National Scoliosis Foundation
EDUCATING, ENCOURAGING & EMPOWERING

SCOLIOSIS MEDIA & COMMUNITY GUIDE

Endorsed by the Scoliosis Research Society and Sponsored by a Grant from DePuy Spine, Inc.

IA
GUIDE

CONTENTS

INTRODUCTION

**A few seconds can possibly save a child you know years of pain later in life.
It's time to spread the word.**

Scoliosis, when left untreated, can get worse and may cause chronic back pain, impact heart and lung function and take a toll on self-esteem. Screening for the condition is non-invasive and takes about 30 seconds. With early detection and proper treatment, people diagnosed with scoliosis can lead healthy, active lives.

Scoliosis is an abnormal curvature of the spine that affects two to three percent of the population, or an estimated 7 million people in the United States. Most are diagnosed with scoliosis between the ages of 10 and 15, but the condition also affects infants and adults. It is a condition that affects people of all races, classes and both genders. Girls are eight times more likely than boys to have a curve that will progress to a magnitude that requires treatment.[1] Scoliosis is common in children with a variety of congenital and neuromuscular diseases, but it is most prevalent in seemingly healthy children, with no known cause (idiopathic).

Most curvatures are minor and require only that patients are monitored by their doctors. According to the American Academy of Orthopaedic Surgeons, about 10% of adolescents have some degree of spinal curvature and one quarter of these children have spinal curves that require medical attention[2]. In 2004, 1.26 million patients diagnosed with scoliosis utilized health care resources[3]. The estimated total hospital charges, excluding professional fees and non-covered charges, for all patients released from the hospital with an idiopathic scoliosis diagnosis was $2.7 billion[3].

Fewer than half of the states in our nation currently legislate screening for scoliosis at schools, so it is imperative that parents, teachers, coaches, healthcare professionals and children are aware of the early signs of scoliosis. Additionally, advances in science and technology mean both the diagnosis and treatment of scoliosis are improving every year. Your doctors and medical staff can help raise the awareness of all these issues through the news media and community events.

Key information can provide parents and their children with a better understanding of the signs and symptoms of scoliosis and where to get help. Community and grassroots events, such as health seminars and support groups, can encourage the sharing of personal stories and connect patients so that no family affected by scoliosis goes through the experience alone.

Media outreach can occur around key interest times like the fall for back-to-school stories and June, which is National Scoliosis Awareness Month. Then, community outreach can fill in the gaps in media coverage throughout the year.

The National Scoliosis Foundation (NSF), a patient-led non-profit organization, designed this Media and Community Guide to help you communicate the scoliosis story to the local news media and local community in an accurate and compelling way. The NSF has been working for more than 30 years to educate communities about scoliosis and the importance of early detection. The information in this guide has been medically reviewed for accuracy. This guide is endorsed by the Scoliosis Research Society and provided with the assistance of DePuy Spine, Inc.

We hope you find this guide useful as you reach out to the media and your local community to make patients and their families aware of the important issues surrounding scoliosis.

SOURCES

[1] National Scoliosis Foundation. Available online: www.scoliosis.org.

[2] American Academy of Orthopaedic Surgeons. Available online at: http://orthoinfo.aaos.org/connect/psa.htm.

[3] United States Bone and Joint Decade: *The Burden of Musculoskeletal Diseases in the United States.* Rosemont, IL: American Academy of Orthopedic Surgeons; 2008.

OVERVIEW

MEDIA AND COMMUNITY GUIDE COMPONENTS

In preparation for National Scoliosis Awareness Month, which takes places annually in June, we have prepared educational resources to assist you in telling the story of scoliosis and learning how your institution can serve as a leading resource for information about this important topic now and in the future. We have developed materials you can customize to meet your individual needs and reflect the medical insights of your doctors and the unique perspectives and experiences of your patients, their parents and families. A hard copy is provided in the guide and is also available on the accompanying CD.

GETTING STARTED

The materials in this media and community guide are designed to help you develop and implement a successful communications program. Within this guide, you will find a set of public and community relations tools, which include:

- Telling the Scoliosis Story - How to Pitch the Media and Obtain Media Coverage
- Selecting Spokespeople
- Customizable Press Materials
- Fact Sheets
    - Scoliosis Overview
    - Anatomy of the Spine
    - Fast Facts on Scoliosis
- Suggested Reporter Questions
- Scoliosis Video and Photos
- Organizations Resource Guide
- Frequently Asked Questions (FAQs)
- Glossary of Terms
- How to Organize a Health Seminar
- Education Materials
- Advocacy Plans
- Networking
- Patient Stories

SECTION 1

MEDIA GUIDE: APPROACHING THE MEDIA WITH YOUR STORY

WHAT IS YOUR STORY?

The news media is always looking for interesting and compelling stories, but if they feel they've already covered a topic, they are unlikely to cover it again without a compelling reason. They will challenge you to make your case.

WHAT IS NEW ABOUT YOUR STORY?

Many institutions, companies and individuals constantly battle for media attention. Some will get it, most will not. So, how do you get your story about scoliosis to spark the interest of a reporter who has hundreds of medical stories to choose from each month? How do you tell the story in a way that provides accurate and responsible information? How do you tailor the story to the reporter's needs?

This section discusses ways to approach local media from making initial contact to preparing for an interview.

Discussion topics include:

- What makes the scoliosis story important
- Pitching the media
- How to select spokespeople
- Media follow-up

It is helpful to do research on each media outlet and reporter to determine what kind of scoliosis stories – if any – they have covered in the past. This will give you a feel for the approach to take with them when pitching your story. For example, which media outlets have covered scoliosis and how did they cover it? Which scoliosis medical practices were featured in the stories? What kind of patient was featured? Did they talk about recent advancements in technology that are changing the way spinal fusion surgeries are performed? Do they know what research is taking place to advance the treatment of scoliosis and what treatments of the future might look like?

In addition, it is helpful to become familiar with the latest and most significant data on scoliosis to give your story additional scientific support.

Recent data include the following:

- Scoliosis is the most common deformity of the spine, affecting two to three percent of the U.S. population, or an estimated 7 million Americans[1]
- One quarter of children with spinal curves require medical attention[2]
- Scoliosis impacts infants, adolescents and adults, but the primary age of onset is between the ages of 10 and 15[1]
- Equal numbers of males and females have scoliosis, but females are eight times more likely to have a curve progress to a stage that requires treatment[1]
- 85 percent of scoliosis cases are idiopathic, meaning the cause is unknown[1]
- Scoliosis can run in families, and a child who has a relative with the condition should be checked regularly
- Scoliosis is a condition that can impact quality of life by limiting activity, causing pain, and negatively impacting respiratory function and self-esteem
- Early diagnosis is the key to keeping the condition from progressing and providing the best treatment

SECTION 1

MEDIA GUIDE: APPROACHING THE MEDIA WITH YOUR STORY

WHY IS THE STORY IMPORTANT?

The media is always looking for great stories. However, there are several story elements they typically look for when deciding whether or not to cover your story. When pitching the media about scoliosis, the following fundamental questions will always come up:

What's new about scoliosis?

Scoliosis is the most common deformity of the spine and early detection is the key to keeping the condition from progressing and providing treatment.

Fewer than half of the nation's states currently legislate school screening of scoliosis, and some states are considering discontinuing those screenings. That means it is imperative that all members of the community are aware of the signs and symptoms of the condition. It's important to provide reminders throughout the year because early recognition of the condition will prevent needless suffering of children and their parents.

New research and advances in technology are constantly changing the way scoliosis is talked about and treated.

What makes it compelling? Why is it important?

Several factors make this story compelling, including:

- The screening test for scoliosis is non-invasive, takes approximately 30 seconds, and could save a child you know years of pain in the future
- New research and development for screening and non-operative interventions are providing opportunities for safer and more effective early diagnosis and patient care
- The way doctors perform surgeries to treat scoliosis is changing; patients and their families need to know about advanced techniques and how that may affect treatment options
- The majority of people dealing with treatment for scoliosis are teenage girls, already facing an awkward time in their lives; this provides an opportunity to explain what they are going through so that classmates are less critical and patients learn that others are sharing the experience
- Approximately one in 40, or 7 million people, have scoliosis in the U.S., so the condition is affecting people in your local area
- There are many inspirational stories of triumph over scoliosis; people with severe cases have gone on to become competitive weight lifters, golfers and orthopedic surgeons
- This is a story that affects parents and their children and the stories of families dealing with scoliosis are emotional and compelling

WHY COVER IT NOW?

The media in your area should cover the scoliosis story now because it is an important health issue in your community. Stories should be done each year talking about what to look for and what to do if a child is diagnosed with scoliosis. New treatments are changing the face of the condition.

HAS THIS STORY BEEN COVERED BEFORE?

There has likely been some media coverage of scoliosis in the past. To be sure, review recent media coverage in your area. If they have covered it, you will need to figure out a new angle to the story or if it has been a while you can convince the media it's time to do it again with a fresh perspective that feature interesting patients and the top experts in scoliosis management.

HOW TO PITCH YOUR STORY TO THE MEDIA:
RADIO, TELEVISION, PRINT & INTERNET

TAILOR THE STORY

While the media generally welcomes health and medical story ideas, reporters from each medium (television, radio, print and Internet) have different needs and approaches to a story.

TELEVISION

What are the visual elements of the story? Here are a few:

- Spine-related elements, including: video of abnormal curves, x-rays of a normal, straight spine as compared to a curved spine affected by scoliosis
- Surgery-related elements, including: video from operating room, animation, video of patients' bodies before and after operation
- Observation and examination-related elements, including: video of screening tests either at school or in doctor's office, video of checkup at doctor's office
- Brace-related elements: video of various types of braces, patient demonstrating putting on a brace, wearing a brace at school or while exercising

When pitching a television reporter, vividly describe the kinds of pictures that can be made available so that the reporter can start to envision the piece.

For example, you can make special arrangements for a reporter to bring a video camera inside the operating room during surgery, into a physical therapy clinic or a school or sports team practice. Of course, permission from the patient and their parents and the hospital, clinic and/or school must be obtained prior to the television shoot.

TV REPORTER IN THE O.R. FOR SURGERY

If permission to bring a TV reporter into the operating room for surgery is obtained, you must brief the reporter and photographer on what they can and cannot do in the operating room; limited use or non-use of lights, protecting patient privacy (i.e. not showing the patient's face) and staying outside the sterile field should all be addressed. In addition, you should describe what the reporter can expect to see during the operation so the reporter and crew are mentally prepared for viewing surgical incisions, blood and the operating room environment.

You should arrange a time before the surgery for the reporter to talk to the treating surgeon. During an interview, your surgeon can provide a description of how the surgery will be performed. An interview prior will help establish a rapport between the surgeon and the reporter so things run smoothly once inside the operating room.

You should also arrange for the reporter to speak with a patient who has already had a successful spinal fusion surgery to treat his or her scoliosis. Parents are also an important part of the story. They can share their perspectives on the condition, and how it affected their child and family. A patient and his or her parents can provide real-life insights about their experience and offer context to a reporter about what it's like growing up with scoliosis. A television crew could interview them at the patient's home, school or at the hospital.

Another option for a reporter is to follow a patient before, during and after surgery. The patient and his or her parents must be willing to allow a camera crew to follow them through their daily activities and struggles with scoliosis and then for several weeks, perhaps months, after the surgery. Selecting the right patient and parents is extremely important to producing a successful story.

Offer television reporters visuals

Broadcast quality video and an animation of how minimally invasive spinal fusion surgery is performed is provided for your use. These materials can supplement what the reporter shoots or in some cases, replace it, if the reporter cannot go into the operating room.

TV REPORTER IN NON-OPERATIVE TREATMENT CLINIC

If permission is obtained, you must brief the reporter and photographer on what they can and cannot film. There may be rules about protecting patient privacy during treatment.

You should arrange a time to speak with a supervisor of the clinic so that he or she knows what to expect from the camera shoot and has time to prepare all patients appropriately. This is a good opportunity to film many patients – if they give their approval – in various stages of treatment.

TV REPORTER IN SCHOOLS OR AT SPORTS PRACTICE

If permission is obtained, you must brief the reporter and photographer on what they can and cannot film. There may be rules about not filming faces of other children in the classroom, hallways or on the practice field.

You should also arrange for a time to speak with the school principal, teacher or coach so that he or she can know what to expect when the camera crew arrives and has time to prepare all students appropriately.

PRINT

Print reporters generally cover health stories in more depth than radio and television reporters. Provide them with comprehensive information and references about scoliosis – most of which are included in this guide. Reporters will likely want to take photographs or may request previous photographs taken of the patient illustrating their spinal curve prior to treatment. More frequently, print reporters are being asked to file stories for the Web site affiliated with their print publication. Ask the reporter if he or she would like an animation or b-roll for the Web version of the story.

RADIO

Most radio stations throughout the country do not have a reporter dedicated exclusively to medical stories. In many cases, however, there are opportunities to get medical stories covered through other means. If you can get the news director or assignment editor interested in the story, he or she will assign it to a general assignment reporter.

Many radio stations have public affairs and community service programs that welcome guest experts like your doctor. You need to convince the station's producers that this is a topic that will be of interest to their listeners and that your doctor can maintain a listener's interest for the length of the program. They will want to know that your doctor is well-spoken and articulate and can discuss scoliosis, its treatment options and the advantages of early detection and treatment in a way that an average listener can understand.

Provide the station with the list of suggested reporter questions, such as those included on page 17 in this guide, to show the range of questions they can pose to the doctor and patient.

INTERNET

Be creative when pitching to Internet reporters because they have a lot more time and space to tell a story than traditional media outlets. The Internet is a multi-disciplinary format, so think about the various ways you can help producers get a lot of information onto their site in a compelling way. Internet sites can have narratives, produced video stories, long-format video segments, still pictures, games and links to other informational Web sites or documents.

Also, think about pitching Web sites that are affiliated with television, radio and print outlets. If they don't have the resources to produce a unique story, find out if they will upload a story or segment that has already aired or has published by their affiliate outlet. Then see if they can link to your institution, or other Web sites, for even more information.

PITCHING THE SCOLIOSIS STORY

The Initial Telephone Pitch

Most reporters will decide if they want to cover your story within the first minute or so of your pitch – so start with the most interesting elements first. Articulate the essence of your story within the first few minutes of your call. If you can get the reporter interested in less than a minute, they usually will listen further or schedule a later time to get more information.

Grab Them With Key Points!

- A screening test for scoliosis is non-invasive and takes about 30 seconds
- People diagnosed with scoliosis can live full, active lives
- Scoliosis is a condition that affects two to three percent of the population, or about 7 million people in the U.S., so it is definitely of importance to all audiences

Follow Up

Follow up with a version of the pitch letter or media advisory provided in this guide on pages 15 and 16 and reference your telephone conversation. Also, include the press releases and fact sheets on pages 14, 18 and 19 in your correspondence for additional background.

The discussion on the phone increases the likelihood that the reporter will be receptive to the information you send. If you have not heard back from the reporter in a few days, make a follow-up call to keep the story on the top of his or her mind.

Maintain Contact

Scoliosis is not necessarily a "breaking news story," so you may not be able to get reporters to do the story on the first, second or even third phone call. However, keep in contact with reporters on an intermittent basis to maintain a good working relationship and to keep the story a priority. Remember that you want to be the person they call when they do decide to cover this story, and you have the resources to help reporters make the story both accurate and interesting.

HOW TO SELECT SPOKESPEOPLE

SELECTING A HEALTH PROFESSIONAL

The spokesperson selected for the media relations campaign will become the "face" of your institution. The spokesperson should be comfortable speaking to the media in layman's terms and should be reminded to use non-technical, patient-friendly language, as they would with patients and their families.

It is important to conduct your own interview with the health professional to hear how he or she discusses the topic. To be most effective, the spokesperson should deliver a focused and balanced message about issues related to scoliosis and the latest thinking on diagnosis and treatment.

When choosing health spokespersons make sure these key questions are resolved to ensure a great interview:

- Has the spokesperson carefully reviewed the information that you have provided to the reporter and are their views consistent with this material?
- Is the spokesperson familiar with key statistics regarding scoliosis?
- Is the spokesperson familiar with how to characterize the medical practice and expertise to the community?
- Has the spokesperson done media interviews before?
- Does the spokesperson know what to expect from media interviews?
- How does he/she feel about the media?
- Does he/she need media training?
- Has the spokesperson recently reviewed the specifics of the scoliosis patient who is featured in your materials?

SELECTING A PATIENT/PARENT

Since many of the patients affected by scoliosis are adolescents, you will first need to speak with their parents for consent to have their child participate in the media campaign. The parents will also likely become spokespersons since most have played an important role in helping their children seek treatment for their condition. Being with the parents during media interviews also helps the child feel more comfortable. However, if you speak with the patient or parents and sense they are reluctant to be interviewed, find another patient and parents. If they are uncomfortable with you, they will be even more uncomfortable with a reporter who may not be as sensitive as you.

When choosing patient/parent spokespersons, make sure these key questions can be answered to ensure a great interview:

- Are the parents comfortable sharing their child's experience with scoliosis with the public? Is the patient comfortable with his/her friends knowing they were treated for his/her scoliosis?
- Can the patient clearly articulate his/her experience with scoliosis? Can the parents discuss the type of support they provided for their child?
- Can the patient clearly discuss how scoliosis affected his/her daily activities, interactions at school with friends and physical activities?
- Can the patient or parents describe the treatments that were tried to correct the scoliosis?
- Can the patient describe how wearing a back brace affected his/her daily activities?
- Can the patient discuss his/her treatment?
- What was recovery like?
- Was the scoliosis corrected after treatment? Was he/she satisfied with the procedure? Was he/she satisfied with the medical staff and hospital overall?
- Are both the patient and parents comfortable having a television crew videotape them at home or participating in an activity?
- What advice would the patient or parents give other children, adolescents and parents about treatment for scoliosis?

PREPARING FOR MEDIA INTERVIEWS

Once the spokespersons are selected, prepare them for media interviews. Keep the following in mind prior to the interview:

- Get as much information from the reporter as possible. The reporter may be willing to share some of his/her questions with you.
- What angle will the reporter take?
- How much time do they anticipate is needed from the health professional, patient and parents?
- Where will the interview take place and in what kind of setting?
- What medical stories has the reporter covered previously?
- Have they interviewed other doctors at your institution?
- Is the reporter interviewing anyone else for the story?

Knowing all these details in advance will help you prepare your spokespersons appropriately.

AFTER THE INTERVIEW

Follow up with the reporter

Follow up with the reporter after the interview to get a sense of where the reporter is going with the story and to clarify any issues. Discuss the story further and provide any additional information. Reiterate the key points to further ensure the reporter took away from the interviews what you hoped to communicate. Get a sense of timing as to when the story will appear so you can alert spokespersons, hospital staff and the National Scoliosis Foundation to be prepared for inquiries from the public.

Review for accuracy and fairness

Once the story airs or is published, review it for fairness and accuracy. Analyze the story to determine if appropriate expectations for treatment were set, if any information or key points were missing and if the story accomplished your public health goals. If there are any deficiencies or factual errors in the story, contact the reporter and offer clarification. If the story was done fairly and accurately, commend the reporter for his/her work. Over time, you may also inform the reporter of the impact his/her story had on patients.

SECTION 1 SOURCES

[1] National Scoliosis Foundation. Available online: www.scoliosis.org.

[2] American Academy of Orthopaedic Surgeons. Available online at: http://orthoinfo.aaos.org/connect/psa.htm.

SECTION 2

MEDIA GUIDE:
SCOLIOSIS PRESS MATERIALS

SAMPLE PRESS RELEASE

FOR IMMEDIATE RELEASE

CONTACT: [INSERT PR CONTACT NAME]
[INSERT PHONE NUMBER]

DOCTORS OFFER LOCAL CHILDREN NEW HOPE IN OVERCOMING SCOLIOSIS

[INSERT CITY] – [INSERT DATE] – About 7 million people in the U.S. suffer from scoliosis, an abnormal curvature of the spine that can cause pain, limited mobility and poor posture. Most scoliosis sufferers are children who without monitoring or treatment could be robbed of their childhood.

Fortunately, doctors in [INSERT CITY] offer a wide range of treatment options from special exercises and braces to scoliosis surgery that allow children to participate in most activities, usually without restriction.

"The key is early diagnosis," said [INSERT NAME OF DOCTOR AND AFFILIATION]. "If we detect scoliosis early enough, braces may be sufficient to stop the progression. If we catch it later or the curvature becomes severe, scoliosis surgery can be highly effective in reducing the size of the curve and allowing people to participate in most physical activities."

Scoliosis symptoms include uneven shoulders, shoulder blades, ribs, waist, or hips, a noticeable sideways curve in the spine when looking from the back, or the appearance of the ribs being higher on one side when the child is bending over. It is sometimes a friend or family member who initially detects an issue and gets a child to the doctor. Other times, scoliosis is discovered during a school screening.

"We consider schools to be the best place to screen for scoliosis so that all children regardless of race, creed, or socio-economic status get an equal opportunity for the least invasive, least expensive and most effective treatment option available," said Joe O'Brien, president of the National Scoliosis Foundation (NSF). "Fewer than half of U.S. states currently legislate screening for scoliosis in schools, so it is imperative that in addition to school nurses, parents, health professionals, coaches and children are aware of the early signs of scoliosis."

Scoliosis, which tends to run in families, causes the spine to curve sideways in the shape of a "S" or "C" greater than 10 degrees. Girls are eight times more likely than boys to progress to a curvature that requires treatment[1]. One quarter of children with spinal curves require medical attention[2]. Each year, an estimated 30,000 children are fitted for a brace and 100,000 children and adults diagnosed with scoliosis undergo surgery[1].

If braces are prescribed as the best method of treatment, they may be worn for a period of time that could range from months to years. The number of hours a brace may be worn per day varies on a case-by-case basis. Patients must be committed to wearing the brace often or the treatment may not be effective.

In scoliosis surgery, vertebrae or bones in the back are fused to together using rods and screws that remain in the back to help straighten the spine and provide stability. Rehabilitation from scoliosis surgery can take several months.

Many major medical associations agree school screenings may be the most important tool in getting pre-teens with scoliosis early treatment. A statement, published in the January 2008 issue of the Journal of Bone and Joint Surgery and endorsed by the American Academy of Orthopaedic Surgeons, the Scoliosis Research Society, the Pediatric Orthopaedic Society of North America and the American Academy of Pediatrics, recommends that girls get scoliosis screenings twice at ages 10 and 12 and boys once at ages 13 or 14[3].

"There is a lot we still don't know about scoliosis, but what we do know is that it is important to catch the disease early," said O'Brien. "Scoliosis can develop quickly and we could miss it if we don't make the time to examine children's spines."

Advances in scoliosis diagnosis are also rapidly improving. In 2007, researchers announced the discovery of the gene that underlies the scoliosis condition and are working to determine how a defect in this gene affects spinal development. Other researchers are developing the first genetic prognostic test for scoliosis that will use specific genetic markers that predict curve progression.

SOURCES

[1] National Scoliosis Foundation. Available online: www.scoliosis.org.

[2] American Academy of Orthopaedic Surgeons. Available online at: http://orthoinfo.aaos.org/connect/psa.htm.

[3] Richards BS and Vitale MG. Screening for Idiopathic Scoliosis in Adolescents: An Information Statement. *J Bone Joint Surg Am.* 2008; 90:195-198.

SAMPLE PITCH LETTER

[INSERT DATE]

Dear [INSERT NAME OF MEDIA CONTACT]:

As we discussed, doctors at [INSERT NAME OF INSTITUTION] are helping children and teens overcome scoliosis, a condition that has the potential to rob them of active and healthy lives.

About 7 million people in the U.S. have scoliosis, an abnormal curvature of the spine that can cause pain, limited mobility and poor posture. Most scoliosis sufferers are children and teens. Fortunately, doctors have a wide range of treatment options from special exercises and braces to scoliosis surgery that help children participate in most activities, usually without restriction.

Dr. [INSERT NAME] has patients who have been successfully treated for scoliosis and are doing things that before treatment would have been impossible. Dr. [INSERT NAME], patients and their parents can discuss:

- Advances in scoliosis diagnosis and treatment
- Why girls are eight times more likely to develop severe scoliosis than boys
- Signs and symptoms of scoliosis
- The state of scoliosis in [INSERT NAME OF CITY]
- The future of scoliosis treatment in this country
- Personal experiences in overcoming scoliosis
- Scoliosis from a parent's perspective

According to the National Scoliosis Foundation (NSF), each year an estimated 30,000 children end up wearing a back brace for scoliosis and another 100,000 children and adults diagnosed with scoliosis undergo surgery. Early diagnosis is key. If scoliosis is detected early enough, doctors have treatments that could stop the progression of the condition. If it does progress, doctors have ways to reduce the size of the curve.

Scoliosis is an important health topic in [INSERT NAME OF CITY] and local schools and the media have important roles to play in helping the community understand scoliosis.

Please take a look at the enclosed materials. I'll call you in a few days to answer any questions you may have regarding the development of this story.

Sincerely,

[INSERT NAME OF CONTACT, PHONE, E-MAIL]

SAMPLE MEDIA ADVISORY

DOCTORS OFFER LOCAL CHILDREN NEW HOPE IN OVERCOMING SCOLIOSIS

Story: Scoliosis has the potential to keep children from playing sports, cause severe back pain, limit mobility, affect posture and rob a child of his or her self-esteem. Fortunately, early diagnosis and a wide range of treatment options from special exercises and braces to scoliosis surgery are helping children and their parents get their lives back.

Why: About 7 million people in the U.S. have scoliosis, most are children and teens. Currently, less than one-half of U.S. states screen for scoliosis in schools, so it is critical that friends and family members learn to recognize the signs and symptoms of the condition and know that help is available. It is often parents, coaches and children who first identify an abnormality. The community needs to know about:

- Signs and symptoms of scoliosis
- Treatment advances and options
- Overcoming scoliosis
- Why girls are eight times more likely to develop severe scoliosis than boys
- The state of scoliosis in [INSERT NAME OF CITY]

Who: [INSERT NAME OF DOCTOR, AFFILIATION] is a scoliosis expert who can provide important perspectives on this important health topic and has patients who can share their personal stories of diagnosis and treatment.

Where: [INSERT NAME OF HOSPITAL]
[INSERT ADDRESS, PHONE]

Contact: For more information or to set up interviews, please contact [INSERT NAME]
at [INSERT PHONE NUMBER or E-MAIL].

SUGGESTED REPORTER QUESTIONS

CONTACT: [INSERT HOSPITAL PR CONTACT]
[INSERT PHONE NUMBER]

FOR DOCTOR

- What is scoliosis? What causes it and whom does it affect?
- What are some common symptoms and/or signs?
- How are patients screened and diagnosed for scoliosis?
- Is the prevalence of scoliosis rising, declining or staying the same? Why?
- What are the latest techniques and technologies for treating scoliosis?
- How effective are back braces for treating scoliosis? When are they indicated?
- How effective is surgery for treating scoliosis? When is surgery appropriate?
- How should patients decide whether or not to have surgery?
- What research is currently being done to better understand scoliosis?

FOR PATIENT

- How were you first diagnosed with scoliosis? How old were you?
- Does scoliosis run in your family?
- How did your scoliosis affect your daily activities? How did it affect your relationship with friends, going out on the weekends, sports or physical activities?
- What was it like emotionally?
- What treatments did you try?
- How long did you wear a back brace? How well did it work? Was it difficult to wear? How so?
- Does scoliosis run in your family?
- What was going through your mind when you first found out you might need surgery? What were you most concerned about? What did your parents think about you having surgery?
- How soon did you go back to your normal activities?
- Are there any new activities you can do now that you were prevented from because of your scoliosis? Are there any activities you can't do?
- What do you wish the average person knew about scoliosis?
- What advice would you give other children diagnosed with scoliosis?

FACT SHEET: SCOLIOSIS OVERVIEW

CONTACT: [INSERT HOSPITAL PR CONTACT]
[INSERT PHONE NUMBER]

OVERVIEW

- A musculoskeletal disorder in which there is an abnormal curvature of the spine, that may lead to chronic back pain, reduced respiratory function or diminished self-esteem
- The most common deformity of the spine

PREVALENCE

- Affects one in 40 people in the U.S., or approximately 7 million people
- In 2004, an estimated 1.26 million patients utilized health care resources for problems associated with spinal deformity; 93 percent of those were diagnosed with scoliosis[1]
- The estimated total hospital charges for all patients released from the hospital with a scoliosis diagnosis was $4.6 billion[1]
- Each year, an estimated 30,000 children are fitted for a brace and more than 100,000 children and adults diagnosed with scoliosis undergo surgery[2]
- The primary age of onset is between 10-years-old and 15-years-old, but the condition can also affect infants and adults[1]
- Girls are eight times more likely than boys to have a curvature that progresses and requires treatment[1]
- Scoliosis is more common in families who have scoliosis and increases a person's risk of having the condition by 20 percent[3]

CAUSES

- Idiopathic: 85 percent of scoliosis patients are diagnosed with idiopathic scoliosis, in which the cause of the condition is unknown
- Congenital: a patient is born with a spinal abnormality that causes scoliosis
- Neuromuscular: associated with another disease such as cerebral palsy, muscular dystrophy or spina bifida

SYMPTOMS/SIGNS

- Uneven shoulders, shoulder blades, ribs, hips or waist
- Entire body leaning to one side
- Noticeable sideways curve of the spine when viewed from the back
- Appearance or texture of the ribs sticking up on one side as the child bends forward

SCHOOL SCREENING

- Fewer than half of states in the U.S. are legislated to screen for scoliosis in schools[4]
- It is recommended that females are screened at least twice at age 10 and 12 (grades 5 and 7) and males once, at age 13 or 14 (grades 8 or 9)[5]
- A standard exam used in schools and by pediatricians is the Adam's Forward Bend Test, in which the patient leans forward with feet together and the spine is evaluated

DIAGNOSIS

- The condition is confirmed by a physician using physical exams, spine x-rays, scoliometer (device measures trunk rotation) and MRI in certain circumstances
- The curve is measured by the Cobb angle method, in which lines are drawn over the x-ray of the spine to determine severity by number of degrees

TREATMENTS

- One quarter of children with spinal curves require medical attention[6]
- Treatment is normally based on:
  - Magnitude of the curve
  - Gender and age of the child
  - Probability of curve progression
- Types of treatment:
  - Observation - Curve is less than 25 degrees
    - Most spinal curves remain small and are observed by an orthopedist every four to six months during growth
    - In some cases, families seek more active treatment at this stage
  - Bracing - Curve is more than 25 degrees
    - Curves that progress require that the child wear a back brace that helps support the spine and prevent progression, while he or she is still growing
  - Surgery - Curve is more than 50 degrees
    - If a brace is ineffective, spinal fusion surgery is recommended to help straighten the spine and prevent further progression

SOURCES

[1] United States Bone and Joint Decade: The Burden of Musculoskeletal Diseases in the United States. Rosemont, IL: American Academy of Orthopedic Surgeons; 2008.

[2] National Scoliosis Foundation. Available online at: www.scoliosis.org.

[3] American Academy of Orthopedic Surgeons. Web: http://orthoinfo.aaos.org/topic.cfm?topic=A00236.

[4] Grivas TB, et al. SOSORT consensus paper: school screening for scoliosis. Where are we today? *Scoliosis.* 2008; 2:17.

[5] Richards BS and Vitale MG. Screening for Idiopathic Scoliosis in Adolescents: An informational statement. *J Bone Joint Surg Am.* 2008; 90:195-8.

[6] American Academy of Orthopaedic Surgeons. Available online at: http://orthoinfo.aaos.org/connect/psa.htm.

SCOLIOSIS GRAPHICS

The enclosed CD contains production-quality graphics and illustrations suitable for a publication on scoliosis. They may be helpful for the media in telling stories visually. The following are examples of the kind of graphics you may want to provide:

X-RAY BEFORE SURGERY

EXAMPLE OF A BRACE

SCOLIOSIS GRAPHIC

TWISTING SPINE

SECTION 3

COMMUNITY GUIDE: SPREADING THE WORD ABOUT SCOLIOSIS

HOW TO CONDUCT A HEALTH SEMINAR

We have prepared materials so that you can provide information about scoliosis to your community in an educational session.

There are three progressively more informative options that hospitals and community centers will have for conducting the seminars:

Option 1: Show a scoliosis video and provide handouts on scoliosis. (15 minutes)

Option 2: Show a scoliosis video and present a PowerPoint presentation on scoliosis. Also, provide handouts on scoliosis. (35 minutes)

Option 3: Show a scoliosis video and present a PowerPoint presentation on scoliosis and invite a local health professional to conduct a Q&A session based on materials provided in this media and community guide. Also, provide handouts on scoliosis. (45 minutes)

The following is the agenda for Option 3 and can be shortened for Options 1 and 2:

Scoliosis: Early Detection is Key to Prevention

AGENDA

1. Welcome (5 minutes)
2. Scoliosis Video (10 minutes)
3. PowerPoint Presentation: Overview of Scoliosis (20 minutes)
4. Audience Questions & Answers (Q&A) (10 minutes)

The presentation contains some audiovisual elements so it would be helpful to have a computer with PowerPoint, an LCD projector and VCR or DVD player. If a computer is not available, you could simply show the video and have a brief discussion afterwards.

The following are 5 easy steps to help you plan your health seminar:

Step 1: Pick a date, time and room at your hospital, school or community center and begin advertising the seminar at least four weeks in advance. Use the sample flyer contained in this guide on page 24.

Step 2: Post a sign-up sheet at your hospital, school or community center's information desk for those who wish to attend.

Step 3: Do what you can to publicize the event for the general community. Tips and tools can be found on page 23 of this guide.

Step 4: Set up chairs and refreshments and hold the session. Refer questions you cannot answer to the National Scoliosis Foundation Web site, www.scoliosis.org, or a hospital or doctor in your area.

HOW TO PUBLICIZE A HEALTH SEMINAR

One of the most important parts of holding a health seminar is making sure that people know about it and are interested enough to attend. The following pages contain examples of materials to help publicize your seminar. Start publicizing your seminar at least four weeks in advance. Feel free to customize the materials to include your letterhead, your contact information and relevant facts about the seminar you plan to hold.

Newsletter:	Include details about the seminar in your hospital or community center's newsletter. Details should include information on the seminar, date, time, location and hospital/center's contact person and/or phone number.
Flyer:	Create a flyer about the seminar and distribute it at your hospital/center's scheduled events. You can post the flyer throughout the hospital/center including the front door, front desk and bathroom stalls. If your budget allows, you can send a mass mailing of the flyer to a targeted list. Or perhaps it could be inserted as a paid advertisement in your local newspaper.
Word-of-Mouth:	Encourage your staff to talk to patients about attending this important seminar.
Calendar Listing:	Submit a calendar listing to your local daily and weekly newspapers and to your local television and radio stations for possible inclusion. The listing should include information on the seminar, date, time, location and hospital or community center's contact person and/or phone number. It should be sent at least four weeks in advance to these media outlets.

SAMPLE FLYER

[insert name of hospital or community center] Presents a FREE Informational Health Seminar

Scoliosis
“You Are Not Alone”

Date: [insert month], [insert day], [insert year]

Time: [insert start time] – [insert end time]

Location: [insert name of hospital or community center]
[insert address], [insert city], [insert state]
[insert zip code]

Find out the latest information about scoliosis at [insert hospital or community center].

Early diagnosis of scoliosis is the key to preventing a curve from progressing and getting treatment. Learn about the signs and symptoms of scoliosis, how the diagnosis is made and options for treatment.

Family members are encouraged to attend.

Come learn how this condition could affect you or someone you love.

Please call to reserve your seat: [insert hospital or center phone number]

SAMPLE CALENDAR LISTING

Scoliosis
“You Are Not Alone”

FOR IMMEDIATE RELEASE
[insert month], [insert day], [insert year]

MEDIA CONTACT: [insert name]
[insert phone number]

CALENDAR LISTING

Event: Free Informational Seminar: Scoliosis - “Early Detection is Key to Prevention”

Find out the latest information about scoliosis from your local [hospital or community center]. Learn what it is, how the diagnosis is made, and how the condition is treated.

Please call [insert hospital or center phone number] to reserve your seat.

Date: [insert month], [insert day], [insert year]

Time: [insert start time] – [insert end time]

Location: [insert name of hospital or community center]
[insert address], [insert city], [insert state]
[insert zip code]

SAMPLE SIGN-UP SHEET

Pre-registration is required – Sign up NOW to reserve your seat

[insert name of hospital or community center]

Presents a FREE Informational Seminar

Scoliosis
“You Are Not Alone”

[insert month], [insert day], [insert year]

[insert start time] – [insert end time]

[insert name of hospital or community center]

[insert address], [insert city], [insert state] [insert zip code]

[insert telephone number]

Family Members Are Encouraged to Attend

NAME	PHONE NUMBER	EMAIL	NUMBER OF PEOPLE ATTENDING

PATIENT EDUCATION HANDOUTS

It is important to have concise and coherent information available for people to take home and read at their leisure.

The following pages provide sample handouts with information you can make available. Feel free to customize them with your letterhead and information relevant to your institution.

SCOLIOSIS: FREQUENTLY ASKED QUESTIONS

WHAT IS SCOLIOSIS?

Scoliosis is the most common deformity of the spine. The condition causes the spine to abnormally curve sideways, into an "S" or "C" shape and to rotate. Most curves are not severe and require only that patients are monitored by doctors, but high-degree curvatures may impact lung and heart function and self-esteem, and can require treatment with bracing or surgery.

HOW MANY PEOPLE HAVE SCOLIOSIS?

One out of every 40 people, or about 7 million people in the U.S, have scoliosis. The condition can affect people of any age, but the most common age of onset is between 10 and 15 years of age. Each year, an estimated 30,000 children are fitted for braces and more than 100,000 children and adults diagnosed with scoliosis undergo surgery.

WHO IS AT A HIGH RISK OF GETTING SCOLIOSIS?

Anyone, at any age, can get scoliosis. Most of the time the person may be the only one in the family with scoliosis, but people who have a family member with scoliosis are much more likely to develop the condition. Girls are more likely to be treated for scoliosis; although girls and boys are diagnosed in equal numbers, girls are eight times more likely to have a curvature that progresses and becomes severe.

WHAT ARE THE SIGNS AND SYMPTOMS OF SCOLIOSIS?

Common signs and symptoms include: uneven shoulders, ribs, hips or waist, back pain, one shoulder blade sticking out, a rib hump at the back of the waist or ribs, one arm hanging lower than the other, discoloration or change in texture in the skin that covers the spine. Idiopathic scoliosis is generally not painful at the onset.

WHAT CAUSES SCOLIOSIS?

In 85 percent of cases, the cause of scoliosis is unknown; this is called idiopathic scoliosis. Before diagnosing a patient with idiopathic scoliosis, a doctor will look for other causes, such as injury, infection, birth defect or underlying syndrome or disease.

SECTION 3

COMMUNITY GUIDE: SPREADING THE WORD ABOUT SCOLIOSIS

HOW DOES A DOCTOR DIAGNOSE SCOLIOSIS?

A doctor will take the following steps to diagnose scoliosis: take a medical history, perform a physical exam, order and review an x-ray and/or MRI and take measurements of the curve.

HOW IS SCOLIOSIS TREATED?

One quarter of children with spinal curves require medical attention. Most scoliosis patients have their spinal curvatures monitored by doctors, on a regular basis, to determine whether the curve is progressing. Some patients may choose a variety of alternative methods for more active treatment of smaller curves or for ongoing management. For children who are still growing and have spinal curves more than 20 degrees, bracing may be recommended as a treatment. Surgery may be advised in severe cases, in which a spinal curve has progressed rapidly, or has progressed to more than 50 degrees.

WHERE CAN I GO FOR MORE INFORMATION?

Ask your local hospital and doctor for information and support groups in your area. You can also call the National Scoliosis Foundation at 800-NSF-MYBACK or www.scoliosis.org. The Resource section of this guide lists the name, address and Web site link information for a variety of scoliosis-related organizations.

ANATOMY OF THE SPINE

IMPORTANCE

The spine is one of the most important structures in the body. It allows people to stand upright, walk, move about freely and bend. Its hard, bony structure wraps around the spinal cord, protecting it. The spinal cord is made up of millions of nerve fibers that connect the brain to the rest of the body. Without the spinal cord, a person could not move any part of the body and organs couldn't function.

SECTIONS OF SPINE

The spine is made up of 24 bones, called vertebrae. Ligaments and muscles connect these bones together to form the spinal column. The spinal column gives the body form and function. The spinal column wraps around and protects the spinal cord, which is a bundle of nerves that sends signals to other parts of the body. The many muscles that connect to the spine help support the upright posture of the spine and move the spine.

CERVICAL SPINE: Consists of the top seven vertebrae at the base of the skull

THORACIC SPINE (midback): Consists of 12 vertebrae

LUMBAR SPINE (lower back): Usually made up of five vertebrae

SACRUM: A set of five fused vertebrae that connects the base of spine to the pelvis

COCCYX (tailbone): A set of four vertebrae at the end of the spine that attaches to muscles and acts as a shock absorber when a person sits down

PARTS OF SPINE WORK TOGETHER

The normal spine has an "S"-like curve when looking at it from the side. This allows for an even distribution of weight. The "S" curve helps a healthy spine withstand all kinds of stress. The cervical spine curves slightly inward, the thoracic slightly outward, and the lumbar slightly inward. Even though the lower portion of the spine holds most of the body's weight, each segment relies upon the strength of the others to function properly.

SECTION 3

COMMUNITY GUIDE: SPREADING THE WORD ABOUT SCOLIOSIS

SCOLIOSIS: FAST FACTS

- Scoliosis is the most common deformity of the spine
- The condition causes the spine to abnormally curve sideways, into an "S" or "C" shape of more than 10 degrees
- Two to three percent of the population, or about 7 million people in the U.S., have scoliosis; that's one out of every 40 people[1]
- The condition can affect people of any age, but the most common age of onset is between the ages of 10 and 15[1]
- Each year, an estimated 30,000 children are fitted for braces and more than 100,000 children and adults diagnosed with scoliosis undergo surgery[1]
- People who have a family member with scoliosis are more likely to develop the condition
- Although girls and boys are diagnosed with scoliosis in equal numbers, girls are eight times more likely to have a curve that progresses and requires treatment[1]
- Common signs and symptoms include: uneven shoulders, ribs, hips or waist, back pain, one shoulder blade sticking out, a rib hump at the back of the waist or ribs, one arm hanging lower than the other, discoloration or change in texture in the skin that covers the spine
- In 85 percent of cases, the cause of scoliosis is unknown; this is called idiopathic scoliosis[1]
- One quarter of children with spinal curves require medical attention[2]
- Fewer than half of U.S. states currently legislate school screening; medical societies recommend that females are screened at least twice at age 10 and 12 and males once at age 13 or 14[3]

SOURCES

[1] National Scoliosis Foundation. Information and Support. Cited 21 May 2008. Available from: http://www.scoliosis.org/info.php.

[2] American Academy of Orthopaedic Surgeons. Available online at: http://orthoinfo.aaos.org/connect/psa.htm.

[3] Richards BS and Vitale MG. Screening for Idiopathic Scoliosis in Adolescents: An Information Statement. *J Bone Joint Surg Am.* 2008; 90:195-198.

SCOLIOSIS: SELF-ASSESSMENT QUESTIONNAIRE

Only a doctor can diagnose scoliosis. However, if you think you or someone you love might have scoliosis, here are some questions to consider:

- Has anyone in your family been diagnosed with scoliosis? Y/N
- Do you have a lot of pain in your back? Y/N
- Is one of your shoulders higher than the other? Y/N
- Are your rib cages different heights on either side when you bend forward? Y/N
- Is your waist uneven or is the appearance of one hip higher than the other? Y/N
- Does your entire body lean to one side? Y/N
- Is there a difference in the appearance or texture of the skin overlying your spine, particularly at the base (e.g. dimples, hairy patches, color abnormalities)? Y/N
- Does one of your legs appear shorter than the other? Y/N
- Does one of your shoulder blades appear more prominent than the other? Y/N
- Do you ever have weakness in your arms or legs? Y/N

If you answered yes to any one of these questions, please make an appointment to see your physician.

FINDING A SPECIALIST

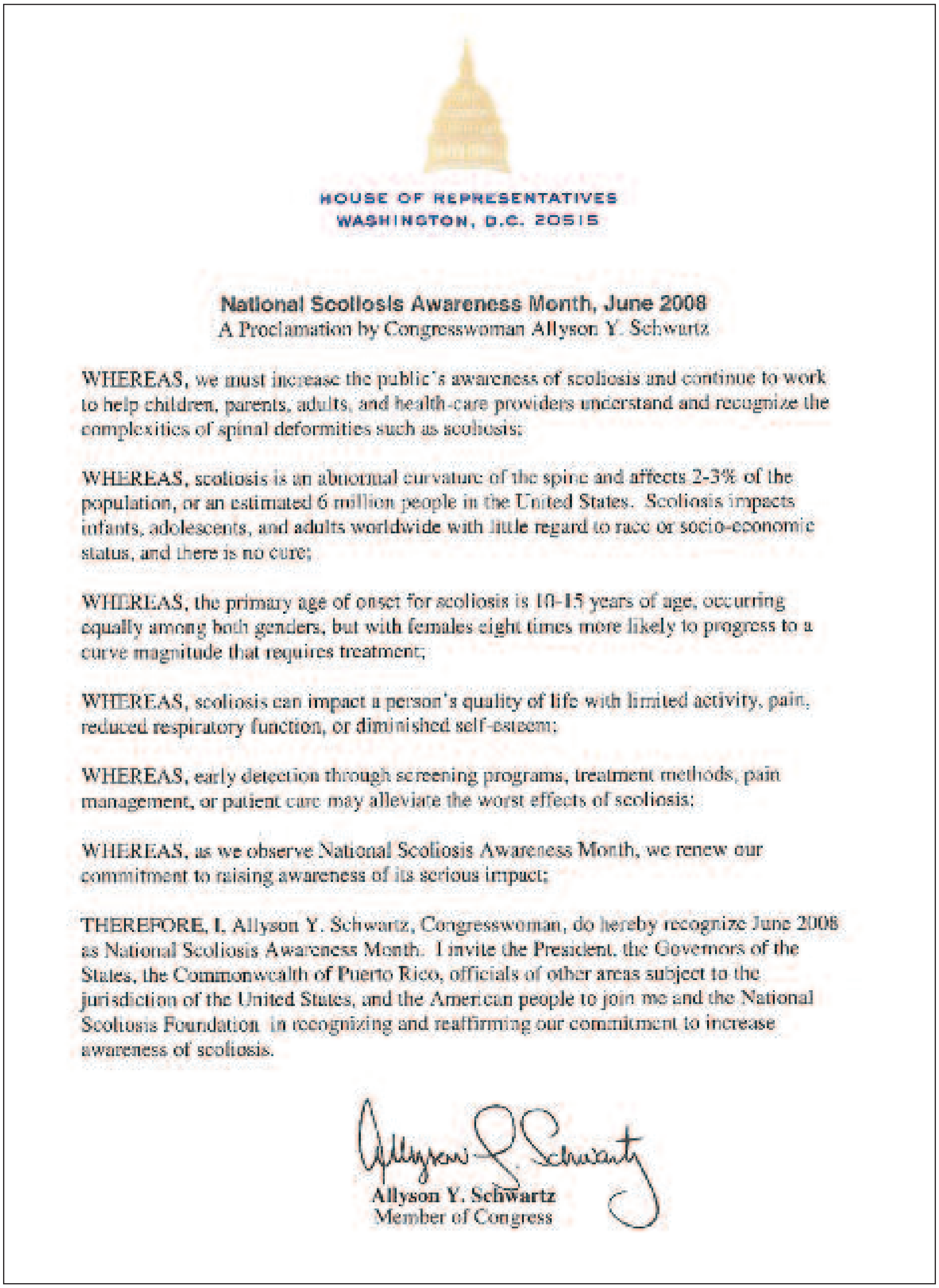
It is important to find a specialist who is well-trained and with whom you feel comfortable. Here are some suggested questions to ask a doctor on your first visit.

SUGGESTED QUESTIONS TO ASK YOUR DOCTOR:

- Are you board certified?
- Are you a member of the Scoliosis Research Society?
- What kind of treatments do you offer?
- Which kinds of braces do you suggest to patients most often?
- How long have you been performing spinal fusion surgeries? How many have you performed?
- What are the risks and benefits of surgery?
- What are the most common complications associated with this surgery?
- What are the complication and mortality rates in your practice?

A physician can provide you with expert advice on whether or not treatment or surgery is right for you. He or she can provide you with the most appropriate options for your condition.

To locate a doctor in your area, please contact your local hospital. You may also contact the National Scoliosis Foundation for information on resources, patient contacts, and listings of scoliosis specialists in your area. The Resource section of this guide lists the name, address and Web site link information for a variety of scoliosis-related organizations.



HOUSE OF REPRESENTATIVES
WASHINGTON, D.C. 20515

National Scoliosis Awareness Month, June 2008
A Proclamation by Congresswoman Allyson Y. Schwartz

WHEREAS, we must increase the public's awareness of scoliosis and continue to work to help children, parents, adults, and health-care providers understand and recognize the complexities of spinal deformities such as scoliosis;

WHEREAS, scoliosis is an abnormal curvature of the spine and affects 2-3% of the population, or an estimated 6 million people in the United States. Scoliosis impacts infants, adolescents, and adults worldwide with little regard to race or socio-economic status, and there is no cure;

WHEREAS, the primary age of onset for scoliosis is 10-15 years of age, occurring equally among both genders, but with females eight times more likely to progress to a curve magnitude that requires treatment;

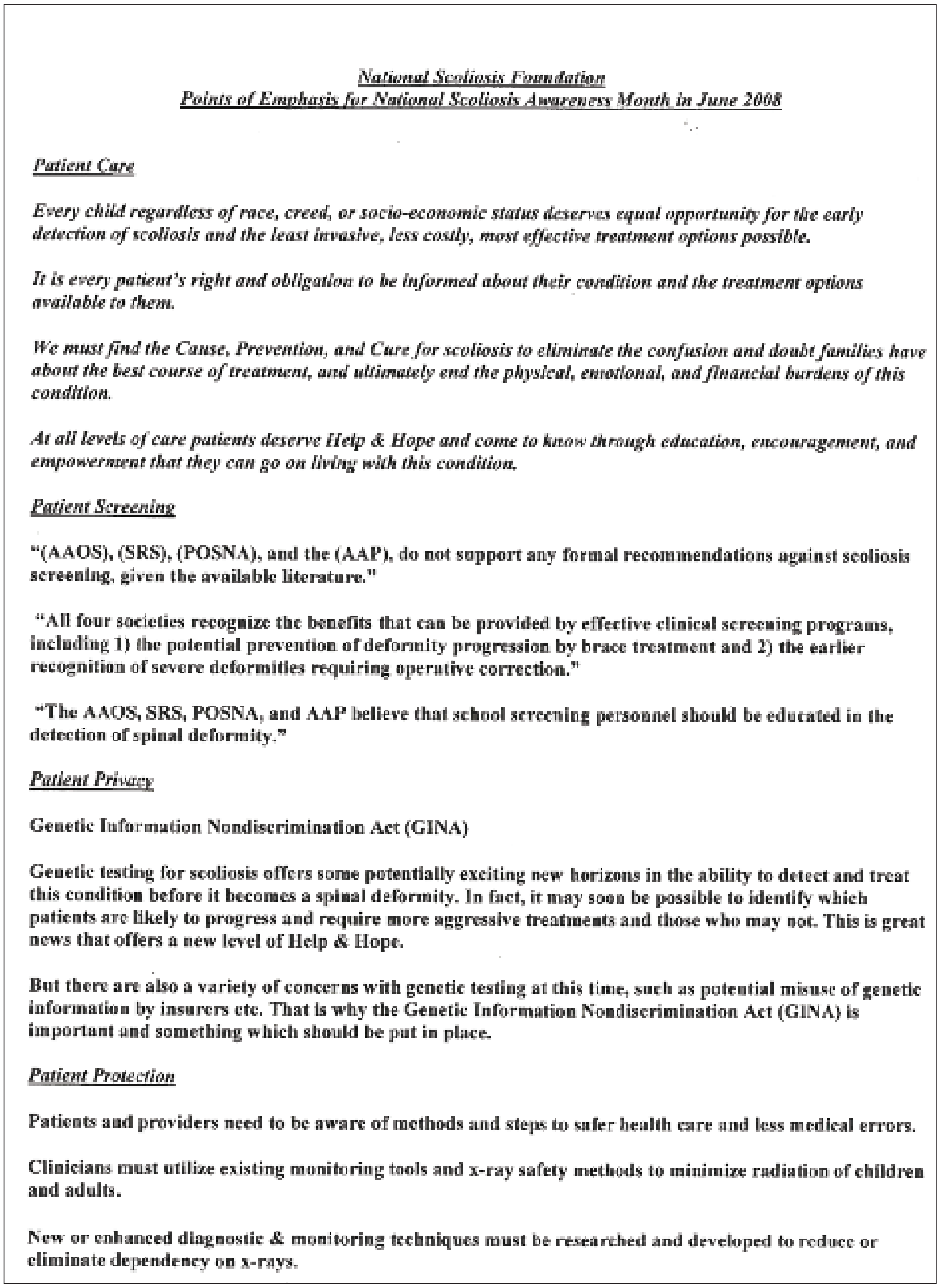
WHEREAS, scoliosis can impact a person's quality of life with limited activity, pain, reduced respiratory function, or diminished self-esteem;

WHEREAS, early detection through screening programs, treatment methods, pain management, or patient care may alleviate the worst effects of scoliosis;

WHEREAS, as we observe National Scoliosis Awareness Month, we renew our commitment to raising awareness of its serious impact;

THEREFORE, I, Allyson Y. Schwartz, Congresswoman, do hereby recognize June 2008 as National Scoliosis Awareness Month. I invite the President, the Governors of the States, the Commonwealth of Puerto Rico, officials of other areas subject to the jurisdiction of the United States, and the American people to join me and the National Scoliosis Foundation in recognizing and reaffirming our commitment to increase awareness of scoliosis.

Allyson Y. Schwartz
Member of Congress



National Scoliosis Foundation
Points of Emphasis for National Scoliosis Awareness Month in June 2008

Patient Care

Every child regardless of race, creed, or socio-economic status deserves equal opportunity for the early detection of scoliosis and the least invasive, less costly, most effective treatment options possible.

It is every patient's right and obligation to be informed about their condition and the treatment options available to them.

We must find the Cause, Prevention, and Cure for scoliosis to eliminate the confusion and doubt families have about the best course of treatment, and ultimately end the physical, emotional, and financial burdens of this condition.

At all levels of care patients deserve Help & Hope and come to know through education, encouragement, and empowerment that they can go on living with this condition.

Patient Screening

"(AAOS), (SRS), (POSNA), and the (AAP), do not support any formal recommendations against scoliosis screening, given the available literature."

"All four societies recognize the benefits that can be provided by effective clinical screening programs, including 1) the potential prevention of deformity progression by brace treatment and 2) the earlier recognition of severe deformities requiring operative correction."

"The AAOS, SRS, POSNA, and AAP believe that school screening personnel should be educated in the detection of spinal deformity."

Patient Privacy

Genetic Information Nondiscrimination Act (GINA)

Genetic testing for scoliosis offers some potentially exciting new horizons in the ability to detect and treat this condition before it becomes a spinal deformity. In fact, it may soon be possible to identify which patients are likely to progress and require more aggressive treatments and those who may not. This is great news that offers a new level of Help & Hope.

But there are also a variety of concerns with genetic testing at this time, such as potential misuse of genetic information by insurers etc. That is why the Genetic Information Nondiscrimination Act (GINA) is important and something which should be put in place.

Patient Protection

Patients and providers need to be aware of methods and steps to safer health care and less medical errors.

Clinicians must utilize existing monitoring tools and x-ray safety methods to minimize radiation of children and adults.

New or enhanced diagnostic & monitoring techniques must be researched and developed to reduce or eliminate dependency on x-rays.

ADVOCACY:
EDUCATE YOUR COMMUNITY ABOUT SCOLIOSIS

There are many ways you can help spread the word about scoliosis in your community, from writing a letter to the editor of your local paper to organizing "Call to Action" events. You can educate more people about this important issue by using the following tools to assist you in your mission.

HOW TO WRITE A LETTER TO THE EDITOR

Writing a Letter to the Editor of your local weekly or daily newspaper may be an effective way to communicate your opinion to the community, local politicians, opinion leaders and policy makers. The editorial section is known to be one of the most-widely read sections of the newspaper, so getting published there is a great way to have your voice heard. You can find a list of weekly and daily newspapers in your area in your local telephone directory or on the Web.

Before you write a letter, here are some useful tips to consider:

- Newspaper Policy – Find out the submission policy of the news organization you are targeting. Some may require you to e-mail the letter to a specific address, while others may suggest sending it via regular mail. Most media will require you to include your first and last name, town and phone number when submitting a letter. Your phone number and address will not be printed, just your name. Many publications will contact you prior to publishing your letter to confirm you wrote it. Some newspapers may also have word count limitations. It is best to keep your letter to 150 words or less.
- Shorter is Better – Your letter should be one to four short paragraphs. A sentence should be less than 20 words. Get to your point in your first paragraph because not every reader will have time to read your entire letter. Use simple language and exclude the use of jargon.
- Timing is Everything – Submit your letter in a timely fashion after an article appears about a particular issue. Be sure to mention the headline and date you are referencing. You can also connect the letter to a specific event or health awareness month.
- Localize the Issue – Include local statistics about scoliosis, if available, by contacting your local health department. Stress the importance of screenings in schools, pointing out which schools in your area are conducting routine tests. Also, if a local legislator supports or opposes a particular issue, note the name of the politician. Finally, encourage other readers to take action by contacting their legislators to request they support continuing education on scoliosis.
- Personal Story – If you or a loved one has scoliosis, discuss your personal story. Personal stories help put a face on the condition and help others understand the issue. Describe how scoliosis has affected your life or the life of someone you know, how the scoliosis was detected and the importance of diagnosing scoliosis as early as possible.
- Expert Opinion – If you are a school nurse, medical expert or healthcare professional who treats scoliosis patients, don't be afraid to use your educational background to leverage your point of view and note it in your letter.

SAMPLE LETTER TO THE EDITOR #1

LETTER 1 – Send in September

[INSERT DATE]

[INSERT NAME]
[INSERT PUBLICATION NAME]
[INSERT MAILING ADDRESS]

Dear Editor:

With the school year in full swing, we are reminded again of scoliosis and the importance of early detection and screenings.

Many national societies recommend school screenings in order to prevent severe scoliosis. In a joint statement, the American Academy of Orthopaedic Surgeons, the Scoliosis Research Society, the Pediatric Orthopaedic Society of North America and the American Academy of Pediatrics recommend that females are screened twice, at age 10 and 12 and males once, at age 13 or 14.[1]

One quarter of children with spinal curves require medical attention[2]. Girls are eight times more likely than boys to have a curve that will progress, requiring treatment[3]. The primary age of onset for scoliosis is between 10- and 15-years-old, so the time to screen our young people is now.

We urge our schools and local representatives to continue to support screenings in our community to help prevent severe spinal deformity and the consequences that it may bring to our children.

Sincerely,
[INSERT NAME]
[INSERT TOWN]
[NSERT PHONE NUMBER]

SOURCES

[1] Richards BS and Vitale MG. Screening for Idiopathic Scoliosis in Adolescents: An Information Statement. *J Bone Joint Surg Am.* 2008; 90:195-198.

[2] American Academy of Orthopaedic Surgeons. Available online at: http://orthoinfo.aaos.org/connect/psa.htm.

[3] National Scoliosis Foundation. Information and Support. [cited: 14 April 2008]. Available from: http://www.scoliosis.org/info.php.

SAMPLE LETTER TO THE EDITOR #2

LETTER 2 – Send in late May/early June

[INSERT DATE]

[INSERT NAME]
[INSERT PUBLICATION NAME]
[INSERT MAILING ADDRESS]

Dear Editor:

I wanted to commend the National Scoliosis Foundation for taking the lead in making June National Scoliosis Awareness Month. We can now reflect on this health condition where there is no cure, but there is treatment for those suffering from severe spinal deformity.

As a mother of a child with scoliosis, I have seen first hand what it is like to live with the condition. If it wasn't for a school screening, my daughter might not have received the proper care for her scoliosis.

I urge our community to continue school screenings for scoliosis.

Sincerely,
[INSERT NAME]
[INSERT TOWN]
[INSERT PHONE NUMBER]

HOW TO CONTACT YOUR LEGISLATORS

Governmental officials can help spread the word about health issues, including scoliosis. You can gain their support for an issue you strongly believe in by calling or writing them about the topic. Before reaching out, consider the following questions:

- Who are your legislators?
- How do you contact your legislators?
- What do you hope to achieve by working with legislators?

WHO ARE YOUR LEGISLATORS?

The easiest way to find out your legislators' names and contact information is on the Internet. The following URLs should point you in the right direction:

- To find your U.S. House of Representative via name, go to: http://www.house.gov/house/MemNameSearch.shtml
- To find your U.S. House of Representative via state, go to: http://www.house.gov/house/MemStateSearch.shtml
- To find your U.S. Senator by state, go to: http://www.senate.gov

The search will provide you with your representative's contact information including his or her mailing address and phone number. An e-mail address will be provided when it is available.

HOW DO YOU CONTACT YOUR LEGISLATORS?

You can reach out to your legislators via e-mail, mail or phone. Since it is their job to represent you, there is a staff member in every legislator's office dedicated to reading about and responding to your concerns. The staff person may record the number of phone calls that come into the office on a particular issue, and that could encourage your legislator to champion that issue. You may receive a response to your letter or e-mail from your representative addressing your concern or validating his or her support or opposition of a particular bill or issue.

WHAT DO YOU HOPE TO ACHIEVE BY WORKING WITH LEGISLATORS?

Support from your legislators can help your mission when it comes to promoting scoliosis awareness. Legislators can influence the allocation of funding for research, awareness and screenings. They can also attract media attention to an issue through public speaking, or by attending an event focused on a particular issue. Be sure to invite your representatives to any educational or awareness events you hold.

SAMPLE LETTER TO LEGISLATOR

[INSERT DATE]

[INSERT TITLE, NAME]

[INSERT MAILING ADDRESS]

To [INSERT NAME]:

I urge you to support scoliosis screenings in our schools.

With the school year in full swing, we are reminded again of scoliosis and the importance of early detection and screenings. In a joint statement, the American Academy of Orthopaedic Surgeons, the Scoliosis Research Society, the Pediatric Orthopaedic Society of North America and the American Academy of Pediatrics recommend that females are screened twice, at age 10 and 12 and males once, at age 13 or 14[1].

One quarter of children with spinal curves require medical attention[2]. Girls are eight times more likely than boys to have a curve that will progress, requiring treatment[3]. The primary age of onset for scoliosis is between 10- and 15-years-old, so the time to screen our young people is now.

Please help our community prevent severe spinal deformity and its consequences in our children, and support scoliosis screenings in our schools.

Thank you for your time.

Sincerely,

[INSERT NAME]

[INSERT TOWN]

[INSERT PHONE]

SOURCES

[1] Richards BS and Vitale MG. Screening for Idiopathic Scoliosis in Adolescents: An Information Statement. *J Bone Joint Surg Am.* 2008; 90:195-198.

[2] American Academy of Orthopaedic Surgeons. Available online at: http://orthoinfo.aaos.org/connect/psa.htm.

[3] National Scoliosis Foundation. Information and Support. [cited: 14 April 2008]. Available from: http://www.scoliosis.org/info.php.

HOW TO SECURE A TOWN RESOLUTION

A town resolution is a formal stamp of approval from a government entity, such as a mayor or local official, supporting a particular issue or topic such as scoliosis. Before you secure a town resolution from your government official, you will need to determine the message you want to communicate about scoliosis.

WHAT IS YOUR MESSAGE

Consider the following questions to determine the key message of your resolution:

- Do you want your town to support additional funding for scoliosis research?
- Do you want your school to continue yearly scoliosis screenings?
- Do you want your town to host educational health seminars on scoliosis?
- Do you want your town to organize and provide support groups on scoliosis?

HOW TO OBTAIN A TOWN RESOLUTION

Once you have determined your message, follow these steps:

- Contact your local government official's office and find out the person who handles processing town resolutions.
- Identify the steps needed to obtain a town resolution.
- Submit the proper paperwork.
- Continue to follow up with the official's office.
- Secure a formal resolution via fax or e-mail once the government official has agreed to support your cause or mission.

AFTER OBTAINING RESOLUTION

After you have obtained your town resolution, make sure that people know about it. Follow up with government officials to ensure it is published on the appropriate city and state Web sites. Email a copy of the resolution along with photos and stories to the National Scoliosis Foundation for publication on the National Scoliosis Awareness Campaign Web site. Let the media know that your resolution has been adopted; this may be a good reason for them to cover a story on scoliosis.

HOW TO PLAN A "CALL TO ACTION" EVENT

Organizing a public event can help draw attention to the issue of supporting scoliosis screenings in schools, secure additional funding for scoliosis research or generally increase awareness of the condition. In order to execute a "Call to Action" event, you may want to consider the following steps to help you prepare for a successful outcome.

MESSAGE

Similar to a town resolution, you will need to define what your message is prior to executing an event. Some of the messages you may want to consider include:

- Support additional funding for scoliosis research
- Continue yearly scoliosis screenings in schools
- Create awareness of National Scoliosis Awareness Month – June
- Connect scoliosis patients with one another
- Increase awareness of the signs and symptoms of scoliosis

AUDIENCE

You will need to determine the specific audience you want your event to impact the most. To whom are you trying to communicate your message? Consider the following audiences:

- Government officials
- School leaders
- Media
- Scoliosis patients
- Teens
- Parents
- Local community

RECRUITMENT

There is power in numbers. Gain support for scoliosis by building a strong list of supporters who believe in your mission. Pick a name for your group. Gather the names and contact information of local parents and children with scoliosis via research on the Internet, contacting scoliosis support groups, or calling the National Scoliosis Foundation. Supporters may be more likely to take the time to participate in an event because of their personal connections to the cause. You may also want to invite friends and family members to participate.

Plan your event at least three months in advance, let people know early and then remind them as the event draws closer.

LOCATION

Choose wisely when determining the location of your event. Consider that people will need to know how to find the event's location and will need parking places. Additionally, if you would like the media to attend, think of how a particular location may connect to your event or draw attention to it. Some places to consider holding an event are:

- State capitol
- Public area, such as a park or playground
- A local school
- A local hospital

Once you select a location, you will need to notify the necessary parties (i.e. police, public authority officials, etc.) and obtain the required paperwork to get permission to hold your event at that site. Some cities or towns may request you to submit information about the event, such as the name of your organization or group, a list of participants, the location, the time and date and the agenda.

TIMING

Timing is one of the keys to the success of your event. Here are some things to think about:

- **Weather** - Pick a day and month when the weather is not too cold, since your event may be held outdoors and your volunteers may need to participate outside. This may help you recruit a larger amount of supporters.
- **Time of day** - Choose a time most accommodating to your group. Mornings and early afternoons tend to be the best times of the day to hold an event.

  If you are planning on media coverage, think about media deadlines. Television stations may need to have stories for a particular newscast, or newspaper stories may need to be written before a deadline in order to be published.
- **Time of year** - Holding an event around a particular time of year, such as the beginning of school or a National Scoliosis Awareness Month, June, may help draw more attention to the event.

MATERIALS

Create posters, flyers, buttons and shirt stickers that speak your message such as "Support Scoliosis Screenings Now – Early Detection is Key" at least three weeks in advance of your event. Each person participating in the event should have at least one of the materials communicating your message.

MEDIA

If you want to draw media attention, you will need to create a media advisory outlining the details of your event (see an example of a media advisory on page 16. Research the local media outlets in your area and invite the television stations, radio stations, newspapers and Web sites to your event at least two weeks in advance and then again closer to the event.

Appoint a responsible person in your group to serve as the media contact and official spokesperson for your cause. Take high-resolution photographs at the event for possible submission to your weekly newspaper. Following the event, you can also create and submit a post-event press release to your local weekly newspaper with notable photographs.

NETWORK: LEARN MORE FROM OTHERS

Scoliosis is a condition that affects two to three percent of the population – so if you, or someone you love, is diagnosed with scoliosis it is important to know that you and your loved one are not alone.

Being diagnosed with scoliosis can be a scary experience if you don't know much about the condition or how it will affect your life. One way to learn more is to reach out to other scoliosis patients and their families. Learning that people have faced the same issues you are facing, or hearing about their experiences of diagnosis and treatment can be both informative and therapeutic.

The following section of this guide offers two ways to learn from the experience of others: 1) start a support group and 2) read profiles of other patients' personal experiences.

HOW TO ORGANIZE A SCOLIOSIS SUPPORT GROUP

You and your loved one do not have to suffer alone when it comes to dealing with scoliosis. You can attend a local support group in your neighborhood or form your own group if one does not exist in your area. Follow these steps to create a support group:

CONTACT THE NATIONAL SCOLIOSIS FOUNDATION

The National Scoliosis Foundation (NSF) can help you get started by connecting you with other patients in your area, identifying scoliosis specialists to contact or invite as guest speakers, referring patients who contact NSF throughout the year, promoting your meeting, providing educational materials and answering your questions.

COMPILE A PARTICIPANT LIST

You will need to obtain a list of people interested in attending a support group. Use contacts from the National Scoliosis Foundation and from schools that may be able to provide you with a list of people interested in learning more about scoliosis and seeking personal support and sharing experiences.

CHOOSE A FACILITATOR

The person leading the group discussion should be knowledgeable about scoliosis, have a personal connection to the issue and be able to facilitate a lively discussion among the group.

PICK A DESIGNATED DATE AND TIME

Determine if you want to hold a group on a weekly, monthly or quarterly basis. This will depend on the level of involvement and participation of your group members.

PICK A LOCATION

For safety reasons, you may want to consider exploring a public place to hold your support groups instead of your home or place of residency. Sometimes schools and local churches may be open to offer you a free room to hold your group if you are member of the community or congregation.

GATHER RELEVANT EDUCATIONAL MATERIALS

Contact the National Scoliosis Foundation or your local health department to obtain educational materials on scoliosis that may be useful to your group. Some of these materials can be found in the community section of the guide on pages 26-31.

PUBLICIZE THE EVENT

Local weekly or daily newspapers and radio stations will often publicize a local event in their newspaper or on their station free of charge. You can send them a calendar listing that briefly describes the support group. Please see the educational seminar section that begins on page 22 of the guide.

You can also consider posting your meeting in the "Scoliosis Support Meetings, Events, Conferences & Clinics" calendar section of the National Scoliosis Foundation's Web site: www.scoliosis.org.

CONTACT PARTICIPANTS

E-mail or mail flyers to your potential participant list a few weeks before your first meeting, and encourage them to bring any guests. There is an example of a flyer on page 24 of this guide. Remind them a week before meetings.

MAKE ARRANGEMENTS FOR FOOD AND DRINKS

Consider bringing refreshments and snacks to the meetings. Depending on the size of your group, you may want to ask for volunteers to bring different items, such as water, soda, chips, pretzels, paper napkins, plates and cups.

SET UP ROOM ONE HOUR PRIOR TO EVENT

Arrive at least one hour early to set up chairs, food, drinks and educational materials. You may also want to have a sign-in sheet so you can keep track of participants and contact information.

SET UP GUEST SPEAKERS

After your first few meetings, consider asking guest speakers to attend your support group. Perhaps there are members of your community who can be resources. Doctors and clinicians at local hospitals and practices may be able to speak on relevant issues and offer new information or guidance. There may also be scoliosis patients who are willing to speak about their experience, or parents who can speak about what it is like to have a child living with the condition. Remember that a member of your group can also be chosen to be a guest speaker on occasion.

BRAINSTORM WITH YOUR SUPPORT GROUP

Every meeting or two, check in with the members of your support group to find out what they hope to get out of the meetings. There may be a topic they would like to know more about, or a speaker they would like to invite. They could have new ideas of ways to structure meetings. You won't know how the group feels about the meetings until you ask.

SHARE PERSONAL STORIES

Reading the personal stories of other patients with scoliosis can help you to learn more about the condition and what to expect through diagnosis and treatment. There are many stories published both in books [see pages 52-54 of guide] and on the Internet from which you can choose and learn.

The following pages contain the personal profiles of a few scoliosis patients to help you get started. Feel free to pass these profiles out at support groups and to encourage others to write and share their own stories.

MELANIE'S SCOLIOSIS STORY

For Melanie McCarroll, 22, scoliosis is a condition that caused her physical and emotional pain, taught her she is stronger than she ever imagined and created within her a fierce determination to become an orthopedic surgeon.

Melanie was first diagnosed with scoliosis in fifth grade, when a school nurse noticed her spine was curved and sent her home with a note to see her doctor. By seventh grade, her curvature had increased significantly, and she got her first brace.

"I had various braces all through middle and high school but I didn't wear them as much as I should have," said Melanie. "They were painful and I was so embarrassed because I felt like I looked different and couldn't wear the same clothes everyone else was wearing."

By age 17, Melanie's curve had progressed to 125 degrees and she was having trouble breathing because her chest cavity was so collapsed. She traveled four hours from home to see a specialist who recommended spinal fusion surgery to straighten her spine.

"I started researching more about scoliosis after I found out I needed surgery," Melanie said. "I didn't know anyone else who had scoliosis. I felt really alone, really hopeless. I needed to learn more."

Melanie had surgery on July 24, 2003. She was a junior in high school. The surgery took 10 hours. She spent weeks in the hospital, re-learning how to sit up and walk. When she read a description of her surgery, she was in complete awe at what the doctors had done.

"I felt like WOW – just complete amazement at the surgery. I went from a curve of 125 degrees to a curve of 10. I gained five inches in height. I could have been paralyzed, I could have died, but there I was, all straightened out. Something just clicked in my head and I knew I wanted to do this kind of surgery some day."

Melanie graduated from Oklahoma State University in May 2008 and will start medical school at the University of North Dakota in the fall. She wants to study orthopedics to help people the way her surgeon helped her, and knows she will be able to empathize with her patients in a way not everyone can.

"Having scoliosis has created in me this passion for the spine that I know will never go away," said Melanie. "Millions of people have this condition and there is help and support out there. When I was going through this, I wish I had known that I was not the only one."

*Scoliosis patients should consult with their doctors for treatment and before engaging in strenuous activities.

SECTION 3

COMMUNITY GUIDE: SPREADING THE WORD ABOUT SCOLIOSIS

JESSICA'S SCOLIOSIS STORY

These days Jessica Fides, 26, can lift one-and-a-half times her body weight straight up over her head. But there was a time, not too long ago, when the petite 5'4" Floridian worried she might never walk again. At age 13, Jessica was diagnosed with a form of scoliosis so severe she had to have surgery to straighten her spine. Now, she's a pre-med college student and a competitive weight-lifter qualifying for Olympic trials. Jessica is walking proof that people with scoliosis can live active lives.

"Jessica was a competitive dancer growing up and always really skinny," said Jessica's mother, Janice. "One day, in sixth grade, she was wearing her leotard and I saw her little shoulder blades sticking out. I thought it was because she was thin, but I looked closer, and her backbone was curved."

Jessica remembers getting diagnosed with scoliosis as a really scary and suspenseful time because she didn't know anything about the condition or how it would impact her life.

"When I first found out that I had scoliosis, I had no idea who to talk to," said Jessica. "I saw three doctors, but I didn't know anyone who was going through what I was or anyone who had been through it. I remember my mom and I crying because we didn't know what having scoliosis meant."

The curve in Jessica's spine got worse very quickly following her diagnosis. She was fitted for a brace, but by the time it was ordered and arrived at the doctor's office, her spinal curve had progressed so much she couldn't even wear it. That's when Jessica, her family and her doctors decided that having surgery was her best option.

"I knew that if I didn't have the spinal fusion surgery then, my back would have gotten worse," said Jessica. "As my curvature progressed, it could have affected my lungs and my heart. It was upsetting and I knew surgery was risky and I didn't know if I would dance again."

Jessica had spinal fusion surgery in 1995. Sections from her upper thoracic to lumbar spine were straightened and fused and four rods were inserted for support. She was in the hospital for less than a week and was walking four days after surgery. Within two months she was dancing again.

"I know the surgery changed my movement. I can't bend backwards, there are certain things I can't do," said Jessica. "But still, I was shocked at how much I could do. When I went into the operating room, I didn't know if I would ever walk correctly again."

Since then, Jessica has tackled any challenge that comes her way. In high school, Jessica discovered that she was good at weight lifting and has been doing it ever since. She is part of Team Florida Gulf Coast and consistently places second in her weight division. Most recently, she qualified to compete in the 2008 Olympic trials. She's also double majoring in biology and biochemistry at the University of Central Florida and plans to apply to medical school this summer. Jessica is also a spokesperson for the National Scoliosis Foundation.

*Scoliosis patients should consult with doctors for treatment and before engaging in strenuous activities.

ANGELYN'S SCOLIOSIS STORY

Angelyn Traylor, 17, was diagnosed with scoliosis when she was in the fourth grade, but only because the school nurse thought her older brother had the condition.

"My mom was researching scoliosis on the Internet and she learned it runs in families," said Angelyn. "So when my brother was checked out by our pediatrician, so was I. As it turned out, my scoliosis was more severe than his and I had a double curve."

Though her brother's curvature never progressed to a degree requiring treatment, Angelyn's curves increased as she got older. When she was in sixth grade and her bottom curve reached 25 degrees, her doctor recommended she wear a brace.

"Wearing the brace was really hard – especially at first," said Angelyn. "I had to wear it for 20 hours a day. It was painful and I was really self-conscious about the way I looked. But you get used to the brace the longer you wear it and we found little tricks for it. I used to wear pants with adjustable waists so I still had something to wear when I took the brace off and I wore shirts with collars to hide the shoulder straps of my undershirts."

Angelyn wore a brace for 2½ years. Her curves did not progress significantly, and according to her doctor, as long as they remain stable, she won't need spinal surgery.

Having scoliosis does not slow down Angelyn's active life at all. She plays the flute, the piano and the organ. She is in her school's chorus and belongs to a handbell choir at her church. She's a dancer and a baton twirler. Most recently, she was crowned the 2008 Miss Troup County's Outstanding Teen in her home state of Georgia.

Angelyn plans to compete in the Miss Georgia's Outstanding Teen Pageant. Her platform is called "When Life Throws You a Curve – Spreading The Word About Scoliosis." She will answer questions about the topic and how she plans to promote it. Currently, Angelyn speaks at community clubs and parent-teacher organizations about scoliosis and the importance of early detection and school screenings. She has also become a spokesperson for the National Scoliosis Foundation. In the future she hopes to speak at elementary schools and assist school nurses as a volunteer screener.

"I want to talk directly to other kids who are at the age I was when I was diagnosed. I remember being really scared about what was happening to me because I had never even heard about scoliosis before my brother and I were diagnosed," said Angelyn. "I also want to tell parents that they should allow their kids get screened at school. The fact that I was diagnosed early meant that I could get braced while I was still growing. That may have saved me from needing surgery."

*Scoliosis patients should consult with doctors for treatment and before engaging in strenuous activities.

SECTION 3

COMMUNITY GUIDE: SPREADING THE WORD ABOUT SCOLIOSIS

STACY'S SCOLIOSIS STORY


Golfweek/Tracy Wilcox

Stacy Lewis is a professional golfer and a rookie on the LPGA Tour. But, this blonde, blue-eyed girl-next-door type is no ordinary golfer. She not only amassed an incredible record of achievement during her collegiate and amateur career, but she has done it after overcoming the debilitating effects of scoliosis.

At the age of 11, a school screening discovered that she had scoliosis – an excessive curvature of the spine. For 7 ½ years, she wore a back brace for 18 hours a day, everyday and even slept in it. She only took it off to play golf. At the age of 18, when she had stopped growing, she knew that she would be able to finally shed the back brace. Unfortunately, without the brace for support, her spine curvature began to reappear such that surgery remained the only option. This was nearly devastating to Stacy because just months earlier, she had accepted a golf scholarship to the University of Arkansas. Now, she wasn't sure if after surgery, she would be able to play golf at that level again. After being told by the Arkansas golf team coach that she would hold a spot for her, Stacy had surgery to fuse a metal rod and 5 screws into her spine. Knowing that she was a golfer, Stacy's surgeon deliberately chose not to use 2 rods in order to allow Stacy to turn more freely. After 3 more months in a brace and then another 6 months of rehab, during which she couldn't hold anything heavier than 5 pounds, Stacy began to putt and chip (very well) and slowly worked her way back unto the Arkansas golf team in 2004.

By the time she graduated in 2008, Stacy had accumulated an incredible 12 NCAA wins including the 2007 NCAA individual championship! In addition, while playing as an invited student during the inaugural LPGA NW Arkansas tournament, Stacy "won" the tournament only to have it declared unofficial when they cancelled the rest of the tournament due to rain. After staying all four years and graduating with a double major in finance and accounting from Arkansas, Stacy played in her final amateur event – the prestigious Curtis Cup at the Old Course at St. Andrews, Scotland. During that tournament, Stacy not only helped the United States win, but she set a record to become the first player in Curtis Cup history to record 5 wins against 0 losses.

Stacy turned pro in mid-summer 2008 just in time for the US Women's Open. Showing the poise and skill of an LPGA veteran, Stacy took the lead of the most prestigious women's tournament in the world after 3 rounds and played in the final group in the final round before finishing in 3rd place. In December 2008, Stacy officially earned her LPGA "Tour Card" by winning the LPGA Qualifying Tournament by 3 strokes over the strongest Q-school field in LPGA history.

Today, Stacy is playing a full schedule on the LPGA Tour but is careful to stretch regularly and to not play too many consecutive weeks in a row. As an LPGA player, Stacy is an inspiration as someone who has done it right and overcome so much to succeed. As a spokesperson for the Scoliosis Research Society, Stacy is now able to be an inspiration to millions of kids around the world who no longer have to be fearful that scoliosis is the end of an active and normal life.

*Scoliosis patients should consult with doctors for treatment and before engaging in strenuous activities.

FAMOUS PEOPLE WHO HAVE SCOLIOSIS

Scoliosis is a condition that affects people from all walks of life. It is important to know that if you are diagnosed with scoliosis, you are not alone. Here are the names of some people you might recognize who have been diagnosed with scoliosis:

- **Jessica Andrews** | Singer
- **Linda Blair** | Actress
- **Kurt Cobain** | Singer
- **Laura Dern** | Actress
- **Sarah Michelle Gellar** | Actress/Model
- **Janet Evans** | Swimmer
- **Daryl Hannah** | Actress
- **Dudley Hart** | Golf Player
- **Jeanette Lee** | Pool Player
- **Robert Loudermilk** | Football Player
- **Yo-Yo Ma** | Cellist
- **Liza Minnelli** | Actress/Singer
- **Jon Olsen** | Swimmer
- **Catherine Oxenburg** | Actress/Model
- **Sarah Polley** | Actress
- **Isabella Rossellini** | Actress/Model
- **Renee Russo** | Actress/Model
- **Chloë Sevigny** | Actress
- **Jenny Thompson** | Swimmer
- **JoBeth Williams** | Actress
- **James Blake** | Tennis Player
- **Stacy Lewis** | LPGA Golfer
- **Elettra Rossellini Wiedemann** | Model (the daughter of Isabella Rossellini)

SECTION 4

ORGANIZATIONS

AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS (AAOS)

Address: 6300 North River Road
Rosemont, IL 60018
Phone: (847) 823-7186
Web Site: www.aaos.org

AMERICAN ACADEMY OF PEDIATRICS (AAP)

Address: 141 Northwest Point Boulevard
Elk Grove Village, IL 60007
Phone: (847) 434-4000
Web Site: www.aap.org

AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS (AANS)

Address: 5550 Meadowbrook Drive
Rolling Meadows, IL 60008
Phone: (847) 378-0500
Web Site: www.aans.org

AMERICAN PHYSICAL THERAPY ASSOCIATION (APTA)

Address: 1111 North Fairfax Street
Alexandria, VA 22314
Phone: (703) 684-2782
Web Site: www.apta.org

INTERNATIONAL RESEARCH SOCIETY FOR SPINAL DEFORMITIES (IRSSD)

Address: The University of Liverpool
Sherrington Building
Ashton Street
Liverpool L69 3GE UK
Phone: 44 151 794 5502
Web Site: www.liv.ac.uk/HumanAnatomy/phd/irssd

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES (NIAMS)

Address: 1 AMS Circle
Bethesda, MD 20892
Phone: (301) 495-4484
Web Site: www.niams.nih.gov

ORGANIZATIONS CONTINUED

NATIONAL SCOLIOSIS FOUNDATION (NSF)

Address: 5 Cabot Place
Stoughton, MA 02072
Phone: (800) 673-6922
Web Site: www.scoliosis.org

NORTH AMERICAN SPINE SOCIETY (NASS)

Address: 22 Calendar Court, 2nd Floor
LaGrange, IL 60525
Phone: (877) 774-6337
Web Site: www.spine.org

PEDIATRIC ORTHOPAEDIC SOCIETY OF NORTH AMERICA (POSNA)

Address: 6300 North River Road, Suite 727
Rosemont, IL 60018
Phone: (847) 698-1692
Web Site: www.posna.org

SOCIETY ON SPINAL ORTHOPEDIC AND REHABILITATION TREATMENT (SOSORT)

E-mail: kotwicki@amp.edu.pl
Web Site: www.sosort.org

SCOLIOSIS RESEARCH SOCIETY (SRS)

Address: 555 East Wells Street, Suite 1100
Milwaukee, WI 53202
Phone: (414) 289-9107
Web Site: www.srs.org

THE SCOLIOSIS ASSOCIATION, INC.

Address: P.O. Box 811705
Boca Raton, FL 33481
Phone: (561) 994-4435
Web Site: www.scoliosis-assoc.org

BOOKS: FICTION

ABBY'S TWIN (BABY-SITTER'S CLUB, 104)

by Ann Matthews Martin

Abby's twin has just been diagnosed with scoliosis, and she tries to help her through her condition.

DEENIE

by Judy Blume

Deenie is a beautiful girl who just got diagnosed with scoliosis and is nervous about wearing a brace for four years or more.

NOTHING HURTS BUT MY HEART

by Linda Barr

The story of a young gymnast dealing with the issues of wearing a brace.

PLASTIC BACK

by Anna Rakes

Anna Beth is an excited 7th grader until she finds out she has scoliosis and has to wear a brace, but she discovers how great life can be, even while wearing a brace.

STAND TALL, HARRY

by Mary Mahony

Harry is an African-American student who endures a serious hockey injury, an eventual diagnosis of scoliosis and then finds himself as a possible United States chess star.

THERE'S AN S ON MY BACK: "S" IS FOR SCOLIOSIS

by Mary Mahony

Told in first person, this book discusses a 5th grader's understanding of scoliosis through the whole process of diagnoses to treatment.

BOOKS: NON-FICTION

SCOLIOSIS AND THE HUMAN SPINE

by Martha Hawes

This book 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 for patients, parents, physicians and other clinicians.

SCOLIOSIS: ASCENDING THE CURVE

by Brooke Lyons

A well-rounded book that covers causes, diagnoses, treatment and surgery.

SCOLIOSIS SURGERY: THE DEFINITIVE PATIENT'S REFERENCE

by David K. Wolpert

Written in plain English by someone who has been through it, this book explains in detail everything you need to know about what is involved in scoliosis surgery, how to decide if surgery is the right treatment, what the surgical options are, what alternatives to surgery exist, and how to prepare for surgery and recovery process.

STOPPING SCOLIOSIS: THE WHOLE FAMILY GUIDE TO DIAGNOSIS AND TREATMENT

by Nancy J. Hooper

Author's experience with scoliosis with discussions of non-surgical treatments and research into the causes of scoliosis.

STOP A LA ESCOLIOSIS (EN ESPAÑOL)

by Nancy J. Hooper

Author's experience with scoliosis with discussions of non-surgical treatments and research into the causes of scoliosis, translated into Spanish.

THE SCOLIOSIS SOURCEBOOK

by Michael Neuwirth and Kevin Osborn

A complete guide to help understand scoliosis and its importance.

WHAT CAN I GIVE YOU: THE MOVING ACCOUNT OF ONE FAMILY'S JOURNEY TO UNDERSTAND THE MANY FACES OF THEIR CHILD'S CHRONIC CONDITION

by Mary Mahony

A story of a mother's journey with her daughter, Erin, who was diagnosed with congenital scoliosis when she was fourteen months old.

WHEN LIFE THROWS YOU A CURVE: ONE GIRL’S TRIUMPH OVER SCOLIOSIS

by Elizabeth Golden

An author’s battle with scoliosis, filled with lessons about courage, acceptance, grace, and the importance of family and friends.

THE CONSERVATIVE SCOLIOSIS TREATMENT

The first of a series of Instructional Course Lectures (ICL) Books of the International Society On Scoliosis Orthopaedic and Rehabilitation Treatment (SOSORT). The philosophy of the commencement of such ICL book series is the achievements of an ultimate aim, the improvement of early detection and non operative treatment of the patient care pathway for scoliosis.

VIDEOS

ELLIE'S BACK

An 8-year-old and her mother worked together to produce a film that portrays life with scoliosis as viewed through the eyes of a young child.

CATCH THE CURVE

An educational unit produced by the National Scoliosis Foundation for the pre-screening education of students in grades 5-9. This video explains what scoliosis is and how it is detected, illustrates the normal screening procedure, emphasizes the importance of follow-up after screening, encourages peer support for students who have scoliosis, and encourages young people to follow their prescribed treatment.

SCOLIOSIS, AN ADULT PERSPECTIVE

A doctor and five female patients provide an overall perspective of what adult scoliosis is, who gets it, the types of curves, myths about the disorder and options for treatment.

SHARING SCOLIOSIS: YOU'RE NOT ALONE

Patients share their experiences with scoliosis including diagnosis, wearing a brace, surgery and recovery.

UNDERSTANDING SCOLIOSIS

Kaiser Permanente's educational video in which four teenagers at various stages of treatment talk about their experiences with scoliosis.

WHAT'S THIS THING CALLED SCOLIOSIS?

A comprehensive overview of scoliosis and its impact on patients, using the latest computer technology.

YOGA FOR SCOLIOSIS WITH ELISE BROWNING MILLER

Three 17-minute sessions at a beginner level appropriate for most people with scoliosis.

SECTION 4

RESOURCES

GLOSSARY

ADOLESCENT SCOLIOSIS – A type of scoliosis that develops before the onset of puberty and before the skeletal system matures

ADULT SCOLIOSIS – A type of scoliosis that presents after the skeletal system has matured

AUTOGRAFT – Tissue transferred from one part of the body to another in the same individual

AUTOLOGOUS BLOOD – Blood collected from a person for a later transfusion to the same individual. This can be used to avoid blood from unknown donors and significantly reduces the risk of acquiring transmitted diseases

AUTOTRANSFUSION – The practice and technique of transfusing previously drawn autologous blood to the same patient

BONE GRAFT – A surgical procedure in which healthy bone is transplanted from one part of the person's body into the affected area

BRACE – A semi-rigid plastic device that pushes on the muscles and ribs next to the spine in order to prevent an abnormal curve from progressing. There are daytime and nighttime braces

CERVICAL SPINE – Part of the spine consisting of the top seven vertebrae, starting at the base of the skull

COBB ANGLE – A measurement defined by a technique used to evaluate the magnitude of a scoliosis curve

COMPENSATORY CURVE – A secondary curve located above or below the structural curvature, which develops in order to help maintain the body's normal alignment

CONGENITAL SCOLIOSIS – Type of scoliosis that is caused by bony abnormalities of the spine, which are present at birth

DECOMPENSATION – The loss of spinal balance when the thoracic cage is not centered over the pelvis

DISCECTOMY – The removal of all or part of the soft tissue that acts as a shock absorber between the vertebral bodies

DOUBLE CURVE – Two lateral curvatures in the same spine

DYNAMIC TENSION BRACE – A new concept and style of bracing using softer, more flexible components to prevent abnormal spinal curves from progressing

GENETIC SCREENING – The review of a patient's genetic material to determine the prevalence of a particular disease and/or its likelihood of progression

HEMIVERTEBRA – A hereditary anomaly of the spine caused by an incomplete development of one side of a vertebra resulting in a wedge shape

HYSTERICAL SCOLIOSIS – A type of scoliosis in which a non-structural deformity of the spine develops as a manifestation of a psychological disorder

IDIOPATHIC SCOLIOSIS – The majority of scoliosis cases, in which the cause of the condition is unknown

INCLINOMETER (also called a scoliometer) – A level used to measure the 'rib hump,' which is helpful in detecting scoliosis and monitoring progression of curve

INFANTILE SCOLIOSIS – A type of scoliosis that appears before three years of age

JUVENILE SCOLIOSIS – A type of scoliosis that appears between the ages of three and 10

KYPHOSCOLIOSIS – A type of structural scoliosis associated with an increased rounding of the back

GLOSSARY CONTINUED

KYPHOSIS – A posterior-angled curve of the spine

LORDOSCOLIOSIS – A type of scoliosis associated with a combined flattening and lateral curvature of the spine

LORDOSIS – An anterior-angled curve of the spine in the sagittal plane

LUMBAR CURVE – A spinal curvature between the first and fourth lumbar vertebrae

LUMBOSACRAL CURVE – A lateral curvature between the fifth lumbar vertebrae and sacrum

NEUROMUSCULAR SCOLIOSIS – A type of scoliosis caused by a neurologic disorder of the central nervous system, associated with muscle dysfunction

NONSTRUCTURAL CURVE – A description of a spinal curvature that is not a fixed deformity

MINIMALLY-INVASIVE SPINAL FUSION SURGERY – A surgical technique using specially-designed surgical tools that result in smaller incisions, less tissue trauma, minimal scarring, and shorter recovery as compared to traditional spinal fusion

MAGNETIC RESONANCE IMAGING (MRI) – An imaging technique that uses magnetism, radio waves, and a computer to produce images of an internal organ or structure, especially the brain and spinal cord

POSTERIOR FUSION – A technique that stabilizes two or more vertebrae by bone grafting with an approach from the back

PRIMARY CURVE – The first or earliest curve to appear in the spine

RISSER SIGN – Crescent-shaped lines of bone formation that appear across the top of each side of the pelvis which indicate spinal maturity

SACRUM – A set of five fused vertebrae that connect the base of the spine to the tailbone

SCOLIOSIS – A condition in which there is an abnormal lateral curve of the spine greater than 10 degrees and a rotation of the vertebrae towards the inside of the curve

SPINAL DISC (Also known as vertebral disc) – A soft, gel-like cushion found between each vertebra of the spine

SPINAL FUSION SURGERY – A procedure used to remove a damaged disc by joining vertebrae together with a bone graft to stabilize the spine

SPINAL INSTRUMENTATION – The rods, hooks, screws and wires that are attached to the spine to improve spinal deformity while the fusion matures

SPONDYLITIS – An inflammatory disease of the spine

SPONDYLOLISTHESIS – A condition, usually developmental or degenerative, in which one vertebra slips forward relative to the vertebra below it

STRUCTURAL CURVE – A segment of the spine that has a fixed lateral curvature

THORACIC CURVATURE – A spinal curvature in which the curve is between the second and eleventh thoracic vertebrae

THORACOLUMBAR CURVE – A spinal curvature that has its apex at the twelfth thoracic or first lumbar vertebra

THORACOLUMBOSACRAL ORTHOSIS (TLSO) – A type of brace that incorporates the thoracic and lumbar portions of the spine and does not extend above the shoulders

VERTEBRAL COLUMN – The flexible supporting column of vertebrae separated by discs and bound together by ligament

NOTES

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