

Summer Garden

I remember my grandmother's gardens. In the summer it had peonies, zinnia, and roses. The other garden grew green beans, pumpkins, cucumbers, and tomatoes. The riot of color in the summer was something to see. From mid-July to September, we had fresh vegetables for nearly every meal.

I never thought that I would be able to be a gardener like my grandma. I couldn't imagine how to do it since my mobility is limited. One day I realized that my garden would not look exactly like my grandma's, but it would be just as enjoyable. I want to share with you how I was able to make a garden that works for me and my ability.

I started with one large wooden box that looks like a horse trough on stilts. It is 4 ft long and 2 ft wide. It is about 3 ft deep. It stands about 3 feet high.

(continued on next page)



Believing in Tomorrow

The iconic British actress and humanitarian, Audrey Hepburn, once said, ***“To plant a garden is to believe in tomorrow.”*** She had a love for flowers, fresh vegetables, and flowering trees and had a garden wherever she lived. She learned this skill and passion from her mother who taught her that if something is important to you, you should devote time and care to it. Hepburn also cared deeply about children, and some people say that this quote may also reflect her ideas that investing in the health and education of children will allow them to thrive. Hepburn's quote can serve as an inspiration to us all to invest in ourselves and what is important to us. The time we spend today on our physical and mental health will reward us in the seasons to come.

Written by Brad Dicianno, MD



I now have four boxes. I can reach my plants and care for them from my wheelchair. I also have an old tub transfer chair. It is perfect for sitting in the middle of the troughs so I can work on all of them at once. All over my deck are different-sized pots filled with every kind of vegetable and herb you can imagine. I have even grown potatoes and corn!



One day I realized that my garden would not look exactly like my grandma's, but it would be just as enjoyable. I want to share with you how I was able to make a garden that works for me and my ability.

I love flowers. I have marigolds growing with my veggies. They look pretty and keep bugs away. The rest of my deck has hanging planters with geraniums, petunias, and anything else I can think of. It's not fancy but it is bright and alive with color. It reminds me of my grandmother.

Planting, weeding, and watering are hard work. I stretch and move while I care for my plants. Gardening is a great way to exercise. It's an excellent way to clear your mind and relieve stress. It gets me outside and into the fresh air. Plus, I get yummy veggies. The only downside is that there are so many things I want to plant and not enough room!

Once you let go about how things, like gardening, are usually done you can find the way that works for you. Adapt your world to suit you.

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



Research and Design Experience for Students with Spina Bifida



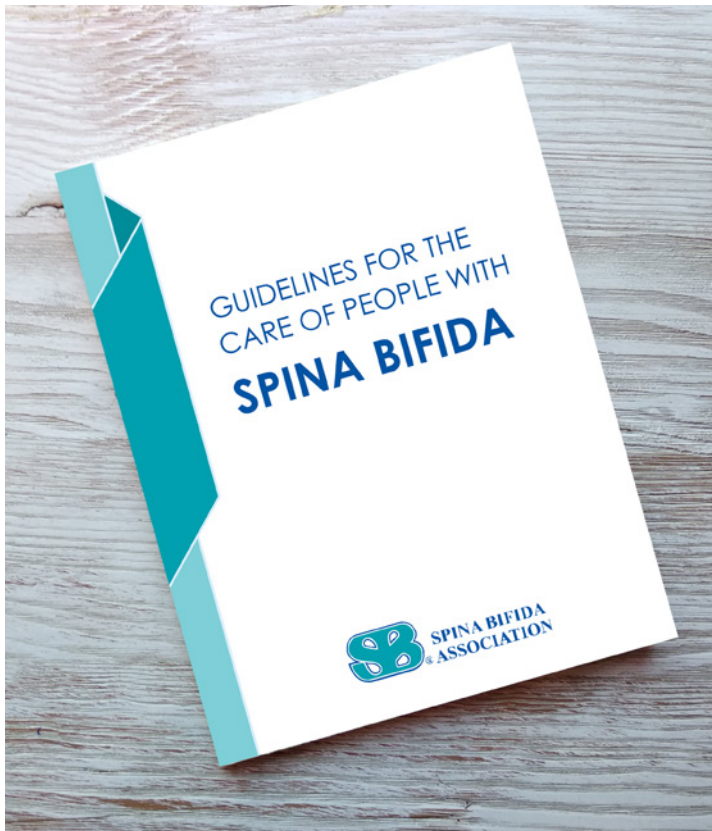
The Human Engineering Research Laboratories (HERL) is pleased to announce the “Research and Design Experience for Undergraduates, Graduates and recent Graduates with Spinal Cord Injury” internship program. Individuals with Spinal Cord Injury (SCI) (including Spina Bifida) have been a historically underrepresented population in science, technology, engineering, and math (STEM) fields of study and careers. This program will increase the likelihood of individuals with SCI continuing to graduate school and—ultimately—becoming researchers, mentors, clinicians, or professors. The program will introduce - and fully immerse - students in STEM opportunities and allow for interaction with faculty and graduate mentors who themselves are individuals with SCI.

The primary objective is to provide students with SCI an exemplary mentoring and resourceful environment that highlights opportunities in STEM. Participants will transition from dependent to independent thinkers, develop a sense of excitement for the opportunities for them in STEM studies and careers through full immersion in on-going research, and establish a foundation for becoming mentors to other students with SCI. Students

will work on research projects that identify and address problems critical to achieving and maintaining the highest possible level of function in areas related to mobility, communications, sensory (e.g., hearing, tactile, vision), and cognition, as well as activities associated with employment, independent living, and education. (See [HERL’s Research Projects page](#) for more information.)

The program is open to individuals with SCI, including Spina Bifida, with special consideration given to students who are currently/formerly supported by the Craig H. Nielsen Foundation – the largest private funder of spinal cord injury research, rehabilitation, clinical training, and programmatic support in the U.S. and Canada. Application deadline for all program options is August 1, 2022. The program offers a \$5,000 stipend and operates on a rolling admissions basis. Participants can choose between a one-year or summer (10-week) option. Participation can be in-person or hybrid (virtual and in-person). For more information, please contact Josh Marino, Education & Outreach Coordinator, at josh.marino@pitt.edu.

Written by Libby Powers and Brad Dicianno, MD



“Spina Bifida: Your Guide to a Healthy Life” Now Available

“Spina Bifida: Your Guide to a Healthy Life” is now available for download on the SBA [website](#). This patient-friendly guide was adapted from the “Guidelines for the Care of People with Spina Bifida” and is meant to help people with Spina Bifida and their families and caregivers navigate questions about living life with Spina Bifida. The “Guidelines for the Care of People with Spina Bifida” were written for healthcare providers, and are available as a PDF at this [link](#). However, they are also available as an [app](#) to be used by patients and healthcare providers alike, and contain useful tools for tracking symptoms. Please download these Guides for yourself and encourage your healthcare providers, friends, caregivers, and family to access them as well. They are especially helpful in situations where you or healthcare providers need to quickly access information about what care is recommended in certain situations. And they have lots of information about adults!

Written by Brad Dicianno, MD

Introducing “Dano on the Counter”

A new show, “Dano on the Counter,” airs on Fox 8 (Johnstown affiliate station) on Sunday mornings. This show stars and is produced by Dan Burkhardt, an adult living with Spina Bifida. In the series, Dan shares his life experiences while making some delicious recipes, and along the way he shows you how he drives an adapted vehicle and shops for groceries. The series is full of great advice, reflections, and humor. You can also watch episodes on [YouTube](#).

Written by Brad Dicianno, MD



“Connect with Tech” Program giving out Free Tablets

Do you live in Pennsylvania and need a tablet? You might be able to get a free one. “Connect with Tech” is a program through Tech Owl that gives free tablets and tech support to people who have trouble getting technology and health care services. To see if you are eligible and to apply, go to this [website](#).

Written by Brad Dicianno, MD

Get the Most Out of Your Doctors' Appointments

How many times have you left an appointment with a healthcare provider and felt unsure of what you were expected to do next, or realized you forgot to ask the provider something important?

With such a short amount of time to spend with your healthcare provider, it is hard to make sure you share the information you need to and absorb what they tell you. By preparing for your next appointment, you can make sure you get the most out of that valuable time with your provider.

BEFORE YOUR APPOINTMENT:

- **Make a list of things you want to discuss with your healthcare provider and be sure to bring it with you.**
- **Keep a personal health record.** Update your personal record regularly, noting all health changes, hospital admissions, and surgeries.
- **Bring an up-to-date list of medications and a list of your allergies.** Be sure to include over-the-counter medications and supplements you take regularly on your list in addition to prescription medications.
- **Bring a pen and paper.** Take notes during your appointment.
- **Bring someone with you.** It is great to have an extra set of eyes and ears with you at your appointment. If you want to discuss something privately during the appointment, you can always ask your buddy to step out of the room.

- **Call ahead to request a translator if needed.** If English is not your first language, call your provider's office ahead of time to ask if they can get a translator or bring a bilingual friend with you.

AT YOUR APPOINTMENT:

- **Answer questions honestly.** Don't be embarrassed! Your provider needs to understand the real details of what is going on to best help you.
- **Ask questions and repeat back.** Make sure you understand what your healthcare provider tells you. If you are not sure what they mean, ask them to explain it in another way.
- **Mention any cultural or religious traditions** that might affect your care.
- **Ask for written instructions.**

AFTER YOUR APPOINTMENT:

- **Reach out to your provider.** Call, message, or schedule another appointment with your provider if you have questions that weren't answered, you need clarification, or if you have a concern. Do not wait a year for your next annual appointment to seek additional information. Your provider wants to know what is going on and can better help you if you keep them in the loop.

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





Power of Protein

Protein, carbohydrates, and fat are the three nutrients that give our bodies energy. This article will focus on protein.

In addition to providing energy, protein acts as a sort of building block for all of the parts of our body – bones, muscles, skin, and more! Protein helps our bodies build up muscle, repair broken tissues, and even supports the cells in our immune system. It is also important for wound healing.

HOW MUCH PROTEIN DO I NEED?

- This varies from person to person. Many Americans consume enough protein. In fact, a diet that is very excessively high in protein in the long term can be taxing on the kidneys.
- However, in general for a balanced meal, it is recommended to include a source of protein with each of your meals. This helps you feel full and satisfied, rather than hungry right after eating! A good rule of thumb is to make about $\frac{1}{4}$ of your plate a protein food. For meat, this portion size is about the size of the palm of your hand or a deck of playing cards.
- If you have a wound or pressure sore, you will need more protein in your diet to help with the healing process. While diet alone cannot prevent or fix a wound, if your diet is poor (not enough protein, calories, vitamins, and minerals) you are more likely to have slower healing times. Protein from food sources is encouraged, but protein supplements may also be recommended by your dietitian or doctor to help with wound healing.
- Talk with your dietitian or doctor about meeting your individual protein needs, especially if you have a wound or pressure sore.

WHICH FOODS CONTAIN PROTEIN?

Protein is found in meats (beef, pork, fish/seafood, poultry), dairy (milk, yogurt, cheese), eggs, beans and legumes, nuts and seeds, and soy (tofu, tempeh, soy milk). Many milk substitutes such as nut or oat “milk” beverages do not contain much protein. This does not make them bad to consume, but it does mean your protein should come from elsewhere in your meal/snack.

It is encouraged to consume a variety of protein foods. The greater variety of foods you consume, the greater variety of nutrients you will get. Including plant-based protein foods in your diet increases your intake of fiber, folate, potassium, and zinc, and can help reduce the intake of saturated fat often found in animal proteins. Certain seafood (such as salmon) can be a way to increase the intake of healthful omega-3 fatty acids. How we prepare our protein foods makes a difference as well. It is best to choose lean protein. “Lean” means lower in saturated fat. A diet high in saturated fat is often associated with high cholesterol levels, which can increase the risk of heart disease. Tips to choose lean protein foods are below:

- Choose lean cuts of meats (such as sirloin or top & bottom round), choose lean ground beef (90% lean or higher), trim fat where able, and remove the skin from poultry before eating.
- Pick foods that have not been battered and fried. Baking, broiling, grilling, or air-frying are lower-fat cooking methods than frying.
- Choose to skim/nonfat or 1%/low-fat dairy products.
- As noted above, plant-based sources of protein are typically lower fat choices. It is still important to read the label on foods though, as many highly processed meat alternatives (such as vegan chicken nuggets or burger substitutes) on the market may still be high in saturated fat.
- When reading the Nutrition Facts label, pick foods with less than 2 grams of saturated fat per serving where possible.

To learn more: [Protein Foods | MyPlate](#)

Written by: Jacquelyn Klunk, MS, RDN, LDN



Grilling with Confidence

This summer, I wanted to start a series on kitchen equipment that may be useful for our spina bifida population. Since it is summer, I thought we could explore indoor grills. One of my favorite activities in the summer is spending time around the grill eating my favorite summertime recipes. However, there is so much preparation and strenuous labor when it comes to charcoal and gas grills; plus, there are also accessibility issues and dangers when around an open flame. Depending on the type of indoor grill, many of these conditions can be avoided and allow you to grill with confidence.

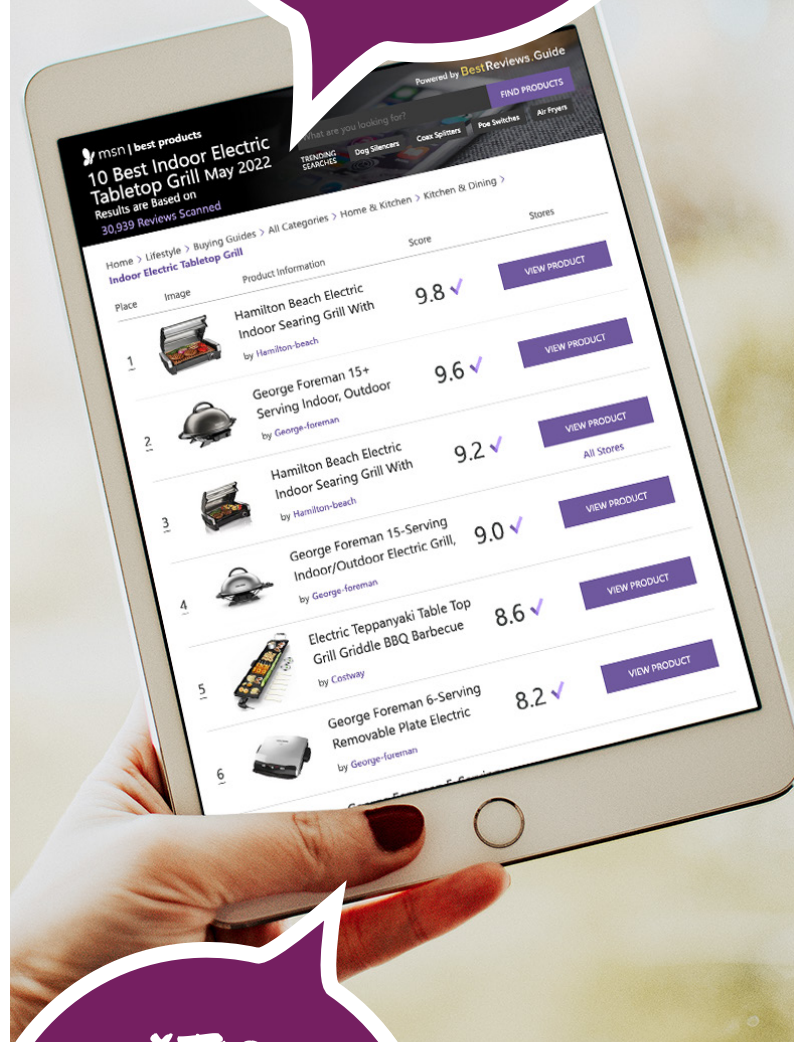


Earlier this year Microsoft Network's Lifestyle online website issued a list of the best indoor grills in 2022. **10 Best Indoor Electric Tabletop Grills**. This list was based on 47,000 reviews on the MSN platform and scaled by 3 categories: popularity, quality, and sentiment. As a shopper, I wanted to use this list to look for things that are important to me: safety features, accessibility, and "bang for my buck!" One safety tip I like to practice is comparing the weight of items, so I know I am getting the lightest option. For example, the grill ranking at #2 is described as being "lightweight" at 9 lbs. However, the item ranking #1 weighs only 5 lbs. The 5 lb. will likely get more use in comparison to a grill that is double in weight. The lighter grill also doubles as a slow cooker and steamer. This feature not only gives me more "bang for my buck", but the high walls provide a safety guard from any splash caused by cooking the food. An indoor grill's tabletop quality also gives you the ability to utilize a table of your choosing that has a more accessible height versus the kitchen counter or stove. Grilling can not only be enjoyable to everyone, but with the right features, you can feel comfortable and confident! The following page has one of my favorite summertime recipes, aromatic grilled jerk chicken with mango salsa.

Written by Sara Izzo

***TIP:**

WHEN SHOPPING, UTILIZE PREEXISTING REVIEWS TO CREATE A PERSONALIZED LIST THAT MATCHES YOUR PRIORITIES. THAT WAY YOU CAN FOCUS ON WHICH ITEMS ARE SAFER, ACCESSIBLE, AND AFFORDABLE.



***TIP:**

DON'T FORGET YOUR HEAT-RESISTANT GLOVES THAT CAN BE USED FOR HANDLING HOT FOODS ON AND OFF THE GRILL!

Jerk Chicken with Mango Salsa

Serving size 2-3 | 15-minute prep time; Cook time 25 minutes; Total time 40 minutes.

Jerk Chicken

- 2 cloves garlic
- 2-inch piece of fresh ginger (2 tsp. Ground)
- 1-2 chilies
- 1 Tbsp. honey
- ½ tsp. cinnamon
- ½ tsp. allspice
- 1 tsp. cumin
- ½ tsp. thyme
- ½ white onion
- Juice from 1 lime
- 3 Tbsp. grapeseed or cooking oil
- 2 spring onions/scallions
- ½ tsp. salt
- 2 chicken breasts or 4 thighs (bone-in)

Mango Salsa

- 1 Mango diced
- ½ Red onion finely diced
- 1 Jalapeño finely diced
- 2 Tbsp. cilantro roughly chopped
- ¼ tsp. salt

In a food processor or blender, combine garlic, ginger, chilies, honey, cinnamon, allspice, cumin, thyme, onion, lime juice, coconut oil, green onions, and salt. Blend until smooth. Place the chicken in a Ziploc bag and pour the marinade over. Seal and massage the marinade into the chicken. Store in the fridge for a minimum of 2 hours but preferably overnight. On the day of cooking your chicken, in a bowl, combine the diced mango, red onion, jalapeño and cilantro. Sprinkle with salt and stir to combine. Set aside in the fridge until ready to use.

Heat your grill to medium-high heat and cook the chicken for 5 to 6 minutes skin side down. Then turn over to finish skin side up. Cover and cook for another 35-40 minutes until cooked through. Alternatively, you can cook the chicken in the oven at 375 Fahrenheit and bake for 45 minutes. Serve the chicken topped with mango salsa.

Written by **Sara Izzo**



“You can’t buy happiness, but you can BBQ and that’s kind of the same thing!”

Unknown



My Experience as an Advocacy Trainee in Leadership Education in Neurodevelopmental Disabilities Program

Children and Family Television Icon and Pittsburgh native, Mister Fred Rogers once said, “In times of stress, the best thing we can do for each other is to listen with our ears and our hearts and to be assured that our questions are just as important as our answers.”

The LEND (Leadership Education in Neurodevelopmental Disabilities) Center at the University of Pittsburgh is a leadership education program funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) in the Department of Health and Human Services (DHHS). The LEND Center at the University of Pittsburgh is one of 68 LEND programs in 47 states across the United States preparing trainees from a wide variety of professional disciplines to assume leadership roles, apply effective interdisciplinary clinical competence, and enhance the capabilities of clinicians to diagnose, treat, and manage complex disabilities in youth, adolescents, and young adults. The programs also promote culturally competent, coordinated care, and integrate families in all aspects of training and service.

LEND training is an academic year-long intensive, interdisciplinary program that prepares graduate students, practicing professionals, advocates, and family members of individuals with disabilities to assume leadership roles in their respective fields. While striving to understand factors that help all individuals attain optimal health and developmental trajectories over a lifetime, the LEND Center forges partnerships of university faculty and students, community service providers, health professionals and educators, leaders in government, business, and philanthropy, as well as individuals with disabilities.

On a professional level, I chose to apply to the LEND Program at the University of Pittsburgh this past summer because I felt that the LEND program would provide me with more advanced skills in advocacy and leadership

within the clinical hospital environment. I am learning to use interdisciplinary, family-centered care skills from the maternal and child health competencies framework. These skills and competencies assist in my daily learning of how to appropriately meet the needs of children, adolescents, and their caregivers while working most effectively and proficiently with them in the LEND Clinic. LEND family faculty member, Dori Cameron Ortman, summed it up by saying, “Having Libby as an Advocacy Trainee at LEND Pittsburgh this year has been so rewarding...for all our trainees, as well as our faculty. She provides first-hand knowledge and wisdom from her lived experiences...experience that simply cannot be taught in a classroom. In turn, Libby is also gaining a wealth of learning experiences that I am so thrilled to have helped her solidify her desire to continue working with families. I know she is going to do remarkable things.”

While in LEND, the student clinicians, family, and advocacy trainees are provided with numerous tools in a supportive, engaging, hands-on learning environment with some of the top professionals in areas such as speech and language pathology, audiology, public health, and social work. They teach the LEND trainees the tricks and tips of working as a professional in their specialties.

While I have always been drawn to working in the human and social fields, participating in the LEND Program has reignited my passion and desire to continue to work as an advocate for individuals with varying needs. The journey through LEND has encouraged me to design a career path to be able to advocate and provide direct support for individuals who need a guiding hand to find the appropriate resources and support to successfully manage and lead their own everyday lives. That being said, my plan once my time in the LEND Program concludes is to begin the Master of Social Work Program at the University of Pittsburgh in the Fall of 2022.

In the end, participating in the LEND Program has opened many new doors, provided me with more knowledge and information, and has brought so many more lifelong friendships and professional relationships into my everyday life, and for all of this, I will always be especially grateful. For more information or to apply for a spot in the University of Pittsburgh LEND Program please visit the [LEND website](#).

Written by Libby Powers



WHEELCHAIR WORKOUT



Finding the Right Equipment for Your Fitness Goals



When starting a new fitness program, it can often be overwhelming trying to decide what equipment we need to start with. One of the ways I like to think about starting a new fitness program is to ask myself, “what are my goals and what do I need to achieve them?”

In previous newsletters, I have written about how to go about defining your goals by creating S.M.A.R.T. goals and using the F.I.T.T. principle. Assuming you have done that, you are now ready to decide what equipment, if any, you should use. There are five distinct types of equipment.

- ▶▶ **Bodyweight movements** Use your body weight to complete exercises. Examples are pushups, chin-ups, pullups, squats, crunches, and sit-ups. These movements do not require any equipment but are the foundation of every subsequent strength and stability movement you will do. Once you get comfortable with bodyweight movements and can complete each of them using proper form, you are ready to move on to using equipment.
- ▶▶ **Resistance bands** are often used to stretch your muscles before an exercise session. If you are just starting out with exercise, resistance bands can also be a great option to develop foundational strength and stability in your joints and muscles.
- ▶▶ **Dumbbells** are hand weights and are good for developing muscular and joint stability, especially on one side. My recommendation would be to start with one sided, or single-joint movements with one arm or leg first and then move to multi-joint movements with both arms or legs to develop more strength and grow your muscles.
- ▶▶ **Machines** are frequently considered one of the best options for strength and muscle growth. Machines can use cables or stacks of weights or plates. Machines are stable and can help you target and isolate singular muscle groups with little risk of injury.
- ▶▶ **Barbells** are often considered the most advanced and most technical piece of equipment you need to use both hands and have good strength and stability. Barbells are loaded with either metal or rubber-coated metal weight plates that are locked in place using weight clips. Powerlifting and weightlifting seen in the Olympics and Paralympics are done using barbells. Utilizing barbells can offer a high level of strength and stability that you may not be able to get with the other types of equipment. Make sure you understand how to carry out the movement before attempting to use the barbell. Also, you should have a spotter, or someone watching you, to make sure you are completing the movement safely with proper form.



Whatever piece of equipment you use, being comfortable with and understanding the equipment and movements will ensure you get the most benefit for your health and wellness journey. Be sure to consult your physician and medical team for advice before starting a program.

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

Upcoming SBA Events



“Join the Conversation” Zoom Calls provide an affirming, empowering, fun, and educational space to chat and share resources and stories, offer insights and encouragement, and forge powerful connections with others who can relate to the experience of living with Spina Bifida. Offered on the first and third Tuesday every month at 7pm ET:

<https://fb.me/e/2gWe3dbFU> and

<https://bit.ly/2SpBEom>

Upcoming SBAWP Events



9th Annual Afternoon JamFest

June 26: 1:00 pm - 5:00 pm Jergel's

Adult Camp

July 3-9: Camp Guyasuta

Youth and Teen Camp

July 10-15: Camp Guyasuta

34th Annual John L. Moroney III Memorial Golf Classic

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

Soup and Salad Fundraiser

September 1: 11:00 am – 2:00 pm

Cranberry Community United Presbyterian Church

7th Annual Noll-Spratt Golf Scramble

September 17: 12:00 pm - 8:00 pm

Beaver Valley Golf Club

Adult Retreat Fall

September 30 - October 2: All Day Camp Guyasuta

Youth and Teen Retreat October

October 7-9: All Day Camp Guyasuta

9th Annual Girlfriends for Good Purse Bash

November 12: 12:00 pm - 3:00 pm

St. Ferdinand's Oldenski Hall

Youth and Teen Retreat December

December 2-4: All Day Camp Guyasuta

Adult Retreat December

December 9-11: All Day Camp Guyasuta

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



Interested in Research?

Research Registries: Signing up for a research registry allows you to receive more information about research studies for which you may qualify. Three research registries that may be of interest to you are:

National Spina Bifida Patient Registry: If you are interested in this registry, please contact: Sara Izzo at (412) 328-1773 or Dan Rusnak at 412-295-7666

Human Engineering Research Laboratories

Department of Physical Medicine & Rehabilitation



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

Hey! There's an app for that!

Do you or someone you know
Currently Receive Service from SCU (Service Coordination Unlimited) ?
Would you like to participate in our research study?



Who is eligible?

- ★ **Clients of Service Coordination Unlimited (SCU)**

What is involved?

- ★ **Try out smart phone app and participate in interviews**

Please fill in the form below so we can call you for more information.

Your Name: _____ Age: _____

If enrolling a minor (individuals under 18 years old) please provide the following:

Your Child's Name: _____ Age: _____

Are you this child's legal guardian? YES / NO

Preferred Number to call:

Home Phone: _____ A good time to call is: _____ AM / PM

Cell Phone: _____

Please sign here: _____

Please give this form to your therapist/Nurse or fax/call/email the Study Coordinator

Study Coordinator
Zara Ambadar
Email: ambadar@pitt.edu
Phone: 412-608-6118

Your participation is completely voluntary.
Your services will not be affected if you decide not to participate.