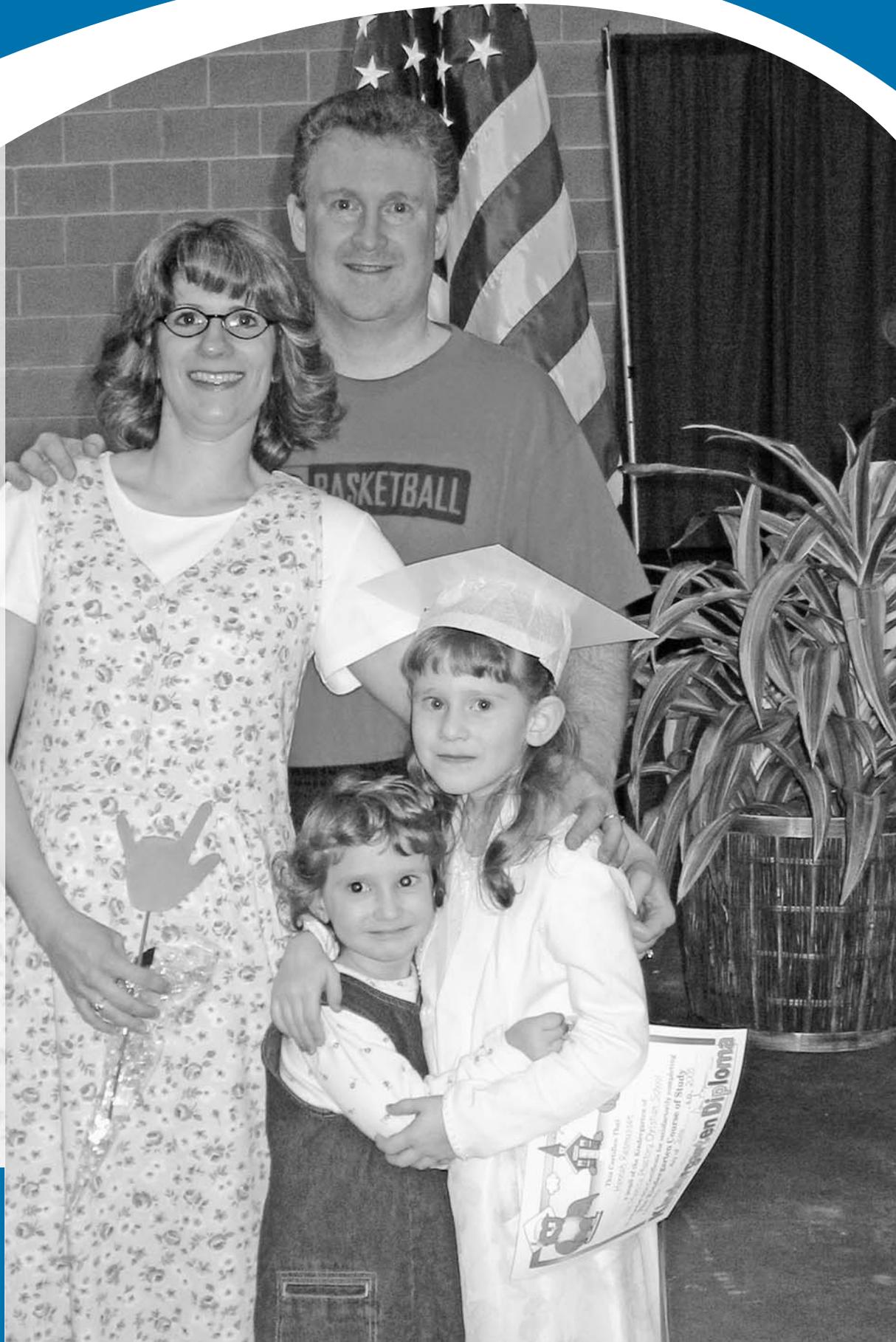


SPONDYLITIS PLUS

january/february 2006



NATALIE RASMUSSEN
SHARES HER STORY

EXERCISE
FACTS
AND TIPS

NEW STUDY
YIELDS CLUES

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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SAA looks forward to our conference with NIH in March

At SAA, we are excitedly looking forward to a prestigious conference we are co-sponsoring with the National Institutes of Health (NIH) to be held March 30-31st. The conference will bring together leading scientists and researchers from around the world to formulate plans and map strategies in the campaign to find a cure for AS and related diseases. However this upcoming meeting *almost* did not become a reality due to a delay in the approval of NIH funding by Congress.

While we fretted over the details of the meeting and whether or not we could pull it off without full participation by the NIH, the bigger picture was painfully obvious to us all: Would federally sponsored research into spondyloarthritis be pushed to the periphery in Washington's never-ending jockeying for scarce resources?

The Bush Administration announced last year that funding for most research categories was not going to keep up with inflation. The latest announced budget increase for NIH for 2006 is even less than the 2-percent increase for 2005.

While funding for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) has steadily increased in the past, for the first time since 1970, the overall NIH budget is actually down a fraction of a percent. And after adjusting for inflation, NIH has a smaller budget in 2006 than it did in 2003; this newest across-the-board cut wipes out the diminutive gains of the past two years.

During the last ten years, SAA has led the fight to draw a greater focus, as well as greater funding, for spondyloarthritis research. The realization of these efforts can be seen in the successful outcomes of our 1998 co-sponsored scientific conference with NIH and in the momentous breakthroughs of the AS Family Genetic Study.

For the future, our one strong voice will need to be a clarion call to Congress; SAA feels it is of critical importance to step up our advocacy efforts to ensure that spondyloarthritis research receives the monies needed to keep it alive.

As such, SAA will remain committed to campaigning for increased government funding. With your help, we hope to ensure that this important field receives the resources necessary to uncover the causes, and the cure, in our lifetimes.

JANE BRUCKEL
 Co-founder & Executive Director



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Dear Editor,

I just wanted to thank you so much for your wonderful publication and for the information it contains. I think it is important to “tell the real story” about this disease and Spondylitis Plus does this quite well.

It is nice to know that I am not alone in dealing with AS and the more I know, the more I can help myself and my doctors with my treatment – yes, doctors can use the help at times. Being proactive is key for proper treatment, in my opinion.

Keep up the good work and keep the “real” stories coming, they have helped immensely.

Sincerely,
Frank Johnson
Wichita, Kansas

Dear Editor,

My husband, a retired judge, 64, has had both psoriatic spondylitis and AS since he was about 30. At that age, he started with a stiff neck. The doctors told him to go home and “live with it.”

The disease process progressed throughout his career with increasing arthritis-type symptoms that would come and go; meanwhile, his spine was fusing.

And then, on March 1, 2005, he fell in the driveway and broke C6 & C7. He, like Scott Thacker, experienced the long emergency-room wait and subsequent “head scratching” by the orthotist, doctors, therapists, etc., who had to design a custom brace for him since surgery had been ruled out— and the halo would have been wildly impractical.

His orthopaedic physician, who was reportedly experienced with AS patients and broken necks, appeared to have been befuddled. My husband subsequently spent 12 weeks laying in an adjustable hospital bed, which forced to him to sleep on his back in excruciating pain; this unnatural position was almost more than he could bear.

After ten weeks it became obvious that the neck was probably healed, according to CT scans, and he still had a tiny amount of nodding movement in his neck. However, the orthopaedic doctor insisted that he wear the brace for an additional month, “just to be careful.”

In two weeks, the remaining nodding movement was gone and the neck totally fused in a slightly downward position. As a result, there is no movement in my husband’s neck at all.

We then consulted with Dr. Richard Ress at Cedars Sinai in Los Angeles. The exam found that indeed there was some movement in

two vertebrae between his shoulder blades and at his waist. Dr. Ress’ advice was to not have any surgery until there were complications. It has been almost a year since the break and life is a bit more difficult for him. But my husband has never been a quitter; nor is he a whiner and we have continued to travel extensively.

His advice to anyone with this condition is to get early diagnosis. Do not take the first opinion that someone gives you; stay as active as you possibly can and find activities that take your mind off the pain. And, if you fall and break your neck, make sure that you have competent medical professionals involved.

We hope this story helps someone in the future.

Leigh Giarde

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:

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New, Improved Rat Model for AS Yields Clues

Researchers are hopeful that a “new and improved” animal model for spondylitis, which in this case is a genetically customized rat, will give up the secrets of the disease process.

A large body of research suggests that a person’s chances of getting ankylosing spondylitis (AS) depends on a certain set of genes that carry a markedly increased risk for developing AS. While it is known that the histocompatibility gene HLA-B27 is the major gene among this set that predisposes people to AS, the precise mechanism by which B27 triggers the cellular domino effect that leads to the disease is not known—yet.

“We are hopeful that this ‘new and improved’ variation on our earlier HLA-B27 transgenic rat will be useful both for learning more about,

*A tool that is
not an end
but a means . . .*

and perhaps finally solving the riddle of how HLA-B27, a normal gene involved in the regulation of the immune system, causes spondylitis and arthritis in humans,” Joel D. Taurog, M. D., SAA Medical & Scientific

Advisory Board member and a rheumatologist and Professor of Internal Medicine at the University of Texas Southwestern Medical Center in Dallas, tells Spondylitis Plus. “The previous HLA-B27 transgenic rats that we made would invariably get severe colitis and sometimes get arthritis, but only rarely spondylitis; in contrast, the new rats have a high prevalence of both arthritis and spondylitis, without colitis.”

About seven percent of Caucasians possess the HLA-B27 gene, whereas HLA-B27 is found in 85-90% of patients with AS, although the disease occurs in HLA-B27 negative individuals, as well. Expressed as a relative risk, an HLA-B27 positive individual is over 80 times more susceptible to developing AS, compared with someone who lacks HLA-B27.

Significant Progress

Dr. Taurog has made significant progress in his 25-year search for the underlying mechanisms in how the HLA-B27 gene contributes to

disease and why people with this gene are so predisposed to getting AS in the first place.

The newly developed rat gets severe arthritis and spondylitis, and, since the only way in which these rats differ from normal rats is in having the components of HLA-B27, it seems likely that whatever is happening in the rats is also happening in humans with HLA-B27. In what is being termed by Dr. Taurog as a “tool that is not an end but a means,” the special rat has a disease course dominated by arthritis and spondylitis. Under the microscope, the inflammation in the spinal joints of the tail looks similar to what is seen in the spine in patients with AS. Dr. Taurog says excitedly that the new HLA-B27 rats seem to be such an authentic model of AS, that they “even get kinks and bumps in their tails at the sites of severe inflammation.”

The Earlier Rats Developed Colitis, but Rarely Spondylitis

In 1990, Dr. Taurog and his colleagues genetically engineered two normal strains of laboratory rats by inserting an HLA-B27 human gene and another gene called human beta-2-microglobulin, both of which are necessary for formation of the complete HLA-B27 molecule. The rats spontaneously developed arthritis in the paws, a colitis-like intestinal inflammation, and occasional inflammation in the spine. This pioneering body of work was described in the Nov. 30, 1990, issue of the prestigious scientific journal *Cell*.

“We found that the disease signs only occurred in the descendants of rats that had incorporated a large number of copies of the B27 gene—more than 20,” Dr. Taurog explained. “In the rats that developed disease, almost all of them developed inflammatory bowel disease, particularly colitis. About 40 percent of the males and 20 percent of the females developed arthritis in the hind paws.”

In the affected rats, inflammation also was found in the male genital tract, skin, nails, and heart. Dr. Taurog’s group wrote that this pattern of organ system involvement showed a striking resemblance to the B27-associated human disorders, namely the spondyloarthritis disease spectrum.

“HLA-B27 Itself Actually Participates in Causing Spondyloarthritis”

They also noted that rats transgenic (genetically modified) for a high copy number of another HLA allele, HLA-B7, remained healthy. “These results strongly suggested to us that HLA-B27 itself actually

References to cited studies:

Cell, 1990, Nov 30; 63(5):1099-112, Hammer RE, Maika SD, Richardson JA, Tang JP, Taurog JD, Spontaneous inflammatory disease in transgenic rats expressing HLA-B27 and human beta 2m: an animal model of HLA-B27-associated human disorders.

J Exp Med. 1994 Dec 1;180(6):2359-64, Taurog JD et al, The germfree state prevents development of gut and joint inflammatory disease in HLA-B27 transgenic rats.

participates in causing spondyloarthritis, a concept that is now widely accepted,” Dr. Taurog recalled. However, when the tail joints and spine were dissected in the 1990-genre rats, Dr. Taurog’s lab occasionally saw inflammation, an indication of spondylitis, but they were disappointed to find that the frequency was too low to be useful in their quest for an experimentally useful animal model of AS.

The research group said they found it puzzling that the colitis was so prominent in the former rat group. “Even though in humans inflammatory bowel disease (IBD) is associated with AS and other forms of spondyloarthritis, IBD by itself is not particularly associated with HLA-B27,” said Dr. Taurog.

But that was Sixteen Years Ago

But that was 16 years ago. Since then, there has been a steady stream of new information on the role of HLA-B27 and its biochemical characteristics, coming from investigators throughout the world. In the course of their continuing studies, Dr. Taurog and colleagues happened to hit upon a modified B27 transgenic rat model that has a much higher prevalence of arthritis and spondylitis in the absence of colitis. “This was a big surprise,” he explained, “and what was even more surprising is that it came from crossing two lines, each of which by itself remains healthy.”

More specifically, one line known in Dr. Taurog’s lab as “21-3,” has some 20 copies of the HLA-B27 gene and 15 copies of the human beta-2m gene. The other line, known as “283-2,” has 35 copies of just the human beta-2-m gene. The rats in each of these lines remain completely healthy.

However, Dr. Taurog’s group observed that when these two lines were crossed together, the male offspring that inherited the transgenes from both parents had a 70-percent prevalence of arthritis in the paws and an estimated 40 to 50-percent prevalence of spondylitis in a spontaneous process—sans any evidence of colitis. The females by and large remained healthy. To test for specificity for HLA-B27, the investigators also crossed a line transgenic for HLA-B7 and human beta-2-m, which is not associated with disease, to the 283-2 line, and the offspring of this cross remained healthy.

If this all sounds daunting, it is de rigueur to this dedicated group of researchers who hope to have all the answers to this baffling disease figured out “before we retire,” as Dr. Taurog put it, “although maintaining adequate research funding until then always seems to be a challenge.”

A Germ-Free Environment Could Yield Some Rich Information

“There are many approaches that we would like to take with these rats,” said Dr. Taurog. One future project with these specially designed rats that could yield particularly useful information, Dr. Taurog said, would be to see how they would do in a germ-free environment.

A dozen years ago, Dr. Taurog’s group published an article describing how, when they raised the original lines of HLA-B27 rats in a completely sterile environment (that is, lacking even the normal intestinal bacteria), the rats failed to develop either arthritis or colitis, while the rats that subsequently were exposed to germs acquired the typical disorder. Those results, published in the December 1994 issue of *The Journal of Experimental Medicine*, suggested a microbial link to both colitis and arthritis. However, one possible interpretation of these results was that arthritis was dependent on the colitis, but only the colitis was dependent on the presence of gut bacteria.

The possible role of intestinal bacteria in AS has been an area of controversy for almost 30 years. Since the original B27 transgenic rats did not develop much spondylitis, it was not possible to use those rats to answer the question. Now, however, this question can be addressed in the newer rat model.

“If B27-associated spondylitis is indeed related to gut bacteria, we would expect that raising these rats in a germ-free environment would prevent the development of spondylitis. Moreover, if the germ-free state does in fact prevent spondylitis, by giving back only specifically defined bacteria, we would have a good experimental system for determining which bacteria are important. And if the germ-free state does not prevent spondylitis, this would also help resolve the controversy about intestinal bacteria. Germ-free experiments are very difficult and expensive, but this would be an important experiment that could be expected to bring us closer to the answers,” said Dr. Taurog. So far, the “new, improved” rats have helped Dr. Taurog’s group to further elucidate the HLA-B27 gene’s behavior as it is synthesized within cells. Their paper describing these results, as well as the new transgenic rat model, will be published in the journal *Arthritis and Rheumatism* in April.

Dr. Taurog says: “This new rat model really does seem to present a golden opportunity to make real progress in understanding the pathogenesis of AS; given sufficient funding, I don’t see any limit to what we can potentially learn from it.”

Members of Dr. Taurog’s laboratory who carried out this work include research associates Martha Dorris and Nimman Satumtira, and postdoctoral fellow Dr. Tri Tran. Other UT Southwestern scientists who participated were Dr. Robert Hammer, Professor of Biochemistry, whose laboratory produced all of the transgenic rat lines in the late 1980s and early 1990s; Dr. James Richardson, Professor of Pathology; and a collaborating postdoctoral fellow, Dr. Jie Shang.

my story

Natalie Rasmussen

Feb. 8, 2006

While most girls in my Gresham, Oregon junior high school in 1981 were thinking about grades, boys and their blossoming figures (maybe not in that order), I was dealing with something that looked like “sausage-digit” toes on both of my feet. I know now that this was a hallmark sign of the spondyloarthritis.

So here I was at the tender age of 12, and I was being evaluated for gout—an old person’s disease, I thought. And while that disorder was ruled out after lab tests came back, the doctor did find that I had scoliosis, an abnormal curvature of the spine.

Now my girlfriends were thinking about an upcoming 1950s-genre sock hop, and I found myself in a Milwaukee back brace, which keeps the spine virtually immobile. It held my head in alignment with metal bars, clear down to a plastic mold over my hips. I wore the brace for two years and the kids in my school would ask if I had been in a car wreck. Boys would flock to me—and they were cute—and ask if they could help me out and carry my books. I always said, “Sure, why not?”

I later started high school in new Nike tennis shoes and the awkward metal brace. And then when I was a sophomore, I developed a severe bowel inflammation episode with bloody diarrhea, which the doctor thought was bacterial dysentery. It was awful.

Antibiotics were prescribed for the so-called bacterial dysentery. About two weeks after the bowel symptoms appeared to have resolved, I developed painful swelling in my right knee. It was severe enough to require removal of an unusually large amount of synovial fluid. It also required a cortisone injection and two weeks on crutches to rest the joint. A few days after the right knee seemed to heal, the left knee swelled up. The same pattern continued for the next several years.

I’m afraid that the problems with the bowel and the knee arthritis continued intermittently for the next few years. A rheumatologist made the connection that the inflammatory problems were most likely related. I was given the diagnosis of “probable Reiter’s syndrome,” which is currently called reactive arthritis.

Now 20 years of age, while attending Oregon Health Sciences University School of Nursing, I developed iritis in my right eye. It was so severe that it needed daily cortisone injections for 10 days, eye drops and resting in complete darkness. My vision was in danger, I later learned. I am thankful I didn’t know it at the time.

My sight returned to its baseline after recovery from this bout of iritis. After the iritis incident, a diagnosis of Reiter’s syndrome was given in certainty by my treating rheumatologist. I was

also found positive for the HLA-B27 gene at this time when they were thinking, “Hmm... could there be a connection between the iritis and the knee inflammation?”

Four years later, at the age of 24, after years of having sacroiliac (SI) pain that made walking difficult, a pelvic X-ray was taken, which showed fusion in one of the SI joints. At that time, the rheumatologist changed the diagnosis from Reiter’s syndrome to a definitive ankylosing spondylitis.

I actually chose to major in nursing in college while undergoing all the various treatments. I had had nurses who were wonderfully compassionate. It made me think about trying to give back some comfort to others.

This was a very special period in my life, though, because I met my future husband, Eric, around the time I was diagnosed with AS. I was 19 years old and in nursing school. When I met him, he knew I was ill. I sadly told him, “I’ve just been given a bad diagnosis with a progressive disease.” He responded, “Well, we’ll get through it together.” He was crazy about me. I was a little scared about my future and I warned him that it might not be pretty. We would be married two years later, but I’m jumping ahead a bit.

My husband has been my support system during the 17 years we’ve been married. Looking back, two weeks before our wedding, I got a huge flare in my hip and I could not walk. Boy, did I cry. I said to my future husband, “I can’t walk down the aisle.” He said, “That’s all right; I’ll carry you if I have to.” He then got me in to the rheumatologist—something he has since done innumerable times. The doctor gave me a cortisone shot—and I did walk down the aisle and our honeymoon was delightful.

Despite having AS, I feel that I am truly blessed. I delivered two perfectly normal, healthy children. My children are Hannah, who is seven years of age and Sarah, who is four years of age; my dear family is my inspiration. I am presently 38 years old and I am so grateful to have been able to commence the anti-TNF therapy about one year ago. It has greatly reduced my pain and stiffness and it increases my energy level. I am hoping its continued use will allow me to preserve my joint function

The most important thing I have learned is to live one day at a time.

tells her story and shares her inspirations

and keep further damage from occurring. I will say that taking any medication has its risks, but in this case, for me, the benefits of this therapy far outweigh the risks.

I have learned so many things from having AS that it is difficult to think of all of them. The most important thing I have learned is to live one day at a time. I hate this disease; it really is inconvenient, and I would love to be healed; however, I would never trade some of the things I have learned from dealing with this disease. I have learned empathy and compassion. When I'm walking behind the elderly in the grocery store and they are moving at turtle speed, I truly understand. It's all right because on some days, I am not able to move very quickly, either.

The compassion I have learned helps me perform my job as a nurse. After working as a nurse in the hospital setting, I recently had to make a job change due to AS. I now work in a clinic setting. I provide medical advice by telephone. When I receive a call from a patient in pain, I immediately go to work as an advocate, and together with that patient's doctor, I try to help that patient get some relief.

On days that I have pain, I think about the things that I CAN do, simple things like enjoying time with family, friends, reading, watching a movie or taking a day trip to the beach. Getting outdoors is a wonderful mood lifter. It makes me happy to bring a friend their favorite chocolate bar or a gift card with a note about how special they are. Days that are too filled with pain, I have to push myself to think about what I need to do to get relief. I like to sing; I'm told I have a nice voice. I sing around the house and it's hard to focus on the pain when you're singing.

To help control pain, I think it is paramount to have a good relationship with a doctor or rheumatologist. By having a regular dosing schedule of medications, combined with other natural remedies, I can reduce my pain to comfortable levels most of the time. I personally get pain control by using my TENS* unit, of course, the anti-TNF, Glucosamine, fish oils, anti-inflammatory drugs and I exercise regularly at the gym (yes, there are days I can't make it), listening to music, singing, using muscle-rub creams, ice or heat, warm baths, distraction techniques (calling a friend), and having a sense of humor.

I ask myself at times, "What can I do to not focus on the pain? What can I do to make myself functional?" Then I remember how I feel when I am finished with a workout. I don't look at any declines in my abilities, either. I rejoice in the fact that I am able to lift 7.5 pounds on certain days and that I did the treadmill and the elliptical machine or went swimming. There's just no option here in my life. This is a MUST to go out the door. I want to contribute as fully and for as long as I can; I want to live life to the fullest and to finish well.

Natalie Rasmussen

Portland, OR.

* **TENS Unit:** This stands for "transcutaneous electrical nerve stimulation". It requires passing an electric current to nerve cells through electrodes placed on the skin.



goals & dreams:

I have learned to set **realistic goals** for myself while still **achieving my dreams**. When I was in nursing school, there was a physician I saw who tried to discourage me from becoming a nurse. She said that I would be "in a wheelchair by the time I was 40 years old" and that people would be taking care of me. My mother was sitting in the room with me when the doctor said these cruel words. She got up, tugged me by the arm, and we left," She said, "Come on, Natalie." My mom's a very strong woman who is a nurse herself. I am fortunate to be blessed with wonderful parents who promptly told me not to listen to that doctor's advice. They sat me down and said to me, "Well, no one but God knows the future. You just take school **one day at a time** and with God's help, **you can accomplish anything.**"



spondylitis and exercise

“Daily living means moving.”

Accidental Diagnosis

In an academic setting where ankylosing spondylitis was being taught some fifteen or twenty years ago, physical therapist Bruce Clark recalls that he was instructing third-year Canadian medical students on how to perform neck and back examinations.

“I was in a room with oh, maybe 12 people,” the SAA Medical and Scientific Advisory Board member recalled to Spondylitis Plus, “and they paired up to examine one another’s back like I had demonstrated. A short while later, one of the med students came over to me and announced with a furrowed brow, ‘Something is kind of funny here.’”

Clark said he went over to have a look at the student’s back for himself. “It was an exceedingly stiff back that was atypical for the young woman’s age.” He went on to question the 20-something coed about her morning stiffness, back pain, hips, knees and shoulders involvement, her family history— and every other possible question that could link her musculoskeletal status to ankylosing spondylitis. Eventually, a concerned Clark told the student that she should see her family doctor.

Later, when he was relating the story to a

colleague, Clark termed the accidental diagnostic encounter “ironic.” “Why would you think it was ironic?” the physician asked of Clark. “There are three million people in British Columbia and 15,000 of them with spondylitis.”

A “Leg Up” on Exercise Pays Off

This young woman’s unconventional but serendipitous diagnosis will nonetheless give her a “leg up” on an exercise program that is of utmost importance in the successful management of spondyloarthritis, an inflammation of the joints and structures around the spine.

“When patients are diagnosed early on in their disease process, they are usually more accepting of advice,” Clark says, quickly adding, “but not everyone embraces advice with enthusiasm, however, so we try not to be too dogmatic.”

Clark explained that many patients come to him who have never done stretching or taken part in

an exercise program in their lives and that it is his job to get them moving. “I tell them to aim for the top of the mountain, to aim for their goals.”

“Tonight I’m stepping lightly and I’m feeling no pain.”

BRUCE SPRINGSTEEN

Respecting pain

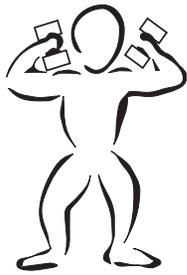
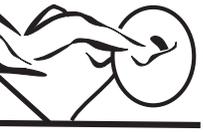
PAIN. What is it good for? We all know the answer to that. Absolutely nothing! All right, seriously, pain is the body’s smoke alarm. It fires a signal to the brain, alerting us to physical harm and letting us

know that something is wrong. Physiotherapist Bruce Clark wants to remind us that we need to respect pain.

Spondylitis Plus asked Clark, *“What if someone comes in and says, ‘I just can’t do this; it hurts too much?’”* Clark suggests, “If you do an exercise and it causes pain, you are probably doing too much or pushing too hard and you probably need to back off a little; start with a few reps and work up, but only as tolerated.”

“Exercise is done against one’s wishes and maintained only because the a

GEORGE SHEEHAN



g and that's important."

BRUCE CLARK, RPT



Bruce Clark, president of Clark Physical Therapy and Medical Liaison to the Ankylosing Spondylitis Association of British Columbia, Canada, spoke at the November 12, 2005 Spondylitis Educational Seminar held in San Diego. He enthusiastically explained the value of exercise to about 200 interested attendees made up of AS patients, their friends and families.

A remarkable feature of ankylosing spondylitis is that muscle stiffness often improves with physical activity. Some of the points the popular physiotherapist made at the seminar included:

Balance rest with activity: "Your disease isn't the same all the time; if you're in a 'flare-up' and you overdo it, that would tend to be aggravating."

Develop a schedule for your exercise regimen: "You need to develop a routine and once you develop that schedule, it just becomes second nature; you need to be exercising on a daily basis. Preparing for exercise, and warming up is always helpful on a firm surface."

Keep up with the range-of-motion exercises: "Range-of-motion exercises are light workouts that are not done with weights; however, you take the body part through the full range of motion. For instance, if you are backing your vehicle into a parking space and you cannot check your blind spot, you'd better be doing some exercises to improve your range of motion."

Recreational exercise is not a substitute for therapeutic exercise: "If you play golf—fine, enjoy golf. But if you've got spondylitis, you'd better be doing your range-of-motion exercises for your neck, mid-back, low back, hips and shoulders; on a regular basis; work on all involved joints. Recreational exercise is great, but it is not a substitute for a specific spondylitis program."

Invest in a good bed: "Your bed is terribly important. You spend one-third of your life in your bed. Live to the age of 90 and that's 30 years. Waterbeds are a liability. A firm surface and pillows will help to maintain good posture."

Good posture is of paramount importance: "You are also at work one-third of the day. For example, if you are a computer programmer and your monitor is too low and your head uncomfortably juts forward, you can get into bad postural situations. Think tall; use mirrors; let your family assist you with good-posture reminders. And if you notice someone is leaning toward 'roundness,' give them some assistance."

Refrain from "jarring" exercise activities: "Swimming is a wonderful activity; tennis is not so wonderful. In the early disease stages, jarring activities are more likely to aggravate your back. There is no point in taking medications to try to rein in the inflammation and then going out and engaging in recreational exercises that exacerbate the problem; that's like pouring water and gasoline on a fire at the same time."

Make good choices for yourself: "If you have a lot of stiffness, body contact sports are not a good idea. Keep yourselves from harm's way and preserve your ability to exercise. And always use common sense when choosing your activities."

Spondylitis Plus wants to know, "*So when a patient is in pain, exercise would most likely be the last thing on their mind, right?*" Clark does not disagree with this statement: "If someone comes in to see me who is in a great deal of pain, it could be realistic that they cannot exercise. They need to work with their rheumatologist first. Some people need stronger medications, but it's important to know that they can get control of their pain and then they can exercise."

Clark says: "Less pain means increased mobility for strengthening exercises. People can get control of pain and then they can exercise. We work collaboratively with the rheumatologists and we teach the patient to move; we instruct them and give them guidelines. Now, if they do a certain exercise and there is some transient discomfort, that's to be expected; it goes away. But if an exercise aggravates pain, then they have done too much."

Clark uses what is known as the "two-hour rule." "If there is moderate discomfort for no more than two hours, that's reasonable, but if the exercise really stirs up pain and makes the patient feel worse, then the exercise was too aggressive." Applying heat for pain is heartily endorsed by Clark, particularly warm baths that can include "everything from Epsom salts to rose petals, whatever makes them feel better."

Alternative is worse."

N, M.D. AND RUNNING ENTHUSIAST, 1918-1993

The Crisis in American Health Insurance:

The current crisis in health-care financing could be eliminated if the nation stops throwing good money after bad and refuses to pay for common medical treatments that simply don't work, according to a professor of medicine from the University of North Carolina

Dr. Nortin Hadler, professor of medicine and microbiology/immunology, attending rheumatologist at UNC Hospitals (and a member of the SAA MAB), has been a crusader for a novel approach to an insurance plan that takes advantage of a wealth of evidence to ensure that insurance premiums underwrite resources that clearly advantage the insured.

Surprisingly, many that qualify have nothing to do with the delivery of services by the health care establishment. Those "medical" interventions that have been shown to be only minimally effective – if at all – would no longer be covered automatically.

"The Institution of Medicine Has Lost its Way"

Dr. Hadler believes that insurance monies are not only being wasted, but that they are being misdirected. "I firmly believe," he tells Spondylitis Plus, "that it is the institution of medicine, and not the practitioners, that has lost its way. The system is ethically bankrupt and soon will be fiscally bankrupt."

Dr. Hadler's proposal would revamp employer health insurance plans into a system that aggressively promotes personal responsibility for good health while, just as aggressively, it would refuse to pay for a dizzyingly long list of protocols, procedures and pharmaceuticals.

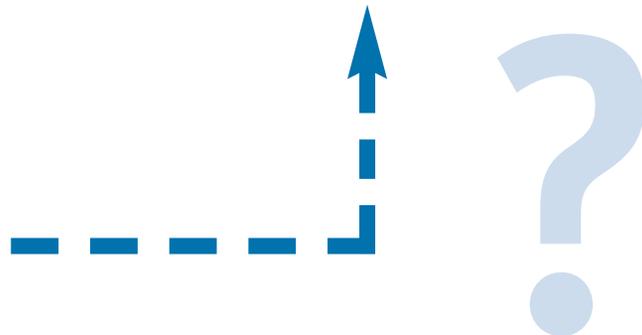
"It would free-up funds for the most critical aspects of health promotion, the wherewithal to seek out a place in society that nurtures the patient and their family," Dr. Hadler notes.

Under the Plan, Dr. Hadler points out that "monies not wasted on ineffective medical interventions would become available for socially valuable activities, such as job retraining, English as a Second Language (ESL), and childcare offered by licensed professionals in one's state."

Ineffective Services Would Be Cut

Based on compelling science in the form of multiple randomized controlled trials, Dr. Hadler's plan would not indemnify services such as cholesterol screening, mammography, prostate cancer screening—and even heart bypass operations.

Furthermore, Dr. Hadler is outspoken about unnecessary so-called medicalization, the tendency to consider natural predicaments of life a "diseases." Dr. Hadler says: "Nearly all backache, knee pain, heartache and headache and the like are intermittent and remittent predicaments of life, which call for empathy and invoke coping skills. If there's a role for medicine, it is for wise counsel, not pharmaceuticals or surgery—and aging is not a disease. For instance, the rationale for screening for and treating 'osteopenia' is as sound as the rationale for treating graying or pattern baldness."



Is there a rational solution?



Hard Outcomes

And Dr. Hadler sets a high bar for determining what works. He contends that a treatment for catastrophic disease should be considered effective only if it helps spare one in 20 patients. These outcomes are what medical statisticians refer to as a “hard outcome,” which means a major health crisis such as a heart attack, stroke, renal failure or even death.

Dr. Hadler applies a hard and critical evidentiary razor to many common health measures. “Cholesterol checks, prostate exams and other routine services pushed by primary care physicians,” he contends, “are not only expensive, but statistically they offer little in the way of keeping a person healthy.”

The “Hadler Plan”

The Hadler Plan turns health insurance on its head with a two-level program. The first stage, dubbed Plan A, gets the lion’s share of the money. It pays for steps to improve the individual’s standard of living, which Hadler and most sociologists see as a major determinant of health status.

“The secret to health and ... longevity is something about your socioeconomic status, job satisfaction, job security and the like,” Dr. Hadler says. “So Plan A offers the worker the possibility of health assurance in this context. The remaining 20 percent is in health-adverse behaviors, bad luck and disease; Plan B covers everything that’s effective in that context.”

Plans B’s coverage, however, is strictly limited. If the interventions have been studied and are found to be effective, then coverage is “full” without a co-payment by the patient. However, if the intervention has been studied and has been shown to be ineffective, it simply will not be covered.

For a “soft outcome,” such as feeling better, Dr. Hadler’s plan’s cutoff is that it must benefit at least one patient for every five patients treated; the patients will have no choices in this regard. There is a fiduciary responsibility built into the management and administration of the Plan.

“If it doesn’t work, it is simply worthless.”

Dr. Hadler, whose popular book “Last Well Person: How to Stay Well Despite the Health-Care System,” expands on his view of the health-care world, states, “If it doesn’t work, it is simply worthless.”

The Last Well Person: How to Stay Well Despite the Health-Care System. By Nortin Hadler. McGill-Queen’s University Press, 320 pages, \$29.95.

NEWS FROM THE SPONDYLITIS ASSOCIATION OF AMERICA

Are you interested

in reading the four premier brochures produced by SAA?

Do you want to learn

more about ankylosing spondylitis (AS) and related diseases?

Do you need information

on treatment, symptom management, proper exercise technique, the most recent research, or do you have other questions?

Our experts have provided high-quality, evidence-based information on AS and related conditions that will answer your questions.

SAA Members!

You are in for a treat since all four brochures can be downloaded directly to your computer from the “members” section of our website at www.spondylitis.org. No postage necessary. Paper copies of the brochures can be ordered through the website or by calling our toll free number 800 777 8189. The first copy is free.

Not a member? Join today!

By joining SAA, you become an integral part of a supportive community with the collective goal of focusing on stopping spondylitis through education, raising awareness—and research.

> MEMBERS CAN LOG IN

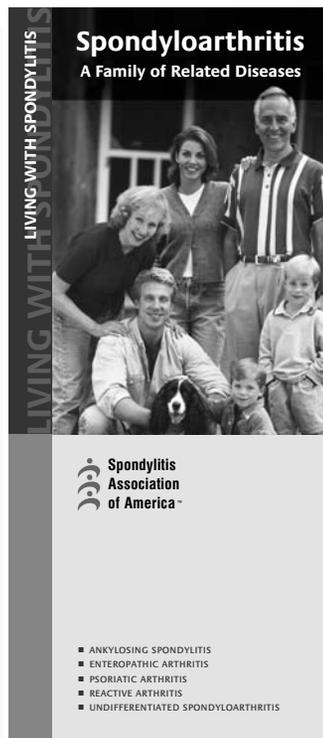
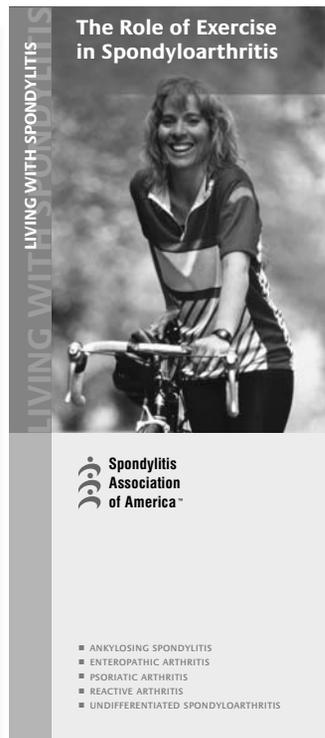
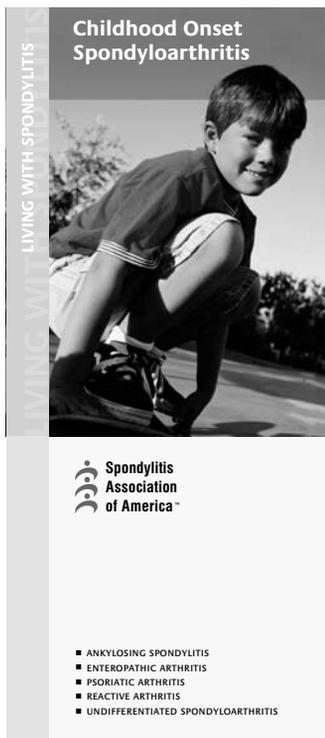
Once you’ve become a member of SAA, you can access our exclusive Member Area at Spondylitis.org by using your email address and zip code.

www.spondylitis.org

These brochures were funded by a generous educational grant from Amgen & Wyeth Pharmaceuticals.

“These booklets were invaluable to me when I needed to educate my extended family about my AS. They’ve practically worn out the pages thumbing through them whenever a question arises about AS.”

TODD MITCHELL, SAA MEMBER SINCE 1992



Childhood Onset Spondyloarthritis

When ankylosing spondylitis occurs before the age of 17, it is called Juvenile Ankylosing Spondylitis or JAS. This brochure covers the different forms of spondyloarthritis in children. Topics include symptoms, the difficulty of diagnosis in children, treatment, coping, and the future of treating Childhood Onset Spondyloarthritis.

The Role of Exercise in Spondyloarthritis

Exercise is an integral part of a spondylitis treatment regimen. This brochure covers why exercise is so important, contains diagrams of sample exercises, describes examples of possible exercises for spondylitis and more.

Spondyloarthritis: A Family of Related Diseases

This 16-page booklet provides a description of the symptoms and management of ankylosing spondylitis, reactive arthritis (Reiter's), psoriatic arthritis, spondylitis of inflammatory bowel, and undifferentiated spondyloarthropathy.

Iritis [Eye Inflammation in Spondyloarthritis]

Many people with spondylitis (spondyloarthritis) will experience inflammation of the eye at least once. Although eye inflammation takes many forms, it is commonly known as iritis or uveitis. Topics in this brochure include symptoms, diagnosis, treatment, possible complications, prognosis and the future of uveitis/iritis treatment.

***** *This month, all members of the American College of Rheumatology in North America, Mexico and Canada will receive sample copies of each brochure. You might wish to ask your rheumatologist for copies of the brochures that interest you.*

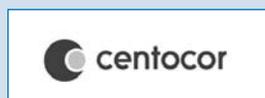
Corporate Partnership Program

During 2005, the following corporations provided significant funding to the Spondylitis Association of America. They are committed to partnering with us in our mission to be a leader in the quest to cure ankylosing spondylitis and related diseases and to empower those affected to live life to the fullest. Their support has made many of our research and education programs possible and we would like to take this opportunity to extend our heartfelt gratitude to our corporate partners.

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*Thank you
for your
support!*

A Walk in the Park: On Your Feet to Defeat AS

The SAA is holding its annual family fun walk on
Saturday, May 20, 2006
 at scenic Lake Balboa in Encino, CA from 8AM – 12PM.

Come out and enjoy the music, free food and prizes as we help raise funds in the fight against spondylitis.



If you can't attend, you can still play a valuable role by supporting one of our walk teams! To learn more, visit us online at www.spondylitis.org/walk

To participate, volunteer, or if you have questions, contact Alice Gluckman at (818) 981-1616 ext. 228 or email her at walk@spondylitis.org

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:

Glendale, AZ	John Kornfeind	(623) 937-1484	jmmkorn@cox.net
Long Beach, CA	Barbara Crofut	(562) 421-9698	crofutgr@netzero.net
Long Beach, CA	Frances Tomich	(562) 429-9685	
Los Angeles, CA	Janelle Haider	(713) 894-6472	janelle_haider@yahoo.com
Orange County, CA	Ms. Kyle Brownfield	(949) 367-0430	kylebrownfield@msn.com
San Diego, CA	Mike Supancich	(760) 438-2962	supancichsr@sbcglobal.net
San Francisco, CA	Clarence So	(415) 297-2803	clarence@clarenceso.com
Chicago, IL	Michelle DeLong	(773) 463-3256	chicagoas@mimiproductions.com
Fort Wayne, IN	Ken Prather	(260) 637-1705	pratherken@yahoo.com
Indianapolis, IN	Ken Prather	(260) 637-1705	pratherken@yahoo.com
Lawrence, KS	Karrie Shogren	(785) 832-8738	shogren@ku.edu
Boston, MA	Mitch Goldman	(617) 964-2811	grarch@comcast.net
Zeeland, MI	Scott May	(616) 786-9032	smay@wmis.net
Great Falls, MT	Jason Jones	(406) 761-1684	montjon66@hotmail.com
Cleveland, OH	Bryan Andresen	N/A	bnkandresen@adelphia.net
Portland, OR	Ken Henschel	(503) 579-8375	Ken.Henschel@comcast.net
Philadelphia, PA	Howard Tevelson	(215) 844-6075	hotbyht@yahoo.com
Myrtle Beach, SC	Alex Best	(843) 655-9762	alexbest@sccoast.net
Houston, TX	Richard Powell	(409) 883-7822	rwpowell@gt.rr.com
Washington DC	Roger Stead	(703) 455-6005	rogerstead@aol.com
Seattle, WA	Paul Stevenson	(206) 524-2186	pastev@Safeco.com

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

Online Poll

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

NEW POLL

Which physical/emotional aspect of spondylitis presents the biggest challenge to you?

- peripheral joint involvement
- muscle stiffness
- movement limitations
- side-effects of medication
- more than one of the above
- mood
- fatigue
- other
- pain

OLD POLL RESULTS

Have you informed your current employer about your spondylitis?

- Yes, I have45%
- No, I have not23%
- No, but I am currently considering doing so20 %
- No, and I do not think I ever will7%
- Yes, but not for years after diagnosis5%

Medical and Scientific Advisory Board

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about your own experiences with
ankylosing spondylitis and related diseases.



You can post your story on our
message boards, or you can
email your story to
Chris Miller at:

chris.miller@spondylitis.org

The Spondylitis Association
is planning an
AS and related diseases
educational forum
just for you
in Houston, TX,
Saturday, April 22, 2006

Additional information will
be available within 2 weeks
at spondylitis.org

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

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

Who is conducting the study?

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

How can I find out more?

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

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

Position Statement from SAA's Medical and Scientific Advisory Board on the COX-2 Inhibitors 9/10/2005

Celebrex, Arcoxia, and Vioxx are examples of a class of drug known as the COXIBS. It appears that all anti-inflammatory agents, COXIB and non-COXIB, may have the potential to increase the risk of heart attacks, heart failure, and strokes. Patients with past and/or current heart disease, and those at serious risk of heart disease (e.g., diabetics), should check with their physicians before continuing to take any of these medications.

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