Relationship is a “state of connectedness between two or more people or groups”. As I reviewed our current issue of Spondylitis Plus, in preparation for penning this column, it occurred to me that such connectedness was the common theme throughout. The news magazine in your hands is about how people, through relationships, have benefited not only their own lives, but those of others, as well.

These are the stories of people working with people towards a better future for individuals affected—directly, or through relationships—by spondyloarthritis. At our Advocates’ Day on the Hill, we campaigned for improved access to healthcare for individuals with musculoskeletal conditions. Read as Phil tells his story about how attending an SAA sponsored support group helped him to gain a whole new perspective on life—and, yes, on AS, too. Read also Dr. Matt Brown’s TASC and IGAS update reconstituted from the newsletter, AStretch, by our sister society in Australia. Therein lies a story of relationship and its contribution to our understanding of these diseases.

SAA’s eight year involvement, initiated and subsequently led by Dr. John D. Reveille and U.S. colleagues, including Dr. Michael Weisman and Dr. Michael Ward, along with the international research consortium, NASC/TASC, has helped to identify critical new gene markers. None of this would have been possible without the selfless commitment of SAA members combined with the selfless leadership of Dr. John D. Reveille. Finally, do not miss the story of Jared, the twelve-year-old who—motivated by relationship—shoveled snow from “long” driveways to raise funds for SAA.

Dear readers, the stories related in these pages flowed directly from our relationship with you. Your questions, queries, and feedback are the source of our direction and inspiration. It is that connectedness that makes what we do possible. So, let these interactions continue to grow. We urge you to make yourself heard. What are we doing well? What can we do better? We are only one phone call or email message away. Use the toll free number 1-800-777-8189 or contact Linda at info@spondylitis.org or me at laurie.savage@spondylitis.org. Let us build upon our relationship with you, so that together we can carry our SAA to its next level of service.

Thank you for your support—and relationship.

Laurie M. Savage
Executive Director
A Correction From Last Issue

We have a correction for the article, “Kyphosis: Is Surgery The Answer?” from the Spring 2010 issue of Spondylitis Plus.

Mr. James Hall, who graciously agreed to be interviewed for the article, writes:

On page nine in the top right hand column, the second sentence mentions “effects, like a broken shoulder.” In fact I was diagnosed with a “frozen shoulder” which is not uncommon with any kind of neck/spine surgery. The rest of that sentence is correct as I now have no symptoms or signs of frozen shoulder thanks to physical therapy and daily exercises at home and the gym.

Later, in that same paragraph, it mentions “a pedicle tunnel release surgery.” I understood that the surgery Dr. Perri performed was a “Cubital tunnel release.” During that surgery, Dr. Perri discovered that the “Osborne ligament” had calcified and was hard and bony. I understand that that ligament encircles the Ulnar nerve and should be soft tissue. Since my rheumatologist had been treating that elbow for enthesiitis, it’s a safe bet that the hardening of that ligament which the Ulnar nerve runs through was the result of my AS.

During the neck surgery, I was strapped to the operating table at the wrist and elbows and as that surgery was approximately seven and a half hours long, the AS in my elbow was bound to make trouble for anything passing that way.

Out of respect and gratitude for the terrific work of Drs. Perri and Siddique I would like to correct the record concerning my post surgery shoulder and nerve problems as I believe my problems were in no way the fault of the surgeons but artifacts of a combination of pre-existing damage from AS and the general after effects of neck surgery. Thank you.

JAMES HALL

Editors Note: We have received tremendous feedback about this article. We sincerely appreciate James Hall for sharing his story.

SAA Offers Support

My husband and I were childhood sweethearts who didn’t get together until later in life. We were told eight months after we married that my husband was suffering from severe ankylosing spondylitis. Jack died August 2nd, 2009 from complications related to years of ankylosing spondylitis. It is difficult to express my grief and yet I really feel the need to talk to others about this disease. I want to thank you and your organization for being a source of information for me. Your website [www.spondylitis.org] and the website Spondyville [www.spondyville.com] were our life lines. My husband was a good man and he is gravely missed.

Thank you,

GAY K.

Editors Note: Gay, we are so sorry for your loss. Thank you for sharing your story with us.

LETTERS TO THE EDITOR

Dear Readers: We want to hear from you, whether it be informative, uplifting or a concern 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 the Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413
This past year SAA’s Executive Director and board members had the opportunity to travel across the U.S. to meet with decision makers, to network with other like-minded organizations, and to participate in committee work to speak on behalf of our members and supporters. You have expressed concerns that include inadequate funding for research and access to healthcare and medicines that are critical for everyday functioning in the home and in the workplace. At SAA, we listen, and so we have been on the road voicing your messages and concerns in front of public officials while joining forces with similarly focused organizations for a bigger voice.

**National Health Council (NHC)**

NHC advocates on behalf of the 133 million individuals affected by chronic diseases. As a full-fledged member of the NHC since 2008, SAA leadership sits on multiple committees of the council, which provides an opportunity to influence NHC strategic and tactical planning decisions regarding our wants and needs.

Leading up to the healthcare reform discussions, NHC developed and executed a campaign titled “Put Patients First.” Essentially, the main drivers of the campaign include access to care for those with pre-existing conditions, the elimination of lifetime caps and increased access to affordable, new and innovative treatments. The latter incorporates the patient’s perspective in the legislative, regulatory, and approval processes for the biosimilars (follow-on/generic biologics). While 20% of the drugs on the market today are biologics—meaning drugs that differ from traditional, chemical based drugs because they are derived from living matter—it is expected that, with 633 biotechnology medicines in development last year for more than 100 diseases, half of the new drugs approved in 2015 will be living matter derived. These drugs are expensive. Biologics average more than 20 times the cost of traditional drugs. And, it has been estimated, by some industry leaders, that the approval of “bioequivalent” drugs would put downward pressure on their cost and subsequently expand their availability to more people.
American College of Rheumatology (ACR)
In April, Board members Michael Pianin, Esq., Craig Gimbel, DDS and SAA’s Executive Director Laurie Savage traveled to Washington D.C. to participate in ACR sponsored Capitol Hill Day.

Your SAA representatives met with Senators and Congressional Members to advocate on behalf of rheumatologists and their patients.

The main thrust of the discussions was focused upon the following topics, each directly affecting the rheumatologist’s ability to practice and thus indirectly, the patient’s access to specialized care.

- Support for fair physician Medicare reimbursement. With many physicians in private practice facing overheads of 55-60%, the proposed severe cuts in reimbursement potentially threaten seniors’ access to care. Physicians are asking for the reimbursement to be based on the Medicare Economic Index (MEI). The MEI would ensure that the reimbursement payments would reflect inflationary pressures on medical practice costs.

- Support of the enactment of the Arthritis Prevention, Control, and Cure Act of 2009. This legislation would expand efforts to discover and to implement new ways to prevent, treat and care for patients with arthritis and related rheumatic diseases. In addition, it would enhance rheumatic disease research and public awareness of these often debilitating diseases by:
  - Providing federal support for initiatives to educate the healthcare professional and public on successful self-management strategies;
  - Bolstering federal juvenile arthritis research efforts and prioritizing epidemiological activities focused on better understanding the prevalence, incidence and outcomes associated with juvenile arthritis;
  - Establishing an education loan repayment program to create incentives for medical students to enter the field of pediatric rheumatology. Currently, there are fewer than 300 practicing pediatric rheumatologists in the U.S., even though over 300,000 children suffer from arthritis and related rheumatic diseases. Still, nine states do not have a single pediatric rheumatologist. The fact is that young physicians who invest in the extra training and are usually deeply in debt cannot afford to go into poorly paying cognitive specialties.

The National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) Coalition Steering Committee
The Coalition is comprised of more than 70 organizations (medical professional, patient advocacy and research based) dedicated to advancing critical research funded by NIAMS through the National Institutes of Health. To the extent that NIAMS is stable and fiscally strong, it can significantly affect the nation’s ability to combat some of the most difficult, chronic and progressive diseases. Among these is the spondyloarthritis group of conditions. Underfunding of NIAMS threatens the agency’s ability to achieve its critical mission. The NIAMS Coalition’s responsibility is to support the goals of the Institute and to advocate for federal investment in its important work to ensure support for critical research into the causes, prevention and treatment of arthritic, musculoskeletal and skin diseases.

SAA’s Executive Director has accepted the invitation to serve on the Coalition’s Steering Committee during 2010. In that role, she has an opportunity to provide guidance regarding the direction of the Coalition’s work and its strategic and practical role in serving its mission to support NIAMS.

“Your SAA representatives met with Senators and Congressional Members to advocate on behalf of rheumatologists and their patients.”
Progress in Ankylosing Spondylitis Genetics
From Matt Brown, Professor of Immunogenetics, University of Queensland

In the past three years major advances have been made in the ability to identify genes that cause common human diseases, such as arthritis, diabetes, obesity and so on. Studying thousands of individuals for hundreds of thousands of genetic markers each, we can now identify many, but not all, of the genes that influence the risk of developing conditions. These studies are expensive (minimum cost >$1 million per study), complex, and generally involve multinational consortia to ensure the skills and patient cohorts are available to complete the studies.

Our group in Brisbane is now well skilled in performing these sorts of studies, and has become an Australasian centre for this type of research. Although we research several different diseases, AS has been a long-standing focus. We are the main genetics centre for an international consortium termed the ‘Australo-Anglo-American Spondyloarthritis Consortium’ (TASC). This group involves more than 20 researchers, and is engaged in studies aimed at identifying genes involved in AS, and also non-genetic factors, such as work, lifestyle and psychological factors which influence the severity of the condition and how it affects patients. We have now completed two major studies which have identified four definite new genes/genetic regions involved in AS, and several others that are very likely to be true AS-genes.

The first big breakthrough came in 2007, when in collaboration with another group (the Wellcome Trust Case Control Consortium), TASC identified two genes, called IL23R and ERAP1, as being involved in AS. These were really exciting findings because of the known function of the genes, and neither had been suspected as having been involved in AS previously. Both tell us a lot about the processes which lead to AS developing.

Since the discovery of the association of IL23R with AS, several genes involved in determining the activity of TH17 lymphocytes have been demonstrated to be involved in AS or the related conditions, inflammatory bowel disease (IBD) and psoriasis. This tells us that this lymphocyte-type is really important in the process by which AS develops. What we don’t know yet is if the genetic variants that lead to AS cause the lymphocytes to be underactive or overactive.

The other gene we identified, ERAP1, most likely works to increase the risk of AS by influences on HLA-B27. We don’t yet know how HLA-B27 causes AS (despite LOTS of research), but one leading theory suggests that HLA-B27 presents short proteins to cells called T-lymphocytes. These T-lymphocytes normally serve to protect us from infection and cancer, but can cause disease themselves if the control of their activity gets upset. It is thought that HLA-B27 may cause AS because it presents particular proteins which induce these lymphocytes to become excessively active, leading to inflammation and arthritis.

The other two genetic regions we have shown to be involved in AS are what we call ‘gene deserts’, which are regions of the genome where the DNA contains no genes. These regions used to be called ‘junk DNA’, but are now known to contain areas which control the expression of other genes. We don’t yet know what the other genes are that these gene deserts control, but we are working at it, and hope that by working this out, we can use the information to develop new therapies for AS.

Many more genes have yet to be identified which cause AS, and there are other large studies underway in Europe, Canada and China that will report findings in the next 12-18 months which will increase this list further. In particular, the International Genetics of AS consortium (IGAS), will be performing a study with about 13,000 samples from all over the world, which we will be genotyping in our lab in Brisbane. So the next two years will be a very exciting time for discovering genes in AS.
Although some pregnant women with inflammatory arthritis may experience an improvement in disease activity during their pregnancy, others may need to continue therapy throughout pregnancy and during lactation as well. Information on the safety of these drugs during pregnancy is limited.

Anti-TNF drugs have demonstrated efficacy in reducing disease activity and joint destruction and improving health-related quality of life in patients with ankylosing spondylitis and other inflammatory diseases such as rheumatoid arthritis, psoriatic arthritis, and juvenile idiopathic arthritis. The anti-TNF agents commonly used include infliximab, adalimumab, etanercept and golimumab. These drugs fall into the United States FDA category B concerning fetal risk, indicating that while animal studies have not shown a risk to the fetus, adequate studies of pregnant women have not been conducted. Consequently, and probably for legal reasons, drug manufacturers have recommended that these agents be avoided during pregnancy and lactation.

A survey of rheumatologists in the USA showed that fewer than half of those questioned agreed that anti-TNF drugs should be avoided in pregnancy. Almost half stated that they were uncertain about their safety during pregnancy. The respondents generally agreed that recommending effective birth control for women taking these drugs was important.

It is interesting that women of reproductive age suffering from inflammatory arthritis who are being treated with anti-TNF therapy may increase their chances of reproduction and pregnancy outcome. It is still controversial if anti-TNF agents have a positive impact on fertility but it has been noted that pregnancy rates have increased in women with rheumatic diseases during the last few years. While most pregnant women with rheumatoid arthritis experience an improvement in disease activity, the picture is different for most women with AS. Ankylosing spondylitis tends to demonstrate persistent disease activity during pregnancy that decreases only in the later months. Disease activity in pregnant women with AS tends to equally either be unchanged, improved or worsened. A post-partum flare of disease activity is experienced by 60-90% of AS patients, generally within six months of delivery. Most often, the post-partum flare is experienced by those who had active disease at conception.

It is considered important to explore the safety of anti-TNF therapy exposure in those women who experience worsening of their disease either during or after pregnancy. Current data do not seem to support a large excess risk of adverse pregnancy and/or fetal outcomes in women exposed to anti-TNF therapy at some point in pregnancy. Evidence is limited by the small number of published case studies and by differences in the type and amount of anti-TNF agents, possible use of other drugs and the timing of exposure during pregnancy. Most of the data relate to exposure in the first trimester and a few patients have been exposed during the entire pregnancy or during the second or third trimester. No long term follow-up studies are yet available on the possible effects of exposure to the offspring. Some effects of in utero drug exposure may not be observed for decades.

To date, anti-TNF agents have been shown to be transferred via placenta to the unborn child. The agents can be found in breast milk but are probably digested in the gastrointestinal tract of the child. No large excess risks of fetal or maternal adverse outcomes have been reported following exposure to anti-TNF therapy during pregnancy compared with the general population. Sporadic cases of congenital malformation have been reported, but do not seem to be in excess of what is expected in the general population.

More data is expected over the next five years which will allow for assessment of the post in utero exposure to anti-TNF drugs.

Reprinted with permission from “Talk Back”, the Canadian Spondylitis Association Newsletter, Volume 1, Issue 3, Fall 2009.
Sports and recreational activities are wonderful additions to your physical fitness routine. In fact, participating in these activities is a critical part of the management of spondylitis. A proper level of fitness and activity helps decrease pain and stiffness. Activity also nourishes bones, and consequently, helps combat osteoporosis (brittle bones).

Considerations and Precautions
People with spondylitis can participate in a wide variety of sports and activities, although certain considerations and precautions ought to be noted before continuing a favorite activity or embarking on a new one.

Selecting Appropriate Activities
Because the extent of the disease varies from person to person, you will have to decide what is reasonable. For example, if you’re in the early stages of spondylitis with primarily low back pain, you may be able to play basketball or tennis and tolerate it well. A person with advanced disease, however, will be more limited, but may find that bicycling or swimming is enjoyable and more suitable. If a flare-up occurs, don’t participate in vigorous sports; wait until you feel better before gradually resuming vigorous activities.

Choosing an activity is an individual matter. Vigorous activities such as aerobics and dancing are very popular, but they can be stressful. Many people with spondylitis, however, participate in such activities and tolerate them well. Exchanging ideas with others with spondylitis can be helpful in selecting activities. Keep in mind that what is good for another may not be good for you. If there are any questions about what you can do or when you should be careful, consult your physician and/or physical therapist for guidance. This is especially important prior to beginning a new sport or resuming an old one after a several-month layoff. Remember to make an extra effort to be sure your arms and legs are kept as supple and as strong as possible. Their added strength and mobility will help compensate for any spinal stiffness.
Using Trial and Error – Experience will tell you just how much activity is enough and how much is too much. The important thing is to start slowly. You can always increase your efforts the next time. Any increase in pain and stiffness with new activities should last no longer than one or two days. If the pain persists, don’t be discouraged by the sport and give up; rather, consider that you may have overdone it and decide on ways you can modify the activity. For example, if you’ve played tennis for an hour and feel stiff, consider using a lightweight racquet. More importantly, analyze your pre- and post-exercise conditioning “warm-up,” and “cool down” routines. A proper amount of vigorous activity on a regular basis (about three times weekly) will help keep the body conditioned and will avoid overuse and unaccustomed use of muscles and joints. A general sports medicine rule for all vigorous athletes is to avoid strenuous exercises or activities on two consecutive days.

Precautions if Your Spine is Stiff – The agility and flexibility needed for certain activities diminish as the neck and back are more involved in spondylitis. Stiffness in the neck and back can lead to strains and sprains. The chance of injury increases when the body cannot assume proper positioning during movement. The ability of the spine to absorb shocks is lost when the spine is stiff or becomes fused. Thus, there is greater risk of injury. Also, with a tendency for osteoporotic (porous) bones, the spine is even more susceptible to injury. Keep in mind that a fracture from a fall can occur during the course of common recreational activities such as horseback riding, skiing, bicycling or ice skating, so you should select your sports with care.

Suggested Sports and Activities
Generally speaking, sports and activities that encourage good posture and spinal extension are recommended. Swimming is an excellent choice because immersion in water eliminates the effect of gravity, thereby allowing stress-free movement. Those who have difficulty turning their necks, but enjoy swimming, can use a snorkel for breathing. Walking, tennis, badminton and low-impact aerobics are other activities that promote good posture. Even though activities such as golf, billiards, bowling and bicycling may encourage a forward stooped posture, these need not be avoided if compensations are made (shorter golf swing, lighter bowling ball, or upright handlebars). It is essential to assume an erect posture and to stretch during rests or breaks in activity.

Some people enjoy working out at the gym. This is appropriate too. Machines that emphasize arm and leg conditioning are recommended. Gymnasium exercise equipment can be helpful for toning up the muscles and for promoting spinal extension. However, you must avoid machines that put undue strain on the back and neck. Weight loads and exercise repetitions should be kept low and increased gradually. Use a program that is designed to tone muscles: low weights and multiple (10-15) repetitions. If the gym has exercise classes, choose low-impact aerobic classes, so that less strain is placed on your back and joints. Aerobic exercises are often invigorating. Every spondylitis patient will benefit from one form or another, even though not every exercise will be right for each patient. For example, swimming is particularly good for people with hip involvement, whereas walking briskly, hiking and bicycling (upright handlebars) are recommended for people with shoulder pain.

There are a number of exercise DVDs that can be used, provided the exercises are modified suitably to your spondylitis. SAA’s exercise DVD, “Back In Action” was developed specifically for the spondylitis patient. If you have marked restrictions in your physical abilities, be creative in devising an activity program. For example, use a stationary bicycle or exercise in a hot tub or spa to music. Tai Chi and yoga, modified to accommodate any restrictions of movement, are particularly valuable for their breathing and stretching techniques and noncompetitive nature.

Reprinted from Straight Talk on Spondylitis, Chapter 6, Enjoying Sports and Recreation. To purchase a copy of the book Straight Talk on Spondylitis, which contains information from experts, lifestyle and exercise tips, information on medications, and more, visit www.spondylitis.org/store
INVEST IN THE FUTURE OF SPONDYLITIS RESEARCH

As you’ve read in this issue of Spondylitis Plus, SAA is doing more than ever before to champion the campaign to accelerate spondylitis research in the United States. From active and vocal participation on the steering committee of the National Institutes of Musculoskeletal and Skin Diseases Coalition to joining forces with the National Health Council’s campaign to “Put Patients First”, SAA is taking on the challenging task of being the voice of the spondylitis community in Washington, DC.

Why is that important? Because the investment in musculoskeletal research in the United States lags significantly behind other chronic conditions. While musculoskeletal diseases, like spondylitis, are common, disabling and costly, they remain under appreciated, under recognized and under resourced by our national policy makers.

According to the Centers for Disease Control and Prevention, ankylosing spondylitis and its associated diseases affect as many as 2.4 million Americans, almost twice as many as rheumatoid arthritis. And yet, research funding for musculoskeletal conditions is less than two percent of the National Institutes of Health budget. And spondylitis, specifically, gets only a fraction of that.

We believe that needs to change.

As a member of the spondylitis community you can play a starring role in changing the status quo – for yourself, your children and for all of us fighting this fight. As a patient with an existing condition, communicating the need for more research to legislators, policymakers, and research funding organizations is vital. Legislators and policymakers need you to tell them about the burden of spondylitis, how it affects you, and how important their role is in approving increased funding for research.

Another way to make sure your voice is heard is to join with SAA in its efforts to take this fight to Washington. The more resources we have, the louder our collective voice. We want to see to it that all the decision makers on “the hill” have the phrase “spondylitis research” ringing in their ears.

Please give as generously as you can. Your gift will go a long way toward providing the resources we need to stay in the forefront of spondylitis research while still providing important programs and services to those affected by AS and its associated diseases. Your renewed financial commitment to SAA will help us continue the work to speed the quest for the cure.

With all of us working together, we can, and will, change the landscape of spondylitis in this country.

Get the Recognition You Deserve

Many of you give generously to support SAA’s commitment to research and other program services through federated giving programs such as the Combined Federal Campaign and United Way. But more than half of the federated funds we receive come to us anonymously. If you give through a workplace campaign, please contact Helene Hart at 1-800-777-8189 or at hhart@spondylitis.org to make sure you’re recognized in our Annual Report and continue to receive the valuable benefits that come from being an SAA member.
SAA was founded by a small group of volunteers in 1983 and today, we continue to rely on the generosity of volunteers around the country to help further our mission. We’d like to acknowledge all of the volunteers who are making a difference in the fight against spondylitis, and to share with you one special story of a young volunteer who exemplifies the true meaning of altruism.

In January, we received a check for $160.00 with the accompanying letter below from 12-year-old Jared who lives in Ohio. His father suffers from AS and Jared wanted to do something to help. On a snowy day when Jared was off from school, he decided to do just that! Instead of sledding and playing with his friends, he went door-to-door in his neighborhood and offered to shovel and clear snow from their sidewalks and driveways to raise funds for SAA. Jared worked for nearly five hours in the cold and snow and as he says in his letter, “some of those driveways were very long.” At the end of the day, he had raised $80.00 and his parents generously matched the money he earned.

We can’t thank Jared enough for his act of kindness. He is not only an inspiration but an example to us all that “one person can make a difference”… even if they are only twelve years old.

If you want to “make a difference” by volunteering, please contact Robin Kindrick at 800-777-8189, ext. 225 or at robin.kindrick@spondylitis.org. Thank you!
Which vitamins do you recommend that spondylitis patients take regularly?
There is evidence that patients with chronic illnesses such as diabetes mellitus do benefit from taking a multivitamin every day. The benefit is that there are fewer infections in diabetic patients who take a multivitamin as opposed to patients who do not take a multivitamin. Beyond a regular multivitamin a day, there is no evidence that taking extra supplements benefits all patients with a chronic illness such as spondylitis. Extra vitamins and minerals should be tailored to each individual patient’s regimen based on other co-existing conditions such as vitamin D deficiency, osteoporosis and inflammatory bowel disease.

Why is it important for people with spondylitis to get enough Vitamin D? How much Vitamin D is enough?
The recommended daily intake of vitamin D for adults is 400 IU. However this may be revised soon since studies have shown low vitamin D levels in up to fifty percent of adult patients studied. The recommended daily intake of vitamin D every day for adults with osteoporosis is 800 IU but with newer assays that have been developed, it is apparent that patients with osteoporosis may need to be titrated to higher doses up to 3000 IU. Patients with ankylosing spondylitis need to be assessed for osteoporosis in their thigh and forearm bones since there is a falsely elevated bone density in the spine due to new bone formation from syndesmophytes. More than half the patients with AS have osteoporosis diagnosed by bone densitometry tests. It is important to maintain a positive calcium balance in patients who are prone to develop osteoporosis. Studies have shown that patients who take 1000 to 1500 mg of calcium supplements along with adequate vitamin D daily improve or prevent a decline in their bone density by 1-2% every year. There is no evidence that taking calcium worsens the bone formation and fusion of ankylosing spondylitis.

Why is calcium an important part of a spondylitis patient’s diet?
Osteoporosis affects more than half the patients with spondylitis, which results in weaker bone that is more prone to fractures with minimal trauma. It is important to maintain a positive calcium balance in patients who are prone to develop osteoporosis. Studies have shown that patients who take 1000 to 1500 mg of calcium supplements along with adequate vitamin D daily improve or prevent a decline in their bone density by 1-2% every year. There is no evidence that taking calcium worsens the bone formation and fusion of ankylosing spondylitis.

Is the antioxidant alpha lipoic acid helpful to people who have spondylitis?
Alpha lipoic acid is an antioxidant that helps to scavenge free radicals in the body and therefore has been proposed as a useful agent in slowing down the aging process in the body. There is no proven evidence in human trials that this is true and there are no studies to support its use in ankylosing spondylitis.
There is a theory that the sodium alkaloids found in plants from the nightshade family (ex. potatoes, aubergines, tomatoes, and red and green peppers) may cause or contribute to arthritis and ankylosing spondylitis in some people. Is this true?

There is no conclusive evidence in humans that suggests that plants belonging to the nightshade family contribute to arthritis pain. However, anecdotal human experience suggests that pain may exacerbate and some animal experiments suggest that calcification may develop in the joints and tissues in animals exposed to unusual levels of extracts of these vegetables. Personal experience should guide the use of these vegetables in patients with inflammatory arthritis.

Probiotics have become very popular recently for treating a variety of conditions. Would you recommend them for treating spondylitis?

Probiotics such as acidophilus and bifidus have been shown to prevent antibiotic treatment associated diarrhea and super infection and are often prescribed to any person who has a digestive ailment. Excessive amounts of probiotic can cause abdominal discomfort and diarrhea. Small amounts of these probiotics containing about 50 billion to 100 billion colony forming units of beneficial bacteria can help to balance the content of the intestinal flora and help to prevent digestive disturbances.

Are Glucosamine and Chondroitin supplements beneficial for a spondylitis patient?

Glucosamine and Chondroitin supplements are generally prescribed to patients with degenerative arthritis such as osteoarthritis. Glucosamine is generally obtained from the shells of crustaceans and Chondroitin is derived from a bovine source. They have a modest effect on the pain of osteoarthritis patients but they do not relieve inflammation and do not rebuild the cartilage of the joints as is often claimed by manufacturers. They will usually fail to improve the pain of patients with AS since the pain in this condition is caused by inflammation.

Some people with AS can experience weight loss and loss of appetite. Are there any vitamins, dietary supplements, or other nutritional items (e.g. protein shakes) that you would recommend for this?

Weight loss in AS patients may be due to multiple reasons and may include a decrease in the abdominal capacity due to stooped posture due to fusion of the spine in a bent position or due to lack of absorption of nutrients from a diseased small intestine due to colitis. Depression and side effects of medications such as non-steroidal anti-inflammatory drugs may also cause weight loss. Treatment of the weight loss should be directed at the cause and may range from corrective surgery for the bent fused spine to more effective therapies for bowel inflammation. Small frequent meals and protein rich supplements can also aid in improving the weight. Taking a multivitamin a day can help in the prevention of infections.

Are there supplements and/or vitamins that can cause harmful drug interactions when used in conjunction with certain medications used to treat spondylitis?

There are a myriad of interactions between prescription medications and between prescription medications and supplements. Some of the natural anti-inflammatory medications such as willow bark have salicylates, which may enhance the irritation of the bowel caused by non-steroidal anti-inflammatory drugs. Supplements such as garlic can enhance the blood thinning effects of prescription medications such as aspirin or Coumadin. St John’s Wort is contraindicated in patients taking traditional anti-depressant medications.

The Spondylitis Plus editorial staff would like to extend their gratitude to David Hallegua, MD, rheumatologist and SAA Board Member for generously providing this important information to our readers.
I walked out of the doctor’s office stunned, armed with several brochures and a million questions. I’d just been informed that I was HLA-B27 positive. This genetic discovery, coupled with the x-rays taken of my spine three weeks earlier, left the doctor little doubt that my pain and suffering was due to a disease, ankylosing spondylitis. With those words, my twenty year history of pain and seemingly random ailments all fell into perfect focus. Whether I liked it or not, I was now in a group.
On one hand, I felt some relief. Through sheer force of will, or maybe even downright stubbornness, I’d forced my enemy out of the shadows into the light. This disease could hide no longer and I firmly believed that I could overcome this and regain control of my life. One by one I read the brochures I’d been given. The first one was about the disease itself; I saw words like brittle bones, spinal fusing and aortal valve leakage. As hard as I looked I found nothing about a cure. Online, the digital world brings me grim story after story. This is not a kind disease; I read testimonials and cautionary tales about people who live with long term chronic pain. This can be a terrible disease, one that will ravage your bones and joints for as long as you can draw a pain filled breath. After hours online, squinting into one medical paper after another, all I felt was alone.

The more I read, the more I hope to find some other affliction that fits my symptoms. I don’t want AS. What I don’t grasp yet is that I’m going through the initiation process. I’m a rookie, and this is only the first step in a long transformative process. The experts call it denial, and I’m buried deep in its clutches.

I set up appointments for a second opinion. I’m angry and little scared, and the medical industrial complex will have to stop and listen. If I were honest with myself, what I’ve done is set up appointments to find a different diagnosis. I have twenty years experience with doctors not getting it right, why should I believe them now? I only need to keep looking and find a diagnosis that sends me into a different group, a different affliction, perhaps one that doesn’t even warrant a brochure.

The weeks and months drag by and every road I travel leads me back to AS. An outbreak of iritis seems to mock me, and at some point I begin to fully grasp that the whole denial thing probably isn’t working. I have to accept that I have AS and it’s devouring all of the good parts of my life. I’ve been a complete jerk to most everyone I know. I deserve to be avoided. I’d avoid me if I could. The friends I still have, look at me suspiciously, and say, “You look fine.” I try to explain that I don’t have any energy, that my joints feel like they have the flu and I am so tired I could sleep on bare concrete. The invitations slowly dwindle and my world shrinks dramatically.

“After hours online, squinting into one medical paper after another, all I felt was alone.”

For nearly two years, I flounder in my group of one. The medications fail and the AS worsens. I endure heart surgery and watch helplessly as most of the things I love fall out of reach. Through my own fault, I lose important people along the way. My group of one is toughest on those close to me.

I finally decide that battling AS through the Minneapolis winters was an ordeal I didn’t have to endure. With connections in Dallas, I feel confident that whatever anemic winter Texas might throw at me would be microscopic compared to Minnesota. In Texas I’m around old friends, and before I can alienate them with my caustic, AS fueled sarcasm, I follow up on a promise I made to myself that I’d attend the Dallas support group sponsored by the SAA.

As an author, I would not generally categorize myself as a group person. I’m more like a loner, even a hermit. At times I’ve been called a recluse as I sit at the computer screen for as long as I can, doing the dance with words that will eventually become a novel. It’s solitary work this novel writing and therefore I’ve never been one to give much thought to groups. As a rule I don’t belong to any group; I pay no annual dues to an organization that would require me to be at a certain spot on a given day.

As the day of the meeting drew near, I gave myself a dozen opportunities to chicken out. I’d been a group of one for so long I will readily admit to being a little uneasy about the whole process. Where I need to go is an hour away via eight-lanes of rush-hour hell, but a promise is a promise. As I played stop and go with the masses, I decided this was stupid, everyone who knows me knows I don’t do groups. I hate traffic and I don’t do groups. Who was I kidding? The last thing I needed was to go hang out in a room full of people as grumpy and bad-tempered as myself. Still, I soldiered onward.

I held my breath and pushed through the door and found myself standing in an empty room. I’d come all this way and I was still a group of one. Moments later, a smiling red-haired woman walked into the room. She introduced herself as Rachel, the group leader, and yes, I was in the right place. Rachel was a blur of motion as she continued setting up the room, so much so that I highly doubted she had AS. Which made sense, why would anyone put a grouchy, pain addled, sleep-deprived person in charge of anything important? We chatted and she asked me when I was diagnosed, then she replied that we were diagnosed at almost the exact
same time. I’d just met the first person on the planet besides me who suffered from AS, and we were nothing alike.

More people began to arrive, and my anxiety slowly went away, replaced with an eagerness to get to know this handful of fellow human beings. Rachel stood before us and told her story. I learned that Rachel’s motivation to become a group leader revolved around what AS did to people. “There is inevitable loss—there isn’t anyone who isn’t changed by this disease. Losses can be anything from mild lifestyle changes, to life altering events. Whatever the case, no one should have to go through this alone.” Rachel said, and then went on to tell us that she was in the process of setting up a website for the group, as well as a Facebook page. What she had in mind for possible future meetings. I knew then that we were in very good hands.

I listened intently as people described their own personal journeys. Each story was as unique and complex as the person doing the telling—or as unique and complex as this disease. I’ve tried two different TNF blockers to no avail. I learned I wasn’t alone, yet there were others who relished the improvement these drugs provided. I was curious about those in the room who’d been fighting the disease for years. Perhaps I could get a glimpse into my own future?

Besides the people who’d been diagnosed, there were also a mother and a husband in attendance, and both remarked that they were glad they came—that the group point-of-view helped them better understand the disease.

Rachel ended the meeting by making it clear that we were the group, not her; she was simply the facilitator and her phone was always on.

It has been months since my first meeting and I still marvel at the experience. I’ve left Dallas, but I still stay in touch with members of the group. Though far away, their presence is still reassuring. I, like most others afflicted with his disease have been subject to a variety of treatments, some benign, others brutally painful. Some worked, most didn’t. But I can honestly say that one of the best treatments I ever received was going from my little group of one, to belonging to an entire community. For the better part of twenty years, as I chased the root cause of my symptoms, I’d known concern, sympathy, even compassion, but among those strangers in Dallas who become my friends, I found something that had been missing…empathy.

“Each story was as unique and complex as the person doing the telling—or as unique and complex as this disease... I learned I wasn’t alone...”

Author’s Note: SAA-Sponsored Educational Support Groups serve members of the spondylitis community in 24 states across the US. The process that SAA requires for its group leaders is impressive. There are applications, followed by evaluations to determine subject knowledge, motivation and personal history. The final stage is an interview with an SAA Board Member. Please do yourself a favor and use every asset SAA provides, including the wealth of information available at www.spondylitis.org. I encourage everyone touched by this family of diseases to reach out and make a connection. Remember, no one need go through this alone.
MAKE A CONNECTION
What Support Group Attendees Are Saying....

“The support group has helped me tremendously!”

“I can honestly say that I left [the support group meeting] feeling about 97% better than I have since the diagnosis was made. It was the first time I felt like I wasn’t the only person in the world with AS.”

“I feel more able to face this disease with some dignity knowing that I have a couple of people that truly understand to confide in.”
MEETINGS WITH MEANING
Spondylitis Educational Support Groups Call On The Experts

Check out just a small sample of the experts who recently presented (or will present) at support group meetings…

- **March 9th in Boise, ID**
  New Treatments for Effective Spondylitis Management with W. Patrick Knibbe MD

- **April 24th in San Francisco, CA**
  Physical Therapy for Spondylitis with Sturdy McKee, MPT, CSCS and Q & A with rheumatologist, Lianne Gensler, MD

- **April 3rd in Deland, FL**
  New Treatments for Effective Spondylitis Management with W. Patrick Knibbe MD

- **May 8th in Woodlands, TX**
  Proper Breathing and Upper Body Exercises with David Neighbors, martial arts expert

- **Upcoming on July 10th in Morristown, NJ**
  Anxiety and Stress Reduction for the AS Patient with Ron Glassman, PhD neurosciences

- **March 9th in Boise, ID**
  Acupuncture, Nutrition and Spondylitis with Debra Gaffney, board certified acupuncture physician

The full listing of support groups is to the right. For more information and meeting times for each group, visit us at www.spondylitis.org/groups
**SAA-Sponsored Educational Support Groups**

The people listed below have volunteered to lead support groups across the US. If you’d like to find out more about support groups and online meetings, visit our website at: http://www.spondylitis.org/patient_resources/

<table>
<thead>
<tr>
<th>AREA</th>
<th>LEADER</th>
<th>EMAIL</th>
<th>PHONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anchorage, AK</td>
<td>Peter Jarratt</td>
<td><a href="mailto:pjarratt@gci.net">pjarratt@gci.net</a></td>
<td>N/A</td>
</tr>
<tr>
<td>Little Rock, AR</td>
<td>Mindy Hunter</td>
<td><a href="mailto:mindyhunter@gmail.com">mindyhunter@gmail.com</a></td>
<td>(501) 351-6374</td>
</tr>
<tr>
<td>Phoenix, AZ</td>
<td>John Kornfeind</td>
<td><a href="mailto:jmmkorn@cox.net">jmmkorn@cox.net</a></td>
<td>(623) 910-4742</td>
</tr>
<tr>
<td>Irvine/Orange Co., CA</td>
<td>Karen Lehrer</td>
<td><a href="mailto:karen.lehrer@gmail.com">karen.lehrer@gmail.com</a></td>
<td>(949) 306-8969</td>
</tr>
<tr>
<td>Oakland/East Bay, CA</td>
<td>Howard Tevelson</td>
<td><a href="mailto:hotbyht@yahoo.com">hotbyht@yahoo.com</a></td>
<td>(510) 991-7549</td>
</tr>
<tr>
<td>San Diego, CA</td>
<td>Mike Supanich</td>
<td><a href="mailto:msupanich@gmail.com">msupanich@gmail.com</a></td>
<td>(760) 438-2962</td>
</tr>
<tr>
<td>San Diego, CA</td>
<td>Tim Tomkins</td>
<td><a href="mailto:tim@digitallightmedia.com">tim@digitallightmedia.com</a></td>
<td>N/A</td>
</tr>
<tr>
<td>San Francisco, CA</td>
<td>Clarence So</td>
<td><a href="mailto:elin.aslanyan@spondylitis.org">elin.aslanyan@spondylitis.org</a></td>
<td>(818) 981-1616</td>
</tr>
<tr>
<td>San Jose, CA</td>
<td>Jigar Shah</td>
<td><a href="mailto:ejigar@gmail.com">ejigar@gmail.com</a></td>
<td>(408) 306-3793</td>
</tr>
<tr>
<td>Denver, CO</td>
<td>Noel Miles*</td>
<td><a href="mailto:Milessterri@aol.com">Milessterri@aol.com</a></td>
<td>N/A</td>
</tr>
<tr>
<td>Stamford, CT</td>
<td>Christine Wu</td>
<td><a href="mailto:cwu108@yahoo.com">cwu108@yahoo.com</a></td>
<td>(914) 837-1190</td>
</tr>
<tr>
<td>Deland, FL</td>
<td>Brent Schlapper</td>
<td><a href="mailto:schlappersangels@hotmail.com">schlappersangels@hotmail.com</a></td>
<td>N/A</td>
</tr>
<tr>
<td>Clearwater, FL</td>
<td>Heidi Walsh</td>
<td><a href="mailto:Heidi.Walsh@baycare.org">Heidi.Walsh@baycare.org</a></td>
<td>(727) 447-8793</td>
</tr>
<tr>
<td>Atlanta, GA</td>
<td>Means Davis</td>
<td><a href="mailto:meansd@mindspring.com">meansd@mindspring.com</a></td>
<td>(770) 529-5272</td>
</tr>
<tr>
<td>Savannah, GA</td>
<td>Wil Carswell</td>
<td><a href="mailto:wlcars@yahoo.com">wlcars@yahoo.com</a></td>
<td>(912) 858-4651</td>
</tr>
<tr>
<td>Boise, ID</td>
<td>Leader Needed</td>
<td><a href="mailto:elin.aslanyan@spondylitis.org">elin.aslanyan@spondylitis.org</a></td>
<td>(818) 981-1616</td>
</tr>
<tr>
<td>Chicago, IL</td>
<td>Joyce Terzick</td>
<td><a href="mailto:alden41@aol.com">alden41@aol.com</a></td>
<td>(815) 744-5017</td>
</tr>
<tr>
<td>Chicago, IL</td>
<td>Kathy Lange</td>
<td><a href="mailto:kd58@comcast.net">kd58@comcast.net</a></td>
<td>(847) 577-9940</td>
</tr>
<tr>
<td>Fort Wayne, IN</td>
<td>Ken Prather</td>
<td><a href="mailto:pratherken@yahoo.com">pratherken@yahoo.com</a></td>
<td>(260) 637-1705</td>
</tr>
<tr>
<td>Indianapolis, IN</td>
<td>Ken Prather</td>
<td><a href="mailto:pratherken@yahoo.com">pratherken@yahoo.com</a></td>
<td>(260) 637-1705</td>
</tr>
<tr>
<td>Augusta, ME</td>
<td>Michelle Andrews</td>
<td><a href="mailto:qualey28@roadrunner.com">qualey28@roadrunner.com</a></td>
<td>(207) 445-2885</td>
</tr>
<tr>
<td>Ann Arbor, MI</td>
<td>Tamara Wilcox</td>
<td><a href="mailto:twilcox@emich.edu">twilcox@emich.edu</a></td>
<td>(734) 975-4414</td>
</tr>
<tr>
<td>Grand Rapids, MI</td>
<td>Scott May</td>
<td><a href="mailto:smay@bloommb.com">smay@bloommb.com</a></td>
<td>(616) 610-9130</td>
</tr>
<tr>
<td>Kansas City, MO</td>
<td>Leader Needed</td>
<td><a href="mailto:elin.aslanyan@spondylitis.org">elin.aslanyan@spondylitis.org</a></td>
<td>(818) 981-1616</td>
</tr>
<tr>
<td>Hettinger, ND</td>
<td>Bonnie Smith</td>
<td><a href="mailto:nbsmith@ndsupernet.com">nbsmith@ndsupernet.com</a></td>
<td>(701) 567-2771</td>
</tr>
<tr>
<td>Poughkeepsie, NY</td>
<td>Kim Ortega</td>
<td><a href="mailto:regabst1@aol.com">regabst1@aol.com</a></td>
<td>(845) 471-8100</td>
</tr>
<tr>
<td>Morristown, NJ</td>
<td>Craig Gimbel</td>
<td><a href="mailto:believe5154@optonline.net">believe5154@optonline.net</a></td>
<td>(973) 476-8976</td>
</tr>
<tr>
<td>Morristown, NJ</td>
<td>Barbara Schiller</td>
<td><a href="mailto:schiller175@verizon.net">schiller175@verizon.net</a></td>
<td>(973) 966-1736</td>
</tr>
<tr>
<td>Portland, OR</td>
<td>Kathryn Houston</td>
<td><a href="mailto:kathair@uno.com">kathair@uno.com</a></td>
<td>(360) 635-3238</td>
</tr>
<tr>
<td>Pittsburgh, PA</td>
<td>George Coppola</td>
<td><a href="mailto:georgecoppola@msn.com">georgecoppola@msn.com</a></td>
<td>(412) 884-6919</td>
</tr>
<tr>
<td>Pittsburgh, PA</td>
<td>Beth Ruposky</td>
<td><a href="mailto:elizabethruposky@live.com">elizabethruposky@live.com</a></td>
<td>(724) 770-0295</td>
</tr>
<tr>
<td>Myrtle Beach, SC</td>
<td>Alex Best</td>
<td><a href="mailto:alexbest@scrr.com">alexbest@scrr.com</a></td>
<td>(843) 655-9762</td>
</tr>
<tr>
<td>Dallas, TX</td>
<td>Rachel Weiner</td>
<td><a href="mailto:Rachel@RachelWeiner.com">Rachel@RachelWeiner.com</a></td>
<td>N/A</td>
</tr>
<tr>
<td>Houston, TX</td>
<td>Richard Powell</td>
<td><a href="mailto:rwpowell@gt.r.com">rwpowell@gt.r.com</a></td>
<td>(409) 883-7622</td>
</tr>
<tr>
<td>Houston, TX</td>
<td>Stephen Haskew</td>
<td><a href="mailto:haskews@verizon.net">haskews@verizon.net</a></td>
<td>(281) 337-3997</td>
</tr>
<tr>
<td>The Woodlands, TX</td>
<td>Wilson McCoy</td>
<td><a href="mailto:wass@GISolutions-LLC.com">wass@GISolutions-LLC.com</a></td>
<td>(281) 460-1033</td>
</tr>
<tr>
<td>Richmond, VA</td>
<td>Sam Brumberg</td>
<td><a href="mailto:Samuel.Brumberg@LeClarRyan.com">Samuel.Brumberg@LeClarRyan.com</a></td>
<td>(804) 968-2981</td>
</tr>
<tr>
<td>Seattle, WA</td>
<td>Leader Needed</td>
<td><a href="mailto:elin.aslanyan@spondylitis.org">elin.aslanyan@spondylitis.org</a></td>
<td>(818) 981-1616</td>
</tr>
<tr>
<td>Spokane, WA</td>
<td>Joan Polzin</td>
<td><a href="mailto:joanp115@webband.com">joanp115@webband.com</a></td>
<td>(509) 624-8214</td>
</tr>
</tbody>
</table>

This issue of **SPONDYLITISPLUS** is made possible through the generous support of...

The Spondylitis Association of America is solely responsible for the content of this news magazine.

**Medical and Scientific Advisory Board**

**Chair:**
- James Rosenbaum, MD . . . . . . . Portland, OR

- Bruce Clark, PT . . . . . . . Vancouver, CA
- Daniel Clegg, MD . . . . . . Salt Lake City, UT
- Robert Colbert, MD, PhD . . . Bethesda, MD
- Atul Deodhar, MD . . . . . . . Bethesda, MD
- Nortin Hadler, MD . . . . . . . Chapel Hill, NC
- Robert Harris, MD . . . . . . . Whittier, CA
- Robert Inman, MD . . . . . . . Toronto, ON
- Muhammad Asim Khan, MD . . Cleveland, OH
- Walter Maksymowych, MD . . . Edmonton, CA
- Allan Metzger, MD . . . . . . . Los Angeles, CA
- David H. Neustadt, MD . . . Louisville, KY
- Millicent Stone, MB, MRCP (UK) MSc . . Bath, UK
- Joel Taurog, MD . . . . . . . . Dallas, TX
- Ruben Burgos Vargas, MD . . Mexico City, MX
- Robert Warren, MD, PhD . . . Houston, TX
- Michael Weissman, MD . . . Los Angeles, CA

**Teen Athletes with AS** located in Orange County - contact WalkerRSM@aol.com

**Support online from NY, NY** with Michael T. Smith, spenser23@aol.com

www.spondylitis.org
SAA is moving its headquarters to:
16360 Roscoe Blvd. Ste 100
Van Nuys, CA 91406

Effective June 15, 2010

What does that mean for you? Don’t worry, you can still send mail to our PO Box address and our toll free phone number will not be changing.

Questions? Call us at 1-800-777-8189 or email us at info@spondylitis.org.