Veteran Fights for Disability Benefits for Soldiers with Spondylitis

High School Senior Raises $1,420 in Honor of Twin Brother

The Job of Living Well: Occupational Therapy and Spondylitis
Today’s economic climate presents challenges for everyone, but it can be especially difficult for those affected by a chronic illness. Each of us -- to one degree or another -- has had to take a closer look at our own finances and make decisions about what is essential and what is not.

For that reason, I want to thank you, SAA’s loyal members and friends, for continuing to provide the funds the organization needs to remain the nation’s primary crusader in the fight against spondylitis. You took a hard look at what should be kept and what could be cut -- and put SAA in the “keep” pile.

Your ongoing support indicates that you recognize and value the work that SAA does on your behalf, and that being a partner in that work is something in which you take pride. We value your commitment; we, too, are committed.

We are committed to utilizing your hard-earned contributions in the most responsible and effective way possible. As the Executive Director of SAA, I must make ongoing assessments of the operational efficiency of the organization, and make adjustments when and where necessary.

SAA has always been “lean and mean”, and each day I seek to make it more so. I work with the SAA staff to ensure that the contraction ongoing in this economy does not require a contraction in the level of essential services we provide to you and the rest of the population we serve. This year there will be no decrease in the volume, variety and quality of the robust library of educational materials and interactive media programs we offer. There will be no reduction in the patient educational seminars, support groups, and physician education programs we offer; in fact, we are expanding those programs. We do not plan to see any reduction in the critical medical research that SAA drives.

SAA is able to do these things because of a successful and enduring partnership: our partnership with you. We at SAA—staff, board members and those in our wide network of tireless volunteers—are continuing our ongoing drive to find and implement new efficiencies in our operations and programs. Meanwhile, your continued support makes it all possible. Together we are winning.

These are challenging times, for you and for us. But, as we navigate this storm, we must never waver from our course. Those who need our services and support cannot wait for a better day; the disease we fight offers no such respite. We will continue to be ever more conscientious and effective stewards of the resources you provide. We will take advantage of every opportunity to advance our mutual cause. With your continued support, we will celebrate together the day that no one, ever again, will be limited by spondylitis.

Many thanks,

Laurie M. Savage
Executive Director
Heterotopic Ossification?
My father and I both have AS. My dad is 66 and has had AS most of his adult life. I am 38 and have had AS since my early 20s. My dad recently had total double knee replacement surgery. In one knee, he has developed Heterotopic Ossification. If my understanding is correct, this is when bone grows in the muscle tissue. It is relatively rare. I have learned that since he has AS he was at a greater risk. He is actually doing very well with the knee replacements but is frustrated by this complication. There is not much written about Heterotopic Ossification. We don’t know how to treat it. We do not know what to do and what not to do. Are there any resources out there that can help us with these decisions?

MARIA from Wilton, CT

Heterotopic Ossification (HO) is rare in the knee after total knee replacement surgery. It is simply overgrowth of bone in any area not normal. Often it is of significance only when it grows around a joint and either causes pain with motion or restricts motion. One higher risk group for developing this condition is in AS patients.

At this point, I would recommend that he not do anything about the HO as long as his knee range of motion and pain levels are acceptable. If they operate to remove the HO this could result in more aggressive overgrowth of bone and worse symptoms. I would only operate for pain or restricted range of motion. And like what should normally be done in this patient population with knee replacement surgery, they should have radiation to the knee immediately before or after surgery with a single dose of 700 rads. This will reduce incidence and degree of HO.

Editor’s Note: Thanks to Brian Perri, DO, an orthopaedic spine surgeon with Cedars-Sinai Institute for Spinal Disorders, for his response.

A Tip for Those Applying for SSA
My story is very typical. I’m 61 and have had AS since I was 19. It took 16 years to diagnose. My spine is fused and I have joint involvement all the way to my fingers and toes. I accepted disability from the Social Security Administration (SSA) in 2001. To those of you who are just beginning your relationship with AS may I make two suggestions. Sign up for a waiver of premiums, if possible, on your insurance. Secondly, keep a record of dates when you have ‘flare ups’, the symptoms, the doctor(s) prognoses, any medications suggested and the result. Early on I suspected my problems might be serious. Eventually, my anecdotal history wound up being rather lengthy (four pages single spaced) and was extremely useful when I finally applied, (my ‘Rheumy’s’ emphatic suggestion), to the SSA.

J.E. SCHIAFFINO

Editor’s Note: Thank you, J.E., for the informative advice regarding the Social Security Administration and disability benefits.
Advocating for Change: 
Veteran Fights for Disability Benefits for Soldiers with Spondylitis

by Scott P. Edwards | January 2009

Mike Parker never really planned to become such a staunch advocate for soldiers fighting for disability benefits. But then, in 1998, when he was a major in the Army, Parker was diagnosed with reactive arthritis, which is one of the spondyloarthropathies. Six years later, his journey with the military medical retirement system began.

After forays into medical evaluation boards, physical evaluation boards, pre-existing conditions, and disability percentage ratings, Parker found a system so confusing and so broken he decided to take action. Because he served in the military for more than 20 years, Parker was lucky. He was able to retire from the military with a pension and lifelong health benefits. Others—including those with ankylosing spondylitis, which can be aggravated by the strenuous activity often encountered by military personnel—were not so fortunate.

“I started posting questions and concerns and opinions on various blogs,” he told National Public Radio’s “All Things Considered” in 2007, “and it just sort of mushroomed from there.”

According to NPR, Parker began examining reams of Pentagon data and found, much to his surprise, that fewer veterans were being given disability benefits than before the Iraq war began. “It’s counterintuitive,” he said. “Why is the number of disability retirees shrinking during wartime?”

Parker brought the issues to the attention of the Military Times in 2006. A subsequent investigation by the newspaper found systemic problems in how injured troops from each branch of the service were receiving different disability retirement ratings for the same injuries or were being told they didn’t qualify for benefits because their condition pre-existed their military service.

In addition, Parker started a message board on the Spondylitis Association of America’s website (www.spondylitis.org) about the physical and medical evaluation board process and the disability rating system. Through the message board, he has helped nearly a dozen service members with their cases.

Unfamiliarity with disease leads to ratings confusion

The medical evaluation process can not only be confusing, but also long. The first step is a physician’s diagnosis of the injury or illness, which initiates the Medical Evaluation Board, or MEB, process. During this phase, at least two doctors examine the patient’s records and determine if the soldier can return to duty. If the doctors determine that the soldier is able to return to duty, the soldier returns to duty and the process ends. If the soldier cannot return to duty, the doctors’ evaluation is forwarded to the Physical Evaluation Board (PEB), which looks at the evidence and determines if the soldier is fit or unfit for duty. During the PEB evaluation, the soldier selects a counselor, either from the military or the
The soldier returns to duty if deemed fit; if not, the PEB assigns a disability rating based on factors specific to the disease or injury.

If the soldier’s disability rating is at least 30 percent, medical benefits and the same percentage of base pay are provided for life. If lower than 30 percent, the soldier receives a one-time severance payment and no other benefits.

“What drives the [ratings] problem,” says Parker, “is that a rating above 30 percent gets a soldier disability retirement. If rated less than 30 percent, they are separated without disability retirement and given a one-time severance. The first, obviously, is much better because it carries benefits such as retirement pay, health care, and PX [a commissary on a United States Army post] privileges.”

Ruling an illness or injury as a pre-existing condition is just as big an issue as inaccurate ratings. A soldier whose condition is ruled to pre-exist military service also can be denied retirement and disability benefits.

Both the Department of Veterans Affairs (VA) and the Department of Defense (DOD) are required to use the VA Schedule for Rating Disabilities, or VARSD, to determine compensation for veterans who experience injury or illness as a result of their military service. Parker says VARSD is a “cookbook for disability. You look up disease criteria and base the disability rating on those criteria.”

Since its inception in 1945, VARSD has been in a continual state of revision, with a body system reviewed every year. Many parts of VARSD, however, remain unchanged despite these reviews. Ratings, which are based in increments of 10, range from 0 percent to 100 percent. The scale is divided into 14 body systems, using nearly 700 codes to describe illness or injury symptoms and their level of severity. This system is different from those used by other governmental agencies, private-sector disability plans, and healthcare providers.

For soldiers with AS, the VARSD rating scale is a problem: it doesn’t have AS listed as a specific condition. Rather, it is generically lumped with other forms of spondylitis in a broad category called “other forms of arthritis.” It is supposed to be rated using the same criteria used for rheumatoid arthritis, says Parker. These criteria are well suited for these conditions, as they cover both active disease process and the impact of residual damage when the disease is not active.

“The VA has the documentation to explain the disease and how to rate it,” says Parker, “but that information isn’t in the hands of the raters at the VA and DOD. Most raters are not familiar with AS and will rate it for residual damage to the spine rather than an active disease process and residual damage in other areas of the body. More than once I have heard raters state that AS is a disease that only affects the spine.”

Parker says DOD, and specifically the Army, refuses to rate AS by VARSD criteria, in particular diagnostic code 5002, which covers the active disease process. In 2003, diagnostic code 5240 (residual damage to the spine from AS) was added. Many raters, says Parker, in particular DOD, mistakenly believe that the introduction of 5240 eliminated the requirement to evaluate and rate AS under the active disease process using code 5002.

Poster children for ratings issues

Parker calls Spc. Linwood Hoffman the “poster child” of the disability rating issue. Before the VA added residual damage to the rating criteria, Hoffman, who has AS, was evaluated by the PEB and given a 40 percent rating, based on active disease manifestations. There were days when he could not even get out of bed. He was told that he would receive temporary retirement benefits and be re-evaluated every 18 months up to a five-year period before his final disability rating was determined. In September 2003, when the VA came out with diagnostic code 5240, the Army and DOD decided “unilaterally,” says Parker, that they could no longer use the disability rating criteria from code 5002.

In 2005, Hoffman was re-evaluated only under diagnostic code 5240 and rated at 20 percent. The Army took away his retirement benefits and paid him a one-time severance. His VA raters also assigned him a 20 percent rating by making the same mistake as the Army, says Parker.

“The medical evaluation process can not only be confusing, but also long.”
Capt. James Wollman served in the Army for just shy of eight years, from March 1998 to February 2006. Wollman suffered exercise-related back pain during ROTC training in the early 1990s. He was thoroughly evaluated by both a civilian rheumatologist and a military physician. They diagnosed him with exercise intolerance and cleared him for active duty, combat arms, and ranger/airborne training. In 2001, after Wollman presented again with back pain, the PEB ruled that the pain was not related to spondylitis, a finding that was repeated on a subsequent evaluation. His SED rate (a blood test that can determine inflammatory activity in the body) was normal, he had no inflammatory markers, and all AS-specific tests were negative. In 2003, Wollman was deployed to Iraq.

“I had a lot of back pain before going, but it was a lot worse after I got to Iraq,” says Wollman. His symptoms were atypical for AS. His pain started in his hip instead of his lower back, and the pain surfaced when he exercised, but subsided with rest.

While on tour in Iraq, his condition dramatically worsened and he was moved from his position as a field artillery officer to a desk job. Soon after coming back from Iraq, the MEB declared that Wollman’s condition pre-existed his military service because, it believed, he had a waiver to enter active duty with ankylosing spondylitis. The PEB used the alleged waiver as evidence that Wollman’s pain came from pre-existing AS, which means he could not be medically retired from the military and receive benefits. In fact, he never received a waiver, but instead was specifically examined for AS, deemed free of the disease, and declared fit for duty by a military doctor.

“Whether my AS started before or after Iraq, I can’t say,” says Wollman. “It always goes back to some environmental trigger. The leading trigger is often an intestinal disease from a bad living environment. Iraq is the perfect place for this.”

A Navy study determined that 20 percent of service members tested in Iraq had Shigella bacteria in their system. Shigella is a leading form of bacteria known to trigger reactive arthritis and produce the same gastrointestinal symptoms that Capt. Wollman frequently suffered while in Iraq.

“The Army ignored the high standards for declaring that a condition pre-existed service. They didn’t even attempt to meet this standard. All they did was to turn a blind eye to the medical facts in Capt. Wollman’s case,” says Parker. “Aggravation of a medical condition is also compensable, but the Army said military service did not aggravate his condition, despite the fact that they offered no evidence to support their position as required.”

Capt. Wollman was found unfit for duty and processed out of the service. His case against the Army is currently in federal court. His case with the VA is also in the appeals process.

Working the issue
There was some immediate good that came out of Spc. Hoffman’s and Capt. Wollman’s cases. Parker took the documentation from those cases to a Congressional staffer and pointed out that the Army refused to address the issues raised by soldiers during their board reviews and appeals. The staff member shepherded legislation that now requires issues brought up to be addressed in board decisions. While the PEBs and appeals boards are still not doing this in a consistent manner, says Parker, it does give the soldiers better footing to challenge bad decisions in federal court.

Mike Parker continues working the disability rating issue, and his work is paying off. Congress has passed legislation that addresses inconsistencies in how the VA and DOD rate disabilities. In April 2008, the House added language into the 2008 defense authorization bill to help expedite soldiers’ claims and bring some consistency to how the VA and DOD rate similar medical conditions. Congress also established a new board that will review cases since 9/11 that have resulted in ratings of less than 30 percent.

“Congress has seen the shenanigans of military disability ratings,” says Parker, “and they are taking action.”

The Spondylitis Association of America is very grateful to Mike Parker, Lieutenant Colonel, United States Army (Retired) for his service and for his dedication to helping his fellow service people in their efforts to obtain benefits that they have earned.

Visit the “Military & Veterans Message Board” at SAA’s website. Go to:
http://forums.spondylitis.org/
Join the discussion!
It hurt to pick up a pencil, walk to class and even get out of bed.

Ross Kirkbaumer was in pain and his twin sister, Blair, wanted to help, but didn’t know how.

“There wasn’t anything I could do,” said Blair Kirkbaumer, a senior at Santa Margarita Catholic High School (SMCHS). “I felt helpless. I just wanted Ross to feel better.”

Ross Kirkbaumer, 17 also a senior at SMCHS, has ankylosing spondylitis. After years battling the pain, countless unsuccessful visits to doctors and being told it was “just growing pains,” Ross is now living nearly pain free thanks to a great doctor, medication and being active on SMCHS’ swimming and water polo teams, he says.

And his sister, Blair, is on a mission to raise awareness about a disease that is under recognized.

Blair, a passionate photographer, is using her artistic talents to raise money for the Spondylitis Association of America. Blair created CardsthatCare.net. The website sells greeting cards made by Blair, which feature her photography. All proceeds from the card sales go to SAA. The cards sell for $10 for a package of three.

Family and friends helped spread the word about the charitable cause, helping Blair to raise $1,420 for the SAA, a leader in finding a cure for AS and empowering those affected. On Dec. 18, SAA Executive Director Laurie Savage visited Santa Margarita Catholic High School where Blair presented Savage with a $1,420 check.

“We are so grateful Blair has taken on this wonderful cause,” Savage said. “It’s a great example of what one person can do.”

During Savage’s visit Blair Kirkbaumer was presented with a “Dunne Good” award from Principal Ray Dunne.

For Blair, the project is a way to make a difference in the fight against AS, a disease that often left her feeling helpless as she watched her brother struggle with the pain associated with it.

“I never knew what I could do to help him,” Blair said. “Now that he’s better I just want to help spread the word about this disease.”

“I hope to raise as much money as I can,” she said. “But more importantly I want to raise awareness about a disease that can be difficult to diagnose.”

There are at least half a million people with AS in the United States but likely more because the disease is under-recognized. AS is more prevalent than multiple sclerosis, cystic fibrosis and Lou Gehrig’s disease combined.

“Until recently it was believed to be rare,” Savage said. “But it is not as rare as people think.”

The Spondylitis Association is developing an awareness program for primary care physicians so doctors can better recognize the disease and send those affected to the appropriate specialist.

It took years of visits to various doctors before Ross was diagnosed in the eighth grade.

Not knowing what caused the severe pain he endured was the worst part, he said.

Ross had to give up sports, suffered sleepless nights and some days the pain was so intense he couldn’t get out of bed.

“I felt like a really old person in a young person’s body,” he said. “It hurt to even walk. I began to feel like an outcast because I couldn’t do anything.”

In eighth grade, when Ross was diagnosed with AS, it was both a relief and frustrating that one doctor could figure out in a visit what had caused him years of pain.

Ross hopes that through his sister’s project the word can get out about AS and its prevalence.

“I want people to know there is hope,” he said. “You don’t have to live in pain.”

High School Senior Raises $1,420 in Honor of Twin Brother

Spondylitis Plus cover floral photography by Blair Kirkbaumer

www.spondylitis.org
Many people consider the period from Thanksgiving through the end of the year to be the “season of giving” -- the time when they pledge their support to the causes that are closest to their hearts. In fact, many nonprofits receive up to half of their annual donations during the final weeks of the year. We are always grateful to those generous supporters who make year-end gifts to advance SAA’s mission.

But the fight against spondylitis is continuous and ongoing -- a fight we must wage each and every day, with no breaks allowed. SAA’s research, educational and advocacy programs are every bit as important in August as they are in December.

The Spondylitis Monthly Automatic Rewards Team (SMART) is made up of loyal SAA supporters who make monthly gifts to support the day-to-day battle against spondylitis. By designating regular donations, SMART Givers provide dependable funding for groundbreaking genetic research, critical educational programs and the awareness and advocacy initiatives that change people’s lives for the better.

As a SMART Giver, you’ll continue to receive all the benefits of SAA membership plus:

- Special updates about the research findings and treatment advances that your gifts have made possible
- Fewer Solicitations -- because we can rely on your monthly contributions, the amount of mail you receive from us will be limited
- Annual Summary Statement -- in January of each year you will receive a consolidated statement of your SMART gifts.

You can sign up using SAA’s secure server at www.spondylitis.org/smart or by contacting Helene Hart at (800) 877-7179 or hhart@spondylitis.org.

To sign up by mail, complete the following registration form and return it in the envelope provided or fax it to 818-981-9826.

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I would like to make a monthly gift to the Spondylitis Association of America:

- [ ] $100 monthly ($3.33/day)
- [ ] $60 monthly ($2/day)
- [ ] $30 monthly ($1/day)
- [ ] $15 monthly (50¢/day)
- [ ] Other $ __________________ (Minimum $5 per month)

This payment will repeat on a monthly basis. You may cancel at any time.

Please charge my monthly gift to my:

- [ ] Visa
- [ ] MasterCard
- [ ] American Express

Card #______________________________________ Exp.________________________
Signature:__________________________________________________________________________
A Personal Financial Affairs Record - Do you have one?

In the hurried pace we live today, we rarely find time to organize our personal information, to write down where important documents may be found, to arrange for duplicates, or to sit down with our loved ones to let them know exactly where we are both personally and financially. One of the most important records you can have is a record of your essential personal financial and legal information. Here are a few reasons why this information is so important.

✓ You will have peace of mind knowing that your personal financial and legal information is well documented and easily accessible to you, your spouse, children or relatives in the event that it is needed as result of fire, flood, earthquake, serious illness or death.

✓ Your personal record provides important information that will prove helpful to you or your family as you attempt to reconstruct records, file insurance claims or settle an estate. Important papers such as titles, certificates, trust agreements, your will and the contents of your safe deposit box can be located easily.

✓ Documenting your personal financial affairs will serve as the basis for creating your estate plan for the future well-being of your family and the causes you care most about. It should prompt you to prepare a valid will, if you don’t already have one, so that your wishes will be respected and your property will pass smoothly and quickly to those you have designated.

✓ Even more important than your financial affairs, is a will, which provides for the care of your minor children. In the event that something happens to both parents, do you want the care of your children left to a vote of family members or the decision of a judge who does not know you or your children at all? If you currently have a will, it will prompt you to review it to see if any circumstances have changed and whether or not you may need to update it. A failure to plan for the care of your children and/or the transfer of your assets can cause confusion and frustration for your family members, plus it could result in increased expenses and estate taxes, which must be paid by your estate.

✓ Your records will also serve as a basis from which to determine what your estate taxes would be under various plans of distribution. Knowing the assets and the values to be considered will help you and your advisors find ways to minimize estate taxes and identify liquid assets to cover estate settlement family expenses.

You owe it to yourself and your family to complete your personal affairs record. Because we feel it is so important, SAA is offering a free pamphlet, A Personal Financial Affairs Record, which will help you to document your essential financial and legal information in a convenient and effective way. You need simply to check the box requesting A Personal Financial Affairs Record booklet on the return envelope enclosed or contact Susan Jones, at 800-777-8189, ext 231 or susan.jones@spondylitis.org to get your free copy.
Occupational therapists spend their days incorporating meaningful and purposeful “occupation” to enable people with limitations and impairments, including spondylitis, to participate in everyday life. In essence, they give people the skills necessary for the “job of living.”

At a recent Spondylitis Association of America educational seminar in Dallas, Regina Campbell, MS, OTR, FAOTA, an associate professor at the Texas Woman’s University School of Occupational Therapy, spoke to a packed house filled with people with spondylitis and accompanying family and friends about how occupational therapy can help spondylitis patients live life to its fullest.

“One of the hardest parts [about being an occupational therapist],” said Campbell, “is explaining what we mean by ‘occupation.’ An occupation, to an occupational therapist, is more than work for remuneration. Occupational therapists believe that health is supported through engagement in occupation. “Everything you want to do; everything you need to do in a day is your occupation.”

Campbell told the audience that a job is, most certainly, an occupation, but so too are social participation, rest, leisure and play, and activities of daily living such as grooming, eating and shopping. Titled “Occupational Therapy Skills for the Job of Living Well with Spondylitis,” Campbell’s presentation focused on three components:

- Gaining an appreciation of the power of engagement in occupation in supporting health and participation.
- Appreciating how the pain, inflammation and fatigue associated with spondylitis can impact health and participation.
- Increasing awareness of the management strategies, services and resources used by occupational therapists to maximize capacities to sustain the skills needed for the “job of living well.”

Power of Engagement In Occupation
Since the early parts of the 20th century, viewing health in the context of performance has been one of the hallmarks of occupational therapy. In an address to the National Society for the Promotion of Occupational Therapy in 1921, noted neurologist and psychiatrist Adolph Meyer—now considered the “father” of occupational therapy—proposed that engagement in occupations provided individuals with a sense of self-esteem and health. Occupational therapy’s concern for the individual’s quality of life, he said, suggests that a relationship exists between life satisfaction and the ability to perform daily occupations.

Today, occupational scientists seek a better understanding of how occupation can support health and the performance of everyday actions. Campbell introduced two primary models that serve to direct occupational therapy practice, the International Classification of Functioning, Disability and Health, or ICF; and the Person-Environment-Occupation-Performance model.
The International Classification of Function was developed by the World Health Organization to shift the focus from illness and disability to health and participation, at both the individual and population levels. The ICF directs attention beyond disease to include an understanding of how activity and environment can support or hinder health and participation. According to the WHO, “the picture produced by this combination of factors is of ‘the person in his or her world.’”

Occupational therapist scholars Charles Christiansen and Carolyn Baum, proposed the Person-Environment-Occupation-Performance (PEOP) model to enable health, function and well-being. In the clinical setting, occupational therapists use the ICF and PEOP to guide functional status assessments, goal setting, treatment planning and monitoring, and outcome measurements.

The goal for occupational therapy intervention, according to Campbell, is directed toward finding a “goodness of fit” between the person’s capacities, demands of the activity/occupation and the environment that promotes health. A client centered approach is used to understand the interaction between impairments, such as pain, activity, and environment in order to support participation, achieve a greater state of health, and reduce the risk of secondary injury and disability.

**Pain is personal, complex**

According to the International Association for the Study of Pain, pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage.” Unfortunately, for AS patients, it is also a way of life. Along with body temperature, pulse, blood pressure, and respiratory rate, clinicians now consider pain to be the fifth vital sign. Unlike the others, however, pain often cannot be described as a number.

“Pain is personal,” said Campbell. “Pain is complex, and not all pain is the same.”

Campbell spoke about the four primary components of pain. Transduction is the pain source, a sensory input that registers in a certain part of the body.” Transmission is the movement of pain messages through the peripheral nerves and up the spinal cord to the brain. Campbell calls this the “ouch phenomenon, where the mind and the body connect. Perception is the brain’s interpretation of these messages as pain, including its location, intensity and nature (such as burning, aching or stinging). Modulation is the process by which the brain sends pain-suppressing chemicals to the pain source and triggers other responses.

Pain, says Campbell, is much more than just tissues damage; it’s a biological, chemical, neurological, behavioral and environmental response that connects the body to the brain and back again.

**Skills for the Job of Living Well**

Believing one can modulate the pain experience by changing behaviors, habits and routines is yet another step toward achieving health and well-being. Important to achieving a greater state of health is an increased awareness of one’s capacities, which includes posture, flexibility, strength, endurance, reflexes, balance and respiration, and how all are interrelated.

“Occupational therapists look at body mechanics,” added Campbell, “for ways to improve capacity and reduce the risk for secondary injuries.”

Changing positions frequently can help improve capacity. Sit down. Stand up. Move around. These help with balance, posture and range of motion, and help make the body work more efficiently.

Breathing exercises, which are often prescribed for AS patients, are important because they affect capacity—not only respiration but also posture, flexibility, strength and endurance.

“Everything you want to do; everything you have to do; everything you need to do in a day is your occupation.”

~ Regina M. Campbell, MS, OTR, FAOTA

www.spondylitis.org
IN FOCUS: OCCUPATIONAL THERAPY

A strategy often used in occupational therapy is ergonomics—what Campbell called the “twenty-first century word for biomechanics.” Ergonomics is the scientific discipline concerned with design according to human needs in order to optimize well-being and improve performance. It includes changing things such as desk heights; the location of furniture, equipment and supplies; altering the way the body is positioned while doing an activity; and using adaptive equipment for certain tasks. Most often thought of in terms of the work environment, ergonomics can also be applied in the home in terms of lighting, floor surfaces, and furniture placement, as well as grab bars in the bathroom and adaptive equipment in the kitchen.

In today’s real estate market, many people are unwilling to make ergonomic modifications to their homes, because if they make changes that fit them, they might not necessarily fit someone else. One way around this, Campbell said, is through universal design, which is a way to design an environment to enhance everyone’s performance. For example, use step-less entries rather than ramps.

“Good ergonomic design,” said Campbell, “helps individuals manage risks, manage stress, and conserve energy.”

Besides changes in the environment, Campbell provided strategies for altering roles and routines that form occupational performance patterns. Skills for the job of living well and safe include being “mindful” of your symptoms and how activity and environment can affect health and safety.

Rest and sleep are ‘most valuable’

Fatigue is a common complaint among people with spondylitis. In fact, nearly two thirds of spondylitis patients describe fatigue as a major problem. Fatigue is more associated with active disease in terms of pain, stiffness, poor functional ability, and lower quality of life. It can also impact general well-being and mental health. Regular physical activity, as well as rest and regular sleep habits, can help alleviate fatigue.


She said that planned rest periods are essential for people with spondylitis, even if they’re not fatigued. “Rest. Really rest,” she said. “That doesn’t mean putting your feet up and thinking about all the things that you’re not getting done. That’s not resting. When resting, you need to be mindless. You really need to empty the mind. . . .”

Adequate sleep is also essential. It is, said Campbell, something that is important to occupational therapists, who work with patients on their habits, and patterns, and that includes sleep. “We have habits of sleep,” she said. “I think they get programmed in and when you try to change one little thing about how somebody sleeps, you realize that that’s a major change. This takes a real customized approach, but it can be done—and it’s important.”

Sleep aides such as custom pillows, body positioning, and sleep routines are important for ensuring that spondylitis patients get a good night’s sleep.

Conserve Energy to Promote Health

In addition to planned rest periods and adequate sleep, occupational therapists help guide patients with a variety of energy conservation principles. These include adjusting priorities, using adaptive equipment and energy-saving devices, ergonomics, and delegating activities to others.

“Energy is probably the most valuable thing that you have,” said Campbell. “If you really look at it, pain influences energy, inflammation influences energy, so you want to look at energy conservation strategies.”

Adjusting and simplifying activities and reducing standards can all help to conserve energy. Organizing work areas and delegating tasks can also create efficiencies that save energy.

“There might not be a lot you can do about your disease process,” said Campbell, “but there is a lot you can control about your activity. How do you do the activity? How do you sit? How do you carry things?”

She stressed the importance of a client centered whole healthcare team approach to evaluation and treatment, because “no one profession, no one person” can help persons with spondylitis manage all aspects of the disease. Upon receiving a physician referral, the occupational therapist will work with other members of the health care professionals to customize an intervention plan to meet individual needs. Education is an important part of the intervention plan. People with spondylitis must understand what is going on in their bodies—physiologically, neurologically, psychologically and biologically, said Campbell, in order to establish a “take charge attitude” needed to manage chronic conditions such as spondylitis.

In closing, Campbell told the audience to “lighten your heart” with humor and live life to the fullest by being positive and focusing on their abilities.

“As an occupational therapist,” she said, “I want to focus on your abilities, not your disabilities. I want to focus in on what strengths you have to maximize those strengths and capacities.”

That, she said, is the “job of living well.”

Listen to an interview with Ms. Campbell in our December 2008 podcast!
spondylitis.org/podcast
**Ankylosing Spondylitis and Gum (Periodontal) Disease**

**Authors:** Jon C Tilburt et al.

A study published in the January 2009 issue of the *Annals of Rheumatic Diseases* examined ankylosing spondylitis patients’ risk of periodontal (gum) disease.

Perio.org describes periodontitis as follows: “Untreated gingivitis can advance to periodontitis. With time, plaque can spread and grow below the gum line. Toxins produced by the bacteria in plaque irritate the gums. The toxins stimulate a chronic inflammatory response in which the body in essence turns on itself, and the tissues and bone that support the teeth are broken down and destroyed.”

The study concludes that “AS patients have a significantly higher risk of PD [periodontal disease], strongly suggesting the need of a close collaboration between rheumatologists, periodontists and dental hygienists when treating AS patients.”

*BMJ 2008;337:a1938*

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**Ankylosing spondylitis (AS) and the risk of fracture: results from a large primary care case control study**

**Authors:** Vose D et al.

A recent study published in the medical journal entitled *Annals of Rheumatic Diseases* sought to determine whether or not the bone loss that is observed in many people with AS results in increased vertebrae and non-vertebrae bone fracture.

The researchers were able to make several observations from the results of the study which included 758 AS patients. They found that people with AS have an increased risk of spinal fracture but not of other types of fracture. They also observed that patients with AS, who also have a history of inflammatory bowel disease, have an increase in any type of bone fracture. The researchers further concluded that an intake of non steroidal anti-inflammatory medications seemed to reduce the risk of fracture. Further studies were deemed necessary to further explore this last finding.

*Ann Rheum Diseases Published Online First 9 December, 2008*
The actions of our government have an enormous impact on the lives of every American citizen - but each and every one of us can make a difference. If more voters support an issue, more pressure is placed on legislators to act on their behalf. Therefore, a mobilized group of like-minded individuals and organizations can have a profound impact on enacting important legislation. With this in mind, SAA is building a grassroots advocacy team made up of SAA Members — people who have already demonstrated a commitment to raising awareness and empowering the lives of people in the spondylitis community.

Why should you get involved?

- You can raise awareness about spondylitis. Most people (including legislators and their staff) do not have a basic understanding of spondylitis — or the issues affecting those living with this painful chronic condition. Let’s change that.

- You are the best spokesperson to address issues related to living with spondylitis — to let people know how it impacts your life, whether it be the prohibitive cost of prescriptions, inadequate funding for spondylitis research, or genetic discrimination. Let your voice be heard.

- Legislators serve the people in their communities and want to hear from their constituents about the issues that are important to them. Let them know what issues you want them to support.

How can you get involved? There are a few simple things you can do today:

1) First, join SAA’s Legislative Action Center. Signing up takes just a few minutes. SAA will alert you to take action when an important piece of legislation comes up. Visit http://capwiz.com/spondylitis/home to sign up.

2) Subscribe to your legislators’ newsletters. These newsletters will keep you informed about your elected officials’ legislative priorities and upcoming town hall meetings. SAA’s Legislative Action Center can connect you directly to your representatives’ websites.

3) Respond to SAA’s emailed Legislative Action Alerts by personalizing the provided sample letter or sending it as is. You can email, print and mail or fax the letter to elected officials.

4) Forward SAA’s Legislative Action Alerts to your family members and friends and encourage them to take action.

5) Attend town hall meetings and express your concerns about legislation that affects those living with spondylitis.

6) Visit your legislators or their staff at one of the state or district offices and discuss issues related to living with spondylitis (e.g. access to prescriptions and health insurance, money for research related activities). SAA can provide talking points and fact sheets for the visits, if requested.

Visit http://capwiz.com/spondylitis/home today to learn about legislation SAA is currently supporting. You can help make a positive difference by becoming a member of SAA’s grassroots advocacy team today!
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: elin.aslanyan@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

www.spondylitis.org
MEMBERS: Check Out SAA’s Podcasts at spondylitis.org/podcast!

Listen to INTERVIEWS WITH DOCTORS ONLINE! Pre-recorded Q&A and presentations from experts in our monthly podcasts!

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- An interview with occupational therapist Regina Campbell, MS, OTR, FAOTA;
- A presentation from clinical psychologist Deborah Garnett, PhD;
- A member Q&A Session with rheumatologist Atul Deodhar, MD;
- An interview with rheumatologist James Rosenbaum, MD
- A member Q&A Session with rheumatologist David Hallegua, MD;
- An interview with rheumatologist and AS patient Muhammad Asim Khan, MD.

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