Tet's Get if Straight BACKTALK

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The Scoliosis Association, Inc., An International Information and Support Network

Minimally Invasive Correction Of Adult Degenerative Scoliosis



Neel Anand, M.D. Director of Orthopaedic and Minimally Invasive Spine Surgery Cedars Sinai Medical Center Los Angeles, CA

Introduction

Dr. Richard Nasca, retired orthopedic surgeon, Wilmington, North Carolina became aware of the work Dr. Anand was doing with adult degenerative scoliosis about a year ago. Dr. Nasca requested and Dr. Anand agreed to share some of his preliminary results with the readers of BACKTALK.

> hose affected with adult degenerative scoliosis may present with back pain

around the convexity of their curve which worsens with standing and activity. Nerve root compression due to narrowing of the neural foramen on the concavity of the curve or stretching of the nerve

roots on the convexity of the curve may result in extremity pain, motor weakness and reflex changes.

Non operative management of adult degenerative scoliosis includes physical therapy and the use of anti-inflammatory and pain medications. Treatment of osteoporosis is paramount. Spinal braces are poorly tolerated by older patients and may lead to further trunk muscle deconditioning and atrophy. Facet and nerve root blocks may be helpful as well as epidural steroids. For those with significant progressive curves, nerve root compression and spinal decompensation, surgical management is usually necessary.

Achieving a fusion across the lumbosacral joint (L5-S1) presents a challenge in patients with scoliosis. Failure of instrumentation and fusion at L5–S1 is not uncommon in patients requiring long fusions for correction of scoliosis. Kim, Bridwell, Lenke and co-workers⁽¹⁾ report a 17% failure of fusion (pseudoarthrosis) in long fusions and higher rates of pseudoarthrosis have been reported if the L5-S1 level is included.⁽²⁾

In order to facilitate fusion at L5-S1, an anterior interbody fusion performed through an open abdominal approach has been done in addition to posterior fusion with instrumentation. In spite of this dual approach, failure of fusion across L5-S1 remains a problem.

A novel surgical approach and implant have been devised which offers a possible solution to the vexing problem of obtaining fusion at

Does My Child Have To Have That X-ray?



Walter F. Krengel, III, M.D. Chief, Spine Program Department of Orthopedics and Sports Medicine Seattle Children's Hospital Seattle, WA

he reason we treat scoliosis (curved spine) is to avoid the long term deleterious effects

of severe back deformity. The effects of severe scoliosis on back pain, pulmonary function and health related quality of life are well known. Smaller degrees of scoliosis have little effect on function and quality of life. When parents bring their children to the doctor, they expect us to be able to tell them if they have scoliosis, how severe it is, and what treatments are available. If the spinal curve is severe, there is general agreement that surgery is the correct choice in most circumstances. However, most children come to the doctor with small or modest degrees of deformity. To be able to tell them

what they want to know, an x-ray of the spine is needed. All our assessment and treatment algorithms are based, to a large extent, on the x-rays and "Cobb Measurements" taken from those x-rays.

With increasing frequency, I am being asked by patients and families whether or not an x-ray is necessary. Public concern over the effects ionizing radiation, and exposure to ionizing radiation have been growing. Recently, an article by Brenner and Hall in the New England Journal of Medicine on the effect of radiation from CT scan made headlines across the country. Though CT scans are not usually needed for scoliosis evaluation, they are increasingly ordered to evaluate 3 dimensional anatomy. This is especially important if surgery for correction of a spinal curve is being planned. They are used preoperatively for surgery planning and for determining the positioning of orthopedic hardware placed to correct the spine postoperatively. The public concern also reaches over into the radiation exposure during standard x-ray evaluation.

As physicians concerned about the long term health of patients we see for scoliosis, we need to critically evaluate the effect of our x-rays and other medical imaging studies, and be able to put that effect into perspective for our patients. I will try to do that here.

Many patients do not understand that ionizing radiation exposure occurs naturally. This is due to a combination of exposure to cosmic radiation, and naturally occurring radioactive isotopes in food, water

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Awards Ceremony For Leah Stoltz

By JoEllen Hegmann, President Scoliosis Association, Inc. President, Scoliosis Association of Long Island Chapter

On Friday night, December 11, 2009, I had the pleasure of attending a very exciting event at the Accompsett Middle School in

Smithtown, NY. It was hosted by Leah Stoltz, a High School senior, who started the independent scoliosis support group here on Long Island called the Curvy Girls when she was 13 years old. Leah had invited friends and family to a special screening of the first annual Teen Nick HALO Awards show. She had the honor of being chosen to be one of the first four recipients of this new Nickelodeon TV award and had spent a few



filming of the awards show. She was invited to Las Vegas for a special surprise, which turned out to be a meeting with Justin Timberlake who had chosen Leah to receive the award. They share similar interests in helping children and also in playing golf, and they played golf together while Leah was there. The awards show was finally being aired that night and approximately 150 friends and family members braved the bitterly cold, very windy weather to support her and share in her joy. There were door prizes and raffles, food and drink, balloons, and music by a local band, Under Spinning Lights, and it was a great night for everyone. Many of the Curvy Girls and their parents were there helping Leah make sure everything ran smoothly while enjoying this wonderful experience with her and her family. Each of the girls told their scoliosis story and it was very encouraging to hear how well they are doing with bracing. There is nothing like the support of people who have been through what you are going through and it can definitely have an impact on the way teens and their parents get through the sometimes difficult bracing and/or surgery experience. Leah and the Curvy Girls and their families have been good friends of the Scoliosis Association of LI, joining us at our past three scoliosis awareness walks and helping us to raise funds for the Scoliosis Association and for Research. They will again be attending our awareness walk, Sweep Across America for Scoliosis, on May 8, 2010 and we are looking forward to it. Congratulations, Leah.

Please see page 13 for more about Leah and the "Curvy Girls."

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Does My Child Have To Have That X-ray? Continued from page 1

<u>Table 1</u> Sources of Environmental Radiation Exposure (mrem/year)				
Cosmic at Sea Level	26			
Stone Dwelling	7			
Food and Water	40			
• Air (Radon)	200			
Computer	1			
• TV	1			
Total	100-300 (=1-3Sv)			

and air. There are small contributions from exposure to radioactive isotopes in the earth, stone and concrete, tile and ceramics, as well as TV and computer screens. (Table 1) Radiation units are typically expressed in millirems. The average yearly ambient radiation exposure is between 100 and 300 mrem per year, depending on the elevation at which you live, the amount of radon gas in your environment and in the soil.

Radiation doses absorbed by the body tissues are expressed in units called Sieverts. The relationship between radiation exposure and body tissue absorption is complicated, but can be simplified as 1 milliSievert (mSv) = 100 millirem (mrem). Normal environmental exposure to an individual human thus averages between 1 and 3 mSv per year. This can vary somewhat depending on where you live. For example, environmental exposure to ionizing radiation in some areas such as Denver, Colorado approximate 10mSv per year. This is because there are small amounts of radioactivity in the native rocks there. Denver is also at a higher altitude than sea level, so there is a little less atmosphere to screen out radiation from outer space (cosmic rays). People traveling on airplanes at high altitudes also receive increased radiation exposure because there is less atmosphere to screen out radiation from outer space, which is not often accounted for when we consider normal radiation exposure levels.

The amount of radiation exposure caused by a single Spinal x-ray obtained on standard film approximates 0.7 - 1.3mSv, or the equivalent of 7 months of ambient environmental radiation exposure. Comparatively, a CT scan of the spine will create an exposure between 15mSv and 30 mSv depending on many factors,^{1,3} or the equivalent of 4.5 to 10 years of ambient

radiation. These doses can be decreased by limiting the area scanned, the scanning technique and avoiding multiple scans of the same area. When patients and families ask about the risk of an x-ray, they are generally asking about the risk of cancer induced by the ionizing radiation from an x-ray exam. The risk of cancer due to radiation exposure is largely extrapolated from the rate of cancers in atomic bomb survivors, and their estimated dose based on position relative to the epicenter of the explosion. Most subjects received vastly larger doses of radiation than those involved with medical imaging. These risks are calculated in what is termed a Linear Non-Threshold (LNT) Model (ie. 1/2 the dose equals 1/2 the risk of developing cancer). However, risks of radiation induced cancer from much lower doses of ionizing radiation (such as those due to normal levels of environmental exposure, or most medical x-rays) may be overestimated based on the LNT model. According to the NRC, observations of populations exposed to 10mSv/year, such as people living in Colorado, do not demonstrate unusual cancer risks. Also some animal and tissue models of radiation exposure do not show LNT model behavior. In other words, low doses of exposure may not result in increased rates of cancer induction because they are not above a "Threshold" level necessary to create unrepairable genetic damage to cells in radiosensitive tissues. These low doses have not been found to have an increased cancer risk contribution compared to all the other health risk factors that people experience.1 Brenner and Hall note in their article that the low dose group of Atomic Bomb survivors (5-150mSv, average 40mSv) had significantly increased risks of cancer and these doses are "similar to a typical CT study involving two or three scans in an adult." This radiation exposure level is still more than 30 times the dosage associated with a single spinal x-ray.

Brenner and Hall point out that it is not the risk to a single individual, of a single CT scan that is of most concern, but rather the possibly considerable effect of 62 million CT scans per year in the US, particularly if the Linear Non-Threshold estimates are valid. Unfortunately, these finer points are not made in the rather dramatic media headlines. A more thorough study of the long term effects of CT scan is currently under-

<u>Table 2</u> Cumulative risk of death for up to age 75 from specific causes			
All Causes	47159		
 Heart Diseases 	12719		
• MVA	1181		
 Homicide 	575		
• COPD	2237		
GI Cancer	3262		
 CT Abdomen 	70		

way. We must also consider the risk of death from undiagnosed disease such as perforated abdomen, bowel obstruction, tumor or appendicitis for which these CT scans are ordered. The effect of vast numbers of CT scans obtained as a routine health screening tool is a different issue altogether and is of much greater concern.

Brenner and Hall, reported the total risk of death attributable to cancer from a single CT scan of the abdomen at age 15 to be 0.07%, or 7 in 10,000. To put this in perspective, compare this to the risk of death from other causes. Table 2 shows risk of death by age 75 per 100,000 population from the CDC 1996 statistics. The numbers represent the cumulative risk for each age group through age 75 for death from specific causes. One can see that the risk attributable to radiation induced cancer from a CT of the abdomen at age 15 is dwarfed by that from most other causes. Compared to all causes it would be 70/47159 or 0.0015, from heart disease 70/12719 or 0.0055, from Motor Vehicle Accident 70/1181 or 0.059, from COPD (smoking induced lung disease) 70/2237 or 0.031.

A standard X-ray of the spine will create an exposure approximating 1/10th of that from a CT scan, and the use of proper shielding, x-ray technique and digital radiography will bring that exposure even lower. Thus, the risk of premature death from cancer caused by a single spinal x-ray should be 1/10,000 or lower than that of all other causes combined. This risk is low enough that if there is any substantial reason to think that the information gained from the x-ray will be helpful in determining treatment, prognosis or ruling out the existence of more sinister problems, the risk associated with the x-ray should not be a deterrent.

However, we must not completely discount the effect of diagnostic x-rays on the *Continued on page 4*

Does My Child Have To Have That X-ray? Continued from page 3

Table 3Effective mean radiation doses (mSv) from Hansen et al.13-18 yo patients				
<u>X-ray View</u>	AP	<u>PA</u>	<u>Lateral</u>	
Standard Film Air-Gap / CR	0.88 - 1.09	0.49 - 0.53 0.03	0.47 0.048	

risk of developing cancer.⁴ Doody and Lonstein studied the rate of death from Breast cancer in 5573 patients treated for scoliosis between 1912 and 1965 in 14 Orthopedic Medical centers in the US. They showed an increased risk of death from Breast cancer between 1.3 and 2.1 times the expected rate. The risk of death from Lung Cancer and Leukemia (Lung and Bone Marrow exposure) were not significantly different from the general population. The risk was correlated with total dose, which was substantial, averaging 108 mGy and an average number of examinations of nearly 25. It must also be pointed out that the doses to which this group of patients was exposed was much larger than the doses patients receive now. Many xrays in the past were



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taken Anterior to Posterior (AP), rather than Posterior to Anterior(PA). The dosage received by radiosensitive Breast tissue is 20 times less in the PA technique than in the AP technique. 25 x-rays taken in the AP technique would give the same effective radiation dose to the breast as 400 xrays taken in the PA technique!

Other advances in radiologic techniques have also markedly decreased the effective dosages of ionizing radiation involved with diagnostic x-rays of the spine² Hansen et al, in 2003 reported the effective dosage attributable to PA and Lateral radiographs of the spine is decreased by a factor of 10, using Air-Gap Computed Radiography as compared to conventional film techniques. In the 37 patients they studied, this would imply a

reduction in risk of death from 1:2000 to 1:20,000 in boys and 1:1000 to 1:10,000 or lower for girls who had an average of 7 x-ray exams. Digital or CR radiographic technique is widely available now in the US, but the expense associated with purchase and maintenance of this equipment is substantial and typically only supportable in larger orthopedic or radiology group practices, or hospitals.

There are studies currently ongoing that may substantially alter our need for routine x-rays of the spine in patients with scoliosis. The results of the NIH sponsored BrAIST study may provide information that alters when and if we use a brace for scoliosis, and thus whether or not x-rays are necessary when following patients with mild to moderate scoliosis. Ongoing genetic studies may also lead to a greater ability to predict scoliosis progression, and greatly diminish our need for routine x-ray monitoring of spine curve magnitude in mild to moderate scoliosis. For larger spinal curves that require surgical treatment, the use of x-ray, CT scan, or intraoperative fluoroscopy may be critical to the safety and efficacy of the procedure, and their risk is usually far outweighed by those concerns.

In summary, there is probably a definable risk associated with obtaining diagnostic x-rays of the spine. We need to keep this risk in mind when deciding whether or not x-rays, or other diagnostic imaging should be obtained. This risk is, however extremely low. By utilizing proper techniques (PA not AP views, Lateral views only when necessary, Computed Radiography or Digital Radiography if possible, minimize repeating of "inadequate" x-rays) the risk of a single diagnostic study should be below 1:100,000, and may possibly be below a "threshold" dose required to create any increased risk.

As a patient or parent, it is appropriate to be concerned about the risk of radiation from medical imaging. However, these risks are typically vastly overshadowed by other risks in life. The risks associated with a single set of diagnostic images for scoliosis are so low that if there is any reasonable need for the information, you should not hesitate to have the x-ray performed. As other diagnostic and treatment methods for scoliosis develop, the need for x-rays may diminish, but currently they are an important and necessary part of your assessment and treatment.

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spent plus what the insurance company covering prescription drugs has spent together

equal about \$2500.00, the senior instead of paying about 25% of the cost of his medi-

cines now must pay about 60% of the cost.

way, when a senior reaches the doughnut

hole then out of every \$1000.00 of cost for

prescription drugs, a senior in the doughnut

hole has to pay \$600.00 instead of \$250.00.

When the cost of prescription drugs paid by

the senior reaches about \$5,500.00, then he

or she from that point only has to pay 5% of

the bill. To make matters worse, the cost of

This is called the "doughnut hole." Put it this

Chairman's Commentary

By Stanley Sacks, Chair & C.E.O., Scoliosis Association, Inc.



irstly, let me wish everyone a happy and very healthy New Year 2010. I hope this year brings us closer to discovering the genes that cause scoliosis,

the chromosomes on which they are located and a blood test to determine in whom scoliosis exists.

As you know, the past year has seen much controversy over health care legislation. While the Congress and President have been immersed in the details of federal legislation, many states are facing continued severe budgetary deficits. The federal stimulus

package which aided states in 2009 will end in 2010, unless new laws are passed. Meanwhile, such deficits will cause states to curtail many services. For the poor, this will mean smaller budgets for Medicaid, and smaller budgets for Medicaid will mean that the children having scoliosis in poor families are less likely to receive treatment. The pity is that CHIP (formerly known as S-Chip), the Children's Health Insurance Program was expanded in 2009. But what good does it do the children that more of

Stanley Sacks, Chair & C.E.O.

Another issue that is much discussed is denying patients coverage or refusing to pay claims for preexisting conditions such as scoliosis. From what has been reported, it is most likely that a separate law to address the issue of pre-existing conditions would command majority support in both parties. Presently, it is part of the controversial package of laws.

Similarly, the issue of

parties. Portability means that if you go

Of course for seniors on Medicare, a

them are included, if the funds to help them

are not there? CHIP gets its funds from both

the federal and state governments, but is

administered by the states.

often the case.

pressing issue is the

cost of prescription

nut hole. What that

means is that when

what a senior has

drugs and the dough-

prescription drugs has risen each year. For many elderly, all too often this has become a question of choices, that is, whether to pay portability of health insurance for food or drugs. Again, this is an issue that a majority in both parties wants to see corwould get the support of a majority in both rected. Perhaps, what needs to be concentrated from one job to another, your insurance coverage goes with you. Presently, this is not upon is what most agree on, and see that those matters are enacted into laws.



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Spread The Word

Dr. Sig Berven is working with Heilo Koller from Germany on a potential study of the natural history of scoliosis. We have been asked if we can identify individuals that fall into the following criteria:

1. Have scoliosis.

2. Have long cassette scoliosis films from at least 3 time points over a period of 10+ years, either prior to fusion or never had fusion.

3. Never had surgery, or did not have scoliosis surgery until adulthood.

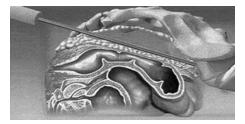
4. Are willing to let us borrow the films for the purpose of copying them (and potentially publishing them). The films will be copied here in San Francisco and the originals will be returned to you.

5. Participants may be asked to answer a short questionnaire.

This is an important study. If we get enough participants to actually undertake this study, it could be quite helpful to adults in the future who will need to make the decision about whether or not to proceed with surgery.

If you are able to help with this important study please contact the Scoliosis Association, Inc. at 1-800-800-0669.

Minimally Invasive Correction Of Adult Degenerative Scoliosis Continued from page 1



<u>FIGURE 1 A</u> Guide pin inserted in pre-sacral space placed in the sacrum.

L5-S1 in patients requiring long fusions for scoliosis correction. Andrew Cragg M.D., an interventional radiologist, developed a percutaneous approach through the presacral space to the sacrum.⁽³⁾ TranS1 of Wilmington, NC designed and fabricated instrumentation to facilitate preparation of the L5-S1 interspace for interbody fusion and an AxiaLIF (axial interbody fusion) rod to stabilize it.(FIG. 1 A, B, C) The surgical approach requires a small incision near the coccyx for entry into the presacral space. Once in the dilated presacral space, a guide wire is placed in the sacrum using C-arm fluoroscopy. A drill is used to remove bone from the central portion of the sacrum to gain access to the L5-S1 disc space. Once in the disc space, special cutters and brushes are used to remove disc material and prepare the vertebral endplates for fusion with bone graft and bone graft extenders. The



<u>FIGURE 1 B</u> Bone graft in L5-S1 disc space. Note guide wire in reamed tract through L5 and S1.

AxiaLIF rod is placed through the sacrum across the L5-S1 disc space and into a reamed channel in the L5 vertebral body.⁽⁴⁾ Interbody fusion cages loaded with bone graft and bone graft extenders are placed through a lateral approach at the other levels and percutaneous pedicle screws and rods are used to correct and stabilize the deformity. (FIG. 2 A,B,C,D)

At the Cedars–Sinai Medical Center in Los Angeles, 60 patients have undergone the Minimally Invasive procedure for correction of scoliosis. All patients had minimally invasive laterally placed cages and percutaneous pedicle screw instrumentation with 42 patients having the AxiaLIF L5-S1 fusion when L5-S1 was included in the fusion.⁽⁵⁾



FIGURE 2 A Pre-op AP standing x-ray of patient with adult degenerative scoliosis. Note the decompensation.



<u>FIGURE 2 B</u> Pre-op Lateral x-ray of same patient standing showing multilevel degenerative disc disease.



<u>FIGURE 2 C</u> AP standing x-ray 6 months post-op AxiaLIF at L5-S1, cages at T12-L1, L1-L2, L2-L3, L3-L4 and L4-L5 and percutaneously placed pedicle screws and rods.

 FIGURE 2 D

 s

 Lateral standing x-ray

 6 months post-op

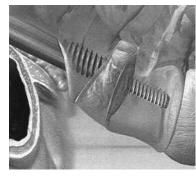
 showing AxiaLIF rod

 across fused L5-S1 disc

 space and fused

lumbar disc spaces

with cages and pedicle fixation T12-L5.



<u>FIGURE 1 C</u> AxiaLIF rod placed across L5-S1 interspace filled with bone graft.

25 patients have more than one year followup and have shown a 100% fusion rate documented on X rays and CT Scans. Excellent correction and maintenance of global coronal and sagittal balance have been achieved with significant improvements in functional outcomes and Visual Analogue pain (VAS) scores. No complications related to the minimally invasive procedure has been noted to date.

The advantages of the AxiaLIF approach compared with the traditional retroperitoneal anterior approach are reduced blood loss, operative time and complications. Perforation of the rectum is a possible complication of the AxialLIF approach though very rare. This has occurred 0.6 % in over 6500 patients. The placement of cages through the lateral transpsoas muscle approach has been associated with transient thigh dysathesias, hip flexor and quadriceps weakness on the same side as the surgical approach. These usually resolve in 2-6 weeks. Using this approach at Cedars-Sinai, only two patients have required a blood transfusion and one patient admission to the ICU. The surgical correction was staged if more than 3 levels were being treated. The lateral transpsoas interbody cages were done during the first stage followed 2-3 days later with the AxiaLIF rod and posterior instrumentation and fusion.

In conclusion, early experience with the use of the AxiaLIF rod, laterally placed cages and percutaneous placed pedicle screws and rods have resulted in a surgical procedure for treatment of adult degenerative scoliosis with less morbidity, good curve correction and a high rate of fusion across the lumbosacral joint. Hopefully these less invasive procedures will benefit more patients.

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The Backwards "S" – Mikayla's Story

A New Book By Michele Colletti

The Backwards "S" – Mikayla's Story is a non fiction, children's book. This book, as told by my 13 year old niece, is her journey from the day they found "the bump" on her back, to the one year anniversary of her idiopathic scoliosis surgery.

Introduction



hat remains etched in my memory is the day I joined a group of eleven teenagers on their pre-op hospital tour. As I

followed the kids through the sterile hospital corridors, what was even more striking than their youthful awkwardness and nervous giggles, was the pronounced bump that each one carried on their backs. I was mesmerized by the fact that scoliosis could affect so many kids and that all were scheduled for surgery during the next few weeks. My daughter marched with this group.

Mikayla's bump was caused by a curved spine, which forced her shoulder blade out. Spinal fusion surgery was needed to stop continued progression of her more than 40 degree curve. Scoliosis affects 2-3 percent of the population in the United States; 38,000 require surgery each year. The primary age of onset is 10 to 15 years old, and girls are eight times more likely to progress to the point where treatment is required. The surgery that required breaking the vertebrae in my daughter's back in order to straighten her spine was the only option for Mikayla.

I was filled with disbelief over what seemed to happen overnight as Mikayla had always been a healthy, positive, active girl. It wasn't poor posture that caused her curve, nor was it exercise, a mattress, cheap shoes or heavy backpacks. In fact, there is no discernable reason why scoliosis develops in some, although genetics is a widely accepted theory. I felt guilty that I had not noticed the bump when she was swimming, doing cartwheels or simply walking. Mikayla's surgeon took great care to make sure we understood that it is not uncommon for parents to miss the signs of curving.

Because scoliosis usually occurs during puberty, a time when kids become quite modest and private about their changing



Michele Colletti

bodies, most don't want parents fussing over them, especially as they dress. Still, motherguilt is a strong force.

The decision was made to correct Mikayla's curved spine by using a posterior approach. As I gained knowledge about her surgery, I drew strength by explaining the steps of the procedure to anyone who asked.

I knew I would need to remain strong throughout her 8-day hospital stay and the

expected yearlong post surgery healing process. What Mikayla needed most was for me to listen to her fears, hold her when she cried and keep her spirits up. I was able to give her comfort while keeping my own tears hidden in my heart.

On the day of Mikayla's surgery, I was somehow able to mask my fears with a forced smile and a cold hand clutched in hers through her pre-surgical prep. I dressed in scrubs and a mask and we held hands as she was wheeled into the operating room. Just before Mikayle fell into a deep drug induced sleep she asked if I was still with her. I told her I was the one holding her hand and she fell asleep. It was time for me to leave but Mikayla's grip was so tight the nurse had to pry one finger off at a time. No longer attached, I was escorted into the hallway and the operating room door closed. Only then did tears find their way to my eyes. It was the release I needed so desperately and for at least the next eight hours, I didn't have to be quite so brave.

Holly DiBella-McCarthy Mikayle's Mother

Minimally Invasive Correction Of Adult Degenerative Scoliosis Continued from page 6

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Editor's Note: A number of spinal deformity surgeons have begun to employ minimally invasive techniques when treating adults with degenerative scoliosis. Early results are promising especially with regard to rapidity of recovery after surgery, and less blood loss during surgery. The reader is cautioned that the techniques described in the article by Dr. Anand have only been used for a short time, so the long term outcomes are not known. No studies have been done directly comparing these techniques with traditional surgery, thus the benefits are not yet proven. If you are contemplating surgical correction of your scoliosis, talk with your doctor about whether these techniques might be appropriate as part of your care.

The Backwards "S" – Mikayla's Story

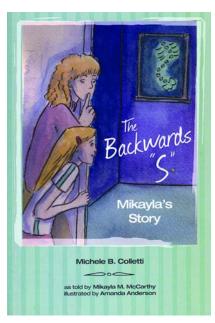
Dedicated to my neice and goddaughter, Mikayla. Thank you for being brave enough to recount your story, so that others facing this surgery will know they are not alone. Michele B. Colletti

The following is an excerpt from the book... Last year on a beautiful summer day at the beach in North Carolina, I watched the ocean waves as mom rubbed suntan lotion on my back. She spread it gently from side to side.

Suddenly, sounding a bit alarmed, Mom said, "I wonder what that bump is? Mikayla, you have a bump on your back. Does it hurt?" She asked if I could have hurt my back in gymnastics. I didn't know what she was talking about.

Mom called Dad over to feel my back. "Yup, that's a bump," he said. Then she called my brother and his friend over. "Mikayla, what did you do?" they all asked. I still had no idea what they were talking about.

Occassionally, we would bring "the bump" up again during vacation. Finally, Mom just said we shouldn't worry about it until we got home and went to see Dr. Sherman.



Just two months before, when I had seen Dr. Sherman for my yearly appointment, he checked my spine. I had stretched my arms over my head and bent over to touch my toes as he ran his finger down the middle of my back. This time, when Dr. Sherman's finger reached the small of my back, he said, "You have scoliosis." Mom and I just looked at each other. Dr. Sherman explained that it appeared to be "rapid onset scoliosis" and, depending on the degree of the curve, I would probably just have to wear a corrective brace. Dr. Sherman asked us to see a specialist named Dr. Thomson at The Children's Hospital in Hartford, Connecticut...

The Backwards "S" shares a young teenage girl's experience with scoliosis. Mikayla's story begins with the day her mom first found "the bump" and follows her ups and downs through doctor's visits, surgery and year-long recovery. Filled with honesty and humor, The Backwards "S" will help comfort other families facing idiopathic scoliosis surgery.

You may order this wonderful book through the Scoliosis Association, Inc. For order details please see page 18.

Childrens Orthopaedic Center Is pleased to announce that Dr. Paul Choi and Dr. Karen Myung

have joined **Dr. Vernon T. Tolo** and **Dr. David Skaggs** in the spine program at the Center!



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Vernon T. Tolo, MD Chief Emeritus, Childrens Orthopaedic Center at Childrens Hospital Los Angeles John C. Wilson, Jr., Professor of Orthopaedics Keck School of Medicine of USC **Specialization** Spinal deformity Cerebral palsy Skeletal dysplasia Hip disorders

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David Skaggs, MD Chief, Orthopaedic Surgery at Childrens Hospital Los Angeles Director, Scoliosis and Spinal Deformity Program Associate Professor of Clinical Orthopaedic Surgery Keck School of Medicine of USC Specialization

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Saving The Life Of Tatiana Cojocaru

By Janice T. Sacks, Vice Chair, Scoliosis Association, Inc.



n December, 2006 our organization, the Scoliosis Association, Inc. received an urgent distress call from Luis

Espinoza in Logan, Utah regarding a 23 year old girl from Moldova, between Romania and the Czech Republic. He had been traveling there and had been informed of this girl's plight by missionaries who were trying to help her.

Tatiana Cojocaru had had surgery in 2003 (age 20) and had a titanium rod inserted for her 135 degree thoracic curve and 85 degree lumbar compensatory curve. The curves were reduced to 85 degrees thoracic and 40 degrees lumbar respectively. However, the rod broke and it still remained inside her. The curves then progressed significantly, worse than before. A website was credited by Mr. Espinoza called "A Gift



Tatiana with Dr. Anthony Moreno.



Tatiana with mom, Julia, holding a mold of her spine before surgery.



This was the photo that captured us on Tatiana's website when she was in Moldova pleading for help.

for Tatiana" that showed x-rays of Tatiana's crooked 135 degree spinal curvature. It appealed to everyone who viewed it to help Tatiana in whatever way possible.

I proceeded to seek help immediately for this young woman, as her internal organs were being compressed. Obviously, she had very severe scoliosis that was progressing. Time was of the essence and my heart went out to this girl who was doomed to die if I didn't try all of our resources of the Scoliosis Association.

Mr. Espinoza had informed me that one of the medical groups in the Intermountain area, Utah was considering performing the surgeries for Tatiana pro bono but unfortunately, the medical center would not shoulder the cost of the surgeries and the rehabilitation.

I began to write online to Tatiana and as I thought, she was a warm-hearted, kind, loving and appreciative young woman who was so grateful that I had undertaken her cause and would try to find a surgeon to perform the surgery for her twisted body. She loved to communicate through the internet and also by telephone. When I did call her, she was so excited and relieved to hear



Before surgery x-ray.



After surgery x-ray.



Tatiana with Debbie Ordes (left) and mom.

my voice and talk with me. She had a sunny personality and told me about her family and her wonderful mother. I resolved further to try every avenue I could to help this sweet, beautiful girl who wanted so much to be pain free and normal.

I next tried New York but was sadly informed of the enormous expense such surgeries would cost in the metropolitan area, and we were rebuffed at every medical center that we attempted. The total expenses would be around \$250,000-\$300,000. Tatiana's x-rays, pulmonary studies, and other data were furnished to each medical center, but to no avail.

At this point, Tatiana's case was passed around the world and not accepted by hospitals and/or doctors in France, Russia, Ukraine, California, Utah, Texas, Georgia, New York, Boston and Missouri.

During this time she was informed of the complications and risks involved in the impending surgeries, but she still was determined to proceed with the surgery. Her breathing was becoming more labored, and her 135 degree curvature was causing

Continued on page 11



Tatiana was able to walk 1.5 miles at the Walk-A-Thon weeks after surgery. Here she is featured with her mom Julia and Dr. Geoffrey Cronen.

Saving The Life Of Tatiana Cojocaru Continued from page 10



Left to right) Brad, Dr. Anthony Moreno, Chris Quinn (back), Dr. Geoffrey Cronen (red cap), and Philippe Olivero with Tatiana's mom, Julia, immediately following Tatiana's operation.

profound pain and twisting of the ribs.

It was at the SRS meeting in Salt Lake City in 2008, that we met with Dr. Anthony Moreno from Safety Harbor, Florida who agreed to help us with his team of surgeons, if his hospital would agree to shoulder the expenses of the operating room and the rehabilitation. Our prayers were answered when the hospital consented to help Tatiana. Dr. Moreno invited Dr. Geoffrey Cronen from Tampa, Florida, and Dr. Samuel Joseph to form the team to perform the two complicated surgeries in January 2009. Also, he invited Dr. Lawrence Lenke to assist with his expertise to correct her broken rod and reduce her tremendous spinal curvature.

Fortunately, we had a very competent Palm Harbor chapter president, Debra Ordes to assist us in coordinating details, finding housing for Tatiana and her mother, Julia. Because

her mother spoke no English, an interpreter was necessary. Debbie arranged a myriad of details, including flights, visa confirmation, church assistance, asking for volunteers from her chapter, etc. as well as driving Tatiana and Julia to doctors' appointments, to take x-rays and giving blood. Debbie was a lifesaver, and gave of herself unselfishly. She shed many tears and felt the weight of Tatiana's troubles and pain, but Debbie was determined to see it all resolved. She is a remarkable person, who amid all of the tur-



moil arranged the Palm Harbor 4th Annual Walk-A-Thon to benefit scoliosis research and to honor the doctors, Dr. Anthony Moreno, Dr. Geoffrey Cronen, and Dr. Samuel Joseph. Naturally, Tatiana was there to receive everyone's blessings and to give her thanks for all the help and efforts of the volunteers, Debbie Ordes, the church members and volunteers of the Church of Jesus Christ

Continued on page 12



The Spine Center

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First row: Roger Cornwall, MD; Viral Jain, MD; Twee Do, MD; Steven Agabegi, MD and Sandy Singleton, MBA Second row: Eric Wall, MD (Division Director); Alvin Crawford, MD; Charles Mehlman, DO, MPH; Junichi Tamai, MD, and Shital Parikh, MD



www.cincinnatichildrens.org

Saving The Life Of Tatiana Cojocaru Continued from page 11





Tatiana in the hospital during rehabilitation.

of Latter Day Saints, the Scoliosis Association, Inc., and Medtronic who supplied the spinal instrumentation and numerous other people who played a significant role in Tatiana's surgeries and recovery.

Tatiana was given a new life and a brighter future. We felt an immense satisfaction in helping to save her life. It demanded much time and effort on our part and that of Debbie Ordes, Palm Harbor chapter president and executive vice president of the Scoliosis Association, Inc. Tatiana returned home to Moldova in April 2009, able to breathe freely and fulfill her dream of attending school in September, something



Tatiana with mom and her sisters after returning home from her journey.

she was not able to do for 11 years. She has posted a video on www.youtube.com "My Miracle Journey" for those of you who would like to view photos of her journey.

A Note from Tatiana: I want to thank everybody who volunteered in this project to save my life. I am profoundly grateful for the effort and work done in order for me to have these surgeries. God bless you for the "Gift of Life." Sincerely, Tatiana Cojocaru



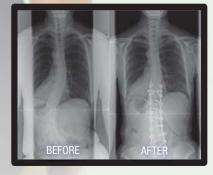
Tatiana after surgery prior to leaving the US.

"My scoliosis wasn't visible, so even though I didn't look like I had a problem, I hurt."

Nancy Swift - Dallas, Texas

Depressing. Painful. Exhausting. Just some of the words that people with scoliosis live with everyday. Scoliosis, which affects over 12 million people worldwide, can lead to progressive deformity in the spine as well as incapacitating pain. Too often people are told that there is nowhere else to turn ... but there is.

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Curvy Girls





verything is spinning. Two thousand kids are shouting but I can't hear them. A tiara is placed on my head and a bouquet of red roses in my hands. "Breathe, Leah. Breathe!" says Nick Cannon, the Chairman of the Teen

Nick Television Network, as he wraps his arm around my shoulders and puts a microphone in front of my face.

I probably wouldn't believe this memory was real if there hadn't been a film crew to record every moment.

Then he announced, "I'm here to give back to someone who's been giving back her entire life."

Tears start streaming down my face; I can't believe he's talking about me!

I vaguely recall being told I had scoliosis, a disease that left me with two titanium rods and 22 screws in my back. However, it was that

fateful doctor's visit six years ago that changed my life. I was finishing my first year of middle school when the curve in my spine seemed to consume my world. I wasn't happy. My body had betrayed me and I didn't feel normal. But who would be happy having to wear a back brace for 22 hours a day, seven days a week for two and a half years?

I felt completely helpless because I had no voice as to what was going on in my life. I did what the doctor and my mother said

was best. I was shoved into a hard plastic brace that encased my entire torso. This *thing* was half an inch thick with three bulky Velcro straps used to yank it shut. The contraption prevented me from fitting in. The seemingly simple task of picking out an outfit at the mall became an overwhelming tear-filled experience. I was surrounded by piles of clothes, none of which fit my awkward, plastic-shaped torso. This was no longer my body, but a body the brace formed.

I wished there were other girls I could talk with who also had to wear a brace so I could find out how they were dealing with this torture. Why wasn't there an outlet? Where could kids like me express their frustration and pain? After weeks of reflection, I decided to channel my energy into creating an environment for girls like me who could comfortably display their braces without being judged. I would create my own support group. I needed to give voice to those who felt as I did, alone and impassive. The Curvy Girls Scoliosis Support Group of Long Island was born the month of my thirteenth birthday.

Five girls attended the first meeting. We talked about school, clothes, friends, and other problems that related to our braces. I closed the group that day with a simple yet poignant message: "We all have something to deal with that will shape who we are to become; this is *our* something." This is a message that I try to live by everyday.

Since that first meeting, we've held our meetings monthly for the past 3½ years where typically ten to fifteen girls attend. The mission of my group is to help girls not feel the loneliness I felt and to be able to learn from each other. I want them to have access to the support that I lacked. I started the group because it felt right to me. It was a simple action and I never realized how much I would be able to affect these girls. *Continued on page 15*



Scoliosis Association, Inc. Opens A New Office In Tampa Bay, Florida Area

By Debbie Ordes,

Executive Vice President, Scoliosis Association, Inc., President, Scoliosis Association of Palm Harbor Chapter



he Scoliosis Association, Inc. will have a second national office in the Tampa Bay area of Florida. Orthopaedic Spine Surgeon, Anthony P. Moreno, MD, has generously donated our new office, which will be managed by

Debra Ordes, our Executive Vice President and President of our Palm Harbor Chapter.

Located on the premises of Moreno Spine and Scoliosis in Safety Harbor, the office, designed by Sandra Moreno, displays a modern image and cozy atmosphere and will serve the Tampa Bay community,



as well as offer national and international support.

Our new office address is: 1800 Mease Drive, Safety Harbor, Florida 34695 and the telephone is (727) SCOLI-12 or (727) 726-5412 Fax (727) 726-7226.



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"Tree Of Hope" "One Person Can Make A Difference, Together We Can Change A Life..."



he Scoliosis Association, Inc. is proud to introduce a commemorative rosewood sculpture which will adorn the

walls of our national office in Safety Harbor, Florida. This beautiful wall hanging, entitled "Tree Of Hope" is a vibrant symbol of hope and strength and provides us with a fitting way to honor, recognize or memorialize a Loved One. With each leaf that is added to the tree, it will continue to grow and your generosity will help us pursue our mission to serve families in the U.S. and around the world.

Memorialize a Loved One or Special Occasion by purchasing a permanent leaf on our "Tree Of Hope". Each leaf may be engraved with a message, as well as the name of the person, group, chapter or business you are honoring. Our leaves are available in Bronze, Silver and Gold with



denominations of \$100, \$250 and \$500, respectively. Pledges of \$500 can be paid in four installments.

For more information on how to purchase a leaf or make your pledge in installments, call (727) SCOLI-12 or (727) 726-5412 or complete the form on page 15 and send your donation via check made payable to: Scoliosis Association, Inc., 1800 Mease Drive, Safety Harbor, Florida 34695.



Special thanks to David Grasso, CRNA who generously donated the "Tree Of Hope" rosewood sculpture. David is a volunteer for the Palm Harbor Chapter of the Scoliosis Association, Inc.

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Curvy Girls Continued from page 13

What began as a self-help group for local teens has developed into a humanistic mission that has touched the lives of teenagers across the country. As a result of the publicity following the HALO- Helping and Leading Others- Award, kids of all ages have written to me about the pain they have experienced in not always fitting the mold of the majority of their peers. I look forward to continuing to make a difference by creating teen-run self-help scoliosis groups, wherever my path leads me.

My scoliosis has been a journey and a struggle, with life lessons learned. The struggles could fill a novel and the tears could hydrate a desert, but the lessons learned show how there really is a light at the end of the darkest tunnel. Looking back, there's no doubt in my mind the brace helped me become the person I am today. I have learned to embrace standing out, as I unwittingly became comfortable with my individuality. I have developed confidence to speak up even if my ideas may not be readily accepted. My voice once stifled by my brace now reverberates with a message of hope and perseverance.

"Speech! Speech! Speech!" The 2,000+ people in the crowd roared. I grasped the microphone in my shaking hand to make a speech I never would have imagined making. I looked over to the girls, "I want to thank them, they have become such a huge part of my life and I have seen so many of them grow in so many different ways. As much as they come up to me saying thank you after every meeting, what they don't understand is how grateful I am to them."

At the most recent meeting with my

group, the girls gave me a small present as a thank you. The necklace has hung around my neck everyday since; when the light hits it just right, it reveals the secret message written on it ---

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Ask The Doctor Your questions answered by the professionals.



he Association submits questions from readers regarding scoliosis and relat-

spinal problems to many doctors. Such questions can be sent to: Ask The Doctor, c/o The Scoliosis Association, Inc., P.O. Box 811705, Boca Raton, FL 33481-1705.

Q:"I am a 43 year old woman who has never had back problems until the past year. My sister 46 does have scoliosis which has never been treated. I was getting pains in my lower back and I went to my primary doctor who referred me to an orthopaedic specialist. He examined me, took x-rays, and said that I had "de novo scoliosis" I was so overwhelmed that I hardly heard his following words."You have a 45 degree curve in your lower back. You have severe scoliosis and will need surgery to correct it." What is "denovo scoliosis"? What causes it? What are the symptoms? What are the complications of surgery? I need information. Thank you so much for your time.

A: I am sorry to learn that your back is giving you pain. Regarding the scoliosis you have, it is naturally difficult to judge without any x-rays. De novo scoliosis happens in individuals who did not have any scoliosis before, in most cases they occur in the late fifties, early sixties. In most cases de novo scoliosis consists of a moderate lumbar curve (therefore located in the low back) measuring less than 30 degrees, and made of a few vertebrae (3-4 in average). De novo scoliosis is believed to be related to assymetric disc degeneration and ongoing "wear and tear" in the lumbar spine.

In most cases the treatment for de novo scoliosis is conservative, and should not be based on pure angular values. Treatment will consist of low impact aerobic exercises, physiotherapy and non-steroid anti-inflammatories. In rare occasion, when de novo scoliosis is associated with nerve compression (or spinal stenosis) treatment like epidural steroid injections or even surgery (fusion with nerve decompression) must be performed.

Late degenerescence of an idiopathic scoliosis or below the curve can also be encountered. In such cases the curve is usually of higher magnitude than 30 degrees, the number of vertebrae involved in the curve is higher. As you have a positive family history of scoliosis in the family, your scoliosis may be of this type.

At any rate, as opposed to the adolescent where surgery is contemplated in curves that are progressive and more than 40-45 degrees, in the adult surgery is only indicated if conservative treatment has failed, or if the pain is too debilating. In some cases observation of the curve over a period of several years will dictate the treatment decision.

Surgical treatment of either denove scoliosis or adult idiopathic scoliosis is a decision that requires thorough understanding of the surgery and possible complications. Basic



Frank J. Schwab, MD



Nicola Hawkinson, MA, NP

Caring For Children And Adults With Complex Spinal Deformity

Dr. Frank Schwab is the chief of the Spinal Deformity Service at NYU Hospital For Joint Diseases and Clinical Professor at NYU School of Medicine. He has dedicated his career to the research and understanding of complex spinal deformities. He specializes in the surgical treatment of complicated spinal deformities and revision spine surgery. Nicola Hawkinson, NP collaborates with Dr. Schwab in the care of these complex patients, ensuring patient education and advocacy. <u>Office Locations</u> <u>Manhattan</u> 303 2nd Avenue, Suite 19, New York, NY <u>Brooklyn</u>

263 7th Avenue, Suite 2B, Brooklyn, New York 1-212-460-0180 • www.orthospine.com principles of surgery is to realign the spine with rods in the back and decompress the neural elements where they are compressed. A fusion must also be achieved so the bones will eventually "stick together."

Complications depend on the extent of the surgery proposed and of "how healthy you are." It is therefore always recommended to stop smoking, and have any other medical condition like diabetes, high blood pressure stabilized. In some cases a simple procedure like a focal decompression of the nerves associated with a limited fusion is all that is required. Complications are in such cases very low. In other cases where a complete spinal reconstruction involve anterior and posterior approach or a long instrumentation, with possible osteotomies of the spine, complications can range up to 40-50%. These figures may make you think twice before undergoing such reconstructions although most of them are manageable and do not affect the final result.

I would therefore advise you to talk to other patients who have scoliosis such as yours and to other members of the National Scoliosis Association, Inc.

> Vincent Arlet M.D. Warren G. Stamp Professor of Orthopaedic Surgery Professor of Neurosurgery Scoliosis and spine Reconstructive Surgery Department of Orthopaedic Surgery University of Virginia

A: Technically, "de novo" scoliosis implies curvature of the spine caused by lumbar degeneration in a patient without provious history of adolescent idiopathic scoliosis. If a patient has any component of multi level rotation in the curve, the presumption though is that a previously unrecognized idiopathic curve existed and the curve degenerated secondarily. This distinction rarely has any implication on treatment though because a curve measuring 45 degrees in a 43 year old should be treated based on the indications of pain or neurologic deficit. Progression as a primary indication for scoliosis surgery in an adult (and for an adolescent in my opinion) should be reserved for patients with curves greater than 50 degrees.

> Robert S. Pashman, M.D. Scoliosis and Spinal Deformity Surgery Spine Center Cedars Sinai Medical Center Los Angeles, CA

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Chapter Bulletin Board

Scoliosis Association of Orange County

Norm and Judi Lipin (949) 830-6068 We are in the planning stages for our meetings. Please contact Judi Lipin by email judithlipin@aol.com or by phone, (949) 830-6068 for further information. Our meetings will also be posted on the Upcoming Events page of our national website.

Scoliosis Association of Palm Harbor Debra Ordes (727) 772-0314 E-mail: palmharborscoli@aol.com Meets the second Friday of each month at the North Pinellas Branch YMCA Conference Room 7:00 PM-8:30 PM Call for information.

Scoliosis Association of Long Island JoEllen Hegmann (516) 935-4534 E-mail: scolioli@optonline.net March 18 May 20 7:30 PM - North Shore LIJ Medical Center Conference Room 1, Lower Level, New Teaching Center, New Hyde Park, NY

Scoliosis Association of South Florida Janice T. Sacks, (561) 368-7666 E-mail: jansac2@aol.com Health Fair including the Scoliosis Association of South Florida Friday, March 5 1:30 PM-3:30 PM South County Civic Center 16000 Jog Road, Delray Beach, Florida (561) 495-9813

Calendar of Events

Scoliosis Association, Inc. Opens A Second Office In The Tampa Bay, Florida Area

Our new office address is: 1800 Mease Drive, Safety Harbor, Florida 34695 and the telephone is (727) SCOLI-12 or (727) 726-5412 Fax (727) 726-7226.

Please see the story on page 13.

Scoliosis Association of Long Island

Fifth Annual Walk For Scoliosis Awareness Sweep Across America For Scoliosis

Saturday - May 8, 2010

Jones Beach State Park Parking Field 5 – 9:30AM Please contact JoEllen Hegmann, Scoliosis Association of Long Island for registration information. Email: scolioli@optonline.net Phone: 516-935-4534 Scoliosis Association of Palm Harbor

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