Treatment of Early Onset Scoliosis (EOS): What Families Need to Know

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Choosing a treatment option for your child can be hard to do. This booklet gives you information and answers to questions you may have about this decision. Age specifications listed in this decision-making aid refer to physiologic age ranges of children and may differ from the chronological age of a child, since variability is possible. The booklet provides evidence-based guidelines, but individual treatment of patients should involve consultation of a spine care provider. You and the doctor will talk about how to make a good decision based onwhat is best for your child and you.

Treatment of Early Onset Scoliosis (EOS): What Families Need to Know

Section I: Key Facts to Know

In this section you will learn about what early onset scoliosis (EOS) is, what problems it causes, and what itmay mean for both you and your child if it gets worse.

A. What is EOS?

EOS is an abnormal curve of the spine in children younger than 10 years of age.

B. What caused my child to have EOS?

There are many causes for EOS. They are divided into four categories. Treatment choices differ depending onwhich category your child's scoliosis is in.

The categories are:

- Congenital EOS: the spinal curve is caused by bones that either are not shaped normally or are connected inplaces where they are not supposed to be connected.
- Neuromuscular EOS: the spinal curve is caused by muscles pulling harder than they normally do or being weaker than they normally are. Among the causes of neuromuscular EOS are conditions such as spinal muscularatrophy, cerebral palsy, spina bifida, and brain or spinal cord injuries.
- Syndromic EOS: syndromes that make spinal curve development more likely. Examples include Marfan,Ehlers-Danlos or other syndromes with connective tissue disorders, neurofibromatosis, Prader-Willi, and skeletal dysplasias.
- Idiopathic EOS: when no medical problem is found other than the spinal curve and we do not know why thecurve happened.

C. Why is EOS a problem for my child?

The height of your child's trunk and space for the lungs increases the fastest between birth and 5 years of age.[1] A large curve in your child's back that develops during that time can crowd the lungs and cause problems with breathing. The combination of spine and lung problems in EOS is often referred to as Thoracic Insufficiency Syndrome. These problems can get worse while your child is growing and even as an adult. A curve that develops between the ages of 5 and 10 years is less likely to result in breathing problems but can cause your child to have pain and concerns about their appearance.

Section II: Treatment Options

Background

Will my child's curve need treatment?

- If your child is less than 2 years old and has an*idiopathic* EOS curve *smaller* than 30 degrees,the curve may get better on its own without treatment.
- If your child has a curve that is *bigger* than 30degrees (Figure 1), it is more likely that the curve will increase with time and need treatment.
- Deciding if a curve will increase and when treatment is needed in children with *congenital*, *neuromuscular*, or *syndromic* EOS is more complicated than for *idiopathic* EOS, and your child's doctor will help you decide this based on your child's specific diagnosis and symptoms.

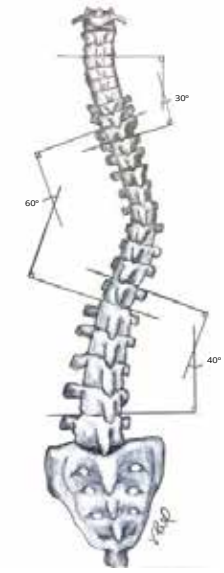


Fig. 1. Diagram of spine with three separate curves:

This is a 30 degree curve

This is a 60 degree curve

This is a 40 degrees curve

What are the goals of treatment?

- The primary goal of treatment is to keep the curve as small as possible to help the lungs work as well aspossible as your child grows.
- Another goal is to keep the spine flexible and allow it to grow as much as possible by avoiding proceduresthat limit growth.

Treatment decisions aim to delay or avoid surgery whenever possible and require the least possible number of procedures and hospitalizations.

B. What are the treatment options for my child?

Treatments for EOS include 1) observation, 2) bracing, 3) casting, and 4) surgery. Physical therapy and exercise programs do not keep the spinal curve from getting worse or correct the spinal curve in EOS.

Treatments are considered based upon:

- age
- curve size
- curve stiffness
- current symptoms
- risk for future symptoms
- other health problems your child may have
- family concerns such as
  - assisting with recovery
  - complications
  - frequency of follow up appointments

1. Observation:

Observation is typically recommended for smaller curves and consists of periodic appointments with their spine doctor for a physical exam and x-rays as needed to detect changes in curve size.[2,3] Your child's doctor will also track any symptoms caused by scoliosis. No activity restrictions are required. Other treatments may need to bestarted if the spinal curve gets bigger.

2. Bracing:

A custom plastic brace may be prescribed alone or in combination with casting or surgery in children from 6 months up to 14-16 years of age (Figure 2). In most cases your child will be awake when the brace is being measuredand will not need general anesthesia. When used without other treatments, the brace is worn 18-20 hours per day to slow down how quickly the curve gets bigger in order to prevent or delay surgery.[4] Bracing by itself does not permanently straighten or improve the spinal curve. The success rates of brace treatment have not been extensively evaluated.

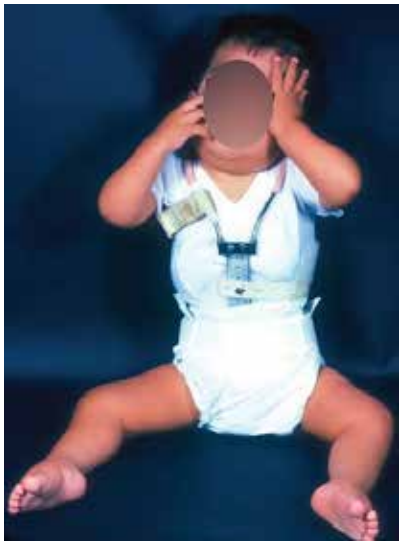


Fig. 2. Custom brace for early onset scoliosis.

3. Casting:

A cast provides a better fit and a constant force on the spine that can improve or even straighten the curve permanently in some cases.[4-6] Casting is particularlyeffective in patients less than two years of age with smaller curves,[6,7] though it may be successful for curves more than 50 degrees.[8] Casting can also delay surgery in patients up to 5 years old.[9,10] Children withweak muscles or severe breathing problems such as asthma may not be able to tolerate a cast. While your child is under general anesthesia, the cast is applied ina way that holds the spine in a straighter position. It ischanged every 2 to 3 months. The cast may extend over the shoulders depending on the location of the curve (Figure 3).[11] As the cast must stay on 24 hours aday, sponge bathing is required and your child cannot shower or go swimming. Casting is continued until the curve has resolved (which often takes at least one year) or it is clear the treatment is not working.[4] Wearing a brace may be recommended at the completion of casting in order to maintain the correction achieved by the cast.[4]

Figs 3a and b. Under (3a) and over (3b) casts for scoliosis.

4. Surgery:

This option is used only when other treatment methods have failed or are not expected to work (such as for larger curves). Surgery in younger patients uses growth-friendly methods that allow the spine and lungs to growwhile trying to keep the spinal curve from getting bigger.

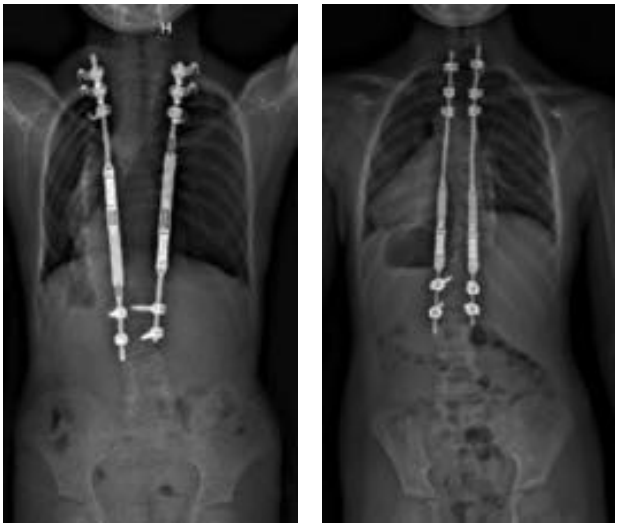
What are the surgical options for my child?

There are four general categories for surgery in EOS:

- distraction-based procedures
- growth guidance systems
- growth modulation procedures
- spinal fusions

a. Distraction-based procedures:

These procedures use metal rods (known as growing rods) to straighten the curve and allow for growth of your child's spine and chest.[12,13] The rods are attached to the ribs or spine using screws or hooks during an initial surgery under general anesthesia (Figures 4a-b). These attachments allow distraction or expansion of the rod length in order to improve the curve. When the rods are attached to the spine, a small portion of the spine is fused in this area, which means that the bones will heal togetheras one bone and that small area of the spine will not growanymore. However, growth of the chest and spine is not significantly impacted as the fused area is so small. It is preferred to wait until children are between 5-10 yearsold so they are big enough to place and hold the hardware, however the surgery can be done in those as young as 1 year old.[14] Children often wear a brace for a few months after this surgery to allow adequate healing.



Figs 4a and 4b. Growing rods with attachments to spine and ribs (3a) and spine only (3b).

After the initial surgery, your child's spine and chest can continue to grow by increasing the rod's length over time.

- Traditional growing rods are expanded at a connector by making a small incision on yourchild's back under general anesthesia in the operating room every six months.[14]
- Magnetically controlled rods do not require a return to the operating room, general anesthesia, or an incision for lengthening (Figure 5).[15] This type of rod is lengthened in the office about every 3 months. However, it is not uncommon for children with magnetically controlled rods to require repeat surgery if there are problems with the hardware (such as loosening) or with lengthening.[16,17] Children with both types of growing rods may needto have surgery to have longer rods put in if they outgrow the rods.[18]

Fig. 5. Rod lengthening in the office for magnetically controlled rods.

When your child's spine is done or nearly done growing, it may be necessary to perform another operation to exchange the rods and fuse the spine bones in between the rod attachments.[18,19] This fusion involves a larger portion of your child's spine and is known as definitive fusion. A definitive fusion will limit growth of a largeportion of your child's spine and therefore is not an option in younger patients. If your child has a stable spineposition and hardware after distraction-based procedures, definitive fusion at the end of growth may not be needed.[19,20] The FDA recommends removal of magnetic rods at the end of treatment.[21]

b. Growth guidance systems:
These systems (such as Shilla or modern Luque trolley) are inserted duringan initial surgery that fusesthe middle part of your child's curve and places gliding screws at the top and bottom of the curve. The gliding screws allow the spine to grow along the path of the rods (which are intentionally long at the time of insertion) without the need for lengthening in the office or operating room (Figures 6a-6b).[22,23,24] This procedure is typically performed in children between 5 and 8 years of age, though it can be done as young as age 2 and as old as age 10.[25] A brace is usually typically worn the first few months after surgery. While a returnto the operating room is not required for lengthening, it can be necessary for other problems with the screws or rods.[23] When growth of your child's spine is nearly complete in the early teen years, a definitive fusion will be considered but may not be required. Rod removal may be recommended to avoid rod breakage and other complications.[24,26]

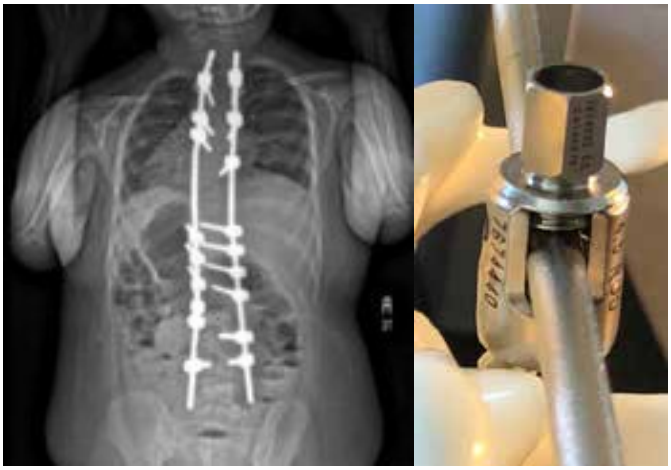


Fig. 6a. X-ray demonstratingShilla hardware with fusion and pedicle screws in middle of spine and long rods at topand bottom so they can "grow with the spine".

Fig. 6b. Loose attachment ofrod within screw allows for trunk growth while keeping the hardware in place.

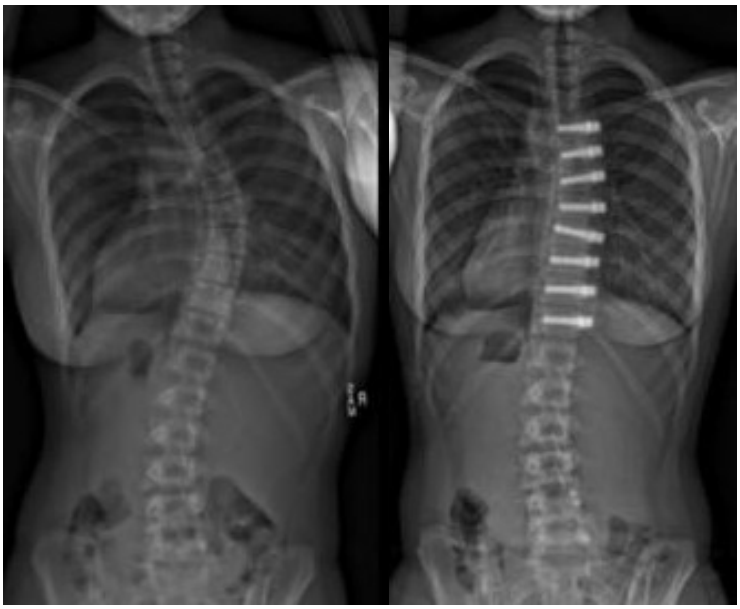
c. Growth modulation procedures (anteriorspinal growth tethering):
These procedures are designed to keep the outward side of the curve from growing without performing a fusion. While the inward side continues to grow, the scoliosis may correct. As correction relies on spinal growth, the procedures must be performed in children who have at least one year of spine growth remaining but not too early, to avoid overcorrection.

The outward side of the curve is kept from growing by inserting a tether under general anesthesia. The spine is accessed using mini-openincisions or via thoracoscopic surgery. Thoracoscopic surgery uses several small incisions on the side of the chest to insert a camera and surgical instruments in order to perform the procedure. A chest tube is often placed during surgery to prevent or treat partial orcomplete lung collapse and is removed prior to leaving the hospital.

Anterior spinal growth tethering uses screws and aflexible tether (Figure 7) made of polyethylene terephthalate that result in correction both immediately after insertion and with growth (Figures 8a-8b).[27] The tethering procedure can be used in curves up to approximately 60 degrees.[28]

Growth modulation procedures are newer techniques, so we do not have information on how patients are doing decades after the procedure. The tether device has a humanitarian device exemption for idiopathic scoliosis from the United States Food and Drug Administration (FDA) and is CE marked to indicate it meets European health and safety standards.

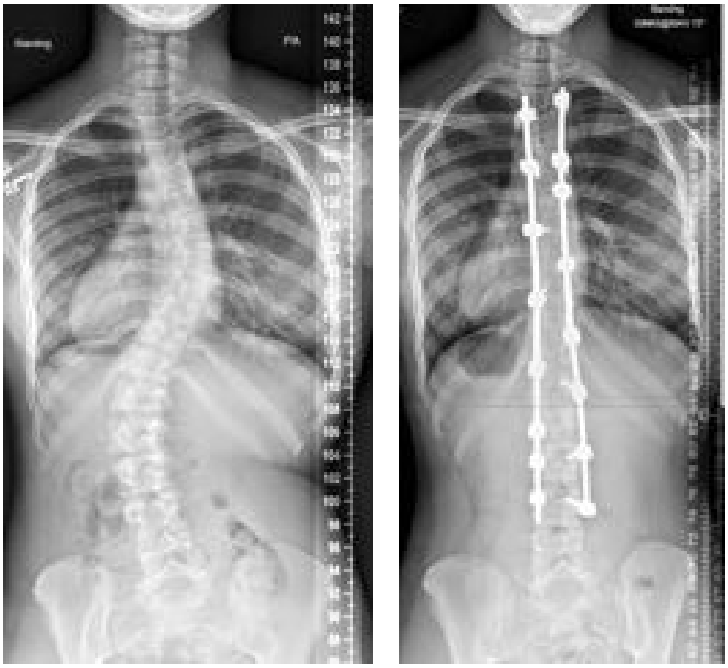
Fig 7. Tether (white band) held by screw



Figs 8a-8b. X-rays before (a) and after (b) placement of screws with tether into moderate scoliosis curve. The tethermaterial is not seen on x-rays.

d. Fusion procedures (limited and definitive):
Spinal fusion procedures remove the joints between the vertebrae to be fused and add bone graft material which allows this portion of the spine to heal into a solid block of bone which cannot grow or bend any further. Hardware (including rods, screws, hooks, or wires) is also inserted to rigidly hold the spine in proper position. The length of the fusion and number of vertebrae included depends on the curve size, location, and the amount of spine growth remaining. The amount of spine growth remaining is critical because fusions involving severalspine bones in younger patients will limit growth too much and can have an adverse impact on breathing.

- A limited fusion procedure involves just a few segments of the spine and can be done in younger patientswithout limiting significant growth.
- A definitive spinal fusion with instrumentation typically includes multiple segments of the spine to allow for greater deformity correction. For this reason, this procedure is reserved for patients age 10 years and older to avoid a significant impactof spine growth or breathing (Figures 9a-9b). It can be performed in slightly younger ages if it appears that a year of distraction procedures would not provide significant benefit.[29] Curve size prior to surgery is usually 50 degrees or greater. Definitive fusion may be performed in children with EOS who had prior spine surgery to further improve their spine position. Definitive fusion may also be performed in children with EOS who did notoriginally need surgery because curve size and progression were not as severe.



Figs 9a-b. X-rays before (a) and after (b) definitive posterior spinal fusion that spans both curves.

C. Summary of Treatment Indications

	Bracing	Casting	Distraction-Based	Growth Guidance	Growth Modulation	Definitive Fusion
Typical ages of patients	6 months to 14-16 years of age	6 months to 5 years of age	5-10 years of age, but as early as age 1.[14]	5-8 years, but as young as 2 and as old as 10 years of age [25]	10 years and older 30	10 years and older
Typical curve size	Between 20 and 45°	Curve or rib-vertebral angle difference more than 20°	More than 40-45°	More than 40-45°	Thoracic curves 35-60° [30]	More than 50°
Goals of treatment	Prevent increase in curve size, alone or in combination with other treatments	Full correction in younger patients.[6,7] Delay/decrease number of surgeries in older patients [9]	Decrease curve size, prevent progression, and allow for continued trunk growth	Decrease curve size, prevent progression, and allow for continued trunk growth	Decrease curve size, prevent progression, allow for continued trunk growth, prevent need for definitive fusion	Decrease curve size and prevent further progression
Method	Plastic removable brace	Full time cast	Metal rods that can be extended to allow spine growth	Rods that "grow with the spine" along gliding screws	Metal hardware placed on outside of spine curve to guide correction	Metal hardware and bone graft placed on spine to keep fused area from moving
Is general anesthesia required?	No	Yes	Yes	Yes	Yes	Yes
Is a brace alsoequired?	-	Sometimes used after casting	First few months after surgery	First few months after surgery	First few months after tether	No
Other considerations	Wearing the brace as prescribed, also known as compliance, can be difficult	May not be feasible in children with asthma or other medical conditions	Magnetic rods require office visits every 3 months; traditional rods require surgery every 6 months	Like magnetic rod, additional surgery may be required for hardware complications	Newer technology, and "off-label" use of hardware	Not feasible in younger patients

Section III: Benefits and Risks

A. Summary of Treatment Benefits

* Results may vary based on study methods, medical history of patients involved, and other factors

	Bracing	Casting	Distraction-Based	Growth Guidance	Growth Modulation	Definitive Fusion
What are the success rates?	1) No progression in 17-67 out of 100 curves; progression in 33-83 out of 100. [31-33] 2) Has the least evidence of any EOS treatment [4,5] 3) Impact of use in combination with other treatments is unknown	1) Best results for patients 18-24 months old with curves less than 50° [6-8] 2) Curve resolution in 89 out of 100 children in average age 1.1 years and curve 37°;[7] insufficient resolution in 11 out of 100 children. 3) Curve resolution in 35 out of 100 curves greater than 50°; no resolution in 65 out of 100 curves. [8]	1) 43%-54% reduction in curve size [12,34,35] 2) 3.6 to 8.8 cm improvement in spine height [23,34,35]	1) 35-45% reduction in curve size [23,24,26] 2) 4.5-6.4 cm improvement in spine height.[23,24,37]	1) 51-70% reduction in curve size [27,28,36] 2) Long term results (more than 5-10 years) are unknown	1) 63% reduction in curve size if noprior spine surgery,[29] 44-48% reduction in curve size if performed in addition to distraction-based procedures [19,29] 2) 18% reduction in curve size when performed after distraction-based procedures [19]
Will my child need additional surgery?	1) Yes, in 40-50 out of 100 children with juvenile idiopathic scoliosis; 50-60 out of 100 do not. [33,38,39] 2) Success rates for younger children and those with other diagnoses are not well known	1) Additional surgery is not expected in patients with curve resolutionafter casting. Predictors of curve resolution listed above 2) In patients greater than 2.5 years) with curves greater than 50°, 28 out of 100 require additional surgery before definitive fusion and 72 out of 100 do not. [9]	1) Always needed during lengthening for traditional rods. 28-60 out of 100 magnetic rods require additional surgery; 40-72 out of 100 do not.[16,40] 2) Removal at theend of growing isoften recommended [21] 3) Definitive spinal fusion maynot be required [19,20]	1) 50-63 out of 100 children require additional surgery for hardware problems or infection, no additional surgery needed for 37-50 out of 100 children. [24,25] 2) It is not known if definitive spinal fusion is required [24]	Sometimes for over-correction or hardware breakage in 18-41 out of 100 children, no additional surgery needed for 59-82 out of 100 children.[28,36] 2) Definitive fusion indicated in41 out of 100 children after tethering, not indicated in 59 out of 100 children.[36]	In patients without prior distraction-based procedures, 8-10 out of 100 require additional surgery and 90-92 out of 100 do not. [41,42] 2) In patients with prior distraction-based procedures, 22-24 out of 100 require additional surgery and 76-78 out of 100 do not. [20,43]

B. Summary of Treatment Risks and Complications

*Results may vary based on study methods, medical history of patients involved, and other factors

	Bracing	Casting	Distraction-Based	Growth Guidance	Growth Modulation	Definitive Fusion
Is there a risk of skin complications?	Redness from the brace may require adjustment	Pressure sores occur in 6-10 out of 100 children; sores do not occur in 90-94 out of 100 children[9,10]	Opening or incision infection	Opening or incision infection	Opening or incision infection	Opening or incision infection
Is there a risk ofinfection?	No	No	4 out of 100 children atskin level; 96 out of 100 do not.[44] Deeper involving metaloccurs in 4 out of 100 children with **magnetic rod** and 11out of 100 with **traditional rod**[16]	At skin or deeper involving metal. Occursin 14-28 out of 100 children; does not occur in 72-86 out of 100 children [24-26,37]	Low risk of infection at skin Infection of tether has notbeen reported [36]	9-12 out of 100 children with prior surgery; 88-91out of 100 children do not [20,43] 2-5 out of 100 children without prior surgery; 95-98 out of 100 children do not [41,42]
What are the otherrisks of treatment?	1) Inconvenience and discomfort from wearingbrace 2) Possible negative effecton self-image in older patients	1) **Inconvenience and discomfort** of prolonged casting including changesin appetite and difficulty eating 2) **Aspiration, or pneumonia** in 14 out of 100 children, no aspiration, or pneumonia in 86 out of 100 children[10] 3) **Vomiting** in 3 out of 100 children, no vomitingin 97 out of 100 children[9] 4) **increase in seizure activity** in 3 out of 100 children; no increase in 97 out of 100 children[9] 5) Requires **multiple exposures to general anesthesia** in children < 3 years old	Complications occur in 39-79 out of 100 patients and do not occur in 21-61out of 100. [12,16,35,44] Greater risk in childrenless than 7.6 years or those with curves morethan 84° [35] 1) **Traditional rod breakage** in 30 out of 100, no breakage in 70 outof 100 traditional rods.[44] 2) **Magnetic rod breakage** in 11 out of 100; no breakage in 89 out of 100 magnetic rods.[16] 3) **Loss of fixation** in 24-39 out of 100 rods; noloss of fixation in 61-76 rods [35,44] 4) **Increase is curve stiffness** with less gains in lengthening over time. 5) **Junctional kyphosis** at top of hardware in 28 out of 100 children; no kyphosis in 72 out of 100 children [45]	Complications occur in 50-73 out of 100 children and do not occur in 27-50 out of 100 children. [25,26] 1) **Rod breakage** occurs in 43 out of 100 children and does not occur in 57 out of 100 children.[24,37] 2) **Loss of fixation** occurs in 14-28 out of 100 children and does not occur in 72-86 of 100 children [24,37] 3) **Worsening of spinalalignment** occurs in 24 out of 100 children and does not occur in 76 out of 100 children.[26] 4) **Junctional kyphosis** at top of hardware in 9 out of 100 children; no junctional kyphosis in 91 out of 100 children [26]	1) **Atelectasis** (partial lung collapse) in 3-12 out of 100 children; no collapse in 88-97 out of 100 children. [27,28,36] 2) **Pneumothorax** (complete or partial lung collapse) is rare but potentially may occur 3) **Tether breakage** in 47 out of 100 children; does not occur in 53 out of 100 children. [36] 4) **Overcorrection** in 18-24 out of 100 children; does not occur in 76-82 out of 100 children [28,36]	1) **Loss of further spine growth** with restrictions in lung function in growing patients. In children w/o prior spine surgery & idiopathic scoliosis: 2) **Junctional kyphosis** at top of hardware in 0-8 out of 100 children; no kyphosis in 92-100 children (varies with different types of implants)[46] 3) **nerve injury, atelectasis or pneumonia, hardware, ileus**; each less than 1 out of 100; do not occur in more that 99 out of 100 children[47] In children with prior distraction surgery: 4) **lung related**: 20 out of 100 children; does not occur in 80 out of 100 children [20] 5) **hardware related**: 16 out of 100 children, does not occur in 84 out of 100 children [20] 6) **surgical wound dehiscence** (opening): 12 out of 100, does not occur in 88 out of 100 children. [20] 7) **persistent pain**: 8 outof 100 children, does notoccur in 92 out of 100 children [20] 8) **failure of fusion**: 8 out of 100 children, does not occur in 92 out of 100 children [20] 9) **curve progression**: 8 out of 100 children, does not occur in 92 out of 100 children [20] 10) **urinary infection**: 8 out of 100 children, does not occur in 92 out of 100 children [20]

Section IV: Risks of general anesthesia in children

It is important to know that anesthesia for children is very safe. There are concerns regarding the possible effects of general anesthesia during longer surgeries on children younger than 3 years old. Currently, we knowthat:

- A single, short (3 hours or less) exposure to general anesthesia appears to be safe.
- There is some evidence that longer (more than 3 hours) or repeated exposures cause behavior or learning problems.

Of the treatment options for EOS, casting is the one that typically involves multiple exposures to general anesthesia prior to age 3 years. The other procedures are often done on older patients, though occasionally maybe performed in this age group. When deciding about surgery on children less than 3 years of age, it is important to consider:

- whether the procedure should be done now or if it can wait
- how long the procedure will take
- whether additional procedures will be needed

Section V: Getting Ready to Choose

A. Things to consider when choosing EOS treatment:

- First, consider the age of your child, curve size, and curve stiffness. This helps to sort outwhich treatments are recommended for different ages, sizes and amounts of stiffness.
- Then think about whether your child has current symptoms (such as lung problems), andlearn about the risk for future symptoms. It can be difficult to proceed with surgery for aproblem that is not currently causing symptoms but it is important to remember that the reason for surgery is often to prevent problems that will occur as the curve gets bigger.
- It is important to think about your child's other medical problems and expectedcomplications.
- Finally, thinking about family concerns such as assisting with recovery, dealing with complications and the time required for follow-up appointments will help you decide onwhat is best for your child and what is possible in your family.

B. Feeling ready to choose:

Fill out this section and discuss any *No* answers with your doctor and health care team to get theinformation and support you need to make this decision.

- Do you and your child understand the options available to treat early onset scoliosis?
  ☐ Yes ☐ No
- Are you clear about which benefits and risks matter most to you?
  ☐ Yes ☐ No
- Do you have enough support and advice from others to make a choice?
  ☐ Yes ☐ No
- Are you sure about the best choice for your child and you?
  ☐ Yes ☐ No

What other questions or concerns do you have?

Section VI. Glossary

Anesthesia: medication given by a mask and/or vein during surgery; keeps your child asleep and free of pain
Aspiration: entry of material from mouth into respiratory tract

Atelectasis: collapse of lung tissue with loss of volume. Symptoms range from none to shortness of breath. May be treated with deep breathing exercises but can also require bronchoscopy to relieve remaining blockage

Bone graft (artificial or cadaver): material used to help bones to join together

Complications: problems that happen because of a treatment; these can be things that are known to sometimes happen (such as infection or bleeding) or things that are unexpected

Congenital: a condition present at birth

Dehiscence: the bursting open of a surgically closed wound

FDA: U.S Food & Drug Administration. Has many responsibilities including the approval of medical devices
Idiopathic: of unknown cause

Ileus: the intestines get blocked up and stop working

Hardware: hooks, rods, screws, wires and other devices placed into the body during a surgery in order to treat a medical problem

Instrumentation: hooks, rods, screws, wires and other devices placed into the body during a surgery in order totreat a medical problem

Junctional kyphosis: forward curve of the spine at the end of spinal instrumentation

Lumbar spine: the lower portion of the back that connects with the thoracic spine above and the sacrum below

Pneumothorax: complete or partial lung collapse that occurs when air leaks into space between lung and chestwall

Pressure sore: areas of damaged skin caused by staying in one position for too longScoliosis: abnormal curving of the spine

Spinal fusion: surgery that removes the movement and deformity across the joints of the vertebra to correct and prevent further deformity

Sympathetic chain dysfunction: changes in temperature and perspiration in the legs which may occur followingopen or thoracoscopic anterior spine surgery

Thoracic spine: the portion of the spine that runs from the base of the neck to the abdomen. This portion of the spine is connected to the ribs.

Thoracic Insufficiency Syndrome: combination of spine and lung problems that may occur in young childrenwith scoliosis

Trunk (torso): upper body from pelvis to shoulders

Vertebrae: individual spine bones connected to one another by joints known as facets

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