



## SPINA BIFIDA CLINIC NEWSLETTER

Issue #18  
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Mimi Ardis is in the office every  
Monday and Wednesday.

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### **In this issue:**

- 2: Update from Mimi
- 3: Spine abnormalities
- 4: Scoliosis
- 5: Kyphosis
- 6: Treatment
- 7: Walk-and-Roll-A-Thon

### **Want to receive this newsletter by email?**

If you have received this newsletter by mail and wish to receive it electronically, please call or email Mimi at the information above, and she'll add you to the Spina Bifida Clinic email list.

### **Send us your topic and story ideas!**

We encourage your comments and input. Please contact us to share your story or any questions or concerns 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**

The times they are a changing! There are many new exciting changes happening at Children's Hospital of Illinois and, in particular, at Pediatric Urology.

### **Staff changes**

We will be welcoming Dr. Ali El Ghazzaoui in January 2023 as he relocates to central Illinois from Toronto, Canada. I will provide more in-depth information on Dr. El Ghazzaoui in a future issue. Tentative plans are for him to attend SBC starting in January.

Until that time, we have a new locum provider, Dr. Charles Gerry Henderson. He's a pediatric urologist from Pensacola, Florida, and will be here periodically starting the week of August 21. He may be assisting at the Spina Bifida Clinic if his schedule coincides with clinic dates. Dr. Noh will continue conducting video visits post clinic as well.

On a sad note, I'm sorry to announce that Dr. Michele Verda, a neuropsychologist, has accepted a new position at St. Louis Children's Hospital. Her last clinic was on August 8. Her expertise will be sorely missed.

### **BASC questionnaire**

Prior to your child's clinic appointment, I will email you a link to Q Global's BASC (neuropsych) questionnaire. The BASC questionnaire provides useful information regarding your child's behavior. It assesses problem behaviors, such as aggression, anxiety, attention issues, hyperactivity and learning issues. It also assesses adaptive skills, such as communication, study and social skills. Other assessed areas include anger control, bullying, emotional self-control, executive function and resiliency.

The questionnaire will take approximately 10-15 minutes to complete. If your child is age 8 or older, you'll receive two emails: one for your child to fill out about themselves and one for you (parent or guardian) to fill out about your child. Tessa Day, a licensed social worker, will review and discuss results and recommendations with you at clinic. I truly appreciate your time and attention to this questionnaire as BASC gives us so much useful information about your child.

### **More about this issue**

This edition will continue with age-specific issues. I will focus on ortho issues in particular that can occur in adolescents, specifically scoliosis.

### **Facebook support group**

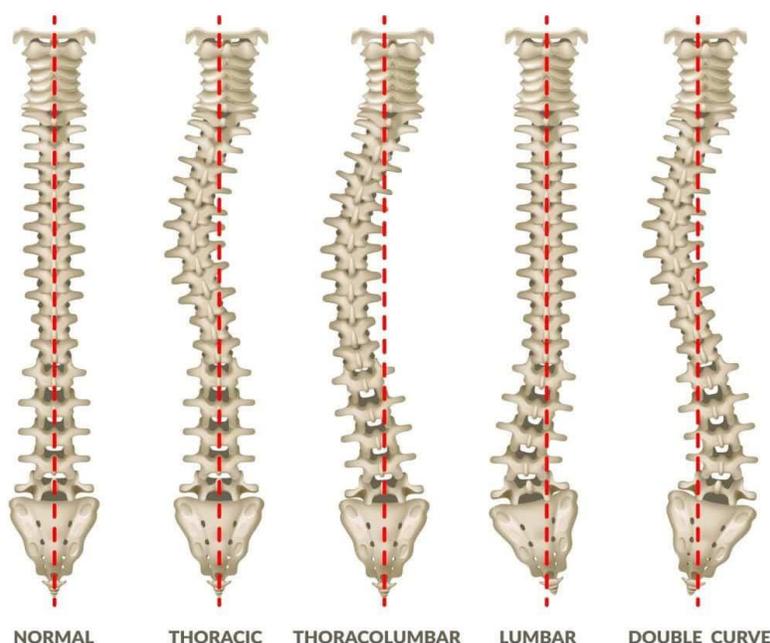
The Facebook group for Spina Bifida Support of Central Illinois is located at the following link and can also be found by searching for "Spina Bifida Support of Central Illinois" in Facebook: <https://www.facebook.com/groups/2583258388573318/?ref=share>. This is a private group, so you'll be asked confirmation questions prior to being accepted into the group.

Anytime you have needs, feel free to call me at (309) 624-4064. Stay safe and stay healthy!

- Mimi

## Spine abnormalities in people with spina bifida

**Scoliosis** is an abnormal curvature in the spine (backbone). Up to 50% of persons with spina bifida will develop scoliosis. The curvature can occur on the right or left side of the spine (known as a C curve) or on both sides of the spine (known as an S curve). The middle spine (thoracic) or lower spine (lumbar) can both be affected. Scoliosis is diagnosed when the curvature is 10 degrees or higher.



There are three types of scoliosis.

- **Congenital:** This occurs due to abnormal vertebrae. Although it can be diagnosed in infancy, it is generally diagnosed later in childhood. The scoliosis may worsen as the child grows, which causes noticeable changes in the body. In general, this is monitored and treated if the curve worsens.
- **Idiopathic:** There is no known cause for this type of scoliosis, which is the most common type of scoliosis. It generally develops at the onset of adolescence – around age 10 in girls and age 12 in boys. It worsens with growth, especially during growth spurts. Girls have a higher incidence of developing idiopathic scoliosis.
- **Neuromuscular:** Children with underlying neuromuscular conditions such as cerebral palsy or spina bifida have a greater incidence of developing scoliosis. This develops from poor core (abdominal) muscle strength and balance. These muscles can be weak or paralyzed, causing the abnormal curve. It is also associated with abnormalities in the spine from the myelomeningocele defect itself. This is the second most common form of scoliosis.

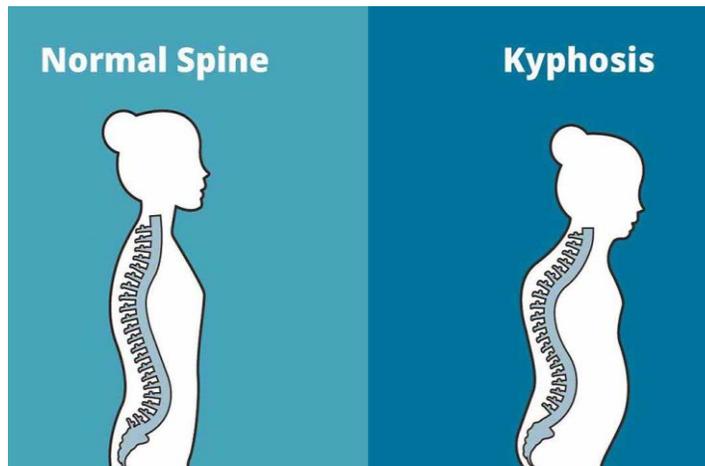
## Causes of scoliosis

- Most cases of scoliosis have an unknown cause.
- Spina bifida, CP and muscular dystrophy are caused by poor muscle strength or spasticity.
- Genetics: Marfan syndrome and Down syndrome
- Family history of scoliosis
- Leg length discrepancies

## Signs and symptoms of scoliosis

- Seating issues: Leaning to one side and/or needing to sit using arms for support
- Differences in shoulder height, uneven shoulder blades
- When the head is off center (not centered on the body)
- Uneven hips
- Arms hanging at different lengths when standing
- Asymmetry of the ribs: One side is more prominent when viewing from the front or back.
- Sides of the back are different heights when bending forward at the waist.

**Kyphosis** is an abnormal curvature – forward rounding – of the upper back. In mild forms, it does not require treatment. Normal cervical (upper/neck) spines have a 20-45 degree curve. Kyphosis is diagnosed if the curve is 50 degrees or higher. Most cases of kyphosis do not cause issues and do not need to be treated.



## Causes of kyphosis

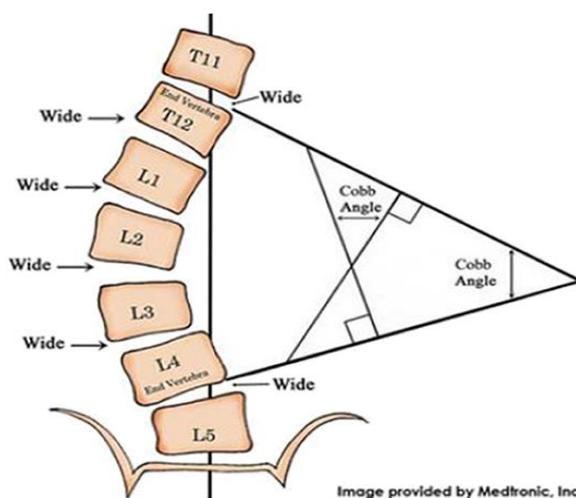
- Broken vertebra or compression fractures occur in weakened bone, causing curvature.
- Osteoporosis causes weakened bones. This is more common in older women or people who have been on long periods of corticosteroids.
- Disk degeneration, which occurs with age
- Scheuermann's kyphosis occurs because the vertebrae are abnormally wedge shaped instead of rectangular. This abnormal shape pushes the vertebrae together, causing the spine to curve. It occurs during growth spurts during puberty and tends to worsen with time.
- Congenital kyphosis occurs in children because the spine does not form normally in the womb. It can also be related to other medical conditions, such as Ehlers-Danlos or Marfan syndromes.

## Signs and symptoms of kyphosis

- Visible hump in the back
- Back pain
- Rounded shoulders that are different in height

## Diagnosing scoliosis or kyphosis

- Diagnosis requires a physical exam by a pediatrician or orthopedic physician. Both scoliosis and kyphosis can cause kids who use wheel chairs to have sitting imbalances, which results in skin pressure areas and sores.
- The easiest, most common diagnostic tool is a 2-3 view (front and side views) X-ray of the spine. A radiologist or orthopedic physician will measure the curves of the spine in the X-ray. This is generally done every six to 12 months to monitor progression but may be done at shorter intervals depending on severity of the curve.
- A spine MRI provides more in-depth imaging and shows the health of the spinal cord.
- A spine CT scan may also be used.



The above diagram is an example of how scoliosis curves are measured from a spine X-ray. The worse the curve, the higher the degree of the angle.

## Treatments

Unfortunately, scoliosis and kyphosis in children with spina bifida tend to worsen as the child grows. The goal of treatment is to stop or minimize the growth of the spinal curve and correct it. Left untreated, scoliosis can cause significant health issues. Severe curves can cause breathing issues, pain, digestion issues, pressure ulcers and changes in the bowel and bladder.

A treatment plan will be decided by your child's orthopedic surgeon. There are numerous factors that are considered prior to treatment, such as age and health of your child, severity of the curvature, how well they tolerate treatment, and your own opinions and choices as the parent.

- **Observation:** Some children will not need treatment. They should be evaluated prior to and after growth spurts. A tethered spinal cord can worsen and is often associated with scoliosis.
- **Bracing:** A thoracolumbosacral orthotic (TLSO) may be beneficial. This is a plastic external torso brace that is used for growing children with curves between 20 and 50 degrees. It should be worn daily for a certain number of hours and can be effective if worn

as prescribed. Many children find it difficult to wear it as prescribed due to physical discomfort, excessive sweating and mobility restrictions. Bracing is only effective if your child is still growing.

- **Surgical options**

**Spinal fusion:** In this procedure, the spine is realigned and stabilized with rods and pins or screws that fuse the vertebrae together. This is to stop the progression of the curve. This is a very extensive, invasive procedure. Some drawbacks include:

- It will not be performed until your child is done growing.
- Most patients will have a hospital stay of one to two weeks at a minimum.
- The spine does not grow after the fusion, and mobility/flexibility of the fused spine is severely impaired or absent after spinal fusion.

**MAGEC growing rods (magnetic expansion control rods):** One or two titanium rods are placed on either side of the spinal column and held in place by hooks and screws. The rods can be lengthened using an external magnetic motor. The motor is placed on the child's back and extends the rods in small increments. The rods are "grown" every three to six months for three years. One main benefit of MAGEC rods is that it's done on younger children who are still growing. The drawbacks include:

- There are frequent visits to the orthopedic surgeon to have the rods "grown."
- If your child is active, they may damage the hardware (rods, hooks and screws).
- The rods are magnetic, so it's not possible to have any type of MRI after placement.

**Vertebral body tethering:** This is a fairly new treatment option in which a flexible cord is attached and anchored to the front of the spine with screws. The cord is tightened during surgery causing the spine to straighten.

Benefits include:

- There are numerous one-inch incisions instead of an extensive back incision
- The flexibility and growth of the spinal cord remain.

Risks include:

- There could be under- or over-correction of the curve.
- There is a higher risk of either needing this procedure repeated or needing spinal fusion at some point.
- Another down side to this procedure is that few facilities are performing it, and since it's relatively new, long-term outcomes are unknown. Mayo Clinic is currently performing the surgery, and they will be doing research at two years post-procedure to check the treatment's effectiveness.

It's important to always follow up with your child's orthopedic physician for routine scoliosis care.

## **25th Memorial Walk-and-Roll-A-Thon**

The 25<sup>th</sup> Memorial Walk-and-Roll-A-Thon will be held in memory of Emma Kenny, Shannon Kolodzieski, Kaylin Rood and Sarah Whitted and is intended to raise funds for programs serving children, adults and families living with spina bifida.

### **When and where:**

- Sunday, October 2, 2022
- Check in: Noon
- Start time: 12:30 p.m.
- Where: Tipton Park, 2201 Stone Mountain Blvd., Bloomington, Illinois

All are welcome, and a free picnic lunch and activities will be provided for all registered participants. To help us cover costs, please raise or donate \$20 per person.

To register, call or text (773) 444-0305 or email [info@i-sba.org](mailto:info@i-sba.org). Find more information at <https://i-sba.org/walkandrollathon>.

## **Free executive functioning coaching**

ISBA offers free executive functioning coaching for adults and high school students in Illinois 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 the course of one month for one hour per week. They're conducted by phone or video chat. If you're interested, please contact us at (773) 444-0305 or [info@i-sba.org](mailto:info@i-sba.org).

## **Free Education Advocacy**

ISBA offers free Education Advocacy services to Illinois families living with spina bifida for:

- Individualized Education Programs (IEP)
- Individualized Family Service Plans (IFSP)
- 504 Plans

ISBA has a trained parent advocate who can offer assistance and advice in navigating the complex world of special education. The parent advocate can support you by:

- Attending meetings with you and your child's educational team
- Reviewing educational plans
- Advocating for the rights of your child

If you have any questions or concerns regarding your child's education, please contact ISBA to be connected with our trained parent advocate. Call or text (773) 444-0305 or email us at [info@i-sba.org](mailto:info@i-sba.org).