

The Whole Story on Whole Grains

A healthy, balanced diet includes a variety of food groups: fruits, vegetables, dairy, proteins, and grains. Frequently, whole grains are recommended as a good choice for a healthy diet. But what exactly are whole grains? What is the Grains food group? Read on to learn more!

Which foods fit into the Grains food group?

The Grains food group includes foods such as wheat, rye, barley, oats, quinoa, cornmeal, and rice, as well as foods made from these ingredients. So, foods such as breads, pastas, cereals, crackers, and tortillas are also included in the Grains group. Grains provide our body with energy in the form of carbohydrates. They also provide fiber, which helps keep us feeling full, promotes regular bowel movements, and can help with lowering cholesterol levels. Unless you have a medical condition for which you have been instructed to eat a low fiber diet by your doctor, fiber is an important part of a healthy diet. Grains also contain minerals such as iron, magnesium, and B vitamins such as thiamin, riboflavin, niacin, and folate. However, the amount of these nutrients depends on whether the item is a whole grain or a refined grain.

What are whole grains versus refined grains?

A whole grain, simply put, contains the “whole” grain. It contains all three layers of the grain plant: the bran, germ, and endosperm. A refined grain is processed to remove the bran and germ layers, leaving behind the starchy endosperm. This gives the grain a smoother texture and lengthens shelf life. The bran and germ layers contain fiber, minerals, and many B vitamins. When these two layers are removed, these nutrients are also removed. Therefore, whole grains naturally contain more fiber, iron, and B vitamins than refined grains. Sometimes, manufacturers will add vitamins and minerals back into grain products after they have been refined. When this occurs, these grains are “enriched.” You can look for the term “enriched” in the ingredient list of the refined grain.

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Autumn Preparations

The poet William Cullen Bryant called autumn “the year’s last, loveliest smile.” The vibrant changes in color that mark the end of hot summer days remind us that we also must adapt and change with the seasons. This newsletter focuses on tips to help you navigate times of transition in your lives.



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One important nutrient added back into refined grains is folic acid. Folic acid is the synthetic form of folate, one of the B vitamins. Our bodies absorb folic acid better than folate. Adequate folic acid intake can reduce the risk of a pregnancy being affected by a neural tube defect such as spina bifida (though is not a completely preventative measure). In 1998, the FDA (Food and Drug Administration) required many common enriched grain products (like flours, bread, cereals, rice, and noodles) to be fortified with folic acid to help reduce the rate of pregnancies affected by neural tube defects. This fortification means manufacturers add higher amounts of folic acid than was naturally in the grain. In 2016, corn masa flour was approved for voluntary folic acid fortification. Although some whole grains may be fortified (such as some breakfast cereals), most whole grains are not fortified with folic acid.

Some examples of whole grains include brown rice, whole wheat bread, whole wheat pasta, barley, quinoa, oatmeal, whole cornmeal, popcorn, and whole wheat flour.

It is recommended that women with spina bifida who are planning a pregnancy consume 4000 micrograms (4 milligrams) of folic acid per day least one month (but preferably 3 months) before they start trying to get pregnant and continuing through the first three months of pregnancy. This is ten times the recommended folic acid intake of 400 micrograms per day for individuals who do not have spina bifida. This higher intake recommendation is typically provided via a separate supplement as recommended and prescribed by a physician. However, you can still include sources of folic acid into your diet, such as enriched refined grains.

So which grains are which? Some examples of whole grains include brown rice, whole wheat bread, whole wheat pasta, barley, quinoa, oatmeal, whole cornmeal, popcorn, and whole wheat flour. Some examples of refined grains include white rice, white bread, pasta, and white flour. However, you don't have to eat only whole grains during the day! Balance is key. A general recommendation for a healthy diet based on the 2015-2020 Dietary Guidelines for Americans and MyPlate is to make half the grains you consume in a day whole grains.

How can you add whole grains into your day?

- Read food labels to identify whole grains:
 - Color alone does not indicate that a food is a whole grain. Ingredients such as molasses can be added to make foods appear more brown. On the flip side, some grains that appear white can still be whole grain. Use the tips below to read the food item's label to help identify whole grain foods.
 - Look for the word "whole" at the beginning of the ingredient list. For example, "whole wheat" bread would be a whole grain, but "multi-grain" bread may not (multi-grain just means multiple grains – they may or may not be whole grains).
 - Look for the phrase "100% whole grain" on the label. But be careful - the phrase "100% wheat" is similar but does not always mean whole grain. It just means the product was made entirely with wheat - but this wheat could be refined.
- Make it a goal to try whole grains you have never eaten before! Items such as quinoa, farro, bulgur, amaranth, or barley can add a new texture and new flavor to your meals. Set a goal that works for you – such as one new whole grain per month.
- Make a swap! Try switching out one refined grain you normally eat during the day for its whole grain counterpart. Try whole grain bread on a sandwich, a whole grain English muffin at breakfast, or a side of brown rice with dinner instead of white rice.
- Add whole grains into recipes you may not have thought of! Mix cooked barley into a vegetable soup, add cooked quinoa to a fresh salad, or add oats to meatloaf.
- Try baking with recipes that include whole wheat flour.
- If you are finding it difficult to get used to the texture of whole wheat pasta or brown rice, try making it half and half! Mix half white rice or pasta with half brown rice or whole wheat pasta, respectively. Note that the whole grains will likely take longer to cook, so you may want to use separate pots.
- For a quick snack, add whole grains into trail mix by including $\frac{1}{4}$ cup whole grain cereal or low-fat popcorn with about $\frac{1}{4}$ cup mixture of dried fruit and nuts.
- For general health benefits, select grains that are lower in fat and added sugars.

Summary

Whole grains are one part of a healthy, balanced diet. They provide our bodies with carbohydrate for energy, fiber to help encourage regular bowel movements, and vitamins and minerals our body needs to function. However, refined grains like white bread, rice, or pasta, can fit in a healthy diet; enriched refined grains are also fortified with folic acid. So, aim to make half the grains you eat each day whole grains. Try new grains you have not eaten before to increase variety on your plate!

Written by **Jacquelyn Klunk, MS, RDN, LDN**



Pumpkin Chili

Makes: 8 servings | Serving Size: 1 cup chili | Cook Time: 30 minutes

2 teaspoons olive oil

1 small yellow onion (*chopped*)

1 green bell pepper

(*cored, seeds removed, and chopped*)

2 jalapeño peppers (*seeded and finely chopped*) -

OPTIONAL, omit to decrease spiciness

2 cloves garlic (*finely chopped or can substitute*

½ teaspoon garlic powder)

1 pound ground turkey

1 can low-sodium or no-salt-added diced tomatoes with juice (15 oz.)

1 can pumpkin puree (15 oz.)

1 cup water

1 teaspoon chili powder

1 teaspoon cumin, ground

Salt and pepper (*to taste, optional*)

1 can low-sodium kidney beans

(*You can choose other types of beans if desired*)

Directions: *In a large pot, heat olive oil over medium-high heat. Add the onion, bell pepper, jalapeños (optional), and garlic. Cook, stirring often, for about 5 minutes or until the vegetables are tender. Add the ground turkey to the pot and cook until the meat is cooked through. Add the diced tomatoes, pumpkin puree, water, chili powder, cumin, salt, and pepper. Bring to a boil. Lower the heat to medium-low. Then, add the canned beans into the pot. Cover and simmer, stirring occasionally, for about 30 more minutes. Ladle chili into bowls for serving.*

To add whole grains into this recipe, serve your chili over ¾ to 1 cup cooked brown rice.

Sources/References used for article and recipe:

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“Look for something positive in each day. Even if some days you have to look a little harder.”

Brian Ford

Baking with Purpose

As we “Fall Back” into my second favorite season, autumn, we have an opportunity to reflect on the changes we have experienced in the first half of 2020. This year has had the biggest impact on all of our lives collectively.

We are all on a path to find a new normal as we embark on a creative way of handling our safety and comfort relating to our health and lifestyle. As a patient with Spina Bifida and an employee in the health care system, I have had a great passion for supporting an independent lifestyle. Independence is a luxury many people all around the world are struggling to obtain, whether it’s financial independence or physical. Many people have had to make extreme adjustments to the changes in our environment due to social distancing. As patients, we have had lifelong, firsthand experience in not having the independent lifestyle so many citizens have taken for granted. In my experience, I have never lived alone in my entire life. I have had family as a form of support in some manner or another since I was born.

I personally suffer from a mild form of claustrophobia (extreme or irrational fear of confined places) when dealing with medical tests such as an MRI. Dealing with social distancing has brought about a new experience of this health issue. And watching social media has paved the way for amazing and creative responses to fulfill our urge to have some form of connectivity. Many of us have taken to video chats connecting to their loved ones, and picked up hobbies they may have neglected. Like many others, I myself, have dove into the kitchen trying to find healthy ways to adapt to the limited resources we have for nutritional benefits. I have a history of eating when upset or bored and social distancing has only intensified

these urges. Many of us are living with family who we normally get along with, but limiting our ability to take a break from one another may have increased a degree of agitation that normally would not be an issue.

Tangerine Jones, a blogger, coined the term “Rage Baking,” and she published a book earlier this year called “Rage Baking: The Transformative Power of Flour, Fury, and Women’s Voices by Kathy Gunst.” This book provided a new and unique way to channel frustrations into a creative and delicious obsession. Baking is an activity for me that does require assistance. Often dealing with heavy pans and a hot oven, I require a family member to assist in the lifting and removal of the pans. These recipes are common and I do enjoy them because it gives us an opportunity to enjoy the fruits of our labor. I wanted to find recipes that allowed me to be in full control, a feeling I was missing desperately. I wanted to make desserts that would not disarm my immune system or enlarge my belly. I found this recipe for a slow cooker berry cobbler that is lightly sweetened with honey and uses gluten free flour and oats that gives you a nice dose of fiber without over doing it with sugar. This recipe also allows you to use frozen fruit so all the ingredients in this recipe have the ability to be stored for long periods of time which is perfect for those that are infrequent shoppers.

This recipe, along with others I will share throughout the rest of the year, won’t fix our entire appetite for independence, but, collectively, we can share the experience of baking. And through that shared experience we will find hidden strengths and talents that can change all of our lives for the better.

Written by Sara Izzo

Slow Cooker Mixed Berry Cobbler

1 ¼ cups rolled oats or Aldi brand GF granola

¾ cups Almond Flour

½ cup sliced almonds or nuts of your choice
(can be left out if using granola with nuts)

½ teaspoon ground cinnamon

½ teaspoon salt (sea salt preferred for health)

6 tablespoons melted and cooled butter or margarine
(vegan swap for coconut oil)

⅓ cup honey

5 cups fresh or frozen mixed berries

1 tablespoon fresh lemon juice

2 teaspoons vanilla extract

½ tablespoon cornstarch
(1 tablespoon if using frozen fruit)

Cooking spray or line bottom of slow cooker with
parchment paper



Directions: Using a 5-6 quart slow cooker spray the nonstick spray or cut out a sheet of parchment paper to line the bottom of your slow cooker. In a large bowl toss oats/granola, almond flour, cinnamon and salt until mixed thoroughly. Pour melted butter/coconut oil and honey over dry ingredients and stir gently until all of the dry ingredients are combined. If using frozen fruit, rinse with warm water to remove ice crystals. They do not have to be completely thawed before use. Make sure to rinse off fresh fruit as well to remove debris or dirt. In another bowl combine rinsed fruit, lemon juice, and vanilla gently tossing and then add cornstarch. ½ tablespoon for fresh fruit, 1 tablespoon if using frozen fruit. Add your fruit mixture to the slow cooker and then sprinkle the oat/granola mixture evenly on top. Cook covered for 1 to 2 hours on high or 2-3 hours on low. The fruit should be bubbly and the top is nice and brown. Using frozen fruit would use the longer time frame of the extra hour. Can be served with vanilla ice cream, whipped cream or dairy free dessert.

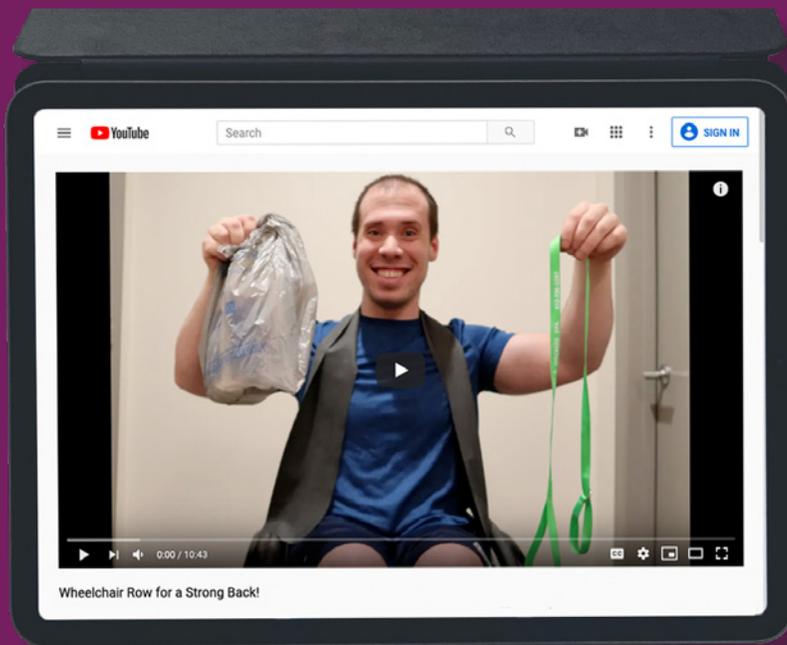
Written by **Sara Izzo**



Important Tip!

Using a clean kitchen towel or paper towel, cover the slow cooker before covering with the lid. This allows your cobbler to crisp as the towel collects moisture while baking.





WHEELCHAIR WORKOUT



The Seated Row

The Row, when done correctly, can have tremendous benefits for your overall health and wellness.

Row for a Strong Back!

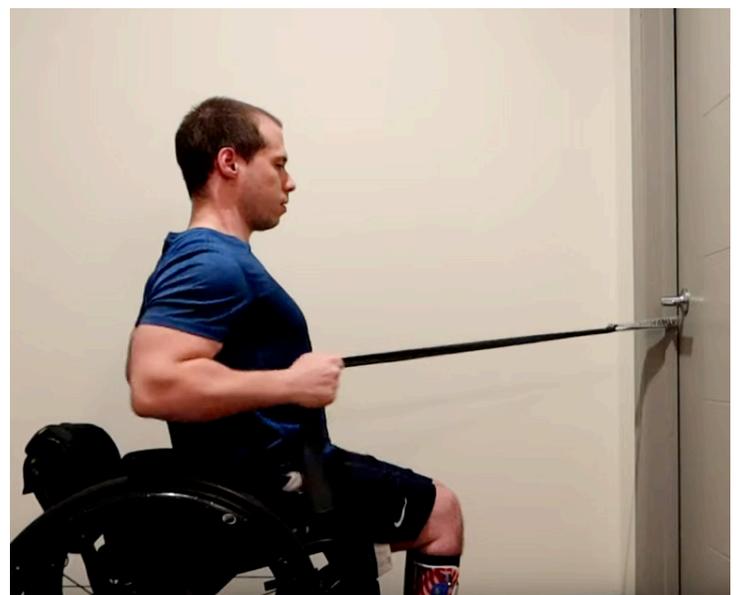
When we think of the most important muscles in our upper body, very often the first muscle group we think of is the shoulders. While the shoulders are an important muscle group to strengthen, it is also very important to pay attention to your back muscles.

Your back is made up of a group of muscles responsible for posture as well as shoulder and neck stability. The Row, when done correctly, can have tremendous benefits for your overall health and wellness.

In the video below, you will see me explaining the proper technique for performing a standard seated row using resistance bands. You will also find a couple of variations involving household items you may have lying around your house. Anything such as a belt, a scarf, a dog leash, or a bag of flour like you see in the video can be used to perform a seated row.

The focus with this movement, as with any movement, is proper form. Moving heavier weight will come with practice and repetitions. Exercising with proper form will allow your muscles to gain the most benefit from each movement you do. Improper form could result in injury, and you will not see the same benefits you could if you used proper form first.

With any bodyweight or resistance band workout, I always like to perform as many reps as possible for up



to 3 or 4 sets with 1-2 minutes rest in between sets. It is important to push yourself as hard as you can in a safe manner in order to strengthen your body and mind in each workout. As always, make sure you hydrate properly for your body and breathe through each exercise! [Click here](#) for a video demonstrating the seated row.

As always, perform the movement in a safe and controlled manner and listen to your body. Follow me on social media [@danmccoyfitness](#) and let me know what videos you want to see next!

Written by **Dan McCoy, ACE-CPT**

Changing Roles

My Stepfather is dying. It really shouldn't be a shock to me. He is 82 and has had lung problems for the past 2 years. He and my Mom live in Connecticut and they have managed on their own, not needing any help, until now.

Within a few short weeks, my Mom will be 79 years old and living alone for the first time, ever.

So, here I am in Western Pennsylvania trying to figure out how I am going to help my Mom. My Mom sees herself as my caretaker. Whether I am 5 years old or nearly 55 years old, living next door or 485 miles away, matters not. I am her baby. As a parent, I understand this. I see my girls much the same way. It is different for my Mom though. She has been told since my birth that she would outlive me and need to care for me. That message has stayed with her no matter what has occurred in my life. It's a big part of what makes it difficult for her to accept my help when its offered.

Aside from convincing my Mom to allow me to help her, there are some other very practical issues for me to consider when aging with Spina Bifida.

I should have had a conversation years ago about her future. Although, I am a retired home healthcare administrator, when it comes to my Mom and Stepfather, I find that I am no different from any other adult child. It never occurred to me that they would need my help so quickly. I guess none of us really see our parents as growing older. They are our parents, always the same in our mind's eye until reality hits you hard. Spina Bifida does put a different twist to this conversation. We have always talked about my needs as I grew older, never theirs. We have even talked about what would happen if I should suddenly die. It's somehow easier for me to talk about those realities about myself, not them. I suppose the constant barrage of what my Mom was told about my longevity made its mark on me as well.

Aside from convincing my Mom to allow me to help her, there are some other very practical issues for me to consider when aging with Spina Bifida. The reality is that as much as I may want to care for her and do everything



that is needed, my disability may not allow me to do so. I need to look at my own needs, her needs, and how both can be met without either of us having unmet needs. I now have to assume the "parental" role in our relationship. This can be challenging for any adult child, but I do think that my disability adds to that challenge.

So, what to do? First is having the conversation that I should have had when my Mom retired. We need to talk about her health, her abilities to perform her activities of daily living, her abilities to continue to grocery shop, clean the house, take care of the yard, drive, and be able to meet her financial obligations. Then we need to look at resources. What is available in her area to help her when I am back in Pennsylvania or when I am unable to provide assistance? Are there people who we can rely on to be her support system? Or do we need to find either a state-funded or privately funded way to get her needs met? Do we need to speak to an eldercare lawyer to ensure that her needs will continue to be met no matter what the future may bring? We need to assess the situation and make a plan much as she did for me when I was born.

We are so blessed to be living in an age of technology. The one thing that I do not have to worry about is being in touch with my Mom. We are upgrading her 20-year-old computer and her phone. Being able to Face-time rather than just talk on the phone will give me a better insight into what is happening in her life that she may not think is important for me to know. It's going to be teaching her how to use all this that will be challenging. I think I might have my kids do that.

For now, I am packing my bags. I am reassuring my Mom and Stepfather that I can make the journey to Connecticut and help care for him. I am promising both them and me that I will not do anything that will harm my health and wellbeing. We will say goodbye, grieve, and mourn. But I will have that long heavy conversation before I return home.

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

Mental Health Minute: The Importance of Self-Care and Self-Compassion

Children’s television icon and Pittsburgh native, Mister Fred Rogers once said, “Some days doing ‘the best we can’ may still fall short of what we would like to be able to do, but life isn’t perfect on any front, and doing what we can with what we have is the most we should expect of ourselves or anyone else.”

According to the National Institute on Mental Health, “Nearly one in five adults in the United States live with a mental illness. Mental illnesses include many different conditions that vary in degree of severity, ranging from mild to moderate to severe (2017).” Regardless of the type of mental health diagnosis or the level of severity of it, having a mental health diagnosis is hard for anyone to cope and manage day in and day out. At times it may seem more challenging to cope and manage the symptoms of your mental illness, but it is not impossible, especially if you put some work into finding some healthy coping and management strategies that work for you. We do still have some control over how we choose to respond to the triggers or stressors that seek to exacerbate your mental health symptoms and that, my friend, is where your superpower exists.

First and foremost, we must remember that how we choose to manage and cope with mental illness is up to each of us to individually decide for ourselves, but that is not to say that having a bridge of support from others in our lives isn’t just as important. In fact, having a supportive network of professionals, family, and friends who are there to support you as you make these decisions is one of the keys to being successful in coping and managing mental illness long term. This is not a case where one size fits all, and that is okay. Another key component to taking care of your mental health is to develop some self-care strategies to help you cope and manage the ebb and flow of mental illness. These self-care strategies can be simple and adaptable.

For instance, taking five to ten minutes out of each day to do something small for yourself like practicing some deep breathing exercises, taking a walk or roll, or doing yoga. If you are anything like me, you take the time to allow yourself to indulge in listening to some upbeat music, have a dance party even if you are alone, or eat a piece of chocolate or your favorite food in reasonable moderation, of course. You can also make self-care a family affair by sitting down all together to read aloud a favorite storybook, coloring pictures in coloring books, or going on a hike together to take in what the great outdoors has to offer.

We also must allow ourselves to feel our emotions and find healthful ways to express ourselves without feeling guilty or ashamed. We can do this not only by practicing daily self-care but also practicing daily self-compassion. Self-Compassion is defined as showing oneself kindness, recognizing that you are a human being who is allowed to make mistakes, express your own thoughts and feelings, and most importantly, allowed to forgive yourself for your mistakes or missteps and to start over and try again tomorrow. Self-Compassion also means actively practicing being in the present moment and being kind and gentle with ourselves. Paying mindful attention to our five senses and taking the opportunity to recognize our surroundings, reminding ourselves of who in your life truly loves and cares about you, and who always reminds you that we are not alone in this journey.

Nevertheless, if you are struggling to stay afloat, feeling overwhelmed, stressed, or depressed please reach out to a trusted loved one, a friend, or a trained mental health professional or your physician to ask for help because you are valuable, your and experiences matter, and that it is perfectly okay to ask for help because we all need another person’s helping hand sometimes to lift ourselves up.

Written by Libby Powers





Online Book Clubs Create a Social Network and Encourage Good Habits

Ever thought about joining a book club? Were you reluctant to commit time to keep up with the readings or attend the meetings? Well, what better time than the fall to join an online book club! I have recently been making an effort to get back in the habit of reading daily. I personally notice that when I practice setting time aside during my day to read a book, I actually am more productive. And it is not just me, there are many studies quoting the benefits of reading. A study, published in *BMJ Open*, found that social group participation in clubs such as book clubs was related to living longer and a better quality of life.

In addition to encouraging the healthy habit of reading, joining a book club, or any club really, connects you with a social network. You can make friends with other readers, share your thoughts about what you are reading and you don't even have to leave your house to join one. Audio-book versions of most books are available too if you prefer to listen rather than read. *Techradar.com* lists the five best audiobook sites of 2020 as: Audible, Google Audiobook, Librivox, Kobo Audiobooks, and Downpour.

If I've convinced you to give it a shot, Goodreads.com is good place to start looking for the right book club for you. Directions for navigating their website to review different book club groups are [here](#). Goodreads is also available as an app for your smartphone.

Written by **Darcie Ilg PA-C**

Guidelines for the Care of People with Spina Bifida: What You Need to Know about Transition

Transition is the process of preparing for and moving from pediatric to adult care. The process should be gradual, much like the change in seasons. You should start preparing for transition when you are a teenager, and you should continue to work on your independence even after you move your care to the adult clinic. There are several things you can do help the process of transition:

- Talk to your healthcare providers about which activities you can do independently and which you will still need help with. These activities might include transferring to and from your wheelchair, cathing, bowel programs, dressing, or supplies. Discuss ways that you can become independent in doing these activities on your own.
- Make a backup plan for who would help you if the people who typically help you with these activities get sick.
- Make sure your backup plan address not only your daily activities but also finances, insurance, housing, and transportation.
- Ask for a referral to vocational rehabilitation services if you have educational or job goals.
- Ask for a referral for a driving program if you will need to learn to drive a vehicle.
- Make sure that you have a medical power of attorney, or someone to assist with medical decision-making.
- Keep a medical summary on hand that includes past medical and surgical history, current care plans, medications, allergies, vaccines, and current providers. Consider using the notes app in your smartphone. The UPMC Adult Spina Bifida Clinic also has special transition binders available if you want to write these down on paper.
- If you want more information or tools to help you with transition, we recommend the Got Transition website: www.gottransition.org

Written by **Brad Dicianno, MD**

Upcoming Events at SBAWP

Some of the upcoming events for adults at the Spina Bifida Association of Western PA (SBAWP) include:

2020 Shoot for SBAWP at Seven Springs

Wednesday, September 9, 2020

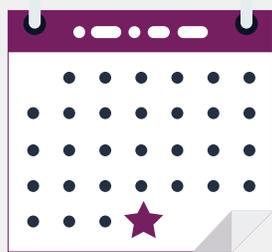
Noll-Spratt Golf Scramble at Beaver Valley Golf Club

Saturday, September 26, 2020

Girlfriend's for Good Purse Bash at Saint Ferdinand's Oldenski Hall

Saturday, November 14, 2020

Dates are subject to change. For more information, please visit the website at www.sbawp.org.



Patient Assistance Fund Program

Patient Assistance Funds are available for Pennsylvania residents with Spina Bifida who qualify. To determine your eligibility, you will need to complete and submit an Income Attestation form, which we will provide annually and upon request. If you are approved to use the Patient Assistance Funds, we can reimburse you for purchases and expenses related to your health and well-being. After approval, you can submit receipts for reimbursement via mail:

Darcie Ilg, PA-C

UPMC Mercy, Dept of Phys Med and Rehab

1400 Locust St, suite G103

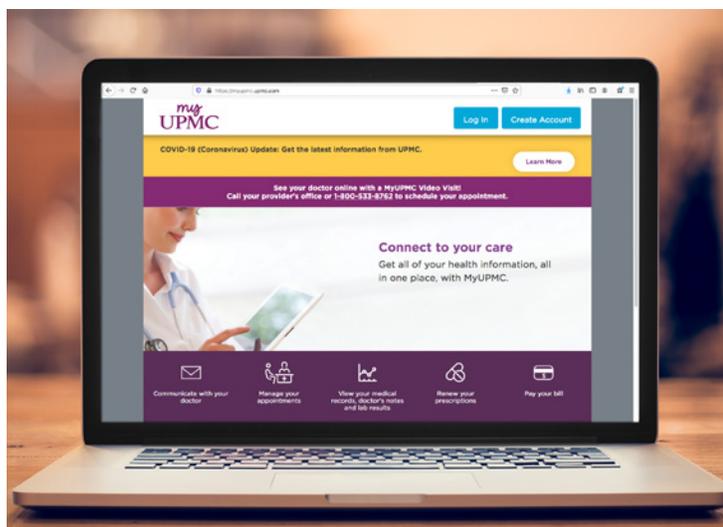
Pittsburgh, PA 15219

Message Darcie Ilg via MyUPMC or call 412-232-8909 for more details and any questions.

Property Tax & Rent Rebate Program



Rebates are available for individuals with disabilities, widows, widowers, and older adults who rent or own property in PA. Some income limits apply. Please see the link [here](#) for details. The maximum standard rebate is \$650, but supplemental rebates for qualifying homeowners can boost rebates to \$975.



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 and create an account. If you have any questions, please ask our front desk or give us a call at 412-232-8901.



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: UPMC.com/SpinaBifida