

School Nurse's Guide to Scoliosis

What to look for, how it's treated—and what it's like to live with

Prepared by
The Spinal Program at
Boston Children's Hospital
Orthopedic Center



**Boston
Children's
Hospital**

Until every child is well™



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Until every child is wellSM

Staying ahead of the curve

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A note to school nurses

How this booklet can help you

This booklet can be printed as a whole unit or as individual sections to share with your students and their families. Please let us know if the booklet is helpful or if you have suggestions for improvement, by contacting the Boston Children's Hospital's Spinal Program at 617-355-6021.

As you know, idiopathic scoliosis accounts for 80 to 85 percent of scoliosis cases, and doesn't happen all at once. It develops gradually over time, and may worsen quickly during rapid growth in the pre-teen and teen years.

Because of the evolving nature of scoliosis, there are a few ways to recognize opportunities for early intervention.

Observation

The work you do in screening for scoliosis is essential because it helps ensure that scoliosis is identified early enough to achieve a better outcome. Once an abnormal spine curve is detected, it's important to monitor the child's growth since curves may progress as growth occurs. Her physician will decide on a treatment plan based on X-rays and physical exams.

Treating scoliosis early to avoid future problems

Scoliosis rarely prevents children and adolescents from living normal lives, but we hope that this booklet will help you communicate to your students and their families the importance of careful screening at age-appropriate intervals during a child's growing years, and of taking early action if a curve is detected.

With the help of the information in this booklet, you can share these critical reasons for early screening with kids and their families:

- Treatment after the curve has already become severe in adulthood is much less successful than treatment during childhood or adolescence.
- Adults with moderate or severe scoliosis can have progressively worsening curves that cause cosmetic disfigurement, back pain and in extreme cases, difficulty breathing.

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What is scoliosis?

Scoliosis is a condition in which the spine has an abnormal side-to-side "S-" or "C"-shaped curvature.

In addition, the spine may also rotate or twist, pulling the ribs along with it to form a multidimensional curve. The Scoliosis Research Society defines scoliosis as a curvature of the spine measuring 10 degrees or greater on X-ray.

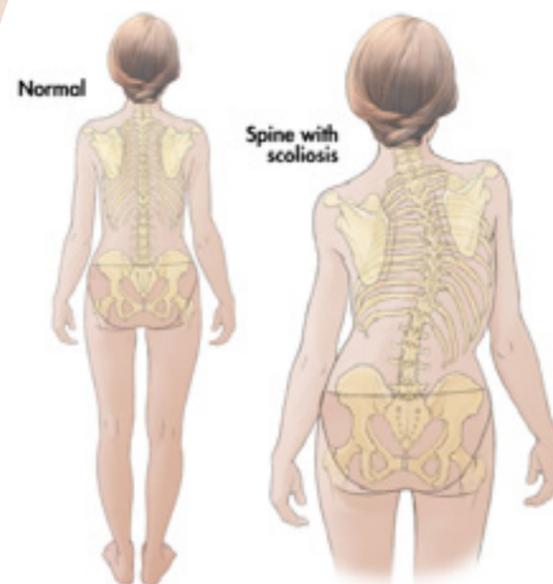
Most of the time, scoliosis is more of a cosmetic challenge than a health challenge, and children may not experience pain or other symptoms. In more severe cases, a child's bones may twist in a way that puts the organs at risk. Usually when this happens, surgery is required.

Scoliosis occurs and is treated as three main types:

Idiopathic scoliosis is the most common form, with no definite cause. It mainly affects adolescent girls, but also appears in infants and juveniles.

Neuromuscular scoliosis is associated with a neuromuscular condition such as cerebral palsy, myopathy or spina bifida.

Congenital scoliosis, the least common form, is present at birth, and caused by a failure of the vertebrae to form normally.



Watch video: Surgical treatment for scoliosis at Boston Children's Hospital's Orthopedic Center



Helping patients
lead healthy,
active lives



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What is the anatomy of scoliosis?

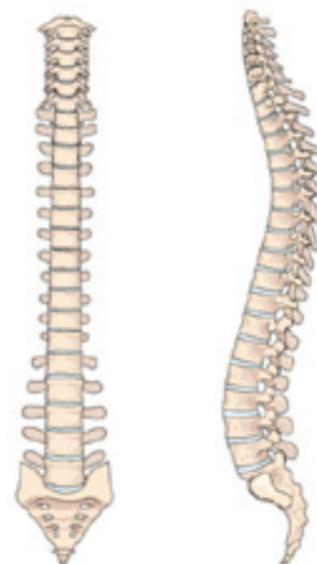
The normal spine is strong and mobile.

While it varies in size and shape from person to person, the healthy spine has natural front-to-back curves that enable us to walk, balance, sit, stand and twist. When these natural front-to-back curves become too large, they can present a potential problem.

The scoliotic spine is rotated or twisted to form a multi-dimensional curve. Spinal curvature from scoliosis may occur on the right or left side of the spine, or on both sides in different sections. Both the mid (thoracic) and lower (lumbar) spine may be affected by scoliosis.



Left: normal spine. Right: scoliotic spine



Spine viewed from the front (left) and side (right)

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Who gets scoliosis?



Visceria was treated for scoliosis as a pre-teen. As a teen, she's now back to sports and cheerleading.

Scoliosis is not rare, and mainly affects girls—many of whom have mild forms of the condition and are never even aware of it or need treatment.

Three to five children out of every 1,000 develop spinal curves that are considered large enough to require treatment. Idiopathic scoliosis tends to run in families, although no definitive genetic link has been confirmed. Girls are more likely to have a curve that progresses.

Risk factors for developing idiopathic scoliosis include:

- **Age:** Signs and symptoms of scoliosis may begin to manifest themselves with the onset of puberty, during the maximum growth spurt.
- **Gender:** Girls are five to eight times more likely than boys to develop scoliosis that requires active treatment.
- **Heredity:** Idiopathic scoliosis tends to run in families.

In most cases, there is no definite cause or way to prevent the spine's failure to grow as straight as it should. Scoliosis is a spinal abnormality—it's neither a cause nor a result of poor posture or use of a backpack.

Unique treatment for every child

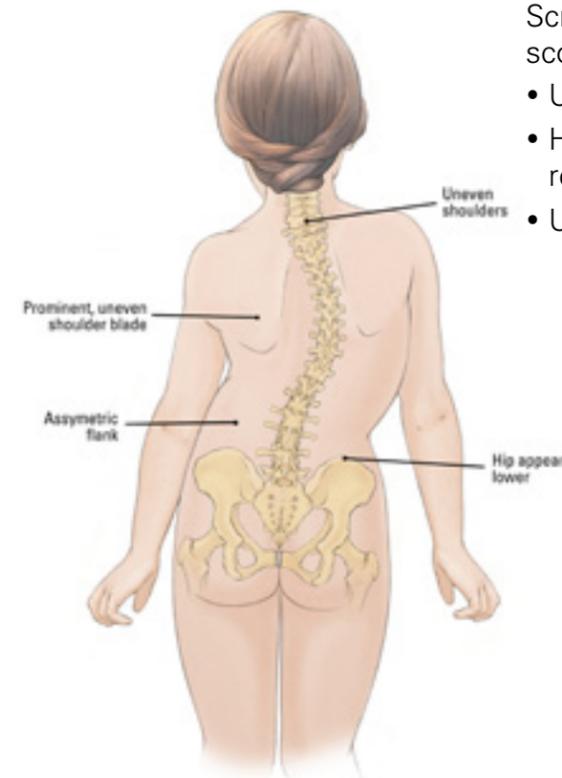
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What are the signs and symptoms of scoliosis?

Because of the many possible combinations of curvatures, scoliosis can be very different in different people.

Screening will reveal common signs and symptoms of scoliosis, including:

- Uneven shoulder heights
- Head not centered with the rest of the body
- Uneven hip heights or positions
- Uneven shoulder blade heights or positions
- One prominent shoulder blade
- When bending forward, the left and right sides of the back are asymmetrical



Translating science into care

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How is scoliosis diagnosed?

Sometimes curves are obvious, but other times they aren't immediately visible. Since scoliosis curves often aren't painful and usually progress slowly, they can be overlooked until a child approaches puberty.

The Adams Forward Bend test is a common way to look for scoliosis. During this examination, the student puts his or her hands together and bends forward while keeping the knees straight—making her spine visible, and curves or unevenness more obvious. The clinician can observe any unevenness in the hips, ribs or shoulder or use a scoliometer to measure the degree of a curve. If a curve measures more than 5-7 degrees on the scoliometer, it may be scoliosis. The curve's overall impact will depend on the child's age and bone maturity.

During your student's physical exams, her physician will be looking for and measuring abnor-

mal contours that indicate scoliosis. Through physical exams and diagnostic testing, the doctor will determine the:

- Shape of the curve ("S" or "C" shape; involvement of ribs and muscles)
- Location of the curve (upper thoracic spine; lower lumbar spine; or both—thoracolumbar)
- Direction of the curve (bend to left or right)
- Angle of the curve in degrees (Cobb angle)

Once a problem is detected, doctors use medical and family history, physical exams and diagnostic tests to determine the nature and extent of your student's scoliosis.

Commonly done:

X-rays (front and side)

Occasionally done:

Magnetic resonance imaging (MRI)

Rarely done:

- Computerized tomography scan (CT or CAT scan)
- Blood tests
- Ultrasound (sonogram)
- Bone scans
- Bone density scans (dual-energy X-ray absorptiometry, DEXA, DXA)
- Pulmonary function tests



The Adams Forward Bend test is a common way to look for scoliosis. Opposite: X-rays detect the magnitude of the scoliosis curve

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How is scoliosis treated?

Treatment for scoliosis depends on the nature and severity of the condition. Treatments can include:

Treatment without surgery

Simple observation and monitoring: Once an abnormal spinal curve has been detected, it's important to monitor it closely as the child grows. In many cases, this may be the only treatment needed. The child's physician will determine the appropriate treatment plan and follow-up based on her X-rays and physical exams. Referral to an orthopedic specialist may be recommended.

Physical therapy: Physical therapy may address any pain and imbalance that can be associated with spinal abnormalities.

Bracing: If your growing student's curve shows significant worsening or is already greater than 30 degrees, your physician may recommend a bracing program, in which a scoliosis brace is custom-designed to suit a

particular curve. The brace holds the spine in a straighter position while it grows both to help correct the curve and prevent it from getting worse. This may help avoid the need for surgery. (See next section for more on bracing.)

Casting: In certain situations—as in some cases of early-onset (infantile) scoliosis—body casting is done to help straighten the spine.

Treatment with surgery

In more severe cases, surgery can help correct spinal problems.

Spinal fusion: The most common surgical procedure for treating spinal problems in adolescents is fusion and instrumentation combined to correct and solidify the curve.

For younger growing children: Dual posterior growing rods (for early-onset scoliosis) control spinal deformity while allowing spinal growth with periodic lengthening.

Expansion thoracostomy/VEPTR™ (titanium rib) is a procedure to control chest and spine deformity while permitting growth of both the chest and spine.

Vertebral stapling is a minimally-invasive surgical alternative to bracing for scoliosis in some circumstances.

Hemivertebra and wedge resections (for congenital scoliosis)

Spinal osteotomy is the controlled breaking or cutting and realigning of bone into a corrected position. It may be performed when there is significant deformity.

Watch video: Non-surgical management of scoliosis at Boston Children's Hospital's Orthopedic Center



Guiding growth

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A closer look at bracing

Treatment of your student's scoliosis depends on the curvature's location and degree of severity.

Slight curves (measuring less than 20 degrees), usually require no treatment, but must be watched carefully for worsening during growth.

If your student's curve shows significant worsening or is already greater than 30 degrees and she is still growing, her doctor may recommend a bracing program.

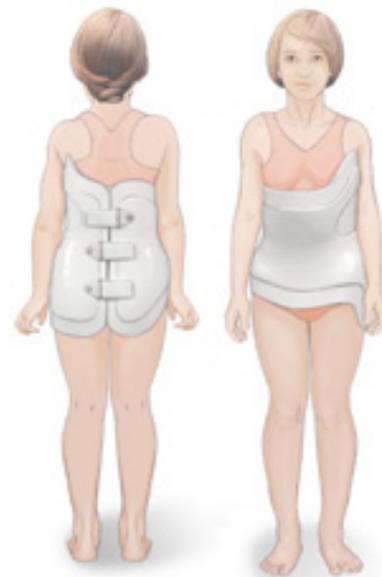
A scoliosis brace is designed especially for each patient and her particular curve, and may help avoid surgery. Your student will need to wear her brace for the prescribed daily time until she finishes growing. Most braces can be hidden beneath normal clothing, and the student can continue to do all athletic activities.

The child's physician usually works with a team of professionals, such as orthotists and physical therapists, who will help her adjust to bracing treatment. An orthotist is a trained professional in the construction and fitting of the spinal brace. Construction of the individual customized brace includes measurement of the patient's body contour, manufacturing of the brace, and final fitting of the brace to the patient. The process takes several visits to the orthotist and several weeks to complete.

The physical therapist (PT) will evaluate the patient's posture, muscle strength and flexibility. The PT will provide her with a home exercise program designed specifically for her. This program helps to stretch and strengthen

the child's muscles so that she is more comfortable in her brace.

A bracing program can be difficult, and the student may need help in organizing her daily activities. In many cases, clinical staff will help the child and her parents with their questions and appointments. Staff members will also teach the child how to care for herself and her brace, give her a schedule to follow and help her plan day-to-day activities.



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What's the long-term outlook for kids with scoliosis?

As the child grows, an orthopedist will monitor her curve through frequent check-ups.

No matter how old your student is, she can be encouraged to live normally and participate in sports or school activities. These will add greatly to her general health and sense of well-being.

The outlook for your student greatly depends on the nature and severity of her scoliosis and her age. Since older teens have already completed the majority of growth, their bones probably won't evolve as much as a

younger child's would. Early diagnosis and early treatment can improve the outlook for many forms of scoliosis—and most children and teens diagnosed with scoliosis can look forward to normal, active lives.

For you to share with
YOUR
-teenage
student-patient

Dear _____,

Being a teenager is complex enough already, so handling your scoliosis might seem even harder. Luckily, there are a lot of ways you can treat it, and continue living a normal life.

If you're undergoing bracing and physical therapy for scoliosis, you can take charge of your medical appointments and learn more about taking personal responsibility for your health. If your scoliosis is mild or moderate, you may wonder why we need to monitor and treat it, since it may not bother you or be painful—but know that we have your best interests in mind.

Fortunately, children and adolescents with scoliosis can usually live happy, healthy and normal lives. Even children with braces or who require surgery have been able to continue playing sports and leading active lives. Checking in regularly with your doctor can help this process go even more smoothly.

The best part is that the sooner you treat it, the better off you may be. So dealing with scoliosis now could make your life easier later. It's important for you to know that if left untreated until you're an adult, your moderate or severe scoliosis can worsen, resulting in curves that might change your appearance, cause back pain and in severe cases, make it hard to breathe.

Treatment in adulthood after the curve has already become severe is less successful than treatment during your teenage years. So, by treating you early, we hope to keep curves from becoming problems when you reach adulthood.

It may also help you to know that you can participate in sports and other normal activities—your general health will actually improve with an active lifestyle.

If you feel overwhelmed, depressed or anxious about the treatment of your scoliosis, please speak to your parent, doctor, counselor or me. We're all on your team—and we're all here to help.

Sincerely,

Your School Nurse

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Living with scoliosis: Visceria's story

Reprinted with permission from Thriving, a blog of Boston Children's Hospital

One patient's story: living with scoliosis

by Boston Children's Hospital staff on November 10, 2010

Visceria Givans is a student athlete, diagnosed with scoliosis in grade school. She received corrective spine surgery at Boston Children's Hospital a few years later and is actively playing sports again. In the following post she discusses her treatment, recovery and how she refused to let scoliosis define her or impact her self-esteem.

Getting checked for scoliosis at school is a little strange. First, you have to wear a bathing suit under your clothes that day because the school nurse needs to be able to see the entire line of your back to make sure your spine is growing correctly. Then, they disrupt the whole school day by checking all the kids for curvatures in their spine, one at a time.

When I had my first scoliosis test back in the fourth grade, it was even stranger for me because after it was over the nurse mentioned that it looked like my back was growing a little crooked, and it was something we'd need to keep an eye on.

I didn't know exactly what to think, but the nurse didn't seem too worried so my parents and I didn't think much about it either. For the next few years my doctor checked my spine regularly and when it was clear the curve was getting worse he suggested I wear a brace to try to correct it.

Wearing the brace took some getting used to. For starter's it's pretty big, so it stretched out a lot of my clothes. Secondly, it's not the most comfortable thing in the world to spend 20 hours a day in a brace that covers you from your shoulders to your belly, so even relaxing things like sitting and watching TV became kind of

a chore. Not a perfect situation, but after a while you get used to it and find ways to adapt. I bought bigger clothes that looked good but still left room for the brace, and quickly learned which positions were more comfortable with my brace on. The hardest part was when it prevented me from cheerleading and playing sports, which have always been a big part of my life, but I managed to find other ways to help the team. When my scoliosis kept me on the sidelines I assisted the coaches and offered suggestions and encouragement to my teammates.

After a year with the brace it became such a regular part of my life I almost forgot I had it on. I think the brace may have forgot too, because by the time I turned 13, Dr. Karlin, the scoliosis specialist I saw at Boston Children's Hospital, said it didn't seem to be doing enough to correct the

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Living with scoliosis: continued



Opposite: Visceria after having her scoliosis treated at Boston Children's

curvature in my spine. I didn't feel any different, and it didn't hurt in any way, but my doctor explained that as time went on it could get a lot worse. I could develop a hunch back, and if my spine got too crooked it could press against some of my organs which could lead to very serious medical problems as I got older. Dr. Karlin explained that best way to prevent this was surgery, where they'd permanently straighten my spine by fusing it with a metal rod.

The surgery took over nine hours, but when I woke up my spine was straighter and I was a full two inches taller. My mom couldn't believe how different I looked standing that straight. She said she always thought my slumping was because I was a teenager and I was being moody,

but it really was just the shape of my back!

Even though my surgery was over, the biggest challenge of my scoliosis still lay ahead: physical therapy and recovery. At first everyday things like getting out of bed and walking up and down stairs were real challenges; I had to work closely with both my physical therapist and my parents to relearn how to do even the simplest tasks. I also lost a lot of weight because the medication I was on took away my appetite, but as soon as I got off the meds I started eating again.

It's been over a year since my surgery and I'm back to cheerleading and playing lots of sports, which feels great. It also feels good to know that my story can help other kids. Last year a girl a few years younger than me found out she had scoliosis, and I was happy to be able to tell her that it doesn't have to affect her

life too much, or keep her from doing the things she liked. It may not be the most original piece of advice, and really it applies to everyone and not just people with scoliosis, but I told her the best thing she could was to just be confident in who she was. If you are a strong person with a healthy self-esteem it's easy to not let something like a curved spine, or any other medical condition, define who you are as a person.

Read another patient story about Anjellina who overcame two scoliosis surgeries.

Glossary

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Terms your students and their families may need to know

Adams Forward Bend test: a screening tool for scoliosis.

Adolescent scoliosis: a classification of idiopathic scoliosis representing the vast majority of cases—mostly occurring in girls ages 10 to 18; many cases of this kind of scoliosis don't require any kind of treatment.

Brace, bracing (spinal orthosis): If a curve significantly worsens or is already greater than 30 degrees, a physician may recommend a bracing program, in which a brace is designed specifically for a particular curve. The brace holds the spine in a straighter position while the child or teen grows in order to partly correct the curve or prevent it from increasing.

Casting: an option for holding the spine in a straighter position while growing. This is used in specific situations, as in some cases of early-onset (infantile) idiopathic scoliosis.

Cobb angle: an angular measurement on X-ray to evaluate the degree and severity of scoliosis curves

Congenital scoliosis: The spine forms and develops between three and six weeks after conception. Congenital scoliosis results from abnormal in utero spinal development, where a vertebra either doesn't form at all or only forms partially, or there is a lack of separation of the vertebrae.

Diagnosis: identifying disease or injury through examination, testing and observation

Dual posterior growing rods: Devices affixed to the spine (for early-onset scoliosis). These control spinal deformity while allowing spinal growth with periodic lengthening.

Idiopathic scoliosis: the most common form of scoliosis. "Idiopathic" simply means that there's no known cause. Nothing a parent or child did caused the problem, and there's nothing anyone could have done to prevent it.

Infantile idiopathic scoliosis (one of several types of early-onset scoliosis): a classification of idiopathic scoliosis representing about 5 percent of cases. The only type of scoliosis occurring more often in boys from birth to 3 years of age; often resolves on its own, but can sometimes be serious

Instrumentation: the metal rods, hooks, screws and wires implanted during spinal fusion surgery to correct the spinal curve, and secure the spine in position while the fusion heals and becomes solid

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Glossary

Juvenile scoliosis: a classification of idiopathic scoliosis representing about 10 percent of cases—occurring in children ages 3 to 9 years

Neuromuscular: affecting, or characteristic of, both neural (nerve) and muscular tissue

Neuromuscular scoliosis: scoliosis that's associated with disorders of the nerve or muscular systems like cerebral palsy, spina bifida, muscular dystrophy or spinal cord injury

Orthopedics: the medical specialty concerned with diagnosing, treating, rehabilitating and preventing disorders and injuries to the spine, skeletal system and associated muscles, joints and ligaments

Orthopedic surgeon, orthopedist: a physician specializing in surgical and non-surgical treatment of the spine, skeletal system and associated muscles, joints and ligaments

Orthotics: the science of designing and fitting of devices such as braces to treat orthopedic conditions

Physical therapy: a rehabilitative health specialty that uses therapeutic exercises and equipment to help patients improve or regain muscle strength, mobility and other physical capabilities

Progression, curve progression: worsening of a scoliosis curve

Scoliometer: a surface measurement device for evaluating the angle of trunk rotation (ATR or scoliometer angle, which is different from the 'Cobb' angle measured on X-ray)

Scoliosis: a spinal condition in which the spine, in addition to the normal front-to-back curvature, has an abnormal side-to-side "S-" or "C"-shaped curvature. The spine is also rotated or twisted, pulling the ribs along with it. Scoliosis occurs in three main types: idiopathic (no definite cause), neuromuscular (associated with neuromuscular diseases) and congenital (present at birth).

Spinal cord: a nerve bundle within the vertebral column that extends down from the brain stem. It conducts signals in both directions between the brain and extremities, and allows for bodily motion and sensation.

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Glossary

Spinal abnormality (spinal problem): a condition in which the spine is abnormal. It may be that the spine's structure has developed abnormally—for example, congenital scoliosis or congenital kyphosis. Some are the result of nerve or muscle (neuromuscular) diseases or injuries—for example, cerebral palsy. In some cases, there is no definite cause (idiopathic) for the spine's failure to develop normally.

Spinal fusion: usually a solid fusion (solidification) of the curved part of the spine, achieved by operating on the spine, adding bone chips and allowing the vertebral bones and bone chips to slowly heal together to form a solid mass of bone called a fusion

Spine (spinal column, vertebral column): the series of moving vertebrae forming the axis of the skeleton and protecting the spinal cord

Spine curves, normal and abnormal: front-to-back and sideways curves of the spine

- All spines have normal front-to-back curves. Abnormal front-to-back curves can indicate "round back" (hyper-kyphosis) or "swayback" (hyper-lordosis).
- Normal spines don't have much sideways curvature. An abnormal sideways "S" or "C" curve can indicate scoliosis.

VEPTR™ (titanium rib) procedure: an operation that expands the chest and allows continued growth of the chest and spine. A curved metal rod fits the back of the chest and spine, helping the spine to become straighter and allowing the lungs to grow and fill with enough air to breathe. The device is made longer as the child grows. The procedure is used for some early-onset scoliosis, with the device attaching to the ribs, spine or both.

Vertebra, vertebrae: the individual bones that form the spinal column

Vertebral stapling: a newer surgical technique to modulate growth that may prevent the curve progression in children and adolescents with moderate scoliosis. A minimally invasive procedure, stapling may be an alternative to bracing for some children at risk for progression of their scoliosis and the prospect of spinal fusion in their future.