On the pages that follow, you will find two decision aids that were developed and tested in our pilot and feasibility project. We hope that these decision aids are valuable to you, whether you are a health care professional interested in shared medical decision making, or a parent or child interested in either of these treatment decisions. These decision aids are:

**Environmental Allergies: Should my child get allergy shots?**

and

**Neuromuscular Scoliosis: Understanding the options.**

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I. Key points to remember

II. Comparing the choices

III. Examples of allergy shot schedules

IV. Thinking about your decision

V. Glossary

VI. References

You are being asked to make an important choice about treatment for your child’s environmental allergies. Allergy symptoms are caused by the body’s immune system overreacting to particles, called allergens. We have performed allergy skin testing and identified your child’s allergens. Allergy treatment plans depend on understanding the allergic triggers, making environmental modifications, and controlling symptoms with medications. We can also give targeted treatment for your child’s identified allergens by giving allergy shots. You are being offered the choice about whether or not you want your child to receive targeted treatment in addition to symptomatic treatment.

You will need to decide between:

– taking medications for symptom control and avoiding allergens
– starting allergy shots (allergen immunotherapy) along with taking medications and avoiding allergens

I. Key points to remember

- There is no cure for symptoms of the nose (allergic rhinitis), eyes (allergic conjunctivitis) or lungs (allergic asthma), but allergy shots may result in fewer symptoms for many years.
- Allergy shots may be especially helpful for children who have:
  – symptoms that are not well controlled by current medications and avoidance measures
  – unacceptable side effects from medications
  – a desire to reduce the amount of medications used to control symptoms and the costs of those medications
- In general, allergy shots are offered for children starting at age 5.
- Children must receive allergy shots regularly for 4 to 5 years to get the greatest benefit for the longest period of time.
- Allergy immunotherapy has been used for over 100 years to help relieve suffering from environmental allergies. Most allergy medications (pills, inhalers, nasal sprays) have been developed over the past 25 years.
- Causes of allergies are different in different parts of the country and other areas of the world. Plants that produce allergic pollens vary by each geographic area. Allergy shots will only work for the regional allergens that were tested and given. If you plan on moving to another part of the country or world, allergy shots given in this region of the United States will likely not be fully effective.
- You may choose to start allergy shots at a later time if you have conflicts, scheduling issues or other concerns. However, it must be within 1 year of the last allergy skin test.
Environmental Allergies: Should my child get allergy shots?

II. Comparing the choices:

<table>
<thead>
<tr>
<th>Frequently Asked Questions</th>
<th>Taking Medication (for symptoms and avoiding allergen exposures)</th>
<th>Allergy Shots (along with taking medication for symptoms and avoiding allergen exposures)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What does it involve?</strong></td>
<td>▪ This option requires BOTH medications and changes to the home.</td>
<td>▪ Allergy shots are small doses of your child's allergy injection prescription. The allergy nurse injects them in the arm just beneath the surface of the skin. This is just like the needle size and injection site used for childhood immunization shots.</td>
</tr>
<tr>
<td></td>
<td>▪ Examples of medications include: oral antihistamines, oral Singular® (asthma inhalers). Some children may need two or three different medications.</td>
<td>▪ Most patients will also continue to require allergy medications, depending on allergen exposure. However, this is usually at a lower dose and less often.</td>
</tr>
<tr>
<td></td>
<td>▪ Changes to the home may include controlling dust mite levels, mold growth and pet dander.</td>
<td></td>
</tr>
<tr>
<td><strong>How often will we need to see the doctor?</strong></td>
<td>▪ On average, two or three times a year.</td>
<td>▪ At least once a year to review progress, medication use and symptoms. You will see the allergy nurse for every shot.</td>
</tr>
<tr>
<td><strong>What allergies do these therapies work for?</strong></td>
<td>▪ Medications are not specific to what your child is allergic to. Medications treat the symptoms of allergy and asthma in a broad manner, but not the causes.</td>
<td>▪ Allergy shots work for allergies to pollens, dust mites, pet dander, molds and cockroaches.</td>
</tr>
<tr>
<td></td>
<td>▪ The allergy injection prescription is made specifically for your child based on results of allergy skin tests.</td>
<td></td>
</tr>
<tr>
<td><strong>How long does it take?</strong></td>
<td>▪ Medications may be required daily for many years and sometimes for the rest of your child’s life.</td>
<td>▪ Allergy shots are given for up to 5 years.</td>
</tr>
<tr>
<td></td>
<td>▪ During the build-up phase, shots are given 1-2 times a week for 28 weeks (at least 48 hours apart and up to 10 days apart).</td>
<td>▪ During the maintenance phase, shots are given once a week for 3 weeks, every 2 weeks for 4 weeks, and every 4 weeks for 4-5 years.</td>
</tr>
<tr>
<td></td>
<td>▪ The next page has examples of shot schedules.</td>
<td></td>
</tr>
<tr>
<td><strong>How do these therapies work?</strong></td>
<td>▪ Medications reduce nose and eye symptoms and asthma. Medications treat symptoms but not the causes of allergies, and therefore, only work while they are taken.</td>
<td>▪ Allergy shots cause a change in the body's immune system, which allows your child to come in contact with allergens without having as many symptoms. They affect the immune system in the same way as your child’s general immunizations.</td>
</tr>
<tr>
<td></td>
<td>▪ Medications offer no long-term benefit because they do not change the immune system’s response to allergy triggers. They work in a similar way to Tylenol® use for pain, reducing the symptom but not affecting the cause.</td>
<td>▪ Because the immune system is no longer overreacting, your child suffers less wheezing, coughing, sneezing, runny nose, nasal congestion and itchy, watery eyes when exposed to allergy triggers.</td>
</tr>
<tr>
<td><strong>What are the benefits?</strong></td>
<td>▪ Medications can be stopped and restarted easily.</td>
<td>▪ Shots may prevent new allergies.</td>
</tr>
<tr>
<td></td>
<td>▪ Shots can be avoided.</td>
<td>▪ Children may have fewer nose and eye symptoms.</td>
</tr>
<tr>
<td></td>
<td>▪ Decreased travel time and costs for clinic/shot appointments.</td>
<td>▪ There may be a decreased need for daily medications.</td>
</tr>
<tr>
<td></td>
<td>▪ During the maintenance phase, shots are given once a week for 3 weeks, every 2 weeks for 4 weeks, and every 4 weeks for 4-5 years.</td>
<td>▪ Shots may prevent the development of asthma in children with nasal symptoms.</td>
</tr>
<tr>
<td></td>
<td>▪ Children with asthma have fewer symptoms (less coughing and wheezing), use fewer asthma medications and have fewer airway reactions.</td>
<td>▪ Children with asthma have fewer symptoms (less coughing and wheezing), use fewer asthma medications and have fewer airway reactions.</td>
</tr>
<tr>
<td></td>
<td>▪ Most children continue to have long-term benefits of less severe asthma symptoms after therapy is completed.</td>
<td>▪ Most children continue to have long-term benefits of less severe asthma symptoms after therapy is completed.</td>
</tr>
<tr>
<td><strong>What are the risks?</strong></td>
<td>▪ If medication is ineffective or not taken consistently, uncontrolled symptoms can lead to:</td>
<td>▪ A whole body allergic reaction called anaphylaxis happens in less than 1 out of 100 shots. Typically, a reaction starts within 30 minutes of the injection. This is why we observe your child for 30 minutes after each injection.</td>
</tr>
<tr>
<td></td>
<td>▪ poor school performance</td>
<td>▪ Small and large local reactions at the site of injection (raised, red, warm swelling) happen in the majority of patients at some point in the treatment. Local reactions are not risk factors for a whole body allergic reaction. Having a local reaction does not mean this will happen again the next time.</td>
</tr>
<tr>
<td></td>
<td>▪ sinus infections</td>
<td></td>
</tr>
<tr>
<td></td>
<td>▪ ear infections</td>
<td></td>
</tr>
<tr>
<td></td>
<td>▪ worsening asthma symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>▪ Daily medications may lead to unwanted side effects, such as nosebleeds from nasal sprays.</td>
<td></td>
</tr>
<tr>
<td><strong>What about costs?</strong></td>
<td>▪ Various medication coverage options are available on most insurance plans.</td>
<td>▪ The cost of health care for children with nasal symptoms who received allergy shots was 33% less per child compared to those who did not receive shots.</td>
</tr>
<tr>
<td></td>
<td>▪ Outpatient visits and pharmacy costs are 1/3 higher than for children receiving allergy shots.</td>
<td>▪ Allergy shots are covered on most insurance plans. Coverage and costs can vary depending on your insurance plan.</td>
</tr>
</tbody>
</table>
### III. Examples of allergy shot schedules

Pictured below are three examples of allergy shot build-up and maintenance schedules. The colors in the examples code for each vial in the progression to maintenance. The blue vial is the weakest strength and is referred to as the cold vial. As we increase the strength of the allergy shot, the color of the vial changes. We progress from blue to green to yellow and then red. The red vial is the strongest and is called the hot vial.

#### 1. Weekly schedule without interruptions - Year 1

Most patients follow Example 1. However, skipping weeks will prolong the build-up phase beyond 30 weeks.

<table>
<thead>
<tr>
<th>WEEK</th>
<th>BUILD-UP PHASE (B)</th>
<th>MAINTENANCE PHASE (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>EVERY WEEK</td>
<td>B</td>
<td>M M M</td>
</tr>
<tr>
<td>EVERY 2 WEEKS</td>
<td>M</td>
<td>M M</td>
</tr>
<tr>
<td>EVERY 3 WEEKS</td>
<td>M</td>
<td>M M</td>
</tr>
<tr>
<td>EVERY 4 WEEKS</td>
<td>M</td>
<td>M M</td>
</tr>
</tbody>
</table>

#### 2. Twice a week without interruptions - Year 1

Some patients choose to speed up the build-up phase and receive shots twice a week which is shown below.

<table>
<thead>
<tr>
<th>WEEK</th>
<th>BUILD-UP PHASE (B)</th>
<th>MAINTENANCE PHASE (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TWICE WEEKLY</td>
<td>M</td>
<td>M M</td>
</tr>
<tr>
<td>EVERY 2 WEEKS</td>
<td>M</td>
<td>M M</td>
</tr>
<tr>
<td>EVERY 3 WEEKS</td>
<td>M</td>
<td>M M</td>
</tr>
<tr>
<td>EVERY 4 WEEKS</td>
<td>M</td>
<td>M M</td>
</tr>
</tbody>
</table>

#### 3. Weekly schedule with significant allergic reactions, back-up, and rebuild - Year 1

Example 3 shows a significant reaction on Week 15 of the first dose in the yellow vial. To help prevent future reactions, we back up 7 steps and rebuild.

<table>
<thead>
<tr>
<th>WEEK</th>
<th>BUILD-UP PHASE (B)</th>
<th>MAINTENANCE PHASE (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>EVERY WEEK</td>
<td>M</td>
<td>X</td>
</tr>
<tr>
<td>EVERY 2 WEEKS</td>
<td>B</td>
<td>M M M</td>
</tr>
<tr>
<td>EVERY 3 WEEKS</td>
<td>M</td>
<td>M M</td>
</tr>
</tbody>
</table>

X= Week 15: systemic allergic reaction. **Rebuild:** Go back to Vial 2 (Green) Week 8 dose

**Figure A:** The build-up phase progresses from the blue, green, yellow then red vial. For each shot, a 30-minute wait is required.

**Figure B:** Some patients choose to have “cold spray” applied to the injection site to help numb the area.
Environmental Allergies: Should my child get allergy shots?

IV. Thinking about your decision

What matters most to you and your child? In the table below is a list of possible reasons to choose or not choose allergy shots. Circle the number in each row below, to show how important each reason is.

1 = Least important  5 = Most important

**REASONS TO CHOOSE ALLERGY SHOTS**

- We want to do whatever is possible to treat symptoms.
  
  1  2  3  4  5

- We are not able to control allergen levels at home.
  
  1  2  3  4  5

- We want to do what we can to treat causes of allergies, not just symptoms.
  
  1  2  3  4  5

- Willing to spend time and money for shots.
  
  1  2  3  4  5

- Medication side effects are hard on my child.
  
  1  2  3  4  5

- Allergy shots offer the best chance of long-term benefit.
  
  1  2  3  4  5

- Now is a good time in my child’s life and family’s life.
  
  1  2  3  4  5

- My other reason: ________________________________________
  
  1  2  3  4  5

**REASONS TO CONTINUE MEDICATIONS AND CONTROLS ALONE**

- We prefer a more conservative approach.
  
  1  2  3  4  5

- We are able to control allergen levels at home.
  
  1  2  3  4  5

- My child doesn’t mind using medications to relieve symptoms.
  
  1  2  3  4  5

- We don’t want to spend time and money for shots.
  
  1  2  3  4  5

- Medication works without side effects.
  
  1  2  3  4  5

- We don’t want allergy shots if we can’t be sure how long they will work.
  
  1  2  3  4  5

- We have too many scheduling issues and other obligations.
  
  1  2  3  4  5

- My other reason: ________________________________________
  
  1  2  3  4  5

If this column has the most 4s & 5s, then it may be the best choice for you and your child.

Getting ready to choose

1. Do you and your child understand the options available to treat allergy symptoms?  
   □ Yes  □ No

2. Are you clear about which benefits and risks matter most to you?  
   □ Yes  □ No

3. Do you have enough support and advice from others to make a choice?  
   □ Yes  □ No

4. Do you feel sure about the best choice for you and your child?  
   □ Yes  □ No

5. What other questions or concerns do you have? ________________________________________

____________________________________________________________________________________________

____________________________________________________________________________________________

____________________________________________________________________________________________

____________________________________________________________________________________________

____________________________________________________________________________________________

____________________________________________________________________________________________

____________________________________________________________________________________________
Environmental Allergies: Should my child get allergy shots?

V. Glossary:

**Allergen** – any substance that can cause an allergic reaction. An allergic reaction occurs because the immune system has an abnormal antibody called IgE which overreacts to particles that we call allergens.

**Allergen immunotherapy** – the medical term for allergy shots. Immunotherapy is the process of getting shots of specific allergens to boost your immune system’s ability to protect itself from allergy symptoms caused by the allergens.

**Allergic asthma** – asthma that is triggered by allergic exposures.

**Allergic conjunctivitis** – eye symptoms such as itching, tearing and redness due to allergic exposures.

**Allergic rhinitis** – nasal symptoms such as sneezing, runny nose and nasal congestion due to allergic exposures.

**Anaphylaxis** – a whole body allergic reaction provoked by an allergic exposure.

**Build-up phase** – during this phase, allergy shots progressively increase in the amount of allergen administered.

**Environmental controls** – modification of the home and personal surroundings to improve allergen avoidance. Examples include pet removal, cockroach extermination and dust mite covers.

**Geographic regions** – pollen seasons and species vary from one part of the country to another. The recognized allergenic regions include: Northeast, Southeast, Southwest, Great Lakes, Plains, Mountain, Desert and Pacific.

**Maintenance dose** – the dose that gives the most therapeutic response without significant systemic reactions.

**Maintenance phase** – begins when the maintenance dose is reached.

VI. References:


Hankin CS, Cox L, Wang Z, Bronstone A. Does allergen-specific immunotherapy provide cost benefits for children and adults with allergic rhinitis? Results from large-scale retrospective analysis jointly funded by AAAAI and ACAAI. Oral presentation at the 2011 Annual Conference of the American Academy of Allergy, Asthma and Immunology. San Francisco, CA; March 18-22, 2011.


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Tim Wysocki, PhD
Catharine F. Clay, MA, BSN
Lindsay Fuzzell, MA
Eric D. Shirley, MD
I. Key facts to know

In this section you will learn about what neuromuscular scoliosis is, what problems it causes, and what it may mean for both you and your child if it gets worse.

What is neuromuscular scoliosis?

Scoliosis is an abnormal curving of the spine. The spine may also be rotated (twisted), which causes the ribs or trunk to become more prominent (see right.) In neuromuscular scoliosis, the curve is caused by conditions with muscle weakness or spasticity such as:

- cerebral palsy (brain and nerve problems caused by brain injury or abnormal development of the brain)
- muscular dystrophy (muscle weakness and loss of muscle tissue)
- spinal cord injury (damage to the nerves inside the spine)
- spina bifida (the spine does not close all the way around the spinal cord during pregnancy)
- spinal muscular atrophy (a genetic condition with significant muscle weakness)

What causes neuromuscular scoliosis?

- Spine and upper body muscles that are too weak or tight (also called spasticity) place abnormal forces on the spine, which pulls the spine toward one direction more than the other. This can result in a curved spine (scoliosis).
- Hip and pelvis muscles that are too weak or strong, causing a shift of the trunk so that the head is no longer centered over the buttocks.
- The abnormal muscle tone is due to an underlying condition (such as cerebral palsy or muscular dystrophy).
**How do we know how severe the scoliosis is?**

- X-rays are used to measure the size of the scoliosis curve.
- The curve is measured by how many degrees the spine bones are tilted. *(See right)*
- The bigger the curve in degrees, the worse the curve, and more likely that problems will develop.

**Why is neuromuscular scoliosis a problem?**

- Small curves (smaller than 40-50°) do not usually cause problems. Regular follow-up is scheduled to measure increases in curve size.
- Once the curve reaches 40-50°, it can be expected to increase in size by at least one degree and as much as sometimes 10 degrees or more. Bigger curves cause more problems.

**Scoliosis progression over nine months in X-rays of same patient. Curve is:**

A: 45°

B: 65° three months later

C: 75° after another three months

D: 90° just nine months from original X-ray

**For your child, big curves (larger than 40-50°) can cause the following:**

- Wheelchair transfers are more difficult.
- Hip and pelvic deformity may increase, which can cause loss of sitting balance or ability to sit independently. Sometimes sitting problems are due to other problems (such as hip dislocations or hip muscle spasticity); your provider will identify the cause of sitting problems for your child.
- There may be more frequent skin ulcers due to pressure points created by tilting of the spine and hips.
- Frequent or constant pain may occur.
- Breathing problems increase in severe curves (larger than 80 degrees). Sometimes breathing problems can also be caused by weak breathing muscles or not being able to clear secretions from the lungs.

**For the parent/caregiver, bigger curves can create difficulties with:**

- dressing
- positioning
- feeding
- wheelchair transfers
II. What are the options?

In this section, you will learn about the options for treatment and expected results, and think about your goals, concerns and questions. There are four options: observation, bracing, wheelchair modifications and spinal fusion surgery.

**Observation**
Doing nothing different from what you are now doing. An untreated scoliosis patient shown to the left.

**Bracing**
Wearing a firm molded plastic brace around the upper body.

**Wheelchair modification**
Seat and trunk supports are molded (shaped) to your child’s curve size and location. This is done in the wheelchair clinic.

### Benefits of nonsurgical options

<table>
<thead>
<tr>
<th>Benefits of nonsurgical options</th>
<th>Observation</th>
<th>Bracing</th>
<th>Wheelchair Modifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoids the risks of surgery</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Improved trunk support</td>
<td></td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>Improved sitting posture</td>
<td></td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>Improved sitting comfort while in the wheelchair</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Same benefits as a brace with less discomfort or time to put the brace on</td>
<td></td>
<td>✔</td>
<td></td>
</tr>
</tbody>
</table>

### Risks of nonsurgical options

<table>
<thead>
<tr>
<th>Risks of nonsurgical options</th>
<th>Observation</th>
<th>Bracing</th>
<th>Wheelchair Modifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seating difficulty caused by increase in curve size</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Breathing difficulty caused by increase in curve size</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Breathing difficulty caused by bracing</td>
<td></td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>Pain caused by increase in curve size</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Increased difficulty providing care due to increase in curve size</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Does not straighten the curve</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Does not prevent curve from getting bigger</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
</tbody>
</table>

### Spinal fusion surgery

Anchors are connected directly to spine; attaching the crooked spine to the straight rods will straighten the spine.

- Spinal fusion is the only treatment that can make the curve size smaller and keep it from getting bigger again.
- Surgery can be expected to make the curve size smaller by 50-75%. For example, a 60° curve may be 30° or less after surgery. 

Department of Orthopedics

Nemours.org
How spinal fusion works:

**What is done:** A long incision (cut) is made along the spine, then hardware anchors, metal rods and bone graft material are attached to the spine to straighten it and fuse the bones together to keep the curve from coming back.

- Surgery straightens the curved spine by attaching hardware anchors such as screws, hooks and wires directly to the spine, and then connecting the anchors to straight rods. The rods start just below the neck and go down to the pelvis, or less commonly, to the lower spine.

- Individual bones fuse (grow) together when the joints between them are removed. Artificial or cadaver bone graft is used as a “glue” to support the fusion, after the rods are attached. Fusion helps prevent the curve from returning which can happen even when the rods are in place.

- The rods are made of stainless steel, cobalt chrome, or titanium, and do not need to be removed after surgery.

- When the curve reaches 50 degrees, whether there are symptoms or not, the risk of the curve getting bigger is high and surgery becomes an option. (In patients with Duchenne Muscular Dystrophy, surgery may be offered when the scoliosis is a little less severe. This is because these patients tend to have lung problems that may prevent surgery later.)

- Waiting to see if problems develop may not be a safe option because curves become more difficult and risky to treat as they get bigger. Surgery is less complicated when done by the early to mid-teens, when the spine is more flexible and easier to treat with a metal rod.

- There are many possible complications from surgery, most of these can be successfully treated. Even when complications occur, 90 of 100 parents are satisfied with the results of surgery because of the benefits.\textsuperscript{9-12}

- Shortly before your child's surgery, you will be asked to read, discuss and sign separate consent forms for your child's surgery and anesthesia. This booklet does not replace the consent forms. **NOTE from designer:** TW requested to move these bullets to this section--but the superscript references 9-12 wold need to affect all references after?

### More about surgery, anesthesia and recovery in the hospital and at home:

**Before surgery:**
- You and your child will have a preoperative visit with your surgeon. Additional X-rays may be taken to assist with surgical planning. The surgery will be reviewed, and informed surgical consent will be obtained. Please ask your surgeon any questions you have so that you are as comfortable as possible with the decision you have made on the day of surgery.

- Your child will have a preoperative nursing visit. Further instructions about surgery, including how to pre-scrub the skin before surgery to decrease the risk of infection, will be given. Blood tests are done to ensure your child is not anemic (low red blood cell count) and has sufficient kidney function for surgery.

**Surgery:**
- You will arrive well before your child's surgery. Additional blood is taken so that blood can be ready as necessary for transfusion.

- Due to the long fusion length, large curve sizes, and associated medical problems, spinal fusions in patients with neuromuscular scoliosis are demanding surgeries. The fusion can be extensive and take several hours or longer.

- You will receive an update from the operating room at least every two hours.

- Spinal cord monitoring (for both feeling and movement) is done during the surgery to detect injury.

**Anesthesia:**
- You and your child will meet members of the anesthesia team before surgery to plan your child’s anesthesia. A pediatric anesthesiologist will carefully monitor your child throughout the surgery so that the risks of lengthy anesthesia are reduced as much as possible.

- All children have a breathing tube in place during surgery, to protect the airway and maintain steady breathing while under anesthesia.

- Bleeding is closely watched because it is common to have significant amounts of blood loss. Special medicines to help with blood clotting are used, and often the patient’s own blood can be reinfused after processing through a cell saver device. Bleeding may also require that your child receive a blood transfusion (blood given by vein to replace blood loss during surgery).

- The donor blood has been carefully prescreened to minimize risks of disease (such as hepatitis and HIV) transmission. According to the Red Cross, the risk of disease transmission during a transfusion is: 1 in 2 million for HIV; between 1 in 200,000 to 500,000 for hepatitis B; and 1 in 1.3 million for hepatitis C.\textsuperscript{4} Your child's surgeon and anesthesiologist will be happy to talk with you further about any questions or concerns you have about this.

- Special attention is paid to body temperature to maintain warmth and to positioning to prevent pressure damage to skin.
— Anesthesia medications are chosen to interfere as little as possible with spinal cord monitoring, while keeping your child asleep and comfortable during the surgery. Pain medication is given throughout surgery.

**Recovery: Immediately after surgery**

— Your surgeon will come to the waiting room to tell you that the surgery has been completed.
— Your child will go to the Pediatric Intensive Care Unit (PICU).
— Some children need help breathing after surgery until awake and strong enough for the breathing tube to be safely removed.
— Once your child is settled in the PICU, you will be allowed to visit. Your child will spend at least one night in the PICU prior to transfer to the floor.

**Recovery: The first few days after surgery**

— The hospital stay is typically one week but may be longer. During this time, the focus will be on pain management, bowel and bladder routine, returning to your child’s usual level of activity, and teaching about caring for your child at home.
— Pain management, diet and bowel/bladder routine will depend on how quickly the stomach and intestines return to normal function, or “wake up.” Once bowel sounds return, your child will progress to the usual intake of food and fluids. Pain medicine will switch from IV to pills/liquids by mouth or feeding tube. A bladder catheter usually remains in place until this transition. Constipation is a common side effect of anesthesia, narcotic pain medicine and decreased activity levels. Medical and nursing staff will assist in managing this.
— Physical therapists will work with your child and you during the hospital stay to assist with transfers and activities of daily living. Physical therapy is usually not needed once your child returns home.
— It is important for families to remember that this is a big surgery for a child with other medical problems to go through. A smooth recovery requires careful monitoring from the nurses and doctors. Monitoring includes frequent bedside visits, blood tests, and the use of machines to check heart rate and blood pressures. This monitoring is an important part of safe and healthy recovery, but sometimes will interfere with sleep and result in frustrations for families. Each day, your child’s care team will communicate with you the expected course of events in order to minimize these problems.

**Recovery: At home**

— The first phase of recovery involves getting used to being at home again and continuing the pain control that was used in the hospital.
— Some patients may feel the rods in their back, which can take some time to get used to.
— Initially, your child will require more assistance with transfers and bathing than before surgery.
— The second phase begins about six weeks after returning home, and involves more mobility and less pain medication.
— In the third phase about 12 weeks after returning home, minimal pain medication is required and the child begins to return to a normal energy level.

**Benefits of surgery**

<table>
<thead>
<tr>
<th>Benefits of surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improvements in ability to participate in activities of</td>
</tr>
<tr>
<td>daily living (such as eating, dressing, bathing)</td>
</tr>
<tr>
<td>Less time needed for resting</td>
</tr>
<tr>
<td>Better sitting balance</td>
</tr>
<tr>
<td>Better overall health status</td>
</tr>
<tr>
<td>Better lung function</td>
</tr>
<tr>
<td>Curve much less likely to get bigger</td>
</tr>
<tr>
<td>Improvement in sleeping comfort and pain relief</td>
</tr>
<tr>
<td>Improvement in appearance and self-attitude</td>
</tr>
</tbody>
</table>
### Neuromuscular scoliosis: understanding the options

#### IV. Things to consider when choosing scoliosis surgery or nonoperative care:

In this section you will review a list of things that you may want to think about or talk about before making a decision. On the next page you can compare your reasons for choosing one treatment or the other and write down any questions.

- It is important to think about your goals as a family. It is also important to think about your child's other medical problems, and, if these problems are severe, whether your child has a reduced life expectancy.

- The time in the hospital and the time required providing the child extra assistance at home after surgery can take a heavy toll on families. It is important to have a realistic sense of what this will mean for you and your family before making a decision.

- Which treatment makes the most sense may depend on how you feel about the problems that may occur as the curve gets bigger.

- While surgery may prevent the problems that come from having a big curve, it will not fix the underlying causes of the curve (neuromuscular disease).

- In general, curves under 50 degrees can be treated with observation if the child is not having any symptoms. Symptoms can be managed with bracing or wheelchair modification.

---

#### Risks of surgery

<table>
<thead>
<tr>
<th>Overall, complications occur in about 25 of 100 patients; 75 out of 100 children do not have complications.1 Complications are highest in children with spina bifida.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wound infection may occur in about 4 of 100 patients. 96 of 100 children do not get wound infections.3,4 Just over half of these infections are close to the skin and can be treated with antibiotics alone. In less than half the cases, the infection is deeper and further surgery is required to treat it. Rarely, rod removal is required.</td>
</tr>
<tr>
<td>Hardware loosening or breakage may occur in up to 16 of 100 children.6 84 or more of 100 children do not have this problem. In general, surgery to fix it is not needed.</td>
</tr>
<tr>
<td>Junctional kyphosis: worsening of spinal alignment at the end of the hardware. It is not known how often this happens.</td>
</tr>
<tr>
<td>Back pain may be unchanged or can develop as a new problem.</td>
</tr>
<tr>
<td>Scoliosis correction makes the patient and the trunk taller, which can make independent transfers and the ability to self-catheterize more difficult.</td>
</tr>
<tr>
<td>Lung congestion, pneumonia, or needing a breathing tube for a longer time after surgery may occur.</td>
</tr>
<tr>
<td>Vomiting and ileus (difficulty eating due to decreased mobility of intestinal muscles) are fairly common complications of any major surgery, including spinal fusion.</td>
</tr>
<tr>
<td>Pancreatitis is a rare complication. It is not known how often this happens.</td>
</tr>
<tr>
<td>Urinary tract infection in 5 of 100 children; 95 of 100 do not have this complication.7</td>
</tr>
<tr>
<td>Spinal cord injury with worsening of spasticity and further problems with bowel and bladder function is a rare complication; spinal cord monitoring during the surgery can detect injury and correct it when it occurs. It is not known how often this happens.</td>
</tr>
<tr>
<td>The risk of death within 30 days of surgery in the U.S. is less than 2 of 100 children.4,8 The risk of death is higher for those with more medical problems and larger curve size.</td>
</tr>
</tbody>
</table>
# Neuromuscular scoliosis: understanding the options

## Thinking about the decision:

What matters most to you and your child? In the following table is a list of possible reasons to choose or not choose spinal fusion surgery. **Circle a number in each row below**, to show how important each reason is to you.

<table>
<thead>
<tr>
<th>REASONS NOT TO CHOOSE SURGERY</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want to avoid risks of surgery.</td>
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<tr>
<td>My child's life expectancy is not very long.</td>
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<tr>
<td>My child is not suffering because of the scoliosis curve.</td>
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<tr>
<td>I prefer to wait and see if the curve gets bigger and causes problems. I understand the surgery is more difficult for bigger curves and the risk of complications is higher.</td>
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<tr>
<td>My child's biggest problem is sitting, so I would like to try modifying the wheelchair.</td>
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<tr>
<td>My other reason: _____________________________________</td>
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<td></td>
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</tr>
<tr>
<td>If this column has the most 4s &amp; 5s, then it may be the best choice for you and your child.</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want to prevent problems caused by the curve getting bigger.</td>
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<tr>
<td>I would like to make daily care easier for me and my child.</td>
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<tr>
<td>I want to improve my child's sitting balance.</td>
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<tr>
<td>The risks are worth it if my child has a better quality of life after recovering from surgery.</td>
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<tr>
<td>My other reason: _____________________________________</td>
<td></td>
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<td>If this column has the most 4s &amp; 5s, then it may be the best choice for you and your child.</td>
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</tr>
</tbody>
</table>

## Getting ready to choose

1. Do you and your child understand the options available to treat neuromuscular scoliosis?  □ Yes □ No
2. Are you clear about which benefits and risks matter most to you?  □ Yes □ No
3. Do you have enough support and advice from others to make a choice?  □ Yes □ No
4. Are you sure about the best choice for your child and you?  □ Yes □ No

## What other questions or concerns do you have?  ______________________________________
V. Glossary

**Anesthesia:** medication given by mask and/or by vein during surgery; keeps your child asleep and free of pain

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

**Cerebral palsy:** brain and nerve problems caused by brain injury or abnormal development of the brain

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

**Hardware:** metal rods, screws, hooks and wires used to attach the rods to the spine bones

**Ileus:** the intestines get blocked up and stop working

**Immune compromise:** the body's protective (immune) system doesn't work as well as it should, to do things like fight infection

**Junctional kyphosis:** forward curve of the spine that makes spinal alignment worse at the end of the hardware

**Lung congestion:** fluid in the lungs

**Muscular dystrophy:** muscle weakness and loss of muscle tissue

**Neuromuscular disease:** conditions with muscle weakness or spasticity, such as cerebral palsy and muscular dystrophy

**Neuromuscular scoliosis:** abnormal curving of the spine caused by conditions with muscle weakness or spasticity

**Pancreatitis:** inflammation (painful swelling) of the pancreas, an organ near the liver and intestines that makes fluids that help with breaking down food in the intestines

**Scoliosis:** abnormal curving of the spine

**Skin ulcers:** sores that break down the skin and cause open areas that are painful

**Spasticity:** muscles that are too weak or tight

**Spina bifida:** the spine does not close all the way around the spinal cord during pregnancy

**Spinal cord injury:** damage to the nerves inside the spine

**Spinal fusion surgery:** hardware anchors, metal rods and bone graft material are attached to the spine to straighten it and fuse the bones together

**Spinal muscular atrophy:** a genetic condition with significant muscle weakness

**Supportive care:** comfort care that aims to make symptoms, such as pain or fever, better. However, this kind of care does not treat the cause of the symptoms

**Trunk:** upper body from pelvis to shoulders

**Urinary tract infection:** infection in the bladder or kidneys
VI. References


