

UPMC Adult Spina Bifida Clinic Autumn 2021 Newsletter

Fall Means Time to Prepare for the Flu!

After over a year and half of a pandemic, it's easy to forget that there are other contagious diseases that we need to prepare for. You cannot forget about influenza – commonly known as "the flu."

Flu season usually starts in late fall and peaks in mid to late winter. Now is the time to prepare for where you are going to get your flu shot. The flu shot usually takes about 2 weeks to be effective. The best time to get it is before the flu virus is spreading through your community. One benefit of getting the flu shot is that

you are less likely to get the flu. Another benefit is that the risk of your being hospitalized if you get the flu is less when you have had the flu shot. The vaccine is the best educated guess that scientists make about which virus will be making its appearance this flu season. That is why sometimes you can get the flu even if you have had your flu shot.

The flu vaccine does not spread or give you the flu.

If you have insurance, flu shots at most pharmacies are free. Many pharmacies have programs offering discounted flu shots, in addition to in-store discounts. Without insurance, you'll pay more out of pocket. If you have Medicare, the shot is free (no deductible, no copay) if you have it administered by a doctor or pharmacist who accepts Medicare — that is, has agreed to accept the Medicare-approved payment as full reimbursement for providing this service. Medicaid and Medicare C plans also pay for the flu shot without a deductible or copay if you go to a doctor or pharmacist in network.

Getting the flu vaccine helps protect you, your family, your friends, and the community.

Written by Monica Albert Still, RN, BSN



Making the Most of Autumn

Nathanial Hawthorne once wrote, "...I cannot endure to waste anything so precious as autumnal sunshine by staying in the house. So I have spent almost all the daylight hours in the open air." This Fall issue of our newsletter will focus on making the most of the season with tips for good nutrition, delicious recipes, and ideas for preventive health behaviors and living with chronic conditions. Take the time to enjoy the crisp, fresh air and the quiet autumn twilight, and remember that our clinic is here to support you and your wellness journey.







Meaningful Employment Opportunities for People Who have the Desire to Work

Individuals with disabilities comprise a disproportionately small percentage of the workforce. Many of these people face additional barriers to gaining meaningful employment compared to the general population. Not only is a large portion of this population missing out on obvious benefits of work such as financial independence, they also are deprived of the feeling of purpose that meaningful employment develops.

Life'sWork is a program that helps find employment for adults with developmental and/or intellectual disabilities, physical limitations, as well as other employment barriers, including people who have limited work experience or education. For 90 years, they



have offered an array of employment-related services. They collaborate with employers throughout Western Pennsylvania to help clients train for, find and maintain meaningful employment.

Life's Work's process involves finding the right job for the right person. This requires assessment of the individual's interests and aspirations. They provide employment support services for adults with disabilities that offer a range of choices in the nature of the job setting as well as the level of support each individual requires.

Life's Work offers group settings for when a more supported environment is desired. Clients can choose to engage in their Community Participation program. This program gives participants the chance to connect with their community through volunteer opportunities. It also is a great way for clients to meet new people.

For clients who are ready to embrace work opportunities outside their structured facility, but who still require on-site job support, Life's Work has partnered with regional businesses who employ small client teams, accompanied by a job coach, to work in an environment where they can grow.

Of note, every individual must have an open case with Office of Vocational Rehabilitation (OVR) before they are eligible for Life's Works services.

If you would like to know more about how this Life's Work could help you find employment, check out their website: www.lifesworkwpa.org.

Written by: Darcie Illg, PA-C



The Seasons are Changing...and so has the Nutrition Facts Label!

Have you noticed any changes on your food packaging? The Nutrition Facts label has gotten an update

Back in 2016, updates were made to the Nutrition Facts label to help better guide individuals in making informed choices about the foods they eat. These changes were based on updated evidence regarding nutrients that Americans get either too little of or too much of, to better address risk of chronic diseases that have a connection to our diets (such as heart disease and diabetes). But if these changes were made in 2016, why haven't we seen these new labels on our food for the past five years? Food manufacturers were given some time to make these changes. Large manufacturers (with more than \$10 million in annual sales) were given a deadline of January 1, 2020, and smaller manufacturers (with less than \$10 million in annual sales) had to make the changes to their labels by January 1, 2021. Now that the new nutrition facts label is more commonplace, take some time to review the major updates: (continued on next page)

Serving size 2/3 cup (55g)

Amount per serving Calories

230

% Daily \	
Total Fat 8g	10%
Saturated Fat 1g	5%
Trans Fat 0g	
Cholesterol 0mg	0%
Sodium 160mg	7%
Total Carbohydrate 37g	13%
Dietary Fiber 4g	14%
Total Sugars 12g	
Includes 10g Added Sugars	20%
Protein 3g	
Vitamin D 2mcg	10%
Calcium 260mg	20%
Iron 8mg	45%
Potassium 235mg	6%

The % Daily Value (DV) tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.

- The **serving size** has been made larger and bold. Serving sizes have also been adjusted to reflect what people typically eat today (compared to when the labels were last updated in 1993). This does not mean it is a recommended amount to eat. However, because it shows a common amount, it is easier for people to relate the information on the label to their daily habits.
- Calories have been made larger and bold, so it is easy to see. Calories from fat have been removed, because the type of fat in our diets is thought to be more important than just the amount of fat (think picking healthier unsaturated fats instead of less-healthy saturated or trans fats).
- The new nutrition facts label now includes a section underneath the "Total Sugars" header which tells you how much added sugar is in a food/drink. Some foods, like fruit and milk, have sugars that occur naturally in the food. However, added sugar is the sugar that a manufacturer adds to a food/drink. We should try to eat less added sugar, because it can quickly add calories without providing a nutritional benefit or helping us feel full and satisfied with our meals and snacks. This change to the label makes it simple to see how much added sugar is in our food/drinks!
- Manufacturers must include vitamin D and potassium in the nutrition facts label. They no longer have to include vitamin A or vitamin C, which used to be in this section. That is because evidence shows that nowadays, Americans are more likely to not consume enough vitamin D and potassium. Manufacturers are still required to include calcium and iron. Other vitamins and minerals are included voluntarily.
- The **footnote** on the Nutrition Facts label has been simplified. The % Daily Value (DV) is based on a 2,000 calorie per day diet for general nutrition advice, but this is not the best calorie amount for every person.
- The % Daily Value (DV) have gotten an update! The %DV have been adjusted to reflect current scientific evidence about how much of each nutrient it is recommended to consume or to not exceed in a day. The %DV shows how nutrients in a serving of food compare to the total daily diet not just one meal.

6 Updates to the Nutrition Facts Label

Nutrition Fa	cts
8 servings per container Serving size 2/3 cup (55g)	
Calories 2	230
% Dail	ly Value*
Total Fat 8g	10%
Saturated Fat 1g	5%
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Cholesterol 0mg	0%
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Image source: FDA.gov; FOR REFERENCE ONLY

Quick Tips for Reading the Nutrition Facts Label

Want to put your new knowledge about the Nutrition Facts label into practice? Here are some tips for reading a food label:

- Check the serving size. The numbers on the Nutrition Facts label are for the serving size listed. So, if you are eating more or less than this amount, you will have to do some math to determine how much of a nutrient you are actually getting. For example, if the serving size is ½ of the container and you eat the whole container, you are getting double the amount of all the nutrients on the label.
- Choose foods that contain LESS: saturated fat, trans fat, sodium, and added sugars. These nutrients should be consumed less often. Diets high in these nutrients may increase risk of certain chronic diseases, such as heart disease, high blood pressure, or diabetes.
- Research shows Americans do not always get enough fiber, iron, calcium, vitamin D, and potassium. You can use the Nutrition Facts label to find foods that are good sources of these nutrients. Talk with your doctor and/or dietitian about your individual needs for these nutrients.
- What counts as low and high? A quick tip is to check the %DV. A %DV of 5% or less is low, and a %DV of 20% or more is high in a nutrient.
- **Compare!** Use your knowledge about the nutrition facts label to compare two similar foods or two different brands so that you can select the option that best meets your health goals.

WHAT'S THE BOTTOM LINE?

The Nutrition Facts label can be a helpful tool in understanding what is in the foods and drinks we are consuming. The updates to the Nutrition Facts label aim to simplify this task as much as possible to help inform the public. Use the Nutrition Facts label as a tool to help you understand what you are eating and make healthier choices. For more information, visit: What's New with the Nutrition Facts Label | FDA.

Written by Jacquelyn Klunk, MS, RDN, LDN

Article References:

- What's New with the Nutrition Facts Label (fda.gov)
- 2. Changes to the Nutrition Facts Label | FDA
- 3. The New Nutrition Facts Label | FDA
- shop-smart---get-the-facts-on-food-labels_nnm2021_english_final. pdf (eatrightpro.org)



Nutrition Facts 8 servings per container Serving size 2/3 cup (55g)

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Living with Spina Bifida AND a Chronic Condition

When you are living with spina bifida **and** one or more chronic conditions too, it can be a lot to handle. For many of us, living with spina bifida since birth is all we've ever known life to be. While spina bifida and chronic conditions all come with their own set of challenges, they can also teach you a lot about yourself.

Living with a chronic condition has taught me about self-awareness, acceptance, and self-compassion, and I have gained a stronger understanding that I do not have to be a resilient, happy, energetic individual person all of the time. I am allowed to give myself permission to be human just like everyone else. I can show my emotions and feel them and continue to move forward. I have learned that I do not have to go through difficult life situations alone. I am allowed to reach out and ask

"Behind every scar or battle wound is an untold story of survival."

Anonymous

others for help when I need it, and not just when I am in the midst of a crisis situation. This includes not feeling ashamed or embarrassed when needing to seek out professional mental health support. Just like there are doctors who treat us for our physical health conditions, there are trained professionals out in the world who work directly with individuals to better understand emotional triggers and traumatic experiences that have occurred in their lives. These professionals can help you to develop a strong, effective set of coping mechanisms such as using visualization of a calm, safe space, body movement through doing yoga stretches, breathing techniques, and journaling. These are just a few examples of available coping strategies. It is important to remember that coping mechanisms are not one size fits all, what may work for you; may not work for another individual. It's all a part of the process of developing a better self-awareness.

Developing a stronger sense of self-awareness takes time and is absolutely vital to the successful, effective management of chronic conditions. You may stumble and make mistakes along the way, and that is perfectly okay. We are always growing and evolving as human beings even if we don't realize it. Developing a stronger sense of self-awareness means making time in your day for self-reflection, making the connections between your emotions, situational reactions and your own emotional triggers, and learning how to differentiate between them so that you can diffuse negative thought patterns and behaviors before they arise. It is important to remember that when we are in the midst of a crisis like a chronic condition symptom flare or a highly emotional situation where we may feel unheard or misunderstood, it is often very difficult to decipher these differences and make these important connections. Once the situation has been diffused and you have had time to wind down, process your emotions, and remove the blame from yourself or others and diffuse negative thought patterns, this is where you can think more clearly, and is when you can best discover how to better handle similar situations in the future.

(continued on next page)

Learning to effectively communicate your needs and your experiences regarding your chronic health symptoms is also critical. Doctors may know the medical facts, best diagnostic tools, procedures, and the most effective treatment options available for your specific ailments, but only you know how you are feeling. When talking with providers about the symptoms you're experiencing try your best to be as descriptive and

detail oriented as possible. You can do this by keeping a symptom journal, where you can document your symptomatic episodes, explaining what kind of body sensations you are feeling, and how long they last. If your intuition is telling you that something isn't right then it probably isn't. Be your own best self-advocate, and if you are finding that you are unable to effectively communicate what

you are personally experiencing asking for help from an experienced patient advocate or trusted loved one can be helpful. It is your right as a patient to seek out additional specialist opinions if you are not satisfied with the treatment options you have been provided or if you are still feeling unheard or misunderstood by a particular medical provider.

Lastly, I want to talk about the importance of self-acceptance, having self-compassion, and accepting your own limitations. Accepting ourselves for who and what we are is the most challenging and most meaningful part of the journey of learning how to live a full and meaningful life even with having multiple chronic conditions whether

you were born with it or you acquired it later on in your life. Self-acceptance does not always mean that you have to put on your brave, happy, resilient face just to make others feel comfortable nor does it mean that you have to fake it until you make it or that you've somehow cured yourself. Self-acceptance means that while your chronic health condition may not be the most ideal situation, you find a way to love yourself and find a way to be your most

Self-acceptance does not

always mean that you have

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authentic, true self even though you may still be experiencing pain and other chronic condition symptoms that are beyond your own circle of control and once you figure out where your actual control lies that is where you find your own healing superpower. You find a way to let your feelings come and go like waves, but that does not mean you don't allow yourself to sit and feel them. It means you no longer let

yourself continue to dwell on the sadness, anger, and negativity of what you can no longer do or dwell on what your chronic condition has taken away from you. You can still find healthy, fulfilling ways to cope and manage your feelings and hopefully find happiness and joy again in your life despite your unforgiving health circumstances. Discovering and adapting to new ways of doing certain activities is infinitely possible. This may include adaptive yoga, various adaptive sports activities or learning new adaptable skills to help with activities of daily living at home or in the community. You sometimes just have to be creative and think outside the box.

Written by Libby Powers

New Media and Podcasts for Adults with Spina Bifida

- Dr. Dicianno was recently a guest on the <u>Lucky Exile</u> podcast, discussing care of adults with spina bifida.
 You can listen on any of the following platforms:
 - Spotify Podbean Google Amazon/Audible



- The Spina Bifida Association also hosted Dr. Dicianno on an "Ask the Expert" YouTube session to discuss issues important to the care of adults with spina bifida.
- Spina Bifida Association is collaborating with MedStar National Rehabilitation Hospital's Rehabilitation Research and Training Center on Neurogenic Lower Urinary Tract Dysfunction (NLUTD, also known as neurogenic bladder). They have created new podcasts focusing on bladder health and wellness, and other topics related to disability, entitled BladderBuzz. In the podcast "Urinary Symptoms Management" you will learn about a new monitoring tool might help you determine if your urinary symptoms may need medical attention or whether you might be able to manage symptoms at home.

WHEELCHAIR WORKOUT

a—**b**

Workout Nutrition

Pre-workout and post-workout nutrition are often overlooked components of a well-balanced health and wellness program. Our bodies need nutrients from food to function daily.

Even processes we do not know or feel happening within our body requires energy that comes from the nutrients in food. Therefore, it is extremely important to make food choices that will help your body function to its full ability. Many people interested in a health and wellness program, specifically a fitness program, are interested in losing fat and maybe gaining some muscle along the way. Often when we talk about wanting to lose weight, we are talking about losing the excess fat on our bodies. Obviously, there is nothing wrong with wanting to lose a bit of fat on our body to maybe make our clothes fit better, to feel better physically and mentally, and to look better to ourselves in a mirror. However, fat on our body is a completely normal part of living. We need fat to survive. Too much or too little fat can have health consequences but having a bit of fat on our bodies is essential to optimal health.

There is a common myth in the health and wellness field that fasted exercise (exercising without eating prior to the exercise) will help you lose weight (i.e., fat). This is not only false but also can be extremely dangerous depending on the type of exercise you are doing. Higher intensity workouts such a 1-hour weightlifting session require much more energy than a lower intensity workout such as a short 10-minute walk around your neighborhood. Proper nutrition is key in getting the most out of your workout to make sure you are alert mentally and your body has the nutrients it needs physically to complete the exercise. As I mentioned above, our bodies require energy to function. When we exercise, we

are burning energy in the form of calories to complete the workout. When we skip a pre-workout snack or meal, we are forcing our body to take nutrients already in our system to supply the energy for the workout. This can cause other processes in our body that we are not aware of to slow down and can be harmful

to our health. Although specific nutrition advice depends on the individual person and the type of exercise being done (and for how long!), there are some common tips for nutrition pre- and post-workout.

If you are exercising in the morning, it is recommended to eat a light breakfast or snack such as a banana or apple no later than 30 minutes before your workout. These foods are high in natural sugars

which are digested very quickly and easily by our bodies so we can gain the energy quickly. If you are not working out right after you eat, it is recommended to eat a more "typical" sized meal that contains a mixture of carbohydrates and protein (such as scrambled eggs and whole wheat toast, oatmeal made with lowfat milk and fruit, or Greek yogurt or cottage cheese and fruit) anywhere from 1 to 3 hours before you exercise. These foods take

a bit longer to digest so exercising right after you eat them may cause your body gastrointestinal distress as well as not allowing enough time for your body to digest the food to use for energy. Whatever you decide to eat before a workout, make sure you are eating a combination of carbohydrates, which are the primary energy source our bodies need from food, as well as lean protein such as chicken, fish, beans and lentils, or quinoa, as a few examples. You can add in a bit of healthy fats such

as avocado or olive oil but be careful to not go too heavy on these as they are higher in calories than carbs and protein.

Withintwohoursafteryourworkout, you should eat a well-balanced meal or snack consisting of high protein and moderate carbohydrates as well as healthy fats to supply your muscles with the nutrients they need to heal and repair from your workout. As always, proper hydration with water or a zero-calorie sports drink are recommended

before, during, and after workouts.

If you would like to check out a library of adaptive fitness exercises you can do whether you are able to stand up or use a wheelchair, click here to view my **YouTube** channel.

Written by Dan McCoy, ACE-CPT

Delicious Healthy Benefits!

As I have mentioned in previous newsletters, Fall is my favorite season. I have truly missed the traditions we were so fortunate to experience before 2020, and, as my most cherished holiday approaches, I have found a deeper understanding of Thanksgiving.

Hopefully, our friends and family have endured the struggles during the pandemic and have embraced the vaccinations that have been provided to us so we may get back to our normal gatherings during the holidays.

I wanted to remind our community of seasonal eating. Last summer, I wrote an article about the benefits of seasonal eating. This seasonal article embraces some of my favorite Fall foods and a couple of recipes that are traditional during the holiday. I also wanted to provide you with a different method of preparation and presentation. Sweet potatoes are often overlooked on dining tables in the fall since pumpkins share their same color and are often advertised for their flavoring. However, sweet potatoes are one of my favorite foods, and the way I prepare them makes a healthier alternative to regular

"Delicious autumn! My very soul is wedded to it, and if I were a bird I would fly about the Earth seeking the successive autumns."

George Eliot

potatoes. Since they are sweet, I often save this delicious side dish for last because it reminds me of a sweet potato pie without the high-carb buttery crust that often pushes my calorie intake over the limit. Sweet potatoes are a historical vegetable eaten not only on this continent but also in the Caribbean and in parts of Africa.

Green beans are a staple in many homes throughout the year, and there are a few traditional ways they are prepared during the holiday season. Often found canned, green beans are more enjoyable out of season if they were frozen after harvesting. However, you won't need to eat frozen green beans in the fall because this is best season to enjoy them.

The pomegranate is a fruit that is filled with tiny edible seeds that are extremely juicy and sweet. The red color of the seeds remind me of the often used cranberry, but,



personally, I love the pomegranate more because they are sweet. Cranberries are very tart and require a large amount of sugar for them to be enjoyed. Pomegranates have been centralized in Greek Mythology and have strong roots in Middle Eastern cuisine.

The two recipes I will share in this issue include the three Fall foods mentioned above and are great for vegetarian meals. They can be eaten on their own for lunch or a light dinner or paired with your favorite protein as wonderful side dish like my crispy slow cooker Cornish hen recipe from the 2019 Fall Newsletter.

Written by Sara Izzo

Baked Mashed Sweet Potatoes

Makes 1-2 servings | 5 minutes prep time; 2 hrs. 15 minutes total time

2 medium Sweet Potatoes

2 tsp Pumpkin Spice

1 tsp Cinnamon

1/4 tsp Vanilla Extract

1 tsp Garlic powder

1 Tbsp Honey (light brown sugar)

2 Tbsp Unsalted butter

Salt and pepper to taste

Pre heat oven to 400°

Wrap each sweet potato in foil and place in a baking dish and bake for 1 hour and 15 minutes. Once potatoes are cooked through, turn the oven off and leave the potatoes in the oven for an hour to cool down. After an additional hour, take the potatoes out of the oven and unwrap the foil. The potatoes should be cool enough to handle to remove the skin by hand. Taking a butter knife, gently cut a slit down the side of the potato and peel the skin off. After removing the skin, add all the ingredients listed into the baking dish with the potatoes and mash them all together with a large fork. Stir until combined and enjoy!









Pomegranate and Sliced Almond Green Beans

Makes 1-2 servings | 2-5 minutes prep time; 15-20 minutes total time







1 half bag of fresh French Green Beans

1/4 sliced Onion

1/2 Tbsp dried Rosemary

1/2 Tbsp dried Thyme

1/4 tsp Garlic powder

1 Tbsp Olive oil

3 Tbsp thinly sliced unsalted butter

Salt and pepper to taste

2 Tbsp Pomegranate Seeds

1-2 Tbsp Sliced Almonds

Pre heat oven to 400°

Cover a baking sheet with foil and spread the green beans evenly. Season the green beans with the rosemary, thyme, garlic powder, pepper, and salt. Place your thinly sliced onions evenly over the green beans as well as the butter. Drizzle the olive oil over the green beans, this will help with sticking and will keep the butter from burning. Bake for 15 minutes. After the green beans have cooked through, carefully place the green beans in a serving dish and sprinkle the sliced almonds and pomegranates over the green beans and enjoy!

Emergency Broadband Benefit

The Emergency Broadband Benefit is a federal program that provides a discount of up to \$50 per month towards broadband service for eligible households. Eligible households can also receive a one-time discount on



the purchase of a laptop, desktop computer, or tablet from participating providers if certain criteria are met. For more information, visit this **link**.



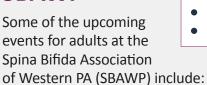
Farmers Markets

The city of Pittsburgh is running farmers markets at four locations through late November. Below are the following locations and operating times:

- East Liberty Garland Parklet lot, North Euclid Avenue and Broad Street Mondays, 3-7 p.m. - May 10-Nov. 22
- Carrick Carrick Dairy District, 1529 Brownsville Rd.
 Wednesdays, 3-7 p.m. May 12-Nov. 24
- Northside Allegheny Commons Park, East Ohio Street and Cedar Avenue Fridays, May 14-Nov. 19
- Squirrel Hill Beacon/Bartlett parking lot Sundays, May 16-Nov. 21

Each farmers market will sell fresh fruits, vegetables, meats, cheese and baked goods -- while a few of the locations will also sell flowers, small gifts and gardening items. They will all accept SNAP (food stamps), credit and debit cards. However, shoppers are asked to pay the exact amount if using cash.

Upcoming Events at SBAWP





Fundraising Events:

September 18 Noll-Spratt Golf Scramble
November 13 Girlfriends for Good Purse Bash
October 24 Soup and Salad Fundraiser

Camps & Retreats:

October 22-24 Youth and Teen Retreat

November 5-7 Adult Retreat

December 3-5 Youth and Teen Retreat

December 10-12 Adult Retreat

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

Access Kaleidoscope (SBAWP's newsletter) 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

UPMC Adult Spina Bifida Clinic

1400 Locust St.

Building D, Suite G-103

Pittsburgh, PA 15219 Phone: 412-232-8901

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