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HAPPENINGS

New Website Launched for WWW.SCOLIOSIS.ORG !

- Improved Product Catalog with full functioning secureweb Estore.
- Enhanced Physician Listing
- New Dynamic Forum & Calendar of Events

Postural Screening Training

- March 13th - 9am-12pm in Joliet, Illinois
- Comprehensive hands on session
- CEU's available

Patient Conferences - April 5th in Boston

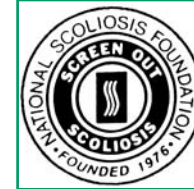
A First Time Ever Meet & Greet ~ Listen to, and Talk with noted authors: Dr Michael Neuwirth, *The Scoliosis Sourcebook*, Nancy Schommer, *Stopping Scoliosis*, Mary Mahony, *What Can I Give You*, "S" is for Scoliosis, *Stand Tall Harry*, Michelle Spray, *Growing Up with Scoliosis*, along with scoliosis artist Laura Ferguson, and gospel singer Sannette Semeion.

Visit our website at WWW.SCOLIOSIS.ORG , or call 800-NSF-MYBACK for more details.

"Stopping Scoliosis" the Gift That Keeps on Giving



Thanks to the hard work of Nancy Schommer, author of the well-known book, *Stopping Scoliosis*, and the generosity of Laura Gowen, founder & President Emeritus of the NSF, patient education throughout the world has become more accessible. At the Scoliosis Research Society (SRS) meeting in Seattle, associate member Bettye Wright, PA, RN helped these two women arrange to provide more than 400 orthopedic spine specialists with free copies of the newly published third edition of Ms. Schommer's book. As an extra bonus, the author was available to personally autograph the doctors' copies as well. In the words of Michael Mendelow, MD at the Children's Hospital of Michigan, *Stopping Scoliosis* is an efficient and effective tool for patient education. Laura Gowen explained, "I know how important this book was to all of Dr. Howard King's patients who received a copy. I hope this gift encourages every SRS member to make it available to their patients as well."



The Spinal Connection

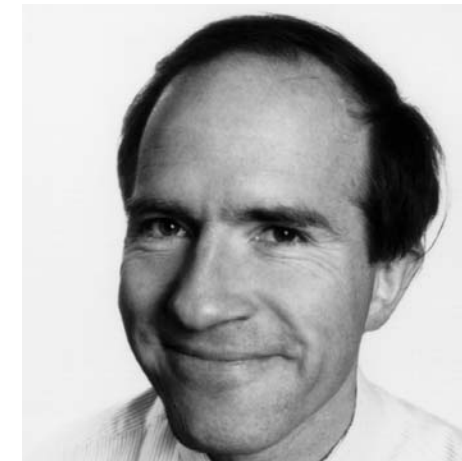
WINTER 2003

NATIONAL SCOLIOSIS FOUNDATION

VOL.19, NO. 1

"Twenty Seven Years of Service to the Scoliosis Community"

Finding the Cause- Where are we in 2003? A call for action



Paul Sponseller MD, Baltimore
Chairman, Etiology Committee,
Scoliosis Research Society

It is a mystery why the spine of an otherwise healthy person would develop a strange twist- one that may keep worsening at an alarming pace. This has interested physicians and biologists for several generations. Many have spent their careers in research of the **etiology**-the Greek word meaning study of cause. They have done biopsies of muscle, bone and disc; animal studies were another tool. Yet the basic truth is still this: *we do not know the cause of most human spinal deformities.*

We would certainly like to have a better treatment for young children than the brace; a better corrective

method than surgery. Understanding the cause is the first step in finding a cure. The National Scoliosis Foundation has been instrumental in efforts to find it. The funding and encouragement provided by the Foundation has been invaluable. Current work on etiology involves tracking down *promising leads* and using new *genetic* techniques to take a fresh look.

Promising leads involve hormones and platelets. It has been shown that removing the pineal gland in the brain of some animals produces scoliosis. Understanding the hormones that this gland produces may shed an important light on the cause of scoliosis. Melatonin is one such product; there may be others. Another clue to the problem may come from platelets. These are small particles found in blood which help to produce clotting. They have a contracting protein called calmodulin which functions like a muscle and helps pull clots together. This protein shows promise of predicting which scoliosis may get worse and which may not. Like other clues, it may lead us closer to the cause of the curves. The problem with animal models and other clues is that they may not necessarily tell what is really happening in people. Some experts feel that the cause of scoliosis may rest with genes which are involved with regulating body order and symmetry throughout life.

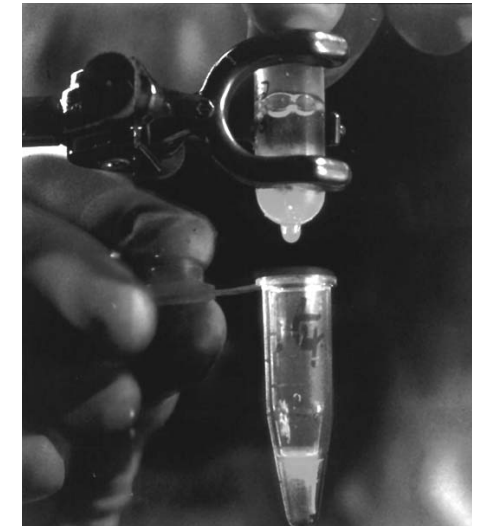


Figure 1. Blood is used to isolate and analyze DNA, which should eventually reveal the cause for scoliosis.

Genetic research has the promise of finding the basic cause of scoliosis. It has helped show the causes of many conditions, such as Muscular dystrophy and various tumors. In scoliosis, researchers first started by looking for abnormalities in several "candidate genes": genes which might logically be thought to cause scoliosis. These involved several dozen basic building blocks of bone, cartilage, and ligament. Blood samples were collected from thousands of persons with scoliosis and their families. From these, DNA was saved and analyzed (figure 1). These did not show any abnormalities. The next step involved screening the entire genome- the entire length of the human DNA. Researchers were looking for areas which were commonly linked to scoliosis- in other words, which were seen more commonly in

Continued on page 2

Finding the Cause
...Continued from page 1

persons with scoliosis than those without (figure 2). This required several thousand blood samples, powerful lab tools and a good command of statistics. Many members of the National Scoliosis Foundation generously participated in this collection. An example of a family with an extensive amount of scoliosis is shown in figure--- 3. This work is still going on in labs such as Nancy Miller's in Baltimore, Carol Wise's in Dallas, and Jose Morcuende's in Iowa City. Separate work on congenital scoliosis is being carried out in Philadelphia and Toronto. Interest has risen since linkage to at least four different chromosomes has been found.

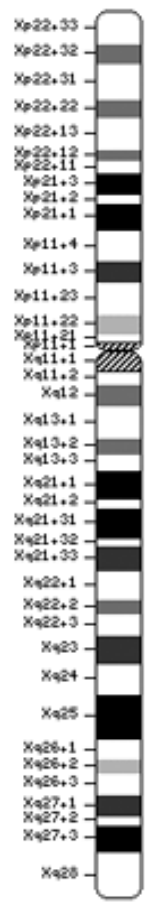


Figure 2. A representation of the X chromosome, with known markers indicated as bands.

In some families, abnormalities in the X-chromosome were found. This may explain some of the gender differences seen in scoliosis. Much more work needs to be done. These findings need to be confirmed, and the genes involved need to be investigated. What we know now is some regions of chromosomes which may hold the genes. This is like knowing the state and city of a friend but not the street and house number. When we find the gene(s), we need to find what they do. Is there more than one gene for scoliosis? How does they cause scoliosis? How can we (safely) intervene? It is also likely that other genes in each person

may interact with the gene causing scoliosis to influence the severity of the curve, and explain why some people develop severe curves and others do not. The road ahead is farther than that already traveled.

Understanding of the etiology of **congenital scoliosis**, or misshapen vertebrae, has advanced through animal models which have been discovered to have defects in certain proteins (the notch pathway). These proteins help to "sculpt" the spine into shape in the early stages of the embryo.

What does the future hold? Until the etiology is found, we can only guess how medicine might intervene with new therapies. It seems quite likely that we will be able to predict which patients' scoliosis will get worse and which will not. Thus we may be able to save some people from the need to wear a brace unnecessarily. We may be able to predict whose scoliosis will rapidly worsen and when, and therefore use more targeted bracing. We may even be able to give medication which slows the worsening and eliminates the need for a brace altogether. A real dream would be a way to make scoliosis better nonsurgically- to reverse the abnormal growth. This may be a long way off. Although there is no such strategy now, a better understanding of the etiology of scoliosis may awaken physicians to such possibilities. It is also likely that the understanding of scoliosis will give us better knowledge of other aspects of the human skeleton.

Research into the etiology of scoliosis is expensive. The money provided by the National Scoliosis Foundation and others is a good start but is only a "seed" to get things going.

It will require millions of dollars to reach the stage where findings can be put to use helping people. Support by the National Institutes of Health (NIH) will be crucial to this process. So far there has been virtually NO NIH funding of research into the etiology of spinal deformity. The NIH realizes that it can't fund everything, so it tries to put its money behind projects which will do the greatest good. Cancer and heart disease are obvious, worthy targets. Scoliosis is more of a silent disease. It is rarely fatal. People with scoliosis tend to deal with it by themselves,

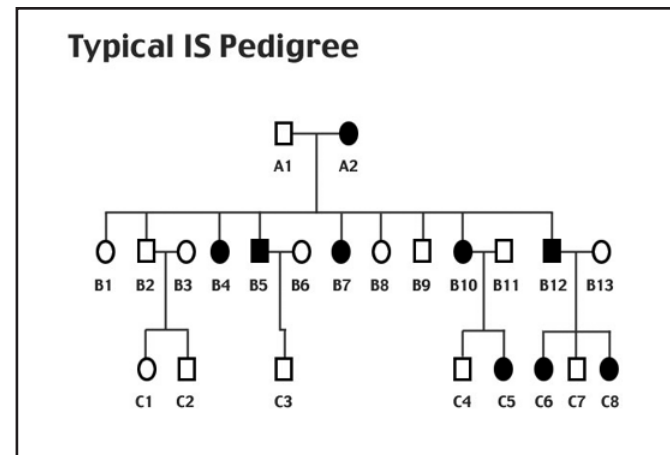


Figure 3. The genetic map of a family with extensive scoliosis. People with scoliosis are shaded. Females are represented by circles, males by squares.

and its impact is not widely felt outside the family. Yet it affects 2-10 people out of every thousand, to some degree. Only by making known the burden of this disease will funding be made available for research into scoliosis by the NIH. Scientists have salaries to pay, equipment to buy... money is needed!!! People with scoliosis are best able to make this known. With the leadership of the National Scoliosis Foundation, people with scoliosis can make their wishes for etiology research. For this reason, the Foundation is launching a grass-roots campaign to highlight the need for funding of etiology research. The voice of every person needs to be heard.

Laura Ferguson,
Continued from page 3

performed by Dr. John Cobb, which was followed by a year in a plaster "turnbuckle" body cast. I also was privileged to be given access to the Anatomy Lab at the Weill Medical College of Cornell University, where I have spent many hours drawing from the skeletons.

At first I used my own x-rays as the basis for my drawings. Later I consulted with several orthopaedic surgeons and radiologists for information and help in having medical images made specifically for the purpose of making art. Most recently, I was able to have a 3D spiral CT scan, an exciting new technology which allows me to view my skeleton from any angle, rotating and tilting it to match whatever movement or pose I'm interested in drawing.

Anatomy is usually illustrated in straightforward views: anterior, posterior

Vertebral Body Stapling,
Continued from page 6

the brace is removed and there are no restrictions on activity.

Q: Would you give us some specific details of the outcomes on your patients?

A: The follow-up on many of these patients is short, but so far most curves have been maintained or improved. The patients whose curves have progressed are in those with double curves where only one curve had the stapling. Some patients now are recommended to have both curves stapled. The curves of the first patient, who had stapling over 24 months ago, actually improved. He was a 12-year-old boy whose curve had progressed from 20° to 38° despite bracing. After stapling and 11 inches of growth, the curve has improved from 38° to 25°. Three additional young patients (each 5 years old) with severe curves have had staples inserted. These patients' curves were progressing despite brace treat-



Laura Ferguson, Crouching Figure with Visible Skeleton, ©2001

and lateral (profile). Showing the skeleton in more dynamic poses provides much more information about the three-dimensionality of the spinal curvature. It also helps viewers relate the skeletal interior of the body to its more familiar exterior look.

Scoliosis is a complicated rotational deformity, and the process of conceptu-

ment. Two of these patients with very severe curves required a posterior growing rod system in addition to the stapling. Their rods will be extended every six months until their spine has finished growing.

Q: At the end of bone maturation, will you then remove the staples?

A: It was originally anticipated that the staples would be removed when bone growth had been completed. Since none of the patients have pain and none of the staples have become dislodged or broken, it is anticipated now that they will not need to be removed.

Q: What are the possible complications with this surgery and are there any potential long-term complications that you worry about?

A: Possible complications are the same

alizing it three-dimensionally has been challenging but rewarding. Creating images of my body that are anatomically accurate, but also personal, has felt empowering, as if I were regaining a sense of ownership of my own body that had somehow been lost when my experience was "medicalized". The more I understood and internalized the configurations of my unusual body, the more graceful and comfortable I felt in my skin and the more manageable my pain and disability became.

In my drawings I don't want to simply show how the spinal deformity looks; I also hope to convey how it feels to be inhabiting this unusual body. My skeletal asymmetry creates the need for a subtle effort of balancing, and a conscious awareness of alignment and of bodily processes like walking, moving, and breathing. My drawings translate this kinesthetic awareness, this "consciousness of the body," into visual form.

as for any patient undergoing anterior spinal surgery or receiving general anesthesia. Fortunately, the complication rate is extremely low and is minimized with the vertebral body stapling procedure because of the minimally invasive insertion technique. The long-term potential complications of the procedure would include possible premature degeneration to the thoracic disks. I do not feel this will happen because of the micromotion that occurs around the staple, which was seen on animal studies and with clinical observation.

Q: Where can patients go for this treatment?

A: Currently, all of the procedures have been done at Shriners Hospital in Philadelphia; however, other surgeons have been trained and are starting to do the procedure, including Dr. John Lubicky at the Shriners Hospital in Chicago and Dr. Keith Bridwell and Dr. Lawrence Lenke at Shriners Hospital in St. Louis.

MEDICAL UPDATE

by Nancy Schommer, Author of *Stopping Scoliosis*

New Experimental Surgical Treatment for Scoliosis: Vertebral Body Stapling

We recently learned of a new experimental alternative to bracing or spinal fusion for treatment of progressive scoliosis, known as vertebral body stapling. To find out more about this treatment, we contacted Randal R. Betz, MD, Shriners Hospitals for Children, Philadelphia, a scoliosis specialist who is investigating this method of fusionless stabilization or correction of spine deformity.

Q: Dr. Betz, tell us about the vertebral stapling technique.

A: For patients with progressive scoliosis (less than 50°) who are still growing (girls up to age 14 and boys up to age 16), vertebral body stapling of the convex (outer) side of the anterior spine may keep the curve from progressing. With the convex growth plates held in check, continued development of the concave (inner) growth plates should stabilize the progression and may allow some slight correction of deformity as the child grows.

Q: What effect does the stapling have on the growth plates?

A: Based on the preclinical studies in animals, the growth plates showed temporary cessation of growth but no permanent adverse effects.

Q: Who is this procedure appropriate for?

A: The procedure is most appropriate for those patients who are candidates for a brace (with curves between 20 and 40°, still have growth potential and therefore at risk for curve progression). There are some patients with curves in the 40 to 50° range that are very flexible and have minimal cosmetic deformity in the trunk. These patients potentially could be candidates, although results of the clinical trials need to be completed before this will be known for sure.

Q: What is the significance of using the vertebral stapling as an alternative to bracing or spinal fusion?

A: By not having to fuse the spine to correct the curvature, movement and flexibility can be maintained, allowing for preserved motion and less chance for back pain in adulthood. One advantage of vertebral stapling is that should the stapling not succeed in arresting the curve progression, the patient is still able to have a spinal fusion with no adverse effects from having had the stapling.

Q: What is the history of vertebral stapling and how has it changed for use today?

A: This concept has been used in children with bowlegs and knock-knees for



Randal R. Betz, MD, Shriners Hospitals for Children, Philadelphia

some time. Using staples in the spine for stabilization of scoliosis was actually conceived 20 years ago but failed because the staples would dislodge and fall into the chest. Improvements in technology have led to development of a staple made of a memory-shaped alloy (nickel and titanium). The staple is shaped like a clamp at room temperature. When placed in an ice bath, the staple can be bent straight for insertion. After inserting the staple into the spine, upon heating to body temperature the staple returns to its original clamp shape, which prevents it from dislodging. This technologic advancement has allowed physicians to reconsider its use for correction of spine deformity.

Q: What has been your experience with the stapling treatment so far?

A: At the Philadelphia Hospital, staples have been used in 22 patients with juvenile or adolescent idiopathic scoliosis (AIS) who didn't want to wear a brace. Most patients had the staples inserted through a thoracoscopic approach. The other patients had mini-incisions because the curve was in the lumbar spine instead of in the chest area. The patients are braced for one month after surgery to stabilize the staples, but then

Continued on page 7

You Can Change the Course of Scoliosis History!

Join NSF Campaign to Fund the Cause

by Joe O'Brien

Scoliosis has been twisting, turning, and curving the spines of our young children for far too long. Down through the ages dedicated physicians such as Hippocrates, Galen, Andry, Hibbs, Blount, and Harrington have attempted to understand the reasons behind the onset and progression of this sinister spinal deformity in the hopes of providing better treatment for the people afflicted with it. Now with some new tools and methods we have an opportunity better than any other time in history to discover the cause, or causes, of scoliosis and truly focus our medical and scientific community towards finding the Cause, Prevention and ultimately the Cure for this spinal disorder. But it will not happen unless all of us get involved.

NIH has spent Virtually \$0 for Scoliosis Research!

Tell them why this must change.

Are you a parent burdened by what you see your child going through with scoliosis and confused about what course of action is best for him or her? Are you a teenager upset about being wrapped in plastic, and not knowing when, or if, the treatment will work? Are you an active woman limited by the curve in your back, and either frustrated that there is nothing to help you, or frightened by being told what may lie ahead? Or, are you someone tired of living in pain, and feeling victimized by the surgical, or non-surgical treatments that failed to help you? No matter what situation you may be in, we often find that the burden of living with scoliosis is in large part due to the lack of understanding what causes it. Knowing the cause(s) of this spinal

deformity is essential to the development of effective, minimally invasive, and less expensive treatment or prevention options. We must get The National Institute for Health (NIH) to realize that directing its funding towards etiology research for scoliosis will help millions of people get the answers and care they deserve. But you need to call, email, and or write to them to get their attention and help them realize how important this is.

Communicate to the NIH Director today!

Please don't delay.

In his lead article Dr. Sponseller, Chair of the Etiology Committee for the Scoliosis Research Society, presents us with the rationale and need for etiology research, and rings out a "Call to Action". We ask everyone within the NSF scoliosis community to heed this call, and begin this campaign immediately. There is no time to waste. We have enclosed a letter to the NIH Director, which you can mail. We also ask you to send a copy of this letter to your Representative or Senator, as well as to us here at NSF so we can compile them into one booklet for future hearings. Please call us if you need help with this effort. For those of you with access to our website WWW.SCOLIOSIS.ORG we have added a "Call to Action" section with a sample letter and links to the various people and places where your voices need to be heard. We have a chance to begin to straighten things out, so please join the National Scoliosis Foundation in this Etiology Research Campaign. A collaborative effort between physicians and patients is a mighty strong voice. Together We Can Make A Difference!

Laura Ferguson, an Artist with Scoliosis, Uses Her Own Body for Inspiration

My project began almost twenty years ago, when I began to experience physical disability related to my scoliosis, and felt the need to understand what was happening to my body. I underwent spinal fusion surgery at age thirteen, and had been fine for many years afterward.



Because I am an artist and tend to think in visual terms, I needed to be able to picture what my scoliotic spine looked like. As I began to learn about anatomy, I realized that the imagery was quite visually compelling, and could be interesting on many levels, from the literal to the metaphorical. I decided to undertake "an artistic inquiry into scoliosis." I would use my artist's duality: living through the experience and at the same time observing it and turning it into art. Scoliosis is a flawed model of the beautifully designed human musculoskeletal system, but I wanted to portray it as having its own more complex beauty, one that viewed deformity as "differentness", and "differentness" as individuality.

I studied anatomy with Irene Dowd, a noted teacher and trainer of dancers at the Juilliard School, who helped me to understand the neuromuscular dynamics of the body in motion. I retrieved and studied the records of my surgery, a fusion of the T5-12 vertebrae, with grafted bone,

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Ann Landers, 1918-2002



Renowned advice columnist, helped to educate the public about early detection

In March of 1983, syndicated advice columnist, Ann Landers, ran a letter from Ken Love. That letter began, "I have scoliosis, a curvature of the spine that was not detected and treated early enough. So, at age 34, I have a spine with 14 fused vertebrae held together by two long steel rods, clamps, nuts, and bolts. I am unable to lift my eight month old son." At the end of the letter Ken identified himself as the Vice President of the National Scoliosis Foundation (NSF) and invited readers to write for a free brochure. Over 10,000 people responded from all over the world!

Six years later, former President and founder of the NSF, Laura Gowen,

asked the advice columnist to repeat this unmatched opportunity to get the word out to the public by reprinting Ken's letter. In her letter to Ann Landers, Laura wrote, "close to half of the letters received from your column came from adults who were suffering because they were not screened as growing children. What a motivation to carry on our work so that the next generation will not suffer such pain and deformity! How exhilarating to know that we have the power, through education, to virtually eliminate major scoliosis curvatures."

In January of 1990, Ann Landers decided to rerun Ken Love's letter, overcoming her editor's concerns of printing medically-oriented columns. A worldwide readership of 90 million people saw the headline in Ann Landers' column: "Early detection saves scoliosis patients pain." The two phone lines into the Foundation were once again jammed with calls. The NSF received over 7,000 additional requests for information from that printing.

Sadly, Ann Landers passed away June 23rd. Her columns helped to increase public awareness of scoliosis and thereby advanced the mission of the NSF internationally. Memorials in her name are being received by the NSF from those who found help from the efforts of this most influential and caring woman.

In Memoriam

It is with great sadness that we report the death of Kay Patterson. Kay was a former member who generously contributed her time and energy to the NSF in many roles, including the NSF's first secretary. We offer our condolences to her family.

The NSF offers its sympathy to Pat Catalano and to the members of the Scoliosis Association in the death of Charles B. Catalano, Jr. Charley was the President of the Scoliosis Association. He and his wife Pat ran a support group in Orange County, CA.

We would like to thank the family and friends of the late Stella Bortz from Ontario, Canada for the many memorial donations received in her name.



Sprint for Scoliosis 5K

Thirteen year old Bianca Manago is planning a 5K Run/Walk for March 22, 2003 in Lansing, Kansas. Bianca's mother has scoliosis and as part of a school project, Bianca decided to organize this event with all proceeds benefiting the National Scoliosis Foundation. This exuberant 8th grader has been running in local races with her dad for the past four years. Bianca's winning spirit has offered her the opportunity to practice with her local High School Cross Country team. If you would like to participate, support, or even to just follow the action of this dedicated teenager then check out her website at www.geocities.com/caramelephant/RUN



Phone-a-thon Brings Out the Best in Donors, Volunteers

For those who answered and responded to a call from our volunteers during our annual phone-a-thon in August, your wonderful generosity raised over \$6,000.

The National Scoliosis Foundation's Board of Directors and other dedicated volunteers turned out on the evening of August 14th to appeal to the scoliosis community. In all, 100 friends pledged support when reached by our team of callers.

This year's event was one of the most successful to date. Former NSF President and founder, Laura Gowen made a very special offer to match all pledges collected!

A special note of appreciation was made to the Boston based company of Pizzeria Uno. The Uno Restaurant Corporation allowed us the use of their corporate headquarters for this fundraising event.

September 2, 2002

Dear National Scoliosis Foundation,

My name is Leah Taradash and I am thirteen years old. I recently had my Bat Mitzvah and was instructed to take part in thirteen mitzvah projects, or good deeds. As one of my projects I decided to give a portion of the money that I received to a charity of my choice. Since I have scoliosis and have been wearing a back brace for a year now, I thought it would be meaningful if I donated the money to a scoliosis foundation like yours. When I was first told that I had scoliosis they said that my curve was small and I should just watch to see if it would change. Two years later I was told that my curve went from sixteen degrees to thirty-three degrees and I would have to wear a back brace. The news was very hard for me to take and it took me awhile to get used to this new adjustment in my life. But with the help of family and friends I was able to overcome this obstacle and get on with my life. That is why I feel that your organization is so important. You are not only making people aware of scoliosis, but you are helping those who have scoliosis overcome it with information on new treatments, research, and most importantly, you are educating people about it. I find this to be the most important aspect of your foundation because so many people do not know about the disease and they could be at risk. Thank you once again for all your hard work and dedication towards helping those with scoliosis.



Sincerely,
Leah Taradash

Ms. Leah Taradash generously donated \$500.00 to the National Scoliosis Foundation!

Are You Moving?

Help us to maintain an accurate data base by reporting any incorrect address labels or a "change of address". The Post Office does not report "change of address" for bulk mail. Thank You!!

The Spinal Connection

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The Spinal Connection is published biannually by the National Scoliosis Foundation, a nonprofit organization committed to educating professionals and the public about scoliosis.

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