

SPONDYLITIS PLUS

winter 2006/07

**GENETIC
RESEARCH
NEEDS YOU!**

**INNOVATIONS IN
HIP REPLACEMENT**

**SPONDYLITIS DOESN'T
PREVENT HER FROM
SPREADING JOY**



SPONDYLITIS ASSOCIATION OF AMERICA

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SAA MISSION

To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest.

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UPFRONT



ALTHOUGH IT IS SOMEWHAT DAUNTING to follow Jane Bruckel's years of distinguished service, I am delighted to be the new Executive Director of SAA!

I join a committed and energetic professional team that brings vast experience and great enthusiasm to the mission of SAA. In particular, I wish to express appreciation to SAA's Associate Executive Director, Laurie Savage, and Director of Development, Susan Jones, who have provided great support and assistance during these early weeks of my tenure.

Prior to joining SAA, I worked in the non-profit arena for many years focusing on the delivery of recreation and information services to seriously ill children and their families. This experience made me very aware of the challenges faced by families coping with the stress of illness and disability. During my short time at SAA, I have become acquainted with some of the specific challenges faced by the AS community. I am pleased to be part of SAA's effort to find a cure for AS, to support advocacy and to assist in providing education and information regarding management of the disease.

Over the next year, I will be joining SAA's program services team at Patient Education Forums around the country. I look forward to meeting many of you at these events. In the meantime, please know that I am committed to continuing SAA's role as a leader in finding a cure for spondylitis.

Katherine Culpepper
EXECUTIVE DIRECTOR



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From our Message Board

As an AS Patient for 15 years, I have noticed that there is a need to help the AS patients like myself with advanced AS. Information pertinent to my category needs to be discussed within the magazine. It is so heartbreaking that we do not have enough information on how to deal with day-to-day life, which gets harder.

Thank you.
WAYNE B. KIRCHER
Mantua, NJ

Editors note: Recently, we have been discussing these same issues, and seeking how to address them in an interactive, reader involved forum, and hence, the receipt of Mr. Kircher's letter coincided with the beginning of a new regular column entitled "Practical Solutions." Do you have a practical solution to help you with an every-day living issue? Is there something that you have found that may be helpful to others with spondylitis? Send your practical solution to Melissa Velez, SAA, 14827 Ventura Blvd., #222, Sherman Oaks, CA 91403. You may also email Melissa at melissa.velez@spondylitis.org.

I have recently been disappointed with the contents in Spondylitis Plus. I think there are too many human-interest stories about individual battles with AS. I would rather see more articles by doctors about new treatments, drug reports, effective medicine, and "what to watch for" as you grow older.

My particular interest area is Remicade and Methotrexate, two drugs I am taking.

Thank you for considering my opinions.

PAUL TANNER
Nagoya, Japan

Editor's note: Dear Paul, Thank you for your feedback, and please know that yes, we do listen to our readers' comments in order to evaluate content on an ongoing basis.

Here is my response to Anne Larrow's letter, which appeared in the 2006 Fall issue:

Dear Anne, I was troubled to read your letter. It is commendable that you wish to learn about our disease, but please pause a minute and think if your own position isn't negative, let alone self-limiting.

I was diagnosed with AS at age eleven. That was in 1961. It wasn't until I joined the SAA that I was able to receive any information, good or bad, about AS.

And because of the magazine, and very special events like the AS seminar presented just for us by a panel during the American College of Rheumatology Convention, or the recent Yoga-For-Spondies class arranged by our area coordinator, Clarence So, I've had face-to-face contact with people who "really know."

On the panel, a Physical Therapist told us

that water below 91 degrees is not comfortable for us. Sure enough, my solar-heated pad reached 92 degrees and I found I could strut straight in and move freely. At the event, the person with spondylitis who sat next to me suggested I try a gel called "Bio-Freeze". I tried it, and it helps!

Where else are you planning to learn anything? You can't just tune into the "happy news", either. For the more difficult elements of our dear disease, it is still better to know what might be ahead for us, and how to prepare for, if not prevent it. Come to think of it, I think that's what people with other incurable diseases do, too.

People tell me I have a "wonderful attitude" about my disease, because I don't complain! I do what I can and keep my eyes and ears open. Tell me if I am missing something?

KENNETH JACOBS
San Rafael, CA 94903

LETTERS TO THE EDITOR

Dear Readers: We want to hear from you, whether it be informative, uplifting, or a gripe you need to express. Include your full name, address and daytime phone number.

We reserve the right to edit for space and clarity.

Please send letters to:
Laurie.Savage@spondylitis.org
Letters to Editor/SAA
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CALL TO ACTION: RESEARCH NEEDS YOU!

KICKING OFF A NEW CYCLE IN AS GENETIC RESEARCH

Announcing TASC (“Triple A” Spondylitis Consortium—Austro/Anglo/American)

IN RECENT YEARS, A GREAT DEAL OF PROGRESS HAS BEEN MADE in shedding light on the potential causes of AS and in seeing the advent of improved treatments that show tremendous hope for people with AS and related diseases. Much of this is due to the work of dedicated researchers, but also to people like you who have participated in the NASC study, (The North American Spondylitis Consortium), which evolved from the AS Family Genetic Project. Data generated in that project include the discovery of regions on chromosomes that further our understanding of susceptibility toward AS. In addition, the data suggest that genes may play a significant role in severity and outcomes of the disease. New and more established theories are being explored in regard to the potential relationship between microbes, genes—particularly B27—and inflammatory mechanisms in the gut/blood barrier that might be involved in triggering AS and enteropathic arthritis.

In addition to the findings directly generated from the NASC study, in a sister study, researchers uncovered a genetic region involved with the cause of potential loss of vision in people with AS, which involves an inflammation of the eye called acute anterior uveitis. This was an important breakthrough given that uveitis strikes up to 40% of people with AS.

Over the years, Spondylitis Plus has recounted the personal stories of people with spondylitis and their family members. Through the voices of the thousands of people with AS who support the SAA, it has become evident that AS and related diseases are not mild conditions. They impact people’s lives with their uncertain outcomes and ever evolving challenges. It is recognized that in moderate to severe cases, spondylitis can lead to progressive functional impairment over time, reduced quality of life, and work disability. In spite of the hope of current new treatments, many people still are not doing well.

The good news is that with the award of this \$5.25M spondylitis genetic research grant to Dr. John D. Reveille, University of TX, Houston, there is every likelihood that within several years, Dr. Reveille will be able to uncover the underlying genetic basis of AS and identify the complexities of familial spondyloarthritis. Also involved in the study are fellow research teams located in the United Kingdom, Australia and the United States, along with the administrative and recruiting efforts of the SAA and people like you willing to help.

This next phase of this study, which will be known as TASC, (Triple A Spondylitis Consortium) brings real hope for the future.

The Interrelated Projects of the Grant

1. To identify the genes that cause AS
(Matthew Brown MD, John D. Reveille MD)
2. To identify the genes that predict severity and outcomes (Michael Weisman MD)
3. To identify the spectrum of related diseases in family members of people with AS (John C. Davis MD MPH)
4. To determine how the genes interact with each other (Momiao Zhong PhD, Xiudong Zhou MD)

We Need Your Help!

Call for research participants:

- People who have been diagnosed with AS
- Non affected spouses of people with AS
- Non affected friends of people with AS

If this describes you and you would like to help, please call:
the SAA (800) 777-8189 x 224 or email info@asresearch.org

MAYA KLAUBER GOES FROM NEW YORK TO AUSTRALIA

She Travels Down Under to Stay On Top of Her Game

Maya Klauber, 20, a Long Island, New York, native, who will be a junior at Colby College, Maine, next year, was diagnosed with undifferentiated spondyloarthropathy when she was a junior in high school. “When I was younger, before I was diagnosed with spondylitis, I had constant joint pain beginning around the age of eight,” she says. “I had a lot of pain in my Achilles tendon and pain in my knees and hips; I remember that I had trouble walking. I was really sensitive to light. My memory also seems to have been affected, which my teachers noticed, especially in the area of math.”

Before she was definitively diagnosed, doctors suspected a whole host of different conditions, which included fibromyalgia and Lyme disease. Finally, Maya received a correct diagnosis four years ago.

The English and creative writing major was recently put on a TNF-a blocker, which has brought tremendous relief to her symptoms. Shortly after starting the therapy, she awakened one morning realizing that she no longer had the constant, horrific body pain to which she had become so adjusted, and found herself somewhat bewildered. “I had forgotten that you’re not supposed to feel this pain in the morning; when it’s not there, it’s so different—you only realize how bad it was when it is not there anymore,” she says with a laugh.

Not content just to attend college out of state, Maya is now in Down Under territory, Melbourne, Australia to be precise, doing international studies for the current semester, where she hopes to find inspiration for her poetry writing, one of her favorite activities. She has been mentored by one of her Colby professors, the award-winning poet Adrian Blevins, who taught her to put more of herself in her work. “And my stuff is now more authentic,” says Maya proudly.

“There is nothing like a poem that takes you along for a ride and lets you see the world through another’s eyes,” Maya tells Spondylitis Plus. “All in all, I want to learn as much as I can about the Australian culture, Aboriginal writing and Australian authors and poets—music, dance, theater, literature—everything. I’m also going to be as active as physically possible with kayaking, running, hiking and swimming.”

Maya’s primary goal when she finishes college is to work with sick kids. She’s been a summer camp counselor for a number of years to youngsters with muscular dystrophy. Maya tells us her plan: “I work in the summer for one week with kids that have muscular dystrophy. For that one week, my favorite week of the year, even though it’s physically demanding on me, and it has been pretty hard at some points, it has put a lot of things into perspective for me. I just feel like a big connection to kids with physical pain. I want to go to graduate school for psychology; my ultimate dream is to help kids deal with physical pain.”



“I don’t want arthritis to hold me back from my life’s experiences at all,” says Maya Klauber, shown here hiking Down Under.

She says she was helped by a wise counselor at Colby who told her it was all right to feel sad and angry at the health card she drew. Maya elucidates: “It’s not one of those things that anyone knows about unless you tell them the extent of it. There’s nothing different about me that you can see, except maybe the way I walk. The one thing the counselor told me was to relax and realize it’s OK to tell people and it’s OK to feel angry about it. She helped me with the mental side of having physical pain.

Maya is putting a book together for kids with disabilities where she wrote the introduction and will then write the ending. She wants youngsters with physical disabilities to fill in the chapters with their own stories based on a 50-question document she wrote. One of her favorite campers, “Mary,” a 10th grader, responded to the question, “If you could have one ‘super power,’ what would it be?” She said Mary told her, “The ability to stand out and not stick out.” Maya said the years and her own health difficulties have taught her to understand that response well.

Maya explains that she would rather define her life through future plans to work with disabled children, and not through her disease: “I want to give something back and not just waste time. If I didn’t have this arthritis, I wouldn’t have figured out what I want to do in the future. I’ll be crossing my fingers that the TNF blocker will be doing the trick. I don’t want arthritis to hold me back from my life’s experiences at all; I want to try everything and see everything. I want to just really be as happy as I can be so I can help other people be that way.”

EXPANDING THE RESEARCH HORIZON

In Ankylosing Spondylitis – Understanding the Role of HLA-B27

By Robert A. Colbert, MD, PhD

Most patients with ankylosing spondylitis (AS) recognize HLA-B27 as a genetic marker that they carry. Indeed, it is found in the vast majority (90-95%) of patients with this disease, compared to less than one of ten healthy people. It is inherited from one parent, and in rare cases both, and is often accompanied by the knowledge that someone else in the extended family has AS or another HLA-B27-associated disease.

We also know that HLA-B27 does not work alone. Several additional genes contribute to AS, and major efforts in North America and around the world are dedicated to finding the location of these genes in the human genome. What is often less well appreciated is that HLA-B27 is already a major focus of research, and understanding its role in disease will provide a key piece to this puzzle. Since the discovery of the HLA-B27 – AS connection over 30 years ago, we have learned a great deal about what HLA-B27 does; unfortunately, this has not answered the question of how it causes disease. Recently, new research has uncovered some very unusual features of HLA-B27, and the paradigm has begun to shift toward the idea that an abnormal property of HLA-B27 may be the basis for its connection with disease.

HLA-B27 – a carrier of peptides

What does HLA-B27 do? The product of the HLA-B27 gene is a member of a family of proteins called human leukocyte antigens (HLA) that have an important role in the immune system. T cells are a type of white blood cell that recognize HLA-B27 and decide whether to react to it or ignore it, depending on its shape or surface contour, which in turn depends on



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—Robert A. Colbert, MD, PhD

the type of peptide it carries. Peptides are small bits of proteins that are produced when the proteins are broken down. The peptides can come either from proteins that our own body makes (self-peptides),

or from microbes like viruses or bacteria (foreign peptides). Normally T cells ignore self-peptides and react to foreign peptides, producing chemicals called cytokines that cause an inflammatory reaction. The ability of T cells to recognize and react to foreign peptides carried by HLA proteins is one means that our immune system uses to fight off infections. We know that HLA-B27 works as well as, or perhaps even better than other HLA proteins in helping to fight off viral infections. For example, people with HLA-B27 who have become infected with HIV tend to stay healthy longer than others, and also infection with the hepatitis C virus tends to be cleared more completely. Why this occurs is not known. For a long time it was thought that people with HLA-B27 developed AS because their T cells were fooled into thinking that the self-peptides carried by HLA-B27 were really foreign peptides. Despite how attractive this idea is, it has been very difficult to find T cells that react against HLA-B27 and its self-peptides (autoreactive T cells). Furthermore, in animal models where HLA-B27 causes an inflammatory disease like AS, there is solid evidence that this idea is not correct.

HLA-B27 – a protein that misfolds

If the peptides carried by HLA-B27 do not cause AS, what does? Several years ago scientists began to look for another explanation. Examining HLA-B27 from a different perspective, they discovered that in addition to its normal activity of carrying peptides, it also has at least two abnormal properties. One is a tendency for the pro-

tein to ‘misfold’ and the second is that it can form an unusual structure called a ‘dimer’ where two HLA-B27 proteins are attached to one another. Both of these findings suggested alternatives to the notion that the peptides were the key to understanding the role of HLA-B27 in AS.

What is protein misfolding? One of the most striking examples of protein misfolding is what happens when you boil an egg. Proteins in the egg ‘white’ and yolk become irreversibly denatured or misfolded, to the point where the process can never be reversed. (Ever try to unboil an egg?) Over the last several years there has been increasing recognition that a number of genetic diseases result from protein misfolding. However, the symptoms of the disease, and the abnormal processes that cause these symptoms, can be quite varied and depend on many factors. For example, proteins that misfold just after being made are often broken down very quickly, and as a result the protein is missing and not available to do its job. This is known to occur in certain types of hemophilia (bleeding disorder). When misfolded proteins are not eliminated quickly and build up in tissues outside the cell, they can also wreak havoc by preventing other cells from carrying out their function or even to die. This is important in certain neurological diseases including Alzheimer’s.

HLA-B27 misfolding and the unfolded protein response. We are just beginning to learn more about the implications of HLA-B27 misfolding. First, since protein misfolding can be a little complicated, it’s worth a more complete explanation. The story begins inside the cell, in a compartment known as the endoplasmic reticulum (ER). HLA-B27 is made here, and stops long enough to pick up its peptide cargo before delivering it to the cell surface. In order to carry this

“The discovery of additional genes that contribute to AS will be important as the function of their gene products should inform us on the role of HLA-B27, and may identify additional approaches to treat the disease. Ultimately, these efforts are aimed at finding better ways to treat AS and perhaps even think about a cure.”

cargo, it needs to fold into a certain shape that allows the peptide to fit. It seems that this is where the problem is – HLA-B27 doesn’t get into shape very well.

There are a lot of other proteins that try to help, but if there aren’t enough or they aren’t working well, HLA-B27 tends to accumulate. This is a particular problem when the cell is trying to make a lot of HLA-B27 such as during an infection or an immune response. These incompletely folded (and/or misfolded) HLA-B27 proteins can cause ER ‘stress’. This in turn activates a series of complex events that result in an ‘unfolded protein response’ (UPR). The UPR increases the assembly line machinery responsible for folding and secreting proteins, and also the capacity to break down proteins that have misfolded, and is one way that the cell adapts to ER stress.

A surprising finding has been that the UPR seems to have additional effects in immune cells. When the UPR is activated, certain immune cells ‘over-respond’ to products that come from bacteria and viruses. Some of the overproduced cytokines not only promote inflammation, but are also linked to increased bone

formation. This could be important in AS, since another aspect of this disease that is not understood is the tendency to form too much bone in certain places and too little bone in others. There are many studies underway to better define how HLA-B27 misfolding may be important in the development of AS.

Abnormal forms of HLA-B27. In addition to misfolding, the formation of HLA-B27 dimers on the cell surface also has possible implications. We have learned that ‘natural killer’ or NK cells, in addition to T cells, can recognize HLA proteins. NK cells use a different type of ‘receptor’ that may be able to selectively recognize HLA-B27 dimers in addition to the traditional forms on the cell surface. NK cells are one of the first lines of defense used by the immune system, and if recognition of the abnormal HLA-B27 dimers changes their function, this could contribute to a chronic inflammatory disease.

Summary

As we gained a more complete knowledge of what HLA-B27 does during the 1980s and 1990s, there was a strong sense that we were only a few years from understanding its role in AS. This was bolstered by the development of animal models where HLA-B27 and the immune system could be manipulated to test various ideas and perhaps even be used to discover better treatments. Although these goals have not yet been realized, there is a renewed optimism that this puzzle can be solved. The discovery of additional genes that contribute to AS will be important as the function of their gene products should inform us on the role of HLA-B27, and may identify additional approaches to treat the disease. Ultimately, these efforts are aimed at finding better ways to treat AS, and perhaps even think about a cure.

Kimberly Cooper: “We must press forward.”

Board Member Kimberly Cooper’s husband – a former NFL player whose career was unceremoniously ended by spondylitis – had lived with the disease for decades when sudden flares triggered iritis and other inflammatory conditions related to spondylitis. “Then we learned that my stepson may have the disease too, and I couldn’t stand on the sidelines any longer. I had to get involved,” says Kimberly.

And she’s never looked back. Kimberly, who is president of Portland, Oregon-based Fortuna Group, a full-service executive consulting company, has spent the last two years volunteering for SAA, helping to educate people about spondylitis and working to increase understanding of the “disease with an intimidating name.”

Her experience with chronic and autoimmune diseases began with the National Psoriasis Foundation, where she served as interim Chief Operating Officer, taking them through an expansion as they doubled their revenues and quadrupled the number of people they served. “I witnessed the impact that a single organization could have on millions of lives. And when I learned that SAA was seeking to expand its impact too, it felt like the right place to volunteer my time and expertise,” Kimberly, late 30s, remembers.

As a member of the SAA Board of Directors, Kimberly chaired the Strategic Planning initiative for SAA, serves on the Governance Committee, and co-chairs the board’s Fund Development Committee where she helped create a fundraising plan that will better enable SAA to achieve its vision and mission in a quest for a cure and improving quality of life.

“We’re really fortunate that so many people really care about the cause; they care enough to give their time and their money to SAA and make a difference for this community. Our fundraising objective is to create strategic opportunities for people to give to the organization in ways that will allow SAA to go farther, faster.”

Kimberly says that SAA’s small size belies its significant accomplishments: “As I became more involved with the Association, I was amazed at how much they do with so little. They achieve twice what one would expect given their staff size and overhead. And the quality and quantity of the work that SAA generates is tremendous. I’m proud to be a part of it.”

Kimberly is most impressed by SAA’s leadership on research and investigative projects. “The work that SAA is doing is truly innovative, particularly for a patient advocacy organization of its size. It’s the kind of work that really puts us on the path for a future free from this disease,” she says.

Kimberly is eager to let others know that there are many opportunities to donate funds to the organization. “Private donations, large and small, form the basis for all of our work at SAA, and I’m so grateful for everyone who contributes their share. My family and I – and thousands of others like us – are personally committed to investing in SAA because we believe in the difference it makes for so many people today and for generations to come.”

She says, “We can’t just sit and rest on what we have. We must press forward until there is a cure.”



Board Member
KIMBERLY COOPER,
Portland, Oregon

“The work that SAA is doing is truly innovative, particularly for a patient advocacy organization of its size. It’s the kind of work that puts us on the path for a future free from this disease.”

Editor’s note: Kimberly would like to extend an invitation to anyone who would like to contact her with ideas to increase research efforts, raise funds – or any other ideas to further the interests of SAA. Please contact her at: kcooper@spondylitis.org

Ann Howat: “I absolutely believe in SAA.”

After a couple of years of declining health, Chicago resident Ann Howat was definitively diagnosed with reactive arthritis, one of the diseases that falls under the spondyloarthritis umbrella. Her rheumatologist suggested that the former long-time corporate communications professional, who was devastated by the news, learn more about the disease by visiting SAA’s award-winning website.

Ann went to the website, where she found quite a bit more than the information she initially sought. What she found was an active community of patients, families, physicians and friends, all eager to share experiences and support each other’s efforts. In time, Ann became an active participant in her local Educational Support Group, learning coping skills from her peers while helping others to better manage their disease.

“I absolutely believe in an organization that dedicates itself to research, advocacy and education—that’s what SAA is all about.”



Board Member
ANN HOWAT,
Chicago, Illinois

Ann’s efforts did not go unnoticed by SAA’s Sherman Oaks headquarters. Always on the lookout for exceptional volunteer leadership, the board of directors extended an invitation for her to apply.

Her response? “You bet! The reason that I chose to become a board member is because I strongly believe in what we’re doing in research and education, too,” Ann, now on the board for two years, says passionately. “I absolutely believe in an organization that dedicates itself to research, advocacy and education—that’s what SAA is all about.”

She goes on to list some of the accomplishments she has been a part of as an SAA board member.

“The last couple of years, we’ve brought in different board members with different areas of expertise that can help SAA grow. We redrafted the bylaws. We put a strategic plan into place to make it a better, stronger organization that will continue to evolve. Personally, my part is to help with the fundraising and with meeting and speaking with donors; that’s what I do best.”

Ann attended the SAA/NIH meeting earlier this year where she personally witnessed the scientific camaraderie and says she was impressed with the high praises for the organization from world-renowned scientists—collectively working toward a cure.

“All these hands-on efforts are part of the advocacy of this incredible foundation—a lot of organizations do not get that involved and it’s an exciting time for AS being this close.” While her hope is admittedly balanced with a realistic assessment of the challenges and the hurdles faced in finding a cure for the baffling disease that affects so many, Ann nonetheless says, “Having a research breakthrough on our watch where all the genes associated with AS are identified would be some unbelievable progress.”

THE BOARD THANKS YOU

Each year, SAA receives gifts from members and donors. Gifts to the Annual Fund, Jane Bruckel Research Fund or special projects and events are comprised of contributions from hundreds of donors in a variety of amounts—large and small, and every size in between. While we are grateful for the generous contributions from our President’s Circle members and the foundations and corporate partners who support us, a large percentage of the contributions we receive are less than \$100. Pooled together, these contributions make a huge difference in helping SAA fulfill its mission to be a leader in the quest to cure AS and related diseases, and empower those affected to live life to the fullest. During this season of giving, we hope you will send a gift to SAA to support the programs and services for thousands of spondylitis patients and their families. Thank you so much for your generous ongoing support.

NEW SURGICAL PROCEDURE OFFERS HOPE FOR A.S. PATIENTS FACING HIP REPLACEMENT



Dr. Matta of California discovered a new procedure for hip surgery in Paris some 25 years ago. Now, he's a leader in this revolutionary surgery.

When the former president of SAA's board of directors, Tom West, faced the discouraging prospect of a second hip replacement, he remembered his last trip to the operating room, where the surgery took seven hours to complete and then two months of recuperation downtime.

But with a new and improved surgical technique for arthroplasty now available, this time around he was out of surgery in 75 minutes and back to work that Monday.

Tom, who is in his 50s and was diagnosed with ankylosing spondylitis some 26 years ago, had his right hip replaced using what is known as the anterior approach. This is a method where a special operating table is utilized that allows for a tidy little three-to-four-inch incision to be made through the front of the hip (as opposed to the side) that does not involve cutting through major muscles and much of the soft tissue; rather, the cut goes directly and precisely between the muscles. The technique has been performed successfully in Europe for three decades, and in the United States, Dr. Joel Matta, who is founder and director of the Hip and Pelvis Institute at St. John's Health Center, is pioneering it. Dr. Matta is considered by his peers to be one of the foremost experts in the world in the area of the pelvis and the hip.

"The difference is phenomenal," Tom wholeheartedly tells Spondylitis Plus. Tom was informed that he was going to have to have his right hip replaced within five or 10 years from his initial left-hip surgery, which was in 1992. But he says he was waiting with the hope that a new technique would emerge. "I'm glad I waited," he says with relief in his voice. "I found this anterior approach when I was checking into surgeons, and Dr. Matta's name came up several times, and then my wife's cousin from Texas knew of someone that had flown to California from Texas for this special surgery."

Hip replacement is a surgical procedure in which the diseased and degenerated parts of

the hip joint are removed and replaced with new, artificial parts. Sir John Charnley, an orthopedic surgeon working in a small country hospital in England, performed the first hip replacement surgery in 1962. The surgery wasn't performed in the United States until 1969 but is nonetheless considered one of the most important surgical advances of the last century. Around 200,000 total hip replacements are now performed each year in the U.S., with an expected exponential increase as the baby boomer population ages.

Dr. Matta tells Spondylitis Plus that he saw an anterior hip replacement surgery performed in Paris in 1981 by French orthopedic surgeon Emile Letournel. "I watched and assisted in the surgery and thought it was very impressive," he says. With the help of a special operating table, Dr. Letournel accessed the hip through a frontal incision without cutting through the large muscles.

Dr. Matta was hooked on the new technique. Fifteen years later, in 1996, a determined patient from Washington State in need of a new hip looked around in the continental U.S. for a pupil of Letournel's. "I've seen this technique; I could probably do it," Dr. Matta told the potential patient; and then, he recalls, the call got him thinking about his experience in France and about how he had been doing hip replacements. After the man's successful surgery, he had even more to think about. He was hooked: "He made a quick recovery and the muscles were preserved around the hip," Dr. Matta notes.

WHERE WE ARE TODAY

Well, 10 years have passed and Dr. Matta has now successfully performed about 1,000 of these hip replacement surgeries using this unique method. By 2003, with a company called Orthopedic Systems Incorporated (OSI), he designed the requisite operating table. He went to them with the procedure and told them that he had information on a patentable device.

Dr. Matta explained to OSI that his invention

consisted of robot-like carbon fiber struts that could be used by a section of the operating table, via a mechanical device, to lift and move the surgical patient's leg, giving direct access to the hip area, thus allowing the surgeon to spare the trauma to the soft tissue and surrounding muscles. "It's not just some guy pulling on the patient's leg," Dr. Matta points out.

Called the PROfx orthopedic table, it smoothly facilitates the anterior approach for hip replacement as it manipulates the operated leg during surgery through a rotational control at the end of the table.

In order to get the replacement parts into the acetabulum (socket) and femur, it is necessary to manipulate the leg. This is accomplished by placing the patient's feet into modified rollerblade boots with the struts attached.

When asked about particular advantages of the anterior approach for patients with ankylosing spondylitis, Dr. Matta lights up in his excitement about the many successes of the procedure. He explains the distinct advantages of the method: "First of all, with AS patients seeking hip replacement surgery, I think there is a higher possibility of dislocation (dislocation remains the leading early complication of total hip arthroplasty), but with the anterior approach, there is a higher resistance to dislocation because of posterior soft-tissue preservation and more precise placement of the acetabular prosthesis."

He further explains: "The fused spine of an AS patient is an extra problem relating to hip replacement that requires special consideration. The normal adaptive changes in positioning that the pelvis makes during standing, sitting, and walking does not occur in the fused AS population (the pelvis can be rigid) as they do in patients with a normal spine, which would normally assist the patient with preventing dislocation."

Another problem with AS patients, besides the spine, he says, is an increased sensitivity to any leg length discrepancy created by a hip replacement. Dr. Matta says: "But the anterior hip replacement addresses both of these potential problems and yields a good outcome. The posterior muscle and hip capsule (hip liga-

ment) preservation, as well as enhanced accuracy of the acetabular prosthesis position, facilitate prevention of dislocation." He attributes the features of the special operating table that so accurately controls hip and leg positioning during the surgery, plus ongoing X-ray checks, to an extremely accurate leg length for the AS patient.

LOOKING AT THE RISKS

A risk of any surgery for any population is a deep venous thrombosis—or blood clot. The clot develops in the leg and can dislodge and endanger a patient's life should it end up in the lung. However, still another benefit to the anterior approach is the surgeon's ability to attach a device, known as a "gator cuff," that squeezes the leg during the surgery. This air-bladder legging is repeatedly inflated and can prevent the patient from developing a potentially fatal blood clot during the surgery.

"First of all, it was the pain difference between the two procedures that convinced me, and the recovery time was amazing."

In the traditional posterior approach, the device is used post-surgically but not while the actual hip replacement operation is taking place. Also, in the posterior approach, the leg is bent and twisted, putting a "kink" in the major femoral vein, cutting off blood flow. Dr. Matta points out: "This in itself could potentially damage the inner wall of the vein and cause a clot to form. With this anterior technique, the femoral vein is not kinked and we have some studies of vein flow during the surgery in a limited number of patients that show that the venous flow is not interrupted, which is potentially a benefit when it comes to blood clots in the leg during or post surgery."

Although fewer than five percent of hip replacement surgeries in the U.S. are currently performed anteriorly, Dr. Matta says that he

believes the anterior approach is will become the standard.

"What I'm trying to do is something that's very good, better than the standard technique," says Dr. Matta. "My opinion, and I'm willing to state this strongly, is that this is the future in arthroplasty. It will be sorted out in the marketplace. It is the educated patient that drives the market, the patient who researches on the Internet. Formerly, there was only the medical library and that was primarily available only to doctors, but the medical information is now available to everyone."

NATIONWIDE PRACTICE

An increasing number of orthopedic surgeons are wholeheartedly embracing the anterior approach. Right now, there are about 200 surgeons in the United States doing the surgery on the PROfx table or on the more economical HANA table, that sells for about one-half the PROfx price tag of \$130,000. And Dr. Matta is in a group of 12 surgeons equipped with the PROfx operating table that are involved in a special collaborative effort where they are tabulating research data from a combined 1,400 cases for a study. They will present this data at a meeting in January in Santa Monica and then also publish their findings.

Two months recovering would have been a disaster for Tom. Now, back to all his normal activities, he is delighted with the outcome of his surgery.

"First of all, it was the pain differences between the two procedures that convinced me—and the recovery time was amazing. Plus, there were no restrictions on weight bearing or crossing my legs or sitting and standing. With me, I'm a branch manager for a stock brokerage firm, and to be laid up for two months would have been a disaster."

He adds that he did have the usual swelling and bruising after the surgery and that he had some nausea issues from the anesthesia. "It's still major surgery because they're using saws and hammers and drills, the same as in 'normal surgery,' but I absolutely recommend this method for anyone considering hip replacement."

Editor's note: For further reading, we invite you to visit www.spondylitis.org

44 Years with AS

Lynda Smith has spent her entire adult life with pain. Still, she finds the time and commitment to helping less fortunate friends – both the 4-legged and 2-legged variety.

From as far back as I can remember I was always active, running, jumping, biking, roller skating, dancing, and playing sports. Even though I wasn't very tall, (5'4"), I was a good athlete. I made the varsity basketball team, won ribbons in high jump and long jump and won several dancing trophies. Life was good!

The same month as my 19th birthday, I started getting pain right in the middle of my left buttock, especially after being on the go all day. Then it started hurting when I first got up in the morning. After a few years, it hurt all the time and was so bad that I couldn't walk without limping. I didn't say anything to anyone. I guess I thought if I ignored it, it would go away. It didn't. It just kept getting worse, much worse.

Finally, I told my GP about the pain. He didn't seem too concerned and suggested that I see a chiropractor. After taking x-rays, the chiropractor told me that my pelvis was twisted and one leg was shorter than the other. When I asked how that could have happened, he told me that I had a broken leg at some time and that was why one leg was shorter than the other one. Even though I told him that I never had a broken leg, he insisted that I did. That should have been a red flag, but being in my early twenties at the time, I was too naïve to think that he might be wrong. After eight years of painful treatments, my condition kept getting worse. I quit going to the chiropractor. Why spend all that money for painful treatments that didn't help at all?

Not only did the pain in my buttock get worse, but my back started to hurt, too. I didn't know what to do until I ended up flat on my back with such pain throughout my entire body that I couldn't even get up without assistance. I had a fever, couldn't eat, and didn't even want to live. My husband was so concerned that he called the ambulance to take me to the hospital. I was admitted and tested for all kinds of diseases. My GP diagnosed me with Rheumatoid Arthritis and sent me to a major medical center for confirmation of my diagnosis and treatment for same. Even though the diagnosis was wrong at that time, at least I was referred to a Rheumatologist. This was ten years after the pain first started.

The teaching hospital did more tests and concurred with the GP: Rheumatoid Arthritis. The Rheumatologist prescribed various Aspirin products. These meds were changed from time to time because I was getting worse instead of better. My hip pain got worse, my back pain got worse, and now my neck hurt, too.



Lynda Smith with friend Ollie, enjoy spreading goodwill to others.

After several years of seeing a Rheumatologist he acknowledged that my symptoms did not indicate Rheumatoid Arthritis, but seemed more like Ankylosing Spondylitis. He ordered a blood test to check for the HLA-B27 marker. It turned out to be positive. That was 18 years after the pain first started.

“Ollie and I go to dog training class every week so he can learn new skills and maintain the old ones. We both love going to dog school, but we really like going to nursing homes and other places that therapy dogs are welcomed. Even though I am bent over and my head sticks out like a turtle and I have an oxygen tank strapped to my back, I feel lucky to be able to walk with Ollie into the nursing home every Wednesday morning where we see people who are in worse shape than I am.”

I read all the information that I could find about AS, did all the exercises, and took the meds that were prescribed, but it just kept getting worse. At age 44, I had a total hip replacement. Prior to the surgery the bone spurs on my left femoral head were so bad that I was in constant pain and had to use a cane to walk. The hip replacement was the best thing that ever happened to me. I could walk without a cane, and best of all, I could walk without pain. I knew the operation was successful when I sneezed two days after surgery and did not have excruciating pain in my left buttock that would literally shock my entire body.

As time went on I experienced muscle spasms in places that I didn't even know you could have them: in my back, my neck, my jaw, and my chest. Along with the chest pain came breathing problems, especially going up steps, walking fast, or doing anything that required more air to my lungs than I could get in them. It was many, many years before it was discovered that I had an extremely low oxygen level. As my ribs fused, my front ribs pushed inward against my heart and lungs. I was unable to fully inhale or fully exhale. By this time, my spine was fully fused as were my ribs.

It has been just over three years since I started using supplemental oxygen, 24/7. It has made a big difference in how I feel. I'm still severely limited in what I can do, but any little bit of help I experience is a blessing.

I have participated in several AS research studies though blood sample donations, x-rays, physical exams, medical histories, and completing many questionnaires. I realize that a cure for AS will probably not occur in my lifetime, but my reason for participating in these studies is to do my part in finding a cure for future generations including my children and their children.

After working most of my adult life, I had to finally stop at age 59 and

go on disability. My condition was so bad that Social Security approved my disability application in less than a month after I submitted it. Of course, having been a Benefits Specialist at a university helped because I knew what to submit and how to approach the many forms that had to be completed. I even coached my Rheumatologist as to how to fill out his forms. He knew my background and was grateful for my suggestions.

The best thing about not working is that I'm now able to take a big afternoon nap. The fatigue that I have experienced has been unrelenting. Another good thing about not going to work every day is that I have time to help others. I do this by adopting homeless Collie dogs and training them to become therapy dogs. My husband became interested in this endeavor, too. We now each have our own rescued Collie. His dog is a three-year-old female named Fancie and mine is a five-year-old male named Ollie.

Ollie and I go to dog training class every week so he can learn new skills and maintain the old ones. We both love going to dog school, but we really like going to nursing homes and other places that therapy dogs are welcomed. Even though I am bent over and my head sticks out like a turtle and I have an oxygen tank strapped to my back, I feel lucky to be able to walk with Ollie into the nursing home every Wednesday morning where we see people who are in worse shape than I am. You see, visiting people in nursing homes, hospitals, and assisted living facilities is a win-win-win situation. The people we visit win because they love petting Ollie and telling me stories about the dogs they used to have. Ollie wins because he loves people, especially when they pet him and talk to him. He does tricks for them to show his appreciation. And finally, I win, too, because I'm not sitting at home thinking about my pain. I'm doing a service for others as well as for myself and my faithful dog.

Corporate Partnership Program

During 2006, the following corporations provided significant funding to the Spondylitis Association of America. They are committed to partnering with us in our mission to be a leader in the quest to cure ankylosing spondylitis and related diseases and to empower those affected to live life to the fullest. Their support has made many of our research and education programs possible and we would like to take this opportunity to extend our heartfelt gratitude to our corporate partners.

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*Thank you
for your
support!*

CHARITY NAVIGATOR AWARDS SAA 4-STAR RATING

The Spondylitis Association of America is pleased to announce that we have earned our second consecutive 4-star rating from Charity Navigator, the largest independent evaluator of charitable organizations in the nation. We were awarded this rating for our ability to efficiently allocate and grow our donated finances. Fewer than 12% of the charities rated by Charity Navigator have received two consecutive 4-star evaluations, indicating that SAA outperforms most charities in America in terms of financial responsibility.

This “exceptional” rating from Charity Navigator differentiates SAA from our peers and proves that our organization is worthy of the trust our members and donors have shown us. To view our page on the Charity Navigator web site, go to:

<http://www.charitynavigator.org/index.cfm/bay/search.summary/orgid/9809.htm>

So know that when you give to SAA, you truly are helping us in our mission: To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest. To learn how you can support the SAA, call (800) 777-8189 or visit our web site at www.spondylitis.org.

Education & Support Meeting Facilitators

The people listed below are a vital part of our support system. They have volunteered to lead support groups across the US because they want to help. If you'd like to find out more about support groups and online meetings, pick up the phone or send an e-mail to:

Phoenix, AZ	John Kornfeind	(623) 910-4742	jmmkorn@cox.net
Long Beach, CA	Barbara Crofut	(562) 421-9698	crofutgr@netzero.net
Long Beach, CA	Frances Tomich	(562) 429-9685	N/A
Orange County, CA	Ms. Kyle Brownfield	(949) 367-0430	kylebrownfield@msn.com
San Diego, CA	Mike Supancich	(760) 438-2962	supancichsr@sbcglobal.net
San Francisco, CA	Clarence So	(415) 297-2803	clarence@clarenceso.com
Fort Wayne, IN	Ken Prather	(260) 637-1705	pratherken@yahoo.com
Indianapolis, IN	Ken Prather	(260) 637-1705	pratherken@yahoo.com
Kansas City, MO	Linea Cooley	(913) 384-0728	linea_cooley@hotmail.com
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Holland, MI	Scott May	(616) 610-9130	smay@wmis.net
Cleveland, OH	Bryan Andresen	N/A	bnkandresen@adelphia.net
Portland, OR	Ken Henschel	(503) 579-8375	Ken.Henschel@comcast.net
Philadelphia, PA	Howard Tevelson	(215) 844-6075	hotbyht@yahoo.com
Myrtle Beach, SC	Alex Best	(843) 655-9762	alexbest@cs.rr.com
Dallas, TX	Elizabeth Smith	(972) 860-7179	elizabethsmith@dccd.edu
Houston, TX	Richard Powell	(409) 883-7822	rwpowell@gt.rr.com
Washington DC	Roger Stead	(703) 455-6005	rogerstead@aol.com
Seattle, WA	Paul Stevenson	(206) 524-2186	pastev@Safeco.com

- Teen Athletes with AS located in Orange County - contact WalkerRSM@aol.com for more info.
- The Chicago, IL and Los Angeles Spondylitis Educational Support Groups are looking for new leaders. Contact Melissa Velez at (800) 777-8189, x227 if you are interested in learning how to become a leader.
- Dallas, TX now has a Spondylitis Educational Support Group!
- Support online from NY, NY with Michael T. Smith, spenser23@aol.com.

Online Poll

You can find this new Instant Poll on our website at www.spondylitis.org.

NEW POLL

Does your insurance cover TNF-blocker therapy for your spondylitis?

- Yes, my co-pay is within my family's means
- Yes, however, my co-pay results in a hardship for my family
- Yes, however, my co-pay is too high for me to afford the medication
- Yes, even though my form of spondylitis does not have an FDA indication (off-label)
- No, since my form of spondylitis does not have an FDA indication (off-label)
- No, my current medical insurance does not cover TNF-blocker therapy

OLD POLL RESULTS

Which medical professional do you see most often?

Rheumatologist.....	59%
Physical Therapist	14%
Primary Care Physician	10%
Gastroenterologist	3%
Dermatologist	0%
Occupational Therapist	0%
Other	14%

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Reach Out and Touch Someone!



The SAA wants to help people with spondyloarthritis (AS or a related disease) connect with others in locations across the U.S. where a support group has not yet been established.



Carolyn Crouse in Roland, AR would like to meet others in her area with spondylitis. If you live in Arkansas and would like to “reach out” to Carolyn, please contact Melissa Velez, Programs Coordinator, at melissa.velez@spondylitis.org and she will put you in touch.

MedAlert: Winter Brings The Flu Season

The Flu Season is upon us again. A reminder from the Spondylitis Association of America to talk to your doctor to find out if you are good candidate for a flu shot.



ARE YOU WILLING TO HELP RESEARCHERS FIND THE GENES THAT DETERMINE THE SEVERITY OF ANKYLOSING SPONDYLITIS?

If so, you may be interested in participating in our study. To participate you need to be at least 18 years of age or older and have been diagnosed with Ankylosing Spondylitis.

Who is conducting the study?

The study is sponsored by the National Institutes of Health (NIH). The doctors conducting this study are Dr. Michael Weisman at Cedars-Sinai Medical Center in Los Angeles, Dr. John Davis at the University of California, San Francisco, Dr. John Reveille at the University of Texas at Houston, and Dr. Michael Ward at the National Institutes of Health in Bethesda, MD.

How can I find out more?

Please contact one of the following Study Coordinators for more information:

- **Southern California:** Felice Lin, (310) 423-2422, linf@cshs.org
- **Northern California:** Stephanie Morgan, (415) 502.1698, smorgan@medicine.ucsf.edu
- **Houston Area:** Laura Diekman, (713) 500.6852, laura.diekman@uth.tmc.edu
- **Washington DC Area:** Lori Guthrie, (301) 435.8434, guthriel@mail.nih.gov

Donate a Car today and help advance research tomorrow!

The process is quick and easy, includes free pick-up or towing, and best of all the proceeds go to a cause near and dear to your heart—The Spondylitis Association of America. The vehicle doesn't even have to run for you to donate it. Consult with your tax advisor prior to donating a vehicle. Call Helene Hart at 800-777-8189 X 229 for more information.

LOG IN

SAA members can now access exclusive content in the member area. Login with your email address and ZIP code at

www.spondylitis.org

Save the Date!



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Association
of America™**

P.O. Box 5872
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**JOIN US IN WASHINGTON, D.C.
for an all-day
SAA spondyloarthritis
educational seminar on
SATURDAY, NOVEMBER 11, 2006.**

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