

SPONDYLITIS PLUS

spring 2008



SPONDYLITIS ASSOCIATION OF AMERICA

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SAA MISSION

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

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SPONDYLITISPLUS

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ON POINT



**As the spondylitis community
celebrates 25 Years of Progress,
I can't help but think back to
some of the earlier days.**

Dear SAA Members,

It was in September of 1996 that my own journey with the Spondylitis Association began. I came onboard that year as SAA's third employee, joining the organization's co-founder Jane Bruckel and an administrative assistant. I was brought in as Director of Program Services; a rather impressive title, but I soon learned that in an organization with such a small staff -- and such a large vision -- everyone must wear many different hats and pitch in where needed.

It was a heady time. Answering questions that came in via the "helpline," designing and building our first website, planning large scale educational seminars, raising funds for -- and building great dreams with -- the SAA-initiated Family Genetic Study, and all the while writing and publishing this news magazine.

Today, much has changed but much has remained the same. Our staff has increased almost fourfold, but so has our vision, so we still all wear many hats. We're still dedicated to providing the most up-to-date news and information through publications, Patient Educational Seminars and e-newsletters; educating the medical community by producing CMEs and providing informative materials; funding and fostering medical research; raising awareness of the disease; championing the rights of the spondylitis community and offering encouragement through our Support Group network, interactive message boards and toll-free helpline.

Clearly, an 11 person staff could not do this alone. We have been blessed with an ever-increasing number of hardworking, dedicated volunteers and the continued support of SAA members like you who have helped turn yesterday's vision into today's reality.

Today's vision is more ambitious still. While continuing to provide all the programs and services that have become the hallmark of the organization's mission, SAA is poised to embrace new technologies such as social networking, web-based seminars and podcasting to get the word out to more people than ever before.

An unfailing commitment to sound fiscal management means that at a time when economic uncertainties are affecting all sectors of the population, SAA is well positioned to make the most of the opportunities available to us and to move confidently toward our future goals.

I am honored to be entrusted with the responsibility of leading this fine organization. In my new capacity as Executive Director, I look forward to continuing working with each and every one of you to realize today's vision, formulate tomorrow's and continue addressing the needs of the community SAA serves.

On pages 8 and 9 of this issue we celebrate our 25th year and I look forward to our continued partnership with you, our valued members, since none of the progress of the last 25 years would have been possible without your commitment, your resources and your courage.

Sincerely,

Laurie Savage
Executive Director



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Dental Care & AS

I would like to suggest that *Spondylitis Plus* do an article on dental care for people with AS. Especially those with more advanced disease. Finding a dentist willing to provide care when you cannot turn your neck or recline back in the dental chair because your head does not reach the headrest and your back does not conform to the chair is difficult. After an exhaustive search and being told by over 30 dentists that they would not work on me due to the difficulty, I finally found a dentist. I would imagine others with more advanced disease have had this problem also. Possibly you could provide some assistance to your members to make the task of finding a dentist easier than it was for me.

PAT SCHATZ, Escondido, CA

Editor's Note: *Thanks, Pat, for an excellent story suggestion. We will be following up with Pat and others on this issue.*

The Need For Education

There is certainly a deep and serious need for the organization and what you all do. I wish we could educate the whole nation about this very serious and terrible disease. I was diagnosed over a year ago now, and it was only just last month that

my brother (a medi-vac pilot) and sister in law (an ICU RN at a VA hospital) finally asked me what AS is. Just a few months ago, I was in a 5-car accident and my car was totaled. During ambulance transport, I told the paramedics that I had Ankylosing Spondylitis and they had never heard of it, much less spell it, when trying to communicate that by radio to the ER. Fortunately, the ER doctor was familiar with AS.

I have been amazed at just how many medical personnel (yes, even doctors!) are not at all familiar with AS. I have had to be the teacher for more than one of my doctors, including my pain management specialist. It was only when my rheumatologist approved my application for a "handicap" license plate, marking the "permanently disabled" box, that my husband has finally taken my condition - and me - seriously. "Invisible" disabilities are very hard to deal with, in that most other people cannot understand and often just plain write us off as "blowing it out of proportion" or even as being a hypochondriac!

Especially since I am HLA-B27 negative, I have encountered quite a few raised eyebrows and doubtful tones from health care professionals...many still think that

one's "sed rate" indicates whether one is having a flare-up or is even experiencing severe pain. It is frustrating and depressing to have a doctor tell me that "it is not as bad as I am making it out to be," and act condescending when I try to educate him with what I have learned by reading *Spondylitis Plus* and all the great information on the website.

JENN V., Sierra Vista, AZ

Editor's Note: *Thanks, Jenn, and you are right, we do have a long way to go in raising awareness, even in the medical community. With our new MedicAlert program, our rheumatologist cultivation program, our presence at the annual meeting of ACR each year, we are continuing to tackle this problem.*

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 the Editor/SAA

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When Sleep Disorders Affect Rheumatology Patients

By Richard J. Castriotta, MD

Excerpted from an article
in “Backbone”

Given the frequent link between sleep disorders and associated rheumatologic conditions, and the possible need for diagnostic referrals, this author discusses some of the common findings as well as helpful diagnostic tests that can be preformed at sleep laboratories.

Although we spend about a third of our lives sleeping, we give very little thought to what happens during the “dark hours” of sleep and how it can affect our patients, their medical problems and treatment. Why we sleep is still pretty much a mystery but what happens during sleep is slowly being revealed through modern research techniques and the dedication of specialists in the new and emerging field of sleep medicine.

Over the past two decades in particular, we have made amazing strides in elucidating the physiology of sleep and defining a host of sleep disorders with which health care providers should become familiar. Some of these sleep disorders are particularly common in rheumatologic conditions and may be easy for clinicians to diagnose and treat.

These rheumatologic conditions may have certain manifestations, which clinicians need to identify as sleep-associated problems even if the symptoms may confound those that one sees with rheumatologic disorders. Indeed, tiredness is the major complaint of those with significant organic sleep disorders.

Being tired all the time is also an especially common complaint of patients with rheumatoid arthritis and fibromyalgia.

Understanding The Relationship Between Rheumatologic Conditions And Sleep Disorders

The first task in recognizing sleep disorders is being able to distinguish between someone who is feeling tired and someone who is suffering from fatigue. If the patient can easily fall asleep or doze off unintentionally during waking hours, this is known as excessive daytime sleepiness (EDS) or hypersomnia, and signals a sleep disorder.

However, if the patient does not have a propensity to fall asleep yet feels physically tired with an active mind, this is fatigue. Those with fatigue may or may not have a sleep disorder but the symptom of fatigue is especially common and is often overbearing in those with fibromyalgia and rheumatoid arthritis (RA).

There is a dynamic and complex relationship between rheumatologic conditions and sleep disorders. Chronic pain at night will disturb sleep and is a common cause of sleep-maintenance insomnia. In part, this is due to medication effects wearing off during the night. In addition, sleep deprivation (especially rapid eye movement (REM) sleep loss) as well as sleep disruption from sleep disorders and pain may actually lower the pain threshold. This in turn renders patients hyperalgesic and increases their suffering. Disruption of deep (delta or slow-wave) sleep may result in musculoskeletal pain and tenderness.

Accordingly, let us take a closer look at some of the causes of excessive daytime sleepiness as well as some organic causes of insomnia and non-refreshing sleep. Having a strong awareness of these disorders, which are often associated with rheumatologic conditions, can go a long way toward facilitating accurate diagnosis and appropriate referral to a sleep medicine specialist.

Making the Referral for Polysomnography: What You Should Know

The most important test that can be done in a sleep laboratory is polysomnography, which means “writing down many things during sleep.” For people with a normal sleep/wake schedule (circadian rhythm), this test is done at night by polysomnographic technologists who continuously monitor the patient.

Some of the important things to monitor are the electroencephalogram (EEG), eye movement and chin muscle tone via electromyography (EMG). These enable the technologist and sleep specialist to determine when the patient is asleep and what stage of sleep the patient is in. This is essential to validate an adequate sleep time and adequate REM sleep time. Without these determinations, the polysomnography could wind up being a “false negative” study.

Other parameters that sleep specialists routinely monitor during polysomnography include airflow, breathing effort and electrocardiogram (EKG). In addition, other monitoring areas include oxygen saturation, end-tidal CO₂ and muscle tone. Sleep specialists monitor all of these with the help of a microphone to detect

movement and breathing sounds as well as snoring, etc. Sometimes, they will also measure esophageal pH in order to evaluate sleep-related gastroesophageal reflux. These specialists monitor airflow via nasal pressure, oral and nasal temperature (via thermistors), and/or expired CO₂. Serving as an auxiliary airflow monitor is a microphone that records the sounds of breathing.

Absence of airflow for more than 10 seconds in an adult (or two respiratory cycles in children) is referred to as apnea, which means the person is not breathing. The sleep specialists score apneas when they are accompanied by oxygen desaturation, EEG arousal or bradycardia in children. In this case, bradycardia is a 25 percent decrease in heart rate. A 50 percent reduction in airflow for more than 10 seconds is called hypopnea, which is low breath. Hypopneas are scored when low breath is accompanied by oxygen desaturation. If the abnormal breathing causes an EEG arousal but no oxygen desaturation, the patient has a respiratory effort-related arousal (RERA). One may see this in cases of upper airway resistance syndrome (UARS) in which there is an exaggerated effort to breathe through a narrow airway. This causes sleep disruption that results in daytime sleepiness. Utilizing impedance plethysmography, piezocrystal belts and/or intercostal EMG, sleep specialists can measure and detect abdominal and chest wall excursion, thus documenting respiratory effort to distinguish obstructive from central apnea during polysomnography.

When an apnea is accompanied by respiratory effort, the patient has an obstructive apnea. When there is no effort or attempt to breathe, the patient has a central apnea. The most common form of sleep-disorder breathing is obstructive sleep apnea, which clinicians may see as often as asthma if they look for it. Central sleep apnea, on the other hand, is not as common and is sometimes associated with a central nervous system (CNS) disorder.

Is There A High Incidence of RLS and PLMD With Rheumatologic Conditions?

About 5 to 10 percent of chronic sleep-onset insomnia may be related to RLS, which is common among those with systemic sclerosis, Sjogren's syndrome or fibromyalgia. Restless legs syndrome is an unrelenting urge to move one's legs with unpleasant sensations, which can be difficult to describe. This usually occurs when the patient's legs are at rest or inactivity. The patient experiences relief once there is movement in his or her legs. This syndrome is usually worse in the evening.

Periodic limb movement disorder is characterized by repetitive cramping and movements of the limbs during sleep with transient arousals. Clinicians see this more frequently among patients who have rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE). It can be a cause of sleep maintenance insomnia or excessive daytime sleepiness. The patient is usually unaware of the limb movements unless he or she is informed by a spouse or bed partner.

Methylxanthines (i.e. caffeine), selective serotonin reuptake inhibitors (SSRIs) and tricyclic antidepressants, along with uremia and metabolic abnormalities, may cause RLS and PLMD. The most common metabolic disturbance is iron deficiency, and iron supplementation is recommended if the ferritin level is less than 50.

The drugs of choice for both RLS and PLMD are ropinirole (0.25 to 4 mg) and pramipexole (0.125 to 0.5 mg), which patients should take 30 minutes before bedtime. One may diagnose RLS via patient history alone but polysomnography is necessary for the diagnosis of PLMD. Most patients with RLS will also have PLMD but not the reverse.

Other Pertinent Pearls About Sleep Disorder and Rheumatologic Conditions

While sleep disorders appear to be most frequent with fibromyalgia and RA, they are frequently overlooked problems with many of the rheumatologic disorders.

Those with SLE are prone to poor sleep quality, OSA and PLMD. Systemic sclerosis patients have a high rate of sleep-related gastroesophageal reflux and aspiration during sleep. In order to make the diagnosis for patients with scleroderma, it is recommended to include esophageal pH monitoring with the polysomnography. These patients also have a very high prevalence of PLMD (48 percent) and RLS (22 percent) in addition to sleep-related GERD, and may present with insomnia or hypersomnia.

Patients with ankylosing spondylitis have very frequent complaints of insomnia (41 percent), both sleep-onset and sleep-maintenance forms of insomnia, as well as daytime fatigue. One may note obstructive sleep apnea in 12 percent of ankylosing spondylitis patients. Insomnia is also the major complaint in Sjogren's syndrome.

When sleep-onset insomnia is present, 24 percent is due to RLS and 45 percent is due to muscle tension. One may also detect alpha-delta sleep with these patients. There are two major sleep problems in those with dermatomyositis/polymyositis: nocturnal hyperventilation and aspiration during sleep. These patients should have end-tidal carbon dioxide (PetCO₂) monitored during polysomnography if they are evaluated in the sleep laboratory during sleep.

In Conclusion

Sleep disorders, ranging from restless legs syndrome (RLS) and insomnia to obstructive sleep apnea and hypersomnolence, are commonly associated with rheumatologic conditions. Understanding some of the signs and symptoms of these disorders as well as having an awareness of key diagnostic tests that can be conducted in sleep laboratories may facilitate improved diagnosis and timely referrals.

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Results From Our Fall - Winter 2007 Survey



Below are the results from our Fall - Winter 2007 survey. We wanted to gauge your interest in research and discover what issues may make you hesitant in participating. These results helped us develop the TASC Q&A, which appears on the next page. Be on the lookout for future surveys on our website, spondylitis.org. By anonymously answering just a few simple questions, you can help us guide our efforts in research, patient advocacy and more.

Question No.1

How old are you?

Age 13 – 19	2.2%
Age 20 – 29	7.8%
Age 30 – 39	20.8%
Age 40 – 59	57.6%
Age 60 +	11.5%

Question No.3

I would potentially be willing to participate in a research study related to spondylitis (check all that apply):

To obtain better treatment	71.0%
To obtain better access to treatment . . .	46.5%
To earn money	25.3%
To obtain free treatment	35.3%
To advance medicine and science	76.2%
To help others with spondylitis	75.1%
To obtain education about spondylitis . . .	59.1%
None of the above	1.5%
N/A (I am not willing to participate)	6.7%

Question No.2

I was diagnosed with spondylitis:

Less than one year ago	24.5%
1-3 years ago	21.2%
3-5 years ago	7.8%
5-7 years ago	7.4%
7-10 years ago	8.9%
More than 10 years ago	23.4%
I have not received an official diagnosis . . .	6.7%

Question No.4

I would be reluctant to participate in a research study related to spondylitis because (check all that apply):

I'm concerned my health info may be shared . .	12.3%
I'm concerned it will take too much of my time . .	26.4%
I live too far away from a recruiting site	43.9%
I don't think I am eligible to participate . . .	12.6%
I'm concerned there may be associated costs .	29.4%
Other	15.2%
N/A (I am or have participated)	19.0%

Question No.5

There are several protections for research participants. For example, the World Medical Association's Declaration of Helsinki is a set of ethical principles the medical community must follow when conducting clinical research with participation from people. Informed consent is a central concept to this document and ensures that participants understand the implications of their participation. Before reading this, were you aware that there are patient protections in regard to research?

Yes 62.8%

No 37.2%



TASC STUDY Q&A

Participating in research may be easier than you thought...

Q: *What is the purpose of the study?*

A: The purpose of the study is to learn more about the genes causing the disease with the hope that the knowledge acquired would lead to better disease management and eventually a cure.

Q: *I have ankylosing spondylitis, but do not have a sibling with the disease. Would I still qualify for enrollment?*

A: Patients who have been diagnosed with ankylosing spondylitis are eligible for the study even if they do not have family members with the disease.

Q: *I live far from the recruiting sites. How do I participate in the study?*

A: We are enrolling participants from the entire US. Participation in the study is not geographically restricted and there may not be a need for face-to-face contact throughout the entire research process.

Q: *I have ankylosing spondylitis but I am HLA-B27 negative. Can I take part in the study?*

A: Patients can enroll in the study if they have been diagnosed with ankylosing spondylitis irrespective of their HLA-B27 status.

Q: *How many times would blood samples be drawn?*

A: The study involves a one-time blood draw for all volunteers.

Q: *How much does it cost to participate in the study and who pays the cost of the blood draw?*

A: Participation in the study is at no cost to participants. The blood draw is usually complimentary but if there is need for payment, SAA would make such payment.

Q: *Who are the best candidates for the control group?*

A: The best candidates for the control group are friends and spouses. Remember -- patients are eligible even if they do not have a spouse or friend who is interested in being a member of the control group.

Q: *Will my information/medical records be released to other parties?*

A: We will not release your information to any third party. Only the research physicians will see your information. Our staff is highly trained to respect patient confidentiality.

Q: *How will I find out about the progress of the study?*

A: We will keep volunteers posted on the progress of the study via timely written reports in Spondylitis Plus, on our website, spondylitis.org, and other SAA educational materials.

Participating in 8 Easy Steps

- 1 Call 1-800-777-8189 x224
- 2 Receive a consent package
- 3 Complete & return
- 4 We review medical records to confirm AS
- 5 A blood kit is sent to you in the mail
- 6 Get a one time blood draw at a local lab or doctor's office
- 7 The blood is sent to the research lab in Houston
- 8 Leading to new discoveries: spondylitis.org/research

For more info, call toll-free 1-800-777-8189 x 224



25 YEARS OF PROGRESS

Because Of You

What started out as a gathering of a dozen patients and physicians in a private home in Sherman Oaks, California has, over the last 25 years, grown into the single largest resource for the spondylitis community in the US. In fact, it was at that meeting, when individuals diagnosed with an isolating illness came together for the first time, that the spondylitis community was born. When Jane Bruckel hosted that small group in 1983, the goal was to share information, compare experiences and exchange moral support. Instead, she began a journey that would change the lives of spondylitis patients everywhere.

Over the course of the last 25 years, those living with spondylitis have seen tremendous advances in education, research, treatments, and support.

Education

When many of our supporters were first diagnosed, spondylitis was an orphan disease, with little or no information to be had. Today, there are books, brochures, DVDs, CDs, a quarterly news magazine and two SAA websites, one specifically targeted to adolescents living with this chronic disease.

Spondylitis patients and their families and friends can now attend Patient Educational Seminars held in cities throughout the country where they can interact one-on-one with the experts in the field.

Younger patients are reporting shorter time periods between onset of symptoms and diagnosis as the medical community continues to be educated about the disease.

Research

Until recently, the only significant gene linked to ankylosing spondylitis was HLA-B27. In November of last year, the TASC Genetic Study uncovered two new genes that contribute to disease susceptibility -- ARTS1 and IL23R. That means that we're closer than ever before to mapping out this disease. This breakthrough paves the way for exciting advances to come.

Treatments

Twenty-five years ago, using NSAIDS to manage the pain was, for many, the best that science had to offer. Today, while NSAIDS are still a staple of spondylitis treatment, a new class of drugs, the TNF-a Inhibitors, are bringing relief and a vastly improved quality of life to patients the world over. These medications, and others, are being improved upon every day and offer hope to millions.

Support

When once many spondylitis patients spent their entire lives without ever meeting another person with the disease, today they can participate in support groups and share experiences with others who understand the challenges of living with a chronic illness, or join a growing interactive message board community to network with their peers.

And you made it happen.

You Are SAA

Many times we've thanked you for choosing to partner with SAA to help make some of these achievements possible. But really, all of us at SAA are grateful for the opportunity to partner with you. Because it really is you, and all of the members of the spondylitis community, who have driven our mission over the last 25 years.





And, with all of us continuing to work together, we hope to reach the cure in the near future.

And so, while we'll take some time this next year to look back on a quarter century of making spondylitis history, our focus remains firmly on the future. *A future where spondylitis is history.*

Membership Has Its Privileges

When was the last time you read or heard something about spondylitis that didn't come from SAA? As the only US organization specializing in spondylitis education, SAA is the premier resource for keeping up with a field that has changed more in the last five years than it had in the previous hundred. SAA membership ensures that you receive the latest news and information that has a direct impact on your life, access to a growing menu of resources to help you manage the disease and a ready connection to others who can lend support, share experiences and offer advice.

From a nationwide network of SAA-Sponsored Educational Support Groups to Patient Educational Seminars held in cities throughout the country to each and every issue of *Spondylitis Plus* and more -- SAA members have access to resources not available anywhere else. And the benefits of membership continue to expand. With new member discounts on SAA products and services, including the updated and expanded book [Straight Talk on Spondylitis](#) and MedicAlert services, SAA membership is more valuable than ever. And now, there's an even easier way to make your membership count.

Monthly Giving Is S.M.A.R.T.

One of the most cost-effective ways to support SAA is by joining the **"Spondylitis Monthly Automatic Rewards Team" (S.M.A.R.T) Program.** It's a safe, secure and convenient way to put more of your money to work advancing the spondylitis community's shared mission of eradicating this disease and making life easier until we do. All you need to do is specify a monthly amount and SAA will automatically deduct the contribution from your credit card.

One significant benefit to this program is that it lowers SAA's fundraising costs. SAA's fundraising program is already one of the most efficient in the nation (as evidenced by Charity Navigator's 4-Star rating), but making it even more streamlined is in everybody's best interest. Postage rates have gone up, as have printing costs. An automatic electronic donation means that your gift can be put to work immediately funding the programs and services you've come to rely upon. And, you get fewer letters in your mailbox.

As a Charter Member of the S.M.A.R.T. Givers Program, your support will help sustain SAA's worldwide leadership role in promoting early diagnosis, dispensing information about effective treatment and hastening the cure.

For 25 years, SAA has been a dependable, reliable source of information, education, programs and services. Having a dependable, reliable source of funding will enable us to better allocate resources and plan for future needs. By joining the S.M.A.R.T. Givers program, you can help to ensure that SAA is able to move forward with opportunities as they arise, rather than having to shelve groundbreaking programs until funding can be secured.

To sign up for the S.M.A.R.T. Givers Program program, go to spondylitis.org/smart or contact Helene Hart at 800-877-8189, ext. 229 or at hhart@spondylitis.org. Becoming a S.M.A.R.T. Giver is a great way to support the Spondylitis Association: you'll receive fewer renewal notices, get a tax credit for the full amount paid at the end of the calendar year and you may change or cancel your pledge at any time.

Thank You

All of us at SAA would like to extend heartfelt thanks to those who made these past 25 years of progress a reality and future achievements a certainty: our founders, volunteer governance and advisory boards, support group leaders, corporate partners, foundation supporters, volunteer fundraisers and most especially -- the committed donors and members who remain the heart of the organization.



Health Insurance Options for People with Pre-existing Conditions (Part 1 of 2)

by Scott P. Edwards | Match 13, 2008

The message boards on the Spondylitis Association of America’s web site light up with talk of difficulties with insurance companies: inadequate coverage for prescription medications and treatments such as physical and occupational therapy; problems with co-pays and deductibles; and lack of coverage for pre-existing medical conditions.

It is the last of these—pre-existing conditions—that Karrie Shogren knows well. An assistant professor of special education at the University of Texas at Austin and a member of the SAA board of directors, Shogren first showed symptoms associated with ankylosing spondylitis (AS) during her last year of undergraduate studies. It took about three years for her to receive a diagnosis of AS, a time during which she experienced ongoing issues with insurance coverage and access to specialists to obtain a diagnosis.

Because she was a student, she found that her student health insurance policy did not provide the level of coverage she needed, so she was forced to take a job during her master’s degree study that provided insurance benefits. The coverage, however, was with a “relatively restrictive HMO,” she says, which led to problems with receiving authorization to see the appropriate specialists to obtain a diagnosis. Most of these problems arose because Shogren had a pre-existing medical condition.

“I had to incorporate health issues into my plans and decision-making process and had to make some difficult choices,” says Shogren. “I also had to learn to advocate for myself with the insurance companies . . . particularly in the early years when my symptoms weren’t managed well.”

Posters on the SAA message boards echo Shogren’s frustrations. In one post, a frustrated AS patient writes: “There are few things more frustrating than dealing with insurance companies . . . I’ve had to battle with many insurance companies over the years. I think they count on a certain percentage of people giving up. The problem with AS is that you are more likely to give up, as you’re already tired and overwhelmed to begin with.”

“I had to learn to advocate for myself with the insurance companies.”

A pre-existing condition is any condition—physical or mental—for which medical advice, diagnosis, care or treatment was recommended or received within a six-month period immediately preceding an individual’s enrollment in a health plan. Certain conditions, such as pregnancy, cannot by law be considered a pre-existing medical condition. Nor can genetic information about an individual’s likelihood of developing a disease or condition, unless a doctor diagnoses the disease or condition. Many health insurance providers consider AS a pre-existing condition.

The definition of a pre-existing condition may vary considerably from one health plan to another. In fact, some policies consider certain medical problems to a pre-existing condition even if the individual did not know they had the problem before buying a policy or joining a health plan. Thus, insurance experts say, consumers should become completely familiar with policy definitions and provisions prior to purchasing an insurance policy.

Location, location, location

The question becomes, then, how do people with pre-existing conditions obtain health insurance or how do they ensure that their health insurance coverage remains intact if they change jobs?

Obtaining health insurance can be tricky for people with a pre-existing medical condition. Insurance companies are naturally reluctant to write policies for people who are likely to need expensive treatments and medications over the course of their illness.

“Unfortunately,” says Mila Kofman, of Georgetown University’s Health Policy Institute, who studies issues concerning the uninsured and underinsured, “there are not many [health insurance] options for people with pre-existing conditions.”

Kofman says that where an individual with a pre-existing condition lives may be a key factor in getting health insurance. “Each state is different,” she adds. “There are more options in New York than there are in Utah, which has few options [for insurance].”

On its website, www.healthinsuranceinfo.net, Georgetown's Health Policy Institute publishes consumer health insurance guides for most states. These guides provide detailed information about consumer rights and protections under federal and state laws. The New York guide, for example, says that the Empire State "has enacted comprehensive reforms to expand your access to health insurance and to guarantee fair pricing of policies." The Utah guide, on the other hand, says that "your health insurance options [in Utah] are somewhat dependent on your health status," meaning that if you have a pre-existing medical condition, your choices for health insurance coverage in the state are limited.

Group health plans the best route

The best route for an individual with a pre-existing medical condition might be group health insurance. These plans are usually sponsored by an employer, union or professional association and cover at least two employees. They typically cover physician visits, surgery and hospitalization for ongoing illnesses or care through a health maintenance organization (HMO). HMOs are centralized service providers that couple a general medical practitioner with specialists upon referral. They also cover physician visits, surgery and hospitalization, as well as reduced-rate prescription medications.

Unfortunately, many group health insurance plans, like other health insurance policies, have what are called pre-existing condition exclusion periods. This is the time (usually six months) during which a health plan will not pay for covered care related to a pre-existing condition. If, for example, an individual has AS when he starts a new job, his new employer-sponsored health plan could deny coverage for AS-related care for a specified period of time. At the end of that period, however, the plan must cover the cost, minus co-pays and deductibles, of his AS care.

“Employers voluntary offer health benefits; they are not required to do so.”

“When you switch jobs,” says Kofman, “and you had continuous coverage [no break in insurance cover for more than 63 days, according to federal law], then pre-existing condition exclusions must be reduced or eliminated.” In other words, the exclusion period is not open-ended and must be stated in benefits materials.

If you had no prior insurance coverage (or a break in insurance for more than 63 days) and took a new job, employer-sponsored health plans can impose exclusions on coverage for the condition you had when starting the job.

However, that exclusion period can last for no longer than one year. For example, if an individual has cancer and no insurance coverage, the employer can impose exclusions for cancer-related care for one year. When that year is up, the employee is eligible for coverage under the employer's health insurance plan.

In both cases — AS and cancer — the insurance plan must pay for any unrelated health services or conditions that arise once coverage has begun.

“There are possibilities, however, that some people can never get health insurance,” says Kofman. “In the United States, employers voluntary offer health benefits; they are not required to do so.”

As part of this system, the employer has flexibility on coverage. Some employer health plans may cover cancer-related care, but only up to a certain dollar amount. Kofman says that employers can do this as long as the same rules are applied across the board to all employees covered under the plan.

Part 2 of “Health Insurance Options for People with Pre-existing Conditions” will appear in the next issue of *Spondylitis Plus*. If you want to read the rest of the story now, go to spondylitis.org/story.



Online Pharmacies Offer Convenience, Savings... ...and Risk

by Scott P. Edwards | February 28, 2008

Nearly 20 years ago, pharmacies began springing up on the Internet, providing consumers with an alternative to traditional brick-and-mortar drugstores. These online pharmacies provide consumers with convenience, privacy and, in many cases, lower prices for their medications. More than anything, that's what has driven many patients with ankylosing spondylitis (AS) to the Internet: the chance to save hundreds, if not thousands, of dollars a year in medication costs.

Convenience, cost and privacy aside, however, online pharmacies are not without risk. In 2001, Ryan Haight, a California teenager, died from an overdose of hydrocodone, a painkiller that he purchased from an online pharmacy. The doctor who prescribed the drug never met or examined the boy, who reportedly simply described himself as a 25-year-old man with chronic back pain on the pharmacy's online questionnaire.

A 2006 study by the National Center on Addiction and Substance Abuse at Columbia University found that 89 percent of Internet sites selling controlled prescription drugs have no prescription requirement and that more than 15 million adults admit to abusing prescription drugs, including nearly 2.5 million children between the ages of 12 and 17. Thus, the Internet feeds a growing demand for illicit prescription medications.

"The ease with which consumers may purchase controlled substances from online pharmacies without a prescription is shocking," said Sen. Jeff Sessions (R-AL) in a press release when he and Sen. Dianne Feinstein (D-CA) introduced the Online Pharmacy Consumer Protection Act of 2007. "Most online pharmacies have no way to verify that the consumer ordering the prescription is actually who they claim to be, or that the medical condition the consumer describes actually exists. Thus, drug addicts and minor children can easily order controlled substances and prescription drugs over the Internet simply by providing false identities or describing non-existent medical conditions."



A 'heck of a savings'

For those with a chronic condition including spondyloarthritis, online pharmacies can sometimes provide a cost-effective and convenient means of buying what are often very expensive medications to treat their condition. Kerry Hawkins, a member of the Spondylitis Association of America's support group in Boise, Idaho, began using online pharmacies because he pays out-of-pocket for his medications since he has no health insurance. "It's a heck of a savings," he says, "and the savings are worth it if you need the drugs."

Another SAA member, who asked to remain anonymous, said she initially balked at buying medications online because friends told her "it was a bad thing to do." After speaking with a neighbor who bought prescriptions online, however, she found that the savings were "astronomical," and she joined the millions of Americans who now buy their prescription drugs over the Internet.

Many of the medications AS patients take can be purchased online through pharmacies in the United States or, more frequently, in Canada. Nonsteroidal anti-inflammatories, such as Celebrex, naprosen and indocin, can be purchased from Internet pharmacies for a fraction of what they cost at the big brick and mortar chains. One online pharmacy offers 60 tablets of 100 mg Celebrex for \$62, or \$1.03 per pill. A well-known traditional retailer sells 30 tablets of the same medication for \$70.99, or \$2.37 per pill, more than double the cost of the online pharmacy.

"If the price sounds too good to be true, it probably is."

Hawkins says Celebrex was the "big savings" for him when purchasing online. He bought Celebrex at a 65 percent savings compared to what he would have paid at his local drugstore.

Other AS drugs, including methotrexate, prednisone and sulfasalazine, can be purchased from online pharmacies as well, though the cost savings are not as dramatic as they are for other medications.

TNF-alpha blockers like Enbrel and Humira can cost up \$20,000 per year. Drugstore.com, an online pharmacy, sells a four-kit supply for \$2,800.

Replacing a trip to the drugstore

In a survey conducted in 2004, the Pew Internet & American Life Project found that 26 percent of American adults had researched prescription drugs online, but only 4 percent had ever actually purchased their medications from an online pharmacy. As the number of pharmacies on the Internet proliferates so too does the number of people replacing a trip to the drugstore with a click of the mouse.

There are multiple legitimate online pharmacies to choose from that offer their customers convenience and privacy, as well as the safeguards that are mandated through federal law. According to the experts, for the most part, consumers can use these pharmacies with the same confidence they have in their local pharmacist. In fact, many of the large pharmacy chains in the U.S., including CVS, Walgreen's and Rite-Aid, offer online prescription drug purchases through their Web sites.

In addition to lower costs and greater convenience, online pharmacies offer a number of other advantages over retail pharmacies, including:

- **Privacy** – people may feel more comfortable asking questions online regarding their medical condition and the medications they take than speaking face-to-face with a local pharmacist. Because privacy can be compromised in online transactions, it's always best to make sure the online pharmacy has an appropriate privacy policy.
- **Access to generics** – due to patent protection differences, some online pharmacies that operate outside the U.S. may have more access to generic drugs

that can only be sold as brand-name versions in the U.S.

- **Medical information** – in addition to selling medications, many online pharmacies provide a wealth of useful information about medications, drug interactions, and diseases that consumers may or may not get from their local pharmacy.

- **Supply** – many online pharmacies sell a 90-day supply of medication compared to the typical 30-day supply from a retail pharmacy.

Caveat emptor

There are many online pharmacies from which to choose. These range from reputable companies to “rogue” sites willing to sell any drug to anyone. Founded by a physician who was the leading evaluator of dietary supplements, PharmacyChecker.com is one of the principal sources of information about online pharmacies. The company “collects, evaluates, and reports credentials, prices and customer feedback regarding pharmacies that operate online and through mail-order and fax.” According to its Web site, PharmacyChecker.com also helps consumers find the “lowest priced products from the most qualified and reputable online pharmacies” and publishes pharmacy ratings and profiles.

Another potential resource is eDrugSearch.com, which provides “tools and resources to help consumers with decision making when purchasing prescription medications online,” including search features that allow consumers to identify pharmacies with specific licensing and third-party accreditation.

Things to Consider before jumping in

In today's day and age, convenience and cost-effectiveness are important; however, because the Internet has changed the way we live, work and shop—in both good ways and bad—people must be forever watchful when buying prescriptions online.

Some online pharmacies don't require a doctor's prescription. Others sell expired or counterfeit drugs. Some aren't licensed, and yet others will sell medications that are not the right ones for certain conditions.

Hawkins, the SAA support group member from Boise, says the biggest problem he faces when buying online medications is that they “come from all different places.” He orders his drugs from a Jandrugs.com in Canada, but they are filled in Turkey, the Philippines and other foreign countries. “It's a little scary,” he says, “but they all have a telephone number so you can call the manufacturer to ask about their authenticity.”

While considering online pharmacies a “lifeline,” Hawkins advises AS patients and others buying their medications over the Internet to stick to the “big” sites. “Disregard the billions of e-mails you get from illegitimate online pharmacies,” he adds. “They don't sell the real stuff. If they don't ask for a prescription, that's a red flag. If the price sounds too good to be true, it probably is.”



For more information, visit the following sites online:

The U.S. Food and Drug Administration - www.fda.gov

Mayo Clinic - www.mayoclinic.com

The National Association of Boards of Pharmacy - www.nabp.net

Oriental Medicine and Ankylosing Spondylitis

By Craig Gimbel, DDS - Morristown, New Jersey Educational Support Group Leader | March 6, 2008

One of our recent educational support group meetings included a guest presentation on traditional Chinese medicine, as alternative or adjunctive medicine, presented by Dr. Henry McCann, L.Ac., Dipl. O.M., a former Fulbright Research Fellow to Japan, a doctoral degree candidate in Chinese medicine, President of the New Jersey State Acupuncture Examining Board and private practitioner in Madison, NJ. Just for informational purposes, I thought our readership would be interested in an overview of his presentation “Oriental Medicine and Ankylosing Spondylitis”. Our Morristown, New Jersey support group was treated to an outstanding morning.

Some of East Asia’s greatest thinkers developed Traditional Chinese Medicine or what is known as Oriental Medicine over a period of 3,000 years. Its therapeutic techniques include acupuncture, moxibustion, Chinese herbal medicine, bodywork therapy (massage) and qigong (physical exercise). Various points of the body regulate vital energy, known as Qi (pronounced “Chee”). Qi is a word used to describe the traditional concept that vitality animates the body. It represents the normal functioning of the internal organs and circulates constantly in the body through “channels”. Chinese physicians recognized various internal organs, but the organ “functions” are not necessarily the same as the analogous structure in western medicine. Organs are divided into Yin and Yang categories, with the Yin organs being more important. For example, the function of the kidney is related to the immune system. Chinese medicine proclaims, “The hundred diseases arise out of Qi”. According to Chinese medicine, pain is the result of stagnation of the Qi or blood in the channels. Just as water being dammed up causes pressure in a river, a blockade of Qi, blood or bodily fluids can cause pain and swelling. This stagnation can result from

internal factors (ie: emotions), external factors (ie: cold, viruses), or other factors (ie: diet, constitution, lifestyle). The body naturally eliminates inflammatory fluid or coagulated blood to decrease swelling and pain. In Chinese medicine, acupuncture, herbs and exercise can increase blood flow to reduce pain due to inflammation.

Acupuncture

Acupuncture is the use of very fine sterile needles that are placed shallow in the skin in order to regulate vital energy systems of organs and control pain. Very little discomfort is felt. Acupuncture treats disease by rebalancing the Qi in the body’s channels by interconnecting the nerves of the extremities to the central nervous system spinal cord. The central nervous system influences the extremities and vice versa. Chinese medicine has been continually remapping the Qi pathways of the body due to trial and error for the past 2,000 years. This stimulation in the extremities had profound regulatory effects on the internal organs of the body. The effects of the needles can be further stimulated by heat, and present-day electrical stimulation or low-level laser therapy.

Moxibustion

Moxibustion is a type of heat therapy which includes the burning of processed dried leaves of *artemesia vulgaris* (mugwort), rolled and shaped into cones, at or over acupuncture points to treat pain, warm the body and strengthen the internal organs. A penetrating medicinal action of the leaf oil has an analgesic action. Continued patient home instructed therapy could augment this effect. It also has been used in Chinese medicine to increase the red and white blood cell count to increase immune function.

Chinese herbal medicine is 75% plant in origin. Other substances are minerals and to a much lesser extent today, animal, due to conservation efforts. Minimally processed herbs can be used both internally and externally (topically). For the last 500 years,

Chinese herbal medicine has been considered the primary modality used by physicians of Oriental Medicine, either used alone or as an adjunct.

Qigong

Qigong is a word that describes various exercises designed to regulate the body’s metabolic processes and internal energy. These exercises utilize specific breathing, posture, meditation and visualization exercises similar to yoga. But, unlike yoga, the exercises are much easier to perform, often requiring no space or time requirements. An example is Tai Chi. Qigong is recommended by the Arthritis Foundation.

Proper lifestyle and diet have their roots in Chinese medicine. Most diseases can be at the very least affected by changes in diet, nutrition and proper lifestyle. Recently, there has been a published study connecting overnight work shifts and cancer. In Chinese medicine, the kidney is responsible for the strength of the bones, regulation of the immune system, the central nervous system, and vice versa. Through the use of herbs and fish oil, the kidney system and immune system would be strengthened.

Through the use of acupuncture, massage, exercise, diet and lifestyle change, Oriental Medicine’s therapeutic techniques are shared by western medicine in some respects. There are published research studies on AS and Oriental Medicine that can be found on the Internet at National Library of Medicine PubMed: www.ncbi.nlm.nih.gov/PubMed/

If you are looking for a provider of Oriental alternative medicine, evaluate if the practitioner is licensed by the State Board of Medical Examiners in your state and that they have attained an accredited bachelor’s degree followed by a 3 year full time master’s degree program. There is an optional 2-year doctoral degree for advanced practitioners and specialists.

SAA-Sponsored Educational Support Groups

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 email to: melissa.velez@spondylitis.org

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*Noel Miles is a temporary contact for Denver, CO

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



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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 doctors conducting the study are Principal Investigator John D. Revielle, MD, University of Texas, Houston and colleagues; Michael H. Weisman, MD, Cedars-Sinai Medical Center, Los Angeles.

How can I find out more?

Southern California: Study Coordinator, (310) 423-2422
Houston area: Laura Diekman, (713) 500-6852, laura.diekman@uth.tmc.edu

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