

## Spina Bifida Association Clinical Care Meeting Updates

Our team just returned from the SBA Clinical Care meeting held at Lurie Children's Hospital in Chicago. The meeting brought together clinicians, researchers, and advocates from the US and even some European locations. Dr. Dicianno was 1 of 3 clinicians who won the "Dr. Tim Brei Outstanding Healthcare Professional" award for his work on developing the Guidelines for Care of People with Spina Bifida. Click [here](#) to watch some of the highlights of the meeting.

We highly recommend watching the video of the panel of adults with spina bifida who ranged in ages up to 70 years, and who spoke very eloquently about their experiences in living with spina bifida and the care they received in different settings. Next year's meeting will be held at Children's Hospital of Philadelphia.

## Taste of Summer *Written by Sara Izzo*

Spring has sprung and now it's time for summer fun! Have you been using the great tips for gardening that was shared in our fall newsletter? Well, now it's time to harvest those yummy herbs you've planted. I have some great tips for you to enjoy them this summer. Rosemary and mint are a few of my favorite herbs I keep on my

windowsill. These rapidly growing herbs are very healthy and have amazing aromatic qualities. One of my favorite ways to stay hydrated and to add new flavor to my dishes is to get creative with the different types of fresh herbs I have available. Here are a few ideas you might enjoy as well this summer:

### Cucumber Mint Water

- 12 servings (8oz)
- 1 small to medium cucumber
- 2 sprigs of Fresh Mint
- ½ lime (this is optional – avoid citrus for aggravated bladders)



### Cooking Instructions

Clean and dry the cucumber and/or lime if using. Slice the cucumber and lime in thin slices and place the slices and mint sprigs at the bottom of a large pitcher. Fill up the pitcher with filtered water and refrigerate covered from 1 to 8 hours.

Save on waste and use refillable bottles throughout the day!

### **Seared Trout**

(or any oily fillet fish with skin)

- 1 whole trout filleted and cleaned
- 3 sprigs fresh rosemary
- 3 sprigs fresh thyme
- 2 whole garlic cloves
- 1 fresh lemon
- Sea salt and pepper to taste
- Olive oil

### **Cooking Instructions**

With clean hands, lightly dry the inside and outside of the fish with a paper towel. Heat up your cast iron skillet or large frying pan to medium heat. Waiting until your pan is nice and hot, pour about 2 tablespoons of olive oil on the skin side of your fillet and salt and pepper. Once your skillet is hot, add 2 tablespoons of olive oil to the pan along with the garlic and fresh herbs. Sautéing for 1 minute, push the garlic and herbs to the side of your pan and add the fish skin side down in the middle of your hot skillet. Cook for 3 minutes. While cooking salt and pepper the inside of your fish and then place the cooked herbs and garlic on top of the flesh side of the fish. Lightly oil the inside of the fish before flipping and cook for an additional 3 minutes.

Remove fish and discard herbs and garlic. Serve hot with fresh lemon for flavor. Be sure to add fresh vegetables with this light and flavorful meal!

### **Don't Forget to Wash Your Veggies!**

- Wash your vegetables by filling up a large bowl of clean water and  $\frac{1}{4}$  cup of white vinegar or apple cider vinegar. Rinse with fresh water and dry with paper towel. Fruits like berries and apples will stay fresh longer in the refrigerator if you wash them soon after from the store.
- You can also dampen a paper towel with vinegar and rinse with water for small amounts of fruits and veggies.



*"Summertime is always  
the best of what might be"*  
– Charles Bowden

### Living an Active Lifestyle with Spina Bifida

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

For individuals with Spina Bifida, living an active lifestyle can be physically and mentally challenging. More often than not, we find ourselves wanting to make a change, but not having any idea where to start. Spina Bifida can make general movements require much more energy than that of an able-bodied individual. Even so, there are many ways in which a person with Spina Bifida can lead a healthy and active lifestyle well into adulthood. Before we talk about the physical aspect of a healthy lifestyle, we need to talk about the mentality of living a healthy lifestyle.



For many of us, depression and anxiety are quite common. The addition of a daily workout routine, while highly recommended, may only increase these feelings. Before you move your body, you need to make a conscious decision

that you want to feel healthier and be as mobile as possible.

Getting over that initial “I don’t want to do this,” or “I am going to be so sore,” or “I don’t have time,” mentality is the first step in starting your health and wellness lifestyle off right. We want to switch our mindsets from the above phrases to more positive thoughts such as, “I **get** to use this wheelchair and roll around as fast as I want,” or “I **get** to use my arms as my legs,” or “I am **able** to strengthen my body and mind with exercise.” Phrases like these will help us see what our bodies can do and not look at what our bodies cannot do.

*“This may be uncomfortable, but I know the more I do it, the stronger I will get.”*

After all, **everyone**, including those without disabilities, has moments or days where they focus on the perceived negatives in life rather than positives. The key is to be proud of our positives and realize everything we have is meant to strengthen us, not weaken us. It’s up to us to use our bodies to be as strong as we can be. Once you make the mental commitment to

yourself that you will lead a healthier lifestyle, you are ready to start planning your fitness program.

The Spina Bifida Association “Guidelines for the Care of People with Spina Bifida” state that it is recommended that adults with Spina Bifida should engage in **at least 150 minutes (2 hours 30 minutes) per week** of aerobic activity that is moderate-intensity, 75 minutes (1 hour 15 minutes) of vigorous intensity aerobic activity, or an equivalent combination of the two. While these guidelines will most certainly get you on the right track to achieving fitness goals, there are increased benefits to engaging in further activity beyond this.

If you are looking to increase muscle mass and strength, it is recommended that you engage in **at least 2 days of resistance training (muscle strengthening)** activity per week as well. Added benefits can be seen by engaging in more frequent exercise. I recommend anywhere from 3 – 6 days per week of some type of exercise for at least 30 minutes at a time.

If you are still having difficulty getting started, ask your friends and family and find out if they would like to exercise with you. Working out with another person has shown to increase

adherence and enjoyment in exercise.

Whichever plan you choose, remember to stick to it as best as you can, but don’t beat yourself up if you aren’t progressing as quickly as you would like or if you miss a workout. We are all human. Health and Wellness is meant to be a life-long event. There is no reason to rush health. Enjoy the process and be proud of your accomplishments no matter how big or small. Remember, it’s not what our bodies **can’t** do, it’s what our bodies **can** do that makes us strong and healthy. Click [here](#) for a more in depth look at ways to begin your health and wellness journey as well as specific exercises to strengthen your shoulders.

### Summertime Tips

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

It’s summertime! Here are some tips to keep your cool and your health during the sultry summer days:

- 1. Check the temperature of any seat before you sit.** Dark colored seats hold heat that we might not feel. When it’s hot enough they can cause a burn.
- 2. Keep your feet covered.** Barefoot feels awesome but it does come with risks, even if you aren’t ambulatory. With diminished

sensation and non-protected feet it's easy to get an injury.

- 3. Keep drinking water.** Dehydration is much worse than having to cath more. Try adding different fruits like lemon or lime to water to make it tastier.
- 4. Look at your medicines.** See if any of them have a warning to not to spend time out in the sun.
- 5. Wear sunscreen.** Remember that the sun can burn your legs when you are sitting.
- 6. Take breaks.** Be sure to plan for rest breaks in between activities.
- 7. Be prepared.** If traveling, keep extra supplies with you. You never know what might happen.
- 8. Have fun!**



### Summer Activities to Stay Active and Healthy

Written by **Rachel Young, CRNP**

We would love to hear about a new connection to a friend or organization that you found within your area that offered an opportunity for

exercise or active community outing. It is important for both our physical and mental health to stay active. It is also important as we transition in to adulthood to establish friendships and relationships that keep us connected. There are many organizations within the Pittsburgh and surrounding areas that are offering fun outdoor adventures. Below are some organizations providing fun activities for active lifestyles:

#### HOPE Network

[Facebook.com/HopeNetworkPA](https://www.facebook.com/HopeNetworkPA)

#### Three Rivers Adaptive Sports

[Traspa.org](http://Traspa.org)

#### National Center on Health, Physical Activity and Disability (NCHPAD)

[NCHPAD.org](http://NCHPAD.org)

#### Mindful Eating

Written by **Sabrina Palmieri, RD, LDN.**

Following a healthful eating plan includes learning about what foods to choose and those to limit. In addition to adjusting what you eat to manage good health, it may be just as helpful to manage how you eat. Mindful eating is not a diet, but a practice of experiencing food with more focus and appreciation. The concept has roots in Buddhist teachings, which focuses on

quieting the mind, slowing down, bringing your attention to a calm place, and eating thoughtfully. Studies have found that mindful eating can help individuals reduce overeating, lose weight, cope with chronic eating disorders and improve symptoms of Type 2 diabetes.

In today's fast-paced lifestyle, meal and snack times are often full of distractions such as eating while watching TV, talking on the phone, working, driving, or using social media. It is rare that when we are eating, we are only eating. Mindless eating habits can influence both what and how much we eat. Over time, small changes in the way you prepare, serve and eat your meals can lead to big improvements in your eating habits and your health.



### Putting it Into Practice

Developing mindful eating practices is a journey that you can work towards over time. Experts

suggest starting gradually with mindful eating – eating one meal a day or week in a slower and more attentive manner. Mindful eating can be practiced anywhere and at any time. The following exercises are not to suggest eating all of your meals this carefully, but by practicing mindful eating, you may discover room for improvement in your own eating habits.

### How to Eat a Meal Mindfully

- 1. Reflect.** Before you begin eating, take a moment to reflect upon how you feel. Are you rushed? Stressed? Sad? Bored? Physically hungry? What are your wants, and what are your needs? Differentiate between the two. After you have taken a moment to reflect, then you decide if you want to eat, what you want to eat, and how you want to eat.
- 2. Have a seat.** Don't eat on the go. You're less likely to appreciate your food when you are multi-tasking. It's also difficult to keep track of how much you are eating when you snack on the go.
- 3. Attend to your plate.** Remove distractions such as the TV or cell phones.
- 4. Appreciate the work.** Before you start to eat, pause and take a moment to acknowledge the work that went into

providing your meal – be it thanks to the farmers, the factory workers, the animals, our planet, the chefs, or even others at the table.

- 5. Take time enjoy your balanced meal.** Put down the fork in between each bite. Enjoy the taste and the texture of your food. About halfway through the meal, check in and assess your hunger and increase in fullness. Ask yourself, “Am I satisfied?” and “Do I need to keep eating?” Listen to what your body tells you.



Mindful practices like these can shift your attention from your environment and thoughts to the present moment and the food you are eating. It may also make you more aware of your hunger level. If you are used to eating quickly or being distracted by other activities, eating mindfully may seem awkward at first. You may notice your mind drifting off the experience of

eating, but don't judge yourself and simply return to the awareness of that bite of food. As you continue to practice mindful eating and establish it as a habit, you will feel more comfortable doing it.

### **Bottom Line**

Eating mindfully is eating with awareness. It is being present in the moment, for every sensation that happens, such as chewing, tasting and swallowing. Mindful eating can help to promote healthful eating habits, prevent overeating and in turn lead to overall good health. Developing mindful eating practices takes time. Be patient, see what you discover about your own eating habits, and savor the flavor of eating right.

### **Upcoming Events at Spina Bifida Association of Western Pennsylvania**

Some of the upcoming SBAWP include:

- **Adult Summer Camp:** June 30 - July 6, 2019
- **John I Moroney III Memorial Golf Classic:** July 29, 2019 ([Click here for event details](#))

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

### **Tools for Techies and Gadget Lovers**

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

Video Visits with Telemedicine – We are very excited to now be able to schedule appointments via Telemedicine. This means that you can talk face-to-face with one of the Spina Bifida Clinic providers without leaving your home. You will need a smartphone or home computer with a camera. This is a great way to have a follow-up appointment or to discuss a specific issue with your provider without having to drive to our office. Please call **412-232-8909** if you would like to learn more or wish to schedule a video appointment.

### **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](http://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](http://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.

### **Contact Us**

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