

Doctors study untreated scoliosis patients to learn prognosis of those who are treated

More than ever before, doctors are able to provide care for medical conditions that were once regarded untreatable. But how do they know if these treatments are worth the time, effort and risks?

"No matter what the disease or condition is, if you don't know how patients do if no treatment is offered, then you have no idea what the treatments you recommend to patients will alter or change," said **Stuart L. Weinstein, M.D.**, president of the American Academy of Orthopaedic Surgeons and current Ignacio V. Ponseti Chair and professor of Orthopaedic Surgery at the University of Iowa. "In other words, if nothing bad happens as a result of having a condition or disease, then that condition or disease needs no treatment."

Dr. Weinstein, who received a research grant from OREF in 1991 and an OREF Kappa Delta Clinical Award in 1998, employed his OREF funding to find out how untreated conditions affect the patient.

"I received an OREF grant to study the long-term natural history follow-up of patients with untreated adolescent idiopathic scoliosis," said Dr. Weinstein. "This study allowed us to present

a 50-year follow-up of untreated patients with this disease. It gives physicians treating scoliosis a better idea of the disease's effect on survival, pulmonary function, back pain, and curve progression."

Dr. Weinstein's study investigated the cosmetic aspects of the disease, such as how patients felt about having scoliosis and how it affected their lives. It also studied how much pain they endured, whether it affected their ability to have children, their ability to work or their ability to participate in activities of daily living. In addition, Dr. Weinstein and his research team looked at how the chest deformity usually associated with scoliosis affected the patients' lung function and if it shortened their life expectancies.

"This study gives surgeons a clearer idea of what they hope to prevent, and it helps determine which patients should have surgery, and which will be fine without it," said Dr. Weinstein. "In the future researchers will be able to see if over the long-term patient lives are indeed improved by comparing surgically treated patients to the untreated patients we reported on."



The results of the study were published in an article entitled "Health and Function of Patients with Untreated Idiopathic Scoliosis: A 50-year Natural History Study" in the March 5, 2003 issue of the *Journal of the American Medical Association*.

Dr. Weinstein said that the investigation will help orthopaedic surgeons, as well as other medical personnel, to help patients diagnosed with late onset idiopathic scoliosis.

"Most children and their parents are alarmed when the diagnosis of late onset — adolescent idiopathic — scoliosis is suggested based on sports or annual physicals, or during a school screening. This study gives orthopaedic surgeons, and all physicians who see patients with late onset scoliosis — family practitioners, pediatricians and internists — a solid foundation from which to advise their patients who've been diagnosed with this disease."

Dr. Weinstein stresses the importance of studying follow-up of untreated diseases. According to Dr. Weinstein, knowing how diseases affect patients when left untreated can aid in developing treatments to prevent or diminish adverse outcomes. Funding for this type of research, he said, however, is difficult to obtain, and he appreciates OREF's support.

"Clinical research on fundamental problems such as natural history, long-term follow-up, and outcomes of conditions is very expensive and funding sources are few and far between," said Dr. Weinstein. "The funding for this particular project would have been unavailable from any other source, and I am grateful to OREF for funding this endeavor and providing orthopaedic surgeons worldwide the fundamental information about the natural history of adolescent idiopathic scoliosis required to make sound treatment decisions."

Contributions to OREF's Anniversary Campaign can be used to support current research, such as that conducted by Dr. Weinstein. To contribute to OREF's Anniversary Campaign, please fill out the donor form on page 15 of this issue of *Impact* or for more information please contact: **Ed Hoover** at hoover@oref.org or (847) 384-4354, or **Maria Aguirre** at aguirre@oref.org or (847) 384-4357



(from left) James Urbaniak, M.D., and Mrs. Muff Urbaniak with Mrs. Lynn Weinstein and AAOS President Stuart L. Weinstein, M.D. at the Shands Gala.

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