



SPINA BIFIDA CLINIC NEWSLETTER

**Issue #14
Summer 2021**

Mimi is in the office every Monday
and Wednesday.

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Want to receive this newsletter by email?

If you have received this newsletter by mail and wish to receive it electronically, call or email Mimi, and she will add you to the Spina Bifida Clinic email list.

Send us your topic/story ideas!

We encourage your comments and input. Please contact us to share your story ideas or any questions/concerns that you feel should be addressed in an upcoming issue of the Spina Bifida Clinic Newsletter. We look forward to hearing from you!

Update from Mimi Ardis

Happy summer!

Just as our COVID-19 concerns were decreasing, new concerns began to arise regarding the Delta variant. This strain is responsible for 83% of new COVID cases in the U.S. It is highly contagious, and children are being affected. The good news is if you've been fully vaccinated, your chances of getting COVID are much less. Once vaccinated, if you were to get COVID, the symptoms should be milder, and hospitalization is not likely to be needed. On that note, I am again strongly encouraging all eligible people to get the COVID vaccine, including children ages 12 and up. (Note: At this time, teens ages 12-18 can only receive the Pfizer vaccine.) Studies are continuing regarding vaccinating younger children.

Did you know that OSF offers COVID-19 vaccines? Visit osfhealthcare.org/vaccine for details. You can also find a COVID-19 vaccine location near you by visiting vaccinefinder.org, which provides vaccine site options based on ZIP code and your preferred vaccine.

Exciting OSF HealthCare news

As of May 1, 2021, OSF is again in network with Meridian Health plan through IDPA. This is great news and allows our patients easier access to care at OSF HealthCare Children's Hospital of Illinois.

New clinic news

Anne Kirchgessner, APN-NP-C

Anne Kirchgessner, APN, will continue to see patients for neurodevelopment and physical therapy needs. Many of you are familiar with Anne as she saw patients in tandem with Dr. Sue Caldecott-Johnson. She will be working with the pediatric orthopedists to cover bracing needs.

Dr. Sean Corbett

Peds Urology has another locum starting: Dr. Sean Corbett. He has an office in Charlottesville, Virginia, through University of Virginia Health. You may see him in spina bifida clinic or as a follow up in regular clinic. He is joining Doctors Noh, Teague, Vandersteen and Chiang to provide urology coverage.

Dr. Jose Ramirez

Peds Ortho will have a new provider this fall: Dr. Jose Ramirez. He completed his bachelor's and master's degrees at Brown University in Rhode Island, graduated from medical school at Columbia University in New York, completed his orthopedic surgery residency and trauma fellowship at Brown University, and is currently completing his pediatric orthopedic fellowship at Children's Health Care in Atlanta. He will be joining Doctors Akeson, Prince and Michalowicz to meet all of your child's orthopedic needs.

This edition's topic

In keeping with the wellness theme of the last couple newsletters, this edition will focus on how to maintain healthy habits and the beauty of rest and sleep.

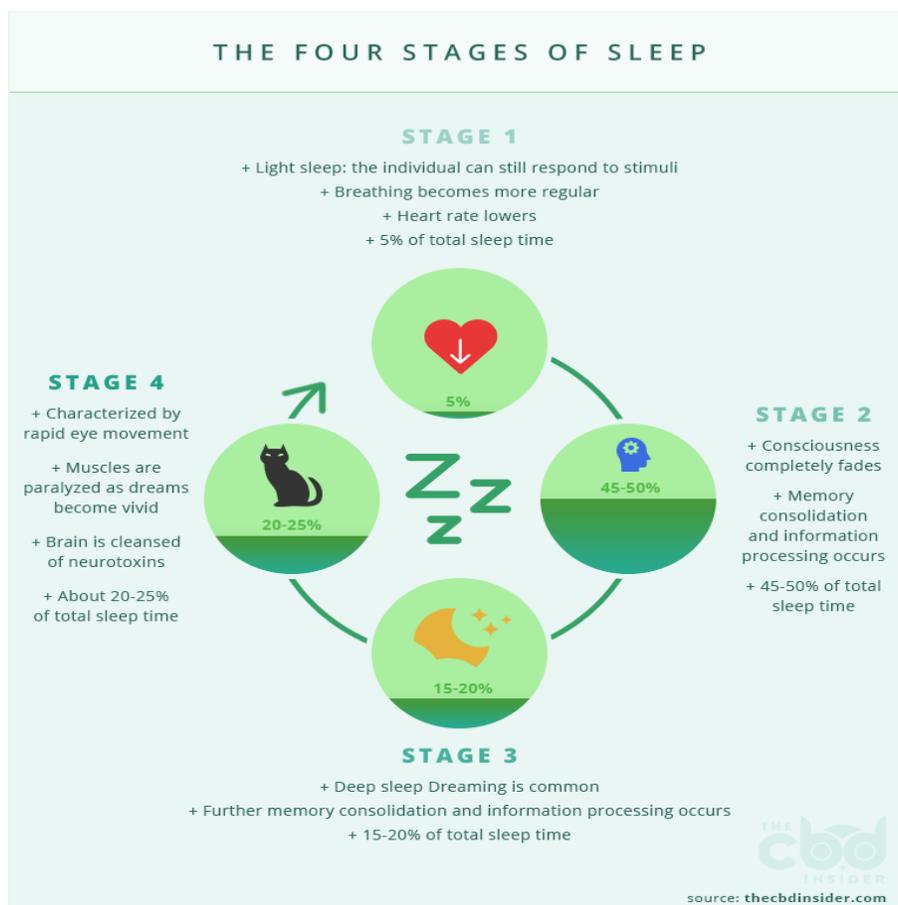
Stay safe and healthy!

Mimi

All you need is sleep

You need to get enough quality sleep for both your physical and mental health. The number of hours you sleep is important, but the quality of your sleep is even more important. Our brains and bodies restore, recuperate and develop while we sleep.

Our brains are active when we sleep. They go through many 60-90 minute sleep cycles in the course of the night. Each sleep cycle includes four sleep stages, but we all have different sleep cycles.



Stages 1 and 2 are periods of light sleep. You may wake up easily during these stages. Stage 3 is critical to quality sleep. It may be hard to wake a person during this stage. This is when our bodies recover and grow. We feel refreshed when we have adequate Stage 3 sleep.

Stage 4 is also called REM (rapid eye movement) sleep. REM sleep is needed for cognitive functions. This includes memory and learning. You may have vivid dreams in this stage. REM sleep can cause temporary muscle paralysis, and your breathing and heart rates will be higher. Brain activity is close to what it is when you are awake.

What happens to our bodies when we sleep?

When we sleep, our brains form new pathways. These pathways help our memory. They also help us to learn new things. Our brains also sort and store what we learn during the day. Sleep helps us be more creative and make better decisions.

Sleep helps regulate and release certain hormones. These hormones help stimulate or curb our appetites. They also help us grow and improve our moods. During sleep, our immune systems release a protein that helps fight infection and trauma. This helps our bodies heal. Sleep also plays a role in puberty and fertility.

What affects a good night's sleep?

Sleep deprivation is when a person doesn't get a "normal" amount of sleep, and it can happen over a short period of time, like a few days. It can also happen over a long time (weeks to months).

Many things can stop us from getting good sleep, including too much caffeine, alcohol or nicotine. A lack of physical activity or exercise can also hurt our sleep as can being overweight or obese. Too much stress or anxiety can hurt your sleep. Your sleep is also affected when you eat too much or too close to bedtime. It's also affected when you take too many daytime naps or have too much screen time or blue light exposure close to bedtime.

Sleep disorders are conditions that change the way we sleep. The most common are insomnia, sleep apnea, restless leg syndrome and narcolepsy. The most common symptom is excessive daytime sleepiness.

People with spina bifida have a higher risk for sleep apnea, especially as adults. Signs of sleep apnea include:

- Slow or shallow breathing
- Making snorting, gasping or choking sounds
- Stopping breathing for short periods of time

Being overweight or obese is the number one risk factor for sleep apnea. Other risk factors include having Chiari II malformation or scoliosis. Studies show that children with Chiari malformation have a much higher chance of having sleep disordered breathing. Moderate to severe scoliosis can affect lung function, and it limits one's ability to move normally.

If you have any signs of sleep apnea, you should talk to your doctor.

What happens when we don't sleep?

Lack of sleep impacts memory, concentration, fine motor skills and judgment. It also hinders your ability to fight off the common cold, and it can slow your reflexes. It can increase pain. It may make mental health issues like depression, anxiety or bipolar disorders worse. It can increase your risk for diabetes, heart and kidney disease, obesity, hypertension and early death.

Teens and children who are sleep deprived may have increased mood swings, hyperactivity or a poor attention span. They may act out or show a lack of motivation. They may feel angry, sad, or depressed.

The chart below contains general guidelines for the amount of sleep a person should get each night. Everyone is different, but we should try to at least get the minimum recommended amount.

How Much Sleep Do You Really Need?

Age	Sleep Needs
Newborns (0 – 2 months)	12 – 18 hours
Infants (3 – 11 months)	14 – 15 hours
Toddlers (1 – 3 years)	12 – 14 hours
Preschoolers (3 – 5 years)	11 – 13 hours
School-age children (5 – 10 years)	10 – 11 hours
Teens (10 – 17 years)	8.5 – 9.25 hours
Adults	7 – 9 hours

Tips for getting a better night's sleep

- Try to get at least your minimum number of hours of sleep shown on the above sleep chart.
- Go to bed and wake up at the same time every day.
- Practice relaxation or meditation before bedtime.
- Make your bedroom a good place to sleep. Keep it dark, quiet and cool. Use earplugs, white noise or a fan to lower outside noise. Make sure your mattress and sheets are comfortable and your pillow is right for your sleep position. Use low lighting. A diffuser with lavender essential oil is calming.
- Do not use computers, LED TVs, cell phones or tablets 30 minutes before bedtime. These emit blue light, which is a high-energy light. One-third of all light is blue light, with sunlight being the highest source. Blue light rays are good during daylight hours because they boost attention, reaction times and mood. But blue light blocks the production of melatonin. Melatonin is a hormone. It is produced and released according to the time of day. It increases with dusk and decreases with dawn. Production of melatonin decreases with age.
- Minimize distractions. Move computers and TVs out of the bedroom so you won't use them. Don't use your phone or tablet in bed.
- Exercise at least 20 minutes a day but not within several hours of bedtime.

- Nap early in the day but for no more than 20-30 minutes.
- Don't eat large meals or snacks within one to two hours of bedtime. Also, avoid sugary beverages and sweets before bedtime.
- Stop drinking beverages with caffeine six to eight hours before bedtime.
- Do not drink alcohol three hours before bedtime. Alcohol decreases REM sleep early in the night, but as it wears off, there is a rebound. This causes prolonged REM stages.
- Quit smoking! Nicotine is a stimulant, and it may keep you up.
- Keep stress and emotional thoughts or talks away from bedtime.
- It may help to keep your pet out of your bed or bedroom.
- According to SleepFoundation.org, there are some foods that may help you sleep better.
- Bananas have potassium and calcium, which are muscle relaxants.
- Honey allows tryptophan to enter the brain more easily. Tryptophan is an amino acid that helps produce serotonin, which is a hormone that makes us feel happy and also helps with sleep.
- Kiwis have antioxidant properties. They are high in folate and serotonin. One study showed that people who ate two kiwis one hour before bedtime fell asleep faster. They also had better sleep quality and slept longer.
- Malted or regular milk is high in vitamins B and D. Drinking malted milk may decrease sleep disruptions. All milk contains melatonin.
- Tart cherries and tart cherry juice have higher concentrations of melatonin. They are also high in antioxidants. Two one-cup servings per day improve total sleep time and efficiency.
- Fatty fish such as salmon are high in vitamin D and omega 3 fatty acids. These help regulate serotonin. Eating salmon three times per week improves overall sleep and daytime functioning.
- Nuts (almonds, cashews, walnuts, pistachios) contain melatonin and minerals.
- Rice has a high glycemic index, and eating it four hours before bedtime helps people fall sleep.

If you have tried all of the above and still have sleep issues, keep a sleep diary to track what affects your sleep. If your lack of sleep is severe or getting worse, talk to your doctor and ask about treatment options.

We need sleep to survive! So, try to improve your sleep habits to promote good sleep.

ISBA tutoring and coaching

Illinois Spina Bifida Association (ISBA) now offers **free tutoring** to Illinois students with spina bifida. Tutoring is done online via Zoom. For more information and to register, visit i-sba.org.

ISBA also offers **free executive functioning coaching** for Illinois adults and high school students with spina bifida who want to work toward personal goals and develop plans and strategies to achieve them. The training consists of four sessions over one month, one hour per week by phone or video chat. If you're interested, contact ISBA at (773) 444-0305 or info@i-sba.org.

ISBA Equipment Fund

Families may request up to \$125 toward out-of-pocket costs for orthotic or other mobility equipment. To qualify, the equipment must be utilized by an Illinois resident with spina bifida. The ISBA Equipment Fund is made possible by a generous gift from "A Helping Hand."

Medical Supplies and Services Fund

Illinois families living with spina bifida can request up to \$125 toward out-of-pocket costs for spina bifida medical supplies and services. Applications are available via ISBA's mailing list. Update or add your address by sending an email to info@i-sba.org or call/text (773) 444-0305. Proof of spina bifida diagnosis may be required if you are new to ISBA. There are no fees to be on the mailing list, and ISBA does not have memberships. We serve all people living with spina bifida in Illinois.

24th Annual Memorial Walk-and-Roll-A-Thon

Join us for the 24th Annual Memorial Walk-and-Roll-A-Thon where we'll be raising funds for Central Illinois programs serving children, adults and families living with spina bifida. There will be a picnic lunch for all registered participants, and Tim Kirk will have hand cycles to try out.

- **When:** Sunday, October 3; noon – 3 p.m.
- **Where:** Tipton Park in Bloomington

For more information, visit i-sba.org.