

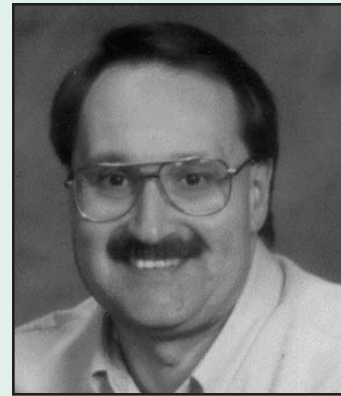
MEMORIAL

Fond Memories of Herb Homer

by Patty Gregory

I can still recall the Autumn of 1989 when Herb Homer joined the National Scoliosis Foundation board of directors. His professionalism, friendly smile and genuine concern for humanity made him a delight to work with. I came to know him as a friend who was compassionate and giving, never seeking to call attention to his many contributions. His keen sense of organization and attention to detail were brought to bear on all that he did. Herb especially enjoyed being in charge of the finances for our many fundraisers.

Herb was an example of the spirit of volunteerism to all of us.



In addition to his work with the NSF, he was active in the Jaycee's, the Special Olympics, community service, and his church. Above all, he was devoted to his wife Karen and their extended family.

Herb Homer died aboard hijacked United Airlines flight 175 on September 11, 2001. His passing leaves a void in the lives of the many people who knew him but it cannot diminish our fond memories of him.

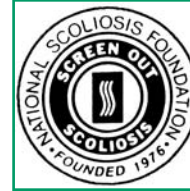
Robert L. Stevenson once said, "That man is a success who has lived well, laughed often, and loved much; who has gained the respect of intelligent men and the love of children, who has filled his niche and accomplished his task; who leaves the world better than he found it; who never lacked appreciation of earth's beauty or failed to express it; who looked for the best in others and gave the best he had."

Such a man was Herb Homer.



5 Cabot Place
Stoughton, MA 02072
781-341-6333

NON-PROFIT ORGANIZATION
U.S. POSTAGE PAID
RANDOLPH, MA PERMIT NO. 85



The Spinal Connection

SPRING 2002

NATIONAL SCOLIOSIS FOUNDATION

VOL.18, NO. 1

Improved Chest Expansion in Idiopathic Scoliosis After Intensive, Multiple-Modality, Nonsurgical Treatment in an Adult

Martha C. Hawes, PhD and William J. Brooks, DO

Introduction

The most serious complication of thoracic scoliosis, compromised cardiopulmonary function due to reduced chest wall expansion, can be fatal when curvatures are severe and is present even in mild idiopathic scoliosis (IS).^{1,2} Chest expansion increases of > 1 cm, and improved vital capacity (VC), have been achieved in children and young adults with IS during a 6-week hospitalization regime using physical therapies.³ Traction was used to achieve improved pulmonary function in a middle aged patient with severe scoliosis due to infantile poliomyelitis.⁴ In the current study, the use of physical methods including comprehensive manipulative medicine (CMM) and daily manual traction was correlated with a progressive increase in chest expansion, a stable improvement in torso morphology, and a reduced incidence of respiratory infections.

Case Report

The patient was a 48-year-old woman in whom a prominent rib hump, scapular and torso asymmetry, thoracic lordosis, and forward rotation of the right shoulder were detected at age 11 years. Radiographic analysis revealed a right thoracic curvature of 43° with lesser cur-

vatures in the cervical and lumbar spine. Pectus excavatum and mitral valve prolapse also were present. An orthopedic surgeon recommended spinal fusion, which was declined. Daily torso strengthening and conditioning exercises were carried out through February 1992. Hypothyroidism was diagnosed in 1971 and was treated with thyroid extract (3 grains daily). The patient described a chronic susceptibility, from infancy through April 1992, to upper and lower respiratory tract infections, averaging four or more a year, each lasting up to 6 weeks,

commonly with temperatures > 102° F and requiring medical intervention.



Martha C. Hawes, PhD, author and patient

Methods and Results

In February 1992, the patient suffered psychological decompensation with emergent incapacitating multiregional physical pain and began outpatient psychological therapy (therapists Diane Breier, MSW, and Nancy Skocy, MSW; Tucson, AZ), which continued through September 1994. No psychopharmacologic or analgesic medications were employed. All strengthening and conditioning exercises were discontinued in February 1992. In April 1992 a spontaneous reduction in the forward rotation of the right shoulder occurred (not shown). From January 1993, one of the authors (WJB) provided instruction, support, and evaluation of posture and movement. Sustained pressure applied directly to muscle spasms, or manual traction to stretch the torso, was used by the patient to relieve pain as needed (4 h daily through 1997). These methods were supplemented with massage therapy monthly in 1993 and 1994.

CMM was performed by one of the



	Cobb angle magnitude			
	1990	1994	1998	2001
T4-T12	47±1	38±2	34±2	27±1
L1-L4	26±1	19±1	17±1	13±1

Improved Chest Expansion in Idiopathic Scoliosis...Continued from page 1

authors (WJB) on four occasions during the period 1993 to 1998 and on seven occasions in 1999 to 2000. Manipulative interventions were dictated by a diagnostic methodology employing a systems analysis of whole-body biomechanics (posture and movement). Specifically, techniques and dosages were applied to the proportionately most severe deficiencies of available motion (W.J. Brooks, DO; unpublished data; 2001). Techniques employed included thrusting, muscle energy, articulation, myofascial release, and counterstrain.

Chest expansion increased from 2.5 to 10 cm (Fig 1), with 33% of the change occurring in correlation with intensive CMM in 1999 to 2000 (Fig 1, arrow). This change was associated with an increase in the mean (\pm SD) resting circumference of the chest from 76 ± 0.5 to 82 ± 0.3 cm, together with stable changes in the morphology of the upper back (Fig 2, top left, A, and top right, B), the anterior chest (Fig 2, middle left, C, and middle right, D), and thoracic lordosis (Fig 2, bottom left, E, and bottom right, F). Radiographically, the thoracic curvature remained moderately severe (not shown). In November 1992, the signs and symptoms of hypothyroidism normalized, and thyroid medication was discontinued. Between 1992 and 2000, the patient experienced four respiratory infections, all of which resolved in 3 to 5 days. Daily severe pain continued through 1997, then

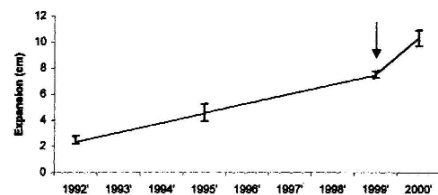


Figure 1. Increase in chest expansion, 1992 to 2000. The values for chest expansion are derived by subtracting the circumference (measured just below the breasts) during maximum exhalation from the circumference during maximum inhalation, and represent the means and SDs from the number of measurements taken by the patient at different times of the day over several days (1992, 10 measurements; 1995, 7 measurements; 1999, 20 measurements; and 2000, 29 measurements). Hip circumference (107 ± 0.5 cm) and weight (133 ± 3 lb) were stable during the test period. The arrow denotes the beginning of a year of intensive manipulative treatments.

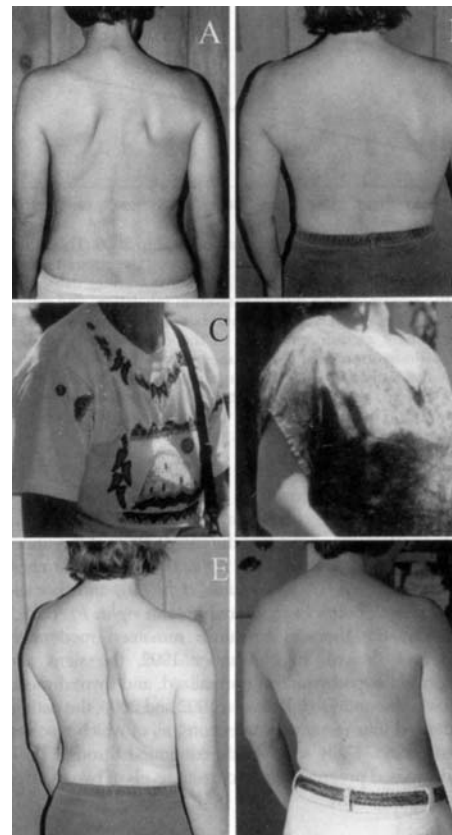


Figure 2. Stable morphologic changes occurring in correlation with increased chest expansion. The photographs are of the patient's back while in a relaxed standing position and show an apparent increase in the breadth of the upper back in January 1995 (top left, A) and November 1995 (top right, B). Casual photographs show morphologic changes in the anterior chest in July 1995 (middle left, C) and July 1998 (middle right, D). Photographs of the patient's back while in a relaxed standing position in November 1995 (bottom left, E) and November 1999 (bottom right, F) show a visual improvement in the appearance of thoracic lordosis.

decreased progressively to current levels of two to three episodes per month.

Discussion

When compared with control subjects, patients with IS exhibit a significantly smaller mean chest circumference and restricted chest mobility.^{2,3,5} A chest expansion capacity of < 3.8 cm in IS patients is strongly correlated with diminished VC.⁵ Pulmonary symptoms characteristic of IS can be duplicated in control subjects by inhibiting chest expansion with corsets or taping.¹ Reduced VC is associated with increased susceptibility to respiratory infection.⁶

In the current report, the achievement of a significant increase in chest expansion in correlation with the near-

elimination of respiratory illness is consistent with a previous study showing that even in middle age, functional defects associated with thoracic scoliosis can be reversed measurably using physical methods.⁴ The increased rate of improvement during the last year of the study suggests that CMM played a significant role in improving chest wall expansion. Mechanisms of improved chest wall expansion probably include altered muscle tonus through neuroreflexive mechanisms (ie, CMM) and plastic tissue changes from directly applied forces (ie, CMM, manual traction, and deep massage) and, over time, self-stretching through deeper breathing. The relief of pain was temporally correlated as an effect, rather than the cause, of the gradually improved physiology.

Footnotes

The first author (MCH) is the patient in the study.

Abbreviations: CMM = comprehensive manipulative medicine; IS = idiopathic scoliosis; VC = vital capacity

References

- Lonstein, JE, Bradford, DS, Winter, RB, et al (1995) Moe's textbook of scoliosis, and other spinal deformities 3rd ed. ,572-581 WB Saunders Philadelphia, PA.
- Leong, JCY, Lu, WW, Luk, KDK (1999) Kinematics of the chest cage and spine during breathing in healthy individuals and in patients with AIS. Spine 24,1310-1317[Medline]
- Weiss, HR (1991) The effect of an exercise program on vital capacity and rib mobility in patients with idiopathic scoliosis. Spine 16,88-93[Medline]
- Block, AJ, Wexler, J, McDonnell, EJ (1970) Cardiopulmonary failure of the hunchback: a possible therapeutic approach. JAMA 212,1520-1522[Medline]
- Collis, DK, Ponseti, IV (1969) Long term follow-up of patients with idiopathic scoliosis not treated surgically. J Bone Joint Surg 51-A,425-445
- Murray, JF, Nadel, JA (2000) Textbook of respiratory medicine 3rd ed. ,2357-2376 WB Saunders Philadelphia, PA.

This article is reprinted with permission from Chest Magazine, volume

ALTERNATIVE TREATMENTS FOR SCOLIOSIS

by Joseph P. O'Brein

The National Scoliosis Foundation (NSF) strives to provide objective, up to date, valid information to the scoliosis community. Today's health care environment necessitates more informed patient participation, and scoliosis is a condition that requires a great deal of patient decision-making, especially in light of the many unknowns. We believe every patient has a right, and an obligation, to know as much as possible about their condition, and the treatment options available to them.

Currently, bracing and surgery are considered to be the only two scientifically proven treatment methods for scoliosis. We recognize however that there is a variety of alternative methods which may offer care and management of the effects of scoliosis, and provide general well being. We also see a growing segment of the patient community concerned about traditional treatments, and seeking out alternative methods for both care and treatment.

In this issue of the Spinal Connection we continue our ongoing look at alternative treatment methods, and present a published case report of a scoliosis patient who improved her appearance and function using osteopathic methods, traction, and massage. We caution the reader that this is one person's journey, and should not be misconstrued as being applicable to any other person, or to a larger community of patients. Nonetheless, we believe that it is important to explore such alternatives in the hopes of finding more definitive answers for people living with scoliosis, and encouraging a multi-disciplinary approach for better patient care.

NSF recommends that patients pursuing such alternative treatments seek the advice of their orthopedic spine specialist.

Living With Pain

By Penney Cowan

Managing life today can be difficult. Managing life with pain is even more challenging, but it is possible. There are ways to balance your life so that you can live the way you choose, rather than your illness dictating. The key is for you to become an active member of the treatment team. It is important to understand what your responsibilities are to ensure a near normal lifestyle. Your health care team will do all they can to provide the necessary medical care, but you will be responsible for much of the day-to day routine.

First, you must clearly understand what your needs are. Personal needs can range from a balance between getting proper rest and physical exercise to taking medications and reducing stress. While managing illness and pain are complex issues, the majority of the key components are simply common sense and good living skills. Things such as good nutrition, open communication with family, asserting yourself so that your needs are met, and finding a balance between activity and rest are all key components in successfully managing pain.

It is important to recognize your limitations to prevent becoming overly tired or risking increasing pain levels. Staying within your limits can enhance your ability to think clearly and concentrate on important tasks. Understanding personal needs will provide a means to develop a workable plan so that you can incorporate important tasks into your daily routine.

Journalizing is an excellent way to ensure necessary tasks are completed while bringing you one step closer to independence. Balancing daily activities with necessary rest periods is easier when you have a written overview of your endurance with everyday tasks.

Your journal can also provide you with insight into daily stressors.

Reducing stress is vital in the fight against pain. Muscles that are already painful will experience increased pain as your stress level increases and your muscles tighten. Recognizing and understanding feelings are another important component to successful pain management. When you ignore feelings, they do not go away, but can show up as increased tension, feeling out-of-sorts, or even anger. Dealing with feelings as they occur can greatly reduce both stress levels and pain. Your journal, with its daily entries, can become your roadmap to wellness and provide you with a sense of empowerment.

Daily exercise should also become a routine activity. Simple stretches can strengthen muscles, improve circulation and maintain energy levels. Ask your doctor about an exercise program designed to fit your ability.

When you plan your day, keep in mind your need to pace activities according to your ability for that particular day. A simple way to remember the importance of pacing is found in the letters of the word PACE.

P is for prioritizing your tasks to ensure that the most important ones are done first.

A is for planning your actions to ensure the best use of your time.

C is to remind you that your physical comfort is important. If a task creates increased pain levels, then perhaps you need to ask for help.

E is for energy. Energy levels are never the same from day to day.

You need to consider how much energy you have at the beginning of each day to ensure you are working and playing within your ability.

By combining PACE - priorities, action, comfort and energy - with your personal commitment to a near-normal life, you can begin to feel like a person rather than a patient.

Penney Cowan is the founder and executive director of the American Chronic Pain Association.

MEDICAL UPDATE

by Nancy Schommer, Author of *Stopping Scoliosis*

Endoscopic Surgery for Scoliosis

Nearly a decade has passed since the minimally-invasive approach known as endoscopy was first used in the treatment of scoliosis. To find out more about how well the technique is faring today, we recently interviewed Peter O. Newton, M.D., a scoliosis specialist at Childrens' Hospital and Health Center, and Assistant Clinical Professor of (Orthopedic Surgery) at the University of California, San Diego. What follows are excerpts from that interview.

Q: Dr. Newton, would you start by describing this technology?

A: An endoscope is an instrument that helps a surgeon visualize something from within. It has a video camera attached to it, so that when it is inserted into a cavity, we can see on a video screen what is inside the cavity. Surgeons use an arthroscope to look inside the body at joints, a thoroscope to see inside the chest, or a laproscope to view the interior of the belly. In the case of spine surgery, we are using this technology to help us see and operate on sections of the spine.

Q: For what purposes does a scoliosis surgeon use an endoscope?

A: We use it in two ways: (1) anteriorly (from the front) to remove discs to release the spine and make it more flexible, or to fuse certain anterior sections of the spine and/or (2) posteriorly (from the back) to insert instrumentation to make the spine straighter. Sometimes we can do both the anterior and posterior

approaches endoscopically. But most often we would do the anterior release with an endoscope and follow up posteriorly with a traditional or "open" approach to inserting instrumentation.

Q: How do you decide which approach to take?

A: Doing the operation endoscopically works best on young patients with a single thoracic (chest) curve, or on youngsters with an S-shaped curve where the thoracic curve is bigger than the lumbar and therefore only the thoracic curve needs to be straightened. At present, the technique is not applicable to patients with two curves in the thoracic area, or S curves where the lumbar curvature is bigger than the thoracic.

Q: Which curves respond well to the endoscopic approach?

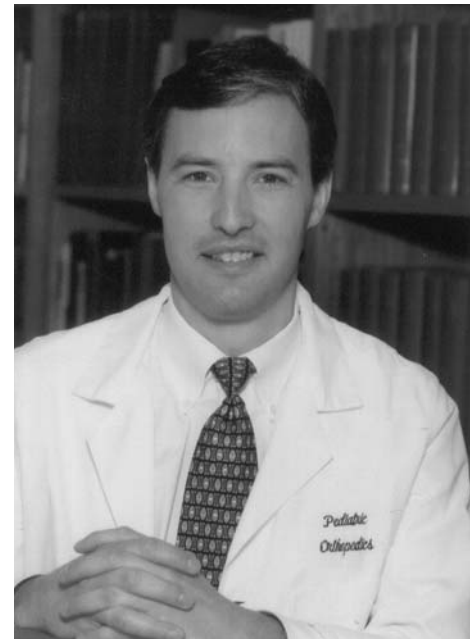
A: Curves in the 40-80 degree range respond well to the technique. Curves of 70-80 degrees would be the upper practical limit. With curves beyond 80 degrees, we would do an endoscopic release anteriorly followed by a traditional posterior approach to insert instrumentation.

Q: How many segments of the spine can you operate on endoscopically?

A: It can vary from two or three to as many as ten or twelve.

Q: How does endoscopic surgery compare with traditional surgery with respect to hospital stay and rehabilitation?

A: We are doing an ongoing prospective study to look at that. Our early data is rather soft, but it suggests that you get out of the hospital a day or two earlier with the endoscopic approach; return of function of the shoulder girdle and muscles around the shoulder seems to



Peter O. Newton, M.D., a scoliosis specialist at Childrens' Hospital and Health Center, and Assistant Clinical Professor of (Orthopedic Surgery) at the University of California, San Diego

be a little quicker with the thoroscopic approach vs. either the open posterior or open anterior techniques.

Q: What about discomfort?

A: There appears to be slightly less discomfort after the endoscopic approach because it is less invasive than the traditional open approach.

Q: How about scarring?

A: Obviously, scarring is minimal because we are entering the body through several small portholes rather than through one longer incision.

Q: What about complications from collapsing the lung?

A: The so-called "collapsing" of lungs is quite straightforward and is rarely a problem. The lung is in many ways like a balloon—it inflates when you take a breath in and deflates when you breathe out. So we just arrest the lung in a state of blowing out so it gets smaller and doesn't get in the way of our

instruments. When we're done, we blow it back up or re-inflate it. At present, our study shows that pulmonary function returns more quickly with an endoscopic approach in the chest area vs. the open anterior approach.

Q: What about the risk of infection?

A: The risk of infection is exceedingly rare for either approach—about 1 percent or less.

Q: What about a cost comparison between endoscopic and traditional surgery for scoliosis?

A: The total cost of surgery—surgeon's fees and hospital stay and equipment—is just about the same. While you may get out of the hospital sooner with endoscopic, you may have more expenses during surgery because endoscopic equipment is more sophisticated.

Q: How should patients choose a doctor to perform endoscopic surgery?

A: Most important, they need to find out exactly what experience their surgeon has in endoscopic surgery of the spine. Make sure the surgeon has at least watched someone do it, and taken a course with hands-on experience in the technique. Although there are no "certificates" in endoscopic surgery, most hospitals have some sort of credentialing requirement for performing the technique, so check with the hospital about your surgeon's credentials.

Q: What's on the horizon for endoscopic surgery?

A: Over time, the equipment will become easier to use, and the video technology and image guidance will become more sophisticated. I'm sure we'll continue to make advances in the types of curves that can be treated: one day we may be able to do bigger curves, and eventually we may be able to address curves that cross below the diaphragm into the lumbar spine.

RESOURCES

New Books Available from NSF

Stopping Scoliosis

by Nancy Schommer

When *Stopping Scoliosis* was first published, Publisher's Weekly applauded the book as "a compassionate, informative guide to the diagnosis and treatment of curvature of the spine." Kirkus Reviews hailed it as "a concise, clear explanation of scoliosis and its treatments, with plenty of practical pointers and support from fellow sufferers." The new edition of Nancy Schommer's book is still considered the best and most comprehensive book presently available for the layperson who is dealing with this baffling disorder.

The revised edition also contains many interviews with new patients, plus an entire chapter devoted to finding and evaluating information about scoliosis on the Internet.

Stand Tall Harry

by Mary Mahony

Mary Mahony, a board member of the NSF, has recently released a new book, *Stand Tall, Harry*. Unlike her first two books which have focused largely on scoliosis, *Stand Tall, Harry* is about an African American student who is bused from the city to the suburbs for his education. Harry shares with his grandfather his desire to find a best friend at his school. Eventually Harry befriends a boy named Jack which ultimately brings them both to the chessboard. Harry endures a serious hockey injury, an eventual diagnosis of scoliosis, and soon finds himself as a possible United States chess star.

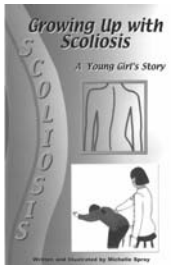


Growing Up With Scoliosis

by Michelle Spray

This is a very personal, individual, thoroughly comprehensive account of what the author felt and experienced while "Growing Up With Scoliosis". It begins with the school screening diagnosis and takes the reader through the stages of observation, long-term brace treatment, curve progression after the end of growth, and scoliosis surgery and its outcome.

"Although some of the technical aspects of the author's brace treatment and surgical care have evolved since she experienced them, the principles have not changed, nor have the scope and depth of feelings encountered by a young person who must with deal scoliosis. The author has had the courage and concern for others to share her deeply personal experience." – Thomas S. Renshaw, M.D.



Scoliosis and the Human Spine

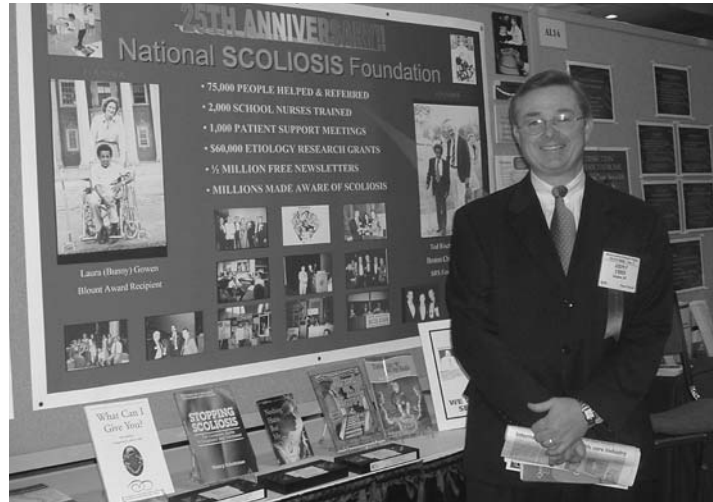
by Martha Hawes

Scoliosis and the Human Spine is the product of an exhaustive analysis of the peer-reviewed literature describing the history, biology, and clinical approach to treatment of spinal deformity, and includes a bibliography of more than 700 medical and scientific papers. The book is written to serve as a reference, which can enable patients, parents, physicians and other clinicians to draw their own conclusions about the current status of knowledge and treatment of spinal deformity in this country.



For a complete listing of NSF resources, visit www.scoliosis.org or call 800-673-6922.

NSF Marks 25th Anniversary



President, Joe O'Brien highlights NSF's 25th anniversary at the American Academy of Orthopaedic Surgeons meeting in Dallas, Texas.

by Joseph P. O'Brien

In the past twenty-five years the world of scoliosis saw some tremendous innovations, such as the Scoliometer, the Boston brace, CD Instrumentation, Cages, Pedicle Screws, PCA pumps, and Endoscopic surgery. During this time, the National Scoliosis Foundation, (NSF) also achieved significant milestones. We helped and referred over 75,000 patients in more than 50 countries, and provided information to more than 30,000 health care providers. We helped to establish, develop, or assist most of the school screening programs in the U.S., and trained more than 2,000 school nurses and physical education teachers in postural screening. We held over 1,000 patient support meetings and spine conferences throughout the country, and championed the campaign to find the cause, prevention, and cure of scoliosis, providing \$60,000 in etiology research funding, and eliciting 200 families to participate in a landmark genetic study at Johns Hopkins University. In addition, we constantly communicated to the scoliosis community by distributing more than 1/2 million Spinal Connection newsletters, free of charge.

And, we made millions of people aware of scoliosis through countless newspaper and magazine articles, radio & TV spots, and written and video educational materials.

In summary, NSF's volunteers and donors gave a vast amount of their time, talents, and resources over the last quarter of a century, to answer the initial plea from Dr. Riseborough to

let the world know about scoliosis, and the importance of early detection and treatment. The hallmark of our foundation, school screening, resulted in the identification of hundreds of thousands of children with scoliosis, which allowed them to gain the benefits of early detection, and provided invaluable information to the medical and scientific community about the prevalence and natural history of this condition. NSF has truly made a difference in the world, and we are extremely grateful to everyone who helped to make it possible.

But our work is far from over. Throughout the history of scoliosis an insufficient level of knowledge has caused a never-ending suspicion that the treatment is worse than the condition. This nagging doubt creates confusion and anxiety for most patients, unable to get definitive answers to the fundamental question of "what is the best thing for my child, or myself?" This anxiety is growing as the accessibility and variability of information increases via the Internet. The doubt also undermines our primary mission of early detection and treatment of scoliosis as

evidenced by a growing rationale among some of the medical community that it's either okay to live with a crooked spine, or that surgery is the only treatment option.

The widening disparity between the medical community's views and parent/patient needs is in large part due to a lack of research time and money to enhance our knowledge about scoliosis, and develop new conservative treatment modalities. We are truly grateful to the medical community, especially the members of the Scoliosis Research Society (SRS), for the significant treatment advances during the past two and a half decades, but we must continue to call upon them to put more emphasis on the non surgical aspects of scoliosis in line with their stated mission of finding the "cause, prevention, and cure of scoliosis".

Reflecting upon the state of the scoliosis community today, we will renew our campaign for Etiology Research, Early Detection/Treatment, and Education. We will step up our advocacy position for early detection, and non-surgical treatment modalities, expand our medical and scientific community liaisons, and enhance our professional capabilities and role in order to ensure the proper treatment of our present and future families.

We don't have all the answers, but we will continue our dedicated efforts to find them. In the meantime, we will keep focused on helping patients navigate this all too often murky swamp of confusion, and hopefully lessen the burden of their personal journey with scoliosis. We cannot do this alone. We need every member of the scoliosis community to help in some way. Together with the generous giving of everyone's time, talents and/or financial resources we can continue to truly make a difference during the next twenty-five years, and perhaps change the course of scoliosis history.

Come Chat with Us

By: Maura Matlak

I remember my first date perfectly – an April Friday evening, eating ice cream with Edward, the intelligent and cute boy from my Geography class. We were 14. He had called on Wednesday to ask me to go and it took me up until Friday afternoon to say yes. Actually, my mother was the one who finally convinced me to accept Edward's invitation – "He's a nice boy, Maura! Just go," she persuaded me over and over until I called him, hands shaking.

So there we were, eating our ice cream outdoors, catching it before it melted and dripped off the cones. We talked about school, our teacher's ridiculously hard homework assignments, Edward's hockey team, my sisters, and our summer vacations coming up. At the end of the date, Edward tried to give me a half-hug and that's when my worst fear came true – his arm hit my back brace and made a knocking thud against my back.

Edward pulled his arm away quickly and, surprised, asked, "What's wrong with your back?" I awkwardly stumbled through an answer, and he mumbled some kind of response, and then I went home, feeling embarrassed and not wanting to see him at school the next week.

I'm sure that everyone who wears a back brace or has had spinal surgery has heard some form of the question, "What's wrong with your back?" During gym class, at school, at baseball or swim practice, at dances, at parties – it can be frustrating and scary to answer this question all the time, especially when you are unsure of how your classmates will respond.

I also understand that, at the same time you have to answer all these questions about your back, you still have questions of your own that you want to ask. Sometimes receiving medical information from your doctor isn't

enough; you might also have questions that aren't so easily answered. Questions about body image – How does my brace look underneath my clothes? Does my bathing suit look weird because my shoulder blades are crooked? What about my scars from surgery? Questions about practical matters – Can I get an extra set of schoolbooks to leave at home so that I don't have to carry a heavy backpack? Am I still able to play contact sports after surgery? How can I make my brace more comfortable and cool during the hot summer? Can my parents force me to wear my brace?

At the end of the date, Edward tried to give me a half-hug and that's when my worst fear came true – his arm hit my back brace and made a knocking thud against my back.

Parents also have their own questions – I know my mother and father did! They wanted to know how they could help make my adjustment easier, if it was permissible to let me take "days off" from the brace, if I needed physical therapy, if there were any

other kids with scoliosis in the school....the list went on and on.

During my sophomore year in college I became involved with the Miss America Organization, a unique scholarship pageant system that gives young women an opportunity to give back to their communities while earning scholarship money for school. I won the title of Miss Commonwealth 1999 and was a finalist at Miss Massachusetts 1999, dedicating my year of service, or "platform issue," to Scoliosis Awareness. My main focus has been, and continues to be, a commitment to kids and teenagers diagnosed with scoliosis.

After being elected onto the NSF Board of Directors while I was a junior at Boston University, I formed an email "chat" group to address these concerns. Currently, about 20 kids with scoliosis participate in the group; Because of many requests, I also hope to extend the group to include an open forum for parents to discuss topics related to their child's journey with scoliosis. As the group grows, my priority remains the same – to provide an honest environment in which the best combats against scoliosis are humor, self-education, and a willingness to see the beauty behind having something "wrong" with you.

Please join us – the group welcomes new members and new situations anytime! You can contact me directly at Maura_Matlak@hotmail.com for more information

The Spinal Connection

Vol. 18, No. 1

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

5 Cabot Place
Stoughton, MA 02072
781-341-6333 FAX 781-341-8333
1-800-NSF-MYBACK (673-6922)
www.scoliosis.org

Editorial Staff:

Patty Gregory, Editor
Joe O'Brien, Copy Editor
Linda Goodwin, Graphic Design

Contributing Writers:

Penney Cowan
Martha C. Hawes, PhD
Patricia Gregory
Maura Matlak
Joe O'Brien
Nancy Schommer