Produced by

setting SCOLIOSIS straight

Supporting Discoveries in Scoliosis

Idiopathic Scoliosis

Navigating Your Journey

A GUIDE FOR YOU AND YOUR FAMILY

4th Edition

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Pioneering Research in Scoliosis

A Note from the Producer

setting SCOLIOSIS straight

Supporting Discoveries in Scoliosis

The **Setting Scoliosis Straight Foundation** and the surgeon members of the **Harms Study Group** are honored to present **Idiopathic Scoliosis (IS), Navigating Your Journey: A Guide for You and Your Family**.

This handbook is the culmination of years of work, which includes extensive feedback from our colleagues and our patients. We are optimistic that the widespread distribution of this handbook will improve the education and support for our patients, their families and the medical community.

This Handbook wouldn't be possible without the devoted support from our Harms Study Group surgeon members.


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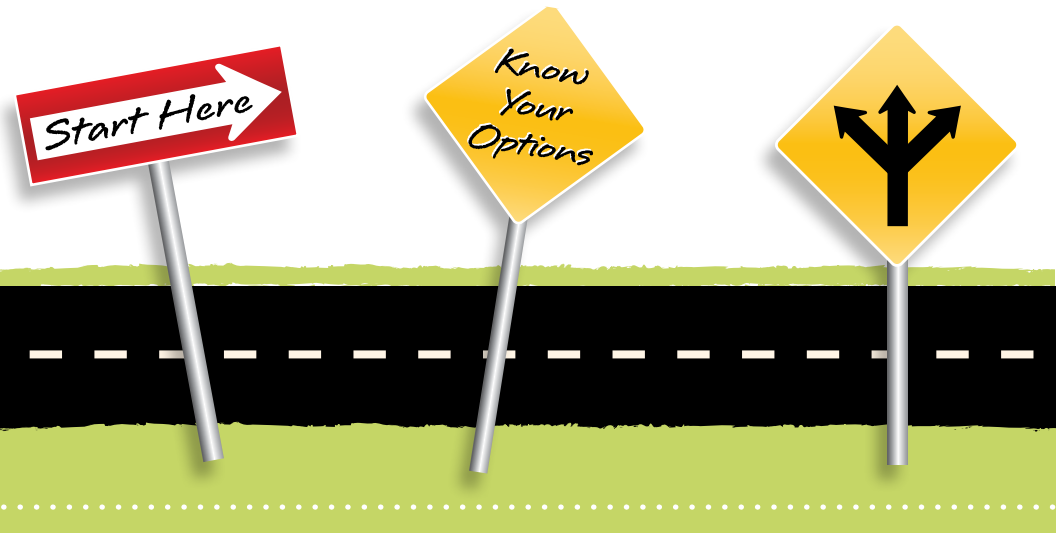


Introduction

This handbook about Idiopathic Scoliosis was written for you—to guide you as you start this journey—and by you, from the experiences and ideas of people who have already traveled the road that lies ahead of you.

Having had the opportunity to care for many teens with Idiopathic Scoliosis (IS), we recognize that each family approaches this diagnosis in their own way.

We hope that the information provided will help you in your journey through scoliosis treatment.

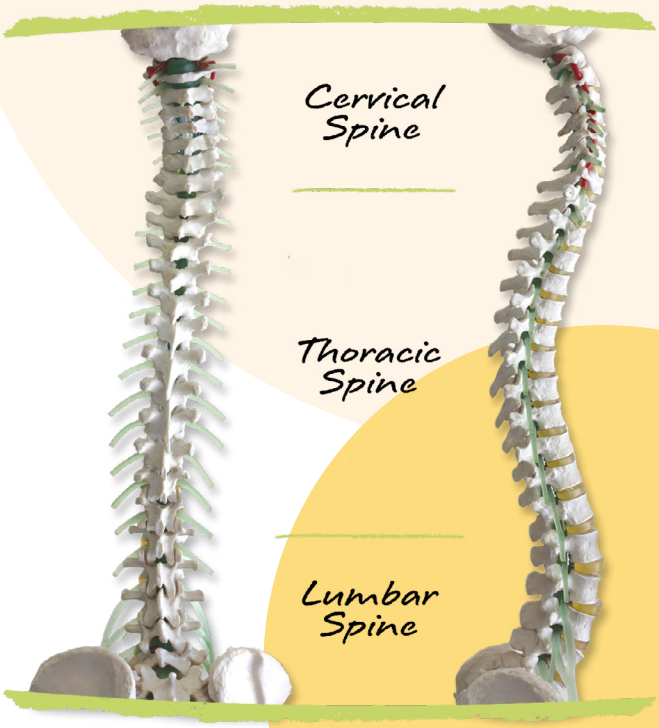
Kalli, after spine surgery in 2002

Quick Anatomy of the Spine

The spine is made up of twenty-four individual bones called vertebrae that are separated by discs. The discs allow the spine to be flexible.

There are three regions of the spine: seven cervical (neck) vertebrae, twelve thoracic (chest) vertebrae and five lumbar (low back) vertebrae. In addition, there are five fused vertebrae below the lumbar spine that make up the sacrum.

The spinal column houses and protects the spinal cord. Spinal nerves project out from the spinal cord through spaces between each of the vertebrae.

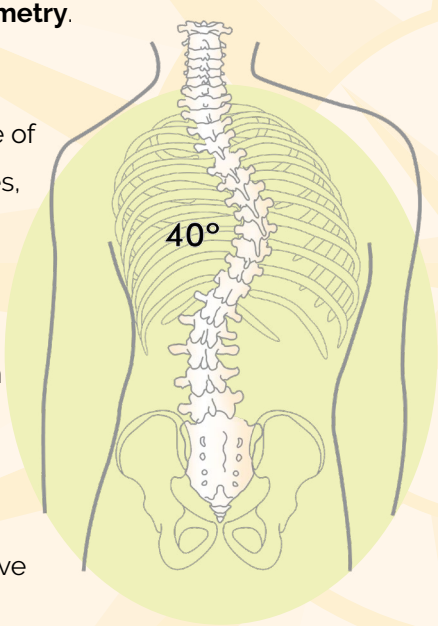


Posterior View *Lateral View*

What is scoliosis?

Viewed from the front or back, the spinal column should be straight. When scoliosis is present, you will see a sideways shift of the spine to the right or left. Approximately ten percent of the population has small curves (less than ten degrees), which are of no consequence to function or health. This condition is called **Spinal Asymmetry**.

When a diagnostic x-ray is done, the lateral (sideway) curve of the spine is measured in degrees, as an angle, and this is called a **Cobb angle**. Scoliosis is defined as a curve greater than ten degrees. It is most common in the thoracic and lumbar regions of the spine and can involve one or both of these regions. The most common curve pattern is a right thoracic curve.



There are naturally occurring curves in the spinal column when it is viewed from the side (laterally). Swayback (lordosis) is normally present in the cervical and lumbar regions while round back (kyphosis) generally exists in the thoracic spine.

Ch. 1

What is Scoliosis?

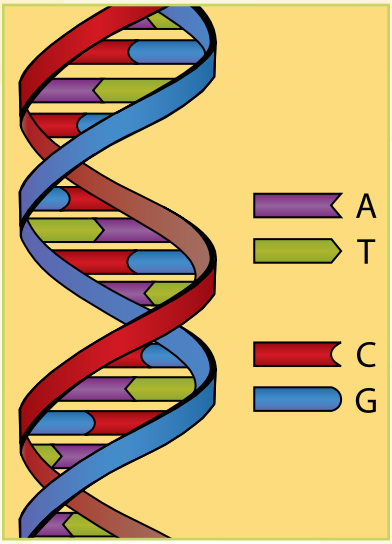
Scan the QR Code to watch this chapter on our YouTube channel and keep an eye out for more throughout this handbook.

WATCH ME

What causes scoliosis?

Scoliosis can arise from a number of underlying conditions, but the most common form is **idiopathic**, which means "cause unknown."

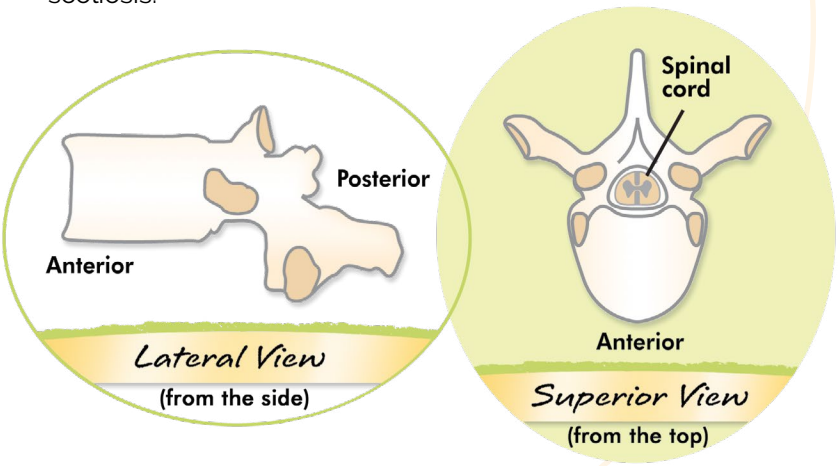
Scientists have identified that idiopathic scoliosis is a genetic condition and continue to work to isolate the combination of individual genes that cause scoliosis.



DNA

The material that holds all of our genetic code

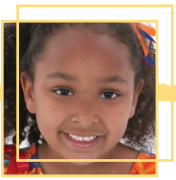
There is some evidence to suggest that uneven growth rates between the anterior (front) portion of the vertebrae and posterior (back) portion of the vertebrae may be one cause of scoliosis.



Are there different types of idiopathic scoliosis?

Idiopathic scoliosis is defined by the age at which it begins to develop. Each age group has unique needs and challenges associated with treatment.

Infantile-Onset Idiopathic Scoliosis: Age 0-3



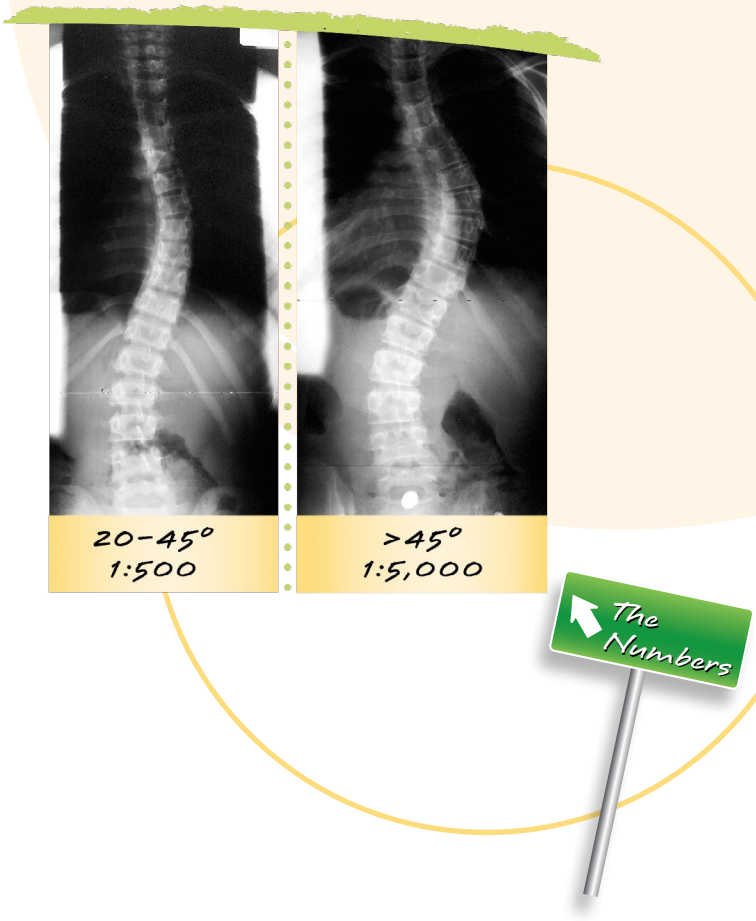
Juvenile-Onset Idiopathic Scoliosis: Age 4-9

Adolescent-Onset Idiopathic Scoliosis: Age 10-18

How common is scoliosis?

Idiopathic scoliosis is thought to be present in two to three percent of adolescents. One in five hundred of these will require active treatment and only one in five thousand have curves that progress to the degree where surgery is recommended.

Girls and boys are equally affected by small degrees of scoliosis. Girls however are eight times more likely than boys to develop progressive curves.



Diagnosis

Ch.2

How to Detect Scoliosis?

WATCH ME

Who might detect the presence of scoliosis in a child?

- Pediatrician or doctor during routine exam
- School screening nurse
- Athletic coach or P.E. teacher
- Parents
- The child her/himself
- Other family members
- Friends
- Incidentally, via an x-ray done for another reason

What is School Screening?

Some states in the U.S. mandate that children in the public school system be screened for scoliosis in early adolescence. Typically, girls are evaluated in the fifth or sixth grade and boys in the sixth or seventh grade. This screening is usually performed by a school nurse.

What are they looking for?

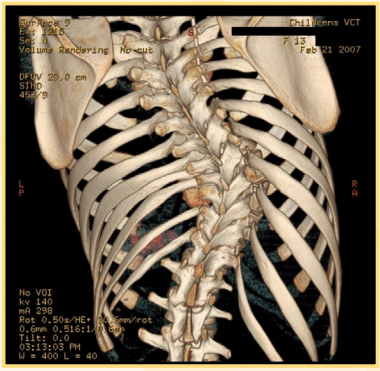
There are a number of things that one might notice:

- One shoulder higher than the other
- One shoulder blade (scapula) more prominent
- One hip higher than the other
- One leg appears longer
- Asymmetry (uneveness) of the waist
- Trunk and ribcage shifted to one side
- Head not centered over middle of hips
- Clothing hangs unevenly & when child bends forward at the waist, one side appears higher

Some of these signs of scoliosis may be very hard to see, especially to the untrained observer.

What causes these changes in appearance?

Scoliosis is a three-dimensional curvature. When a curve develops, the spine also twists, or rotates to the left or right. The amount and type of change in body shape depend on the curve pattern, and there is variation among individuals because each person's body responds a bit differently to scoliosis.



As the spine curves, the ribs also twist and bend.

What we're seeing might be scoliosis. How did we miss this?

It is not uncommon for someone other than a parent or a child to notice scoliosis. Changes to the body occur rapidly during pre-adolescence and adolescence. Children typically become more private about their bodies, so parents often don't see their children in situations where it is easily noticed. The early changes in body shape that are the result of scoliosis can be subtle, and there may be little outward curvature despite a significant curve. In addition, scoliosis is not typically a painful condition, so patients may not notice they have it.

Katie, back to skiing after spine surgery

We see signs of scoliosis. What is the next step?

When there is concern for scoliosis, the first step is often an evaluation by one's pediatrician or family doctor. S/he will do a complete exam and may refer you to a specialist with expertise in scoliosis.

An x-ray will be required to confirm the diagnosis of scoliosis. Ideally, the x-rays should be obtained at a facility that routinely screens for scoliosis.

The x-rays should be done with the patient standing upright. To best assess the overall alignment of the spine, all regions of the spine should be included on a single film rather than obtaining individual films of each region.

What will happen at the visit to the specialist?

- The patient's health history and family history of scoliosis will be gathered.
- The patient's height will be measured.
- A physical examination will be done.
- An Adam's Forward Bend Test will be performed. (*See next page*)
- X-rays of the spine will be obtained.
- The results of the exam and x-rays will be reviewed and explained to you.
- Initial questions will be answered.
- A treatment plan will be recommended.

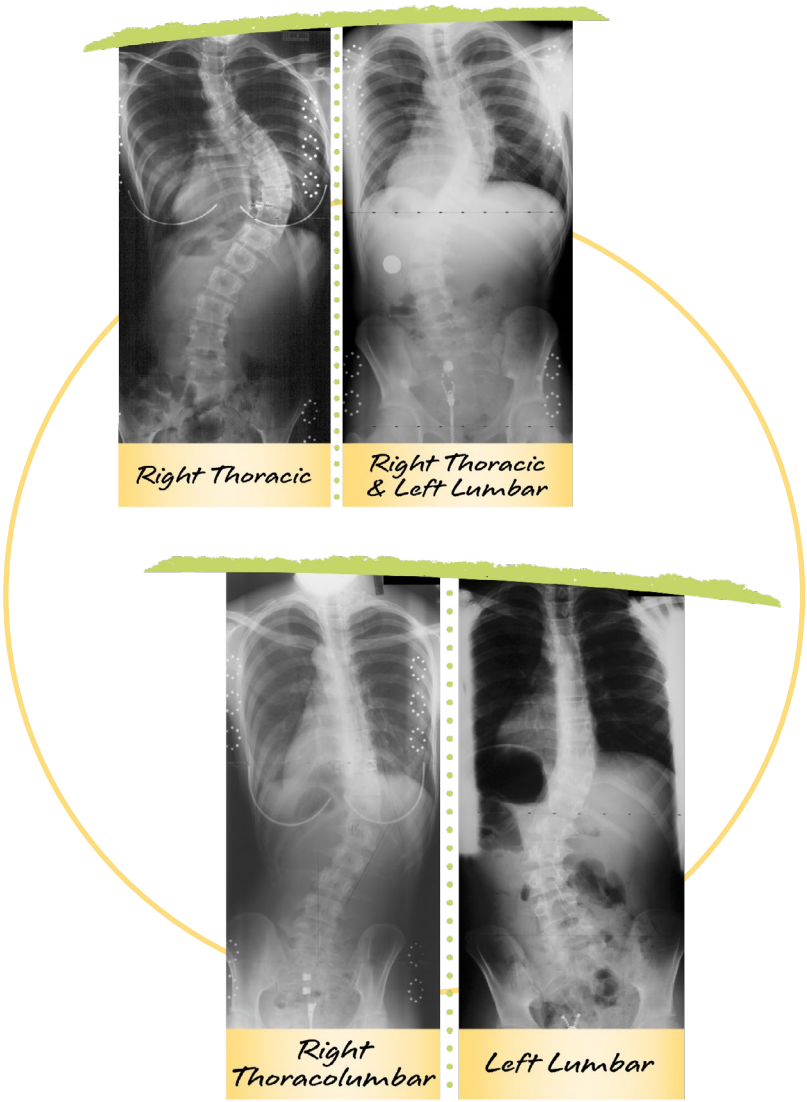
What is the Adam's Forward Bend Test?

As a spinal curve develops and the spine twists, asymmetry of the rib cage and/or waist is created. A **scoliometer** is used to measure the amount of rotation (in degrees as an angle).

During this pain-free test, you will be asked to bend forward and touch your toes. The trunk rotation is determined with a forward bend at the waist and is a reflection of the severity of scoliosis. A rotation of greater than five to seven degrees suggests that scoliosis may be present.

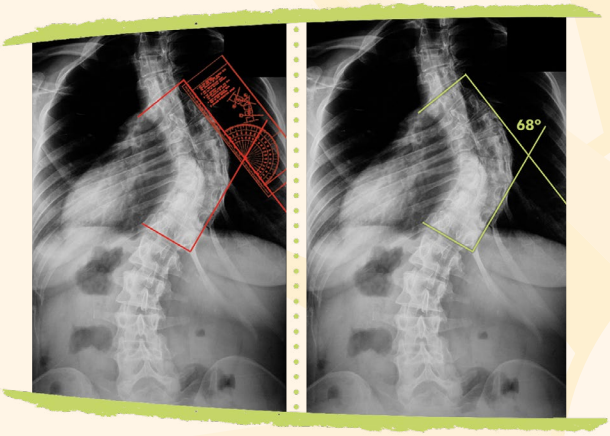
What does scoliosis look like on an x-ray?

Scoliosis is defined by the region of the spine where the curve or curves develop (upper thoracic spine, thoracic spine or lumbar spine). Scoliosis may be present in one or more sections producing single, double or triple curves. The direction of the curve may be to the right or left.



How is the size of the curve measured?

The size of the curve is measured on an x-ray in degrees and calculated as an angle. This is called the **Cobb Angle** or **Cobb Measurement.**



When is an MRI or further diagnostic testing recommended?

In the presence of an unusual curve pattern (ex: left thoracic curve) or other symptoms, additional testing may be recommended. An MRI (magnetic resonance image) checks the spinal cord for problems.

Will the curve get bigger?

There isn't always a way to know if scoliosis will continue to progress, though there are a number of factors that increase that risk.

If scoliosis is going to progress, the time of greatest risk is during the adolescent growth spurt when curves can increase one to two degrees per month.

There are two factors that are most important in predicting each child's curve progession. They are the current size of the curve and the amount of growth remaining.

Amanda, back to softball after spine surgery

How is the potential for skeletal growth determined?

At each visit to the specialist, a height measurement will be taken. Two subsequent measurements (months apart) without a gain in height is the surest way to know that growth is complete.

In addition, a skeletal maturity marker on the pelvis called the **Risser Sign** is visible on x-ray, and this indicates how much bone maturation remains.

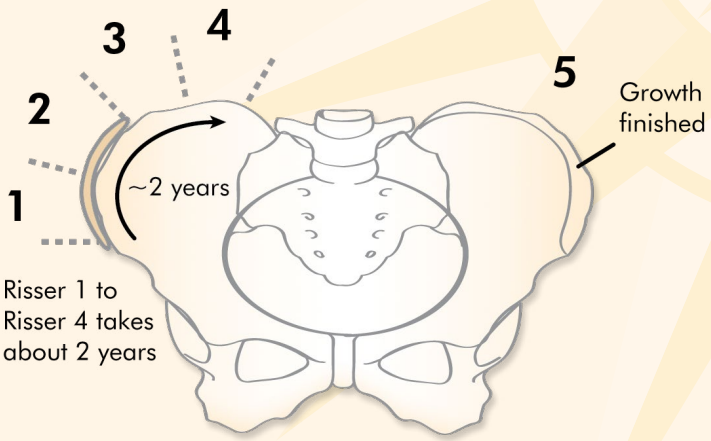
Also taken into account are signs of puberty. In girls, onset of menstrual periods and breast development are observed, and in boys facial hair and voice changes can be assessed.

Indicators of skeletal maturity do not always correlate, and an x-ray to evaluate the growth centers in the bones of the hand (see page 17) may be recommended.

Some clinicians perform a digital analysis of the contours of a patient's back to determine if their curve is getting bigger. This is a promising new technology but is currently not widely used.

What is the Risser Sign?

The Risser Sign is used to evaluate skeletal maturity. When the skeleton is fully mature, a "cap" of growth cartilage covers the top of the pelvic bone (iliac wing) and solidifies. This growth cartilage turns to bone and becomes visible on x-ray. As the skeleton begins to mature, the cap of cartilage appears first at the outer edge of the iliac crest (Risser 1) and over a period of eighteen to twenty-four months grows to cover the iliac crest. The stages of skeletal maturity are classified as Risser 0 up to 5, with zero being the time before the bone cap appears and four being complete coverage. Fusion of the growth cap to the iliac wing (Risser 5) signifies completion of spinal growth. This process occurs during puberty.

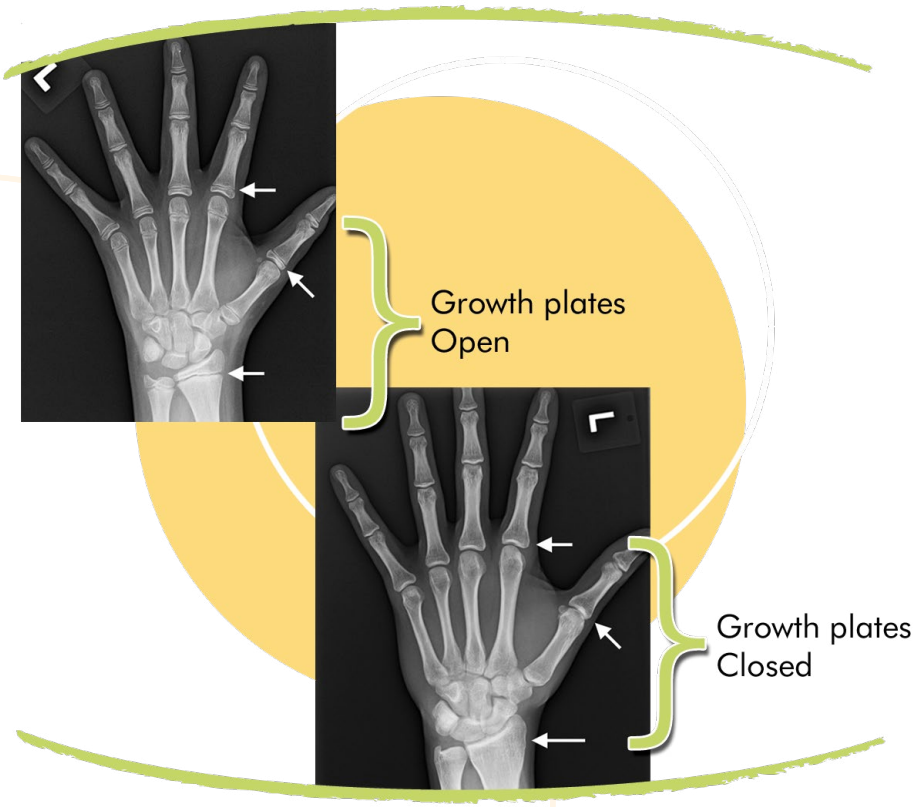


The Risser Sign

What will an x-ray of the hand and wrist show?

An x-ray of the hand and wrist will show the growth plates of the individual bones in the hand. These growth plates remain open during growth and have a pattern of closure with skeletal maturity that is actually more reliable than the Risser sign.

Hand x-rays also allow the doctor to compare chronological age (how old you are) with skeletal age (real bone age), which may or may not match up to one's chronological age. This can be helpful in determining how much skeletal growth remains.



What is the Sanders Maturity Scale?

Dr. James Sanders created the Sanders Maturity Scale to further understand how skeletal growth and the spine interact. This scale is a simplified evolution of the Tanner Whitehouse system and evaluates fusion of the epiphyses of small long bones of the hand. The use of the Sanders Maturity Scale has been validated and has been used to predict curve progression in idiopathic scoliosis.

Scoliosis Prognosis Calculator

A prediction calculator has been developed by Dr. Lori Dolan and Dr. Stuart Weinstein that utilizes the Sanders Maturity Scale, scoliosis curve pattern and magnitude (Cobb angle).

The tool calculates a percent probability of a poor prognosis or outcome, defined as curve magnitude progression to greater than 45 degrees prior to skeletal maturity without any treatment. Patients and families should consult their physician for shared treatment decision making when utilizing this calculator.

Check out the Sanders Calculator

READ MORE

This calculator is brought to you by:

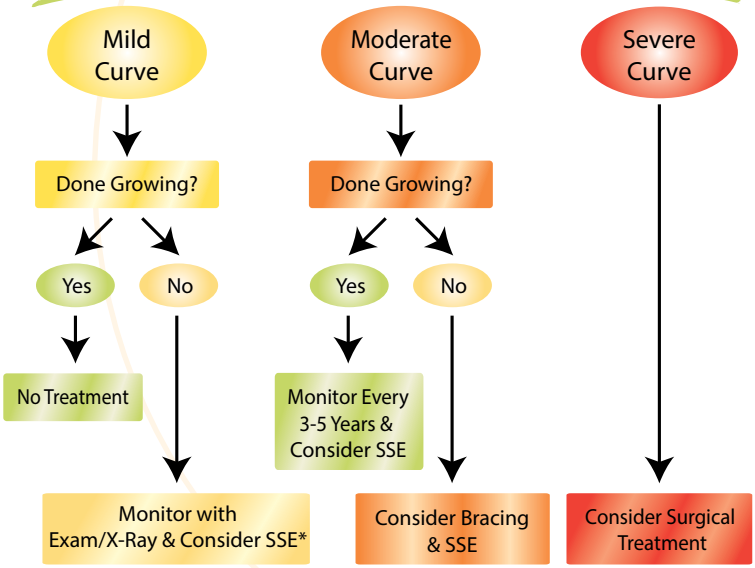
University of Iowa Stead Family Children's Hospital

Scoliosis is the diagnosis. What are my treatment options?

Scoliosis can be treated non-operatively or operatively, depending on how large the curve is. Non-operative treatment entails observation, which means a scoliosis specialist periodically checks a smaller curve for signs of progression, and the patient may or may not be asked to wear a brace.

Operative treatment (surgery) may be considered if the curve is larger and will likely continue to progress after growth is finished.

Patient Presenting with Idiopathic Scoliosis



*SSE - Scoliosis Specific Exercises

Route 1: Non-Operative Management

What does observation entail?

Observation means that the patient will be regularly checked by the scoliosis specialist, who will perform an exam and take x-rays every four to twelve months. The frequency of visits is based on the patient's stage of growth. Due to slight variability (up to five degrees) in day-to-day x-ray measurements, comparative x-rays should not be done more frequently than every four to six months. Progressive curves generally increase at a rate of one to two degrees per month, so taking x-rays more frequently than every four months will not reliably determine true progression.

Observation is usually recommended for patients who are still growing with curves that measure less than 20 to 25 degrees and for patients who have finished growing with curves that measure 40 to 45 degrees.

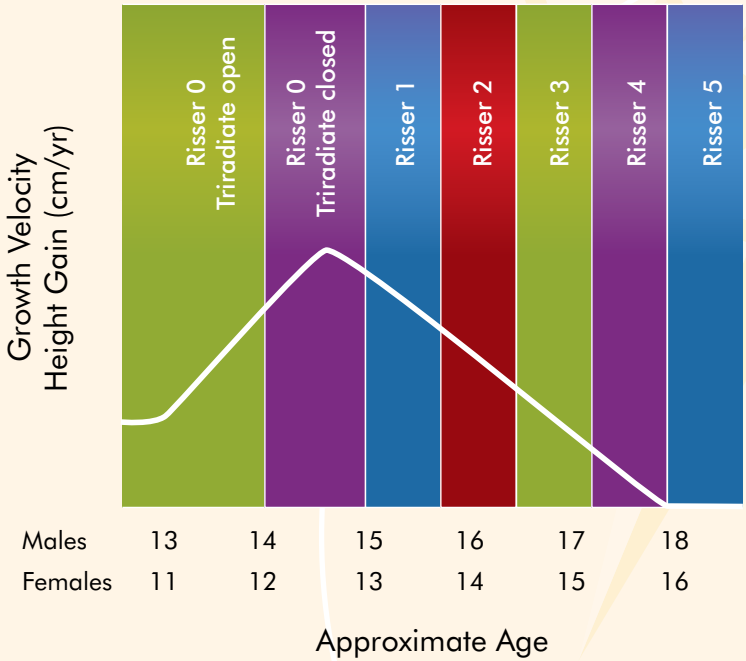
Will my curve progress?

In general, the younger the patient and the larger the curve(s) at the time scoliosis is identified, the greater the potential for progression.

Remember, most small curves stay small.

The graph below shows the rapid rate at which adolescents grow during the approximately eighteen months before the first Risser Sign appears. This is called the stage of peak height velocity, or growth spurt. They will continue to grow taller but, as shown below, at a slower rate. Females go through this growth spurt earlier than males, usually before menarche (their first period).

Clinicians will also look at the triradiate cartilage, a growth plate in the pelvis, which starts to close as the patient enters rapid growth.



We've been observing the curve, and it has increased. What's next?

There are a few different scenarios for curves in the 20 to 40 degree range:

1. If growth is finished and the curve has progressed but is less than 40 degrees, there is little risk that the curve will continue to progress in adulthood. Curves over 45 degrees are more likely to progress and should be monitored periodically.
2. If the patient is still growing and the curve has progressed but is still in the non-operative range (less than 45 to 50 degrees), bracing with close observation may be considered.

What is Bracing?

Bracing is a treatment protocol in which the patient is referred by the doctor to an orthotist (a bracing specialist), who will evaluate, design, and fit an external support brace in an attempt to stabilize progressive curves. The primary goal of bracing adolescents with idiopathic scoliosis is to halt curve progression. Although it rarely leads to a significant or permanent decrease of the curve, a successful course of bracing might prevent the need for surgery.

Ch.3

What is Scoliosis Bracing?

WATCH ME

What is a scoliosis brace?

The typical scoliosis brace (also called an orthosis or TLSO: thoracolumbosacral orthosis) is made of contoured plastic that fits snugly around the torso and hips. It applies "directed" pressure to the curve(s). There is a variety of brace styles; some designs are to be worn full-time (i.e., 18 to 21 hours per day), and others are to be worn only at night (i.e., 8 to 14 hours). The specific brace configuration will open either in the front or back and will be secured by Velcro straps. The biomechanical principles of bracing are founded on evidence that "directed" pressure reduces the curve(s) and moves the spine into better alignment while the brace is worn.

How do I know which brace should be used?

The patient's age, stage of skeletal maturity, curve size and pattern, and physician's preference all influence which type of brace is recommended. Patients and parents are encouraged to thoroughly investigate all bracing options and to work with an orthotist who has lots of experience in scoliosis bracing.

As discussed earlier, three main regions of the spine can develop curves—upper thoracic, main thoracic, and lumbar—and a patient may develop curvature in one or all of these areas. Upper thoracic curves are more difficult to treat with underarm bracing because the upper section of the thoracic spine is blocked by the arms and shoulders. A TLSO is usually the brace worn full time, and the nighttime brace can be used for all curve types but is typically suggested for lumbar and thoracolumbar curves.

While x-rays and physical exams help guide the physician's recommendation, opinions regarding the use of a brace and specific brace designs vary widely among scoliosis experts. Communication between the patient, parent, and physician will help determine the most effective brace and bracing scenario for each patient.

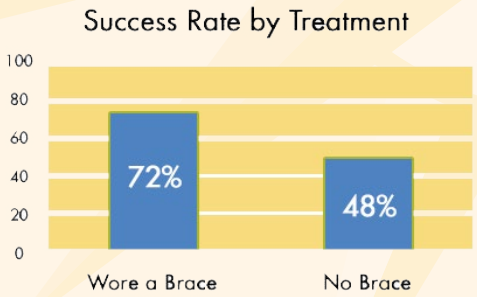
Will bracing be effective?

Plainly put, bracing is frequently effective but occasionally is not. There is often a tendency by professionals, parents, and patients to focus on the brace. However, many variables influence bracing success or failure, including the following:

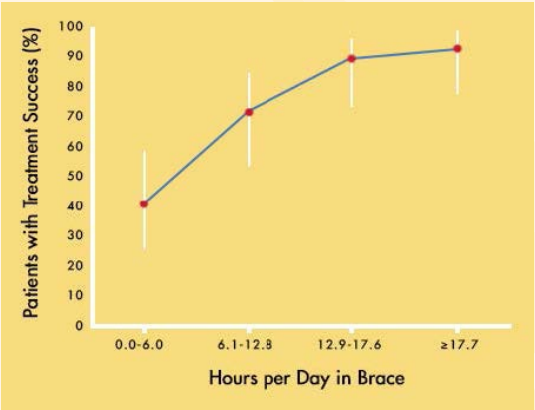
- Patient age
- Rate and stage of growth
- Curve size, curve pattern, curve flexibility
- Competency of the doctor and orthotist
- Specific brace design
- Adherence to wearing time
- Proper brace wear
- The patient's attitude toward bracing
- Consistent follow-up with the doctor and orthotist
- A positive support network

Research indicates that one of the most critical predictive factors of bracing success is the patient's adherence to the prescribed wearing time and protocol. Unfortunately, some curves do progress even when a brace is worn properly.

Data on the effectiveness of bracing can be found in studies such as 'Bracing in Adolescent Idiopathic Scoliosis Trial,' in which Stuart Weinstein, MD, and his colleagues collected information from 242 patients. As shown in the graph below, data from this study clearly show that the patients wearing a brace were less likely to experience curve progression to fifty degrees or greater compared to the patients who did not wear a brace. Ultimately, this means that people who wear a brace are less likely to develop a curve that may require surgery.



In addition, as shown in the graph below, the data from this study plainly illustrate that wearing a brace for more hours per day yields better results.



Also shown in the above graph, participants who wore braces an average of six hours or less per day had about the same outcome as those who did not wear a brace at all, with 41% ending up with a curve of less than 40 degrees. However, the success rate was much higher (90%) for those who wore braces an average of 13 or more hours per day.

Ultimately, it is the responsibility of the patient/parent and the physician to determine the best course of action and treatment method. This determination should be based on many factors, including the degree of curvature, stage of skeletal maturity, and the patient's willingness to adhere to the bracing program. If bracing is chosen, open communication between the patient/parent, physician, and orthotist is essential to achieving success.

Following are some patient responses to being told that a brace is recommended:

NO WAY!

What will my friends say?

You expect ME to wear THAT?

I'll wear it every day. I'm NOT having an operation!.

It fits under my clothes? Oh, that means new clothes... and Shopping!

I'll wear it, but NOT to school.

Sports and other activities will not make scoliosis worse, so continuation of playtime and physical activity is highly encouraged.

Josh, after spine surgery in 2008

We've decided not to proceed with a brace. What's next?

Choosing observation rather than bracing is your choice. Your doctor will recommend how frequently you should follow up for x-rays and an exam, but those typically occur at four to twelve-month intervals.

Are there other treatments that will stop scoliosis from getting worse?

This is a topic of great interest and debate. Proponents claim that a variety of treatments and techniques can stop scoliosis progression, including acupuncture and acupressure, electrical stimulation, biofeedback, traditional physical therapy, magnets, nutritional and vitamin supplements, chiropractic manipulation, shoe orthotics, and other less traditional treatments. Currently, none of these methods have evidence to prove their claims. However, there is interest and early research in "Physiotherapy Scoliosis Specific Exercise" (PSSE), like the Schroth Method, that specifically addresses postural awareness, spinal balance, core strength, and pain management issues common to patients with scoliosis. These exercise can have a role in mild or moderate curves with or without brace treatment.

We chose to proceed with bracing. What's next?

The doctor will write a prescription for the brace and refer you to an orthotist they like to work with and/or is covered by your insurance. The orthotist will evaluate the patient and capture their body shape using measurements, casting, and/or scanning. Within two to four weeks, the brace fitting and first adjustments should be complete, and the patient will return to the doctor, who will check the fit and may take an in-brace x-ray to see how the brace is working i.e., how much the brace reduces the curve(s).

At this point, the doctor will tell you when to return for follow-up exams and x-rays. The patient should see the orthotist, who will adjust the brace based on the in-brace x-ray and feedback from the doctor. Also, the orthotist should ensure that the brace continues to fit appropriately and that the patient is wearing it properly. Please note that insurance coverage can sometimes affect bracing choices.

How long does the brace need to be worn?

A brace is worn until a patient is done growing or the curve progresses to a degree where surgery is recommended. Most girls are done growing 18 to 24 months after the start of their menstrual periods. Boys tend to grow into their late teens, so they often need to wear a brace longer than girls.

Are there social and psychological impacts from bracing?

These are years of rapid change, a time of heightened sensitivity to differences between oneself and one's peers, and increased peer pressure. Having to wear a brace can affect how one adjusts to an already challenging time of life. Having a supportive network of family, friends, and peer support groups makes the challenge of wearing a brace easier.

We do have helpful tips from brace-wearers and their parents:

From teens:

- Talk to others who have scoliosis.
- Enjoy shopping for new clothes that fit over the brace.
- Keep doing everything you did before you got your brace.
- Don't be embarrassed by it or try to hide it. It's just like braces on your teeth: temporary!
- Don't expect it to get you out of P.E.
- Decorate the brace.
- It's hard, but you can do it.
- Be proud of how strong you are!

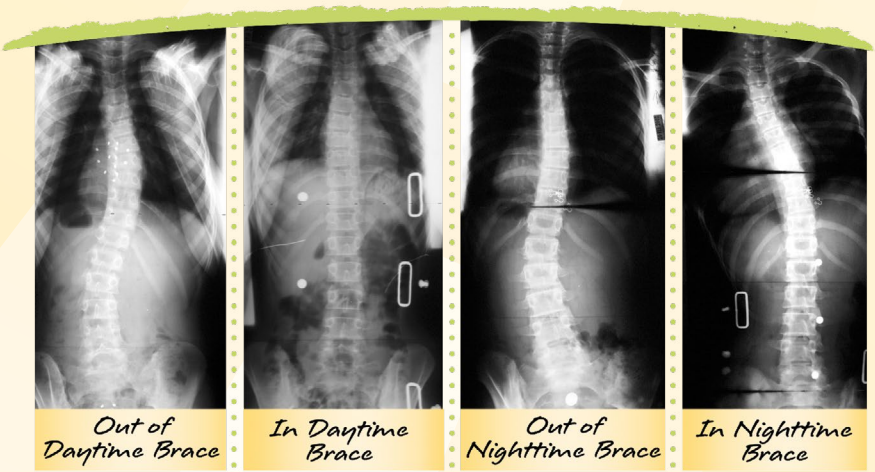
"Yes, I'm wearing a brace. Can you tell?"

From parents:

- Keep your children involved in sports and activities.
- Give them a break sometimes—for a sleepover, a vacation or special event.
- Recognize that it is difficult, both for the parents and the patient.
- Hug your child every day when they are in (and out of) the brace.
- Talk to other parents whose teens are wearing braces.
- Support your teen in their efforts.
- Communicate with your child. Most importantly, listen to their thoughts and concerns.

Despite wearing my brace, my curve has progressed. What's next?

Unfortunately, even when you've done your best, some curves continue progressing. Scoliosis experts' opinions may differ regarding when surgery is recommended, but most agree that this condition is rarely life-threatening or one that demands immediate action. An informed decision can be made when the patient and parents talk with their doctor and understand their options.



If the curve keeps getting bigger with the brace, what's next?

This partially depends on the stage of growth, the location and severity of the curve(s), the curve pattern, and the surgeon's preference.

In general:

- At skeletal maturity, curves measuring greater than fifty degrees are at greater risk for continued progression throughout adulthood, although at a slower rate (i.e., approximately one to two degrees per year). As a result, surgery will likely be recommended.
- When a curve reaches forty-five to fifty degrees, surgery may be recommended even though growth is not complete.
- At skeletal maturity, some curves between thirty to fifty degrees progress and some do not. Treatment recommendations vary.

Route II: Operative Management

What are the goals of surgery?

The goals of surgery are to prevent further progression of scoliosis and to correct the spine as much as can be done safely. Stopping progression will prevent the significant health issues later in life that are associated with severe scoliosis (curves greater than seventy to eighty degrees). Some of the problems associated with large curves include breathing trouble, heart and muscle weakness, and pain.

Ch.4
What is Scoliosis Surgery?
WATCH ME

What is Spinal Fusion Surgery?

During surgery, the curve is corrected as much as is safely possible. To do that, implants (generally rods, screws, wires and/or hooks) are attached to the vertebrae at the section of the spine that is curved. After correction is achieved, bone graft is placed over the implants. With time, this bone graft fuses (or grows together) with the existing bone and forms a solid column of bone in that area. The implants act as an internal brace to hold the spine in the corrected position while the bones are fusing. This generally takes six to twelve months.

The fusion of the bones takes away the growth potential in that part of the spine, which is what has caused the scoliosis to worsen. An individual vertebra grows approximately one millimeter per year, and potential height lost is generally balanced by the amount of height gained with correction of the curve(s). The fusion also permanently stops the motion of the spine in the segments that are fused. The loss of flexibility is modest and limits function of the trunk very little.

Why now?

Shouldn't we wait until my child is done growing?

Why not wait until the Scoliosis is causing symptoms?

With moderate scoliosis, you wouldn't expect your child to be having any health problems. Surgery is often recommended before pain and other symptoms develop for a variety of reasons. The ease of addressing the smaller, more flexible curves present in a child or teen versus the larger, rigid curves in adults involves less risk, a less complicated surgery, and the potential that fewer vertebrae may need to be fused.

In addition, the recovery is easier and life is less complicated (in terms of school, family, career) during adolescence.

How do we decide if surgery is the right decision?

Educate yourself and ask questions. We suggest that the most important questions to ask are:

- What are the risks and benefits of having surgery at this time?
- What are the risks of not going ahead with surgery at this time?
- What are the risks and benefits of the suggested surgical procedure?

Everyone will interpret the answers and weigh the risks and benefits a little differently, but these questions are an excellent place to start analyzing information that will allow for the most informed decision.

The specialist may be able to connect patients and families with other patients and families who would be willing to share their experiences.

What about getting a second opinion?

Good idea. Recommendations on who to see can come from the current specialist, pediatrician, family doctor or from an internet search. Some patients and families may know people who have been in this situation--asking them about their experiences with their surgeon can be helpful. Whatever you choose, we do recommend getting a second opinion from a board-certified spine surgeon.

We don't want surgery...What's next?

Choosing not to proceed with surgery is choosing observation, and the treating doctor will recommend how frequently the patient should follow up for x-ray exams. Bracing curves in the surgical range is of little or no benefit. It is important to continue to monitor the scoliosis by following up with your doctor for x-rays and exams as recommended since the curve may get larger.

We want to proceed with surgery. What comes next?

Choosing a surgeon and then formulating a surgical plan (deciding which procedure to choose) together and selecting a date for surgery are the next steps.

How do we choose a surgeon?

It is recommended that you choose a surgeon who:

- is Board Certified
- specializes in the treatment of pediatric and teenager with scoliosis
- is affiliated with a hospital facility with a staff experienced at caring for adolescents during and after spine surgery
- has successful experience treating pediatric with scoliosis.

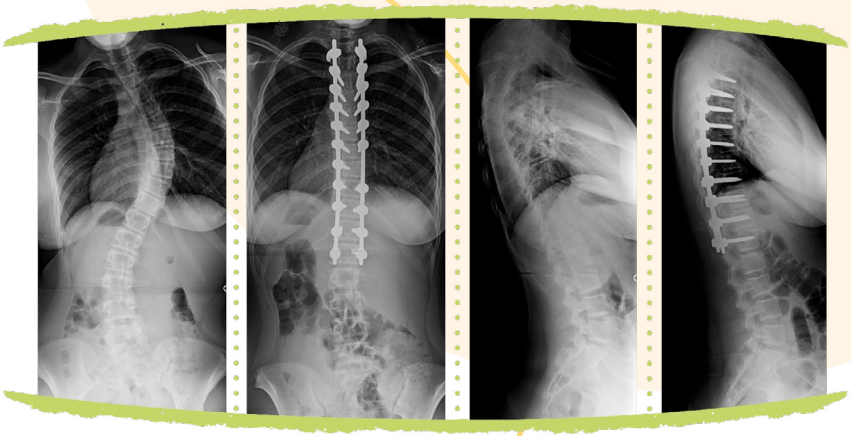
What is a surgical plan?

There is more than one way to surgically treat scoliosis. The surgeon needs to determine which levels of the spine are going to be fused and by which approach/procedure. Surgeons can approach the spine either through an incision on the back or on the side of the chest or flank. The approach recommended will depend primarily on the curve pattern, physical deformity, and skeletal maturity.

What are the possible procedures?

There are two general surgical approaches to the spine: posterior and anterior.

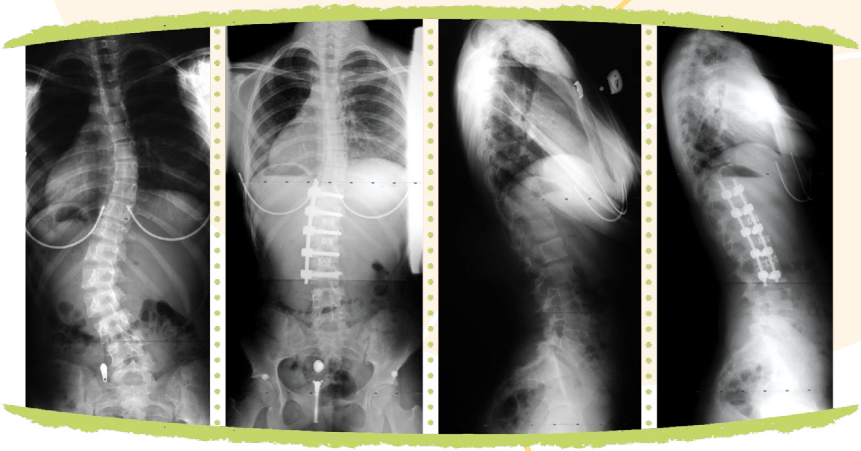
The most common approach is through the back and is known as a *Posterior Spinal Fusion with Instrumentation*. With this procedure, an incision is made along the spine, screws and/or hooks are then attached to the vertebrae, and rods are then attached to the screws or hooks. These screws and hooks act as anchor points to secure the rods. Bone graft is then placed over the spine so that the spine can fuse in the corrected position. All curve patterns can be treated with this approach.



Posterior Spinal Fusion with Instrumentation

An *Anterior Spinal Fusion with Instrumentation* is done through an incision either on the flank or chest and is an option when there is a single curve to be treated. One or two screws are placed from the side through the front (anterior) part of each vertebra that is going to be fused. Rods are then attached to the screws lengthwise along the spine.

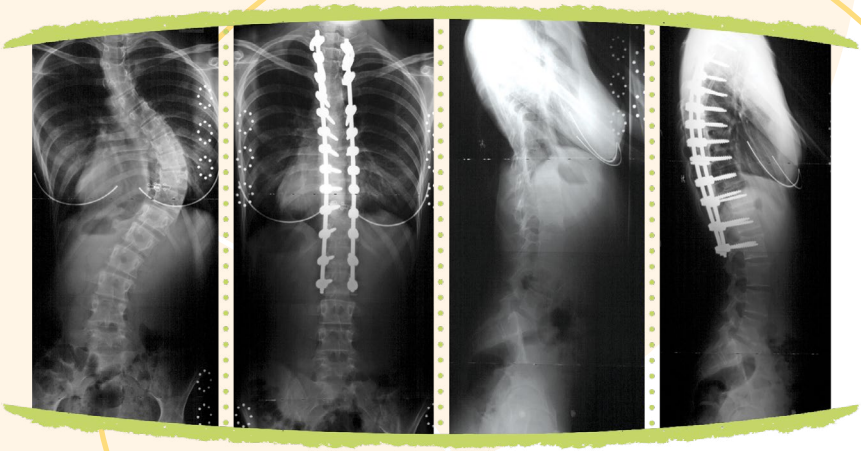
The discs between the vertebrae are removed and replaced with bone graft and in some cases, metal mesh cages at some levels, which allows the spine to fuse in the corrected position. This approach is an option for single curves in the thoracic region of the spine and is also well suited for single lumbar curves.



Anterior Spinal Fusion with Instrumentation

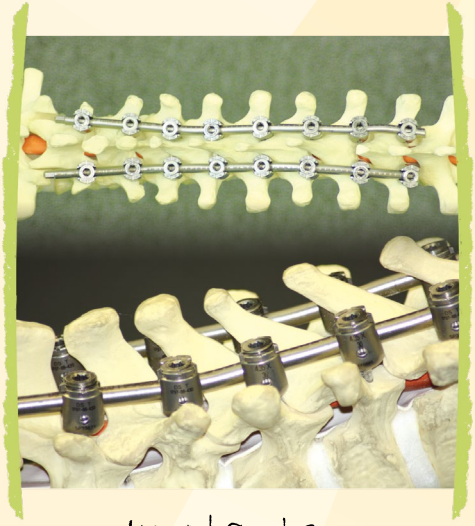
In special circumstances, both anterior and posterior approaches may be accomplished with less invasive incisions. Some curve patterns may be best treated with a *Combined Anterior and Posterior approach*. The combined approaches are reserved for very young patients and those with more rigid curves.

A *Thoracoscopic Anterior Spinal Fusion with Instrumentation* is done through four or five small incisions on the chest. This approach is best suited for single right thoracic curves.



Anterior Disc Excision/Fusion Combined with Posterior Spinal Fusion with Instrumentation

What do the implants look like, and what are they made of?



Implants

Implants are made of metal. They are either Stainless Steel, Titanium or Cobalt Chromium. There are a wide variety of implants available.

Most surgeons have individual preferences and will discuss this with their patients.

How long will the implants stay in?

Except in uncommon circumstances, such as infection or discomfort, implants will stay in the body forever. The rods maintain the spine in its corrected position, acting as an internal brace while the vertebrae grow together and fuse, creating a column of solid bone. After the bones fuse together, the implants don't really have a job, as the fusion is what maintains the correction. However, the surgery to remove the implants (rods, hooks, screws) is major and not necessary in most cases.

How do the bones fuse together?

Bone grafting is used to fuse the spine in its corrected position and can come from a variety of sources. These sources will depend on the surgical approach and will likely include a combination of bone removed from the spine during surgery and supplemental bone products.

What are the effects of a fusion?

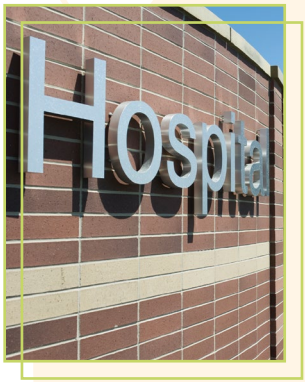
Besides maintaining the spine in its corrected position and preventing further progression of scoliosis, a fusion also stops growth in that section of the spine. This is not troublesome to most teenage patients because some height is gained when the spine is straightened.

Additionally, the fused section of the spine is no longer flexible. This is of little consequence in the thoracic spine because this region of the spine has relatively little natural motion. However, the lumbar spine is more flexible, and a fusion in this area limits some motion. Concentrating motion on just a few lumbar discs may cause them to wear out sooner, so every effort is made to fuse as few of the lumbar vertebrae as possible.

Which procedure will be best?

The best procedure will depend on the curve pattern, skeletal maturity, amount of physical deformity and surgeon. There are risks and benefits associated with every surgery. Discussing these options with the surgeon will be part of the surgical planning.

What should I look for in a hospital or surgery center?



- Board Certified Pediatric Anesthesiologist on site
- Specialized pediatric staff
- Availability of a pediatric Intensive Care Unit (ICU)
- Intraoperative spinal cord monitoring
- Other features such as availability of pain management and other pediatric specialists

What is spinal cord monitoring?

A little more anatomy first: the spinal cord and nerves control voluntary and involuntary activities of the body—movement, sensation, bladder and bowel function, to name a few. The brain processes all of the messages transmitted to it via sensory nerve pathways to the spinal cord then directs activity by sending messages back through the spinal cord to the muscles.

Throughout surgery, the message-sending and receiving ability of the spinal cord and nerves are monitored, as well as the brain's response to these messages. This is to catch any changes in spinal cord and nerve signals that might indicate a problem.

This testing is done by a trained professional using a sophisticated computer system. This monitoring significantly lowers the risk of spinal cord dysfunction following surgery.

How do we decide on a date for surgery?

There are a variety of factors—for example, the surgeon and patient schedules. Discuss the risks of waiting longer than six to twelve months with the surgeon. There are some cases where there may be enough progression during that time that additional levels of the spine may need to be fused. A surgeon can help you decide how long it is safe to wait.

Okay, we've got a plan and a date. What's next?

In the time just before surgery, the patient and family will meet with the surgeon and his/her staff for additional discussion of the planned surgery. At this visit, additional x-rays may be needed. This visit is an excellent opportunity to ask questions, but do not hesitate to contact the surgeon's office at any time during this process with questions or concerns.

The surgeon's staff will assist with obtaining authorization from insurance providers, arrange for blood products to be available for the procedure and arrange for additional diagnostic tests that may be recommended by the surgeon.

At this point, the patient and family may have the opportunity to tour the hospital and speak with other families that have had this experience.

Ch.5

What to Expect Before and After Surgery

WATCH ME

It is the day of surgery. What can we expect?

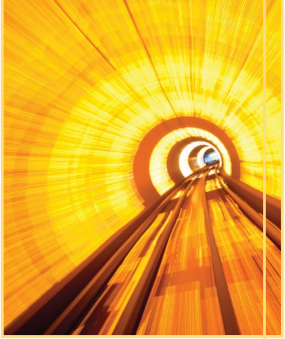
- More paperwork
- To meet with the anesthesiologist (the doctor that puts you to sleep)
- To meet with the surgeons and their assistants
- Repetition--a lot of different people asking the same questions
- An opportunity to ask questions prior to surgery
- A long day with minutes passing like hours for parents and the day passing like seconds for patients
- Support and patience from the hospital staff
- To feel great relief when you meet with the surgeon after surgery and even greater relief when patient and family are reunited

Art by Brianna, age 15, spine surgery 2009

What can we expect before and after anesthesia?

Spine surgery is a major operation that requires general anesthesia. This puts the child completely to sleep; they have no memory of the surgery and do not feel any pain. The pediatric anesthesia team, which is made up of specially trained doctors and nurses, works closely with the surgeons, nurses, and other staff involved in spine surgery to make sure everything goes smoothly and safely. The anesthesia team will meet with the child and family before the surgery to explain what will happen and answer any questions. They will check the child's medical history and do some tests to ensure the child is ready for anesthesia. On the day of surgery, the anesthesia team will give medicine to the child through an IV or a mask. Once the child is asleep, they will also put a tube in the child's throat to help them breathe during the surgery and place sensors to monitor vital signs (e.g. heart function, blood pressure, oxygen level).

After surgery, the anesthesia team will continue to take care of the child until they wake up from anesthesia. They will help manage any pain or nausea the child may have following surgery. After spinal surgery, people usually feel pain, so doctors give them medicine to help. A wide variety of medications are given and vary from doctor to doctor. However, the end goal remains the same: to keep you comfortable but allow you to do the activities that are necessary after surgery such as eating, walking, and taking deep breaths.



Surgery is done. What's next?

After surgery, most patients will go to the Recovery Room so that they may be closely monitored while waking from anesthesia. After time spent in the Recovery Room, they will be transferred to their hospital room.

The patient will likely be in the hospital for less than a week. During that time, the focus will be on pain management, sitting, walking, eating, bowel and bladder routine, and education--the multitude of things that will allow the patient to meet the necessary milestones before going home.

Individuals recover at different rates, and surgeons' post-surgery regimens vary. Patients are generally in the hospital two to three days, depending upon the extent of the procedure.

Pain management, diet and bowel/bladder routine will depend on how quickly the stomach and intestines return to normal function, or "wake up," and bowel sounds can be heard.

Once bowel sounds return, the patient can begin to eat and drink. This usually starts with liquids and then progresses to solid food. They will then be transitioned to oral pain medicine. Typically, a bladder catheter remains in place until this transition. Constipation is not uncommon as it is a side effect of anesthesia, pain medicine and decreased activity levels. The medical staff will assist in managing this.

When can we leave the hospital?

While there will be differences among individuals, in general, parents will see their adolescent making progress in their recovery each day, going from:

- Being in bed all of the time to taking walks in the halls
- Transitioning from intravenous pain medication to oral (swallowed) pain medicine
- Not eating or drinking to eating and drinking again
- Urination managed with a bladder catheter to urinating normally

Parents will also see themselves going from being nervous and wanting the nurses to do everything involved in their child's care to becoming confident that they can do it instead. They can!

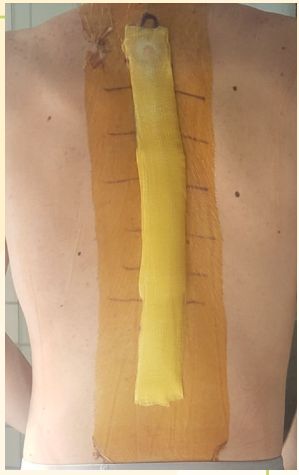
When these milestones are achieved, the patient is ready to go home.

Kalli, after spine surgery in 2005

What can we expect with the bandage after recovery?

In most cases, your child's incision will be closed with sutures that dissolve over the course of 4 weeks, negating any removal of sutures in clinic. At the end of your child's spinal fusion, after the incision is sutured closed, your surgeon may decide to apply steri-strips (medical grade band aids), skin glue (Figure 1), or a ZipStitch ™ to help the incision stay sealed. There is no evidence to support the use of one skin closing method over another.

Figure 1



The entire incision is usually covered with a sterile dressing, usually based on surgeon preference. There is no evidence to support the use of one surgical dressing product over other available dressings. The image on the left is an example of a patient's back after a spinal fusion with the incision covered with gauze and secured in place with Ioban (yellow material).

What can we expect with scars after recovery?

Each surgeon has their own protocol on when to remove the dressings after surgery. However, most incisions are nearly completely healed by 4 weeks after surgery. The appearance of the residual scar left behind depends, in general, on how your child's body utilizes its connective tissue cells during the wound healing process. Most children's scars are flat and blend in well with the surrounding skin (Figure 1). However, some children's bodies utilize too many connective tissue cells resulting in keloid formation (Figure 2). This phenomenon may be more common is children with darker skin complexions.

Figure 1

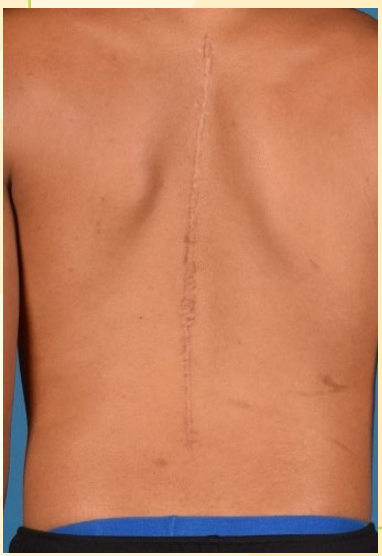


Figure 2. Keloid Formation

Are there other surgical methods?

There's a new fusionless correction called Vertebral Body Tethering (VBT)

Many centers are utilizing vertebral body tethering as a treatment option for their patients. This is a technique gaining in popularity which offers patients who qualify an alternative to spinal fusion.

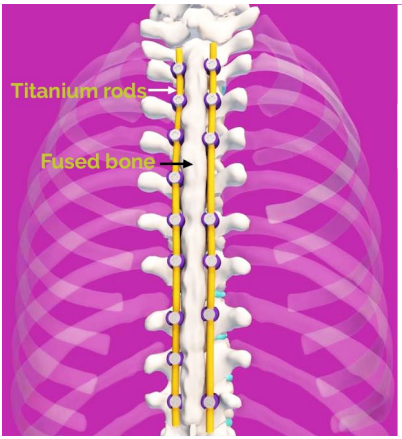
Spinal Fusion

Vs

Vertebral Body Tethering

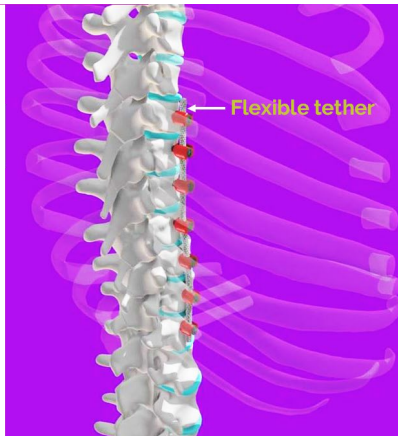
WATCH ME

Spinal Fusion



Spinal fusion surgery results in fused bone that is inflexible

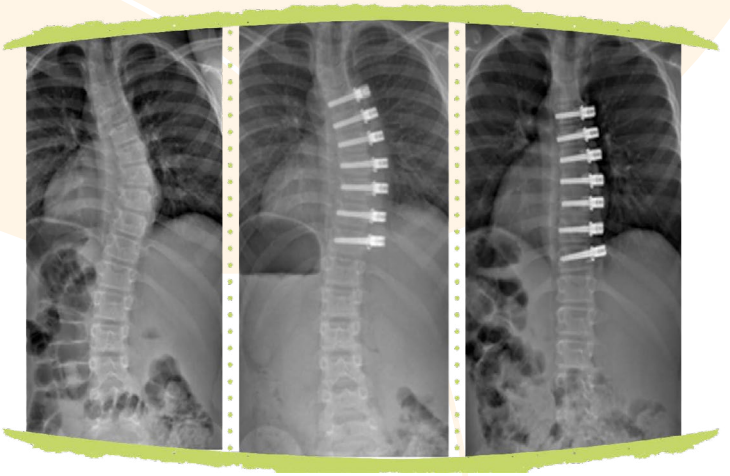
Vertebral Body Tethering



Vertebral body tethering allows for the spine to remain flexible

What is Vertebral Body Tethering?

Vertebral body tethering is a fusionless procedure. Patients need to fit certain criteria for vertebral body tethering to be a possibility. Generally, patients need to be between the ages of 8 and 16, have spinal curves greater than 35 degrees, less than 65 degrees, and have significant spinal growth left. Tethering is only conditionally approved in the US for patients who have failed or are not otherwise candidates for brace treatment. Patients must also have spinal curves that are deemed "idiopathic," meaning they are not associated with any other conditions. Your physician evaluates how much growth remains by evaluating the growth plates on your hand x-ray. Patients treated with vertebral body tethering have curves that, without tethering, are likely to lead to a spinal fusion. For those patients who fail bracing and who would like to avoid a spinal fusion, this may be an option to explore with the surgeon.



This area is still undergoing research to determine the outcomes of the procedure and to determine who the optimal candidates would be.

How does Vertebral Body Tethering work to correct scoliosis?

The surgery consists of minimally invasive surgery to correct scoliosis without a fusion. The surgeon will place screws on the convex (outside) side of the spinal curve. For most patients this is usually the right side in the chest and the left side in the lower part, the lumbar spine. A tether (rope-like device) is then secured to the screws along the side of the vertebrae.

The rope is then tensioned, thus correcting the scoliosis and guiding future growth. This tension helps to pull the spine straighter, with the possibility for additional straightening as the child grows. Thus, patients need to have adequate growth for the procedure to work effectively. The procedure is performed by a spine surgeon, often with the assistance of a general surgeon or chest surgeon. The spine is accessed through small, minimally invasive incisions on the side of the chest, and a fiber-optic video camera is often used to help place the screws and tether. However, since the spine is accessed through the side, the lung needs to be deflated so the surgeon can see. At the end of the surgery before the patient wakes up, the lung is re-inflated, and a chest tube is placed to keep the lung re-inflated after surgery. The chest tube is left in place for approximately 1-2 days, and chest x-rays are done to check the status of the lungs.

What to expect prior to VBT surgery?

Prior to surgery the patient may undergo an MRI of the entire spine to be sure there are no unusual conditions within the spinal cord that is causing the scoliosis. Routine bloodwork is also performed. Special bending x-rays as well as standing x-rays are done at the pre-op visit prior to surgery. The patient will also see the anesthesia team before surgery.

What to expect on the day of VBT surgery?

The patient will arrive the morning of surgery and be admitted directly. Parents can stay with their child in the pre-op area until they are ready to go back to the operating room. After surgery the patient may go to the PICU (Pediatric Intensive Care Unit) or surgical floor. During the surgery, special monitoring is used to check the patient's nerves throughout the prodecure since the surgery is conducted near the spinal cord. IVs and a catheter for urine are placed after the patient is asleep. Depending on the levels of the tether, the entire surgical process usually takes between 3-6 hours.

What to expect after VBT surgery?

The patient is out of bed the day after surgery and walking with the help of nurses and therapists. IV pain medication is administered until the patient can tolerate food and drink, and then oral pain medications are used. Depending on the patient, medications may be prescribed such as oxycodone; however, many patients only require ibuprofen or other non-narcotic medications.

Recovery of the lungs is an important focus after surgery, and the patient must perform frequent exercises to help their lungs recover quickly. The chest tube is normally removed within 48 hours of surgery as is the urinary catheter. Most patients are out of the hospital within 2-4 days after the procedure.

What are some complications with VBT?

One major complication the team will monitor for immediately after surgery is the risk of **pneumothorax** (collapse of lung). Since the device is inserted via access through the chest, this is the area that is most carefully monitored in the post-operative period. Most often the lung reinflates on its own but in the rare case that it does not, a chest tube may need to be reinserted. Vertebral body tethering carries some of the risks as other spinal surgeries including bleeding, infection, neurological injury, low dose radiation, and pain. Signs of implant failure will be carefully checked and, in some cases, may require additional surgeries to resolve.

In other cases, it is possible for the curve to overcorrect (Fig 1) with time to the extent that it curves in the opposite direction. Such cases may need an additional surgery for correction. The patient is taken back to the operating room for a small procedure where the tether is loosened to provide less tension. Also, the curve may worsen, or the tether may break at one or more places between two screws (Fig 2). If this occurs, your surgeon may discuss with you the need for revision surgery of the tether or a fusion surgery.

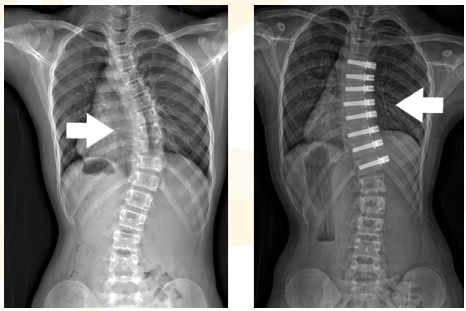


Fig 1: Overcorrection

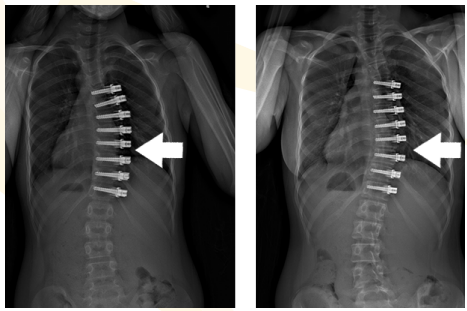


Fig 2: - Broken Tether

The long-term outcomes of treatment have not been as thoroughly established as fusion nor have the expected rates of complications or curvature correction been as clearly determined.

What to expect during recovery from VBT surgery?

The expected recovery course sees patients going home walking, climbing stairs, and able to do most normal activities. No physical therapy is required nor special equipment in the home. Patients are restricted from bending and twisting excessively as well as gym class and sports until they are seen at their post-operative visit. Normally, no bracing is required. A physical therapist will see the patient in the hospital to instruct them how to move with proper body mechanics.

Depending on pain, energy levels, and the surgeon's recommendations, patients may be out of school for as little as 1 week to a maximum of 4 weeks. They will be sent home with a dressing covering the chest tube site. This will be removed a few days after the chest tube is taken out. Provided a scab has formed, you may leave the site open to air. Otherwise, a band aid should be placed over the area. The other incisions will have little strips covering them which will eventually curl up and fall off. If, however, they have not fallen off 3 weeks after surgery, you may peel them off.

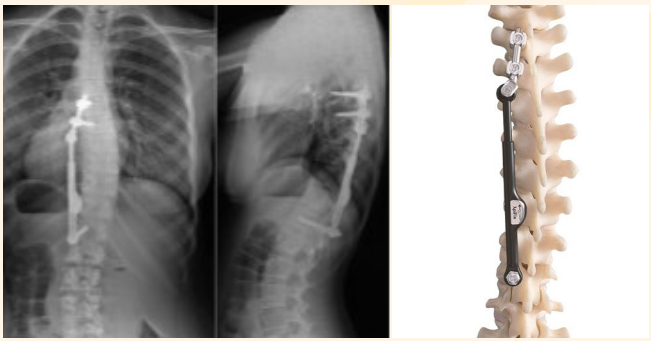
Rachel, after VBT spine surgery

Follow-up after VBT surgery

You will return for a check-up with your surgeon around 6 weeks post-op and have a set of x-rays done. If everything looks stable, your surgeon may allow you to resume sports and activities. Restrictions and return to sports are directed by your surgeon. You will be followed with x-rays approximately every 4-6 months depending on your stage of growth. Children who are growing more rapidly will be x-rayed more frequently to check the status of their curve.

What is a Posterior Fusionless Device?

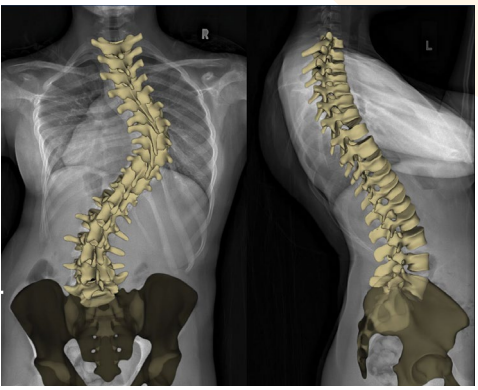
A posterior fusionless procedure, developed by ApiFix, recently received conditional approval from the FDA in the United States for use in adolescent idiopathic scoliosis. While it is secured with screws into the spine, it does not involve a fusion and therefore theoretically preserves motion. It is implanted posteriorly into the back and utilizes a ratchet system to straighten the spine. Once recovered from the implant surgery, the patient performs exercises to advance the ratchet over time.



Radiographic Imaging

Because patients with scoliosis may need frequent x-rays, and radiation can be potentially harmful, alternatives to traditional x-rays are now available at some centers. Ultra low dose imaging with special slot scanners can obtain very high quality images of patients' spines and lower extremities at a fraction of the dose of radiation. This is particularly important for our youngest patients or those who have had surgery, since they need frequent x-rays over their period of treatment. Perhaps even more exciting, with special software, these images can be used to reconstruct an image in three dimensions (3D) so that a surgeon can see particular nuances of a curve and decide how best to treat it.

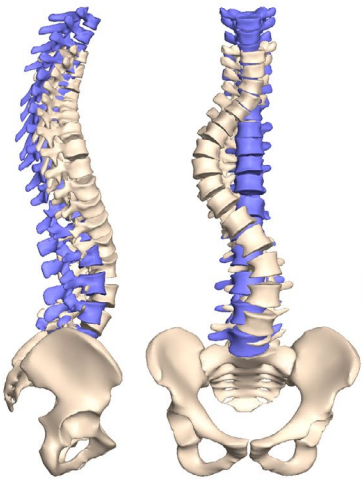
Since scoliosis is a 3D condition, it is exciting that, for the first time, we are able to appreciate what is happening in 3D when we view patients in the standing position. Also, after surgery, by using 3D imaging we are able to more accurately assess the quality of the correction of the curvature. This area has spawned a new field of 3D classification of scoliosis and will change the way we treat scoliosis.

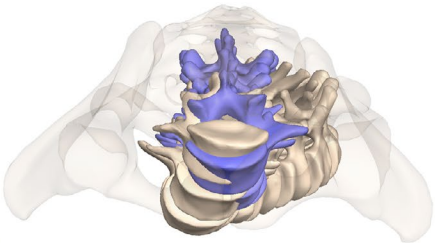


3D Radiographic Imaging

Advanced Technology in Spinal Instrumentation

Before the 1970s, the notion of placing screws in the bone around the spinal cord was unheard of as there was no safe method of doing so. In the ensuring decades, spine surgeons have capitalized on a better understanding of the bony anatomy, better designed instruments, and intraoperative x-rays to safely place these screws. As with all things in medicine, technology is advancing at a rapid pace, and many of these advancements involve the imaging technology spine surgeons use to insert pedicle screws. Which imaging technology your surgeon uses is entirely up to them but is also influenced by which device company their hospital chooses to partner with. Below are the various imaging technologies your surgeon may employ to safely insert pedicle screws:





Fluoroscopy (aka C-arm)

A C-arm is a C-shaped device that can be manually rotated around a patient to take x-rays from different views (Figure 1). More recent versions of flouroscopy machines can recreate images that use right-angle views to increase the safe placement of screws (Figure 2). Fluoroscopy does involve radiation, but often at a lower dose than that utilized in a CT scan.

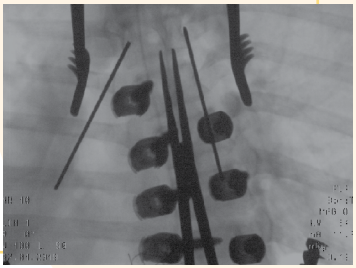


Figure 1

Figure 2

Intraoperative CT-Scan

Computed tomography (aka CT) scans utilize ionizing radiation to produce images from multiple views. Machines utilizing CT scan technology must rotate around the patient in order to produce their 3D images. The images produced allow surgeons to place pedicle screws with improved accuracy, although these results are highly dependent on the skill and experience of that surgeon.

Pre-Operative CT-Scans & 3D Printed Models

3D printed models have revolutionized many parts of medicine, and spine surgery is no exception. Using a CT scan of your spine, obtained weeks before surgery, a 3D model is created. Your surgeon will evaluate every spinal level where a screw is planned and make sure that the trajectory for the screw is appropriate. Once these trajectories are confirmed by your surgeon, special drilling guides are also 3D printed that hook into various bony landmarks on your spine. Your surgeon can then create the bony pathways needed, using a drill and other dilating instruments, and then insert the appropriate pedicle screw.

Pre-Operative CT-Scans & Machine Vision Navigation

Using GPS and camera technology like those present in self-driving cars, machine vision utilizes intraoperative cameras to identify the bony landmarks of the spine. Radiation is required, in the form of a CT scan performed days or weeks before surgery, which is loaded into the same machine with the machine vision camera. The system then correlates the anatomy from the CT scan to the spinal anatomy that is exposed by the surgeon. 3D visualization is possible using this technology.

Robotic Spine Surgery

The future of your child's spine surgery being performed completely by a robot is very far away. Instead, if your surgeon utilizes a robot, they are actually utilizing a robotic arm, mounted to the surgical table, that helps to aim their drill or other instruments in the correct trajectory (Figure 1). The robot can utilize information obtained from a preoperative CT scan or an intraoperative CT scan, but regardless, radiation is required.

Figure 1

In summary, the technology utilized in spine surgery is advancing rapidly, but none of these technologies substitute for the skill and experience of your surgeon. Most imaging technologies utilized today involve some level of radiation which is an important consideration when dealing with children and adolescents. Future technologies will hopefully employ non-radiation imaging such as MRIs to help surgeons safely insert pedicle screws.

Life Does Go On After Surgery

During the first few weeks at home after surgery, the focus is on:

- Pain management and weaning from pain medicines.
- Healthy eating as appetite returns to normal.
- Patients getting back to independence with their own care (Parents often comment that these weeks are like having a newborn again).
- Increasing activity and endurance.
- Returning to school two to four weeks after surgery.

At six weeks after surgery, most teens are:

- Feeling good, with your pre-surgery energy level back to normal.
- Back to your normal life except for activity/sports restrictions.
- No longer requiring pain medicine.

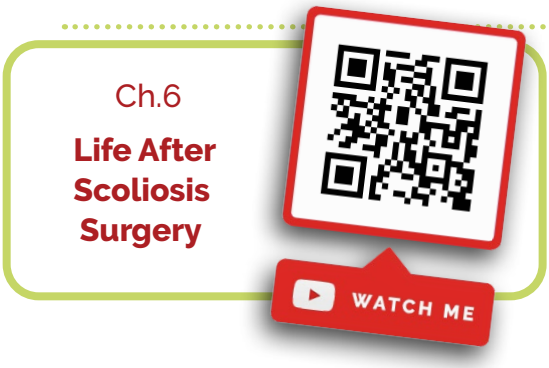
Ryan, back in the pilot's seat after spine surgery in 2010

Weeks to months after surgery, activity restrictions may remain.

- Restricted activities are those that put too much physical stress on the healing muscles, which would prolong your recovery.
- Many surgeons will gradually ease up on restrictions as the year after surgery progresses.
- Activities to avoid until cleared by the surgeon may include contact and high impact sports, physical education, heavy lifting and aggressive twisting, or stretching of the spine.

The rest of your life:

- There is little physical effect from surgery throughout life's stages.
- The risk of developing complications is low.
- Scoliosis runs in families, so watch the next generation.
- There are no limitations in your choice of profession.
- Young women can expect normal pregnancies and deliveries.
- A back-healthy lifestyle is recommended (maintain weight, remain active, no tobacco).



Suggestions on how to navigate through treatment:

1. When you receive unexpected or unwelcome news at a doctor's visit, it can be difficult to then focus on further information. Please come back to talk to your doctor when you've had time to think about the visit. It is important that you get all of your questions answered.
2. Write your questions down.
3. Educate yourself. Knowledge empowers you and will allow you to make informed decisions.

Kayci, after spine surgery

4. Talk with one another—parents, children/teens and medical staff.
5. Listen to each other—parents, children /teens and medical staff.
6. Work together to make decisions and to develop a trusting relationship.

Lisa, training for a career as a Radiologic Technologist, had spine surgery in 2000.

You are not alone!

Each patient with scoliosis has a unique story to tell. Setting Scoliosis Straight has shared over 100 inspirational stories from patients who have had spinal treatment and wish to give hope to others. Explore the stories on our website to learn more about patients with various spinal issues.

Jamie, back to playing soccer after spine surgery

Read stories from patients around the world

READ MORE

Read over 100 inspirational stories from patients with various treatments, such as bracing, spinal fusion, and vertebral body tethering.

Watch patient stories & interviews

WATCH ME

Watch our new patient story and interview series called Scoliosis Strong Stories. These interviews provide helpful tips and advice for newly diagnosed patients.

If you're interested in sharing your personal story or becoming a scoliosis ambassador for the Setting Scoliosis Straight Foundation, contact us at **info@ssshsg.org** to get started.

FAQs

1. **What is Scoliosis?** Scoliosis is a curve in the spine.
2. **How can you tell that I have scoliosis?** Sometimes it is not noticeable, but you might see that one shoulder or hip is higher than the other, one shoulder blade more prominent, or that your trunk and waist are not equally balanced.
3. **What causes scoliosis….carrying a heavy backpack, not drinking enough milk, poor posture?** No, scoliosis isn't caused by anything that you did or didn't do. It is a genetic condition.
4. **Does scoliosis hurt?** Adolescents with mild to moderate scoliosis do not have any higher incidence of back pain when compared with adolescents who have back pain but no scoliosis.
5. **How common is scoliosis?** It is present in two to three percent of the population.
6. **Does scoliosis run in families?** Scoliosis is a genetic condition most common in girls. At this time, scientists continue to work to identify the specific genetic markers of DNA that indicate scoliosis.
7. **Is there a way to tell if my scoliosis will get worse or not?** Not at this time, though part of the current genetic research is trying to find an answer to this question.
8. **Can I still exercise?** Yes, staying active is important to overall health. There are no exercises, sports, or activities that will make scoliosis worse or better.
9. **What is the treatment for scoliosis?** Basically, there are three options: to monitor it with routine check-ups and x-rays, to wear a brace, or to have surgery.
10. **Are there any alternative treatments?** There are no scientific data that prove alternative methods such as chiropractic, physical therapy, vitamins, etc. will affect the natural history of scoliosis, but there is no evidence that they do harm either.
11. **What is the purpose of a brace?** The goal is to prevent the curve from getting bigger and therefore prevent surgery.
12. **Will a brace make my scoliosis better?** Not permanently. The curve(s) are somewhat corrected by the brace but once the brace is taken off, the curves can return to their original form.
13. **Do I have to wear the brace all of the time?** It depends on the type of brace, and the type of brace depends on the location of your curve. Some braces are worn full-time (20 to 23 hours/day) and some only during sleep. If you are wearing a brace full-time, it is important to continue to participate in sports, P.E. and other activities. You can remove the brace during this time.

14. **How long do I have to wear the brace?** You should wear the brace until you are done growing.
15. **What is the goal of surgery?** The goal of surgery is to prevent scoliosis from continuing to get worse and correct the curves as much as can safely be corrected.
16. **What kind of surgery do I need?** Spinal fusion with instrumentation depends on the location of your curve(s). Surgery is done through an incision on your side (anterior) or through an incision on your back (posterior). Some curve patterns can be treated by either method.
17. **How long will I be in the hospital?** Two to three days.
18. **How much school will I miss?** Two to three weeks.
19. **When can I play sports again?** Opinions vary among surgeons, but most release people back to sports and other activities by weeks to months after surgery.
20. **What will the scar look like?** While everybody heals differently, incisions tend to fade and become less noticeable over time. The goal is for it to heal as a flat, thin line that is the same color as your skin. Please ask your surgeon about this.
21. **If I have metal in my back, will it set off alarms in the airport?** This is not likely.
22. **Will I need to have more surgery later on?** Subsequent surgeries are unlikely, but it is important to keep your follow-up visits with your surgeon for at least two to five years to make sure your spine heals properly.
23. **What if I decide not to have the surgery?** Good question. We recommend that you discuss this with the surgeon. Knowing risks and benefits of not having surgery, as well as the risks and benefits of having surgery, will be important as you make decisions.
24. **Are my children going to have scoliosis?** It is possible. There is a higher likelihood that your children will have scoliosis, although it may skip a generation or more.
25. **How do I chose a scoliosis surgeon?** You should speak to your family doctor and other people in your area who may be familiar with scoliosis surgeons. Your surgeon should have significant experience treating young people with scoliosis, should have performed many surgeries like yours, and should be comfortable discussing the procedure with you and your family. Your surgeon should also be a member of the Scoliosis Research Society and be board certified with proper credentials.

Glossary

You are going to be getting an education that you may never have thought you'd need. This includes a new vocabulary, so we have included some common words and phrases here. Some of the websites provided here have a more complete and user-friendly glossary. These definitions will be very helpful!

Adams Forward Bend Test–test used by many primary care physicians and school nurses to screen for scoliosis and to measure in degrees the amount of rotation associated with a scoliotic curve

Allograft Bone–bone that is taken from one individual, sterilized and available for use in a patient needing surgical fusion

Anterior–front

Anterior Spinal Fusion–surgical approach where the anterior section (vertebral body) of adjacent vertebrae are fused together. To access the anterior part of the vertebrae, an incision is made on the side of the body. The intervertebral discs are then removed and replaced with bone graft. Sometimes instrumentation is placed anteriorly to assist with the fusion.

Apex of Curve–the vertebra in a scoliotic curve that is most laterally displaced – usually the stiffest, middle part of the curve

Autogenous (or Autologous) Bone–bone removed from one location in an individual and placed in a different location in the same individual (for example, pelvis, rib graft or portions of the spinal bones can be used in the spine to assist with fusion).

Bone Graft–bone (allograft or autologous) that is placed over implants or between other bones to assist with fusion

Cervical–pertaining to the seven vertebrae of the neck

Cobb Angle–x-ray measurement, in degrees, of the magnitude (size) of a spinal curve

Coccyx–the bottom-most segment of the spine, located below the sacrum, also known as the tailbone

Compensatory Curve–a curve that develops above or below the primary curve as an attempt to maintain normal balance of the body (to keep your head above your pelvis)

Corpectomy–surgical removal of all or part of a vertebral body, also called a Vertebral Column Resection or VCR

Decompensation–refers to loss of balance when one section of the spine is not centered above or below the adjacent section; a trunk shift is an example of decompensation

Disc–soft, fluid-filled structure between the anterior segments of each vertebra that allows for absorption of loads and flexibility of the spinal column

Excision–removal of tissue, bone or tumor

Facet Joint–laterally located joints between individual vertebrae that allow for movement, sometimes excised and used as supplementary bone graft

Idiopathic–unknown, refers to cause of a disorder

Internal Fixation or Instrumentation–immobilization of the mobile segments of the spine with implants to promote correction and fusion of these segments (an internal brace)

Lateral–located away from the midline of the body

Lumbar–the section of the spinal column that is between the thoracic spine and sacrum, made up of five vertebrae

Kyphosis–a front to back curvature, sometimes called a sagittal plane deformity or "hunchback"

Medial–located close to the midline of the body

Osteotomy–cut in a bone

Pedicle–part of the vertebra, shaped like an arch that connects the anterior and posterior segments of each vertebra

Pedicle Screw–screw placed posteriorly across the pedicle into the anterior part of the vertebral body, used as an anchor for a spinal rod

Posterior–back

Posterior Spinal Fusion–surgical approach where the posterior elements of the spine are fused together, accessed through an incision on the back

Primary Curve–the main curve of a scoliotic deformity, usually the first curve to develop and the largest one needing treatment

Pseudarthrosis–failure of the bones to fuse after corrective spine surgery (also called non-union)

Rib Prominence (AKA rib hump) –prominence caused by rotation of ribs as scoliosis develops

Rotation–twisting of spine when scoliosis is present, creates three-dimensional deformity

Sacrum–five fused vertebrae that comprise the bottom of the spinal column between the pelvis

Scoliometer–tool to measure, in degrees, rotation that is associated with a scoliotic curve

Scoliosis–a lateral curve of a section of the spine, usually accompanied with rotation

Spinal Canal–long canal between the anterior and posterior segments of the spinal column, houses the spinal cord

Spinal Column–refers to the column of bone and discs created by the individual vertebrae of the spine

Spinal Implants–metal devices (screws, rods, hooks, wires) used to instrument and stabilize the spine

Spinal Instrumentation–the attachment of implants to the spine to achieve correction of a scoliotic curve

Spinal Fusion–union or stabilization of two or more adjacent vertebrae with bone graft

Spondylolisthesis–forward slippage of one vertebra on another (usually L5 on S1)

Structural Curve–curve that is not flexible and is usually included in the fusion

Thoracic–refers to the twelve vertebrae between the cervical and lumbar regions of the spine that attach to the twelve ribs of the rib cage with cartilage

Thoracolumbosacral Orthosis (TLSO)–a rigid brace, custom molded to apply counter pressure to a scoliotic curve with the goal of preventing the curve from progressing to a degree where surgery may be needed

Thoracoplasty–resection/removal of rib segment, sometimes done to obtain additional correction of the rib prominence

Vertebra–one of the thirty-three bones (vertebrae) that make up spinal column

Other Types of Scoliosis

While idiopathic scoliosis is the most common type of scoliosis, there are others.

Neuromuscular—an underlying neurologic condition such as Cerebral Palsy, Muscular Dystrophy and Spina Bifida can cause scoliosis to develop.

Kayla, a competing triathlete, after spine surgery in 2002

Congenital—present at birth, failure of vertebrae to either separate (creating a fused block of vertebrae) or to form completely (hemi-vertebra), causing uneven growth of the spine and scoliosis.

Syndromic—scoliosis is a component of many syndromes such as Marfans syndrome or neurofibromatosis. Scoliosis in syndromes can have characteristics of either neuromuscular, congenital or idiopathic scoliosis.

Other—examples include individuals who have had prior heart or chest surgery and may develop scoliosis from weakness of the chest wall, or patients who have had prior surgery for tumors or radiation.

Research

Many aspects of scoliosis have been, and continue to be, studied. These include the causes, varied treatment options, and long-term effects.

Some ongoing research aspects that are noteworthy include:

- Genetic research
- Effectiveness of bracing
- Fusionless treatment
- Study of the long-term effects on adolescents who have undergone surgical treatment

Information learned through research has already improved the available treatment options, and ongoing study will further advance these.

Be Part of Our Foundation Family

Join the national effort focused on a future without scoliosis. The Setting Scoliosis Straight Foundation supports ongoing research and educational efforts that improve the lives of children and adolescents affected by scoliosis.

By joining the **Foundation Family**, you will have the opportunity to receive updates on the latest research and information about surgeon members and their innovations, and you will gain access to resources created just for families like yours.

Please take a moment to complete this form to opt in to receive updates. Your personal information will be held in confidence and will not be given to other organizations without your consent.

SIGN UP TODAY

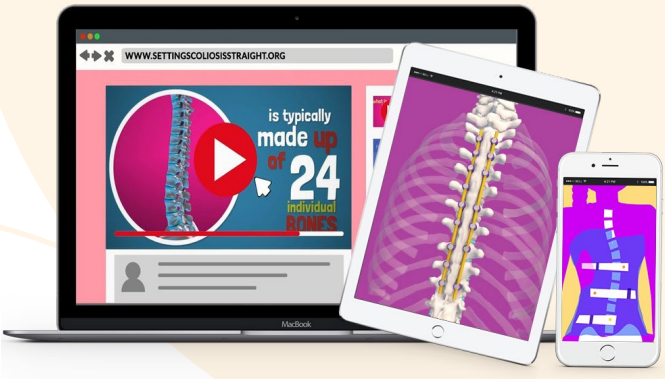
Scan the QR Code to sign up to our Foundation Family today!

Jennifer & Liam, Foundation Family Members

Additional Resources

Learn more from home

Setting Scoliosis Straight is proud to present our large video library, which consists of evidence-based information conveyed through animated infographics, recorded webinars, and a wide range of interviews with renowned surgeons and patients who have experience with different treatments.



Visit our website or YouTube channel to view our large video library. Also, don't forget to subscribe to our YouTube channel today so you don't miss out on new scoliosis information and research findings.

Scan the QR Code to visit our YouTube channel and hit that SUBSCRIBE button!

Conclusion

As you travel on this journey, please be reassured that Idiopathic Scoliosis is a very treatable condition and generally will not affect your ability to fully participate in and enjoy life.

We hope that the information provided here will be helpful and ask that you keep in mind that this information is very general. It is intended to give you a framework as you are presented with choices, not to recommend specific treatments.

Scoliosis is a complex disorder and there will be challenges along the way, but we're confident that you will rise to meet them!

Appendix

Websites

There are a number of informative websites that provide reliable information. Visit our website to check out additional resources:

A Special Thank You to our Road Crew

The production of this booklet would not have been possible without the contributions and efforts of:

Setting Scoliosis Straight Foundation

Harms Study Group

Dr. Jaysson Brooks

Dr. Lori Dolan & Dr. Stu Weinstein

On The Edge Design

NebCal Printing

Order Form

If your organization or institution would like to order large quantity hard copies of this handbook to distribute to your patients, please complete the order form by scanning the QR code below, or email us at **info@ssshsg.org,** or call us at 619-810-1430.

Scan the QR Code to complete the order form

We appreciate your feedback!

This version of "Idiopathic Scoliosis, Navigating Your Journey, A Guide for You and Your Family" was created using extensive feedback from our patients and colleagues. If you would like to give us feedback, please email us at **info@ssshsg.org**.

THANK YOU!

About the Harms Study Group and Setting Scoliosis Straight

This booklet was written by nurses and surgeons who care for patients with scoliosis every day. The **Harms Study Group** (named after Professor Juergen Harms from Germany) is a group of caregivers who have dedicated their careers to learning how best to treat patients with scoliosis. These individuals participate in a research group that studies, in great detail, the surgical outcomes of thousands of their patients.

The group studies the outcomes of various treatment options, analyzes the results, and publishes their findings in peer-reviewed scientific journals—which ultimately educate the medical profession and the public. Committed to patients and focused on advancing the science of scoliosis treatment for the future, the Harms Study Group delivers these goals through multi-center research studies.

We thank the patients who have contributed to our numerous research publications that allow all scoliosis physicians to offer the optimal treatments for every individual patient.

Setting Scoliosis Straight is a non-profit foundation established to support the Harms Study Group. If you would like to assist with the production of this handbook and the efforts of Setting Scoliosis Straight, please visit www.settingscoliosisstraight.org to make a donation. A one-time gift or a multi-year pledge can make a huge impact.

This booklet is endorsed by:

SRS Scoliosis Research Society

www.srs.org

POSNA Pediatric Orthopaedic Society of North America

www.posna.org

EPOS European Pediatric Orthopaedic Society

www.epos.org

National Scoliosis Foundation

www.scoliosis.org

Asociación Mexicana de Cirujanos de Columna Fundada en 1997

www.amcico.org

GEER Spanish Spine Society

www.geeraquis.org

turkishspine

www.turkomurga.org.tr

COA 2012 Chinese Orthopaedic Association

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