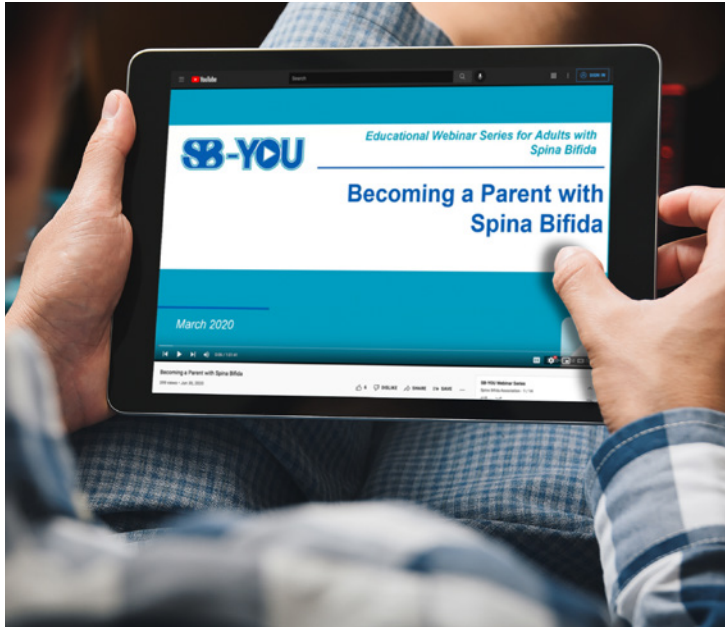


SB-You Webinars

The National Spina Bifida Association presents four SB-YOU live and pre-recorded sessions a year. SB-YOU is SBA's online informational program for, about, and presented by adults with Spina Bifida. The free, hour-long sessions may be viewed live via Zoom on the day of the session, or anytime by accessing the SB-You session archive on [SBA's YouTube page](#). The health care and social topics covered in each session are suggested, selected, and developed by members of SBA's Adult Advisory Committee. The presentations are spearheaded by SBA staff and delivered by health care professionals and adults with Spina Bifida who are "life experts" on the topic being discussed. Ample time is allowed for questions, answers, and comments from the live attendees.



SBA has developed 12 SB-YOU sessions since the program began in December of 2018. These webinars are on a wide variety of important everyday life topics for both men and women living with Spina Bifida. The topics range from mental health, bowel and bladder incontinence management, relationships, sexual health for both men and women, and so much more.

Written by **Libby Powers**

“HERE COMES THE SUN and I say, it’s all right.”

— from the song “Here Comes the Sun” on
The Beatles’ Album, *Abbey Road* (1969).

Spring is back, but “it feels like years since it’s been here.” “Here Comes the Sun” was written by George Harrison after a period of being disappointed with the music industry. Feeling discouraged, he visited his friend, Eric Clapton, and felt a sense of renewal. During the visit, he wrote the song to celebrate the coming of spring, a feeling of being free and back in love with music. It serves as a reminder that we can fall in love again with what we are passionate about. During this spring season, we hope that you will rekindle your love for the book that’s still unread on your nightstand, your favorite family recipe filed away in a box, or that special tune on scratched vinyl that you haven’t listened to in a long while. It may be time to rediscover yourself!

Written by **Brad Dicianno, MD**



Warming up to Spring

As Spring attempts its passage into warmer weather, I can't help but to hold on to my savory slow cooker dishes that are more common in the winter months. Pot roast is possibly the most consistent meal prepared in most homes with a slow cooker. The traditional chuck roast accompanied by potatoes and vegetables usually becomes a soup-like broth as it cooks down. However, after looking for different recipes to switch up my taste buds, I came across "Mississippi Pot Roast". This recipe consists of ranch seasoning and a packet of gravy to thicken up the broth. My method also allows for the potatoes to cook tenderly so they can be removed, mashed for savory gravy, and then paired with the shredded beef. Due to the

ranch seasoning packet, there is higher sodium intake in this recipe than I prefer, so I am sure to use a low sodium gravy packet in conjunction with high quality sea salt. This recipe also includes pepperoncini peppers which is usually a mild pepper unless the jar is labeled "hot". These peppers and their juice add amazing flavor, but if you are sensitive to heat or spicy foods, you can just add the juice of the peppers for flavor. This recipe can be easily portioned out and frozen if you are cooking for one, and it's perfect for leftovers for lunch or a second dinner!! This dish is honestly my new favorite dish and I hope it becomes one of yours too.

Written by **Sara Izzo**

Mississippi Pot Roast

Makes 4 servings | 5 minute prep time; 5 hours cooking time

- 1 (3 pound) chuck roast
- 3-4 potatoes quartered
- 2 large carrots quartered
- 1 diced onion
- 1 Tbsp. minced garlic
- ½ (12 ounce) jar pepperoncini (optional if too spicy)
- ½ (12 ounce) jar pepperoncini juice
- 1 (1 ounce) packet gravy mix
- 1 (0.4 oz) package ranch dressing
- 1 cup of filtered water
- 1 stick of butter or butter substitute.
- Sea salt and ground black pepper to taste

Directions In an unplugged slow cooker, add the chuck roast. Sprinkle both packets of ranch seasoning and gravy mix to the chuck roast. Place a stick of butter on the roast, uncut. Spread vegetables evenly on the sides of the chuck roast. (You can season the vegetables with your choice of seasoning here. I used sea salt and pepper.) Measuring out half the jar of pepperoncini juice, add the juice to the slow cooker along with the peppers, if using. Add a cup of filtered water and set your slow cooker on the setting High. Cook for 5 hours. If you want to use the Low setting, cook for 8-9 hours until chuck roast can be pulled apart with a fork. Season with extra sea salt and pepper to taste. Enjoy!!!

Written by **Sara Izzo**





It's More Than Your Spina Bifida History that You Should Know

I don't know about you but when any clinician asks about my history I take a deep breath and begin the very long story of my medical history with Spina Bifida and all that includes.

It's easy to forget other parts of our medical history that do not have to do with Spina Bifida. It's even easier not to remember our family's medical history. Often heart disease, diabetes, high blood pressure, and too many other health issues tend to run in families. It is important to know your family's history as well as your own. This is especially true as you get older.

It can be very intimidating to try to remember not only your history but everyone else's in your family. When I was about 13 or so my mother taught me my medical history. She also sat down and went over my family history. Some of it I knew, but some I did not. She had me write everything down in a notebook that I could carry with me to doctor's appointments. It had three sections. One for my history, the second for my family history, and the third for the dates of my appointments and what I wanted to ask on that day. I also included what the doctor told me. It was a bit bulky and took up a lot of room in my purse. Eventually, I transferred most of it to a file that I can access from my smartphone. Now, I can easily look up what I need to without carrying a big book with me. It also ensures that I always have those records on me. It also helps to use the patient portal app that UPMC offers ([myUPMC](#)). It keeps track of so many

things so that I get to write less! I also have the patient record numbers for me listed at the hospitals I went to over the years in case anyone needs those records.

I want to tell you how having that information helped me. About 2 years ago, I had nurses visiting me everyday to care for a wound on my leg. They checked my blood pressure at every visit. It was always normal. The problem was that every time I went to any doctor my blood pressure would be a lot higher. I have to admit that I was more concerned about my wound than my blood pressure. I figured that I was just very nervous at the doctor's office and that was why it was high. Some people do have that problem. It is called "white coat syndrome". My primary care doctor noticed this. She saw in my patient portal how high my blood pressure was at every doctor visit. She also had my homecare nurses' notes that showed that it was normal most of the other times. She saw what I had written in the family history part of the My UPMC app. My father, maternal grandmother, and my paternal grandparents all had high blood pressure and heart problems. She sent me to a cardiologist who did an ultrasound of my heart. She found changes in my heart that were usually caused by high blood pressure. She started me on medication to lower my blood pressure and it worked! My blood pressure at home and at the doctor's office was now the same! Knowing my family history and telling my doctor made sure that I received the care I needed.

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

Fiber Facts

In addition to other parts of a bowel routine that are recommended by your doctor (such as timing strategies or medications), consuming enough fiber and staying hydrated are two important nutrition habits for helping to prevent constipation and encouraging more regular bowel movements.



- **What is fiber?** Fiber is a carbohydrate that comes from plant foods. These include fruits, vegetables, whole grains, beans and legumes, and nuts and seeds.
- **How does it work?** Our body cannot digest or break down fiber. Instead, as the fiber moves through the intestines, it helps to add bulk to the stool. It also draws water into the stool. This bulk and moisture helps keep the stool easier to move along and push out for a bowel movement.

WANT TO LEARN MORE? ▶▶▶

(continued on next page)

There are actually two different types of fiber: soluble and insoluble fiber.

Soluble fiber attracts water. So, it pulls water into the stool and adds bulk that is more formed and viscous (this means thicker, or more gel-like). Soluble fiber can be helpful for both diarrhea and constipation. It helps diarrhea because it adds bulk that makes the stool more formed. It helps constipation because it keeps the stool moist which helps it move along. Plus, soluble fibers are often good fuel for the healthy gut bacteria that live in our colon.



Insoluble fiber does not dissolve in or attract water. This type of fiber is what we may think of as “roughage” (such as skins or peels of fruits and vegetables) that “cleans the pipes.” Insoluble fiber also adds bulk to the stool, but it doesn’t become “gel-like” by absorbing water.



Instead, its presence encourages the body to secrete water into the colon and speeds up how quickly stool moves through the intestines. Thus, insoluble fiber can be helpful for constipation. Foods higher in soluble fiber include oats, beans, barley, Brussels sprouts, and oranges. Food sources of insoluble fiber include the skins and peels of many fruits and vegetables, nuts, seeds, and beans. Ultimately, most foods contain a mix of both soluble and insoluble fiber, so don’t worry too much about separating these out. If you are regularly eating fruits, vegetables, whole grains, beans, or nuts/seeds, you are likely on the right track to meeting your fiber needs.

- **How much fiber do I need?** The Academy of Nutrition and Dietetics Evidence Analysis Library suggests for persons with neurogenic bowel an initial fiber intake of 15 grams per day, with increases up to 30 gm fiber per day as tolerated and as appropriate for each person based on their needs. However, it is important to increase fiber intake gradually for better tolerance. Introducing a lot of fiber all at once can cause stomach upset such as gas, bloating, and cramping because our body isn't used to it. Go slow and steady when increasing fiber intake.
- **Don't forget fluid!** Hydration is crucial when increasing fiber intake, especially for persons with neurogenic bowel. Without enough fluid, adding more fiber can actually make constipation worse. Remember, fiber needs fluid to do its job! While hydration needs vary for each person, 8-10 cups of fluid per day is a good rule of thumb (this is about 64-80 ounces of fluid). Water is encouraged as a best choice for hydration.

TIPS TO INCLUDE FIBER:

- Read food labels and aim to include foods with 3-5 grams of fiber regularly in your eating patterns.
- Include whole grains at your meals. For example, have a whole grain cereal at breakfast, whole wheat bread at lunch, and brown rice at dinner.
- Make half your plate vegetables at lunch and dinner! Choose colorful, non-starchy vegetables often.
- Include fruit during your day. For adults, 2-3 servings of fruit per day is often encouraged.
- Add nuts and seeds into your day. Include 2 tbsp. of mixed nuts with a snack, add 2 tbsp. of sunflower or pumpkin seeds to a salad, or toss chopped almonds or walnuts onto oatmeal or yogurt in the morning, for example!
- Try out new ways to enjoy beans. Add beans to soups, chilis, on top of salads, or pick bean dips like hummus with a snack.
- Fiber supplements can also be an option. Discuss with your doctor and dietitian about options for fiber supplements to see if they are right for you.

Written by Jacquelyn Klunk, MS, RDN, LDN

Article References:

1. [Guidelines for the Care of People with Spina Bifida](#)
2. [Academy of Nutrition and Dietetics Evidence Analysis Library. "SCI: Executive Summary of Recommendations \(2009\)"](#)
3. Roland Lee, A, Lebovitz J, Jaffe, N. "Nutrition Therapy: Fiber Basics." Academy of Nutrition and Dietetics. Dietitians in Medical Nutrition Therapy. 2020.



FISA Grant Awarded to the UPMC Adult Spina Bifida Clinic

The UPMC Adult Spina Bifida Clinic was awarded a grant from FISA to develop a peer counseling program. The clinic is training staff members and volunteers who are adults with Spina Bifida to serve as peer counselors for other adults living with Spina Bifida. The program will use education, advocacy, and support to assist those receiving support in achieving self-directed goals in any aspect of their lives. This program is patient-created, patient-led, and patient-centered. The goal is to improve the health and and experience of patient care. Partnership with the Spina Bifida Association, the national organization that helped to develop this program, will allow our program to be a leader and future model for other clinics and program across the nation. If you are interested in participating in the peer navigator program, either as a patient receiving services or as a mentor, please contact us.

Written by Brad Dicianno, MD

Sara Izzo Wins Research Support Chancellor's Staff Award

Sara Izzo was awarded with a 2021 Research Support Chancellor's Staff Award by Chancellor Patrick Gallagher at the University of Pittsburgh. The Research Support category of this award recognizes a staff member who has worked to advance the University of Pittsburgh's research efforts. In particular, she is being recognized for her work to support Spina Bifida research at Pitt within our National Spina Bifida Registry (funded by the CDC) and on an NIH funded research grant. Her award was announced in Pittwire and the University Times. Her name was also added to a plaque on display in the William Pitt Union. This award is well deserved and a great honor for Sara and our research program. Congratulations, Sara!



Written by Brad Dicianno, MD

Upcoming Events at SBAWP

Adult Retreat Spring 1

March 4-6 — Camp Guyasuta

Youth and Teen Retreat Spring 1

Mar 11-13 — Camp Guyasuta

Adult Retreat Spring 2

Apr 29 - May 1 — Camp Guyasuta

Youth and Teen Retreat Spring 2

May 6-8 — Camp Guyasuta

5th Annual Shoot for SBAWP

May 22: 11:00 am - 4:00 pm — Seven Springs

Summer Camp-staff training

Jun 28 - Jul 1

Adult Camp

July 3-9 — Camp Guyasuta

Youth and Teen Camp

July 10-15 — Camp Guyasuta

34th Annual John L. Moroney III Memorial Golf Classic

Jul 25: 8:00 am - 6:00 pm — Hickory Heights Golf Club

7th Annual Noll-Spratt Golf Scramble

September 17, 2022 — 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.



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