COLUMBIA UNIVERSITY DEPARTMENT OF ORTHOPEDIC SURGERY

What to Expect
Neuromuscular Scoliosis
Surgical Intervention

A patient and parent's guide for pre-operative expectations and post-operative recovery and rehabilitation

COLUMBIA | ORTHOPEDICS

NewYork-Presbyterian KIDS

columbiaortho.org/peds-spine

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Welcome

Dear Patient,

We would like to welcome you and thank you for selecting Columbia Doctors Division of Pediatric Orthopedic Surgery to care for your child. NewYork-Presbyterian Morgan Stanley Children's Hospital (MSCHONY) is Manhattan's only hospital dedicated solely to the care of children, and we perform the most children's spine surgery in New York. We are also a major international referral center, meeting the special needs of children from infancy through adolescence worldwide.

We understand your child's individual developmental needs and take a holistic approach to care. MSCHONY offers a multidisciplinary approach which includes collaboration between nationally recognized pediatric physicians from every subspecialty. You will encounter pediatric specific providers throughout your stay including our Pediatric Spine ICU Intensivists, Anesthesiologists/Pain Service, Physical and Occupational Therapists, Child Life Specialists, and Nursing staff. Our team treats hundreds of surgical spine patients every year and that expertise leads to improved patient outcomes, like having one of the lowest infection rates in the country.

It is our hope that this book will answer many of your questions about Neuromuscular Scoliosis and assist you in preparing for your child's surgery. We encourage you to read and refer to it throughout your time with us as it contains information useful during the preoperative planning, hospitalization and recovery stages.

Sincerely,

Dr. Michael G. Vitale and Dr. Benjamin D. Roye

Columbia Pediatric Orthopedics

Your Clinical Care Team

The best way to get in touch with your doctor’s office is to call the office number listed below Monday-Friday between 9:00am and 4:30pm. This will connect you with a member of the office staff who may be able to help you or can direct your call to a member of the clinical team. If you reach the voicemail, please leave a detailed message and your call will be returned promptly.

On weekends, holidays, and after business hours, calls to this number are directed to an answering service and forwarded to the doctor on call.

Dr. Michael G. Vitale’s Team

212-305-5475: Option 3, and then option 3

For clinical questions: Amber Sentell Mizerik PA-C or Ameeka George, CPNP

Surgical scheduler: 212-305-5732

Dr. Benjamin D. Roye’s Team

212-305-5475: Option 3, and then option 2

For clinical questions: Nikki Bainton, CPNP, ONP-C or Ameeka George, CPNP

Surgical scheduler: 212-305-7603

Other Columbia Specialty Referrals:

- Plastic Surgery – Dr. Thomas Imahiyerobo - 212-305-5868
- Physiatry – 212-305-3535
- Neurology – 212-342-6867
- Cardiology – 212-305-8509
- Pulmonology – 212-305-5122
- Neurosurgery – 212-305-1396
- Nutrition/GI – 212-305-5903
- Columbia Weinberg Family Cerebral Palsy Center – 212-305-2700 or weinbergcpcenter.org
- Columbia SMA clinic – 212-342-0263 or columbiasma.org

NewYork-Presbyterian:

The Columbia Doctors Department of Pediatric Orthopedics is located at NewYork-Presbyterian Morgan Stanley Children’s Hospital on Floor 8 North:

Address:
3959 Broadway
Floor 8 North, New York, NY 10032

Office Phone: 212-305-5475
Fax: 212-305-9754
Appointments: 212-305-4565

Important Resources

School Notes, Physical Therapy Prescriptions, and X-ray Requisition Requests:

Our Medical Assistants are available to help with these requests. Please call, 212-305-5475 and submit a request and any details that you would like included. Also, please make sure to have a fax number or address available. You can also send a request through your connect/MyChart account.

Online Message – Connect/MyChart (page 35 for more info)

ColumbiaDoctors offers a patient portal called MyChart that allows you to send messages online to the clinical staff. To create an account If you do not have a MyChart account, visit myconnectnyc.org, complete the form, and respond to the security questions to confirm your identity.

Scheduling MRI/CT

The clinical team will order any necessary imaging and then the surgical schedular will reach out for any coordination that needs to be done. If you have any questions, please check with the surgical scheduler.

Parking

Discounted parking is available for families who stay 5 days or more. In order to take advantage of this discount, please ask your surgical scheduler for a letter to give to the garage. You then purchase a discounted parking card from the garage at the beginning of your stay. The garage is located at 115 Fort Washington Avenue between 164th and 165th Streets and the phone number is, 212-305-4903.

There is also valet parking at 3959 Broadway between 165th and 166th Streets and the phone number is 212-342-8486. Unfortunately, we are unable to validate parking for office visits.

Medical Records

If you would like a copy of your child's medical records, please visit: columbiaortho.org/medical-records or contact our medical records office at 212-305-8255. You must sign a release form which is available in the office or on the website. You may return them to the medical records office via email or fax.

Radiology Results

Reports and CDs may be obtained through the Department of Radiology by calling, 212-305-3342. Your images can be viewed in MYChart on the computer as well.

Important Resources

Insurance and Financial Information

Pre-Op

After you schedule surgery, our surgical schedulers obtain prior authorization for the surgery and the hospital stay from your insurance company. You will be contacted by one of our financial coordinators prior to the surgery to inform you of any financial responsibility you may incur.

Anesthesia

If you have questions about whether the anesthesiologist is par with your insurance, please call their billing office at 646-317-3150.

Post-Op

If you have questions after the surgery about the surgical part of the bill, please contact our billing office at 212-305-1125. If you have a hospital billing question, please call 212-305-5437.

Radiology Billing: 866-815-6994

FMLA/Home Schooling Paperwork

If you are planning on taking time off from work during your child's recovery, your job may require you to fill out a Family Medical Leave Act form. Please give us this paperwork as soon as possible, along with details of how long you are planning to take off and whether you are seeking intermittent leave as well. We ask for a 72-hour turnaround time on this paperwork.

Most school districts will provide home schooling for children who must be out of school for more than 4 weeks for medical reasons. Please have this conversation with your child's school as soon as you know the date of surgery. They may ask that you have our office complete a form.

What is Neuromuscular Scoliosis?

About

Neuromuscular scoliosis is a condition that affects children with neuromuscular disorders and is characterized by the presence of one or more abnormal curvatures of the spine. This curvature causes the spinal column to bend to the left or the right, in the shape of an S or a C. Because there is such a wide variety of the types of diseases that may cause neuromuscular scoliosis, the clinical presentation and severity of this condition is extremely variable. However, most children with this disease have poor balance and coordination of their trunk, neck, and head.

This type of scoliosis often has unique features that differentiate it from other types of scoliosis, such as pelvic obliquity (tilt), kyphosis, and a long sweeping curve pattern. Children with pelvic obliquity, hip dislocation, or other hip issues may find that in correcting their spinal alignment, their hips may change and require a procedure in the future. This should be discussed with your surgeon before proceeding with spine surgery. There is also a high frequency of concurrent kyphosis, which is an abnormal forward-bending curve of the spine. The condition is generally classified into two categories, based on the type of disease that the child suffers from, and which causes the abnormal curve.

Neuromuscular scoliosis is also different from other types of scoliosis because it often continues to progress even after a child is fully grown. This may lead to curves that become quite large and begin to affect organ function and quality of life. The goals of surgery include straightening and stabilizing the spine, achieving balance, preventing further progression, improving pulmonary function and enhancing quality of life. Therefore, we recommend surgery before curves become very large. The type of surgery that is most often recommended is called Posterior Spinal Instrumentation and Fusion (PSIF).

Neuromuscular scoliosis involves diseases that are primarily afflictions of the nervous system, such as cerebral palsy or spinal cord trauma, whereas myopathic scoliosis involves muscular disorders, like muscular dystrophy or arthrogryposis. There are a number of neuromuscular disorders that may cause scoliosis; therefore, the needs of each patient are unique. It is important that we understand your child’s normal level of function before surgery including:

- all medical problems, provider names and contact info, complete medication list
- assistive devices they might use for ambulation or activities of daily living (wheelchair, walker, stander, shower chair)
- respiratory support (CPAP/BIPAP/Vent, cough assist, Chest PT)
- your child’s methods of communication
- your current home care team if you have one

The goal of this guide is to help you improve your child’s health in preparation for surgery, introduce best practices which improve the safety and outcomes of spine surgery, and help you plan for the post-operative period.

Understanding the Procedure

Posterior Spinal Instrumentation and Fusion (PSIF)

During this operation your child will receive general anesthesia in the operating room and will fall asleep facing up. After your child is asleep the anesthesiologists will place IVs, an arterial line, a urinary catheter and sometimes a central venous line. The team will then position the child so that they are lying face down and carefully pad any pressure areas to prevent skin issues.

Once the prep is complete, IV antibiotics are given, and the surgeon makes an incision down the middle of the back. They place two screws in each vertebra. Then they use two vertical metal rods to connect the screws to reduce the size of the curve so that the child is well-balanced with the head centered over the pelvis when upright. There is usually some residual curvature in the spine because complete correction would make the child unbalanced.

The surgeon then places bone graft and antibiotic powder over the spine and around the new rods and screws. This graft is made up of both the child's own local bone, collected from the spine during the surgery, as well as cadaveric bone which has been irradiated to destroy any pathogens. The graft helps to stimulate the body's normal healing process. Over the next several months, the body will deposit new bone into this area, fusing the vertebrae together and preventing further progression of the scoliosis. Initially, the instrumentation is needed to maintain the correction. However, once the spine is fused, the bone keeps the spine straight. The instrumentation is not removed but does not typically cause any problems.

MAGEC/VEPTR Spinal Growing Rods

When children have a scoliosis greater than 50 degrees but are years from the end of their growth, the Orthopedic Surgeon may recommend a surgical implant that straightens the spine without fusing the vertebrae. The hospital stay and recovery for this type of surgery is very similar to PSIF, though typically a bit shorter. Children are usually in the hospital for 3-4 days and miss approximately 2 weeks of school.

MAGEC (MAGnetic Expansion Control) growing rods are expandable rods that are attached to the spine or ribs - decreasing the magnitude of the scoliosis while still allowing the spine to grow with the child. After the surgery, these rods are then lengthened in the doctor's office using an external remote controller every few months. The lengthening is a quick and often painless procedure that does not require sedation.

VEPTR growing rods are similar to MAGEC, however they are not magnetic so must be lengthened in the operating room every 6-9 months. Sometimes you are able to go home the same day while other times you may need to stay overnight. Usually, some pain medicine is needed for a couple of days after. VEPTR rods are used when children require routine MRIs due to other medical problems because while MRIs can sometimes be obtained with a MAGEC rod in place, the image quality around the rods is poor.

Understanding the Procedure

Halo Traction

Halo traction is a treatment method occasionally used in severe scoliosis prior to PSIF, especially when children have curves greater than 80 degrees, kyphoscoliosis, or congenital defects in the spine. Halo traction applies a gentle stretch to the soft tissues of the trunk over a period of weeks, allowing the spine to straighten. This promotes improved heart and lung function, weight gain and better postoperative correction. Halo traction may look uncomfortable, but children tolerate it well and often comment that they feel better while in traction.

A halo ring will be placed on your child's head in the operating room under general anesthesia. The ring is attached to the skull with pins. This is a short procedure and your child will be transferred to the Pediatric Intensive Care Unit (PICU) afterward because traction is always initiated under close monitoring. Often when a patient is having a halo placed, a PICC (peripherally inserted central catheter) is placed in the OR at the same time to help with medications, blood draws, nutrition and antibiotics while your child is in the hospital. A rope is attached to the ring and threaded through several pulleys attached to bars at the head of the bed. A small amount of weight is then added to the other end of the rope and slowly increased each day until a goal weight is achieved. The length of time each child stays in traction varies and will be determined by your surgeon. We will periodically take x-rays of your child's spine to assess their progress.

During this period of time your child will be in traction most of the day, but that does not mean that they must be in bed all the time! We have specially designed traction wheelchairs and walkers so your child can be active and engaged in school, Physical Therapy, and child life activities.

Understanding the Procedure

Quality and Patient Safety

Surgical Site Infections (SSI)

Infections can occur after any surgery, and spine surgery is no exception. Here at MSCHONY, your surgeons take the risk of infection very seriously and take many steps to minimize the risk. We have created cutting edge protocols that have dramatically reduced infection rates at our hospital and other hospitals around the country. Our protocol starts with YOU and the chlorhexidine baths you give your child the three nights leading up to surgery. It goes on to include a multi-stage skin cleansing in the operating room as well as broad spectrum intravenous antibiotics that are used before, during and after the surgery.

Blood Transfusions

It is common for our neuromuscular scoliosis patients to require a blood transfusion during or after their surgery. We take steps to minimize blood loss and have methods to return some of the blood lost during surgery to the patient. However, sometimes it is in the best interest of the patient to transfuse donated blood products.

Our hospital regulations do not allow pediatric patients to donate their own blood prior to surgery. We also do not recommend that family members donate blood for their child’s use because if it is not used then it must be wasted. We would encourage you to make a general donation to your local blood bank instead.

Many parents worry about the risks of blood transfusions, but in the United States the risk of getting an infection from a blood transfusion is extremely low because all blood donors are screened, and their blood is tested extensively. For example, the risk of getting the HIV or hepatitis B virus is approximately 1 in 2 million.

References:

Transfusion-transmitted infections. J Transl Med. 2007; 5: 25. Published online 2007 Jun 6. doi: 10.1186/1479-5876-5-25

Understanding the Procedure

Quality and Patient Safety

Neuromonitoring

One of the greatest concerns about spine surgery of any type is the potential for injury to the spinal cord and spinal nerves. Such complications are exceedingly rare in modern day scoliosis surgery, in large part because of tremendous improvements in our ability to monitor spinal cord function in real time during the surgery. We have an extremely experienced team of neurophysiologists who are present for the entire operation, and who utilize an array of techniques to ensure your child's safety. We certainly credit our experienced team of neurophysiologists with contributing to our incredible safety record here at MSCHONY.

After the patient is under anesthesia, a technologist, skilled in all phases of intraoperative monitoring (IOM), prepares the patient in the OR suite by placing sterile subdermal (needle) electrodes over the scalp and torso, as well as nerves and muscles of the arms and legs. These electrodes, when linked to the IOM system, provide the means of stimulating and recording responses from the patient throughout the procedure, though the patient under anesthesia feels nothing. Additionally, the systems here at Columbia, are networked directly to Neurologists who oversee the procedure and have the capability of interacting with the surgeon, anesthesiologist, and monitoring technologist at a moment's notice. The electrodes are removed at the completion of the operative procedure, prior to the patient waking up from anesthesia.

Although the benefits far outweigh the risks, there are some minimal risks associated with IOM. Possible tongue bite during motor stimulation is avoided by placement of a bite block between the patient's upper and lower teeth. Minor bleeding and bruising from the site of subdermal electrode placement is possible, albeit temporary.

We are proud of our longstanding and continuing relationship with Pediatric Orthopedics. The positive outcome of these corrective spine procedures is very much a collaborative effort by a team of dedicated individuals. If you have any other questions related to monitoring, feel free to contact us:

Neurophysiology/IOM – The Neurological Institute of NY (212)-305-0392

Understanding the Procedure

Patient Checklist:

Specialist Clearances

We would like your child to be in an optimum state of health when entering into surgery. In order to meet this goal, we will ask you to obtain clearances and recommendations from your child's other specialists as well as their pediatrician. In addition, we may ask you to meet with other specialists such as Cardiology, Plastic Surgery or Physiatry (Rehab Medicine). Anesthesia needs to review your chart several weeks in advance, so please see your outside specialist at least a month prior to surgery, so we can have your clearances in the chart at least 3 weeks before surgery.

Pediatrician: Make an appointment for pediatrician clearance within two weeks of surgery. There will be paperwork in your pre-op packet for the Pediatrician to fill out and return to us.

Plastic Surgery: We often have a Plastic Surgeon assist on our Neuromuscular Scoliosis cases. If your Orthopedic Surgeon recommends this, we will have you meet with the Plastic Surgeon ahead of time so that they might examine your child and discuss expectations. This appointment may be at any time prior to surgery.

Cardiology: If your child sees a cardiologist we will ask for a clearance note and an Echocardiogram report from within 6 months of surgery. Anesthesiology requests that all Muscular Dystrophy and SMA patients have a current ECHO.

Pulmonology: If your child sees a pulmonologist regularly we ask that you obtain clearance within one month of surgery. This clearance note should include current device settings, recommendations about post-operative extubation, and recommendations regarding medications. If your child has Sleep Apnea we would like a copy of the most recent sleep study.

Neurology: If your child has a seizure disorder and takes medications we ask that you get clearance from your Neurologist within one month of surgery. Their clearance note should include seizure medication protocols, and your child should have medication levels drawn at that visit if applicable.

Neurosurgery: If your child has a VP shunt or Baclofen pump, or if they see a neurosurgeon on a regular basis we will ask for clearance within 6 months of surgery.

Urology: If your child sees a urologist we ask that you see them 2 months before surgery. They should perform a UA/Urine culture and if it is positive treat with antibiotics.

Patient Checklist: Months Before

Specialist Clearances

Physiatry:	Some children with complex medical needs require discharge to a rehab facility following their hospital stay. Your surgeon will discuss with you whether this is right for your child, and sometimes the decision is made during the hospital stay. However, if this is a possibility, we ask that you meet with a Physiatrist before surgery for evaluation of baseline function, discussion about rehab goals, and to make an expedited referral if necessary.
Anesthesia:	We will request an anesthesia clearance for all of our Neuromuscular Scoliosis patients. This will be done over the phone 1-2 weeks before surgery. If you need to contact Pediatric Anesthesiology call (212) 305-2413
Other:	Otolaryngology (ENT), Dermatology, Gastroenterology/Nutrition, Psychiatry

Medications

Please use the area below to list your medications and specialists and bring this book with you to the hospital.

Medications	**Dose:**	**Timing:**

Patient Checklist: Months Before

Current Specialists

Physician:	Specialty:	Contact # or Facility:

Clearances/Consults Required

- ☐ Anesthesia
- ☐ Cardiology
- ☐ Neurology
- ☐ Neurosurgery
- ☐ Nutrition/GI
- ☐ Pediatrician/PCP
- ☐ Plastic Surgery
- ☐ Pulmonology
- ☐ Urology
- ☐ Other: ______________________________

Patient Checklist: Months Before

Weight

We encourage all of our patients who are underweight to try to gain 10% of their weight prior to surgery. Adequate nutrition is vital for wound healing and all of our patients lose weight after surgery due to decreased appetite. We understand that many patients with neuromuscular scoliosis have difficulty gaining weight on their own so we may refer you to a Nutritionist for further evaluation. If your child is not able to gain weight using oral supplements, we may suggest a temporary feeding tube, which your doctor will discuss with you. On the other end of the spectrum, it also very important for the patient not to be overweight, so your surgeon may speak to you about this as well. It is good to have a healthy balance for optimal post-operative healing.

Assistive Devices

Please let us know if your child uses any assistive devices at home such as wheelchairs, walkers, standers, shower chairs, transfer aids, communication devices, or respiratory support.

If you use a manual wheelchair, be sure to bring it or arrange for it to be available during your stay. If you use a power chair, be sure it is fully charged. If you have a custom seating system, there might be the need for adjustments to help you comfortably fit into your chair. In cases where there is a big difference in posture after the surgery, a rental chair may be needed until your vendor can make any necessary changes to your personal chair. The adjustments to the wheelchair are usually made once the patients has recovered to the point where they can sit more comfortably so we recommend making an appointment with your vendor around 6 weeks after the surgery.

Generally, the hospital will provide all respiratory support devices that your child might need during their stay. However, if your child uses CPAP or BIPAP please bring their mask with you. If they use a Chest PT vest, please bring the vest only, the hospital will provide CPT compressors. Patients who use a Trilogy ventilator and would like to use it during your stay should inform the clinical team ahead of time so that the vent may be checked by Biomedical Engineering.

Patient Checklist: Months Before

Pediatric Rehabilitation Facilities

Sometimes your doctor might recommend that your child be discharged to a short-term rehabilitation facility so they can receive intensive physical and occupational therapy as well as around the clock nursing care. This decision is made on a case-by-case basis and you will be included in this discussion. There are several pediatric rehab facilities in the area that we frequently use. If you know that your child will be needing their services, we encourage you to contact them directly and tour the facility.

Blythedale Children's Hospital (Acute and Subacute)

95 Bradhurst Avenue, Valhalla, NY 10595
Theresa King, Admissions: (914) 831-2431

Children's Specialized Hospital

Acute Care Location
200 Somerset Street
New Brunswick, NJ 08901
Jeannie Brooks, Admissions: (908) 301-5461

Subacute/Long Term Care Location
150 New Providence Road
Mountainside, NJ 07092

St. Mary's Hospital for Children (Acute and Subacute)

5 Dakota Drive, New Hyde Park, NY 11042
Joanne, Admissions: (718) 281-8773

Elizabeth Seton Pediatric Center (Subacute)

300 Corporate Boulevard South, Yonkers, NY 10701
Jane Reinish, Admissions: (914) 294-6335

Rusk Rehabilitation (Acute)

301 E 17th Street, NY, NY 10003
Admissions: (212) 263-6034

Sunshine Children's (Subacute)

15 Spring Valley Rd, Ossining, NY 10562
Admissions: (914) 333-7080

Patient Checklist: Months Before

Touring the Hospital

Pre-Operative tours are offered by Child Life Specialists who are professionals specially trained to help children (birth – adolescence) and their families understand and manage stressful life events and healthcare experiences.

What Child Life Specialists can offer:

- Developmentally appropriate medical, hospital and procedural education
- Comfort and support when a patient expresses specific fears regarding hospitalization, doctors and/or procedures
- Preparation for any medical procedure, treatment or surgery
- Information and techniques for relaxation, pain management, & coping
- Distraction, alternative focuses & support during procedures and surgery to help ease anxiety and decrease fears

During a preoperative tour you will be able to:

- Have your questions answered
- Tour the preoperative area, operating room (if available), recovery area and the inpatient unit (if necessary)
- Learn what to expect on the day of the procedure
- Learn about medical equipment, anesthesia and what it's like to fall asleep for the operation

Tours are offered Monday-Friday 11:00am-2:00pm. However, we are flexible, so if these times do not work for you we can try to schedule a time that best fits your needs. If you are interested in scheduling a tour before your child's upcoming surgery, please call 212-342-0688

Pre-Operative Spine Class

A couple times a year our department conducts a pre-operative spine class for patients and families preparing for upcoming spine surgery. These are held at MSCHONY on weekday evenings and usually last 2 hours. We begin with a presentation by a panel of representatives from all of the departments you will encounter during your stay in the hospital. We discuss expectations of surgery and recovery in detail and allow you to ask questions. We finish up with a tour of the pre-op area, PICU, and med/surg floor. We do recommend attending the class if possible because we find that families who attend are more comfortable with the surgical experience.

Patient Checklist: The Week Before

Pediatrician Clearance

Schedule an appointment with your child's pediatrician approximately 1-2 weeks prior to surgery for pre-op clearance. You should bring the 3 page "Pediatrician Clearance Form" found in your pre-op packet for them to fill out and fax back to our office.

If your child develops any illness AFTER their pediatrician appointment you should call our office as soon as possible to let us know.

Anesthesia Consult

About a week before surgery one of our Pediatric Anesthesiologists may contact you by phone to discuss your child's medical history and medical needs. We will arrange this consult but if you need to contact the department of Anesthesiology, the number is (212) 305-2413.
This is an opportunity for you to bring up any concerns you might have about anesthesia, any reactions your child may have had in the past to medications and ask about whether to give a certain medication on the day of surgery.

Current Medication List

Please make a list of ALL of the medications your child takes on a regular basis to bring with you to the hospital. This should include the name, dosage (mg), and frequency. It is not necessary to bring the actual medications with you. The hospital pharmacy will provide all of the medications while your child is admitted. We ask that you not give your child any home medications while they are in the hospital. **Do not give your child Ibuprofen (Advil) for at least one week prior to surgery.** You may give them Tylenol if they are having pain.

Medications	Dose:	Timing:

Patient Checklist: The Week Before

What to Bring to the Hospital

- Pajamas, toiletries
- Flip flops
- iPad/laptop/chargers
- Headphones
- Earplugs/eyemask
- Special pillows, blankets, comfort items
- Child's favorite foods/special dietary items
- Wheelchair
- BiPap mask
- Chest PT vest

What Time is the Surgery?

You will receive a phone call the afternoon prior to the scheduled surgery from one of the nurses in the OR recovery area. They will ask questions about your child's current state of health; review your child's medications; tell you when to have your child stop eating and drinking before surgery; give you all of the instructions about when and where to arrive the next day. If you do not hear from them by 5:00 PM, you may call the nurses' station at 212-305-8670. If surgery is scheduled for a Monday, they will call you the Friday evening before the surgery.

CHG wash

We ask that all neuromuscular scoliosis patients wash with 4% Chlorhexidine Soap for the **3 consecutive nights before your surgery** to reduce the bacterial levels on the skin and help prevent infection. We will provide you with 3 bottles of soap at your pre-operative appointment.

If you have sensitive skin, CHG soap may cause skin irritation such as temporary itching and/or redness. Shaving immediately before applying CHG soap may enhance this effect. You should stop shaving for at least 2 days before surgery on all areas of the body, including the face, legs, underarms, etc. If itching or redness continues, rinse affected areas and stop using CHG soap. Please carefully follow the steps below.

Patient Checklist: The Week Before

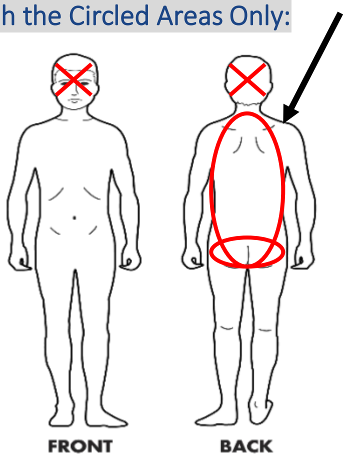
Directions:

When Should You Prepare Your Skin?

- Wash your skin using the Chlorhexidine (CHG) soap at home in the shower **for 3 straight nights before your surgery**

How to Prepare Your Skin the 3 Nights Before Your Surgery

Wash the Circled Areas Only:



- With each shower, wash and rinse your hair first using your normal shampoo. Completely rinse the shampoo from your hair and body.
- Use (CHG) Soap to lather a clean wet washcloth and lather your entire body from the neck down. Turn the water off in the shower to avoid rinsing the CHG soap off.
- Do not use the CHG soap in areas above the neck (face, eyes, nose, mouth, ears).
- Gently wash your body and scrub the areas where the incision(s) will be located for 3 minutes. Avoid scrubbing the skin too hard.
- Once you have completed the scrub, turn the water on and rinse the CHG soap off your body completely.
- Do not wash with regular soap or apply any powders, deodorants or lotions, or makeup afterwards.
- Pat the skin down with a clean towel to dry.
- Dress in clean sleepwear for the night.
- Do not shower, bathe, or shampoo on the morning of surgery

Patient Checklist: The Week Before

Bowel Regimen

The anesthetic and opioid medications that your child will receive for pain control will significantly slow their GI system for several days after surgery. Since many children with neuromuscular scoliosis are constipated at baseline, this slowing can cause further discomfort.
If your child already takes medication for constipation or has a bowel regimen, please discuss this with your surgeon. We may ask you to increase some of these medications in the week before surgery to generate a partial "clean out". In addition, we also ask that you give your child two enemas to empty their lower intestine.

Two nights before surgery administer one Fleet Saline Enema, following the package instructions. Administer another Fleet Saline Enema the following morning. Do this before the CHG bath.
For example, if your child were having surgery on Wednesday morning you would give the first enema on Monday night and the second on Tuesday morning.

Fleet enemas are available over the counter at the pharmacy. It is also fine to use a generic brand saline enema.

Dosage Information
Adults and children, 12 years and over: 1 Fleet enema per day (4.5 oz)

Children between 2 and 11 years: Pedia-Lax Enema (2.25 oz)

- For ages 2-4: Half bottle
- For ages 5-11: Full bottle

Children under 2 years: DO NOT USE

What to Expect: Day of Surgery

- Nothing to eat or drink the morning of surgery (no gum, candy, or water)
- Your child may brush their teeth but please make sure that they spit out all the water
- Do not take a shower
- No makeup
- No hair product
- Remove all jewelry
- Remove nail polish unless it is clear
- Bring your What to Expect Book
- Bring all the necessary paperwork
- Report to the security desk on the first floor of Children's Hospital. You will be directed to the surgical unit on the fourth floor.

Anesthesia

In the pre-op area, your child may receive pre-medication prior to going into the OR. If you feel that this would benefit your child, please speak with the team in the pre-op area. The anesthesiologist will meet with you on the morning of surgery, examine your child and answer all of your questions. This may not be the person you spoke with during the Anesthesia consult but they will have been given all of the information about your child's history. The exact type of anesthesia used is determined on a case-by-case basis but it is always general anesthesia and your child will be fully asleep and unable to feel anything during the surgery.

In the pre-op area, you will also meet a Child Life Specialist who will explain everything that is going on in a developmentally appropriate manner, provide distractions, and offer relaxation strategies. The Child Life Specialist is also able to accompany your child into the OR and stay until they fall asleep. Restricting family from the operating room is an Infection Prevention measure intended to protect your child. Parents may be present in the recovery area when the child wakes up.

During the Surgery

Once your child is asleep, the anesthesiologist and surgical team will take some time preparing for the surgery. This involves setting up the Neuromonitoring equipment, obtaining IV access, placing a foley catheter, and positioning your child face down on a well-padded table. This process can take 1 ½ - 2 hours. When you see your child, they will still have several tubes and wires attached to them. These will include:

- Arterial Line – a small catheter in the artery of the wrist that measures blood pressure and makes it easier to draw blood tests. This will be removed before your child leaves the PICU.
- Intravenous Line (IV) – there will probably be 2 or more IVs in your child's arms to provide them with fluid and medications. These will stay in place until you are ready to leave the hospital.

What to Expect: Day of Surgery

- Foley Catheter – this is a tube that goes into the bladder to drain and measure the urine. This is usually removed 1-2 days after surgery once your child is more awake and mobile.
- Surgical Wound Drain – there may be 2 or 3 flexible drain tubes coming out of your child's back next to the surgical incision. These are there to prevent fluid from accumulating under the incision. These might be removed before you leave the hospital or you may go home with them, depending upon how much fluid is draining.
- Venodyne boots - These are special wraps that Velcro around the lower legs and are connected to a pump that fills them with air every few minutes. This encourages normal blood circulation in the legs and is used to prevent blood clots from forming while your child is immobile.

Your child might also have one or more of the following:

- Central Venous Catheter (CVC) – In some cases the anesthesiologists will place a longer IV catheter into one of the larger veins in the chest or neck. This allows them to give fluids and medications quickly; these lines can also be used to give IV nutrition if necessary. It will be removed several days after surgery, as soon as it is no longer needed.
- Nasogasric (NG)/ Nasoduodenal (ND) tube – a tube inserted from the nose into the stomach or small intestine for feeding. These tubes are used to provide nutrition and administer medications when children are not able to take enough food by mouth. This tube is removed when a child is eating normally.

Intubation

During the surgery a tube is placed in the child's trachea to help them breathe, this is called intubation. Sometimes children have the breathing tube removed before they leave the OR, but other times they are kept intubated for hours to days after surgery to assist with their breathing. The decision to keep the tube in is made by the Anesthesiologist and the decision about when it is safe to remove the tube will be made by the PICU Intensivist. This tube will be attached to a ventilator which provides oxygenated air and pressure. Your child will remain in the PICU while this tube is in place.

Patient Navigator

Your child will be in the operating room for many hours, with the exact length of time dependent upon the type and complexity of the surgery. We understand that waiting for hours can cause a lot of anxiety for families, but recommend that you do take breaks, eat, and take care of yourself. You will have access to a Patient Navigator, who can periodically call into the OR to get updates on your child's case.

What to Expect: Day of Surgery

Recovery

After the surgery is complete the team applies a sterile dressing to the incision in the operating room and then flips the child onto his or her back. Usually there will be quite a bit of facial swelling from being face down on the table during the surgery. This can be a surprise to families when they first see their child, but keep in mind that the swelling will subside over the next couple of days. From the OR your child may go to the Post Anesthesia Care unit (PACU) to recover briefly before being transferred to their room, or they might be brought directly from the OR to the Pediatric Intensive Care Unit (PICU). In either situation, you will be allowed to be there when your child wakes up.

Hospital Stay

The PICU is a special unit in the hospital for patients who require close monitoring and most often one-to-one nursing care. You will be able to spend the night with your child in the PICU, sleeping on a futon. Both parents may stay but visitors should be limited to 2 people at the bedside at one time. There are waiting areas nearby so multiple family members can visit.

The PICU is run by specially trained doctors called Intensivists, along with Pediatric Nurse Practitioners, and Pediatric Medical Residents. While you are in the PICU they will be in charge of your child’s care, in collaboration with your Orthopedic Surgeon. The PICU team will gather outside your child’s room each day for rounds, and you are encouraged to listen and participate.

Early each morning, usually around 7 am, you will also see the Orthopedic team, consisting of: Orthopedic residents (MDs who are undergoing specialty training in Orthopedics), Fellows (MDs who have finished a 5-year residency and are specializing in an area of Orthopedics), Orthopedic Surgeons, and Pediatric Nurse Practitioners. They will check the drains and dressing and discuss the goals for the day.

Once your child’s vital signs, fluid status, and respiratory status have stabilized and there is no longer a need for one-to-one monitoring you will be transferred from the PICU to a room on one of the pediatric medical/surgical floors. This may happen as early as 2 days postoperatively or may take longer.

Your child may be assigned a single or double room, depending on bed availability. Single rooms are used first for isolation of patients with communicable diseases so may not always be available. Great effort is made to match the age and sex of the children in the double rooms so that everyone is comfortable. You will still be able to stay with your child overnight on a futon. The patient to nursing ratio on the med/surg floor is 4:1. Before your child is discharged, we will get new spine x-rays in the most upright position possible. This is done in the CHONY Radiology department once your child is able to be out of bed in a wheelchair.

Pain Management

Every person reacts differently to pain medication, there is not one medication or dose which works for everyone. It is our goal to establish a medication regimen that safely and adequately controls pain while minimizing side effects. After spine surgery we do not expect children to be pain free. They will have some discomfort even with pain medications but should be able to sleep at night, to be alert and comfortable enough to participate in Physical and Occupational Therapy during the day and have minimal side effects like constipation or itching. It is a balance that sometimes requires some adjusting and your input is appreciated. We know that you know your child best and are with them throughout the day and night and we respect your intuition.

When your child first comes out of surgery, pain will be managed with a PCA pump. PCA stands for Patient Controlled Analgesia. These are special pumps for opioid medications that can be programmed to give a specifically calculated, safe, weight-based dose whenever the patient presses a button within a window of time. If your child is unable to press a button, then the pump can be set to administer a low-dose, constant “basal” rate. You should NOT press the button for your child. If you feel that the pain is not being adequately controlled, speak to your child’s nurse and the dose or medication may be adjusted.

The PCA is managed by the Pediatric Pain Service, which is a team of Anesthesiologists and Nurse Practitioners who will round on your child every day to make sure that his or her pain is adequately controlled, and the side effects are manageable. The Pain Service is available 24 hours per day so if there is a problem you should speak to your nurse right away.

In addition to managing the PCA, the Pain Service will transition your child to the oral medications that you will give at home. This will happen while they are still in the hospital so that we can be sure there are no adverse side effects, and the medications are controlling the pain adequately. Once a good regimen has been established, the Orthopedic team will give you prescriptions to fill. **We highly recommend that you get these filled at a pharmacy near the hospital and have them with you when you are discharged**, as some of these medications are not commonly stocked by many pharmacies.

The nearest pharmacy that carries all of the medications we prescribe in pill and liquid form is:

Melbran Pharmacy, 605 West 168th St, New York, NY 10032
Phone: (212) 568-1300
Hours: M-F 9 am – 6 pm; Sat. 10 am – 3 pm; CLOSED ON SUNDAY AND HOLIDAYS

Pain Management

Inpatient Physical and Occupational Therapy

The goal of PT/OT is to help your child return to their baseline level of physical activity and will teach you and your child how to safely move in the immediate post-op period. Here is more specific information from the PT/OT Team:

Who are the people on the therapy team?

Typically, on the day after your surgery, the physical and occupational therapists will work with you and your parents at your bedside. If you were able to walk before your surgery, the PT would help you with standing, walking, transfers, strengthening, balance and endurance. If you were not able to walk prior to surgery the PT will assist you and your caregivers in adapting your transfer for your comfort and safety. The OT will help you and your family with your activities of daily living, which includes dressing, transfers to and from the wheelchair/ toilet if needed, and bathing. Both therapists will also assist in preventing loss of flexibility and regaining or preventing loss of strength during your recovery. Also, they may order or adapt your equipment to help get you home comfortably and safely.

How can you and your family help the hospital therapists provide the best possible service?

If you wear braces or splints, be prepared to bring them to the hospital during your stay. At times, normal swelling after surgery might make fitting braces and splints difficult, but if they are necessary and can be safely fitted, they can be helpful for positioning, transfers, standing and walking. If you needed them before the surgery, it is likely that you will need them while recovering from the surgery.

In the past, families have shown us pictures of the patient's position in their wheelchair before the surgery or of the way they perform their transfer. These are not required, but if available, they can be helpful to give the therapists a good idea of how you were able to move or what positioning was comfortable before the procedure.

Expectations:

The first day after surgery be prepared for PT and OT to arrive separately to your hospital room and begin to help you and your family member(s) begin to get comfortable repositioning you in bed, help you to sit at bedside and stand if you are able. We will make an effort to contact the nurse (& family) before we arrive. This is to allow for the patient to be prepared for participation. Caregivers are always encouraged to participate in sessions since it is expected that they will be in charge of patient care and assistance.

Pain Management

Timelines: (subject to change)

Post-op day 1:

- Up to sitting either at the edge of the bed or in a bedside chair.
- Transfer to stand if able
- Parents and caregivers educated on using bed controls to help sit patient up in bed many times during the day.
- Patient and caregiver to be shown and asked to perform suggested exercises.

Post-op day 2:

- Continue transfers and activities of previous day with caregivers performing portions of the activities with cues from therapist(s).
- Patient and caregivers to practice dressing skills.
- Patient to sit in bedside chair as tolerated.
- Exploration of tolerance of positioning for feeding and personal hygiene.
- Parents expected to help patient to sit in bedside chair and transfer as needed, if cleared by therapist.

Post-op day 3 until discharge:

- Continue activities from post op days 1 & 2. Working towards returning to your previous level of function
- The patient should spend most of the time out of bed, sitting up or walking.

Discharge:

Therapists and Social worker will assist with any equipment, if needed, for discharge. The information above is a general guideline. Reaching the stated goals may take some patients a little longer or shorter depending on each patient's experiences during their hospital stay.

Discharge Criteria and Planning

Discharge planning begins on admission. We encourage you to be involved with the team in planning your discharge. You should be in close communication with the inpatient Nurse Practitioners and Social Workers about any discharge needs that you foresee. Some examples may include: transportation home by ambulance or ambulette, Home PT/OT/Nursing/Home Health Aide, or discharge to a Rehab facility. Your child will not require any special devices for lifting, though you may find that you may need to adjust your method of lifting to accommodate their new straighter shape.

III. INITIAL RECOVERY

Pain Management

In order for your child to be discharged home they should be:

- Back to their baseline respiratory status or optimized
- Able to urinate without a catheter (if able to before surgery)
- Be passing gas
- Tolerating feeding by mouth or G tube
- Have adequate pain management with oral/G-tube medication
- Must be able to sit in a chair for at least 30 minutes
- You and your child must feel comfortable with discharge

Your first post-op appointment will be set up for you before you leave the hospital and will be listed on your discharge papers. It will be scheduled with either Amber Mizerik, PA, Nikki Bainton, CPNP, or Ameeka George CPNP, for 10-14 days after the surgery for dressing removal. If a Plastic Surgeon assisted in your child's surgery and you are being discharged with drains you will also have a follow up appointment scheduled with them. We try and coordinate the orthopedic and plastic surgery appointments together at the same time.

Your other post op appointments will consist of

☐ 6 weeks after the surgery with your surgeon. You will get scoliosis xrays at this visit and the subsequent visits.

☐ 6 months after the surgery with xrays

☐ 1 year after the surgery with xrays

☐ On an annual basis with xrays

Inpatient Rehab

When you are with your child in the hospital, if you feel like their care will be too difficult for you to manage at home and would like to consider discharge to an Inpatient Rehab facility please speak with a Social Worker or one of the Nurse Practitioners as soon as possible.

Inpatient Rehab offers intensive PT/OT as well as around the clock Nursing care. You will likely be able to stay with your child at the rehab facility. Most children stay at a rehab center for 10-14 days. We work closely with several centers in the tri-state area and are in contact with the medical staff there. We will work to get your child in to the facility of your choice; however, space can be limited and we ask you to be flexible.

Caring for Your Child at Home

Dressing

At the end of the surgery, the spinal incision is closed using a plastic surgery type closure with internal dissolving sutures. Then a dressing called Prineo is placed over the incision to reinforce the incision and provide a waterproof barrier. Prineo is a long, thin mesh that is applied with special surgical glue. Finally, a large Aquacel dressing is placed on your child's back while still in the OR under sterile conditions. This dressing is intended to stay in place for up to 10 days, until it is removed at the first post-op appointment. Occasionally the dressing must be changed prior to discharge from the hospital because it has become soiled or there is drainage. If this is the case, the dressing will be changed at the bedside using sterile technique.

You will not be expected to change the dressing at home; however, we do ask that you check the dressing daily to monitor for drainage. You should also check the skin visible around the dressing for any redness or swelling. If you have any concerns, please take a picture of the area and call the surgeon's office. You should not remove the Aquacel dressing. If it begins to peel off reinforce it using a clear Tegaderm dressing. If the wound below the dressing becomes soiled by stool, rinse the area as thoroughly as possible with water and call your surgeon's office right away.

While the Aquacel dressing is on, you should clean your child with sponge baths, no showers. The dressing should remain dry. At the first post-op appointment the Aquacel dressing will be removed but the Prineo tape will be left on. Your child can then begin to take showers but should not submerge the incision in a bath for 4 weeks after the surgery. If your child has drains in place, please refer to the section below regarding showering. The Prineo tape will gradually begin to fall off on its own.

Drains

After a major surgery it is normal for blood and fluid to accumulate in the tissues below the incision. The surgical drains placed next to the incision are used to remove this fluid in order to decrease tension on the healing wound.

It is possible that your child will be discharged from the hospital with one or more of these drains. You will be taught how to empty the drains while in the hospital and will be responsible for emptying them twice a day at home and recording the amount of fluid that comes out. You will also need to make sure that they are secured when your child is out of bed so that they are not accidentally pulled out.

At the first post-op appointment the plastic surgeon will look at your record of how much they are draining and decide whether they can be removed. If they are still draining a significant amount we will leave them in and continue to follow up approximately once a week. If they can be removed, this is done in the office and it is a painless procedure. Your child may shower 48 hours after the drains have been removed to ensure that the area closes.

During the post-op period it is helpful to maximize your child's protein intake, as this helps the body to naturally reabsorb some of this fluid and facilitate earlier drain removal.

Caring for Your Child at Home

Positioning and Skin Issues

After surgery your child will have a very different posture. They will likely need more assistance positioning themselves in bed or a custom wheelchair. This creates the potential for skin breakdown; therefore, it is important to frequently check any prominent areas and inform your surgeon if any skin breakdown is developing. A pressure ulcer in the post-op period increases the risk of wound infection and should be treated aggressively. It is important to speak to your wheelchair vendor ahead of time to make an appointment for adjustment after surgery.

Constipation/Diarrhea

It is extremely common for people to become very constipated after spine surgery because the anesthetic and opioid medications slow down the bowels and most children have a greatly decreased appetite for several weeks. Your child will be prescribed stool softeners and laxative medications such as Colace, Senna and/or Miralax and it is important to give them regularly while your child is taking opioid pain medications. However, if your child develops diarrhea or loose stools, stop giving the laxative medications.

It is extremely important that your child drink plenty of water while taking the laxative medications to help them have a soft bowel movement. Activity is also helpful to get the bowels moving and is important for general recovery.

If your child has not had a bowel movement by 7 days post-op AND they are very uncomfortable, please call your surgeon's office to discuss further treatment with a member of the clinical team.

Reasons to Call Your Doctor Once You Are at Home

- New drainage from wound
- New swelling
- New pain
- Nausea/Vomiting/Diarrhea
- Fever >101
- Ill-appearing (different from when you were discharged)

Diet

It is very normal for your child to have a diminished appetite after surgery. You should let them eat any food that they would like - with a preference for high protein, high calorie foods. Foods high in iron such as red meat, leafy green vegetables, and legumes are also helpful to replenish iron stores. The body has a higher calorie demand as it works to heal the surgical wound and replace the blood and fluid that has been lost.

Caring for Your Child at Home

Pain Management

Each child's pain management regimen will be different, and we encourage you to work with the inpatient team and ask questions while you are in the hospital so you will feel comfortable giving pain medication at home.

However, there are some general guidelines:

- For the first 1-2 weeks your child will likely need around the clock opioid pain medication. If your child is sleeping, then we ask that you wait until they wake up to give their medications. They may be stiff and uncomfortable, but they will be rested. The narcotic medication works within 30 minutes.
- Write down the time that you give each dose of medication. You can use a chart like the one on page 32 or 33.
- You should stagger Ibuprofen (Motrin) and/or Acetaminophen (Tylenol) doses between doses of opioid so that your child is able to take some sort of pain medication every 2-3 hours.
- If you are giving all the prescribed medications around the clock and your child's pain is not being managed, you should call the surgeon's office to discuss with a member of the clinical team. Remember that we except your child will be sore and uncomfortable but able to sleep and participate in therapy and activity.
- Remember that medication usually takes 30-45 minutes to work. You should NOT wait until pain is severe to give medication, because then it is difficult to get back under control. It is better to give the medication as pain is beginning to increase.

Weaning pain medication:

- As your child's pain levels begin to decrease you will be able to wean the opioid medication with the goal of discontinuing completely by 3 weeks post op.
- During this period, continue to give Ibuprofen and Acetaminophen as scheduled.
- Begin by increasing the interval between daytime doses of opioid (for example extend from 4 to 6 hours). If your child is comfortable with this, then extend the nighttime interval. And then you can begin to omit doses when they are sleeping or seem comfortable.
- The bedtime dose should be the last dose to stop.
- After the opioid medication is discontinued, you can begin to omit doses of the Acetaminophen and then Ibuprofen.
- In addition to medication, try alternative pain management strategies such as heating pads or ice packs, distraction with activities or visitors, or massage.

Medication Tracking

If you are running low on medication, call the office for a refill at least 48 hours before you run out.

Here is a system to keep track of medications – when they were last given and when they are due next is helpful to write down:

Daily Chart

Type of Medicine	Date:	Time:
Oxycodone Medicine can be given for severe pain every 4 hours as needed.		
Tylenol / Acetaminophen Medicine can be given for mild to moderate pain every 6 hours as needed.		
Motrin / Ibuprofen Medicine can be given for mild to moderate pain every 6 hours as needed.		
Colace Medicine can be given for constipation every 12 hours		
Senna Medicine can be given for constipation every 12 hours.		
MiraLAX Medicine can be given daily		

Medication Tracking

WEEKLY CHART

	MON	TUES	WED	THURS	FRI	SAT	SUN
Oxycodone Medicine can be given for severe pain every 4 hours as needed.							
Tylenol / Acetaminophen Medicine can be given for mild to moderate pain every 6 hours as needed.							
Motrin / Ibuprofen Medicine can be given for mild to moderate pain every 6 hours as needed.							
Colace Medicine can be given for constipation every 12 hours							
Senna Medicine can be given for constipation every 12 hours.							
MiraLAX Medicine can be given daily							

Other

Return to School and Activities

The average time to return to regular activities is 4-6 weeks. Sometimes families decide to start their child back to school on a half day schedule for 1-2 weeks before going to full days. In general, your child can return to school when they are no longer taking opioid medications and can sit comfortably in a chair for the school day. Children can return to non-collision sports at 6 weeks as tolerated.

Please remember that we as a team are here to support you. Your care does not end when you are discharged from the hospital. You should feel comfortable contacting us with any questions or concerns.

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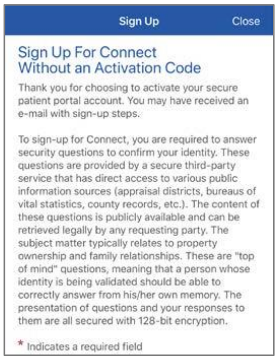
Tap **Self Sign Up**


Sign Up
Close
Please Identify Yourself
Step 1
All fields are required.
Connect Activation Code
Enter your Activation Code as it appears on your enrollment letter (your code is not case sensitive). You will not need to use this code after you complete the signup process.
xxxxx - xxxxx - xxxxx
No Activation Code? Self Sign Up

You will be asked to answer security questions to confirm your identity. These questions are provided by a secure third-party service. Fill in your information to complete sign up.

If you are unable to self-enroll, you can request an activation code from your provider at your next visit.


Sign Up
Close
Sign Up For Connect Without an Activation Code

Thank you for choosing to activate your secure patient portal account. You may have received an e-mail with sign-up steps.

To sign-up for Connect, you are required to answer security questions to confirm your identity. These questions are provided by a secure third-party service that has direct access to various public information sources (appraisal districts, bureaus of vital statistics, county records, etc.). The content of these questions is publicly available and can be retrieved legally by any requesting party. The subject matter typically relates to property ownership and family relationships. These are "top of mind" questions, meaning that a person whose identity is being validated should be able to correctly answer from his/her own memory. The presentation of questions and your responses to them are all secured with 128-bit encryption.

* Indicates a required field

Specific Instructions & Notes

Specific Instructions & Notes

What to Expect **Neuromuscular Scoliosis**

COLUMBIA | ORTHOPEDICS

NewYork-Presbyterian KIDS

Columbia University
Pediatric Orthopedics

3959 Broadway, Floor 8
New York, New York 10032

columbiaortho.org/peds
212.305.4565 appointments