

Introducing a New Team Member: Dr. Stanford

We are thrilled to welcome Lisa D. Stanford, PhD, ABPP to our clinic team. Dr. Stanford is Vice Chair for Neuropsychology and Rehabilitation Psychology in the Department of Physical Medicine & Rehabilitation. She is a double-Board certified Lifespan Clinical Neuropsychologist and licensed psychologist. She will be providing clinical services including outpatient neuropsychological assessment; consultation regarding transition to adulthood needs; assistance and provision of resources to families regarding American with Disabilities Act (ADA) Accommodations, legal guardianship, and Supplemental Security income (SSI); and psychotherapeutic support as needed for adjustment, emotional impact, and/or behavioral challenges. Welcome, Dr. Stanford!

Written by Brad Dicianno, MD

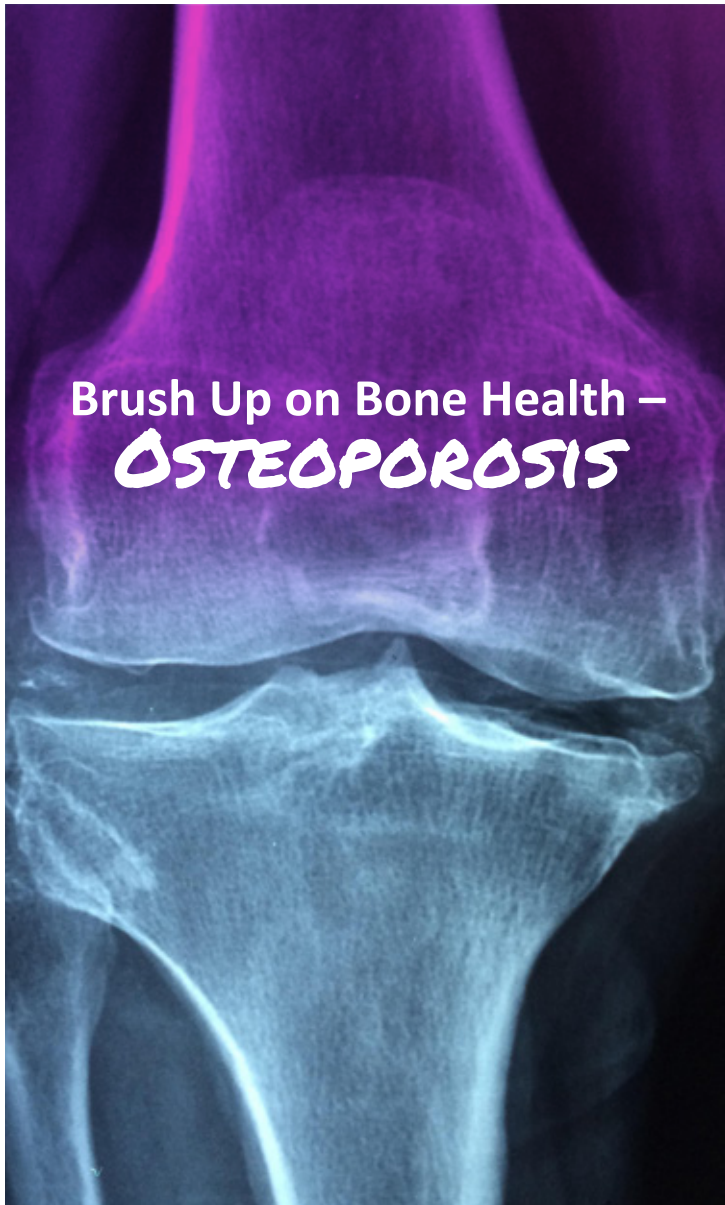


DON'T FALL,

Fly

A popular book and movie at the moment is *Where the Crawdads Sing* by Delia Owens. Owens writes, "Autumn leaves don't fall, they fly. They take their time and wander on this their only chance to soar." In this issue, we present a lot of resources for prevention of secondary complications and health maintenance, as a way to keep you afloat during the changing winds of Autumn.

Written by Brad Dicianno, MD



Brush Up on Bone Health – **OSTEOPOROSIS**

Osteoporosis is a condition in which bones become weaker, which causes a higher risk of fractures. As we age, bones get weaker because old bone breaks down, but new bone does not form in the same way as it did when we were younger.

However, it is not uncommon for “early onset” osteoporosis (that is, occurring in your 20s or 30s instead of at older ages) to occur in adults with spina bifida – it may occur in up to 50% of adults with spina bifida. Risk factors can include: being female, family history of osteoporosis, immobility, prior ileal diversion surgery, long-term use of corticosteroids, epilepsy medications, or kidney failure. There are some steps you can take with your diet and lifestyle to help reduce the risk of osteoporosis.

CALCIUM

Calcium is an important building block in our bones that helps to keep them strong. Diets low in calcium and vitamin D can increase risk of osteoporosis. Calcium needs vary by age and gender:

- Women ages 18-49 years, and men ages 18-69 years: 1000 mg calcium per day
- Women ages 50+ and men ages 70+: 1200 mg calcium per day

Dairy products are a common source of calcium (including milk, yogurt, and cheeses). If you do not consume dairy, check that your dairy substitutes (such as soy, almond, or oat milks/yogurts) are fortified with calcium – this means that the manufacturer added calcium to the food when it was being made. Other non-dairy sources of calcium include dark green vegetables (kale, collards, mustard greens), nuts, calcium set-tofu, canned fish with soft edible bones, fortified breakfast cereals, and beans. While it is best to get nutrients from food first, if you are having trouble meeting your calcium needs by food alone, talk to your healthcare provider about a calcium supplement.

VITAMIN D

Vitamin D both helps our body to absorb calcium and helps to ensure processes within the bone are working properly to maintain bone strength. Our body can make vitamin D when our skin is exposed to the sun. However, people who live in northern climates or spend a lot of time indoors may not be able to make enough vitamin D on their own. Foods that are higher in vitamin D include dairy products, fortified dairy alternatives, fortified cereals and juices, fatty fish like salmon and tuna, egg yolks, and shitake mushrooms treated with UV light (such as sun-dried). It is recommended that adults up to age 69 consume 600 international units of vitamin D daily, and 800 international units for adults over 70 years of age. Discuss if you need a vitamin D supplement with your healthcare provider.



(continued on next page)

BALANCED DIET

Eating a balanced diet is also important to bone health. Eating enough (but not too much) protein keeps our bones and muscles strong. Although calcium and vitamin D are important, our bones need other vitamins and minerals from our foods too (such as vitamin K, magnesium, and zinc). Eating a varied diet with all 5 food groups helps provide our bones with the nutrients we need.

REDUCE: ALCOHOL, CAFFEINE, AND SALT

In excessive amounts, both alcohol and caffeine can be detrimental to bone health. Moderation is important if you consume either. A diet high in salt or “sodium” can also be bad for bone health. Use less salt in cooking and at the table and read labels to pick lower sodium foods. The recommended limit of sodium intake for healthy adults is less than 2300 mg sodium/day.



PHYSICAL ACTIVITY

Being active also helps to keep bones strong. Resistance or “weight-bearing” exercise (where your body is working against gravity) can help with preventing bone loss. Exercise is also important for people who use a wheelchair to maintain wrist strength for transferring. Physical activity can also help with muscle strength and coordination to reduce fall risk. Talk with your healthcare provider regarding any new exercise programs to make sure they are safe for you.

Article References:

1. <https://www.spinabifidaassociation.org/wp-content/uploads/Osteoporosis-Updated.pdf>
2. <https://www.uptodate.com/contents/osteoporosis-prevention-and-treatment-beyond-the-basics>
3. http://www.bonehealthandosteoporosis.org/wp-content/uploads/BoningUpBrochure_8.5x11.pdf Therapy. 2020
4. http://www.bonehealthandosteoporosis.org/wp-content/uploads/2016/04/Healthy-Bone-Brochure_FINAL.pdf

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

Get Mentorship from a Peer, or Be a Mentor

In the spring, the Adult Spina Bifida Clinic received a grant from FISA to develop a peer counseling program. The clinic has trained staff and volunteers who are adults with Spina Bifida to serve as peer counselors for other adults living with Spina Bifida.

You might be asking yourself, “What does a mentor do”? A mentor can help you set goals for yourself and reach them. Mentors serve as coaches who can help you during times of change and/or transition. Mentors serve as cheerleaders, challenge you, and push you to go further than you thought you could go! Mentors can inspire you and keep you focused, but the ultimate decisions about your goals and how to get there come from you.

Mentors and mentees set up a schedule to meet virtually. The schedule is whatever you both agree upon. Contact the Adult Spina Bifida Clinic at Mercy if you are interested in having a mentor or being a mentor.

Written by *Monica Albert Still, RN, BSN*

Educational Scholarships

A variety of scholarships are available to students with spina bifida and other disabilities. Please check out some of the examples below or visit [SBA's scholarship page](#):

- [180 Medical Scholarship Program](#)
- [American Association on Health and Disability Scholarship Program](#)
- [Everylife Foundation for Rare Diseases](#)
- [Patient Care Medical Scholarship](#)
- [The Bryon Riesch Paralysis Foundation](#)



WHEELCHAIR WORKOUT



Set Up Your Fitness Plan for Success

Daniel McCoy
Personal Trainer, UPMC Mercy

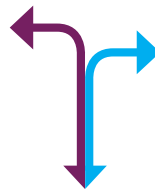


We've all heard the phrase, "If you fail to prepare, prepare to fail." While this can be daunting to hear, there is truth to it. The most successful individuals always have a plan before they start.

When thinking about starting a fitness routine, this is especially true. There are many ways to set up fitness routine and many routines you can follow to get you the results you are looking for. The main idea to keep in mind is how much effort you put into your program.

The Guidelines for the Care of People with Spina Bifida state that if you are exercising at moderate intensity, it is recommended that you try to hit 150 total minutes of exercise per week. This can mean exercising 30 minutes five times per week or exercising 50 minutes 3 times per week, or anything in between, as long as it adds up to 150 minutes in one week. An example of moderate intensity exercise would be light cardio exercise for a few minutes before and/or after weightlifting. If you are exercising vigorously, the Guidelines recommend that you try to hit 75 minutes per week. You could exercise for 3 sessions at 25 minutes per session, as an example. Vigorous intensity exercise can be thought of as sprints and/or quick movements with light weights or bodyweight with short rests in between quick bouts of exercise. These generally take more energy from your body, hence the need for longer rest between vigorous intensity exercise. Keep in mind, your body will be able to recover more quickly from moderate intensity exercise due to the lower stress on your central nervous system.

Three of the most popular ways to split up a fitness program are listed below. This would require at least 3 days per week of 1-2 exercises per muscle group.



Option 1 (Push, Pull and Legs workout):

On day one, you would hit all of your pushing muscles (i.e., chest, shoulders, triceps). On day two, you exercise your pulling muscles (i.e., back and biceps), and on day three you would exercise your legs if you have use of them. Then alternate.



Option 2 (Upper versus Lower Body workout):

On day one, you would exercise of all of your functioning upper body muscles. On day two you would exercise all of your functioning lower body muscles. Then alternate.



Option 3 (Full body workout):

Work out functioning muscles in your whole body, and repeat each day of exercise.

Rest periods for each of these workout splits can vary anywhere from 30 seconds to 2 minutes in between exercises, depending on the volume (i.e., sets, reps, weight). The more volume in your workout, the longer the rest period you want in order to give your body enough time to rest and recover. Be sure to give yourself enough of a challenge to hit your goals but also be conscious of how your body responds to the program, and take rest days when you feel they are necessary. Success in fitness requires dedication and consistency, so make sure to have a plan to keep yourself accountable and have fun with your program! Check out [this video](#) about what it's like to meet with Dan at the UPMC Adult Spina Bifida Clinic.

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

Sepsis is Serious

In July of 2001, I was pregnant and had a heel crack on my right foot. I did not know about the heel crack. I was on vacation and was too busy enjoying myself to worry about checking my skin every day.

One of the fun things we did was go into the Saco River. We left that evening. I didn't know it at the time, but I had brought home bacteria along with my souvenirs. I went very quickly from feeling a little bit tired to feeling very ill. By the time I got to the hospital, I was septic. I am lucky both I and my baby survived my war with sepsis. Losing a leg is a small price compared to losing a life. Other people are not so lucky. Currently, sepsis kills 270,000 people in the U.S. per year.

Sepsis happens when you have an infection. Sepsis is when your body's defenses against infection go into overdrive and start attacking your body's systems. It is a toxic reaction to infection. It is a serious problem that needs to be treated immediately. It can make you very sick, put you in the hospital, and even kill you.

I am lucky both I and my baby survived my war with sepsis. Losing a leg is a small price compared to losing a life. Other people are not so lucky.

The best way to avoid getting sepsis is not to get an infection. Urinary Tract Infections, wound infections, and shunt infections are the most common kinds of infections that people with Spina Bifida get. Sometimes, no matter what you do, an infection happens. If you have an infection the best way to prevent sepsis is to tell your doctor that you think you have an infection. Your doctor can then treat the infection.

It is possible for you to get sepsis quickly after the infection starts. You can also get sepsis if you do not finish all the medicine the doctor gave you to treat your infection. It is important to know the signs and symptoms of sepsis. It is important for you to get treatment quickly if you think that you may have sepsis. According to the Sepsis Alliance (www.sepsis.org), you only must remember one word, **TIME**, to know the symptoms of



sepsis. **T: TEMPERATURE HIGHER OR LOWER** – Your temperature should stay consistent — around 98.6° F. A temperature of about 100° F is a fever. Sometimes, with sepsis, your temperature can go lower than usual. That is why either a high or low temperature can be a sign of sepsis. **I: INFECTION** – you may have signs and symptoms of an infection. **M: MENTAL DECLINE** – may be confused, sleepy, difficult to rouse. **E: EXTREMELY ILL** – Sepsis survivors say that the worst they have ever felt in their lives was when they had sepsis. **If you experience a combination of these symptoms seek urgent medical care, call 911, or go to the hospital with an advocate. Ask. “Could it be sepsis?”** For more information about sepsis contact your doctor or go to www.sepsis.org.

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



Baking with Confidence

Autumn is finally here, and we are continuing the newsletter series on accessible kitchen equipment. This season we are highlighting a lightweight kitchen appliance that is not typically thought of as versatile, but by the end of this article, I am sure I will convince you that the rice cooker is the perfect addition to your home.

Rice cookers are often seen in Asian restaurants as a method of preparing the perfect batch of rice without the hassle boiling water from a stove. This feature makes the rice cooker a safe option for those who want to prevent spills and burns on their stovetop.

Rice cookers vary in prices, ranging from less than \$20 to over \$200; however, they all produce excellent results. The prices can be based on a couple features: manufacturing and size. You might see pricier models originating from Japan, or American models that range from 2 cups to 6 cups in size. When you begin your research on rice cookers, you may see the same model for different prices. That is usually because more accessories are featured in the more expensive version, e.g., steaming baskets. However, they all usually come with a measuring cup and a rice paddle to prevent scratches.

The question you may be asking yourself is, “Do I need a larger rice cooker or the steaming basket?” The answer is, yes! The larger rice cooker and steaming basket allows you to use your rice cooker beyond the usual rice, quinoa, and lentil side dishes you may be used to. You can prepare an entire meal for yourself and a guest, using your steaming basket to prepare protein and vegetables while your healthy grains cook below it. Would you believe that you could bake a personal cake in a rice cooker? Well, that is the benefit of having a larger model. Having a rice cooker that can make at least 3 cups of rice provides you enough room for a cake to bake and rise without using an oven. The size of a cake from a rice cooker is perfect for two people to share, and the convenience will encourage you to bake more often from scratch. On the following page is a caramel cake recipe perfect for the Autumn season or holiday. This recipe uses monk fruit as a sugar substitute to lower the sugar content due to the use of melted caramel. Some rice cookers are complex with different settings, and some include a setting for baking, which is not usually needed. Even the “one touch” models produce an amazing tender cake, every time!

Written by Sara Izzo

Rice Cooker Caramel Cake

Serving size 2-3 | 10-minute prep time; Bake Time 45-70 min; Total Time 55-80 min.

¾ Cup All-Purpose Flour

(Red Mills All-Purpose Gluten Free Flour)

1 tsp baking powder

5 Baking caramel squares

(7 Werther's Chewy Caramel Candies)

¼ Cup milk (dairy free milk)

2 large eggs

½ cup monk fruit sugar substitute

(regular sugar is acceptable)

¼ vegetable oil (avocado or grapeseed suitable)

Butter for the pan

Pinch of Sea Salt

OPTIONAL FOR ICING*

5 Baking caramel squares

(7 Werther's Chewy Caramel Candies)

¼ Cup milk (dairy free milk)

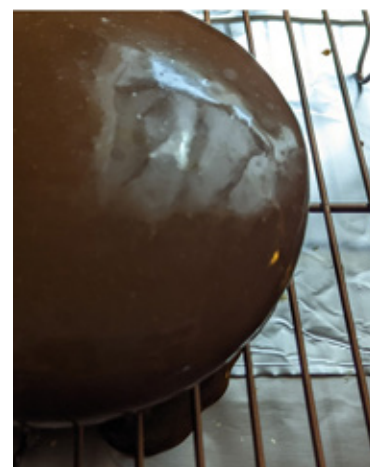
Directions Sift flour and baking powder into a bowl and set aside. In a microwave safe bowl, melt caramel and milk together for 25 seconds on high. Stir and continue to microwave an additional 10 seconds until caramel is melted and combined with the milk to make a sauce. In a separate bowl beat eggs, sugar, and oil with an electric mixer or wooden spoon. Add the flour and baking powder mix, stir until combined (batter will be thick). Add in the caramel milk and mix until smooth. Coat a layer of butter in the rice cooker bowl covering all sides and bottom of the pot. This is to prevent your cake from sticking. Pour batter into the pan and turn the rice cooker on "cook". Depending on your model the cake can take 45 min to bake up to 70 minutes. Check for doneness at 45 minutes with a toothpick and check every 10 minutes until the toothpick has no uncooked batter on it. Let cake cool and decorate as desired.

***TIP** You can take the remaining caramel squares and milk to make more caramel as a topping (double the caramel/milk recipe above) or use your favorite icing. I used vanilla!!

Written by **Sara Izzo**



BEFORE ICING



AFTER ICING

"People who love to eat are always the best people"

Julia Child

Preventing and Managing Burn-out

According to the National Institute of Mental Health, “1 out of 5 adults in the United States live with a mental health diagnosis.”

However due to the historical, widespread stigma that exists around mental health and mental illness, individuals who have lived-experience with mental illness or a mental health diagnosis like depression or anxiety often have intense feelings of loneliness, hopelessness, or shame, which can cause them to feel like they must hide their struggles. They may do this by putting on a smile or a brave face just to get through the day, or by “faking it” in hopes that they will eventually get through a tough situation. Similar to individuals who experience burn-out from stress at work or school, those who live with mental illness or other mental health diagnoses can experience burn-out from trying to keep up with the balancing act of maintaining their daily responsibilities and duties while also trying to hide their mental health symptoms from others.

Several strategies may help you prevent and manage burn-out. Consider seeing a trained professional like a licensed social worker, psychologist, counselor/therapist, or psychiatrist. Work with a professional to develop coping mechanisms such as keeping a mood journal, deep breathing exercises, visualization, or talking with a trusted loved one or friend. Use whatever coping strategies work for you; it is not a “one size fits all” situation. Work with your loved ones, friends, or a professional to develop a plan for dealing with a crisis, should one arise. This is especially important, so that they can do their best to help you and can assist in advocating for you and your needs when you can’t be your own best advocate. Finally, keep a record of phone numbers and agencies that can provide support. Vibrant Emotional Health, is a nonprofit that operates a lifeline on behalf of the US Department of Health and Human Services’ Substance Abuse and Mental Health Services Administration. A new 988 dialing code is now available to everyone across the United States. You can also reach the lifeline at 1-800-273-TALK (8255), which will remain operational during the current expansion to 988. Text messages can be sent to the three-digit number as well. Resolve Crisis Services can also be reached at 1-888-796-8226. Their walk-in crisis center is located at 333 North Braddock Ave, Pittsburgh, PA 15208.

Written by Libby Powers, MS



Research Studies

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.

A research team at the Bloorview Research Institute at Holland Bloorview Kids Rehabilitation Hospital is doing a study to explore eating behaviours and body image in young people with spina bifida and/or hydrocephalus (SBH). As part of this, they are asking young people aged 12-26 with SBH to fill out an online survey to tell them about their eating behaviours and body image. The results of this study will help healthcare professionals improve their care when working with young people with SBH. If you, or someone you know, is interested in participating in this study, please click on the following [link](#). If you have any further questions, please contact the Research Coordinator, Revi Bonder, at rbonder@hollandbloorview.ca. Students are eligible to receive volunteer hours for their time.

Hey! There's an app for that!

Do you or someone you know

Currently receive service coordination from Service Coordination Unlimited (SCU)?

Would you like to participate in our research study?

Who is eligible?

- ★ Have a disability
- ★ Receive Service Coordination via SCU
- ★ Able to Use Smart Phone or Tablet

What is involved?

- ★ Try using our smartphone app
- ★ Give feedback about the app in interviews (~ 60 mins)
- ★ Interview can be over the phone or zoom meeting, and scheduled at your convenience
- ★ Study participants will receive compensation for their time



Your participation in this research study will not impact whatsoever any current or future services you receive from SCU.

Note: We can provide the phone or tablet if needed.

Please call/email the Study Coordinator

Study Coordinator

Zara Ambadar

Email: ambadar@pitt.edu

Phone: 412-608-6118

Your participation is completely voluntary.

Upcoming SBAWP Events



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.

Upcoming SBA Events



Spina Bifida Parents Group

<https://www.facebook.com/groups/601772426532557/about/>

Living with Spina Bifida in Central PA group

<https://www.facebook.com/groups/1480882882212462/about/>

Bowel Management for Spina Bifida

<https://www.facebook.com/groups/729598100490391/about/>

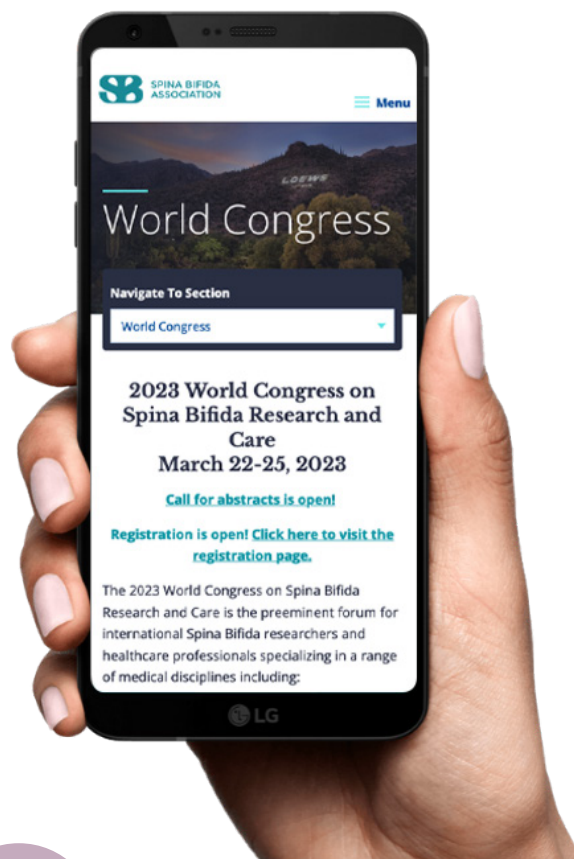
Join the Conversation” Zoom Calls

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

2023 World Congress on Spina Bifida Research and Care

The 2023 World Congress on Spina Bifida Research and Care is the preeminent forum for international Spina Bifida researchers and healthcare professionals. It will be held March 22-25, 2023 in Tuscon, Arizona. For more information, visit <https://www.spinabifidaassociation.org/world-congress-2/>.



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