

### We've Become a Clinic Care Partner of SBA!

We are very excited and proud to announce that our Adult Spina Bifida Clinic has been designated a Clinic Care Partner of the Spina Bifida Association (SBA). This program recognizes clinics that hold themselves to the highest standards of care. These 10 standards are based on practices that we believe, based on the best available research, provide the best opportunity to improve care over time. SBA created this new designation in 2020, and our clinic is one of only 4 in Pennsylvania and 31 in the nation to receive this recognition. The Pediatric Spina Bifida Clinic at UPMC Children's Hospital of Pittsburgh also received this designation. More information about this designation can be found on the SBA website: [SBA Clinic Care Partner](#). *Written by Brad Dicianno, MD*



### Meet our Newest Team Member, Jackie!

Jacquelyn "Jackie" Klunk, MS, RDN, LDN is a Registered Dietitian who is our newest member of the Adult Spina Bifida Clinic this year. Jackie is originally from Pittsburgh, and completed her education at the University of Pittsburgh, during which time she completed her supervised practice hours at UPMC Mercy. She has been working at UPMC Presbyterian in the inpatient setting since 2018 and recently moved to the outpatient setting. Jackie will be replacing Sabrina Palmieri who recently accepted a full time position at UPMC to support patients with liver conditions. Jackie writes that she is "looking forward to becoming more involved with one-on-one nutrition counseling to work with patients to achieve their individual nutritional goals. Good nutrition is an important part of a healthy lifestyle, and even small changes can add up over time to help you reach these goals and support overall wellbeing. I am excited to be a part of this team!" We are also excited to welcome Jackie to our spina bifida clinic and wish Sabrina all the best in her future career. *Written by Brad Dicianno, MD*



### Spring in the New Year!

It is amazing how time flies! I remember as if it were yesterday; we were just turning our clocks to Fall back and here it's time to Spring forward again.

One of the highlights of writing this newsletter is its dual benefits; I get to share my love for cooking, but it has also helped me to be more social. I too, have spina bifida. At first appearance, it may not be evident, but like other experiences in life we find ourselves having a lot more in common with the person next to us than we think.



Food is that one thing we all have in common; we all need to eat and we usually love doing it. Talking about food always made me happy, but learning how to cook it myself has been the most rewarding and pleasing experience.

I have learned so much being in the kitchen. I gained skills like creativity and patience, but I also improved my memory skills and confidence in myself. This confidence increased even more writing this newsletter and encouraged me to reach out to the Spina Bifida Association of Western Pennsylvania about testing out one of my recipes with their Fithian House and Gatehouse residence. Needless to say, they were excited with the idea, and I had the pleasure of working with a friend and resident of the Fithian House. We discovered great things working together for 3 weeks leading up to our demonstration. So many tips and tricks were created in our test bubble that I thought it was extremely important to share it with the rest of our community. This newsletter will start off this series and I thought a rehash on our 2019 Fall newsletter's [Crispy Cornish Hen Recipe](#) would be a great start. Here are some tips we rediscovered using our slow cooker:

### Slow cooker Tips:

- When operating a slow cooker from a wheelchair it is often difficult to check on your dish when it is sitting on a basic countertop. A side table or flat chair securely set next to an outlet can help with this limitation.\* Ask for assistance in case you are not sure the table or chair can support your slow cooker.
- Use a clean bowl that can securely rest on your lap with your uncooked food inside. If using a manual chair this method can help you transfer your food into your slow cooker that is on the side table or flat chair while you propel yourself.
- Add your liquids last to avoid spills.
- Always plug your slow cooker in last.

\*Most slow cooker recipes require a liquid of some kind but this Crispy Skin Cornish Hen recipe uses the fat rendered from the hen as its moisture content. This recipes should not be used with slow cookers are older than 15 years old or that were purchased from garage sales. This is a safety measure that I established to prevent fires or sparks.

If cooking is something you've never thought about or you haven't found the confidence to try something new, just remember a saying I love around this time of year, "Spring is a lovely reminder of how beautiful change can be." *Written by Sara Izzo*

### New Year's Resolutions: Why They Fail and Tips to Improve Consistency

With the Holidays behind us, a new year and a new decade beginning, people all over the world have begun starting their New Year's Resolutions. Unfortunately, many people have already given up for a variety of reasons. Whether they ate something they were trying to avoid, ate more than they wanted to, or didn't go to the gym as often as they would like. Some people may not have reached goals at work or with family and friends as quickly as they would have liked. Whatever your 2020 goals are, make a pact with yourself that this year will be the **last** year you set a New Year's Resolution. Whether you hit your goal(s) or not this year, make this year the year you continuously set your mind in the right direction. When you get off track, as we all will, remember this phrase, "You Can't Mess This Up."

To me, that phrase means no matter how badly I overeat, or how long I go without working, I can always get right back on track. Many people will come up with every excuse out there when they don't see their weight going down (or up), when they don't see their strength increasing, or when they don't feel like they are getting better

sleep. While there are many reasons for why you may not be seeing the progress you would like, very often the best place to start would be to look at how many calories you are taking in throughout each day. Start with tracking your calories and macronutrients (Carbs, fats, protein) throughout each day. You can use apps such as MyFitnessPal or simply write down the types of foods you are eating and look up the macros for those foods later. Apps are good for calculating how many calories you *have eaten*, but are not very accurate in predicting how many calories a person with spina bifida *should eat* in a day. Our dietitian can help you calculate the amount of calories you should eat in a day. As you monitor your calories eaten, I am sure you will have a better understanding of how many calories are in foods, which foods fit best with your goals, as well as which foods you should avoid or limit the intake of. You may be surprised to see the amount of food and drinks you ingest throughout the day. Calorie tracking doesn't have to be a constant in your health and wellness lifestyle but it is a great tool to help you get started. After you track your calories for a week or two weeks, or even a month, you may feel the urge to give up if you feel your progress isn't where you want it to be. This is where you need to hold yourself accountable and, for example, tell yourself, "I am doing this for my family, friends, and/or myself. I am doing this to live a longer, healthier life and to be the healthiest I can be. I can do this." If you say this each day when you feel like giving up, it won't be easy to keep going but I promise it will be worth it when you reach your goals. Once you reach your goals, DON'T STOP THERE! Keep going and work each and every day to be better than you were the day before.

You can do the same thing with your workouts. As the current [Guidelines](#) note, you should spend a minimum of 150 minutes per week on moderate intensity exercise or 75 minutes of vigorous intensity exercise. If you set up your S.M.A.R.T. and F.I.T.T. goals (as discussed in the [Winter 2020 Newsletter](#)) you will be well on your way to achieving your goals. Not sure where to start? Try [these exercises](#) without having to go to a gym! Remember, YOU CAN'T MESS THIS UP! *Written by Dan McCoy ACE-CPT.*

### What is in your Beverage Choice?

Have you ever considered what is in your beverage choice? With the variety of options out there it can be difficult to know if you are making the healthiest choice. Some drinks are packed with calories and sugar but are not good sources of vitamins or minerals. In contrast, some drinks do contain beneficial nutrients, but may also be packed with high calories and sugars. These drinks can hinder your weight loss efforts or pack on pounds when you are trying to maintain your weight. The following information can help you make healthier choices when quenching your thirst.

#### Water

Did you know your body is composed of 60% water? Through normal activities we lose some of that water every day. It is important to replace it so your body can function at its best. There are a variety of reasons why water should be your first choice when you are thirsty. Adequate water in the diet allows for improved digestion, absorption of nutrients, circulation, transportation of nutrients and maintenance of body temperature. Additionally, it contains zero calories and can be filling, which could help you not to overeat and snack between meals. Water is also easy on the wallet and has little cost compared to other beverages on the market. Water can be easy to carry by using a reusable water bottle you can refill throughout the day.

### Tips to help drink more water:

- Make it a goal to have one glass with each meal and snack.
- Carry a water bottle with you that can be refilled throughout the day.
- Add fruit, such as lemon to the water and let it sit in the refrigerator for a couple hours to give it an extra kick of flavor.
- Set alerts on your phone as reminders to drink a glass of water every couple hours.
- Think about the cost savings when choosing water to drink when going out to eat.

### Milk

There are a variety of choices when it comes to milk. When talking about cow's milk, each type offers the same nutrients such as calcium, vitamin D, and potassium, but the calorie amount varies. For a healthy and nutritious diet, 1% and skim milk are recommended because they have fewer calories coming from fat. See the difference in calorie amounts in the chart below.

### Juice

Choose juice that is labeled 100 % fruit juice, because it contains natural sugar, not added sugar. Although the sugar is natural, it is suggested to limit your serving size to 4-6 ounces a day due to the high calorie content. Be careful of beverages labeled as "fruit drink," "fruit beverage," or "fruit cocktail," as these beverages do not contain 100% fruit juice and therefore may contain little to no nutritional value. It is recommended to eat your fruit rather than drink it. When eating the fruit itself, you are getting the benefit of fiber, which the juice is missing. So, grab that apple or orange and take a healthy bite.

### Soft Drinks

While soft drinks tend to be calorically dense, they are not nutritionally dense. This means that while soda is a significant source of sugar and calories, it is a poor source of beneficial nutrients. High rates of soda consumption have been linked to numerous health problems, including weight gain, poor dental health, diabetes, and cardiovascular disease. There is much debate today over whether diet soda products are better or worse. If you are trying to lose weight, and are currently drinking regular soda, diet soda can act as a good bridge to ween yourself back to the most healthful choices, such as water. However, recent research suggests that it is likely best to avoid having constant sources of sugar substitutes in the diet. Substitutes may be harmful to the gut microbiota, and may cause additional unintended side effects on blood sugar maintenance.

### Coffee / Tea

Generally, coffee and tea are good beverage choices, although caffeinated drinks should be limited to no more than 3-4, 8 ounce cups a day. Remember, decaffeinated choices are also available. Keep in mind, it is easy to add calories from added sugars and fat to these pick-me-ups by ordering specialty drinks. Do you add sugar or creamer to your coffee and tea? Any whipped cream on top? These specialty coffees and teas can be loaded with

### Compare the Calories\*

Each calorie amount is based off 1 cup (8 ounces).

Beverage	Calories	Total Sugar (g)
Water	0	0
Whole Milk	149	13
2% Milk	122	12
1% Milk	102	13
Skim Milk	83	12
Apple Juice	114	24
Orange Juice	112	21
Soft Drink, Cola	91	22**
Coffee/Tea, Black or unsweetened	2	0
Sports Drink	65	13**

\*Information taken from <https://www.suprtracker.usda.gov/foodapedia.aspx>  
 \*\*These contain added sugars

a variety of flavored syrups and toppings. It is easy to forget that these added ingredients can be high in calories. Making small changes can make a big impact on the number of calories in your drink. Try adding to your coffee and tea, half the amount of sugar that you normally do, or consider using 1% or skim milk instead of the flavored creamer.

### Sports Drinks

This beverage choice contains calories, a small amount of nutrients, and sugars. They can replenish some nutrients, such as sodium and potassium, which you may need during or after a long workout. However, most of the time you can replenish these nutrients through food, rather than a sports drink. Remember, it is important to consider the serving size when reading nutrition labels.

### Summary

With so many beverage choices out there, it is tempting to choose one that is high in calories and sugar. These beverages may be a contributor to the weight gain we see in our population. Remember that water works best to give you the fluids you need while quenching your thirst. There will be times when you want something other than water, and this can be included in a healthy diet. Always remember the importance of moderation and portion control. Limit the amount you drink of sugar sweetened beverages, such as soda pop or sports drinks. Remember, the goal is to get the fluids you need each day without adding in sugars and calories to your beverage choice. *Written by Sabrina Palmieri, RD, LDN*

### Tools for Techies and Gadget Lovers



**Flush App:** I was out having dinner with a friend of mine who has Irritable Bowel Syndrome (IBS), and the topic of finding a bathroom when you are out and need one quickly came up. This is a common scenario when I am out with her; we must stop what we are doing and focus on finding a bathroom, preferably a clean one, and do so as soon as possible. I was thinking of how this challenge would be even more difficult if she required an accessible restroom. Regardless of your level of mobility or complexity of your toileting routine, being able to locate an accessible public toilet in good time is a real challenge. With my friend's help, we searched to see what apps were available for this specific challenge. The free toilet finding app "Flush" lists thousands of accessible toilets and can help simplify your search when nature is calling. There are nearly 200,000 bathrooms in its database located all around the world. You can even search for restrooms without an internet connection. The app tells you about a restroom's accessibility, allows people to rate the cleanliness, and gives immediate directions on how to locate them. Don't let the fear of not being able to find a bathroom stop you from doing what you want to do. *Written by Darcie Ilg, PA-C*

### What's Happening at SBAWP

Spina Bifida Association of Western PA (SBAWP) will be holding retreats in March followed by the Firefly Camp this summer. At summer camp, participants will travel "Around the World" through activities, food, crafts, and fun. SBAWP looks forward to making great memories, reuniting friends, and enjoying time with Firefly's and Camp Guysuta's staff and the campers.

### Upcoming SBAWP Events –

- Adult Retreat:
  - March 6-8, 2020
- Youth and Teen Retreat:
  - March 13-15, 2020
- Youth and Teen Camp:
  - June 28 – July 3, 2020
- Adult Camp:
  - July 5-11, 2020

For more information, please visit the website at [www.sbawp.org](http://www.sbawp.org).



### Guidelines for the Care of People with Spina Bifida: What You Need to Know about Health Promotion and Preventive Healthcare Services

Did you know that some of the most common reasons that adults with spina bifida are hospitalized are possibly preventable? The new healthcare guidelines stress the importance of preventive healthcare, which means preventing problems before they occur instead of waiting to treat them when they are already a problem. Yearly follow up with your spina bifida provider and your primary care physician is important for prevention. At these visits, make sure you are talking to them about:

- High blood pressure and cholesterol
- Diabetes, weight, healthy eating and exercise
- Cancer screening, including skin cancer
- Fall prevention
- Alcohol, drugs and smoking
- Hearing and vision
- Bone density (Osteoporosis)
- Sexually transmitted infections
- Sleep apnea
- Concerns about your shunt or other neurological changes
- Pain, or concerns about bones or joints
- Bracing or equipment needs
- Concerns about bowel, bladder, kidney function
- Concerns about sexual function, fertility, family planning, and intimate partners
- Skin breakdown
- Leg swelling or Lymphedema
- Prenatal vitamins and folic acid
- Depression and anxiety

Written by **Brad Dicianno, MD**

### **Don't Forget Reproductive Health**

There are times when the number of doctors, tests, and appointments make me feel like I am a hamster on an exercise wheel. It can be overwhelming, especially when you are trying to have a life beyond simply meeting your healthcare needs. It's especially easy to procrastinate about your reproductive healthcare needs. I know that this can be a difficult subject to talk about but it is something that we need to discuss. We may have Spina Bifida but we are still women and men like everybody else. Below is meant to be a general guide for reproductive healthcare for both men and women. Your needs may vary, and I encourage anyone who feels they need more guidance to discuss your individual concerns with your physician.

#### *Women's Health:*

Per the American College of Obstetricians and Gynecologists, starting in adolescence women should have a Well Woman healthcare exam annually. The screenings and exams recommended for each year are determined by your age. In addition to an exam, a Pap test which is a test that takes a sample of cells from your cervix and looks for changes that may lead to cancer should be done every 3 years from ages 19- 29. After age 30 a pap test may be combined with a test looking for the Human Papilloma Virus (HPV). A breast exam by a healthcare professional is usually included during the exam. If you are sexually active the exam may include tests for sexually transmitted infections. At least once during your lifetime, you should get an HIV test. Your healthcare provider will review with you if your risk factors have changed over the past year. After the age of 40, a yearly mammogram should be added to your annual wellness check.

Your annual checkup is your opportunity to talk with your doctor about any concerns you may have. You can discuss any issues that you are having with menstrual pain, PMS or any other concerns you have about changes happening during your cycle. It's also the time to talk about any problems or concerns that you may have about sexual activity and/ or contraception. Don't forget to mention if you have a latex allergy if you are discussing condoms as a method of contraception. Or if you are planning to start a family it is the perfect time to discuss folic acid and how your Spina Bifida may be affected by pregnancy and what you need to do to ensure a healthy pregnancy and baby. As you age, you may want to discuss what to expect from perimenopause and menopause ([reference](#)).

#### *Men's Health:*

Your Primary Care Physician can be the doctor who screens for sexually transmitted infections. He or she can also discuss risk factors for and test for HIV. As they age, men have an increased risk for an enlarged prostate and prostate cancer. The usual symptoms that trigger a doctor to check for an enlarged prostate or prostate cancer are difficulty starting and stopping the flow of urine and increased frequency of urination. If you have a urostomy or catheterize yourself you likely wouldn't have these symptoms. You should discuss this with your doctor, as he or she may feel that you would benefit from a blood test called a PSA to screen for prostate cancer or other tests. Your PCP may have you follow up with a urologist for further evaluation.

Most men with Spina Bifida do see a urologist regularly for issues related to Spina Bifida. But did you know urologists are the ones who deal with men's reproductive health? There are even urologists who specialize in men's reproductive health exclusively and it might mean that for some issues you may have to see a different urologist than the one you are accustomed to.



# UPMC Adult Spina Bifida Clinic

## Spring 2020 Newsletter

When you see your urologist you might want to take the time to talk about any concerns regarding sexual activity, Contraception is an important topic to discuss especially if you have a latex allergy. Most condoms are made of latex because it provides a barrier to sexually transmitted infections. Fertility is something that you can discuss with your urologist. Your urologist would also be another doctor to discuss your risk for prostate cancer. ([reference](#)).

Just remember good health and wellness includes reproductive healthcare! *Written by **Monica Still, RN, BSN***

### **MyUPMC Patient Portal**

In order to serve you better and improve communication, we are asking that you join MyUPMC. MyUPMC is a free, secure online portal that allows you to communicate with our office, view test results, refill prescriptions, and manage your overall health. To sign up, go to [MyUPMC.com](https://www.upmc.com/myupmc) and create an account. If you have any questions, please ask our front desk or give us a call at **412-232-8901**.

### **UPMC Financial Assistance Program**

If you qualify for the UPMC Financial Assistance program, you may receive help with medical expenses such as reduced copays. The general financial aid program is available regardless of where you live. If you live in Pennsylvania, you may also qualify for additional refunds for medical expenses through our Adult Spina Bifida Clinic grant. Apply by going to [UPMC.com/FinancialAssistance](https://www.upmc.com/FinancialAssistance) or ask someone in our office for an application. If you apply, please let us know so we can track your application and let you know if you are approved. We also ask that you save a copy of your medical receipts and expenses.

### **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](https://www.upmc.com/SpinaBifida)