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

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.

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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.
persons with scoliosis than those with-out (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 particip-at ed 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. More work on congenital scoliosis is being carried out in Philadelphia and Toronto. Many members of the National Scoliosis Foundation and others is a good start, but is only a “seed” to get things going, and as 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 grave-roots campaign to highlight the need for funding of etiology research. The voice of every person needs to be heard performed by Dr. John Cobb, which was followed by a year in a plaster ‘backyard’ 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 models 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 am interested in drawing.

Anatomy is usually illustrated in straightforward views, anterior, posterior, 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 conceptualizing it three-dimensionally has been challenging but rewarding. Creating images of the 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 unhuman 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 living with 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.

Finding the Cause

There are two 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. A: At the end of bone maturation, will you then remove the staples? A: Possible complications are the same 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. This is made possible by an intravertebral bone insertion technique. The long-term potential complications of the procedure would be minimal, including 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 Shriner’s Hospital in Philadelphia, however, other surgeons have been trained and are starting to do the procedure, including Dr. John Lubicky at the Shriner’s Hospital in Chicago and Dr Keith Bridwell and Dr. Lawrence Lenke at Shriners Hospital in St. Louis.
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 and without fusionless stabilization or correction of spine deformity.

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. The vertebral staple 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: 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 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 (ABS) 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 can be removed if the staples have stabilized the spine.

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

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 causes, 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 are involved.

NIH has spent Virtually $0 on Scoliosis Research!

Tell them why this must change.

A: You are a parent burdened by the weight of seeing your child going through with scoliosis and confused about what course of action is best for him or her? Are you a俊gerunt alter 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 by being told what may lie ahead? Or, are you someone tired of living in pain, and feeling victimized by the surgical, or medical treatments that failed to help you? No matter what situation you may be in, we often find that the best way 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. Spoonser, 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 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 a wooled letter to the NIH. Please call us if you need help with this effort. For those of you with access to our website www.SKOLO-ISIS.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 to make 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 ideally 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 dance at the Juilliard School, who helped me to understand the neuro-muscular dynamics of the body in motion. I retrieved and studied the records of my surgery, a fusion of the T5-T12 vertebrae, with graft bone, continued on page 7

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 visually compelling, and could be interesting on many levels, from the literal to the metaphorical. I decided to turn this into 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 ideally 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.

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In Memoriam

Ann Landers, 1918-2002

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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 NSF internationally. 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.

In 1972, Laura Gowen, former Executive Director of the NSF, got permission from the editor of the Chicago Tribune to run a column by an advice columnist, Ann Landers, on scoliosis. Mrs. Landers did so for over 10 years and the letters received from your column “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 to the National Scoliosis Foundation. This exuberant 8th grader 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

Sprint for Scoliosis 5K

Three 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.

Ten years later, Laura Gowen wrote, “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.”

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