Spondylitis PLUS
winter 2009

Spondyloarthritis & Surgery: Advance Planning is Key to an Optimum Post-surgical Outcome

Health during the Holidays: An Interview with Occupational Therapist Regina Campbell

National and Regional Pharmacies Offer Low-Cost Substitutes for Spondylitis Medications
ON POINT

The field of spondyloarthritis (SpA) has seen tremendous progress during the past decade with regard to new treatments, earlier diagnosis, improved imaging technology and a better definition of outcomes measures in clinical trials.

This progress was evident during the SpA sessions at the recent Scientific Meeting of the American College of Rheumatology (ACR) in Philadelphia. During one general session, several thousand people crowded into the auditorium to hear about advances in SpA and about the different theories regarding inflammation, new bone formation and potential triggers such as biomechanical issues which have been written about in this news magazine in recent months.

To mark the 75th anniversary of ACR, during the opening session on Sunday night, we were taken on “a historical journey” through the advances in arthritis medicine during the past two centuries which served to reinforce just how far we’ve come and why the work must continue unabated.

With more than 600 lectures, poster sessions and symposia in rheumatology to choose from, clinicians, researchers and healthcare professionals attending the conference sometimes had difficulty making a selection.

There was much discussion regarding TNF blockers. So far, studies indicate that the concerns about potentially increased risk of skin cancers and infections have not been settled definitively for the time being but that the clinical picture might become a little more clear. Encouraging data from a U.S. rheumatoid arthritis patient registry, totaling 33,000 patient-years, which reported no increase in overall rates of serious infections with anti-TNF therapy, whether seen in hospitalized patients or in outpatient clinics.

For those who suffer from NSAID related GI issues, there may be something to look forward to. In one study, a new compound that combines an NSAID and a proton pump inhibitor in an enteric-coated pill significantly reduced the rate of gastrointestinal ulcers in high-risk patients with arthritis, even when the drug was taken on top of low-dose aspirin.

If you have arthritis in your hands and have difficulty self-injecting your TNF blocker medication, there is a new syringe on the market in the treatment of Crohn’s and rheumatoid arthritis; an easy-on-the-hands, large scale plastic syringe that can be activated using either the thumb or the palm of the hand. The new syringe provides a soft, non-slip grip which allows individuals to hold the syringe steady using various grip positions so it is easy and comfortable to use.

To raise awareness and funds for arthritis research, SAA Programs Coordinator Elin Aslanyan and I participated in the ACR sponsored 5K race which took place in the Philadelphia Zoological Gardens on a chilly morning before sunrise. More than 200 people participated and Elin came in 2nd in her age range. I am happy to tell you that I finished!

Sincerely,
Laurie M. Savage
Executive Director
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**SAA’s Podcasts**

Although I knew there were SAA podcasts for download on [spondylitis.org], I got way behind in my listening and only recently realized how many there are now accumulated in the archives. I have since downloaded all of them and have been enjoying every minute! Melissa Velez Coelho does a great job handling the guest speakers and fielding good questions of interest to us all. I am also pleased with the type of topics being covered. I just wanted to say, keep up the good work and thank you for making these resources available! If anyone out there still has not yet checked out the podcasts, you do not know what you are missing!

MARK D., Forum Member

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**Kudos**

You should be proud of what SAA has accomplished in a short time. There is such a wealth of information out there now that many people are - I don’t know if the word ‘comfortable’ fits exactly, but at least they are not frantically searching for information as many of us did way back when - right after the earth’s crust cooled. It is a positive sign and something of a point of pride.

Well done you!

J.E. SCHIAFFINO, SAA Member

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**LETTERS TO THE EDITOR**

Dear Readers: We want to hear from you, whether it be informative, uplifting or a concern you need to express. Include your full name, address and daytime phone number.

We reserve the right to edit for space and clarity.

Please send letters to: laurie.savage@spondylitis.org

Letters to the Editor/SAA

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

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**SAA On Facebook #1**

Spondylitis Association of America: Thank you SAA for being a great support for us all. I’m thinking about getting my first tattoo soon. It’s going to be a permanent “Stand Tall” bracelet. If I’m going to have this disease for the rest of my life, why should I just wear a rubber one?

RICK POKERWINSKI, SAA Facebook Friend

**SAA On Facebook #2**

I want to thank you for having this page & your site with all the info. Until yesterday, as odd as it sounds, I felt like I was the only person out there with AS. It is comforting to see I can get info & also read things that people have experienced that seemed so similar and how they helped the situations. THANK YOU!

AMANDA PARKER UNREIN, SAA Facebook Friend

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**Listen To Interviews With Experts Online!**

SAA produces monthly podcasts for members that are chock-full of the latest information on spondylitis. Visit the member area to listen at: www.spondylitis.org/members

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**Become A Friend Of SAA**

Find us on Facebook.com and join our community. Search for “Spondylitis Association” and look for our logo! Almost 900 friends and growing!
As many of our readers are well aware, having directly participated in both the TASC and its predecessor the NASC study, the Astralo-Anglo-American Spondylitis Consortium, (TASC) Genetic Study, led by Drs. John D. Reveille and Matthew Brown, seeks to characterize the genes and genetic networks involved in the predisposition, cause and outcome of ankylosing spondylitis (AS). The study, which spans five years, is one of the largest genome-wide association studies ever conducted, examining more than 317,000 genetic markers for the disease. Its recent discovery of two new genes—IL-23R and ERAP1—could lead to new medications to treat AS. What the TASC study has not yet done is to examine non-genetic factors, such as socioeconomics, mood and personality, and their potential impact on the disease. Latter parts of the study will, however, seek to determine if certain behaviors or lifestyles impact disease severity and, if so, what if anything, can be done to influence outcomes in a positive way.

*Spondylitis Plus* sat down with Perry M. Nicassio, Ph.D., a clinical professor of psychology and bio-behavioral science at the University of California, Los Angeles, to explore in detail some of the psychosocial aspects of AS. Dr. Nicassio’s research concentrates on the adjustment process in people with chronic illnesses and the development and evaluation of behavioral interventions for individuals with rheumatic diseases, including AS.

In a soon-to-be published study, funded in part by TASC, Dr. Nicassio investigated the role of psychological variables in self-reported disease activity in patients with AS.
In latter parts of the TASC study, researchers will be looking at certain non-genetic factors of AS to see how they influence disease progression. How does your research fit into the TASC framework?

I’m a clinical psychologist, with a specialization in behavioral medicine. What both of these disciplines look at is the integration of psychological factors, behavior and health outcomes. My group and I have been focusing on that same question. This framework is very common in people with chronic illnesses. That is, there’s a link between psychological factors and health outcomes. Patient outcomes in chronic illness are only partly determined by biomedical factors. There are psychological and behavioral factors that affect patients’ quality of life as much as medical issues do.

In terms of the TASC genetic study, my work is complementary. We’re all working together to examine AS on all different levels—genetic, medical, psychological and behavioral—with the goal of improving patient outcomes.

Your study found that things such as helplessness and depression increased as self-reported disease activity increased. How does this work?

When people feel that they can’t control their illness, they commonly feel helpless. That, in turn, makes their disease more difficult to manage. Helplessness is, in part, associated with depression in all sorts of arthritis-related illnesses. It’s common to find that when disease activity increases, there is some sort of psychological impact. We don’t yet know the chicken from the egg with this; my study is just a one-time slice.

We usually find, though, that when helplessness and depression increase, so too does disease activity. We don’t know exactly how depression affects the disease; we’re trying to find this out now. We do know, however, that it is uncommon to find reports of high disease activity in the midst of positive psychological function. This is true across all chronic diseases, but particularly so with arthritis. In arthritis-related diseases, pain has a lot to do with this. When disease activity is higher, patients report more pain. If that pain is not controlled well, then it affects mood and patients feel more helpless.

You say that some underlying biological process – or the disease itself – may impact depression and self-reported disease activity. What biological process might be at work here?

We know that medical factors aren’t the only contributors to self-reporting of disease activity. That doesn’t rule out the possibility that the inflammatory process of AS could be part of the process. In our study, we measured C-reactive protein and found that it was not correlated with self-reports of disease activity [CRP is a protein found in blood, the levels of which rise in response to inflammation. CRP tests can determine if you have inflammation in your body, but they cannot tell its exact location.] Most of the drugs that are available to AS patients decrease disease activity by down-regulating inflammation. That is, the medication acts on disease activity to reduce pain. These drugs, however, may not help patients adjust psychologically to their condition. We don’t yet know exactly what biological process is in play.

What is BASDAI?

Bath Ankylosing Spondylitis Disease Activity Index, or BASDAI, scores validate diagnostic testing, which allows a physician to determine the effectiveness of current drug therapies or the need to institute new treatment for AS patients. The BASDAI score consists of a one-through-10 scale (with 10 being the worst), measuring pain, discomfort and fatigue. It measures fatigue, spinal pain, joint pain and swelling, localized tenderness (enthesis), morning stiffness duration, and morning stiffness severity.

How you can help further research

The TASC study is enrolling parents, siblings and offspring (ages 12 and up) of individuals who have been diagnosed with AS. Please note that the person with AS must also be enrolled or be willing to be enrolled in the TASC study for family members to take part. For more information, please contact Mamatha Hanumanthaiah, study coordinator at 713-500-5478 or by email: Mamatha.Hanumanthaiah@uth.tmc.edu

Thank you!
The psychological effects of AS seem to have more sway over BASDAI scores than medical variables. Why is this?

The BASDAI score, which is based on self-reports of disease activity, captures the psychological dimension of the disease in a way that X-rays or other biological measures might not. This score tells us a different story about the illness. In the field of arthritic diseases, there is a lot of emphasis on patient reported outcomes. That is, patients’ interpretation of how they’re doing. Blood tests for lab markers don’t account for a patient’s experience with their illness. Rheumatologists are doing this more now and relying less on lab data to infer how their patients are doing. All the things a patient is dealing with in life affect how they’re doing. Indices of disease activity just don’t give us this interpretation.

Other than depression and helplessness, can AS affect such things as sleep (and thus fatigue), anxiety, and other quality of life issues?

We don’t know a lot about sleep and AS. Usually with chronic pain conditions, patients report poor sleep habits and fatigue. We don’t yet know if poor sleep aggravates the disease over time. We do know that in inflammatory diseases, sleep is often disturbed, which aggravates fatigue and mood.

Anxiety has not been studied as much as depression in arthritic diseases. Some studies have shown that patients with rheumatoid arthritis have more anxiety disorders. We don’t know if we’ll find the same in AS, but the potential is there. Depressive symptoms are correlated with anxiety; they are comorbid conditions. Anxiety with chronic illness usually involves worrying about the future, family function, managing well, employment—all very real problems.

What types of screening can be done to identify AS patients who might be susceptible to certain psychological issues as a result of their disease?

It’s possible to use the same measures that we used in our study [see below] in clinical settings to determine which AS patients are susceptible to certain psychological ramifications of the disease, whether that’s the depression tool we used or the five-point helplessness scale.

Depression screening is something that I would recommend be implemented in the rheumatology clinic, not by a rheumatologist, but by the healthcare team providing services to the patient. Very little interpretation between medical and behavioral variables goes on in rheumatology, so these psychological issues often go undetected in many patients. There’s an objective component to the disease—laboratory data, etc.—and a subjective component. These don’t always align on the map. It’s important to have some sort of assessment of the subjective impact of the disease because the medical evaluation doesn’t always tell the whole story.

What are the next steps in your research?

Our next step is a longitudinal study of the same patient cohort as our most recent study to determine the reaction of disease activity and depression over time. We’re also interested in the relationship between helplessness, disease activity, and function over time. In many illnesses, helplessness drives disability. That is, the more helpless one feels, the more disabled one may become. We’ve not yet begun this work, but we’d also like to develop interventions to help patients cope with the pain and disability caused by AS. There is much to be done to better understand AS and how it affects a person. We look forward to working with individuals with AS to find out how we might be able to improve long-term outcomes from a psychosociological perspective.

About Dr. Nicassio’s Study

Dr. Nicassio’s study used several self-reporting measurement tools, including the Vanderbilt Pain Management Inventory, which assesses the frequency with which patients with chronic pain use coping strategies when pain is moderately intense or greater; the Patient Health Questionnaire, also known as PHQ-9, a brief, nine-item survey that measures the severity of depression; the Brief Resilient Coping Scale, which measures a patient’s ability to feel challenged by and cope adaptively with adversity; and the Arthritis Helplessness Index, which is designed to measure patients’ perceptions of loss of control in association with chronic arthritis. Two additional measures were used to assess patients’ belief that they are in control of their arthritis and their perceptions of helplessness in coping with chronic arthritis.
Surgery always requires careful contemplation and is considered to be a risk for any patient, but more so for individuals with ankylosing spondylitis (AS) or a related condition. A range of complications, including undetected fractures and bleeding, can occur if proper care is not taken prior to and during the surgical procedure. Advance planning is key to a successful post-surgical outcome.
AS is characterized by inflammatory arthritis of the spine, sacroiliac and other joints; however, AS disease manifestations are not limited to the musculoskeletal system. AS patients can also have cardiovascular, pulmonary, gastrointestinal or renal involvement, any of which can affect the outcomes of surgery. Proper pre-operative assessment and planning can help to lessen potential complications to any of these body systems for AS patients who require surgery. There is much that can be done to affect positive outcome.

“The entire surgical staff—surgeons, nurses, anesthesiologists, OR staff—needs to be aware that a patient has AS and take the necessary precautions,” says Brian Perri, D.O., a board certified orthopedic spine surgeon at the Cedars-Sinai Spine Center in Los Angeles.

Dr. Perri says most surgical concerns for AS patients and their medical team must be addressed prior to surgery so that the anesthesiologist can prepare the airway without further injuring the patient and surgeons can correctly position the patient to accommodate for any spinal deformity.

**Intubation requires extreme caution**

Patients with AS present specific challenges for anesthesiologists, including airway management and potential cardiac and pulmonary complications.

“If someone with AS needs surgery,” says Dr. Perri, “they will likely need to be intubated [the placement of a flexible tube into the throat to protect a patient’s airway and provide a means of mechanical ventilation]. This requires the anesthesiologist to extend the neck and, with rigid ankylosis, this can present problems, including the potential for neck fracture.”

Stiffness of the cervical spine, ranging from limited movement to complete ankylosis, may cause problems and reduce the options available for intubation. The cervical vertebrae are prone to fractures, especially with the hyperextension required for intubation, so proper care must be taken to prevent injuries.

Anesthesiologists have several options available for intubating AS patients. These include a laryngeal mask airway, or LMA, a tube with an inflatable cuff that is inserted into the pharynx, the portion of the throat that is part of both the digestive and respiratory systems. Much easier to insert than a standard laryngoscope, LMAs are used in situations that require limited manipulation of the head and neck. Now, more and more anesthesiologists are using fiberoptic bronchoscopy, a visual examination of the breathing passages that helps the anesthesiologist intubate a patient without overextending the neck.

Despite these options, says Dr. Perri, anesthesiologists still need to take precautions when managing a patient’s airway during surgery so that injuries can be prevented.

**Handle with care**

In AS patients, there is an ever-present risk of spinal fracture and cervical instability. Because of this, the surgical team must take care when positioning the patient on the operating table. Patients who are improperly positioned or not handled carefully are at increased risk of fracture.

“The spine in AS patients behaves differently,” says Dr. Perri, “and surgeons need to know how to position the patient prior to the procedure. This can be very involved, and great care needs to be taken. [AS] patients need to be handled very gently. They’re different from other patients; fractures can be induced easily.”

Atlantoaxial subluxation (AAS), a condition in which the vertebrae of the cervical spine are malaligned, occurs in anywhere from 2 percent to 21 percent of people with AS, generally occurring in later stages of the disease (although it can sometimes be an early manifestation of AS). Extreme neck extension with these patients, either during intubation or surgery, can result in nerve damage or potential paralysis. Preoperative radiography can guide the surgeon if a patient has AAS.

Many AS patients also have kyphosis, a curving of the spine that causes a bowing of the neck, which leads to a hunchback or slouching posture. Dr. Perri says AS patients with kyphosis can develop microfractures (tiny fractures in a bone caused when the force applied to bone exceeds the strength of the bone) that go undetected.

“What happens,” says Dr. Perri, “is that patients fracture, bleed a little, then heal in kyphosis, where their head falls forward and the patient is looking at the ground. They develop a generalized forward bend.”

Dr. Perri says that, because of AAS, kyphosis and the potential for fractures, positioning for patients having surgery is extremely important.

“Surgeons need to accommodate for a patient’s deformity,” he adds. “We need to build positioning around the spine and plan pre-operatively to adapt patient position. Sometimes, this can make for unconventional approaches for the surgeon, but it best for the patient.”

Further, Dr. Perri considers positioning patients with AS to be “an art, not a science.” Thus, he says it is important to have a surgeon who is familiar with AS and experienced in treating patients with the disease.

**A ‘must’ for AS patients having surgery**

The inflammation caused by AS can lead to new bone formation in the spine. This can lead to hypervascularization, an abnormal or pathological and excessive formation of new blood vessels. Hypervascularization can lead
to undetected bleeding, especially in the spinal column. It is essential that patients who have known hypervascularization alert their doctor prior to surgery so that the condition can be monitored during the procedure to ensure that any bleeding is controlled. This bleeding increases the risk of neurological injury.

Dr. Perri says a cell-saver system should be used for all AS patients having surgery. A cell saver is an autologous (from the same organism) blood recovery system used in the operating room when rapid bleeding or high-volume blood loss can occur. The cell-saver machine suctions, washes and filters a patient’s blood so that it can be given back to the patient’s body. The primary advantage is that the patient receives his own blood, rather than that of a donor, so there is no risk of contracting an outside disease. In addition, because the blood is recirculated, there is no limit to the amount of blood that can be given back to the patient.

“The surgical team needs to use a cell-saver during surgery,” says Dr. Perri. “A cell saver is a must for patients who are prone to excessive bleeding.”

**Emergencies present challenges**

Emergency situations present difficult challenges, for AS patients, first responders, and other caregivers. It is the AS patients’ responsibility to tell emergency personnel in the field or in the emergency room—if they are able—that they have AS so that proper precautions can be taken when moving and treating them.

Medical personnel called to care for an AS patient who is the victim of an accident or other emergency situation must know that a patient’s spine is inflexible and cannot be moved. Further, the fused spine can be extremely fragile and subject to fracture with resultant spinal cord injury. Numerous techniques are available to accommodate AS patients, including airway management and splinting techniques and transport considerations.

“Identification is critical for emergency situations and ER visits,” says Dr. Perri, “especially if an AS patient is in trauma, has had an accident or otherwise cannot speak to emergency personnel. This identification [such as a Medicalert bracelet] alerts the ER staff, paramedics or other first responders in the field, to the inflexible spine, so that they can take precautions while intubating, and warns them about potentially brittle bones.” First responders have indicated the term “Brittle Spine Disease” will get their attention fast.

In addition, says Dr. Perri, because patients may be unconscious in emergency situations, they cannot indicate that they are in pain or protect themselves, making it critical that they are identified as having AS.

With proper planning and preoperative consultation with the surgical team, AS patients need not fear surgery. The onus, however, is on the patient to tell the doctor or surgeon about their AS and that proper care should be taken prior to and during any surgical procedure. While all surgery carries risks, those risks can be lessened with careful planning.
A message from...

...The Membership Director

Medical research, fraught as it is with regulatory compliance issues, can sometimes seem to move frighteningly slow. Slower still when the interest, and the funding, are not present. For many years in this country, there was little interest, and even less funding, for spondylitis research.

With your help, the Spondylitis Association changed that.

In 1996, SAA embarked on a quest that many believed to be impossible – to ignite spondylitis research in the U.S. When SAA entered into the research field to raise seed money for the AS Family Genetic Study, our efforts motivated the National Institutes of Health to take a closer look at the unmet needs in spondylitis research.

This year, further scientific validation by the TASC Genetic Study has confirmed that ERAP1 plays a major role in influencing an individual’s risk of developing AS. This discovery is a critical piece of the puzzle that we must solve in order to fully understand the causes of the disease.

But we’re not done yet. We know what ERAP1 does but we still don’t know how it does it, although we have several theories. There’s more important work to be done.

To investigate further, we need to know the structure of ERAP1 and which specific variants of the gene are associated with AS. Answering these questions may also help to shed light on how HLA-B27 itself influences the disease. All of which brings us closer to unraveling the mystery of spondyloarthritis once and for all.

Today, there is renewed interest in the genetics of spondylitis and researchers are making breakthroughs at a rate never before imagined. The medical research that once seemed slow moving is now difficult to keep up with. Great strides are being made every day – in part because of the dedication and commitment of SAA’s loyal friends and supporters like you.

I recently mailed you our year-end appeal for donations. I hope that you’ll give generously to ensure that the progress that’s been made in the field of medical research will continue to accelerate and that all of SAA’s vital programs and services will continue to educate, inform and support the community we serve.

The researchers we work with believe that we’ll see truly significant breakthroughs in the next few years. With your continued support, I can’t help but believe that that’s true.

Many thanks,

Diana Peterson
Leadership Circle

The Spondylitis Association of America (SAA) would like to acknowledge Leadership Circle members whose gifts totaled $1,000 or more in fiscal year 2009 (July 1, 2008 through June 30, 2009). While all gifts to SAA, no matter the size, are greatly appreciated, individual and family foundation members of the Leadership Circle play an essential role in sustaining the organization today and in the future.

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Quest Legacy Society

The Quest Legacy Society was established to recognize and honor those special supporters who have notified the Spondylitis Association that they have designated a planned gift to the organization. Quest Legacy Society members play a principal role in ensuring that SAA can continue to fund research, provide educational resources and advocate on behalf of the spondylitis community.

Cecelia Bunch
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In fiscal year 2009, planned gifts were received from
The Estate of Marvin Kallison
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(given through the Community Foundation Alliance)
The 5 Rs for Promoting Health During the Holidays

Reflect
Re-think
Redesign
Revisit
Restore

An Interview with Occupational Therapist Regina Campbell

Melissa Velez Coelho: We know that for many the holiday season can be perceived as more stressful than joyful. What strategies would you recommend for those affected by spondylitis to make the most of this holiday season?

Regina Campbell: It’s ironic that we even use the word “holiday” for the season because holiday is defined as a day of rest from regularly scheduled activities and a time away from our work and duties. Yet we know for many the holiday season has been reported to be one of the most stressful and, unfortunately, unhealthy times of the year. People are often doing too much during the holiday season for others and not enough for themselves. That is where the focus starts and one of the first strategies is to gift yourself first. To achieve this, I suggest 5 Rs to keep in mind during the holiday season.

First, reflect on the holiday habits, routines, roles and rituals that give meaning to your season. This is another way of saying “look at your priorities”.

The second R is re-think what the holiday really means to you and those you love. I think we can get distracted by the media and advertising and what it should mean, but we need to really reflect back on what it means to us and our significant others.

As we reflect and re-think, then it’s time to redesign. In redesigning your holiday performance patterns you want to look at what you love to do. When do you love to do it? With whom do you love to do it? Think about the person, the activity and the context and fit that into what your current capacities are. You cannot deny your symptoms but you can look at them differently. This helps you to create a lifestyle plan that will help you to think about each day. You have to look at this as a daily plan. “What can I do in terms of redesigning how I’m managing my holiday season this year so that I can move more towards health and the happiness that I’m looking for?”

The fourth R is revisiting and revising this daily. With chronic conditions such as spondylitis there are good days, there are better days and there are not so good days. Each day requires one to look at how they’re going to manage that day not only to accomplish everything that they want, but also to put health first.

The last R would be to restore your spirit for the holiday. You really want to be looking for the “dos” that you can do. To restore that spirit you really need to realign your expectations of yourself and others and then that helps you to work towards finding the right balance between doing and not overdoing.

MVC: What can those affected by spondylitis do to manage stress during the holidays?
Regina Campbell: There is probably not a person in the United States today that is not stressed to some degree about our economy. It is a stressful time and it is a time for us to really go back to those five Rs in terms of trying to realign. The old saying “don’t spend more than you have” is just as relevant to the state of our economy today as it is to the state of improving our health. Think about your health as a resource and how much capacity you have physically and emotionally as well as financially.

Learning to say no is difficult for a lot of people and this in itself can cause stress during the holiday season. If saying no is difficult you can say “I need to think about it” so that you don’t add the stress of not being able to do something that might be meaningful. Think about how you might be able to redesign a new way to do it, or do it at a different time, so you can work toward reducing that stress. We need to accept that stress is a mind-body process. One influences the other and so we really need to treat them and think about them as a unit.

Examining our performance patterns during the holiday season to identify which ones we believe might hinder our health and those that we believe might help is really a start for managing that stress. It gives you the control back to look at what you might be able to do differently. We need to be more mindful, to be more intentional about how we examine our habits, our holiday routines, our roles and our rituals.

MVC: Do you have any suggestions for holiday gifts that would help our members to sustain health for years to come?

Regina Campbell: I think the first thing I would recommend is to give to yourself first. The best gift that you could give yourself and others is the gift of health. Re-think how you can reduce any risk that might potentially impact your health and well-being and your ability to enjoy the season.

Individuals with spondylitis have increased risks beyond the active disease process. We know that because of the disease process they’re at greater risk for secondary conditions such as osteoporosis, so look at the risk of falling during the holiday season and what you can do to reduce that risk. It does go back to changing your habits and your routines.

“Think about your health as a resource...”

Think about stopping short of the point of fatigue. When we’re tired we’re more at risk for injury and we’re more at risk for falling. Re-evaluate where you store items, especially those seasonal items that are often put on top shelves and require a ladder. Climbing a ladder when you’re tired can increase the risk.

Re-evaluate your capacity for lifting heavy items -- from the groceries that we tend to buy more of during the holidays, to the shopping that we might do at the mall, to the decorating that we might do around the house or outside. There’s obviously a greater risk in terms of heavier items that we’re carrying this time of year. Put things in smaller loads. It’s been noted also that many back injuries, particularly in the work place (it would also be true at home) occur at the end of the day when people are physically and mentally fatigued. Look at the time of day that you might be doing some of your heavier work and make sure that you don’t already feel fatigued and at that point stop before you are fatigued.

When resting, physically do nothing. Sit down and take your mind to a point where it is restful. There’s a strategy called guided imagery that’s inexpensive and an effective way of managing stress. Research has found that guided imagery is an effective strategy in directing our mind and restoring our spirit. Use guided imagery when you’re in stressful situations, for example while waiting in a line, and you may want to use some of the symbols of the season to help you relax -- a lit candle sitting by the fireplace, watching the Christmas tree, looking out the window or watching children play in the snow. The use of music can also help you to relax and reminisce about those pleasant and playful times. A gift of aromatherapy, burning a candle with the scent of the season, cinnamon or any other aromas may help you relax.

Lastly, give yourself the gift of sleep which is often depleted during the holiday season when we’re trying to do too much. Remember how important sleep is to restoring your spirit and that mind and body balance. Physiologically our bodies cannot function without adequate amounts of sleep and when we’re stressed further by chronic disease processes we have to take extra care to make sure that we find ways to get restored of sleep, to restore our spirit. Just as we think about the environment to reduce risk we need to think about what we have in our environment that helps us to prepare for sleep. Think about those things that give you the most joy at the end of the day rather than all the things you didn’t accomplish. Start the day with a positive attitude and end the day with a positive attitude. Think about those things that give you the most joy and fuel your faith.

If you give one gift to yourself this season I suggest you also give the gift of hope. Thomas Carl said, “He who has health has hope and he who has hope has everything.”

This interview is part of one of our audio interviews with experts. Visit us at: www.spondylitis.org/podcast for more.
In today’s economy, saving money is on everybody’s mind. And, as the economy has declined and competition has increased, retail pharmacies across the country have joined the fray, entering a prescription-drug price war in an attempt to attract and keep customers . . . and save them money. For people with spondylitis, who often have to take numerous medications, that price war has let them keep more of their hard-earned dollars in their own pockets.

The key to this price war is generic drugs, which national companies from CVS, Target and Costco to regional retailers like Hannaford Bros. and Sav-Mor now offer consumers for as low as $4 for a 30-day supply.

A sampling of 10 large national or regional pharmacy chains (see table) shows that spondylitis patients can receive significant savings on common generic prescription drugs, including nonsteroidal anti-inflammatories (NSAIDs) used to treat the pain, stiffness and inflammation associated with the disease. All of the drugs indicated in the table are available through the companies’ generic prescription drug programs.

### Here are some of the pharmacies’ programs:

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<td><strong>BJ'S WHOLESALE CLUB</strong></td>
<td>BJ’s Physician’s Rx Care Discount Card offers consumers a 46 percent discount on a wide range of generic drugs. There is no enrollment fee for the program; however, customers must have a membership with BJ’s (from $45 to $80 for a 12-month membership). BJ’s generic drug prices vary; check <a href="http://www.PhysiciansRxCare.com">www.PhysiciansRxCare.com</a> for more information and pricing. BJ’s operates 180 wholesale clubs in 15 states from Maine to Florida and west to Ohio.</td>
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<td><strong>COSTCO</strong></td>
<td>The Costco Membership Prescription Program allows members with no prescription drug insurance coverage to purchase generic medications at greatly reduced prices. The program, which is free with a $50 annual Costco membership, is a value-added benefit of membership with Costco, says the company. Non-members can also purchase reduced-price generic drugs in certain states. Prices vary by drug; check <a href="http://www.envision/rx.com/costco/cmpp.aspx">www.envision/rx.com/costco/cmpp.aspx</a> for more information on drugs and pricing. Costco is the nation’s largest membership warehouse chain, with 405 stores in the United States and Puerto Rico. In addition, there are 77 Costco warehouse stores in Canada and 31 in Mexico.</td>
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<td><strong>CVS/PHARMACY</strong></td>
<td>CVS/Pharmacy’s Health Savings Pass offers generic prescription drugs for $9.99 for a 90-day supply. More than 400 generic drugs are available. There is a $10 annual fee to enroll. CVS operates more drugstores in the U.S. than any other corporation, with more than 6,900 CVS/Pharmacy and specialty pharmacy locations from coast to coast. Visit <a href="http://www.cvs.com/healthsavingspass">www.cvs.com/healthsavingspass</a> for more information.</td>
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<td><strong>HANNAFORD BROS.</strong></td>
<td>The Hannaford Bros. supermarket chain offers a Healthy Saver Plus program that discounts more than 450 generic drugs. A 30-day supply costs $4, while a 90-day supply costs $9.99. A $7 annual enrollment fee covers everyone in a household. Hannaford Bros. owns 170 supermarkets in Maine, New Hampshire, Massachusetts and New York. Its parent company, the Belgium-based Delhaize Group, owns the Food Lion, Sweetbay, Bloom, and Harvey’s grocery chains, which also offer the Healthy Saver Plus program. Go to <a href="http://www.hannaford.com">www.hannaford.com</a> for more information.</td>
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Kroger’s discount generic drug program includes more than 300 different medications, which are available for $4 for a 30-day supply and $10 for a 90-day supply. The company is one of the largest grocery retailers in the U.S., with more than 2,475 grocery, multi-department and convenience stores, in nearly 20 states. The company says the program saved its customers $194 million last year. No membership fee is required. For details, visit www.kroger.com/generic.

The Target retail chain, which operates 1,700 stores in 49 states (except Vermont), offers consumers a $4 generic drug program. The price is for a 30-day supply, with hundreds of generic drugs available. Target’s website, www.target.com, has additional information on available medications.

Consumers can purchase more than 500 generic medications with the Rite Aid Rx Savings Card. No enrollment fee is required to purchase these drugs, which cost $8.99 for a 30-day supply and $15.99 for a 90-day supply. Rite Aid operates 4,900 stores in 31 states and Washington, D.C., with a strong presence on both the East and West coasts. The website www.riteaid.com/pharmacy/rx_savings.jsf has more information.

The Walgreens pharmacy chain’s Prescription Savings Club offers more than 400 generic medications priced at $9.99 for a 30-day supply and $12 for a 90-day supply. Membership in the program is $20 for an individual, $35 for a family. There are more than 7,000 Walgreens drugstores in all 50 states, Washington, D.C., and Puerto Rico. Visit www.walgreens.com for more information.

The nation’s largest retailer, Wal-Mart and its Sam’s Club membership clubs offer discounted prices on hundreds of generic drugs and thousands of over-the-counter medications. A 30-day supply costs $4, while a 90-day supply costs $10. Wal-Mart says the program has saved consumers more than $1 billion. Wal-Mart operates nearly 4,200 stores, including Wal-Mart supercenters, discount stores, Neighborhood Markets, and Sam’s Club warehouses. Visit www.walmart.com/4prescriptions for more details.

More than 250 generic drugs are available through Sav-Mor’s Prescription Rewards Club program. These drugs cost $4 for a 30-day supply and $11.99 for a 90-day supply. There is a one-time $10 enrollment fee per family. Sav-Mor operates dozens of pharmacies in the state of Michigan. Visit www.sav-mor.com/reward_program for more information.

Availability of Common Generic Drugs for Spondylitis at National and Regional Pharmacy Chains

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*Hannaford Bros. parent company, the Delhaize Group, owns the Food Lion, Sweetbay, Bloom and Harvey’s chains, which offer the same generic drug program
These discount prescription programs are not insurance policies and are not available for individuals participating in federally-qualified programs.

**Competition drives down cost**

Generic drugs are simply copies of brand-name drugs. They contain the same active ingredients as brand names, undergo the same rigorous approval process, and are similar in dosage, safety, strength, quality and performance.

When a drug is developed, it is given a name that indicates its chemical make-up. This is also the drug’s generic name. For marketing purposes, the drug is also given a brand name, which is generally simpler to say and remember (think Plavix, the blood thinner, rather than clopidogrel bisulfate). After the patent on the brand-name drug expires, a generic form of the drug can be manufactured and sold.

When acetaminophen, a nonsteroidal anti-inflammatory drug, was developed in the 1950s, it was available only under its brand name, Tylenol. Today, many generic versions of acetaminophen can be found on store shelves throughout the United States. Many drugs, both prescription and over-the-counter, have generic versions. According to IMS Health, nearly 70 percent of all prescriptions in the United States are filled using generic drugs.

“More than half of the people taking prescription medications in the U.S. are using generics,” says Robert A. Ulrich, Pharm.D., senior clinical research science manager at Abbott Laboratories and a member of the SAA board of directors. “That’s up from 4 percent when generics first came out. Today, testing is better, the generics have a good track record [of success in treating patients], and many manufacturers are making them.”

Generic drugs are cheaper than their brand-name counterparts because manufacturers do not incur the costs of developing and marketing a new drug. When a new drug comes on the market, its manufacturer has already spent substantial amounts of money on research and development, marketing and promotion. A patent for the drugs is granted for up to 20 years, giving the manufacturer exclusive rights to sell the drug while the patent is in effect. As the patent nears its expiration date, the Food and Drug Administration allows drug manufacturers to apply for permission to produce and sell a generic version of the drug. Because the drug is not new to the market, these manufacturers are spared the start-up costs of development, so the product is less expensive for consumers. When multiple companies make the same drug, competition drives the price down even further.

**Billions saved with generics**

The cost savings with generic drugs can be significant. According to the Centers for Medicare and Medicaid Services, generic drugs cost anywhere from 30 percent to 80 percent less than brand-name drugs, saving the American public billions of dollars. A 2006 study by Consumer Reports magazine found that American consumers save more than $25 billion per year by switching from brand-name to generic drugs.

Spondylitis patients take a range of NSAIDs to help control the pain and inflammation caused by the disease. These patients receive a healthy savings when they choose to use generic drugs rather than brand-name medications. For example, brand-name Disalcid (salsalate), a salicylate-based drug that reduces substances in the body that cause pain and inflammation, costs from $25 to $49 for a 30-day supply, according to Revolutionhealth.com, a comprehensive health and medical Web site. Other common NSAIDs, including Meclomen (meclofenamate), Indocin (indomethacin), and Lodine (etodolac), range from $50 to $99, while others such as Tolectin (tolmetin) and Dolobid (diflunisal) can cost more than $200 per month.

The cost of these brand-name drugs is based on the average wholesale price for a drug, which is the suggested retail price of the drug, similar to the sticker price on a car. Insurance companies use this information as the basis for reimbursement, says Revolutionhealth.com, and the price does not necessarily reflect what one would pay for the drug if it is covered by a prescription drug benefit plan. Nonetheless, the prices are much higher than the cost of generic drugs, many of which are available for as little as $4 for a month’s supply.

A newer class of drugs used to treat spondylitis, called TNF-alpha inhibitors, are very expensive. These drugs block the action of tumor necrosis factor-alpha, a chemical substance that is involved in the inflammatory process. Four of these drugs are currently available: Enbrel (etanercept), Humira (adalimumab), Remicade (infliximab), and, the newest, Simponi (golimumab). Because they are new drugs and still under patent with their manufacturers, there is no generic, or biosimilar, drug available.

“The manufacturers of the drugs are aware of their cost and have programs that pick up the bulk of a patient’s co-pay,” says Ulrich. “These companies are doing things to help patients, especially low-income patients, afford these necessary medications.”

The Enbrel Support co-pay program (1-888-4ENBREL, 1-888-436-2735) offers six months at no co-pay cost to the consumer and a $10 or less co-pay thereafter. The Humira Protection Plan (1-888-HUMIRA3, 1-888-4723) reduces co-pays to as little as $5 per month, and the Remicade Patient Assistance Program (1-866-489-5957) is designed to provide assistance to patients who cannot otherwise purchase the medication due to inadequate health insurance coverage. The SimponiOne savings card offers patients with private insurance support for out-of-pocket costs. Uninsured or underinsured
patients with financial need are referred to a patient assistance program for help. Visit www.access2wellness.com for more information.

TNF blockers have different pricing schedules, as well, depending on where they are purchased. Patients are advised to contact the pharmacy to determine what types of discounts are available for these drugs.

**Safety and quality ensured**

Some people worry that generic drugs are less safe than those that carry popular brand names. The FDA requires that all drugs be safe and effective, whether they are brand-name products or generic equivalents. Generic drugs are laboratory-tested to ensure that they have the same quality, strength and purity as their brand-name counterparts. In fact, the FDA inspects thousands of drug manufacturing facilities each year to ensure that safety standards are adhered to. Since 1984, the FDA has not approved the use of a generic equivalent unless it has been shown to have the same rate and amount of active drug absorbed by the body as the brand-name drug, according to the FDA. Other than cost, the only difference between generics and brand-name drugs are the colors, flavors and inactive ingredients in the products. U.S. trademark laws do not allow generics and brand-name drugs to look exactly alike.

Ulrich says it is “generally simple” to switch from a brand-name drug to a generic counterpart. “Patients should feel comfortable that the product they are getting has been evaluated properly and is a proven bioequivalent so they and their doctor can be assured they are getting the type of treatment they need.”

He says that patients making the switch from brand-name to generic should make sure the new drug is having the same effect as the brand-name medication. “That’s no different for spondylitis patients,” he adds. “It’s good counsel for everyone.”
A Special Thanks To Our Corporate Partners

The Spondylitis Association of America (SAA) would like to thank the following Corporate Partners for their generous support. The Corporate Partnership Program provides a way for SAA’s pharmaceutical partners to positively impact the spondylitis community by contributing funds to the organization’s general operating budget and to support special programs and services.*

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*The Spondylitis Association of America is solely responsible for the content of all educational programs and services.
### SAA-Sponsored Educational Support Groups

The people listed below have volunteered to lead support groups across the US. If you’d like to find out more about support groups and online meetings, pick up the phone or send an email to: elin.aslanyan@spondylitis.org.

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<td>Little Rock, AR</td>
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<td><a href="mailto:elin.aslanyan@spondylitis.org">elin.aslanyan@spondylitis.org</a></td>
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<td>Dallas, TX</td>
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**Teen Athletes with AS** located in Orange County - contact WalkerRSM@aol.com

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

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www.spondylitis.org
Flu Shot Reminder...

It is important for spondylitis patients planning to get vaccinated against the flu to discuss the various options of vaccine delivery with their rheumatologists. However, the nasal spray form of both the seasonal and H1N1 vaccines is made from a live virus. Persons who are immuno-compromised should not take live vaccine.

American College of Rheumatology researchers have stated that patients currently being treated with TNF-a inhibitors (Enbrel, Remicade etc…) should not be vaccinated using a nasal spray treatment.

SAA participates in the Combined Federal Campaign -- the largest and most successful annual workplace charity campaign. Simply enter CFC code #89466 on your pledge card during your agency’s fund drive or contact your Human Resources Department or the Office of Personnel Management (www.opm.gov).

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