The Faces of Ankylosing Spondylitis

The 5 Rs for Promoting Health during the Holidays
ON POINT

Dear Readers,

Recently on the train ride back to LA after participating in the annual gathering of 13,000 health care professionals at the American College of Rheumatology Scientific Meetings in San Diego, I enjoyed time to think. The five-day meeting, which often stretched from 6:00 a.m. to 10:00 p.m., was filled with discussions, formal meetings, side conversations and debates, plus the opportunity to work with our spondyloarthritis-dedicated colleagues, and underscored the reasons why we continue to be optimistically engaged in serving those affected.

There was good news: increased knowledge, better science, and patient management techniques in spondyloarthritis that have the potential to lead to improved quality of life. In addition, a variety of sessions were dedicated to lifestyle and habits, including exercise and physical fitness, mental health and fatigue management. Furthermore, it is now well substantiated that certain habits such as smoking and lack of physical activity more often than not lead to much worse outcomes and pain in those with ankylosing spondylitis.

Specifically what came to mind during the four-hour train ride that evening was the belief that it is critical for all affected to take charge and to manage the disease from all angles. These would include the mental and emotional as well as physical. Medical research informs us that patients benefit immensely from participating in their own healing. I think that we each would agree that there are no magic bullets and that successful disease management is dependent upon determination and courage, imagination and support from others.

We at SAA look forward to supporting your efforts in your own reach for optimal health in the New Year.

With gratitude for your support of our efforts in serving our mission, please accept my warmest personal regards to you and to yours throughout 2014 and beyond.

Laurie M. Savage
Executive Director
So Excited
To say I’m excited is an understatement! The Fall 2013 Issue is terrific anyway, but to open it up and actually see my story is so cool!

I posted a picture of me holding it and posted it on Facebook – I tagged SAA so it shows up on your page. There’s been nearly 200 likes on my post, and I’ve had people Googling to find out about the disease – so I would say it has done its job!

Thanks again so much!

~KATIE, Sundance, WY

Editor’s Note: Thank you, Katie, for your efforts in raising awareness of spondyloarthritis and for sharing your inspirational story with our readers. SAA Members can access past issues of Spondylitis Plus online at StopAS.org/members. You can visit SAA’s Facebook page at Facebook.com/spondylitis.

Thank You For Telling Our Stories
It was a great surprise when I heard that my article would appear in the November publication of your quarterly.

The articles proceeding mine were so informative and the effort those women put into having a “normal” life was indeed inspiring. Thus, I am very much pleased with the impressive treatment you gave my simple article. What I hear ringing in my ears is that “Nana Del” is featured in a national quarterly.

May this quarterly continue to affect other lives to become more productive with confirmation that there is always hope in their futures.

Sincerely,

~ ARDELLE “Del”, Robesonia, PA

Editor’s Note: Your story was inspiring as well, Del! Thank you for allowing us to print your story. In this special Holiday Issue, we feature three more personal stories, this time from the “Faces of Ankylosing Spondylitis” series, starting on page 8. To send us your story, please email or mail us using the “Letters to the Editor” information to the right.

Best Ever Issue
I just received my copy of the new Spondylitis Plus. Thank you.

This is, in my opinion, the BEST issue of Spondylitis Plus ever!!

The new graphics, page layout and design are the BEST!! It’s colorful and informative and has a couple of wonderful human interest stories... I’m going to stop now before I start gushing, but I wanted to let you know how GREAT this is!!

Congrats to all involved!!

~MICHAEL, New York, NY

Editor’s Note: This is great to hear, Michael. Thank you. It was only a year ago that we started this new, longer format (28 pages), and the feedback we have received regarding the new design and content has been overwhelmingly positive. We’ll keep striving to make each issue of Spondylitis Plus better than the last.
The 5 Rs for Promoting Health during the Holidays:

Reflect
Re-think
Redesign
Revisit and revise
Restore

Editor’s Note: The following is an excerpt from an SAA podcast with Regina Campbell, MS, OTR, FAOTA. Regina is an Occupational Therapist and Associate Professor at Texas Woman’s University School of Occupational Therapy. You can listen to the full podcast by logging in at StopAS.org/members.
SAA: 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 duty. 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. “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.

“Learning to say no is difficult for a lot of people and this in itself can cause stress during the holiday season.”
SAA: 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 experience and realize that we can’t really address one without addressing the other. Stress — physical stress and emotional stress like pain and fatigue that accompany spondylitis — are bi-directional. 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 support our health and those that we believe might hinder our health 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.

SAA: 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 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.

“Give yourself the gift of sleep which is often depleted during the holiday season when we're trying to do too much”

Re-evaluate your capacity for lifting heavy items — from the groceries, 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.

Last, 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 they’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.”
Editor’s Note: “Faces of Ankylosing Spondylitis” is a website dedicated entirely to the stories of those with AS. As of this writing, over 1000 stories have been published on the site, and more are being added regularly. Men, women, and children from numerous countries and continents have shared their stories and photos, and we would like to share a few of them here, with our gratitude to all. You can read all of the stories on the Faces of AS Site, as well as read a selection of the stories on SAA’s site, StopAs.org/faces.

The woman behind “Faces of AS”, SAA member Cookie Hopper, explains her reason for starting the website: “It was important for me to do this, not for myself, but for each one of the Faces on this site and those who are still unknown. I wanted to show the reality of this disease and the courage it takes to live our lives. I wanted to honor those who have Ankylosing Spondylitis, who I admire and respect.”

We hope you find the following three stories inspiring...

As many others with ankylosing spondylitis, I’ve become passionate about helping raise awareness. It’s my hope (our hope) that future generations will receive early diagnosis and treatment before permanent damage is done to the body, less pain, and better yet ... a cure.

Four years ago my stress levels greatly increased. It was like an avalanche hit me and my family. In the span of a year I was diagnosed with ankylosing spondylitis, psoriatic arthritis, mixed connective tissue disease, neuropathy, “awake” seizures, osteoporosis (lost 1 1/2” of height), carpal and cubital tunnel,
fibromyalgia and vasculitis. Inflammation affected my entire body, including my vascular system. My blood vessels were bursting which greatly frightened me. My immune system attacked everything including my heart, lungs and kidneys. I lost hearing in one of my ears for about a year, but am very happy to say that I’ve regained most of my hearing.

My story begins at a very early age. I was diagnosed with chronic inflammation of the lungs and allergic asthma when I was only 2 years old. I grew up sick, hospitalized a couple of times a year, so I knew nothing different. The joint pain started when I was around 16, but I remained silent about it as I had learned to hide my illness as much as possible for the sake of being able to participate in the activities I loved. Over the years the pain steadily increased. I made excuses and put it out of my mind as much as possible. I worked and went to college full-time, got my degree in graphic design, and continued to push myself for the future I had planned for my life. I’ve now come to realize that for the most part I lived in the future. Most tasks revolved around a long-term goal. That wasn’t much fun and I was riddled with anxiety about whether or not I was on “schedule” with that plan. People aren’t trains. We each have a different path to take on this journey. Finding that ever-so-difficult balance between past, present and future is a great feat and a task that never ends.

Life forced me to confront many issues, head-on and quickly. What does one do when they’ve spent their life working hard, focused on the future, and then that near future becomes questionable? Live in the present, and draw strength from the past, with a beautiful glimmer of the future. Once I stopped trying to figure out who I was, or was meant to be, I became who I am. By truly releasing the past and the future, a total surrender, I was able to free myself to live in the moment and love fully.

Why can’t life remain like a calm stream instead of a rapidly flowing river? Consider the way a river beautifully sculpts the earth. Smooth is easy but also monotonous and uniform. Curves and grooves are provocative and thrilling, but can also be dangerous. Challenge brings about strength through humility and truth, and by recognizing faults and refining good qualities. Obstacles and pressures break down false pride and reveal who we truly are.

My favorite color is a unique cobalt blue – a beautiful, distinctive, deep, metallic blue that comes from Raku fired pottery. Raku pottery is fired twice and reaches temperatures around 1800°F. It’s able to endure this type of heat because it’s made from a special type of clay found in Japan that’s capable of withstanding “thermal shock.” I mention Raku firing because I can’t help but compare that special clay to people put through the fire of life. It’s such an incredibly difficult process, but the result can be something truly extraordinary and beautiful.

At times I have a passionate dislike for character building events in life, but I know in the end they turn out to be worthwhile. How tormenting and paradoxical life can be while one matures. I sometimes find myself possessing a negative outlook on life just to prepare myself for the worst outcome possible … but never without a mustard seed of faith that a mountain might actually move beneath my feet. Pessimism is a way to spare one’s self, but not entirely. Faith is the key to survival. It’s the acceptance of what is, but also the knowledge, hope, and appreciation of something better, no matter how small the improvement. Life’s calamity builds strength for future trials, and with each new tragedy comes a renewed peace and spirit equipped for the next turn of the kaleidoscope of life.

Forth Worth, Texas
My name is Alan Beaulieu. I am 29 years old and was just recently, within the past few months, diagnosed with Ankylosing Spondylitis (AS). My story begins like so many others’ that suffer from this disease. It involves pain, stiffness, fatigue, frustration and feeling hopeless. However, we must not just give up. Even though we have our daily struggles and pain, we must not give in to them. We must do whatever is in our power to face this disease and defeat it. I hope in writing my story I can get a lot of my own questions answered, as well as maybe help raise awareness of what AS is and what it does to the bodies of those who suffer from it.

Background: I joined the United States Air Force in March 2001 and became a part of the Security Forces career field. For the first six years I was a regular “Air Force Cop.” The last four years I was fortunate enough to be a Military Working Dog Handler. I have worked with both drug and bomb detecting dogs. It was the best job that I have ever had. During my time I have been stationed at Ellsworth AFB, South Dakota, Ramstein AB, Germany and am currently at Joint Base Mcguire-Dix-Lakehurst, New Jersey. During the last ten years I have been deployed 4 times, twice to Iraq. I have enjoyed my time in the military. Unfortunately, it is coming to an end. I am being medically retired due to having AS, 6 bulging/herniated discs, moderate Traumatic Brain Injury, and PTSD. I look forward to “hanging up the boots” and re-starting my life back at home in Michigan.

The Pain and The Journey: My AS story starts in spring of 2006. I had just returned from a 7 month deployment to Kirkuk, Iraq. During my deployment I noticed some back stiffness but didn’t really think anything of it; I figured it was from all the gear and ammunition. Little did I know I was in for one rude awakening. One morning while on R&R I woke up, got out of bed, and when I went to take a step I fell to the floor. I had no idea what was going on. I felt terrible pain in the lower part of my back along the spine, and debilitating pain on the lower left side and down the left leg. My entire lower back and left leg felt “seized up.” It felt like it was fused together. Each step was painful, each movement that involved the left leg or back was excruciating painful. I limped slowly for the next few months. No one really had a clue as to what was going on. When I went to the medical clinic on base the doctors thought my hips were uneven. They laid me down on the table and my left leg was yanked on twice in an attempt to even out the hips. Obviously, this made my pain worse. After several failed chiropractic visits, I was sent for an MRI. The results showed a bulging disc in the L4-L5 area of the spine. After receiving the results of the MRI, I was sent to physical therapy.

Physical therapy was a waste of time. I rolled around the floor on a ball and did a bunch of stretches. The point was to keep my back straight and my core muscles strong. They said it would help with the pain. It didn’t do anything for the pain. It took months upon months to start running again. After a few months, it got easier to walk. The easier it got to walk the easier it got to jog ever so slightly. When I finally tried running it was horrible. As soon as I got a few steps my entire lower back and left side would tighten up and eventually seize. My left leg would go numb and feel like “jello.” The more I tried to run through it the worse it seized up before eventually I
would hobble around. I was baffled. I had no idea what was wrong. All the medical doctors would do is feed me motrin or naproxen. They couldn’t understand why I was in so much pain.

I wasn’t able to run until the summer of 2007. Even though it wasn’t like what I was used to, I was still barely passing my physical training tests. Sit ups and running were painful. As much as I wanted to say something, the mentality in the military is to “press on.” You don’t show weakness. If you’re hurt then you better suck it up and keep going. For the next year, all I did was take naproxen for the pain and do my best on my PT tests. It got so bad I had to take 6-8 naproxen just to keep the inflammation down so I could pass my tests.

In August 2008, I was deployed to Baghdad, Iraq. My bomb sniffing dog, Cici went with me. I was really worried that my back would give out on me during the deployment. I had to do whatever I could to keep my dog and me in the mission. I went to the medical tent several times for the back pain. I spent many nights laying on heating pads and taking NSAIDs and motrin like crazy. At this point, I had been dealing with this pain for 2 years, with no understanding of what the problem was. No one knew what was going on.

My problems took a turn for the worst in the fall 2010. The pain was getting more frequent and worse. The exacerbating episodes lasted longer and longer. Before, I would hurt for a few months then it would return to normal. This time it never went
away. This time was like all the others, except it
never left. I was never to stabilize my back again.
For 4 years I felt pain. There were times I would be
in tears from the pain. There were times I had to use
a cane just to help me walk. It was horrible.

I underwent another round of MRIs. This time they
found bulging/herniated discs in my C-spine and L-
Spine. I went to two neurologists and to pain
management. I was prescribed a whole slew of
narcotics and pain medications. None of them
provided relief. I underwent an EMG test and the
results were “normal.” I was in so much pain and no
one had a clue as to what was going on.

My frustration reached its peak in the spring of 2011.
I was in the office of my former Primary Care
Manager. After all the visits to the specialist he was
growing suspicious that I was faking it. He sent me
for a round of blood tests. About a week later, I was
called back in. He looked at my tests and said, “You
know I was real skeptical about your pain when you
first started coming in. However, according to your
blood tests you have some real issues going on.” I
wanted to scream at him. I wanted to smack him for
basically telling me I was lying. I asked to go to a
Rheumatologist. My request was shut down. I was
instead sent to mental health for a psychological
evaluation. He seriously thought my pain was “in
my head.” I was at a loss. I started to feel like I was
going crazy. I began to think, “Am I just making this
up?” I knew I wasn’t, but after 5 years, no one had
a clue as to what was going on. To make matters
worse I was also told I could no longer work with
military working dogs; that the physicality of the job
was too much for my health. I was devastated. I
had been working with bomb/drug dogs for 4 years.
I deployed with a bomb dog who saved mine and
others’ lives. It hurt badly. I was moved to an office
job, where I am currently working as I await the
results of my medical retirement board.

(On a side note: It is a good thing I was sent for the
mental evaluation. I was having problems from my

“I won’t let this disease beat me.”
time downrange for a while. It was then I was finally diagnosed with PTSD and mTBI, so all was not lost in getting sent to mental health. There is a stigma in the military about PTSD. Those of us who suffer it are seen as weak. When I was taken off the road and away from dogs, it allowed me to quietly get help without fear of being judged. It’s not my fault I saw what I saw and experienced what I experienced. To be judged and viewed as weak by my own brethren was painful.

When I went to mental health, the LCSW that was working with me noticed my pain. She noticed I walked with a limp daily. She noticed I couldn’t sit in a chair for more than 10 minutes without grimacing and having to stand up due to the pain. She asked me what was wrong. I told her the whole story. She looked at my blood tests and made a few phone calls. I was then able to switch to a different Primary Care Manager. Finally, after 5 years, I had a doctor who gave a damn. She immediately sent me to a rheumatologist. The rheumatologist sent me for more blood work and a bone scan. The blood work showed high levels of C-reactive proteins and I tested positive for HLA-B27. The bone scan showed high levels of inflammation along my lower back and in my SI joints (sacroilitis). After listening to my symptoms the rheumatologist finally diagnosed me. It was ANKYLOSING SPONDYLITIS. Now, normally people would be devastated upon hearing they have a lifelong debilitating disease. I was actually relieved. I was so relieved because I knew I wasn’t crazy.

Currently, I am on Humira. I inject myself every two weeks. I think I need to go to weekly injections. For the first couple of days I feel okay - I don’t have the inflammation in the SI joints and the pain in the left leg. However, my neck is still stiff and my lower back (along the spine) still hurts. If I try to do any type of physical activity the pain gets worse.

It’s frustrating. I fear getting bamboo spine. Over the last few weeks I have been getting a pain in my chest and I have had shortness of breath for a while now. I am worried spondylitis has affected the joints in my rib cage. If this is indeed true that means my chest is seizing up and my lungs can’t expand like a normal person. I am 29 years old. I can’t lift more than 29 lbs; I can’t sit for too long without being in pain. I can’t bend over very much, nor can I bend to the side. I can’t turn my neck too much without being in pain. I am on an immune suppressant which leaves me tired all the time. When I tell people what I have I get the same response - “What is that?” It’s frustrating. It’s frustrating to have a disease that impacts my life so severely, yet no one has a clue what it is.

Even though I get frustrated, I am focused. I won’t let this disease beat me. I am confident they will find a cure. This disease is real; it has the potential to be extremely debilitating; but I can’t focus on that. Each day I try to stretch as much as I can. I try to stay active. It is difficult because I am limited but I do what I can. I am choosing to look at the disease like a blessing in disguise. Instead of 20 years in the military I am able to get medically retired. I will be able to move back to Michigan and achieve my lifelong dream of graduating from the University of Michigan. I also have the assistance of a great service dog named Bella. She’s a service dog trained to the specification of the Americans with Disabilities Act. She is trained to assist me not only with PTSD symptoms but also to “fetch” things off of the ground so I don’t have to bend over to pick them up. She is a lifesaver. Once I get medically retired I will be able to re-start my life. I understand what I have. Now I just have to find what I call, a new “normal.” I have to learn to live within it and also find a way to defeat it.

I am Alan Beaulieu and I have Ankylosing Spondylitis.

Joint Base McGuire-Dix-Lakehurst, New Jersey
The working life of a hospital nurse can be extremely busy, stressful, and complex. Making life or death decisions goes part and parcel with a caring heart and gentle touch. I thrived on it. Caring for a patient was my calling. Along came AS and that chapter in my life closed forever.

I was 32, a mother of two daughters, ages 5 and 3 years. My husband, daughters and I had just moved from our lives on the farm to a city; I had a new job and we knew absolutely no one in town. Needless to say, there was no support system on which we could rely. My diagnosis came relatively quickly, but hearing the news shocked me into denial. The issues that led me to seek medical attention got worse instead of better. Every morning I awoke with low back pain. Getting out of bed was excruciating because my heels were so painful that standing on them made me want to cry. In fact, there were many mornings when I did just that.

Originally I thought the heel pain was from a stone bruise, as I was nearly always barefoot at home. I reasoned that the persistent low back pain was due to lifting heavy patients or bending over a patient’s bed to perform wound care or another nursing task. After a period of about six months with no improvements in either the back or heel pain I began to think there was something else wrong. In addition to the pain, I felt exhausted all the time, but easily dismissed that as an effect of my hectic work schedule and the challenges of having recently moved.

I remember the day I went to see the doctor. He was an internist; one of the physicians with whom I had become acquainted at the hospital. After asking numerous questions and completing an exam, he said he felt he knew what was going on with me, but wanted to get an x-ray of my sacroiliac joints and draw some blood for testing. Once the x-ray was completed, I was directed back into the exam room. Within moments the doctor arrived, a radiograph in hand. He said, “Mrs. Hyder, I am quite certain I know what is happening. I believe you have a condition known as ankylosing spondylitis.” That moment was the first time I had ever heard those two words. For the next few seconds my mind was flooded with questions. I felt scared and alone, relieved that I had a diagnosis, yet perplexed as to why this happened to me. I wouldn’t be able to answer that particular question for almost 15 years.

Throughout the next few months I was prescribed a variety of medications. Some didn’t work, others made me physically ill. Still I continued to work and live the life of a normal woman with a husband and children. Although the pain and exhaustion persisted, I began to deny the fact that I had AS. My husband was having difficulty finding a job in his field of expertise, and money was tight. I began to feel isolated and weary. My girls understood that something was wrong with

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Tyler Hyder

Winter 2013

FACES OF ANKYLOSING SPONDYLITIS
Mommy, but because they were so young, they could not understand. I didn’t want them to feel as though they had a Mommy that couldn’t measure up, so I redoubled my efforts to make everything appear unchanged. I had always been energetic, with a positive, ebullient nature and to the world, that didn’t change. But inside, I was beginning to fall apart.

Seriously, I don’t know what I would have done without my husband. He was always by my side, ready to do anything he could to help make my life easier and more comfortable. It was he who first introduced the idea that we should consider moving closer to my family so I could have some help and support from them as I tried to get this strange and hurtful disease under control. Feeling as though I could take no more, we made arrangements to uproot our lives once again. We packed our belongings, and our little family journeyed to the Seattle area to be near my family.

The years since then have been filled with highs and lows. The disease continued to progress to the point where I could no longer ignore it and still go on living. It was then that I finally was able to accept AS as part of my life. Having done that, I set out to learn everything I could about the disease. I wanted to have the ability to control AS and not let AS control me. I found a rheumatologist, and we worked on a treatment program, constantly refining it until we found the best plan for me. I was then able to go back to work, but my days as a hospital nurse were over. I could no longer handle being on my feet for 9 or 10 hours a day. So I had to rethink my career, and come up with something I was able to do.

In 1995 I became involved with supporting others with AS. While I no longer felt alone, I knew there were other people who may be feeling that way. I became part of a small group of people involved with forming an online support group for people with AS. Family members were also encouraged to join our group, and since its inception to the present day it is one of the largest and longest running support groups on the Web.

Today, I am no longer able to work full time, but I still maintain my nursing license...just in case. My children are grown; I have three grandchildren. Now I write. And I am still living with AS — a face of Ankylosing Spondylitis — even after all these years.

Redmond, Washington
The holidays are a time of celebration and all of us here at the Spondylitis Association are celebrating the great strides our supporters have enabled us to achieve in making life a little brighter for all those affected by spondylitis.

Although there’s still much work to do, with the help of generous supporters like you, SAA is leading the fight to promote earlier diagnosis, advocate for access to care, educate the medical community, inform the public and advance the medical research that will someday lead to a cure.

One of our long-time donors, who has asked to remain anonymous, has given us yet another reason to celebrate. He has generously offered to match all donations, up to $30,000, between now and the end of the year.

Each and every gift received during this period will pack twice the punch — galvanizing research, providing education and support, and shaping public policy on behalf of all those affected by spondylitis.

As someone who’s already shown a commitment to advancing our mission, you know that SAA is the driving force behind spondyloarthritis research, advocacy and education in the U.S. But we can only channel and focus the contributions of others.

If you donate today, your gift of $50 becomes $100; $100 becomes $200 and so on. Your generosity will have twice the impact in hastening our shared goal of a world free of the pain and disability of spondylitis.

It’s easy to get caught up in the excitement (and the challenges) of the holiday season and it’s often easy to set things aside to revisit later. But please take just a moment to reflect on the work that your donations have made possible. On the impact that work has had on your life or the lives of your loved ones. And on the potential benefits it may have for your children or grandchildren.

Once you do, you may decide to take advantage of our anonymous donor’s offer to match your gift today. It’s easy to give using SAA’s secure website or feel free to call Helene Hart at 800-777-8189, ext. 229.

All of us at SAA are wishing you and your family and friends a happy Holiday Season.

Happy Holidays!
HOLIDAY WISH LIST!

- Promote Earlier Diagnosis
- Advocate for Access to Care
- Educate the Medical Community
- Inform the Public
- Advance Medical Research
- All of the Above

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Our mission is to be a leader in the quest to cure AS and related diseases, and to empower those affected to live life to the fullest.

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### Highlighting The Most Active

**SAA-SPONSORED EDUCATIONAL SUPPORT GROUPS**

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*CL designates Co-Leader. These are two leaders working together to lead their group.

If you’d like to learn more about support groups or for a complete list of groups and meeting dates, visit our website at: [http://www.stopas.org/groups](http://www.stopas.org/groups)

You can also contact Elin Aslanyan here at SAA by calling 1-800-777-8189 ext. 222 or by email at elin.aslanyan@spondylitis.org for more information.
SAA hosts FREE Spondyloarthritis Patient Educational Seminars all over the country - 37 since 2002. In addition to in-depth presentations from doctors, rheumatologists, physical therapists and experts, each seminar has ample time for Question & Answer sessions with the speakers as well as time to mix and mingle with other patients, families and friends. Thus, SAA’s seminars are not only a great way to get the latest information on spondyloarthritis treatment and research, but also to make valuable connections with others.

The Brooklyn seminar on Saturday, September 21, 2013 was unique in that the event was held at the world renowned Barclays Center - home of the NBA’s Brooklyn Nets. There, Dr. John Reveille volunteered his time to present on Medical Management of Spondyloarthritis & Current Research.

The seminar was only made possible by a generous donation of meeting space by Barclays Center in addition to an educational grant by AbbVie. We’d like to thank them both for helping to make this a truly special event.

A video of the seminar - compliments of the AV crew at Barclays - will be made available online to SAA Members at StopAS.org/members in the coming months. The slides from Dr. Reveille’s presentation will also be made available at StopAS.org/press.

You can stay informed of SAA news and upcoming events in your area by signing up for SAA’s free monthly eSUN - the electronic Spondylitis Update Newsletter at StopAS.org/esun.

All seminar photos by Barbara Alper
MADRID—Nonsteroidal antiinflammatory drugs (NSAIDs) might still have a role in the treatment of axial spondylarthritis, an expert said here at the European League Against Rheumatism (EULAR) 2013 Annual European Congress of Rheumatology, held June 12–15. But other drugs are quickly being explored, with the understanding of the effectiveness of tumor necrosis factor (TNF) inhibitors, as well as other biologics, expanding all the time, others said.

Role of NSAIDs

Nigil Haroon, MD, PhD, assistant professor of rheumatology at the University of Toronto, said the recent INFAST trial suggests that there might be a role for NSAIDs early in the treatment of patients with ankylosing spondylitis (AS).

Early AS patients—with an average disease duration less than two years, and who had not been on a maximal dose of an NSAID previously—were given either both naproxen and infliximab or naproxen and placebo. Their infusions were stopped at 24 weeks and response was assessed after 28 weeks.¹

Researchers found that 62% of the patients were in partial remission in the naproxen–infliximab group, compared to about 35% of the naproxen–placebo
Dr. Haroon noted that the remission rate in the naproxen-placebo group was relatively high.

“Maybe by diagnosing and treating these patients early, we may get significant benefit just from antiinflammatories alone,” Dr. Haroon said.

Dr. Haroon pointed to a 2005 study as most compelling on the disease-modifying potential of NSAIDs. Those on a continuous dose of NSAIDs showed significantly less radiographic progression than those taking NSAIDs as needed.2

Further analysis showed that the difference between the groups was limited to those with elevated C-reactive protein (CRP) at baseline. “If you have a predictor of progression (high CRP or syndesmophytes on X-ray) right at the beginning, then you’re more likely to respond with antiinflammatories, and progress less,” Dr. Haroon said. Researchers have also found that the lower the dose, the more likely patients are to progress.

There seems to be a biologic basis for this disease-modifying potential of NSAIDs. Bone density and osteoblastic activity have been shown to be impaired by systemic NSAID application in a mouse model.3 But, he said, the NSAID effect was not replicated in a large study led by Dr. Haroon, with participating centers from Canada and the U.S.

Another factor that can’t be ignored, he said, is cost, which is “a big advantage for naproxen.”

“That’s something you should always consider when you come up with guidelines and treatment recommendations,” he said.

In the end, when determining the role of NSAIDs, physicians have to consider several factors—the symptomatic state of the patient, the likelihood of radiographic progression, the risks of continuous NSAID treatment to the patient, and the treatment alternatives, Dr. Haroon said.

How Many TNF Inhibitors to Try?

Elisabeth Lie, MD, PhD, of the rheumatology department at Diakonhjemmet Hospital in Oslo, Norway, turned to TNF-inhibitors, discussing the potential benefits of switching from one to another.

Trying a second TNF inhibitor is an option many patients want to consider, since many of them won’t respond to the first—and Assessment of Spondyloarthritis International Society
(ASAS)–EULAR recommendations from 2010 advise switching to a second TNF blocker, especially in patients who have failed on a first due to a loss of response.

Across eight studies on a variety of TNF inhibitors, the ASAS20 response rate was found to range from 60% to 70%, and the ASAS40 found to be 40% to 50%, Dr. Lie said. “This, then, means that there are at least 30% of patients not being counted as responders in these studies,” Dr. Lie said.

Antibodies to TNF inhibitors have been found to be a culprit in loss of response, she noted. Researchers found an ASAS20 response rate of 74% in patients with no antiinfliximab antibodies, but only a 9% rate in those with antibodies.4 A similar pattern was found in patients taking adalimumab.5

In RHAPSODY, a 12-week study of adalimumab in AS patients, included 1,250 patients—326 of whom had prior use of infliximab, etanercept, or both. One of the predictors of achieving a response was a patient being TNF naive.6

Another study—DANBIO—found lower response rates in those receiving a second TNF inhibitor—37% on Bath Measures on Ankylosing Spondylosis Disease Activity Index (BASDAI)—compared to those receiving their first—54%.

RHAPSODY’s data show that the reason for the switch can be a powerful predictor of the response on a second TNF inhibitor. The BASDAI50 response rate was 26% for those who switched because of a lack of response, compared to 43% for those who switched because of a loss of response and 39% for those who switch because they were intolerant. For ASAS20, those rates were 26% for lack of response, 42% for loss of response, and 46% for intolerance.

“Response rates,” Dr. Lie said, “were lower in those who had registered primary lack of response to the first TNF inhibitor as compared to those who had either loss of response or intolerance.”

New Therapies Under Investigation

Joachim Sieper, MD, professor of rheumatology at Charite University Hospital in Berlin, said that, beyond TNF inhibitors, there is not much that is proven in the way of biologics in axial spondyloarthritis. But several prospects are on the horizon.

Abatacept, anti–IL-6R-antagonists, and anakinra, an IL-1-receptor antagonist, have been shown not to be effective.

Rituximab might be one avenue that deserves to be explored further, he said. A study—involving 10 patients who had never tried a TNF blocker and 10 with whom a TNF blocker had failed—showed promise among the TNF-naive patients. In that group, at Week 24, 50% had achieved an ASAS20 response, 40% an ASAS40 response, and 50% a BASDAI50 response.7

“I think the data would justify to go the next step, to do a small, placebo-controlled trial,” he said.

In his own lab, there are plans to further explore ustekinumab, an interleukin (IL) 23 blocker, after a trial of 20 patients with active AS showed benefit, Dr. Sieper said. The patients had shown an inadequate response to two more NSAIDs taken for at least two weeks or demonstrated an intolerance or contraindication to them.

In the pipeline, Dr. Sieper said, are several studies that are ongoing or are about to begin. They include trials on anti–IL-17 and anti–IL-23 drugs, as well as apremilast, a phosphodiesterase inhibitor, and tofacitinib, a JAK inhibitor.

There is a lot of activity, he said. But, he added, “TNF blockers are still the only proven biologic to be effective in AS if conventional treatment fails.”

Thomas R. Collins is a freelance medical writer based in Florida.
References


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At: teens.spondylitis.org - Two new personal stories from teens have been added!

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