

Staying Active and Social in the Times of COVID-19 and Self-Quarantine

Children's television icon and Pittsburgh native, Mister Rogers once said, "If only you could sense how important you are to the lives of those you meet; how important you can be to people you may never even dream of. There is something of yourself that you leave at every meeting with another person."

Let's be real for a minute; during these times of unimaginable stress and overwhelming concern for your own health and well-being, as well as the health and well-being of those around you because of COVID-19, it can be extremely challenging to learn and adjust to doing your everyday activities differently. This includes but is certainly not limited to your social activities and interpersonal interactions with fellow peers, friends, and family members. Even if it is only temporary. Add this concept of physical distancing into the mix, and it creates the perfect storm.



Over the last several weeks, I have found ways to stay connected with friends, work colleagues, and family members through the use of various technologies, such as email, text messaging, and picking up the phone and calling someone. If you are more of an internet savvy individual, you can also connect with others using social media websites such as Facebook, Twitter, Instagram, etc. While we are all experiencing this temporary new

normal in our own individual ways, there are still plenty of similarities between all of us, including feeling overwhelmed, lonely, or fear of the many unknowns. However, in this day and age with infinite technological advancements available to us at the touch or click of a button, there are simple and fun ways to curb the feelings of loneliness, physical and social isolation, and boredom. Some ideas include downloading free virtual games on your tablet, mobile phone, or computer to connect and play with your friends, or virtual books for coloring, drawing, and painting if you are the artistic type. Also some art and history museums have created virtual tours of their artifacts and paintings. Some other ideas include going for a walk to stretch your legs, going for a roll outside to get some fresh air, or inviting friends to join you in a virtual watch party where you can all watch the same movie or television show together while never leaving the comfort of your own home. If you are interested in learning a new skill or picking up a new hobby, but do not know where or how to start, check out how to videos on YouTube or the world wide web to get yourself started.

Lastly, it is important to remember that while we might be physically separated from others right now, we are all in this together, even though we may be physically distant from one another for the time being. See sidebar for links to some of the virtual social activities mentioned above.

Written by **Libby Powers, MS**

COVID-19

In this newsletter, we are focusing on resources to support you during the COVID-19 pandemic. The Spina Bifida Association has prepared information about the virus that is specific for people living with Spina Bifida. Please see this [link](#) for updated information.

Virtual Social Activities

[Virtual Netflix Party](#)

[Stream and Download from Carnegie Library of Pittsburgh](#)

[Print Out Crayola Coloring Pages](#)
Printer Needed

[Virtual Tour of National Museum of Natural History](#)

[The National Aquarium](#)

[The Google Art Project](#)

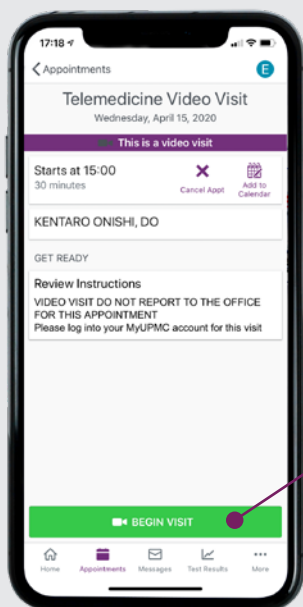
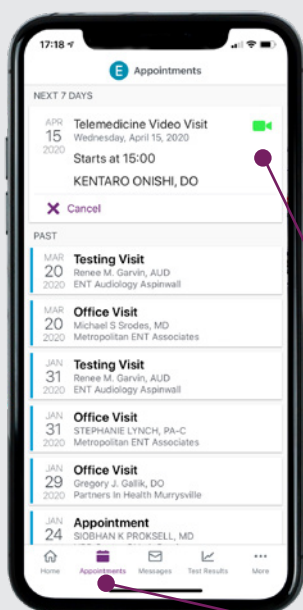


See your Provider from the Comfort and Safety of your Own Home

MyUPMC Video Visits: With recent concern for COVID-19 spread, a transition to virtual healthcare has been emphasized. Appointments with the Spina Bifida Clinic, or with your other healthcare providers, can take place in the safety and comfort of your own home. During the pandemic, video visits are available for new or established patients, and also to patients living in any state. After the pandemic, video visits will be available only to established patients who are Pennsylvania residents.

You access Video Visits via the MyUPMC app on your smart phone or tablet. You will use the camera on you device to interact with your provider. In addition to having a smart phone or tablet, you will need to have a MyUPMC account and the MyUPMC app downloaded on your device in order to use MyUPMC Video Visits.

You will first need to schedule a Video Visit by calling our office or sending us a message on the portal. To start the visit, which you can do anytime between the scheduled Video Visit time and 30 minutes prior, open the MyUPMC app on your tablet or smartphone. Then log in using your username and password.



- Once logged in, click on the “appointments” tab on the bottom of the screen.
- Once you are on the appointments screen, you will be able to see the scheduled appointment with a green video icon to the right. Click on the green video camera icon which will take you to the next screen.
- At the bottom of the next screen, you will see a green “Begin Visit” button. Clicking on this will begin your visit. You will see your face on your screen at this time. You may have to wait until the provider starts the visit from their end. Once the provider joins the visit, you will be able to see them on the screen and the visit will begin.

If you wish to schedule a visit over the phone, without using the app or video, simply call us to schedule.

Written by **Darcie Ilg, PA-C**



Seasonal Eating

Summer is here! Whether you believe it or not, it has arrived!!! With all of the weather changes and news about our environment, it can seem like an overwhelming issue too big for us to make a difference. Honestly, I avoid the news quite often because it can be such a source for agitating anxiety. Recently, I have gained a different perspective on some of those issues. One of the things I've noticed, talking to other patients like myself who have spina bifida, is that most of us have a deep compassion for animals, the environment, and the people around us. We have a deep understanding of empathy and a desire to make a difference. Oftentimes, this increased instinct in our population is overlooked because of a lack of resources. A lack of resources is a definite obstacle that needs to be constantly evaluated, but I think we may have an opportunity to be creative in our own endeavors. Small changes in our everyday life, over time, create new habits that in turn benefit those around us. Eating seasonally is one of those changes.

Eating seasonally has such a positive impact that affects so many people. It would be a shame to see it as just a trend instead of a sustainable way of life. Seasonal eating means eating foods that are available at their peak harvesting time, based off your location. Rest and digest is a term to research. It helps explain the health benefits of eating seasonally. For example, eating high sugar fruits in the hot summers are friendlier to your body versus high sugars in the winter when we often see the extra weight accumulate in the gut. Fall and winter root vegetables have extra fiber to help slow your digestion and sugar absorption, aiding in a healthy gut. Fruits and vegetables aren't the only thing to consider seasonally. Recently, I inquired about my annual spring leg of lamb for this past Easter and was saddened to find out the local farms did not produce a livestock that was bountiful enough for sale. It was a tradition for my family that's gone on as long as 10 years. *However, char-fired Greek trout was a lovely new substitute and much easier on my wallet.* When purchasing locally, ensuring healthy livestock becomes easier. I find supporting local farms and businesses also gives me the best deals for seasonal meats and produce. When not shopping seasonally, all our meat and produce must be imported which increases risk for exposure. Sometimes, we find ourselves overwhelmed with problems in our lives. I believe we can shift our perspective and with a little bit of creativity; we can focus on making little changes in our own lives that can ultimately benefit everyone around us.

“Problems that remain persistently unsolvable should always be suspected as questions asked in the wrong way.”

Alan Watts

These aren't ideas meant to change your entire shopping experience, but small changes that you may find increase your own cooking creativity. Below is a simple grilled vegan/vegetarian sandwich that I just adore! It uses seasonally-jarred roasted red peppers with fresh rosemary from the garden. I, personally, love to pair it with a freshly stewed plum tomato soup and fresh summer basil. It does, however, go perfectly with a summer salad. The sandwich can easily be prepared with a griddle and the soup can be made with a blender and slow cooker.

Written by **Sara Izzo**

Ingredients to Make Grilled Roasted Red Pepper and Garlic Hummus Sandwich

- 2 slices bread of choice
(Sourdough bread personal favorite)
- 1 tbsp. butter/margarine
- ½ Roasted Red Pepper
- 2 tbsp. Garlic Hummus *(your preference flavor)*
- Goat cheese/any cheese *(optional)*
- 1 tsp. finely sheared rosemary or dried thyme
- Pepper and garlic powder



Directions: Butter 2 slices of bread on one side. Sprinkle seasoning and herbs on both buttered sides of the bread and spread butter knife over seasoning, securing it to the butter. Spread the hummus on one unbuttered side. Dry the roasted red pepper with a paper towel and slice in strips with the butter knife. Carefully place the peppers over the hummus. Place cheese (if using) now on top of the peppers. Take your sandwich and carefully put it together placing it on your griddle or pan like a regular grilled cheese sandwich, grill to desired doneness.

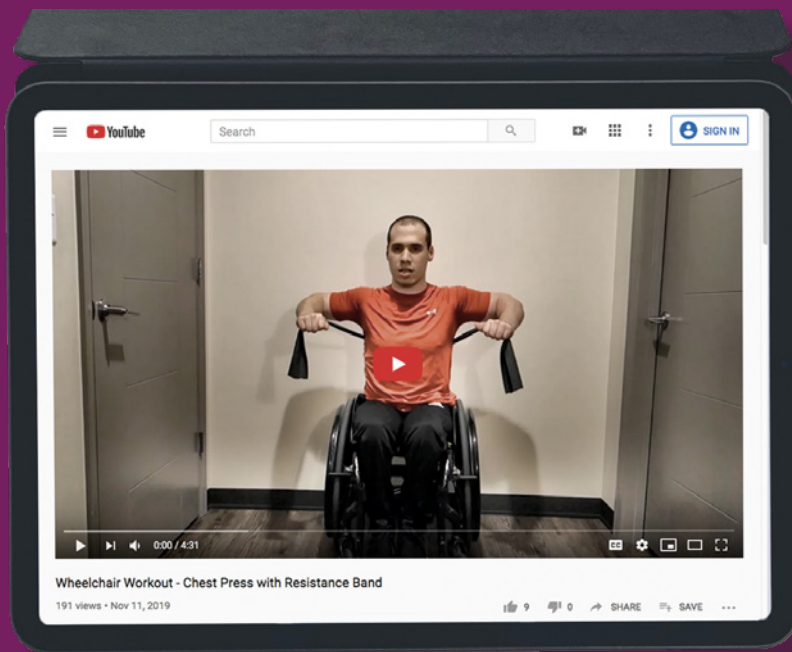
Ingredients to Make Slow Cooker Basil Tomato Soup

Serving size: 4

- 1 can whole peeled tomatoes 28oz
(do not drain)
- 1 carrot (4-5 baby carrots)
- 1 celery stalk
- ½ diced white onion
- 2 garlic cloves (1 tbsp. minced garlic)
- 1 roasted red pepper *(optional but very tasty)*
- 2 cups vegetable or chicken broth
- ½ cup milk *(Almond, Oat or Soy my preference)*
- Fresh Basil 8 leaves, extra for garnish
- ½ tsp black pepper
- ½ tsp. dried oregano
- 1 tsp garlic powder, onion powder each
- Sea salt and Crushed Red Pepper Flakes to taste.

Directions: Using kitchen shears for safety, cut your carrot and celery into 2 cm thick chunks (tip of pinky for size). Into the blender, add your onion, garlic, celery, and carrot. Add a small amount of the broth to the blender to help with smoothness. Blend until vegetables are like a paste. After unplugging your blender, scrape veggie mix with a spatula and pour mix in your unplugged slow cooker. Add half the can of whole tomatoes and roasted pepper (if using) into the same blender, blend until smooth and add to your slow cooker. If you want a velvety smooth tomato soup, finish the rest of the can in the blender as the last batch but if you want a slight texture to your soup, crush the remaining tomatoes with your hand directly into your slow cooker. Tear 8 fresh basil leaves with your hands and add to your soup along with the rest of your dry seasonings. Add the rest of your broth and mix well. Set slow cooker on low for 4 hours. After 4 hours add milk and cook for an additional hour. Finish the soup with extra basil and parmesan cheese if desired.

Written by **Sara Izzo**



WHEELCHAIR WORKOUT

Chest Press with Resistance Band

This SIMPLE and EFFECTIVE movement will improve the power you put into your wheelchair push the more you do it.

Building Stronger Wheelchair Propulsion

One of the most important muscle groups you can develop when propelling your wheelchair is your chest muscles. These are often very strong muscles in wheelchair users due to the amount of use they endure on a daily basis. Even so, what if there was a way to make your wheelchair propulsion even STRONGER? The “chest press,” can be done as the resistance band chest press, dumbbell chest press, machine chest press, and finally the barbell chest press.

The movement we are talking about in this article is the first in a ladder of movements: the resistance band chest press. This **SIMPLE** and **EFFECTIVE** movement will improve the power you put into your wheelchair push the more you do it. While the chest press is a “chest focused” movement, it involves two other muscle groups, the shoulders as well as the triceps. This makes it a “compound” movement. To start, hold your resistance band in both hands between your thumb and pointer finger. Bring the resistance band around your back and as high into your arm pits as you can. This will allow the resistance band to be in the best possible position to get the most muscle activation from the movement. Next you want to bring your elbows at a 90° angle so they are half way between shoulder level and your sides.

From here, all you do is push your fists straight out in front of you until your arms are fully locked out. Once you reach full lockout, slowly control your arms back to your sides so your elbows are bent at 90° again, making sure to keep your arms halfway between your sides and shoulder level. Repeat this motion as many times as you can (up to 20 or 30 reps) for 3 sets, resting 2-3 minutes between sets. If you feel any pinching, popping, pulling or sharp pain in your muscles at any point, stop immediately. Be sure to use ice, drink fluids, (ideally water), and rest the muscle that hurts. Muscle soreness or throbbing in the muscle can be normal as this can be a sign that your muscles simply aren’t used to that movement. [Click here](#) for a video demonstration of this movement: **Wheelchair Workout — Chest Press with Resistance Band**

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

Make a Colorful Plate: Tips to Add Fruits and Vegetables to Your Day

As more items become in-season, summer is a great time to try out new fruits and vegetables or rediscover old favorites. Fruits and vegetables provide fiber, which helps to keep us feeling full and also promotes regular bowel movements. They also contain vitamins and minerals that help keep our bodies functioning. It is important to include all food groups throughout the day (grains, protein, dairy, fruits, and vegetables) when building healthy meals. As a part of building this healthy plate, it is recommended to fill **half your plate with fruits and vegetables**. Variety is important too – a rainbow of colorful fruits and vegetables helps to provide a wide range of nutrients. So, the more color on your plate, the better!



Fresh, Frozen, or Canned?

Fresh fruits and vegetables are a great choice, but they are not the only option for adding produce into your day. Frozen, canned, and dried fruits and vegetables can be healthful choices. Some frozen produce is frozen at the peak of ripeness, which helps preserve nutrients. Preparation time is also decreased with frozen produce, with less time required for peeling, chopping, and cooking. But what about canned produce? Canned fruits and vegetables can receive a bad reputation. However, they are still nutritious and offer a simple and budget-friendly way to incorporate fruits and vegetables into your day. A well-stocked pantry helps you to have options on hand that can be transformed into quick, easy, but healthy meals.



Choosing frozen and canned produce:

- Select plain frozen fruits without additional sauces or added sugar.
- Choose plain frozen vegetables without added sauces, creams, or gravies.
- Select canned fruits in 100% juice or in water, instead of in heavy syrup.
- Pick canned vegetables, beans, and tomatoes that are low sodium (less than 140mg sodium per serving) or no-salt-added. Dried beans are also a good option.
- If you already have canned vegetables/beans that are not low sodium, drain and rinse them in a colander under running water. Rinsing helps to reduce the sodium content.



Food Safety Tips

Make sure to follow good food safety practices for fruits, vegetables, and all foods!

- Wash produce under cool running water, including produce with skin that is not eaten. For firm-skinned produce, scrub with a clean vegetable brush. Soap is not necessary.
- Clean the lids of canned goods before opening.
- Keep raw meat, poultry, and seafood separate from ready-to-eat items like fruits and vegetables to avoid cross-contamination. This includes storing separately in the refrigerator and using separate cutting boards and utensils.
- If you're taking your meals to go, make sure that your refrigerated food stays cold in the summer heat! Place your cold items in a cooler or lunch box with food-grade ice packs. To stay safe, perishable food should remain below 40 degrees F.
- Perishable foods, including leftovers, should not sit out for longer than 2 hours of preparing or purchasing (1 hour if the temperature outside is above 90 degrees F).
- Safe food storage tips:
 - For canned (shelf-stable) items, store in a cool, dry, clean pantry/cabinet away from heat producing appliances (like your stove).
 - Never use canned foods from cans that are cracked, leaking, dented, or bulging.
 - Pay attention to expiration dates on foods. When in doubt, throw it out!

For additional food safety information, you can visit: [this food safety link](#).

Summary

Fruits and vegetables help brighten our plates with color, variety, and key nutrients to support our health. Whether fresh, dried, frozen, or canned, making half your plate fruits and vegetables is helpful in building a healthy plate. Whichever fruits and vegetables you choose to try, keep variety in mind – fruits and vegetables that are full of color not only look great on your plate, but they're good for you too!

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

Ways to work colorful fruits and vegetables into your day:

- Try adding canned, fresh, or frozen fruit to yogurt, oatmeal, or cold cereal at breakfast. Or, try whole wheat toast and peanut butter topped with berries or apple slices.
- Add canned beans, tomatoes, and/or vegetables to pasta, rice, or casserole dishes.
- Microwavable, steam-in-bag frozen vegetables are a quick way to add a vegetable side dish to your meals or can be mixed into your favorite dishes for a healthy add-in.
- Need a flavor boost? Utilize herbs, spices, lemon juice, olive oil, or vinegar to add flavor to plain vegetables.
- Add shredded or chopped vegetables into lasagnas, pasta sauce, or meatloaf.
- Make a smoothie with frozen or fresh fruit. Add 1% or skim milk, nonfat yogurt, or peanut butter for a protein source to help keep you full.
- Try hummus as a spread on your usual sandwich or wrap.
- If you're dining out, ask for extra vegetable toppings on your sandwich, wrap, or pizza. You can also swap out a typical side dish for a salad or a side of cooked vegetables.
- Right after getting your groceries, immediately prepare and cut fruits and vegetables to have on hand for snacks, and store in individual containers in the fridge. You're more likely to reach for these options if they are already prepared.
- Keep it visible! Keep fruits and vegetables in the front of your fridge and in easy to see places of your pantry to help encourage you to reach for these items.
- Challenge yourself to try one new fruit or vegetable the next time you go grocery shopping, or to add one extra vegetable serving to your lunch or dinner.

For more nutrition information, you can visit: www.choosemyplate.gov or www.eatright.org

Teenagers!

Say the word teenager and what comes to mind? An adolescent saying, “I know, Mom” in a tone that makes it sound more like “OK, Boomer!” It sometimes takes all your effort to recall the adorable kid that emerging young adult once was. And then you remember that this is their job during this stage in life. It is their mission to stretch their wings, find out who they are outside of the family, and sometimes be exasperating in the process. Children born with Spina Bifida are no different. They too need to find their way to adulthood while coping with being different from the majority of their peers. The destination is the same but the journey can follow a different path.

One hallmark of being a teen is conformity. No one wants to be the one who is seen as different or odd. Having Spina Bifida adds to this challenge. So many aspects of our lives are dictated by our disability. In some very basic ways, we do things differently from our peers and some things are more noticeable than others. Sometimes the acceptance of our support systems and instilling self-confidence simply isn't enough. As a teen, I had to carry my catheter supplies with me. I did not want to be the only one of my friends dragging a purse around with me everywhere I went. For a while, I simply refused to take the supplies with me. I quickly found that didn't work out as I had planned. I am not sure which was worse, having an accident in front of my friends or telling my mom that she was right. I was fortunate that my mom understood how I felt and helped me find an answer. I needed to have my feelings validated and I needed guidance to find a solution that did not harm me. By communicating not lecturing, being open and listening to me, my mom allowed me to look at the problem and find my own solution. In short, she taught me how to adapt to the situation. In case you are wondering, I used a sterilized cigar tube to carry my catheter in my sock or pocket instead of a purse. I also had betadine soaked cotton balls in a plastic baggy. I will admit that a purse is easier; although, I still don't want to tell my mom that, some 40 years later.

The other thing that goes along with adolescence is rebellion. Aside from wanting to do things differently from the last generation, it comes down to a need for control over their lives. In kids with spina bifida, much of their lives they cannot control. They can't change how spina bifida affects them. But they can control how they respond to those effects. You see teens and young adults refusing to cath, take meds, or even perform self-care. The tricky part is to see if some of this might be problems with executive function or maybe even a sign of depression. Again, open communication, flexibility, and working with the child to find a mutually agreeable solution might be what's needed. In the example above I rebelled by refusing to catheterize myself. My mother allowed me to learn that there were consequences to my actions. Wetting myself in front of friends did teach me that not cathing was not an option. By allowing me to vent and guiding me I found a way that I could do as I wished safely without harming myself. In the end, you will be teaching them how to make decisions that allow them to live their lives as they wish while still caring for themselves in the best possible way.

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



One hallmark of being a teen is conformity. No one wants to be the one who is seen as different or odd. Having Spina Bifida adds to this challenge.

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

Women with spina bifida who are planning a pregnancy often ask about the risk of having a child who also has spina bifida. Women who have already had a child with spina bifida also often ask the same question. While conditions affecting the development of the neural tube (like spina bifida) are not completely understood, folic acid has been recommended as a way to reduce the risk.



Folic acid can help diminish the chance of a pregnancy being affected by a neural tube defect like spina bifida, but it is not entirely preventative. When planning a pregnancy, women with spina bifida or women without spina bifida who have already had a child with spina bifida should consume 4 milligrams (4000 micrograms) of folic acid beginning at least one month (but preferably 3 months)

before they start trying to get pregnant and continuing through the first three months of pregnancy. This dose is ten times the dose recommended for women who's lives are unaffected by Spina Bifida.

Written by **Brad Dicianno, MD**

Melanie Lynn Vaughn Memorial Scholarship

A new scholarship fund has been established in memory of Melanie Lynn Vaughn. The scholarship fund will provide \$500 scholarships to students planning on studying special education or a related field. Those interested in contributing should send donations to the Melanie Lynn Vaughn Memorial Scholarship c/o Curwensville Area High School, Beech Street, Curwensville, PA 16833. All donations are tax-deductible.

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:

[Youth and Teen Summer Camp](#)

June 28 – July 3, 2020

[Adult Summer Camp](#)

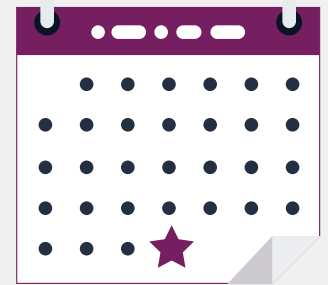
July 5 – 11, 2020

[SBAWP Jergels JamFest](#)

August 2, 2020

Dates are subject to change.

For more information, please visit the website at www.sbawp.org.



Amazon Smile

Did you know that AmazonSmile is a simple way for you to support your favorite charitable organization every time you shop? When you shop at smile.amazon.com, Amazon will donate 0.5% of your eligible purchases to the charitable organization of your choice, and the best part is that **there is NO cost to you**. To shop at AmazonSmile simply go to smile.amazon.com from the web browser on your computer or mobile device. You can choose from over one million organizations to support. Spina Bifida Association of Western Pennsylvania and Spina Bifida Association of America are two organizations you may want to consider supporting. Just remember to log into smile.amazon.com with your Amazon account each time you shop.

Written by **Brad Dicianno, MD**





Tools for Techies and Gadget Lovers

Making your Home Smarter – Home automation with smart technology can make everyday tasks around the home easier. There are many smart product categories allowing one to use their voice to control things from light and temperature to locks and security in the home, eliminating the need to transfer from bed and go across the room to flip a switch or close the blinds.

There are several brands of Bluetooth speakers that enable you to operate house-hold devices with your voice. Some of the most popular devices include *Amazon Echo*, *Sonos One* and *Google Home* or *Nest*. They range in price from around \$70.00 to \$180.00. If you are looking for an inexpensive way to turn regular, non-connected home appliances into smart home devices, consider the *Samsung SmartThings Wifi Smart Plug*. At \$17.99, it's one of the more affordable smart plugs. Its functions include power usage reports, voice control, and flexible scheduling. It also will integrate with other smart devices if you pair it with a *SmartThings hub*.

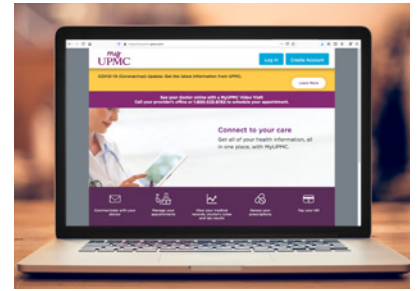
Smart speakers and other smart devices can be bought online but it is recommended that you investigate these options at a retail store where you can try them out and ask questions about setup and compatibility. You will want to make sure that your devices will work together and perform the tasks you are hoping to automate.

Google Nest partnered with the Reeve Foundation to provide up to 100,000 free Google Home Minis to people with disabilities. To see if you are eligible, go to this [link](#) for more details.

Written by **Darcie Ilg, PA-C**

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.



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 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