

SPONDYLITISPLUS

summer 2007



TEENS MOVE
INTO S.W.I.F.T.
ACTION

RESEARCH CALL
FOR PARTICIPANTS

WHAT TO KNOW
ABOUT DISABILITY
INSURANCE

THE REWARDS OF
PHILANTHROPY



SPONDYLITIS ASSOCIATION OF AMERICA

P.O. Box 5872
Sherman Oaks, CA 91413
Phone (818) 981-1616 or (800) 777-8189
Fax (818) 981-9826
e-mail: info@spondylitis.org
www.spondylitis.org

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.

BOARD OF DIRECTORS

David Hallegua, MD, Chair
Brian MacKenzie, Vice Chair
Jeff Horn, Treasurer
Hon. Ellen Carroll, Secretary
Kimberly Cooper
Leslie Kautz, CFA
Charlotte Howard
Ann Kittell Howat
Michael Supancich, MD
Robert Ulrich, PharmD

HONORARY BOARD MEMBERS

Rico Brogna
Val Halamandaris
Mimi Kennedy

EXECUTIVE DIRECTOR

Katherine Culpepper

ASSOCIATE EXECUTIVE DIRECTOR AND PROGRAMS DIRECTOR

Laurie M. Savage

DIRECTOR OF DEVELOPMENT

Susan L. Jones

DIRECTOR OF MARKETING AND COMMUNICATION

Diann Peterson

SPONDYLITISPLUS

Published four times a year
Laurie M. Savage, Editor-in-Chief
Diann Peterson, Contributing Writer

Design by Cause Communications
Layout/Printing by PMF Prods, Inc.

Content is for informational purposes only. The SAA does not endorse or recommend any medications or products for spondylitis, and always advises that you seek the counsel of a physician before initiating any treatment for spondylitis. Annual subscriptions are available with a membership.

UPFRONT



I'VE BEEN ON BOARD NOW FOR ALMOST A YEAR AND I can't count the number of times I've had to explain "spondylitis" to someone before I could move on to my request for assistance. Several weeks ago, in anticipation of presenting our Patient Educational Seminar in Chicago, I contacted the Chicago Sun Times, the Chicago Tribune and the local NBC affiliate.

Not one of the editors or reporters I spoke with had heard of the disease! Before I could address the purpose of my call – to obtain media coverage of the seminar – I had to give a short course in Spondylitis 101. What a challenge this adds to our efforts to secure time and space in today's busy media market.

Luckily, I love a challenge. So in order to proactively focus resources on strategic efforts to increase awareness of AS and related diseases, we've recently reorganized the SAA staff. Our new department, Membership & Communications, led by professional staff member, Diann Peterson, will focus on better targeting our various audiences (members, patients, donors and physicians) and strengthening our message to build awareness.

To spearhead our strategy in this area, we are pleased to welcome our newest board member, Charlotte Howard, who will chair our newly formed Communications Committee. Charlotte brings with her twenty years of experience in public relations and communications, most recently in her professional affiliation with Houston Exxon. We are very fortunate to have her volunteering her time on behalf of SAA. On behalf of the entire SAA family, I would like to thank Charlotte and long-time board member, Ann Howat, who joins the new committee to assist in developing effective plans and strategies to get the word out to more people than ever before.

Katherine Culpepper
EXECUTIVE DIRECTOR



FEATURES

6 | FOCUS

THE MONEY PUZZLE:
DISABILITY INSURANCE



10 | Q & A

EXPERTS RESPOND TO
PATIENT QUESTIONS



13 | NEW DEVELOPMENT

TEENS DEVELOP
WEB SITE FOR PEERS

ARTICLES

4 | RESEARCH

WHAT IS "TASC"?

8 | FUNDRAISING:

EVERY CENT COUNTS

15 | NEWS BRIEFS

ALSO IN THIS ISSUE

15 | NEW POLL

16 | ANNOUNCEMENTS

Dear SAA,

This is a letter to all those of us who have difficulty fastening our seat belts. There is help. I recently purchased a Toyota Prius. It is arguably the easiest car I have ever owned to enter and leave but that is not the reason for this letter. While reading the owners manual I discovered that I could get a "seat belt extender" in various sizes. I got one! There are two things I really, really like about them: 1) They work! Fastening your seat belt is so much easier it's ridiculous. 2) It's free! All you have to do is ask for it. (Just like riding with the driver of the monorail at Disney World.) So if you are like me and have difficulty with this you might look into it.

J.E. SCHIAFFINO
Bel Air, MD

Dear SAA,

I recently read the "Car Driving" article in the Spring '07 publication, in which my husband, Brad Sawyer, and his "MultiFlex" mirror are mentioned. We want to thank you for the calls and e-mail it has generated. That, however, is not the purpose of this letter to you. I would like to share another device that my husband uses.

There is about a 5" gap between the back of Brad's head and the headrest. He went to an auto upholsterer and had a headrest made (to match his truck's upholstery) that slips over the existing headrest. The interior consists of closed cell foam and it fits snugly over the truck's headrest. We also had one made for my car for when Brad drives or rides in it. Since

there is one in each vehicle, and they are transportable to a friend's vehicle, he is never riding or driving without one.

P.S.: I also took the liberty of copying Bryan Bledsoe's article, "Ankylosing Spondylitis Patients Need Special Care" and sent it to several fire chiefs in our area asking them to share it with the firefighters and rescue personnel. I received wonderful letters thanking me for sharing your special report about a disease that many had not heard of.

Thank you for such a wonderful publication

DIANA SAWYER
Yarmouth Port, MA

Dear SAA,

I was diagnosed with AS three years ago, at the age of 22, after visits to my chiropractor and subsequent x-rays revealed that I have extremely calcified sacroiliac joints (I also visited an osteopath, I am HLA-B27 positive, and have spondyloarthritis on both sides of my family). I had always had a great deal of pain and stiffness in my joints, and it gradually increased until last January, when I took the suggestion of a friend who works as a massage therapist. She advised giving up nightshade plants (potatoes, tomatoes, eggplant, sweet potatoes, and peppers - but not black pepper), as they (she said) contain alkaloids that irritate cartilage in patients with joint sensitivity.

I didn't know - and actually, still don't - whether the science of her explanation was

sound, but I was constantly in pain, so I tried her idea. I gave nightshades up completely, and after about a month, I felt "normal" for the first time in my life. I have been off nightshades for a little over a year now, and I no longer feel as though I'm seventy-five (a good thing, as I am now 25!); I have almost no joint pain and only occasional stiffness in my spine. My lower back has "gone out" only slightly a couple of times since beginning this regime, which was formerly a frequent and severe occurrence that left me unable to work or move for a few days at a time.

I realize that a single case is hardly grounds for an official diet recommendation, but given the life-changing results I have had, I felt that I needed to share it with your association. I hope that this information is helpful. If you have any questions for me about this, please feel free to contact me at TsipaSwan@yahoo.com.

TSIPA SWAN
via E-mail

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

P.O. Box 5872, Sherman Oaks, CA 91413

Genetics, Environment and Lifestyles of People with Spondyloarthritis—Unlocking the Secrets

WHAT IS TASC (TRIPLE “A” ANKYLOSING SPONDYLOARTHRITIS CONSORTIUM)?

As many of you know from scanning these pages and by attending the SAA Patient Educational Seminars during the past several years, a great deal has been happening in spondyloarthritis research. In brief, up until June 1998, there was very little activity in AS research in the U.S. except for a very small dedicated group of researchers. Then in 1998, under the guidance of Dr. John D. Reveille, the SAA initiated, with member support, the AS Family Genetic Project. Following suit, during the next ten years, the situation in AS research in the United States vastly improved as interest grew and activity increased as more researchers became involved in this group of diseases:

- In 1999, the AS Family Genetic Study evolved into an National Institute of Musculoskeletal and Skin Diseases (NIAMS) multimillion dollar funded consortium of eleven medical centers nationwide called NASC, out of which came the identification of the regions on several chromosomes implicated in AS;
- in 2001, NIAMS funded the first prognostic study of outcomes in AS, called PSOAS;
- in 2002, the first genome-wide scan results from the NASC study were presented and were subsequently published in a peer-review publication;
- in 2003, a group of AS “thought leaders,” comprised of researchers, clinicians and the SAA, joined forces to form SPARTAN, which stands for the Spondyloarthritis Research and Treatment Network;
- in 2004, the genome scan results from the NASC study were combined with a large British genome-scan and a smaller scan from France—soon to be published;
- in 2006, the NIH and the SAA co-sponsored the “Spondyloarthritis: The Unmet Needs” conference which led to a more comprehensive picture of where spondyloarthritis research needed to be heading.

What is a Genome-Wide Scan?

In diseases and other characteristics that form who we are as individuals, it is our chromosomes that determine what gets passed on to the next generation. Most people have two sets of 22 chromosomes, each inherited from a parent. Then there are the chromosomes that determine our sex. These are called the X and Y chromosomes. During a Genome-Wide Scan, the DNA, which has been extracted from the blood sample, has markers placed along the chromosomes, each of which are different sizes. This method of observation allows researchers to see whether a gene for the disease lies near one of the markers to determine risk areas—in our case—for AS. For example, the HLA-B27 gene, which is very much implicated in AS, is located in a group of genes called major histocompatibility complex (MHC). This is a large genomic region or gene family found in most vertebrates and is located on chromosome 6 in humans. Genome-Wide Scanning technology has vastly improved in recent years. This improvement allows for more efficient scanning with less likelihood of missing information in between the markers, which means, potentially, good news with regard to all of our efforts. For more information, please visit an online tutorial called “What is Inheritance?” <http://learn.genetics.utah.edu/units/basics/tour/inheritance.swf>

- concurrently, along with these events, a new class of drugs, called biologics or TNF-blockers, was brought to market that immediately began to show tremendous promise in the treatment of spondyloarthritis patients.

Furthermore, the results of the NASC study eventually formed the building blocks upon which Dr. John Reveille and his colleagues were able to found a new NIAMS-funded AS genetic study called TASC (Triple “A” (Anglo/Australian/American) Ankylosing Spondylitis Consortium). In addition, during this time span, doctors also learned how to

There is still much work to do—we are not out of the woods with regard to early diagnosis...Even so, many doctors now believe that today they are much better equipped to care for people with spondyloarthritis than they were ten years ago.

take better care of spondyloarthritis patients by developing scoring systems to measure disease activity, functional impairment and spinal mobility, as well as by improving techniques in radiography. What these scoring systems potentially enable doctors to do is to listen more carefully to how people with spondyloarthritis are functioning in their daily lives and responding to treatments.

There is still much work to do—we are not out of the woods with regard to early diagnosis, better treatments and access to those treatments for all, and ultimately to learn what causes this disease in the first place. Even so, many doctors now believe that today they are much better equipped to care for people with spondyloarthritis than they were ten years ago.

As we move forward, the researchers who lead the TASC study believe that the future burns bright in spondyloarthritis and that this project, with its multiple components, will truly make a difference, not only on the research bench, but more specifically in the lives of people living with AS and its related diseases.

What is TASC and what is it seeking to accomplish?

The purpose of the TASC Genetic Study, which is supported by a grant from NIAMS and led by Dr. John D. Reveille,

is to characterize the genes and genetic networks involved in predisposition, cause and outcome of ankylosing spondylitis. The study will span five years from 2007 through mid-2011. In the initial phase of the study, Dr. John Reveille in Houston, Dr. Matt Brown in Australia and Dr. Paul Wordsworth in Oxford will be comparing data, via a genome-scan, from 1,000 people in the United States with ankylosing spondylitis, and 1,000 people from the U.K. who have ankylosing spondylitis to uncover all of the genes throughout the entire genome that are associated with the disease

The big difference between the old techniques and what we are able to do today is that in the old scan, researchers were looking at 400 markers and today, Dr. Reveille's team will be looking at 317,000 markers. What this means is that a much wider area of the genome will be covered and hence, the spaces in between the markers will be much, much smaller.

In the next segment of the study, the researchers will be looking at family members of people with AS to find out more about the associated diseases such as reactive arthritis, inflammatory bowel disease in spondylitis and psoriatic spondylitis to try to find out how all of these work together within the family group. Later in the study, the researchers will be looking at the data from 900

We need you!

Moving forward, we would like to thank all of the people who have already so generously participated either in NASC or in TASC. We could not have gotten this far without you. We still need to enroll more patients and their non-affected family members or friends in order to meet our goals. If you have not yet participated in an AS Genetic Study and would like to help, please turn to the back cover of this issue of your Spondylitis Plus to find out how to contact us in order to help. Thank you.

patients to examine the non-genetic factors and how these may relate to disease severity. For instance, socio-economic factors will be examined—mood, and different personality traits will be plotted. All of these things will be identified to see how they may influence disease progression. The objectives of this part of the study will be to determine whether in the future, it might be possible find out whether certain behaviors or lifestyles might have an impact on disease severity, and if so, what potential changes might be adopted in order to improve the outcome or prognosis of the disease in the individual.



THE MONEY PUZZLE

Disability Insurance Issues Facing People with Spondylitis

Despite the availability of new therapies for spondyloarthritis, many of us have to deal with the issue of loss of employment secondary to a personal disability. This article is intended to provide a guideline to better understand what disability coverage is available. The article is divided into private insurance disability coverage and government provided disability coverage. References are provided to help search for issues related to your particular disability.

The Wall Street Journal published an article “The Growing Appeal of Disability Insurance” on December 19, 2006. A short summary from that article is provided. 1. Before you buy a private policy ask your employer about disability insurance available at work. It is important to coordinate with your employer-provided policy so you don’t over insure. 2. Determine what conditions are covered as disability under the policy. 3. Closely scrutinize definitions in the policy. 4. Choose a long-term plan over a short-term policy if you cannot afford both and your employer provides neither. 5. Check that any policy you buy in the workplace is portable or convertible so that you can take it with you to another job. 6. Check the complaints record of the prospective insurer with the National Association of Insurance Commissioners (www.naic.org).

Metropolitan Life Insurance Company actuarial studies indicate that “one in three Americans will become disabled for 90 days or more

before age 65. The average disability absence is 21/2 years. More than 90% of working Americans do not have disability income insurance or are not covered adequately.” The Principle Financial Group Web Page on Disability indicates “Nearly half a million Americans who filed for bankruptcy protection in the year 2000 did so after being sidelined by an unexpected illness or injury.”

Work related disability is carefully defined and determined by each insurance entity. Two types of definitions of disability exist in the marketplace. The first of these is a general definition that says you cannot perform any occupational work type. The second is more specific and say that you cannot do the work of your specific occupation. These are basic, but they are used in many different applications. References will be provided to help you determine whether you may qualify within the restricted guidelines.

http://www.guardianlife.com/solutions/product_portfolio/disability_insurance.html.

<http://www.unumprovident.com/products/individual/whatToExpectClaim.aspx>

<http://www.metlife.com/Applications/Corporate/WPS/CDA/PageGenerator/0,4132,P2431,00.html>

An insurance reviewer makes the disability determination based upon the information you and your physicians provide. You should keep a log of disabling events as they occur. What issues prevent you for performing meaningful work activities? Your physician also needs to provide documentation regarding the history of your illness, as well as, what limitations are currently present.

Private insurance disability coverage is available both as individually plans and group plans offered by some employers. Individual plans normally must be purchased before the diagnosis of spondyloarthritis is made. (Since insurance companies do actuarial studies to lower their risk exposure,) once spondyloarthritis is diagnosed most individuals plans are either not available or are available with reduced benefits at significantly higher premiums or an alternate policy in the substandard market. Group plans are usually provided through an employer. Group plans spread out the actuarial expose risks for the insurance company. By law they cannot exclude you because of a preexisting disease. However, the specific requirements for the determination of disability are defined by your plan. To help determine whether you are disabled you should understand the definition of the terms used in this field. Do not assume that everyone you talk to, no matter what his or her credentials, understands your situation! Also, try not to become impatient; perseverance and determination are attributes well employed here, when seeking an adequate and positive result. Ask questions till you gain the answers you need and make sure you do a good job of listening and continuing to take notes (if you are not able, please have someone assist you).

<http://www.eeoc.gov/ada/adahandbook.html>

<http://www.disabilityconcepts.com/faqs.html>

<http://www.ilr.cornell.edu/library/research/subjectGuides/employmentAndDisability.html>

<http://www.northwestern.edu/hr/benefits/plans.std/faq.html>

Social Security

<http://www.ssa.gov/disability/>

The Social Security Disability Insurance claim process can be confusing with many gray areas. Social Security Disability Insurance is not Medicaid or SSI (Supplemental Security Income). Social Security disability income money is generated through the FICA (Federal Insurance Contributions Act) tax payments are deducted from your payroll. Requirements to be classified under the social security disability program are defined. To qualify you must be unable to perform any type of work for a minimum of one-year due to a medical condition. Partial disability or short-term disability claims are not covered. The claimant for benefits needs the required amount of work credits under Social Security's definition of FICA credits. The definition of work credits changes yearly. The current definition is available on the SSA web site. The number of work credits you need to qualify for disability benefits depends on your age when you become disabled. Generally, you need 40 credits, 20 of which were earned in the last 10 years ending with the year you become disabled. Younger workers may qualify with fewer credits. The dollar amount of the benefit is not based on the number of credits; it is based on your earnings history.

Social Security employs a State DDS, (Disability Determination Services) division consisting of a medical consultant and disability examiner that will be deciding your claim. The medical consultant usually is not a rheumatologist. You, your doctor, family members or friends that think you are disabled and are concerned for your situation, although sincere, mean nothing. Accurate, consistent medical documen-

When dealing with a private disability insurance plan or Social Security disability, be prepared. Meticulously prepare the documents prior to submission.

tation from your health providers can be one of the most important aspects to your claim. The disability determination is made by an evaluation process which reviews many facets of a person's life including; the claimant's current work activity, the severity of their impairment, their functional capacity, past work experience, age and education.

Preparation is critical to your successful disability claim. Review your medical records or have them reviewed. Be sure the diagnosis is consistent with spondyloarthritis. As you know, spondyloarthritis is a different disease from rheumatoid arthritis. Dates and information you provide need to be accurate with facts that will be verified by Social Security. Most of us are not trained to review medical records. Help from a professional, such as an attorney or disability advocate may be indicated.

There are a myriad of parameters involved surrounding your claim for benefits. One of the more important aspects is the Social Security parameters appearing under the Listing of Impairments. Examine the list of impairments; look for your corresponding diagnosis. Part A, 14.00, Immune System. Ankylosing Spondylitis appears under this listing. Be clear, concise, direct and to the point with your application. Leaving anything out, example: Doctor's names and telephone numbers, incorrect addresses, missing dates, etc., could lead to delaying the processing of your case. Be certain your application is complete before filing.

The decision regarding your qualification for disability by Social Security will take months and sometimes years. Your initial claim may be denied. If so, you can appeal. Be sure to pay special attention to the time allowed for appeal.

Should Social Security find you qualified for disability coverage it does not mean you cannot return to the work force at a future date. In the future, should you feel capable of returning to the work force, have a plan and review the current Social Security regulations. There are work place supports and incentive programs, such as trial work periods, in place so that you may return to work and protect your benefits for a defined period of time.

In conclusion, whether you are dealing with a private disability insurance plan or Social Security disability, be prepared. Be aware of all the facts pertinent to your case. Meticulously prepare the documents prior to submission. Get professional advice on document preparation and representation when necessary. Finally, consider recommending to your family members at future risk of developing spondyloarthritis that they obtain disability insurance prior to the onset of symptoms.

We would like to thank Dr. Michael Supancich, board member, support and educational group leader, and Alex Best and John Kornfiend, who are group leaders in SC and AZ, respectively, for their hard work in researching and writing this article.

Bill Gates, Warren Buffett, Bono...and You?

When we think of philanthropy, we think of building a new wing at a local hospital, endowing a chair at a university or helping to alleviate Third World debt. But did you know you were a philanthropist? Being a philanthropist doesn't necessarily mean making large gifts; it means giving at any level, to any cause that you value. By partnering with SAA as a member, you have stepped up to the plate to support a need that is both deserving and underserved.

Chances are, most of the people you interact with each day are philanthropists too. Gifts from individuals account for three-quarters of total charitable giving in the US. Somewhere between 70 and 80 percent of Americans contribute annually to at least one charity. In the wake of the devastation caused by Hurricane Katrina, Americans opened their hearts and wallets to help the affected communities in the Gulf Coast to the tune of one billion dollars and climbing.

Being a donor is not without its risks, but the rewards of responsible giving are tremendous. We've all heard about the less than ethical "charities" that seem to pop out of the woodwork whenever a critical need arises. Being a savvy, and even a skeptical, donor can help you avoid the worst of these scams.

But even legitimate organizations vary when it comes to how responsibly they use your donations. That's why it's important to combine generosity with caution to ensure that your donation dollars benefit the people and organizations you want to help. One way to do that is to seek an independent assessment before you open your checkbook.

Charity Navigator, America's premier evaluator of nonprofit organizations, was founded to give donors the type of information they need to be more discriminating about the charities they choose to support. The organization provides the data needed to evaluate accountability, transparency and quantifiable results.

SAA has received its second consecutive 4-Star rating from Charity Navigator. The rating is their highest and most prestigious, signifying that SAA outperforms most other charities in America in its efforts to efficiently manage its finances (your donations.) Fewer than 12% of the charities rated have received two consecutive 4-star evaluations.

SAA has received its second consecutive 4-Star rating from Charity Navigator. The rating is their highest and most prestigious, signifying that SAA outperforms most other charities in America in its efforts to efficiently manage its finances (your donations). Fewer than 12% of the charities rated have received two consecutive 4-star evaluations.

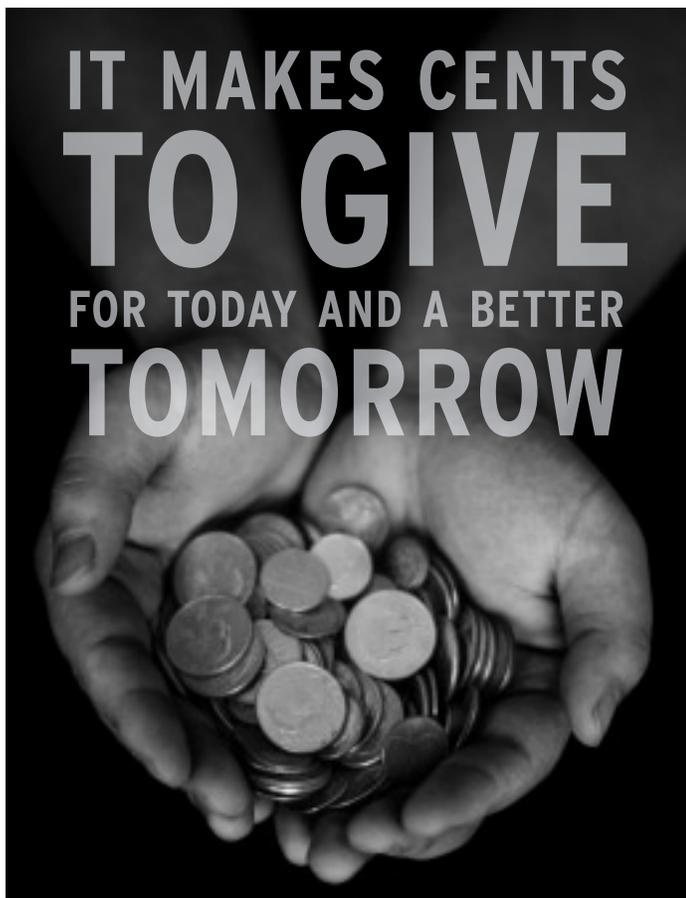
That's why, as an SAA member, you can rest assured that your membership dues and other donations are being put to work in a responsible way. Your membership dues help to pay for the array of benefits that you currently enjoy. Four issues per year of Spondylitis Plus, our exclusive Member-to-Member Rheumatologist Directory, access to the Members Only section of our website and the AS Guidebook are just a few of the programs and services your yearly dues help to pay for.

But SAA provides many more programs and services than those covered by the membership fee. In fact, membership fees each year account for less than 9% of our operating budget.

That's why SAA recently mailed you our Spring Appeal letter. Our twice-annual appeals help to raise the money that can be put



IT MAKES CENTS TO GIVE FOR TODAY AND A BETTER TOMORROW



to work funding the programs and services that cannot be covered by membership fees alone.

If you've already responded with a gift, please accept our most sincere thanks. If not, your tax-deductible gift today will be put to work to maintain—and expand—the wide menu of programs necessary to inform, educate and support the spondylitis community and the physicians who serve them. Please take a moment to think about all the important programs these additional gifts support:

SAA Leads the Quest for the Cure

SAA remains at the forefront of spondylitis research—from studying the genetic components of the disease to developing a validated questionnaire to speed early diagnosis.

SAA Brings the Experts to You.

In recent months, SAA has presented Patient Educational Seminars in Houston, Washington, DC and Chicago and our calendar for upcoming months includes Los Angeles, New York and Seattle. These seminars are not only a wonderful opportunity for spondylitis patients and their families to interact with the experts in the field of spondylitis, but they also provide us with invaluable insight on pressing concerns within the spondylitis community.

SAA is Available When You Need Us.

Even though SAA's websites and scores of printed publications contain all the up-to-date information available today, sometimes you need an answer fast. SAA's Toll-Free Information Hotline ensures that your questions will be answered by a knowledgeable, friendly staff member who has the tools to provide assistance when you need it – now.

SAA Educates the Medical Community.

In May 2006, SAA mailed out samples of our three new educational brochures to over 4,000 rheumatologists throughout the country. The response was positive and immediate. A large number of physicians ordered additional copies to have available to their spondylitis patients and many requested further information to help them better serve the patients they treat.

And Not Just Rheumatologists

In October, SAA plans to attend the American Academy of Family Physicians Annual Assembly in Chicago where we'll distribute information to the practitioners who are often the first to see patients who are as yet undiagnosed. Plans are also underway to reach out to the nation's OB-GYNs who are increasingly becoming the primary physicians for women experiencing back pain. SAA is also partnering with spinal surgeons, physical therapists and ophthalmologists to get the word out about spondylitis and its treatments.

SAA is a Major Player in the International Spondylitis Community.

Each year, we join over 10,000 clinicians and researchers at the annual scientific meeting of the American College of Rheumatology where advances in disease management and research are shared. SAA's information booth is visited by thousands of medical professionals eager to obtain valuable resources to better serve their spondylitis patients.

But all of these projects have one thing in common—they require funds above and beyond the low membership fee that SAA has maintained for almost a decade.

If you believe that it's important for SAA to continue its work in the areas of medical research, patient services and medical education, please consider making a gift in addition to your annual membership dues. You can do so with the confidence that SAA will put your donation to work responsibly and with the specific needs of the spondylitis community in mind.

The Experts Answer Your Questions

The Spondylitis Association of America sponsors several Spondyloarthritis Educational Seminars annually. We are pleased to bring you this series of Questions and Answers from our most recent conferences which were held in Washington, D.C.

What is known about juvenile onset spondyloarthritis?

From recent studies, researchers have been able to determine that people with early onset spondyloarthritis have a two-fold risk of needing a total hip replacement later on.

Is there any new data on women and AS?

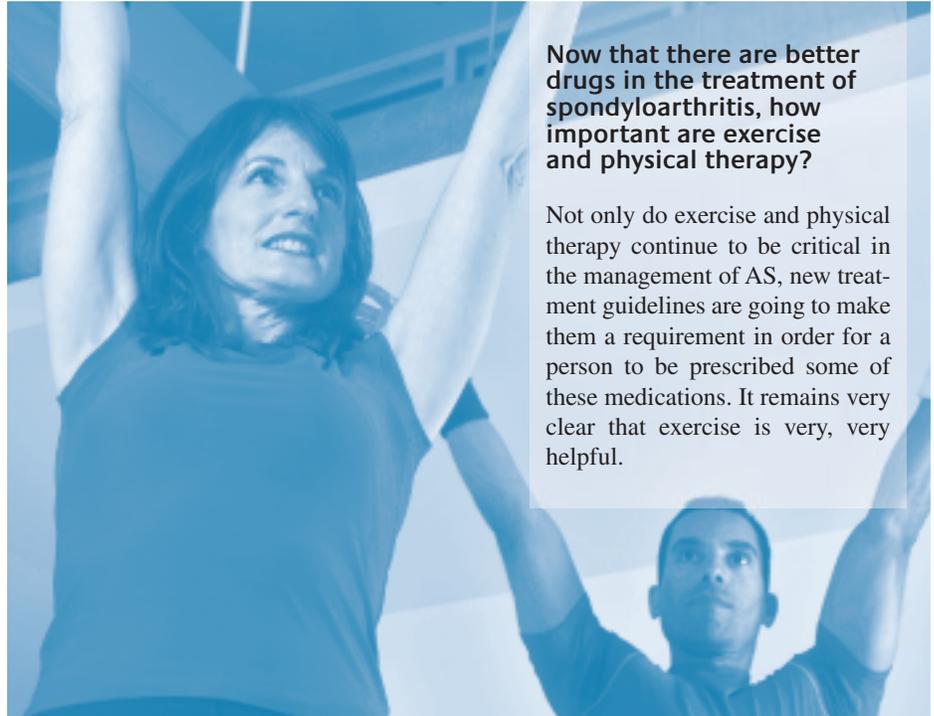
The researchers involved in the PSOAS study have been able to determine that women with AS have a different disease experience than men with AS, and that this possibly points to one of the reasons that doctors have greater difficulty in making a diagnosis in women. The study results showed that women get sacroiliac involvement, then the symptoms sometimes skip the spine, and then involve the neck and peripheral (small) joints much more significantly than in male disease, but can be equally functionally impaired as men with the disease.

Are there any blood markers in AS that can tell us anything about the disease in one person compared to another?

Yes, there are. Dr. Maksymowych from Alberta and his research team have identified a new blood marker called MMP3, which can be an independent predictor of damage progression in patients with AS. (Reported in the Spring issue of Spondylitis Plus, page 6) So, we now have another marker to help in examining AS patients.

Is there anything new that is known with regard to the prevalence of AS in other countries?

It has been recently recognized that the prevalence of spondyloarthritis in China is 1% as apposed to 0.2% in rheumatoid arthritis. So, in China, spondyloarthritis is a much bigger problem than previously thought.



Now that there are better drugs in the treatment of spondyloarthritis, how important are exercise and physical therapy?

Not only do exercise and physical therapy continue to be critical in the management of AS, new treatment guidelines are going to make them a requirement in order for a person to be prescribed some of these medications. It remains very clear that exercise is very, very helpful.

Is there any new information with regard to nonsteroidal anti-inflammatory drugs (NSAIDs) such as Naproxyn and Celebrex?

Yes, it is currently estimated that when taken at a full anti-inflammatory dosage, NSAIDs can provide adequate relief to about 50% of people with AS.

What can be done for a person who cannot take NSAIDs or TNF-blockers?

Sometimes Prednisone (cortisone) can provide some help to this group of people. In addition, even though there is no good data to support the use of sulphasalazine in spinal disease, it can be helpful in some people. Everyone is different, and hence, a very thorough workup by a rheumatologist would be strongly advised.

Though most people with ankylosing spondylitis are HLA-B27 positive, what is known about people who have AS who are HLA-B27 negative?

Recent studies have shown that the majority of people with AS who are HLA-B27 negative often have other HLA-B genes that are associated with other types of spondyloarthritis. These include psoriasis. There seems to be about 5% of people with AS who have no HLA-B explanation for their disease whatsoever. Furthermore, this group goes on to develop just as severe spinal disease as the HLA-B positive group over time. The only difference seems to be that these people have less iritis (inflammation of the eye).

I have heard that sometimes the disease “burns itself out” over a period of years to where the symptoms go away.

Could you please explain that phenomena?

Quite often in older patients, once the bones are fused together, the disease activity can completely shut off. Though this phenomenon is not uncommon, it is not true for everyone. Even when this does happen, it is important for physicians to look for other potential complications. These complications can include cauda equina syndrome, where the bony overgrowths can start affecting the nerves in the spine.

What is known about chiropractic care in the AS patient?

It really depends upon the different chiropractic treatments. Though manipulation of a fused spine is contra-indicated, there are sometimes other gentle techniques that can be helpful. In this situation, it is important that the rheumatologist and the chiropractic communicate with each other with regard to the care of the individual with AS. A lot of chiropractors are focused on manipulation and so it is important to differentiate between that and other approaches.

What is known about the benefits of exercise in ankylosing spondylitis?

There are two different types of activity that one could think about. There is any type of exercise, just moving around and being physically active, whether that is sports, running, jogging, tennis or swimming. Then there are specific exercises such as back stretching and strengthening. There is evidence to show that both types of exercise are important in helping to maintain function or even improve function in spondyloarthritis.

Researchers found several years ago that when people were charted for five years to measure how much exercise they did on a regular basis and how that impacted the functioning over time, that those who reported doing back stretching and strengthening exercises at least five days a week had much better outcomes than people who engaged in that activity less often. It was also found that when people engaged in this type of activity for 200 minutes a week, over time, they were able to function much better. That may sound like a lot, but actually, it is only 30

minutes a day and the payoff can be tremendous.

What do you think would be one of the most important daily exercises?

One of the very best exercises is called a “chin tuck.” This can be helpful to just about anyone who sits a lot during the day. You can do this exercise while standing or sitting. What it requires is that you pull your head backwards while pulling your chin in—keeping the eyes as straight ahead as possible. This can be helpful because we all tend to lean forward and this exercise can help to counteract the negative aspects of that type of posture habit.

Another helpful and very simple exercise to do during the day is to raise the arms above the head because it stretches the upper and lower back. It can be helpful to do this exercise with the shoulders against the wall. Sometimes when a person has difficulty with this exercise, it can be helpful to use one hand to support the other arm.

What can I do to help stretch when my sacroiliac joints are fused?

Many people with AS have lower back stiffness even without fusing and hence, it is really important to exercise the pelvis. A “pelvic tilt” exercise can be important

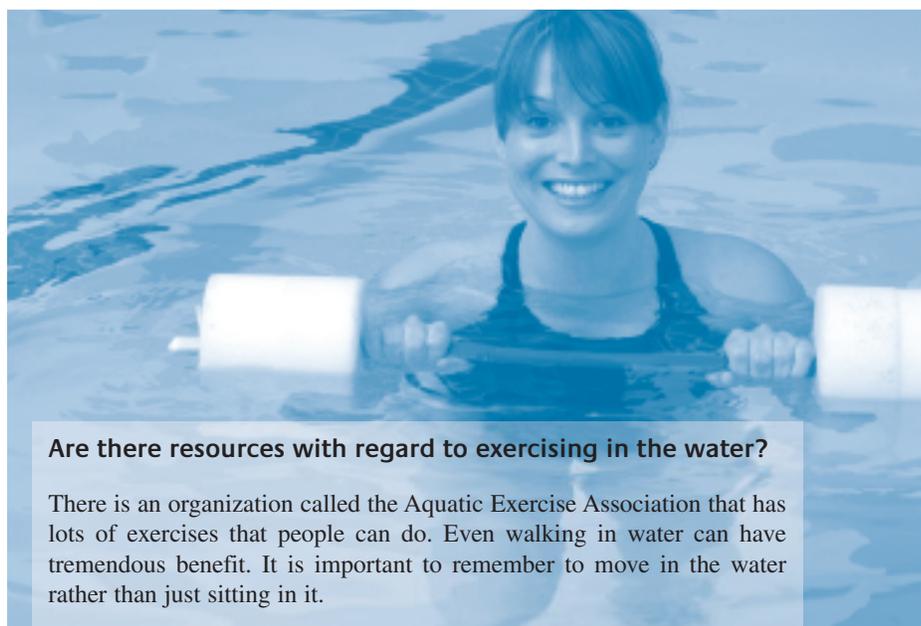
because once the lower back has lost motion; it becomes much more likely that the upper back will also lose motion since everything is connected.

With regard to stretching exercises, I have been told to hold a stretch for 20-30 seconds in order to gain the most benefit. What do you think about that?

It is advised in the sports literature to hold a stretch for that length of time, but for a person with AS, the most important thing is that the stretch is held without bouncing because bouncing stretches the little mechanisms in the muscle, which can cause them to tighten up even more. 20 seconds is a good recommendation, although most people do not hold that long.

Compared to the general population, what are the risks associated with spondyloarthritis with respect to becoming work disabled?

After 30 years of disease, research has shown that relative to the general population, a person with spondyloarthritis is likely to have a three fold risk of becoming work disabled. That said, most people with spondyloarthritis are still working 30 years after disease onset. More physically demanding jobs can cause a higher risk of



Are there resources with regard to exercising in the water?

There is an organization called the Aquatic Exercise Association that has lots of exercises that people can do. Even walking in water can have tremendous benefit. It is important to remember to move in the water rather than just sitting in it.



Doctor John Reveille and attendees of the D.C. seminar share a moment of fun during the break-out sessions.

Osteoporosis medication is commonly used in ankylosing spondylitis. There is no thought that they would promote abnormal bone growth and they certainly do a very good job in maintaining bone density.

becoming work disabled. Lower education seems to also impact work disability, as does arthritis in the hips.

One of my worst symptoms is fatigue. Doctors seem to have difficulty in understanding just how debilitating this can be.

Fatigue is a very important symptom in this group of diseases. When studies are done on

people with spondyloarthritis, fatigue is always brought up as one of the top four symptoms that affect daily living. Pain, stiffness, fatigue and poor sleep are dominant symptoms for most people.

What is known about spontaneous remissions that last for any amount of time from one day to several months? Are there recognized triggers that cause symptoms to be better or worse?

We have very, very poor understanding from a medical research perspective with regard to triggers and particularly what makes symptoms go away, apart from medication. It is really difficult to study these things, mostly because spondyloarthritis is a very individual disease. Sometimes it can be helpful for a person to keep an activity diary to find out if there are triggers that affect how poorly or how well you are doing.

Since it is well recognized that osteoporosis is a very big problem in

spondyloarthritis, are osteoporosis drugs contra-indicated in AS because of the extra bone growth tendencies?

Osteoporosis medication is commonly used in ankylosing spondylitis. There is no thought that they would promote abnormal bone growth and they certainly do a very good job in maintaining bone density. There are no reservations whatsoever in this regard. There are lots of patients using them.

Could you please comment on the use of TNF-blockers in ankylosing spondylitis? If a person takes them for a while, is there any possibility that a short course of these drugs can course the AS to go away permanently?

No. Research has shown that for 100% of patients who go off TNF-blockers, symptoms return. It might take a year, but our current thinking is that there is nothing permanently switched off with short-term use of these medications. What we don't know, is if you use them for 5 years or even 10 years, whether you can withdraw the medicine or not. That data is not yet available.

Are women less likely to fuse than men?

That is a difficult question. The spine involvement in women has historically been thought to be different than in men. The difference is that men tend to have a more uniform involvement in the spine, in general, than women. Women seem to have more of a patchy type of fusing with more neck involvement.

Editor's note: The SAA would like to acknowledge, with great gratitude, Dr. John D. Reveille, Dr. Michael Ward and Ms. Victoria Gall, PT for sharing their time and expertise during this program.

This program was made possible by an educational grant from Amgen and Wyeth Pharmaceuticals, Centocor Inc, and Novartis Pharmaceuticals

TOTALLY COOL

**Announcing A New Website From SAA:
S.W.I.F.T. (Spondylitis Web Info For Teens)**
<http://teens.spondylitis.org>

Inspired by a conversation with Spondylitis Association of America (SAA) founder Jane Bruckel, Orange County high school student Katlin Poladian was motivated to reach out to fellow teens with spondylitis. “I was so touched by the impact Jane had made among the adult spondylitis population,” says Katlin. “I wanted to address the needs of affected teens by developing a website that would have a worldwide reach.”

Under the guidance of SAA Programs Coordinator Melissa Velez, Katlin joined forces with other area teens Tyler Walker and Brian Annett. They each spent the latter part of last summer writing content for a groundbreaking website they named “S.W.I.F.T.” (Spondylitis Web Info for Teens), specifically for teens, ages 13 – 19.

“A disease like spondylitis can make you feel isolated and forgotten,” says co-contributor Tyler Walker. “The S.W.I.F.T. website was created to help promote a sense of community and support among teens with spondylitis. It’s the first of its kind.”

Designed by SAA Web Designer Chris Miller, S.W.I.F.T.

features teen bios, interviews, photos, important information from doctors, helpful tips and support group information. The site examines what it's like to live with spondylitis, how it affects relationships with family, friends, teachers and coaches, as well as how to stay positive in the midst of pain and stiffness. "My dream is to get an Olympic trial cut in swimming and become a doctor," says fellow creator Brian Annett. "I refuse to let this disease stop me from doing what I love to do."



S.W.I.F.T. also features a section called Your Stories. "For the first time, teens with spondylitis can make their voices heard," says Katlin, "sharing their stories with a community of spondylitis patients who may never have met anyone else with this disease."

For more information, please contact Melissa Velez at Spondylitis Association of America by email at Melissa.velez@spondylitis.org or by telephone at (800) 777-8189, extension 227. Visit S.W.I.F.T. at <http://teens.spondylitis.org>



Members of the S.W.I.F.T. support team

Spondylitis Association Working on Your Behalf

■ SAA continues to focus efforts to operate in the most efficient manner. For Fiscal year ending June 30th 2006, SAA was audited by an outside audit firm, Levitt & Rosenblum, which conducted the audit in accordance with auditing standards generally accepted in the United States. SAA's total expenditures for the fiscal year were \$1,376,863. Of this total, 83% were allocated to Program, 4% were allocated to Fundraising and 13 % were allocated to Management & General expenditures. Please note that with 83% of total expenditures allocated to program, SAA far exceeds the minimum standard of 65% established by most groups that evaluate charity effectiveness.

■ Recently, we teamed up with the MedicAlert Foundation to establish a discounted price of membership for you. Details of about this collaboration will be announced in the next issue of Spondylitis Plus.

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: melissa.vez@spondylitis.org

AREA	FACILITATOR	EMAIL	PHONE
Little Rock, AR	Mindy Hunter	mindy.hunter@sbcglobal.net	(501) 351-6374
Phoenix, AZ	John Kornfeind	jmmkorn@cox.net	(623) 910-4742
Long Beach, CA	Barbara Crofut	crofutgr@verizon.net	(562) 421-9698
Long Beach, CA	Frances Tomich	not available	(562) 429-9685
Orange County, CA	Kyle Brownfield	kylebrownfield@msn.com	(949) 367-0430
San Diego, CA	Mike Supancich	supancichsr@sbcglobal.net	(760) 438-2962
San Francisco, CA	Eric Passmore	eric.passmore@gmail.com	(510) 644-0864
Denver, CO	Jennifer Visscher	jvisscher@myedl.com	(303) 478-9985
Washington, DC	Roger Stead	rogerstead@aol.com	(703) 455-6005
Boise, ID	Tim Schaap	tjschaap@msn.com	(208) 453-5006
Boise, ID	Cindy Salo	csalo11@hotmail.com	(208) 850-3313
Fort Wayne, IN	Ken Prather	pratherken@yahoo.com	(260) 637-1705
Indianapolis, IN	Ken Prather	pratherken@yahoo.com	(260) 637-1705
Kansas City, MO	Linea Cooley	linea_cooley@hotmail.com	(913) 384-0728
Augusta, ME	Michelle Andrews	qualey28@roadrunner.com	(207) 445-2885
Portland, ME	Penny McAuley	spondylitis.portlandmaine@yahoo.com	(207) 878-9414
Detroit, MI	Laura Russell	mrussell.21@netzero.com	(586)-530-9988
Grand Rapids, MI	Scott May	smay@wmis.net	(616) 610-9130
Long Island, NY	Roni Figueroa	fourthever@aol.com	(631) 334-1655
Summit, NJ	Craig Gimbel	believe5154@optonline.net	(937) 476-8976
Portland, OR	Ken Henschel	Ken.Henschel@comcast.net	(503) 579-8375
Philadelphia, PA	Howard Tevelson	hotbyht@yahoo.com	(215) 844-6075
Pittsburgh, PA	George Coppola	georgecoppola@msn.com	(412) 884-6919
Myrtle Beach, SC	Alex Best	alexbest@sc.rr.com	(843) 655-9762
Dallas, TX	Elizabeth Smith	elizabethsmith@dcccd.edu	(972) 860-7179
Houston, TX	Richard Powell	rwpowell@gt.rr.com	(409) 883-7822
Houston, TX	Stephen Haskew	haskews@verizon.net	(281) 337-3997
Richmond, VA	Sam Brumberg	Samuel.Brumberg@LeClairRyan.com	(804) 968-2981
Seattle, WA	Paul Stevenson	pastev@Safeco.com	(206) 524-2186
Spokane, WA	Joan Polzin	joanp115@webband.com	(509) 624-8214

- Teen Athletes with AS located in Orange County - contact WalkerRSM@aol.com for more info.
- Support online from NY, NY with Michael T. Smith, spenser23@aol.com.

Online Poll

Our polls have a new look! With the help of an online survey tool, SurveyMonkey.com, SAA has created a new poll. You can find a link to our newest informal survey about how your work is affected by spondylitis on our website at www.spondylitis.org. When you click on the survey link, you will be directed to SurveyMonkey.com to complete our poll. With this new tool, we can track survey results more effectively to serve you better. We will continue to report the results in Spondylitis Plus. We hope you enjoy this new feature.

OLD POLL RESULTS

Are you receiving Social Security Disability Insurance (SSDI) benefits?

Yes 56%
 No 30%
 I am currently applying for SSDI12%
 I receive other disability benefits 2%

Medical and Scientific Advisory Board

Chair:

- Dr. Robert Colbert, MD, PhD. . . . Cincinnati, OH*
Bruce Clark, PT. Vancouver, BC
Daniel Clegg, MD Salt Lake City, UT
John Davis, Jr., MD, MPH. . . . San Francisco, CA
Atul Deodhar, MD Portland, OR
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 Alberta, BC
Allan Metzger, MD Los Angeles, CA
David Neustadt, MD Louisville, KY
John Reveille, MD Houston, TX
James Rosenbaum, MD Portland, OR
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 Weisman, MD. Los Angeles, CA
David Yu, MD West LA, CA

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.



Reach Out

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.

These people would like to connect with others in their area:

Robert Sauls, Modesto, CA
Kelly Riedesel, Weaverville, NC
Kerry Krow, Mountain View, MO

If you would like to "reach out" to any of these people, please contact Melissa Velez, Programs Coordinator, at melissa.velez@spondylitis.org



Are you willing to help researchers find the genes involved in ankylosing spondylitis?

How can I help?

If so, you may be interested in participating in our study. To participate you need to be at least 18 years of age, and to have been diagnosed with ankylosing spondylitis. The study is also enrolling non-affected spouses and friends.

Who is conducting the study?

The study is sponsored by the National Institutes of Health. The researchers conducting the study are Principal Investigator, John D. Revellie, MD, University of Texas, Houston; and colleagues, Michael H. Weisman, MD, Cedars-Sinai Medical Center, Los Angeles; John C. Davis, MD, MPH, University of California, San Francisco.

How can I find out more?

Southern California: Felice Lin, (310) 423-2422, lif@cshs.org
Northern California: Stephanie Morgan (415) 476-3735, smorgan@medicine.edu
Houston area: Laura Diekman, (713) 500-6852, laura.diekman@uth.tmc.edu

Spondylitis Association of America Toll Free 1-800-777-8189 x 224



SAA'S SPRING ONLINE AUCTION is just months away. The 7-day eBay event beginning May 13, will spread awareness of AS and related diseases as well as raise funds for furthering SAA's mission to improve the lives of spondylitis patient throughout the country.

LOG IN 24/7

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

You are invited to attend an SAA Educational Seminar in New York City to be held on Saturday, Sept. 29, 2007. We are pleased to announce that Dr. Asim Khan will be our special guest speaker. Be sure to visit www.spondylitis.org for additional information or email Melissa.velez@spondylitis.org



**Spondylitis
Association
of America™**

P.O. Box 5872
Sherman Oaks, CA 91403

NON-PROFIT
U.S. POSTAGE
PAID
WHITTIER, CA
PERMIT NO.1