Quality of Life for Kids With Ulcerative Colitis and Other Inflammatory Bowel Disease

For children whose chronic ulcerative colitis can’t be managed with medication, Mayo Clinic Children’s Center offers expertise in single-incision laparoscopic ileal pouch-anal anastomosis (IPAA). The procedure is a safe alternative to standard laparoscopic-assisted IPAA and can reduce postoperative length of stay without affecting short-term postoperative morbidity, according to a study of Mayo Clinic patients reported in the February 2015 issue of the Journal of Laparoendoscopic & Advanced Surgical Techniques.

The study found that children who have single-incision laparoscopic IPAA have a median hospital stay of four days compared with seven days after standard laparoscopic-assisted IPAA. Single-incision laparoscopic IPAA also generally causes minimal scarring.

“We make a single 1.5-centimeter incision versus four ports and a Pfannenstiel incision for a laparoscopic-assisted procedure. That reduces pain and speeds recovery,” says D. Dean Potter Jr., M.D., a pediatric surgeon at Mayo Clinic Children’s Center in Rochester, Minnesota.

“IPAA surgery allows children with chronic ulcerative colitis to have their lives back,” he adds. “Children who have a chronic disease develop ways to deal with it. But that often involves giving up activities that they need and want to do, such as going to school or doing sports. After surgery, patients in general are very happy that they can control the stool and predict when they will have bowel movements, versus the urgency and pain they have with uncontrollable inflammatory ulcerative colitis.”

As a center of excellence for gastroenterology and pediatrics, Mayo Clinic has pediatric surgeons with extensive experience performing IPAA in children. “It’s one of the most complicated gastrointestinal procedures that’s done, so it’s beneficial for patients to seek treatment at a large-volume center,” Dr. Potter says.

A long-term study of Mayo Clinic Children’s Center patients found that an estimated 92 percent who had IPAA for ulcerative colitis had pouch survival at 20 years after their procedures. That study, reported in the October 2015 issue of the Journal of Pediatric Surgery, also found that quality of life for these patients was generally excellent and stable over time.

“However, we don’t want to do surgery on patients without first making sure we’ve tried the proper medications,” Dr. Potter says. “Once the patient has failed medications or doesn’t want to progress onto a more aggressive medical therapy, then it might be time for surgery.”

Multidisciplinary Inflammatory Bowel Disease Center for Children

Children with ulcerative colitis or Crohn’s disease are treated at Mayo Clinic’s Inflammatory Bowel Disease Center for Children, which provides a multidisciplinary approach to care. Patients and caregivers meet with a treatment team that includes a pediatric gastroenterologist specializing in inflammatory bowel disease, a psychologist, a social worker and a surgeon if needed. Experienced pediatric radiologists use MR enterography and occasionally capsule endoscopy to distinguish ulcerative colitis from Crohn’s disease, which is crucial for decisions about treatment.

“We no longer offer IPAA to children with Crohn’s disease,” Dr. Potter says. “Our study
showed that the long-term outcomes for pouch survival is dramatically reduced in patients with Crohn’s disease versus ulcerative colitis.”

The Inflammatory Bowel Disease Center for Children also has experience diagnosing and treating children with very early-onset inflammatory bowel disease. Children with that condition can have genetic testing for immunodeficiency at Mayo Clinic’s Center for Individualized Medicine.

Recognized as the best Gastroenterology & GI Surgery hospital in the United States by U.S. News & World Report, Mayo Clinic’s campus in Minnesota offers a smooth transition from pediatric to adult care. “We’re fortunate because we’re essentially on the same floor in the same building. Our pediatric gastroenterologists work with adult gastroenterologists every day. If there are questions about a patient, our gastroenterologists can walk down the hall and talk to each other,” Dr. Potter says.

“Patients don’t suddenly have to go to a different hospital,” he adds. “They’re coming to the same place — they’re just seeing an adult physician rather than a pediatric physician.”

For more information


Robotic-Assisted Urologic Surgery
Mayo Clinic Children’s Center is one of a few specialized centers in the United States that offer robotic-assisted urologic surgery for children. Although the minimally invasive technology was originally designed for adult surgeries, it is routinely used to treat the large number of children with complex conditions who are seen at Mayo Clinic.

“The robotic-assisted technique allows us to do a fairly complicated surgery through very small incisions,” says Patricio C. Gargollo, M.D., a pediatric urologist at Mayo Clinic Children’s Center in Rochester, Minnesota. “Scarring and pain are decreased because there is less tissue damage. We’ve found that we can minimize the hospital stays and the amount of pain medication that children take. It all translates to a faster recovery so children can return to school, and parents to work, more quickly.”

At Mayo Clinic Children’s Center, robotic-assisted pediatric urologic surgery is used most commonly for procedures involving kidney reconstruction or treatment of vesicoureteral reflux. “But we are also able to use it for very unique circumstances where open surgery would normally be employed,” Dr. Gargollo says. “Congenital defects in the urologic tract are so varied. Robotic-assisted technology gives us another option for the unusual cases that we see at Mayo Clinic Children’s Center.”

The robotic-assisted technology, which is controlled by the surgeon, offers several advantages over other minimally invasive techniques. “The robotic technology has 10-times magnification and 3-D vision, unlike the 2-D field with traditional laparoscopic surgery,” Dr. Gargollo says.

The technology also includes a tremor-nulling feature to overcome distortions that can arise when surgeons make the tiny moves necessary in these procedures on small patients. Dr. Gargollo notes that surgical outcomes are comparable to traditional open surgery outcomes, in terms of success and complications.

Hidden incisions and complex simulations
Dr. Gargollo developed the hidden incision endoscopic surgery (HiDES) technique, which results in minimal scarring after kidney surgery. “We hide the incisions in the normal creases of the body — the bellybutton and an area below the bikini line. So even if a child is wearing a bathing suit, you would never see scars,” he says. “When you’re working on the kidney, HiDES is the only way to truly hide incisions. The instrumentation in traditional laparoscopy doesn’t allow you to configure the channels you’re working through in the way that hides these scars.”

In addition to these groundbreaking techniques, Mayo Clinic has well-equipped simulation centers where urologists can plan complex surgeries. “Simulating these surgeries in real time is a robust tool for surgeons and also for training our research fellows and medical students,” Dr. Gargollo says. To enhance planning and simulations, Mayo Clinic’s 3-D printing laboratory can provide surgeons with models of a patient’s anatomy.

“Mayo Clinic is unique in having these capabilities,” Dr. Gargollo says. “They offer hope that pediatric patients with complex urinary conditions will have better outcomes than what was previously possible.”
New Standards in Pediatric Airway Reconstruction

Mayo Clinic Children’s Center plays a lead role in defining complex airway reconstruction in children. In addition to providing multidisciplinary coordinated care, including endoscopic reconstructive procedures, Mayo Clinic is at the forefront of an international effort to standardize outcome measures for pediatric laryngeal and tracheal reconstructions.

“We are building a body of evidence to guide decision-making about these patients with complex breathing problems,” says Karthik Balakrishnan, M.D., M.P.H., a pediatric otolaryngologist at Mayo Clinic Children’s Center in Rochester, Minnesota, and leader of the international collaborative group. “The goal is for any surgeons performing these procedures to know what experts around the world think are important considerations.”

The collaborative group comprises more than 30 physicians — including otolaryngologists, general pediatric surgeons, cardiothoracic surgeons and pulmonologists — from 10 countries. Dr. Balakrishnan led a similar project on standards for treating lymphatic malformations in the head and neck, as described in the 2015 issue of Otolaryngology-Head and Neck Surgery, and is planning future efforts on airway reconstructive procedures for swallowing and voice problems.

“We’re working on creating an international database,” Dr. Balakrishnan says. “So a surgeon who hasn’t done many airway reconstructions and wonders, for example, how long to keep a child sedated afterward could pull up that information on a website or app.”

The outcome measures for airway reconstructions involve dozens of variables to be weighed in presurgical planning as well as during and after surgery. Presurgical considerations include not only the severity and cause of the patient’s problems but also overall health.

“We want to think about the comorbidities that could affect the procedure’s outcome and the child’s recovery. Sleep apnea, pulmonary disease, gastrointestinal status, Down syndrome — there is a vast range,” Dr. Balakrishnan says.

Post-surgical variables include general factors that would apply to any surgery — such as quality of life, and patient and caregiver satisfaction — as well as factors specific to the procedure, such as complications and adverse events, and breathing and swallowing outcomes. The standardized measures can also serve as reporting measures in research studies.

“When everyone is reporting different types of outcomes, it’s impossible to pool data from multiple studies,” Dr. Balakrishnan says. “We can do better than learn by trial and error.”

Mayo Clinic Children’s Center’s treatment expertise

As a large-volume center, Mayo Clinic diagnoses and treats many children with airway problems due to premature birth, congenital anomaly or acquired conditions. “We see excellent outcomes,” Dr. Balakrishnan says. “We have treated children who had tracheotomies for years, who failed multiple previous reconstructive surgeries and who now are rid of the tracheostomy tube and getting on with life.”

Mayo Clinic is one of the few centers in the United States that routinely performs complex endoscopic reconstructions of the pediatric larynx and trachea. Endoscopic surgery generally involves less risk and morbidity, and faster recovery.

“One common presentation is kids who have both vocal cords paralyzed and the airway obstructed,” Dr. Balakrishnan says. “In the past many of those children would have needed a major open surgery or tracheotomy. With an endoscopic laryngeal reconstruction, we can preserve some of the voice and some swallowing function but still open the airway and avoid a tracheostomy.”

When planning a complex pediatric airway reconstruction, Mayo Clinic Children’s Center surgeons use 3-D-printed models of the patient’s anatomy. “The models help us plan the surgery and sometimes even practice the procedure,” Dr. Balakrishnan says. “These models often change the surgical plan in ways we didn’t anticipate from looking at the standard CT scan. We have seen the beneficial changes in surgical outcomes.”

In addition, Dr. Balakrishnan and R. (Richard) Paul Boesch, D.O., a pediatric pulmonologist at Mayo Clinic Children’s Center, are leading a national effort to define and standardize aerodigestive care for children.

Patients also benefit from the multidisciplinary, coordinated approach to care provided by Mayo’s Aerodigestive Clinic. The integrated practice model followed throughout Mayo Clinic Children’s Center facilitates communication among a team of specialists. Depending on the patient, the aerodigestive treatment team might include pediatric subspecialists in otolaryngology, pulmonology, gastroenterology, neurology, sleep medicine, speech pathology and occupational therapy. These pediatric subspecialists, including Dr. Balakrishnan and Dr. Boesch, are leading national efforts to define and standardize aerodigestive care for children.
Erick D. Bothun, M.D., consultant in Pediatric Ophthalmology at Mayo Clinic Children’s Center in Rochester, Minnesota, answers questions about pediatric cataracts.

When should pediatric cataracts be treated?
Pediatric eyes have a critical role in feeding the brain clear images of the world so that the brain can learn to process vision. Severe cataracts impede that development. Cataracts that are present in a newborn for only a few months before removal can profoundly impact future vision. Thus, cataracts should be evaluated and treated promptly. After the first months of life, the development of vision slowly becomes less time sensitive. The ideal time frame for removing cataracts in a newborn is often urgent, whereas in a 1-year-old it is more routine, and very elective in a school-age kid.

What conditions are associated with pediatric cataracts?
Cataracts are often isolated and not associated with any other anomaly. However, they may be the presenting feature for an underlying metabolic, genetic or congenital condition. Those conditions might involve other eye anomalies such as retinal disease, craniofacial abnormalities or systemic findings such as cardiac disease, renal dysfunction, cognitive impairment or hearing loss.

How does the team approach of Mayo Clinic Children’s Center benefit these patients?
Our comprehensive team approach is critical in delivering the best outcomes for children with pediatric cataracts. I often draw from my Mayo Clinic colleagues and resources to help diagnose ocular anomalies, curb systemic disease and rehabilitate vision in children. This may include pediatric rheumatologists, metabolism specialists or neurologists. I have the utmost trust in our surgical team, including pediatric anesthetists who can manage even the smallest and most delicate patients. For children who have genetic conditions with effects beyond the eye, Mayo Clinic Children’s Center has geneticists with vast experience in pediatric eye anomalies who can expedite prompt diagnosis.

What surgical expertise does Mayo Clinic Children’s Center bring to these complex cases?
My experience with performing complex cataract procedures allows us to care for children with unique structural challenges. This may involve removing a cataract from extremely small eyes, after trauma, or from patients with associated glaucoma or systemic disease. We have a robust Marfan syndrome care center within Mayo Clinic Children’s Center. These children have very particular needs — often their eyes can’t support the normal lenses that we implant in adults. We offer special surgical techniques and expertise for such patients, including researching new lens designs for children with Marfan syndrome. Lastly, we are adept at providing multispecialty surgical approaches, including corneal transplantation services or vitreoretinal procedures.

What is Mayo Clinic Children’s Center’s approach to rehabilitative care?
Rehabilitating the eye and the brain after cataract surgery may be considered a marathon that extends over years. Some children will start wearing contact lenses in the first month of life. Some will be patched to occlude one eye at a time for asymmetric vision for years to maximize vision. It’s important to have a care team that understands the projected growth of the child’s eye, the options...
in rehabilitation, and how to bond with and educate families. Our team includes orthoptists — specialists in vision and alignment testing — as well as contact lens experts and providers of child life services. We work to guide families to a rehab program that is impactful yet sustainable. We all strive to give children the best chances for optical success when they finish developing.

Families with capable ophthalmic care close to home can have some follow-up evaluations performed by local eye care providers. Yet families and children grow to appreciate the care and bonds we create and choose to make at least some trips back to Mayo Clinic Children’s Center.

**What outcomes do you see for these patients?**

Bilateral cataract conditions caught at a reasonable age tend to have excellent outcomes. Provided complications such as glaucoma do not interrupt the progress, driving vision and even 20/20 vision in both eyes are not uncommon outcomes. For unilateral cataracts, the outcomes can also be good. However, because of the severe optical asymmetry between the eyes, the development of vision in the cataract eye may continue to struggle. Outcomes vary but are maximized by ideal optical correction through contacts, intraocular implant and glasses, and the family’s success with adhering to patching. For one-eye cataracts, about one-third of kids will obtain driving vision in their poor-seeing eye, one-third will have more moderate “walking-around” vision and one-third never reach quality vision in the affected eye, largely due to complications and lack of compliance with patching.

**What clinical studies are underway?**

I was a surgeon and investigator in the Infant Aphakia Treatment Study, which compared treatment of aphakia with a primary intraocular lens or contact lens in infants with a unilateral congenital cataract. Because we found that young infants experience a higher rate of complications with intraocular lenses, we typically choose contact lenses for infants up to age 6 months.

At Mayo Clinic Children’s Center, we are collaborating with various institutions to evaluate the use of intraocular lenses in children ages 7 months to 2 years. I believe that study may shape the role of intraocular lenses in toddlers and young children for years to come.

**For more information**


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**Coordinated Care for Children With Vascular Anomalies and Malformations**

Mayo Clinic goes beyond a multidisciplinary approach to offer coordinated appointments and consultation among specialists for children with vascular anomalies and malformations. At Mayo Clinic’s Vascular Malformation Specialty Clinic, patients generally have imaging completed on a Monday, see several specialists as needed on Tuesday morning and receive a plan of care by the end of that day.

“Very few centers have this interdisciplinary approach. Our specialists meet in person to discuss a patient’s imaging and evaluations, and to determine a plan of care,” says Megha M. Tollefson, M.D., a pediatric dermatologist at Mayo Clinic Children’s Center in Rochester, Minnesota, and director of the Vascular Malformation Specialty Clinic. “These vascular disorders are so heterogeneous that they require thorough, comprehensive, holistic care.”

Mayo Clinic specialists have experience with a wide range of venous malformations, lymphatic malformations, combined malformations and rare syndromes such as Klippel-Trenaunay’s and Sturge-Weber’s syndromes.

“Before the visit, based on patients’ records and other information they send, we put together a list of which services and physicians they need to see. Usually by noon on Tuesday, the patients have seen all the specialists they need to,” Dr. Tollefson says. “Then all of the physicians, including the radiologists, meet to go over the imaging and discuss ideas about how to care for each patient.”

**Subspecialized expertise in diagnosis and treatment**

In addition to specialists in dermatology and interventional radiology, including neurointerventional radiology. Mayo Clinic’s Vascular Malformation Specialty Clinic has pediatric orthopedic, vascular and plastic surgeons, as well as neurosurgeons and specialists in ear, nose and throat (ENT) surgery. Other members of the team include specialists in pediatric physical medicine and rehabilitation, pain, lymphedema, and medical genetics. Diagnostic radiologists in the vascular...
anomalies clinic have subspecialties in neurological, musculoskeletal and ultrasound radiology.

“Depending on the malformation’s type and location, it can require entirely different sets of specialists, appointments and procedures,” Dr. Tollefson says. “For example, for a patient with a veno-lymphatic malformation of the head and neck, the team might include an interventional radiologist specializing in neuroradiology, an ENT specialist and a dermatologist. For Klippel-Trénaunay’s syndrome, the patient might see an interventional radiologist, dermatologist, orthopedic surgeon and specialist in lymphedema.”

Pinpointing a diagnosis is crucial to determining treatment. “A lot of patients come to us with a possible diagnosis of an arteriovenous malformation or hemangioma when really they have a venous or a lymphatic malformation,” Dr. Tollefson says. “Our imaging expertise allows us to make an accurate diagnosis. Those various diagnoses have very different implications for the patient’s prognosis and the type of treatment needed.”

At Mayo Clinic, treatment focuses on alleviating symptoms and preventing future complications — while avoiding overtreatment.

“Some providers have a strategy of, ‘If it can be treated, it should be treated.’ In our experience, that’s not necessarily true,” Dr. Tollefson says. “Sometimes treatment causes a lot of pain, not just immediately but also later down the road. Overly aggressive sclerotherapy, for example, can injure the skin. That can cause open sores and even damaged nerves. We’ve seen a lot of that. And some lymphatic malformations that are operated on are likely to recur. The lymphatic vessels underneath the surgical site often ooze and drain for quite some time, which can lead to infections, pain and other complications.”

Assessing the risks and benefits of treatment requires experience and expertise. “Every treatment has potential complications,” Dr. Tollefson says. “We recommend treatment when we believe there’s a very good chance of improving the patient’s quality of life. Sometimes the right answer is to treat, but to wait some time to perform that treatment. Every patient and every situation is different, and we take that all into consideration when making our recommendations.”

Treatment options might include compression therapy, sclerotherapy or surgery, or a combination of them. “If sclerotherapy or surgery isn’t a good option for a patient, our team has been using some cutting-edge laser technology to treat challenging superficial or even internal malformations,” Dr. Tollefson says.

**Center of excellence for rare disorders**

Mayo Clinic pediatric specialists are leaders in treating and researching rare conditions involving vascular anomalies. The Sturge-Weber Foundation has designated Mayo Clinic part of the foundation’s Clinical Care Network. The K-T Support Group for people with Klippel-Trénaunay’s syndrome holds its biannual meeting at Mayo Clinic’s campus in Minnesota.

In addition, Dr. Tollefson has participated in efforts by the Hemangioma Investigator Group to compile treatment guidelines for PHACE syndrome. PHACE refers to posterior fossa anomalies, hemangioma, arterial lesions, cardiac abnormalities/coarctation of the aorta and eye anomalies. As described in the November 2016 *Journal of Pediatrics*, the guidelines cover immediate and long-term care for patients’ neurological, cardiac, ophthalmological and hearing health.

“Vascular malformations can have a profound impact on a child’s life,” Dr. Tollefson says. “Even if we’re not able to offer a cure, our team of specialists is able to offer treatment strategies to improve quality of life.”

**For more information**


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**Scoliosis: Research to Improve Patient Treatment**

Mayo Clinic Children’s Center has a comprehensive spine deformity treatment program with state-of-the-art spinal care for children from birth to adulthood. This clinical care is supported by an extensive research program aimed at improving treatment and quality of life for children with scoliosis.

“We are involved in many projects to learn about the etiology of scoliosis, to advance treatment and to understand how our treatments are impacting families,” says A. Noelle Larson, M.D., an orthopedic surgeon at Mayo Clinic Children’s Center in Rochester, Minnesota. “There’s a significant need for novel approaches in the treatment of scoliosis and other growth-plate disorders.”

Dr. Larson and colleagues at Mayo Clinic Children’s Center participate in a number of...
nationwide study groups and registries for pediatric spinal disorders. “We have a good sense of what’s being done in the world of pediatric orthopedics,” she says. “Coming to Mayo Clinic Children’s Center gives patients and their families access to that global knowledge and the opportunity to enter into clinical trials.”

Among other groups, Mayo Clinic is a member of the Children’s Spine Study Group, which compiles a registry of patients with early-onset scoliosis, and works to improve their quality of life. “The advantage is that, in our own practice, we might see 100 to 200 patients with early-onset scoliosis. But the registry has 3,800 patients,” Dr. Larson says. “We can use that combined experience to improve treatments for our patients and look into specific rare conditions.”

The registry facilitated a recent study of 200 patients with congenital rib fusions. “The registry gave us access to that larger group so we could ask relevant clinical questions,” Dr. Larson says.

Seeking optimal outcomes
The options for treating pediatric scoliosis include casting, traditional and magnetic growing rods, and other methods of surgical correction. Each approach poses challenges for young, growing patients and for physicians striving for optimal outcomes that avoid complications and the need for future surgery.

At Mayo Clinic Children’s Center, early-onset scoliosis in children under age 4 is often treated with elongation, derotation and flexion casting — also known as Mehta casting. The treatment utilizes a custom-made thoracolumbar cast that acts simultaneously in the frontal, sagittal and coronal planes. Outcomes are often excellent, but early diagnosis is critical.

“There is a high rate of cure for children under the age of 2 who have a curve under 60 degrees,” Dr. Larson says. “Unfortunately, we also see children who were braced or had no treatment at a young age. Suddenly, we have missed the treatment window and the child has a very large curve that is frequently too big to cure with casting.”

If surgery is required, Mayo Clinic Children’s Center has highly specialized orthopedic pediatric teams. Those specialists are researching improved surgical techniques. Mayo was one of 14 centers that enrolled patients in the Minimum Implants Maximum Outcomes Clinical Trial, which randomized patients to groups having scoliosis surgery with fewer or more pedicle screws to determine how many surgical implants are needed to have a successful surgical result.

“Some surgeons like to use two pedicle screws for every single level of the spine that’s fused, while other surgeons will use far fewer,” Dr. Larson says. “Fewer screws might offer advantages. Once two-year follow-up data is available, we will be comparing factors such as blood loss, curve correction, operative times and complications between the two surgical groups.”

Orthopedic surgeons at Mayo Clinic Children’s Center also have access to the low-dose intraoperative CT-guided navigation technology. The system provides real-time, multidimensional intraoperative imaging of a patient’s anatomy. In a study published in the April 2016 issue of Clinical Spine Surgery, Mayo Clinic researchers found that intraoperative image-guided navigation resulted in a 97.8 percent rate of accurate screw placement in patients age 10 years or younger. Previous studies have noted that up to 15 percent of freehand pedicle screws in children are reported to be malpositioned.

“More recently, we have had a zero percent return to the operating room for malpositioned screws using the CT-navigation system compared with the 0.3-1.0 percent return reported in the literature,” Dr. Larson says.

To minimize radiation exposure from intraoperative CT, Mayo Clinic Children’s Center developed a protocol for pediatric patients using a lower radiation dosage than that recommended by the manufacturer. In the September 2016 issue of Journal of Pediatric Orthopaedics, Mayo researchers reported successful clinical use of the pediatric protocol that reduces radiation from intraoperative CT to less than one-fourth the mean annual natural background radiation compared with 2 times the annual background radiation at the settings recommended by the manufacturer.

One current project is studying the level of activity before and after surgery of patients with scoliosis. Patients wear activity trackers for four days before treatment and then again a year after bracing and surgery.

“Unfortunately, we’re finding that patients with scoliosis are less active compared with controls, and potentially even less active after treatment,” Dr. Larson says. “Our treatments probably have effects on children’s lives that we’re not fully aware of. But now that we know this, we can develop treatment plans for children undergoing scoliosis treatment to bring patients back to a healthy level of activity.”

A longer term target for Dr. Larson is the epigenetics of scoliosis. That research is facilitated by a Mayo Clinic Children’s Center biobank that collects waste tissue from scoliosis surgeries for laboratory analysis.

“We do high-throughput RNA sequencing, which allows us to identify genetic factors that
might make children susceptible to idiopathic scoliosis,” Dr. Larson says. “If we can find a gene that is malfunctioning — a drug-gable target — we could have a big impact on patients’ lives. My dream is to develop pharmacologic treatments for scoliosis — hopefully I will see this come to pass during my lifetime.”

For more information