs can be a wonderful way to add flavor to your water without lots of extra sugar. This can make it more likely that you will drink enough to meet your needs. While there is no single "right" way to make infused water, here are a few tips that may make the end result all the more refreshing!

While fluid needs are different for each person, a general starting point is 8-10 cups of fluid per day.

PUTTING IT TOGETHER:

- To get the most flavor, chop, slice, or mash fruit pieces and either rip or lightly chop herbs.
- Frozen fruit can work, but it will take longer for the flavor to appear (until the fruit thaws).
- Peel citrus fruit before adding. The peel (called a rind) of citrus adds a bitter taste to the water.
- Some produce flavor water very quickly, like citrus and mint. Other foods like berries, apple, or cinnamon need more time for the flavors to develop.
- Let sit in a lidded pitcher, jar, or container for at least 30 minutes in the fridge – this lets the flavors come together. The longer the mixture is stored in the fridge, the stronger the flavor will become.
- If you prefer to not have pieces in your water while drinking, you can also use water bottles or pitchers with an infuser "basket" that allow the fruit/herb flavors to infuse into the water without any pieces floating freely in the water.
- While the flavors of fruits, vegetables, and herbs in infused water taste great, remember that it does not count as any of your servings of fruits and vegetables for the day.

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FOOD SAFETY TIPS:

Infused water only lasts at room temperature as long as the food items inside it (such as slices of fruits or vegetables). It should be treated like any other refrigerated food/drink item. That means food safety is a concern.

- Wash produce in clean, cool running water before using
- Store leftover infused water in the fridge. If you don't use it all within 24 hours, strain out the solids and refrigerate the infused water for up to 3 days.
- Do not leave out at room temperature for more than 2 hours (1 hour if outside on a hot (>90°) day)
- Don't forget to use clean hands, materials, and work surfaces just as you would with any cooking activity.

FLAVOR COMBINATIONS:

Generally, you can use ½ cup to 1 cup produce for every 4 cups of water. For herbs, try a few (2-4) leaves/sprigs or a pinch to start. But you can adjust this to your flavor preferences!

- Lemon + blueberry + basil
- Melon + basil or mint
- Cherries + lime
- Mango + ginger
- Carrot + apple + lemon + ginger
- Celery + grapes + lime
- Cucumber + lime + strawberry + mint
- Lemon + mint
- Lime + ginger
- Apple + orange + cinnamon
- Pineapple or lemon + cucumber + cilantro or mint
- Raspberry + lemon

Flavor ideas modified from:

- [Infused Water \(va.gov\)](https://www.vh.edu/extension/infused-water/)
- [Thirst-Quenching Infused Waters – Nutrition and Food Safety \(uwyoextension.org\)](https://www.uwyoextension.org/infused-water/)

OTHER EASY WAYS TO FLAVOR WATER:

- Add a splash of lemon or lime juice. Simple, but satisfying!
- Add few tablespoons of juice to a glass of water
- Make ice cubes out of juice and add 1-3 cubes to water. You can also make ice cubes with water, fruit, and herbs – infused ice cubes!

To learn more, check out the references used in this article:

- [Infused Water with Ohio Local Foods | OhioLine \(osu.edu\)](https://ohioextension.osu.edu/infused-water/)
- [Infused Water \(va.gov\)](https://www.vh.edu/extension/infused-water/)
- [Enjoy infused water safely - MSU Extension](https://www.msu.edu/extension/infused-water/)
- [Thirst-Quenching Infused Waters – Nutrition and Food Safety \(uwyoextension.org\)](https://www.uwyoextension.org/infused-water/)

Written by Jacquelyn Klunk, MS, RDN, LDN



A man in a gym, wearing a dark t-shirt and shorts, is lifting two dumbbells. The image has a purple tint. In the top right corner, there is a black box with white text that reads "SPRING INTO FITNESS!".

SPRING INTO FITNESS!

Coming out of Winter and the holiday months, getting back into a fitness and nutrition routine can be a challenge, especially for those of us who like to indulge a bit during the holidays with all the amazing food we, our family, and friends cook!

I am personally a big fan of enjoying time with friends and family during the holidays and not stressing too much about staying super strict on a diet and exercise routine, within reason of course. No matter how you spent the Winter months, there is no denying that once the weather warms up and we can comfortably go outside and not have to wear big bulky jackets anymore, we feel a sense of freedom and excitement. Whether you had a fitness and nutrition plan during the Winter or not, the Spring season is usually the time where we like to shed those holiday pounds and, sometimes, put on more muscle to show off our hard work and, most importantly, feel the best we can in the warmer weather!

Usually during the holidays, we are eating in a caloric surplus; that is, we are taking in more energy into our bodies than we are expending, due in large part to all of the holiday parties and leftovers! Getting back into a state of being where we are moving our bodies more efficiently and focusing on strengthening our muscles and limiting the excess fat and stress we put on our bodies is an important transition to make.

Tracking calories for 3-7 days can be a great way to see what we are taking into our body and what our body needs to function efficiently. Often times, folks tend to underestimate the number of calories they consume on a daily basis. Eating 300-500 fewer calories below our calorie needs will help reduce the amount of fat our body holds on to, as long as we are eating adequate protein, usually 0.7-1g per pound of body weight.

Along with eating less, gradually moving more in our daily lives is another great way to increase our metabolism and also maintain or improve our mental health coming off of cold, cloudy months of Winter. Remember, something is always better than nothing! Perfection doesn't exist so as long as we are trying to move more every day. Even if it's a few minutes of cardio, 1 or 2 weight training exercises, or simply playing casual sports with friends, we can set our lifestyle up for success in the future warmer months leading into Summer!

Written by Dan McCoy, CPT, PLY

ADULT SPINA BIFIDA PEER NAVIGATION

GROUP SESSIONS

Spring 2023

March 9th Monica, Deidre, and Sara- What We've Learned in the Medical Field All Patients Should Know

April 13th Monica and Sara- Spina Bifida World Congress Update. What Can We Do?

April 27th Monica - How Can We Improve Advocacy with the Available Resources

May 11th Dan -Fitness Challenges and Barriers.

May 25th Dan - How to set Fitness Goals and Get Best Outcomes

June 8th Elizabeth (Libby) Powers- Pride Month- Gender Identity and Sexual Orientation

June 22nd Elizabeth (Libby) Powers- Pride Month- Disability Pride and How We Can Express It

7:00 pm (Eastern Time)

Zoom Meeting ID: 937 3399 6022

<https://pitt.zoom.us/j/93733996022>

JOIN US!!!

Contact Sara Izzo for more information (412) 328-1773

SBA “Join the Conversation” Zoom Calls for adults with Spina Bifida

<https://fb.me/e/2gWe3dbFU>

<https://bit.ly/2SpBEom>

First and third Thursday of every month at 7pm ET

Upcoming SBAWP Events

Adult Retreat

March 17 - 19: Camp Guyasuta

Youth and Teen Retreat

March 31 - April 2: Camp Guyasuta

6th Annual Shoot for SBAWP

May 17: 11:00 am - 4:00 pm – Seven Springs
Sporting clays is a form of clay pigeon shooting,
often described as “golf with a shotgun”.

Summer Camp-Staff training

June 27-30: Camp Guyasuta

Adult Camp (ages 21+)

July 2-8: Camp Guyasuta

Youth and Teen Camp (ages 6-21)

July 9-14: Camp Guyasuta

35th Annual John L. Moroney III Memorial Golf Classic

July 24: 8:00 am - 6:00 pm – Hickory Heights Golf Club

Soup and Salad Fundraiser

September 1: 11:00am - 2:00 pm
Cranberry Community UP Church

8th Annual Noll-Spratt Golf Scramble

September 16: 12:00 pm - 8:00 pm
Beaver Valley Golf Club

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



Research Studies

Access to Care Study Do you have a disability and use the healthcare system in the Pittsburgh area (or provide care for someone who does)? We would like to interview you about your experience! We want to understand what makes it difficult to get the care you need and how we might improve access to health care for people with disabilities. Most interviews will be via video call, but accommodations will be made for an alternative interview method if that is not appropriate. Interviews will last approximately one hour, and participants will receive a \$60 prepaid master card with our thanks for assisting us in this research. Please contact the study at kristynfelman@pitt.edu or (412) 692-8189.

Heating Assistance/Low-Income Home Energy Assistance Program (LIHEAP)

The Low Income Home Energy Assistance Program (LIHEAP) helps families living on low incomes pay their heating bills in the form of a cash grant. Households in immediate danger of being without heat can also qualify for crisis grants. The cash grant is a one-time payment sent directly to the utility company/fuel provider to be credited on your bill. These grants range from \$300 to \$1,000 based on household size, income, and fuel type. Remember: This is a grant and does not have to be repaid. You can find out more and apply [here](#).



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