

Produced by

HARMS STUDY GROUP
FOUNDATION

Adolescent Idiopathic Scoliosis



*Navigating
your Journey*

**A GUIDE FOR YOU
AND YOUR FAMILY**



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A Note from the Sponsors



Miami Children's Hospital is honored and proud to be one of the sponsors of this scoliosis handbook. The initial version assisted many families in dealing with the various aspects of scoliosis treatment. Surely, many more families will benefit from this edition. Congratulations to the Harms Study Group for production of such an outstanding manual.



Nemours/Alfred I. duPont Hospital for Children is pleased to partner with the Harms Study Group Foundation to help guide families through this journey. As pioneers in scoliosis treatment and leaders in the healthcare of children, we understand families' need for education and support along the way. Thank you to the Harms Study Group Foundation for creating this comprehensive roadmap for scoliosis.



Cincinnati Children's Crawford Spine Center is committed to helping the whole patient stand tall. Our multidisciplinary team treats the patient both physically and emotionally, and we are proud to sponsor this exceptional scoliosis resource from Harms Study Group, which helps serve the critically important need of supporting and educating families throughout the diagnosis and treatment process.

A Note from the Producer

H A R M S S T U D Y G R O U P
F O U N D A T I O N

The Harms Study Group Foundation is honored to present this second version of “Adolescent Idiopathic Scoliosis, Navigating your Journey: A Guide for You and Your Family.”

This handbook is the culmination of over two years of work, which includes extensive feedback on version one 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.

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Introduction



This handbook about Adolescent 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 Adolescent Idiopathic Scoliosis (AIS), 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.



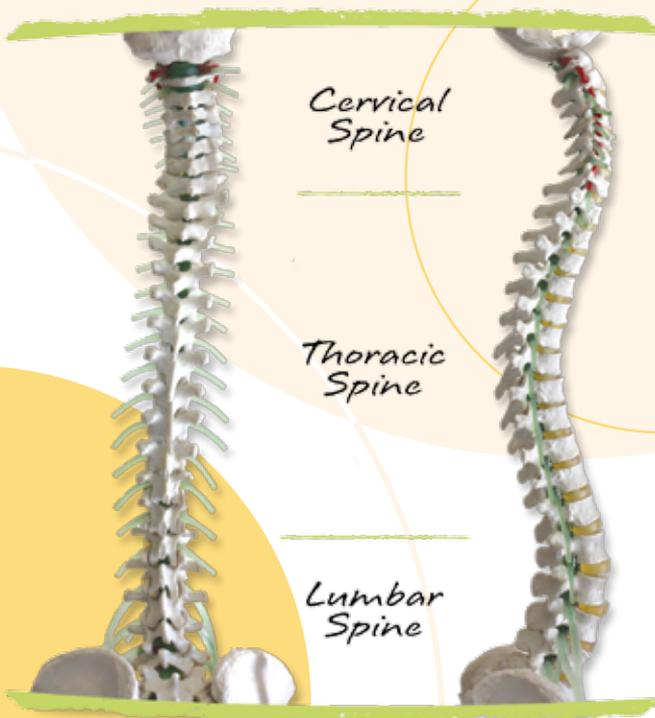
Kalli, after spine surgery in 2002

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.

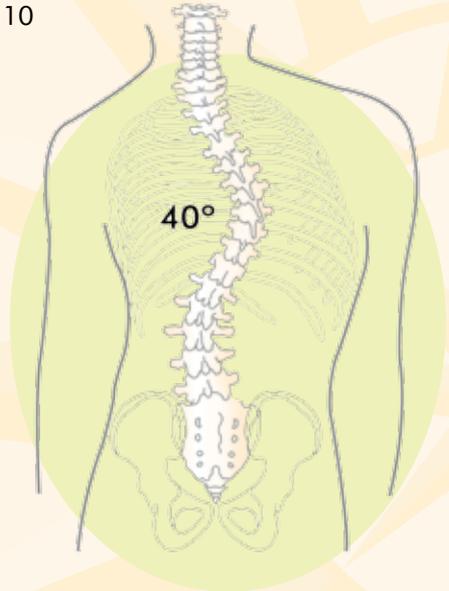


What is scoliosis?

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 10% of the population has small (less than 10 degrees) curves, which are of no consequence to function or health. This condition is called Spinal Asymmetry.

When a diagnostic x-ray is done, the 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 10 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.

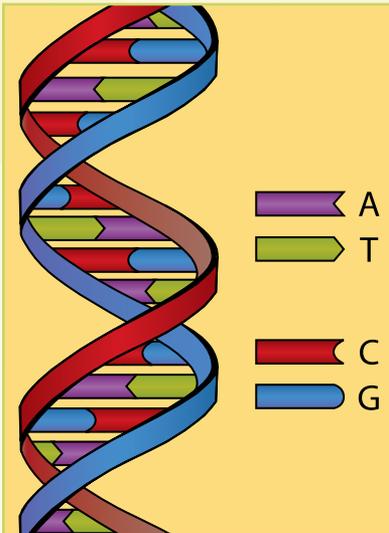
There are naturally occurring curves in the spinal column when it is viewed from the side (laterally). Swayback (lordosis) is normally present in the cervical and lumbar regions while round back (kyphosis) generally exists in the thoracic spine.



What causes scoliosis?

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

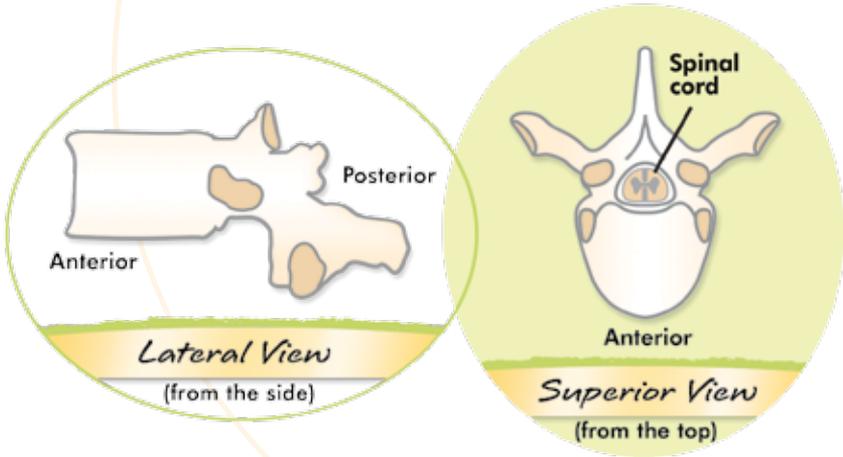
Scientists have identified that idiopathic scoliosis is a genetic condition and continue to work to isolate the combination of individual genes that cause scoliosis. A test has been developed that may help to determine the risk of progression of scoliosis (whether or not the curve will get bigger). This may eventually allow for earlier diagnosis and more accurate selections of the "best" treatment for each patient.



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.



Categories of idiopathic scoliosis

Idiopathic scoliosis is defined by the age at which it begins to develop.



**Infantile-onset
Idiopathic Scoliosis:**
Age 0 – 3



**Juvenile-onset
Idiopathic Scoliosis:**
Age 4 – 9



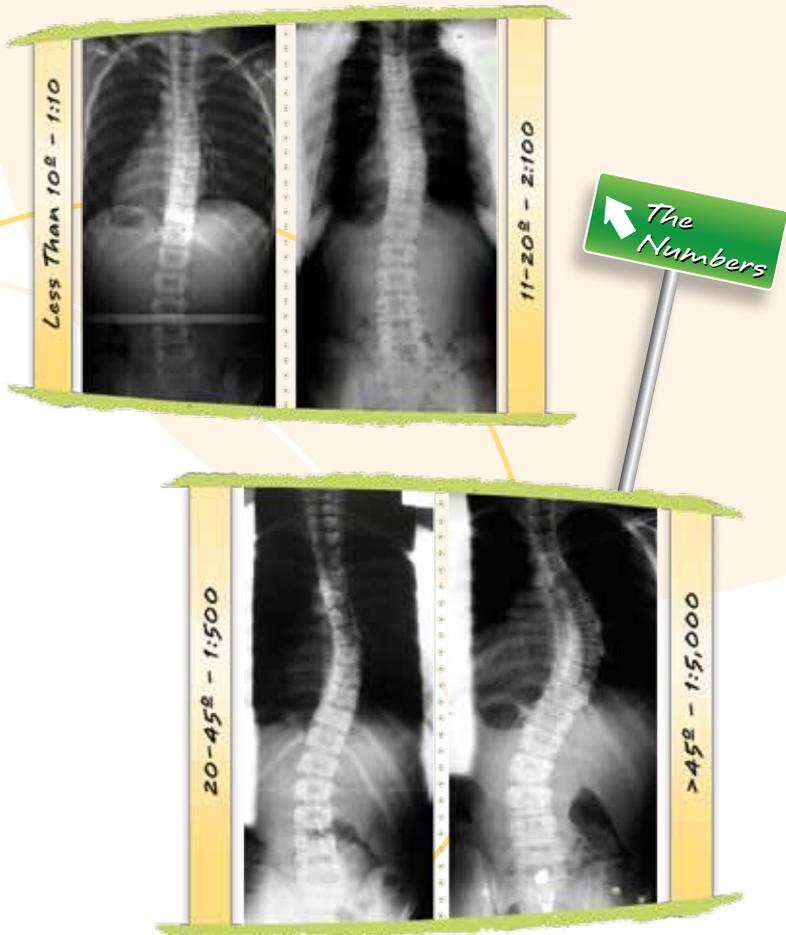
**Adolescent-onset
Idiopathic Scoliosis:**
Age 10 – 18

Each age group has unique needs and challenges associated with treatment.

How common is scoliosis?

Idiopathic scoliosis is thought to be present in two to three percent of adolescents. One in five hundred 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

Who might detect the presence of scoliosis in a child?

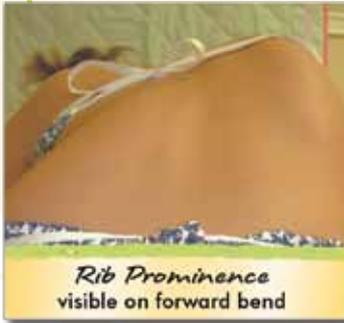
- Pediatrician or family doctor during routine exam
- School screening nurse
- Athletic coach or P.E. teacher
- Parents
- The child her/himself
- Other family members or friends
- Incidentally, via an x-ray done for another reason



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 5th or 6th grade and boys in the 6th or 7th 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 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 3-dimensional deformity. When a curve develops, the spine also twists, or rotates to the left or right. The amount and type of change in body shape can 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. In addition, in its early stages, scoliosis does not cause pain so it can go undetected.

Katie, back to skiing after spine surgery in 2001



We noticed 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.
- 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?

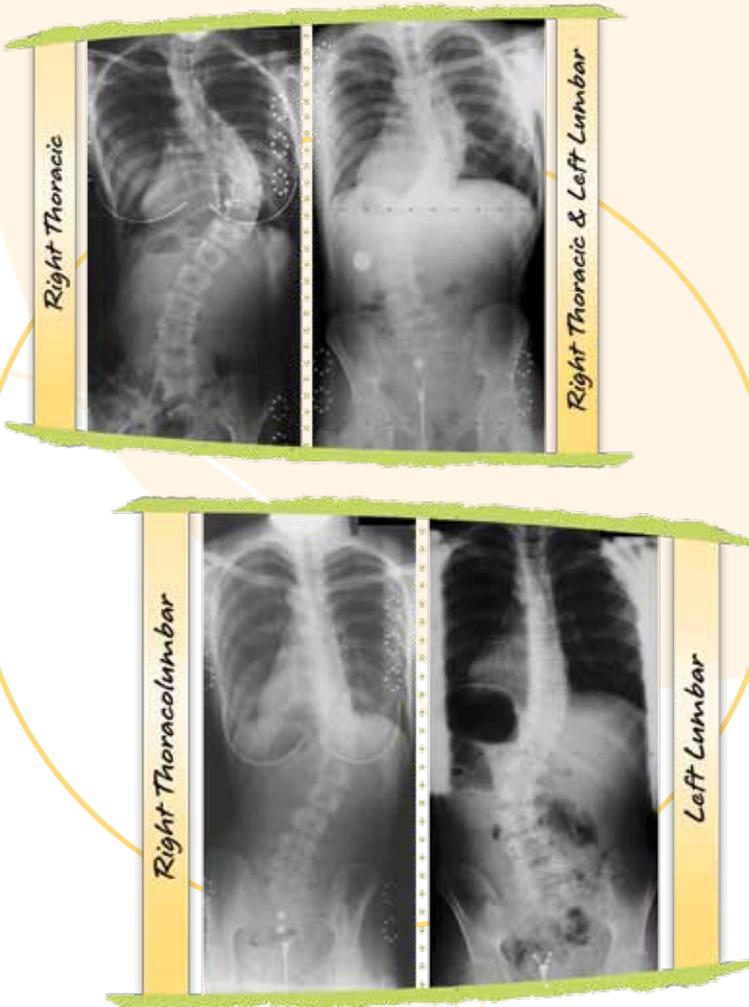
As a spinal curve develops and the spine twists, asymmetry of the ribcage and/or waist is created. A scoliometer is used to measure the amount of rotation (in degrees as an angle).

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: 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 as an angle. This is called the Cobb Angle or Cobb Measurement.



When is an MRI or further diagnostic workup 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.



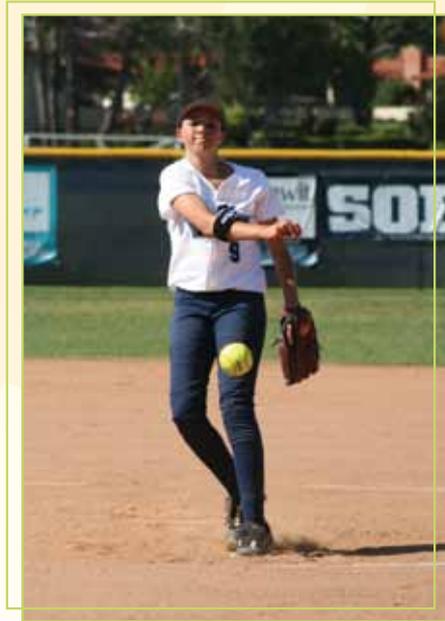
Will the curve get bigger?

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.

Two factors are most important in predicting progression:

1. Size of the curve and
2. The amount of growth still to come



Amanda, back to softball after spine surgery in 2009

Know
Your
Options

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.

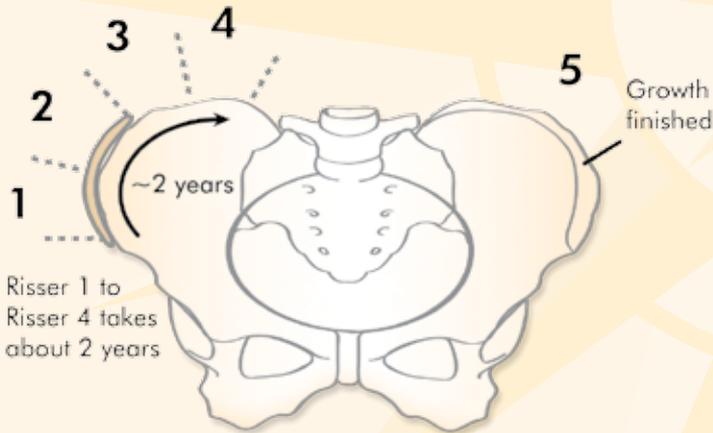
In addition, a skeletal maturity marker on the pelvis called the Risser Sign is visible on x-ray, and this indicates how much bone maturation is left.

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

These indicators of skeletal maturity do not always correlate and an x-ray to evaluate the growth centers in the bones of the hand may be recommended.

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 to bone. This process occurs during puberty. 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--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.

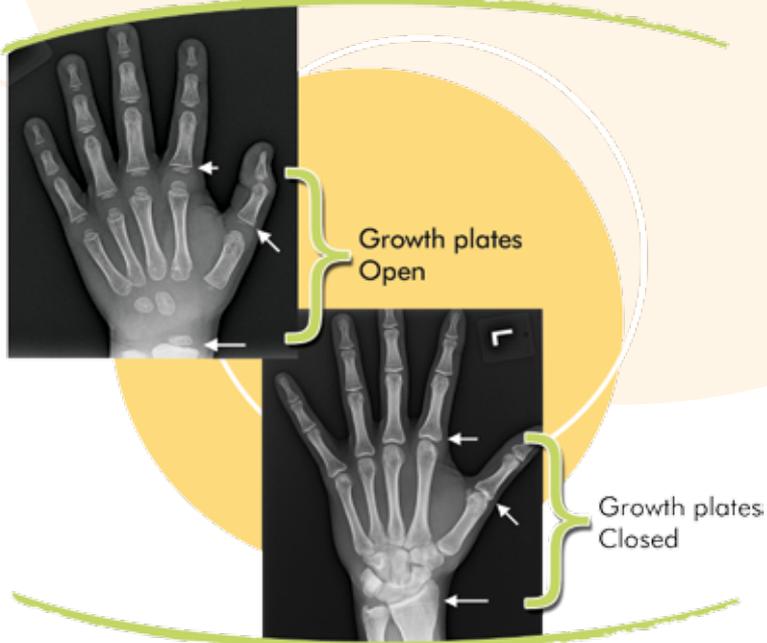


The Risser Sign

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 (years since birthday) 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.



It is scoliosis.

What are my treatment options?

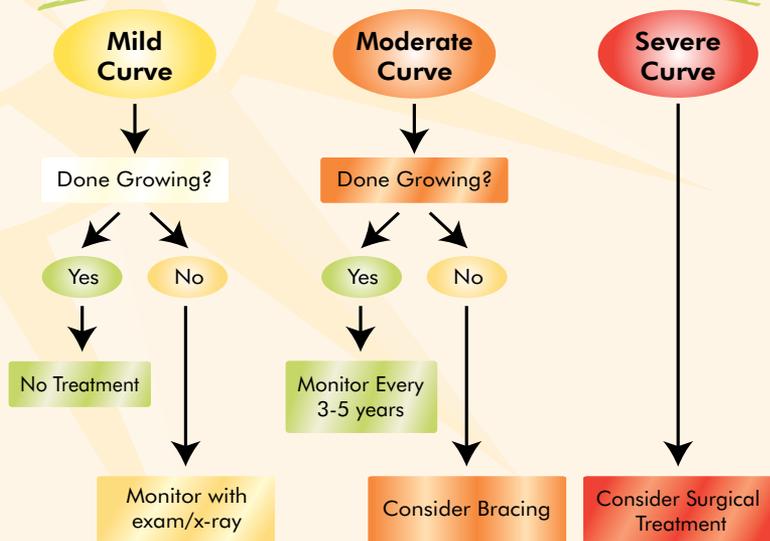
Scoliosis can be treated non-operatively or operatively, depending on the size and severity of the curve. Non-operative treatment includes either observing the curve for progression or wearing a brace.

Operative treatment may be considered if the curve reaches a point where it will continue to progress even after growth is finished.



Route I: Non-Operative Management

Patient Presenting with Idiopathic Scoliosis



What does observation entail?

Observation means that the patient will continue to be monitored via returning to the specialist every four to twelve months for x-rays and an exam. The frequency of visits will be based on what stage of growth the child is in. Because of small variability (up to five degrees) in day to day measurements of x-rays, it is not recommended that comparative x-rays 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 x-rays more frequent than every four months cannot reliably determine true progression.

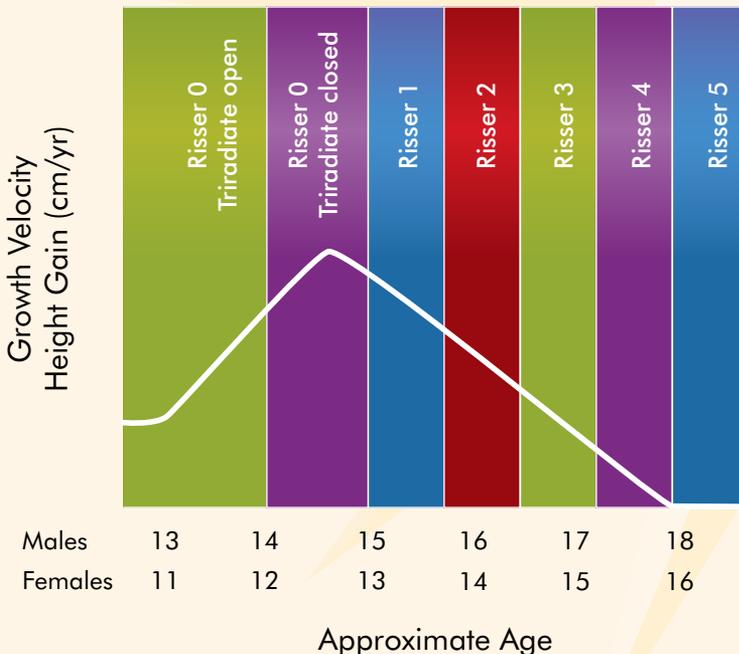
Observation alone is usually recommended for curves less than twenty to twenty-five degrees if growth remains and for all curves less than forty to fifty degrees in those patients who are done growing.

Will my curve progress?

In general, the younger, less skeletally mature the patient and the bigger 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 with which adolescents grow during the approximately 18 months before the first Risser Sign appears (called the stage of peak height velocity). 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 their first period.



We've been observing the curve and it has gotten worse. What's next?

There are a few different scenarios for curves in the twenty-five to forty degree range:

1. If the curve has gotten worse but is less than 40 degrees and growth is complete, there is little risk of the curve continuing to progress in adulthood.
2. If the curve has gotten worse, but not enough that surgery is recommended, and you're still growing, observation is required and a brace may be considered.

What is Bracing?

At some point in treatment for scoliosis, the doctor may need to discuss whether or not a brace could be beneficial. This discussion is held when curves are progressive and there is enough skeletal growth remaining that bracing might be effective in preventing further progression.

Bracing is typically considered when curves reach more than twenty to twenty-five degrees and there is enough growth remaining that the brace may limit progression and avoid surgery. The goal of bracing is to halt progression. Bracing rarely leads to any significant or permanent correction of a curve.

What is a scoliosis brace?

A scoliosis brace is a rigid plastic brace (also called an orthosis) that fits around the trunk and hips and applies counter-pressure to a curve. The theory behind bracing is that pressure against a curve from the outside may allow more normal growth of the spine.

What does a brace look like?

There are a variety of brace styles, some designed to be worn full-time and others just at nighttime during sleep.



How do I know which brace should be used?

The curve pattern, location of the primary curve and physician preference will determine which brace is recommended.

As discussed earlier, there are three main regions of the spine that can develop curves—upper thoracic, main thoracic and lumbar—and these can occur in combination. Upper thoracic curves are not typically amenable to underarm bracing because that section of the spine is blocked by other bony structures.



A TLSO (thoraco-lumbo-sacral orthosis) worn full-time (the doctor will define “full-time”) is typically the most commonly recommended brace type and can be used for single curves in the thoracic region and for double curves. For a single lumbar curve, some physicians suggest a nighttime only brace. An x-ray and physical exam will help determine which brace has the most potential to be effective. Opinions regarding the use of a brace and specific brace designs vary widely among experienced scoliosis experts.

To brace or not to brace: Is bracing effective?

The answer is sometimes yes, sometimes no. Bracing is a reasonable choice. Yet it continues to be debated as it may help some patients, but it is not uniformly or consistently effective for all patients. Experts suggest that bracing may prevent progression of scoliosis in some individuals to some degree and thus avoid surgery. It is also known that some curves progress and require surgery even when a brace is worn. Conversely, some curves won't progress even when a brace is never worn.

Though doctors and scientists continue to work to answer the bracing question, what is not known at this time is whether scoliosis progression can be prevented in any individual. This leads to braces being worn both by teens whom never needed a brace and by teens whose curves will progress despite wearing one. What is known is that if bracing is going to be successful in preventing progression of a curve, the brace needs to be worn. Effectiveness is dose dependent--the more hours the brace is worn, the greater the potential for it to be effective.

At this time it is not possible to determine the natural history (how the curve will behave over time) of scoliosis, though there is a test in the early stages of development that may provide that information in the future. Although the debate on effectiveness continues, bracing only makes sense when significant skeletal growth remains (Risser 0--2) and there is a strong commitment from the patient to wear the brace. If a patient does choose to proceed with bracing, it is very important that the patient continues to participate in the sports and other activities that s/he enjoys.

**Patient responses to being told
a brace is recommended include:**

You expect **ME** to wear
THAT?

NO WAY!

I'd rather have an operation.

I'll wear it,
but **NOT** to school

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

Shopping!

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

Sports and other activities will not make your scoliosis worse, so please continue to play and be active.

**We've decided not to go ahead with a brace.
What's next?**

Choosing observation rather than bracing is also a reasonable choice. Your doctor will recommend how frequently you should follow up for x-rays and an exam, but it is typically every four to twelve months.

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

There are a variety of other treatments and techniques that proponents claim can stop scoliosis progression. These include acupuncture and acupressure, electrical stimulation, biofeedback, physical therapy, magnets, nutritional and vitamin supplements, chiropractic manipulation, shoe orthotics and other types of less traditional treatments. None of these to date have been proven scientifically to have any effect on scoliosis.



Josh, after spine surgery in 2008

We chose a brace. What's next?

The doctor will write a prescription for an orthotist to make a brace. Though insurance coverage can affect brace choices, generally the doctor will refer an orthotist whom they have confidence in and have worked with before.

It generally takes two to four weeks to receive the brace. The doctor will want to check the fit and have an x-ray done in the brace to evaluate its effectiveness (how much the curve corrects). The doctor will help schedule an appointment for a few weeks after the brace is received. The patient will then return periodically to follow the progress of the curve with an exam and x-rays.

How long does the brace need to be worn?

A brace is worn until an adolescent is done growing or the curve progresses to a degree where surgery is recommended. Most girls are done growing eighteen to twenty-four months after the start of their menstrual periods. Boys tend to grow into their late teens so they often need to wear a brace for longer periods of time than girls.

Are there psychological effects with bracing?

The teen years are years of rapid change, of a heightened sensitivity to differences between one's self and their peers, increased peer pressure and a sometimes fragile self-confidence. Having to wear a brace can affect how teens adjust to an already challenging time of life.

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

From teens:

- Enjoy shopping for new clothes that will fit over the brace.
- Keep doing everything you did before you got it.
- Don't be embarrassed by it—it's just like braces on your teeth.
Temporary!
- Don't expect it to get you out of P.E.!
- Decorate the brace.
- Name the brace.
- It's hard, but you can do it.



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

From parents:

- Keep your children in sports and activities.
- Give them a break sometimes—for a sleepover, a vacation or special event.
- Recognize that it is difficult, both for you and your teen.
- Talk to other parents whose teens are wearing braces.
- Support your teen in their efforts.

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

If scoliosis progresses to the point where it will continue to get worse in adulthood and lead to significant health issues later in life, surgery may be recommended.

When might surgery be recommended?

This depends partially on the stage of growth, the location of the curve and the curve pattern.

In general:

- When a curve reaches forty degrees, surgical intervention may be recommended even though growth is not complete.
- At skeletal maturity, curves less than forty-five to fifty degrees tend not to progress any further, but lumbar curves may have a lower threshold of thirty-five to forty degrees.
- At skeletal maturity, curves greater than fifty degrees are at high risk for continued progression throughout adulthood, though at a slower rate (approximately one to two degrees a year). Surgery will likely be recommended.
- At skeletal maturity, some curves between forty 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 as well as pain.

What is the 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. Individual vertebrae grow approximately one mm 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 it 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 can come from the current specialist, pediatrician, family doctor or from the internet. Some patients and families may know people who have been in this situation--ask them about it.

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-rays 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 exam as recommended since the curve may get larger.

We want to proceed with surgery.

What comes next?

Choosing a surgeon, 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 teenage spinal deformities
- is affiliated with a hospital facility with a staff experienced at caring for adolescents during and after spine surgery &
- has successful experience treating pediatric spinal deformities

What is a surgical plan?

There is more than one way to surgically treat scoliosis. One needs to decide which levels of the spine are going to be fused and by which approach/procedure. Surgeons can approach the spine through either an incision on the back or on the side of the chest or flank. The approach(es) 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.

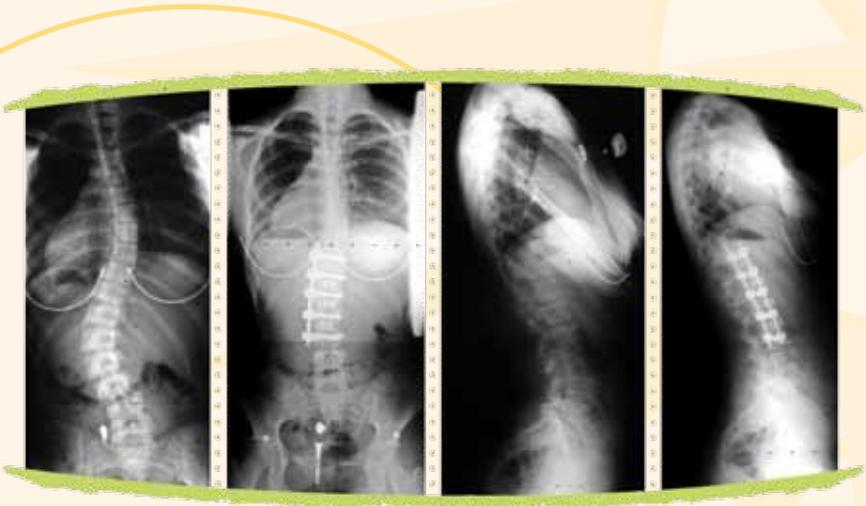
The most common approach is through the back and is known as a **Posterior Spinal Fusion with Instrumentation**. With this procedure, an incision is made along the spine, screws and/or hooks are then attached to the vertebrae and rods are then attached to the screws or hooks. These screws and hooks act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



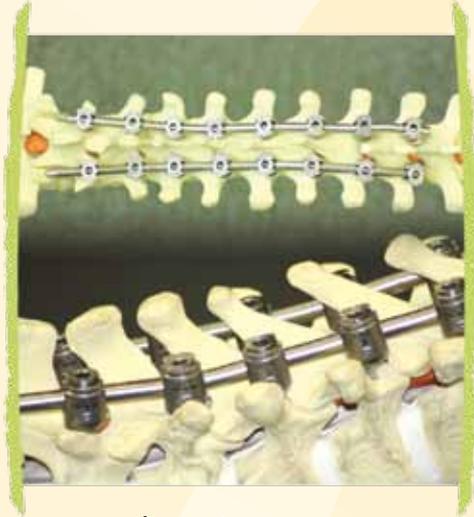
*Anterior Disc Excision/Fusion
Combined with Posterior Spinal Fusion
with Instrumentation*

What do the implants look like?

What are the implants made of?

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.



Implants

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 teenaged 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 do I look for in a hospital facility?



- Board Certified Pediatric Anesthesiologist available
- 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.

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 surgeon's 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

Surgery is done. What's next?

After surgery, the patient 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. If the patient will be going to the ICU after surgery, they may go directly there rather than the Recovery Room. The nurse and other staff will help everyone get settled in the 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.

While individuals recover at different rates and surgeons' post-surgery regimens vary, a general post-op plan includes:

Activity:

- **Post-op Day 1** – turning in bed every two hours and sitting up on the side of the bed.
- **Post-op Day 2** – turning in bed every two hours and standing at the side of the bed.
- **Post-op Day 3** – turning in bed every two hours and taking a few steps and sitting up in a chair.
- **Post-op Day 4** – turning, walking to the bathroom, sitting up more and walking in the hall.
- **Post-op Day 5 – 6** – walking in the hall two to four times.

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.

Until that happens (usually two to three days after surgery), narcotic pain medicine will be given through an IV, often via a pump called a PCA. Typically, a nasogastric tube remains in place until bowel sounds return. Once bowel sounds return, the nasogastric tube is removed and the patient begins to eat and drink, usually starting with liquids and progressing 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, narcotic 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

Life Does Go On After Surgery

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

- Pain management and weaning from narcotic pain medicines
- Healthy eating as appetite returns to normal
- Children 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 three to six weeks after surgery

At six weeks after surgery, most teens are:

- Feeling good, with their pre-surgery energy level back to normal
- Back to their normal life except for activity/sport restrictions &
- Do not require narcotic pain medicine.

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



Six weeks to one year after surgery, activity restrictions may remain

- Restricted activities are activities that put too much physical stress on the healing bones that may prevent them from fusing together.
- Many surgeons will gradually ease up on restrictions as the year 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.

One year after surgery:

- There are no restrictions on activity or sports and life back to normal!
- The surgeon will recommend how often to return for checkups. It is very important to return for recommended check-ups!

The rest of your life

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

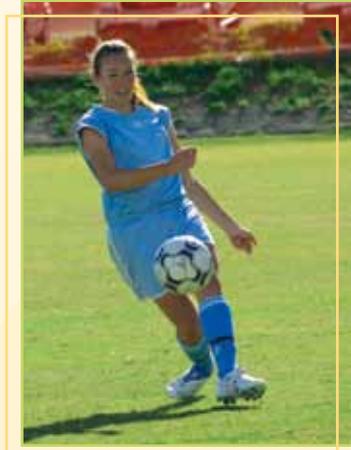
A Personal Journey

My name is Jaimie and I am currently 20 years old. I was diagnosed with scoliosis at age fourteen in the middle of eighth grade. When I first found out the news while sitting in the office, I was devastated, heart-broken, and confused. I wasn't even sure what scoliosis was, all I knew was that I had a severe case and surgery was necessary to prevent life-threatening complications later in life.

The first thing that came to mind was How am I going to play soccer?!

Soccer has been my life since I was four-years-old, and knowing I had to give it up for a year to receive surgery to straighten my spine was something I could not comprehend. But after much needed support from my family and doctors, I knew the surgery was something I had to do for myself to live a healthy life. Thinking about the surgery, I was scared with so many endless thoughts running through my head, but once I got to know my doctor and learned more about his skill, I was more calm and relaxed.

Looking back to those dreaded days before surgery, I could not be happier with my decision to follow through with the surgery. My results are phenomenal and I am more satisfied with my self-image and appearance now after the surgery than before. I am so thankful for the constant support I received from my family, friends, soccer team, and most importantly my doctors who performed such an extraordinary surgery. Support and self-determination are the two most significant aspects that pushed me through the surgery and also the recovery process. I had such a strong will to spend continuous hours in physical therapy to get back to playing soccer the second I received permission. I played soccer after six months when the normal recovery period is one year, I ran again before the usual time period, and experienced so much more because of the motivation that surrounded me. I had such a positive experience with all I encountered through the process. I am stronger now than ever before. I would not change one day from before or after the surgery because it has made me who I am today.



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.
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.



Kayci, after spine surgery in 2005



Kalli, after spine surgery in 2005

Conclusion

As you travel on this course, please be reassured that Adolescent Idiopathic Scoliosis is a very treatable condition and generally will not affect the 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 websites that provide reliable information. These include:

Harms Study Group Foundation	www.hsgf.org
American Academy of Orthopedic Surgeons	www.aaos.org
Scoliosis Research Society	www.srs.org
Pediatric Orthopedic Society of North America	www.posna.org
National Scoliosis Foundation	www.scoliosis.org
The Scoliosis Association	www.scoliosis-assoc.org
Kids Health	www.kidshealth.org/scoliosis



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 that 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 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 is no scientific data that proves 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 preventing 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 (twenty to twenty-three hrs/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?** Five to seven days.
18. **How much school will I miss?** Three to four weeks.
19. **When can I play sports again?** Opinions vary among surgeons, but most release people back to sports and other activities by one year 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 this question.
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. S/he should also be a member of the Scoliosis Research Society and 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 have included some common words and phrases here. Some of the websites provided here have a more complete and user-friendly glossary. 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 7 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

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 vertebrae 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 5 vertebrae

Kyphosis—a front to back curvature, sometimes called a sagittal plane deformity or “hunchback”

Medial—located close to the midline if 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 vertebrae

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

Posterior—back

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

Primary Curve—the main curve(s) of a scoliotic deformity, usually the first curve(s) to develop and the largest one needing treatment

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

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 ribcage 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

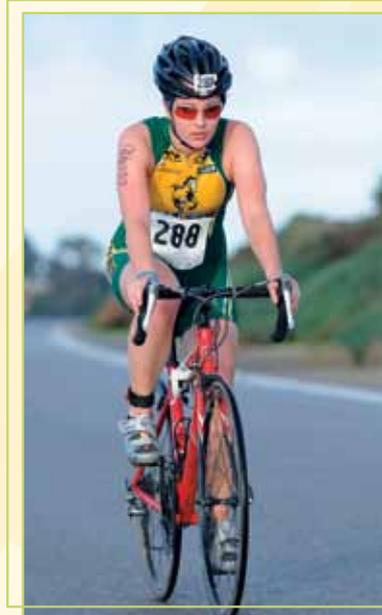
While Idiopathic scoliosis is the most common cause of scoliosis, there are others.

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

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

Syndromic—scoliosis is a component of many syndromes such as Marfans 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 those patients that have had prior surgery for tumors or radiation.



Kayla, a competing triathlete, after spine surgery in 2002

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.



About the Harms Study Group Foundation

This booklet was written by nurses and surgeons who take care of patients with scoliosis every day. The Harms Study Group Foundation 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 focusing on advancing the science of scoliosis treatment for the future, the Harms Study Group delivers these goals through multi-center research studies. Find out more by visiting www.harmsstudygroup.com.

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.

To support the production of this handbook and/or support the research and efforts of the Harms Study Group Foundation, please visit www.hsgf.org/support to make a donation. Your financial support will influence the future for untold numbers of children. A one-time gift or a multi-year pledge can make a huge impact.

A Special Thank You to our Road Crew

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