Through Sickness and Health: Planning a Wedding With Chronic Illness

Osteoporosis is a readily preventable complication of ankylosing spondylitis
Dear Readers,

Recently while reviewing the latest papers in research in spondyloarthitis (SpA) I was reminded not only of the dedication and hard work of researchers in our field during the past two decades, but also how vital patient involvement is in deepening our knowledge. Without you, this work would not be possible. Many of you over multiple years have travelled to research centers to participate in long-term studies. You have been willing to travel great distances, sometimes by airplane and sometimes in heavy traffic to help. We know that this effort requires personal sacrifice. Moreover, your support has yielded critical breakthroughs upon which the work can be expanded.

Now the good news. Findings since the launch of the SAA NASC Family Study in the late 90s have been widely disseminated in multiple abstracts and peer-reviewed publications in first-rate journals. These publications have generated a cascade of expanded interest in SpA. Furthermore, today, results from that work guide the next upcoming cycles of research into the cause, and the potential prevention of SpA. Questions currently being asked or previous conclusions being reconfirmed include whether our therapeutic tools address progressive bone disease in SpA; does HLA-B27 predispose to sub-clinical chronic infections that ultimately lead to spine inflammation and potentially early cardiovascular disease; how to shed light, using new imaging technologies, on the role of the gut and its resident organisms in disease initiation, pathogenesis and progression - - potentially with the outcome of prevention.

There is much work to be done. I am proud to be working alongside all of you toward a better future for those affected.

Thank you.

Laurie M. Savage
Executive Director
Re: My Life... My Aching Back! by Ardelle Staudt

As I read, “My Life, My Aching Back!” by Ardelle Staudt, it sounded so familiar that I could have been reading about my own life.

I have had back pain since I was a young girl that was explained as everything from, “she was premature,” “she fell on her tailbone,” to “herniated discs” and “in her head.” I was treated by every remedy known to man - including surgeries, without much help, and at times suffering greater pain due to them.

I’m 61 years old now and was diagnosed with AS about 10 years ago. Similar story too – I’d been to numerous doctors and they all told me the same things Ardelle was told. The final doctor I went to is my current Rheumatologist who ran the right tests and scans and I finally had a real diagnosis. I’ve taken every NSAID, steroid, pain pill, and even Enbrel and Humira. I’ve had side effects, allergies, hair loss, chronic, enormous hives and swelling of lips and eyes, but there hasn’t been much relief. I also tried the message boards and support groups early on in my diagnosis, but found no real solutions for our ailment. I learned that when I focused on my pain and disability, I felt worse.

Staying as active as I can, keeping a good sense of humor, visiting with friends, being involved with my children and playing with my grandchildren are the most effective remedies I’ve found. I know it sounds as though I’ve given up, but I haven’t. I’ve just given up on medications. Knowing that I’m not alone, that I have a true illness with a name is a lot of comfort; that comfort, and having a positive attitude have made the greatest of differences.

~KATHLEEN, Modesto, CA

Editor’s Note: Thank you, Liz. Dr. Jim Rosenbaum’s “Does the microbiome cause ankylosing spondylitis?”, can be found in the online archive of Spondylitis Plus - http://www.spondylitis.org/members/archive.aspx - in the Winter 2011 issue.

Still enjoying Spondylitis Plus...
Expanding The Therapeutic Horizon In Ankylosing Spondylitis

Osteoporosis is a readily preventable complication of ankylosing spondylitis

By Dr. Walter P. Maksymowych

Editor’s Note: This article by Dr. Maksymowych was originally published in the September / October 2004 issue of Spondylitis Plus. Over the last decade it has become one of the most referenced articles we have on hand when dealing with questions of osteoporosis in AS, the role of vitamin D in spondylitis, and related issues. We asked Dr. Maksymowych to update the article with the most current research and information. Here we present the updated article to you.
There are several aspects of Ankylosing Spondylitis that are only now becoming more widely appreciated in the medical community that have major implications for its treatment. As is so often the case, this has arisen following the application of a new technology, in this case Magnetic Resonance Imaging (MRI). This has enabled us to better understand the conundrum as to why patients with AS have a more fragile skeleton despite the overgrowth of bone that is so typical of this disease. This, in turn, has led to the introduction of additional therapeutic approaches for this disease.

Why do patients with AS have a more fragile skeleton? It is of some considerable interest that this was first noted almost a century ago when post-mortem analysis of spines was the only available approach to conducting research in this disease. Several pathologists remarked on the fact that cutting through the bones of patients with AS was like cutting through putty — the knife met no resistance whatsoever. These observations were largely forgotten and/or ignored until the modern era of advanced radiological imaging techniques and molecular immunology.

The introduction of MRI showed several interesting findings that readily helped to show just how different AS was from rheumatoid arthritis (RA). Although AS patients understand that, like RA, this is an inflammatory disease of joints, what is not well appreciated is that the major site of inflammation is in the bone next to the joint. We call this an osteitis, which means inflammation in bone. Very often, MRIs from AS patients show minimal inflammation in the joint but striking inflammation in the bone next to the joint. This is different from RA where inflammation within the joint is the major feature of disease. In addition, what is essentially unique for AS is that this inflammation in bone is also typically seen where ligaments and tendons attach to the bone.
A classic example would be the Achilles tendon attachment to the heel bone. In our institution we have seen examples where the entire heel bone is inflamed. These patients often receive cortisone injections around the Achilles tendon with little benefit. This is not surprising since the major source of pain and inflammation is actually within the heel bone. Another example is the shoulder. This is a problem that is not well recognized by medical practitioners and often dismissed as "bursitis" or "tendonitis." These patients also have inflammation within the bone where the shoulder tendons attach to the point of the shoulder. Cortisone injections around the tendon are unlikely to be of benefit for many patients because the major site of inflammation is within the bone. These same features are observed on MRIs in the spines of patients with AS. The major site of inflammation is within the bone of the vertebrae.

If this local inflammation in the vertebrae is not checked, it will ultimately cause severe loss of bone mineral, resulting in fragile bones. But there is also a second way in which patients with AS can get fragile bones.

We now know that severe inflammation — wherever it exists — causes the release of certain chemicals into the blood that activate cells in bone that can literally dissolve bone mineral. These cells are called osteoclasts. They are normally present in bone but are only activated periodically when bone undergoes re-modelling in response to the stresses of various activities, e.g., sports. These cells secrete acid, which dissolves bone very efficiently. It is therefore understandable that the body keeps these cells under tight control — most effectively by secreting sex hormones, which typically shut these cells down. This is why the menopause is a precarious period for the bones of women. The rapid decrease in sex hormone production results in the activation of osteoclasts — as if they are emerging from a period of hibernation. Women then become at high risk for osteoporosis. Long-standing inflammation also causes persistent activation of osteoclasts. How does this occur?

Inflammation, whether it occurs in the joints, the intestine, the lungs, causes the release of a whole variety of molecules into the blood. Some of these cause an elevation of body temperature. Others cause fatigue. Yet others cause persistent activation of osteoclasts. This is why RA is a major risk factor for osteoporosis and fractures of the spine, even though the inflammation of RA does not occur within the spine other than the neck. Similarly, chronic inflammation of the bowel — colitis — also results in osteoporosis and an increased risk for fractures of the spine and hips. AS patients also release these same molecules into the blood that cause activation of the osteoclasts. So AS patients suffer from a double-whammy when it comes to the development of fragile bones. They have inflammation locally within the bones of the spine but also release molecules into the blood that cause...
activation of osteoclasts. This is one of the reasons why patients with AS are at much higher risk of developing fractures of the spine. To make matters worse, the AS spine is not that flexible and so is more likely to fracture if subjected to any significant impact. We don’t usually advise patients to play football!

“It is surprising how many patients with AS are vitamin D deficient — about 20% in my practice.”

Is there anything that can be done about this? The answer is — a great deal. First, patients must make sure that they stay active, not only to preserve strength and flexibility but also to preserve bone mineral. The cells that make bone mineral — osteoblasts — love weight-bearing exercise. But they can only make bone effectively if they are supplied with the proper nutrients. This means plenty of calcium, about 1500mg per day. A good rule of thumb is that a good helping of a dairy product, e.g., yoghurt, cheese, tall glass of skimmed milk, amounts to 300mg of elemental calcium a day. So does one tablet of extra-strength Tums. Beware of expensive calcium preparations that often fail to deliver on the required amount of elemental calcium. Read the label and make sure you know how much elemental calcium is in the product because this is what really counts and not the total grams of each tablet (which is what is often on the front label). Good nutrition also means at least 800 units of vitamin D per day. It is surprising how many patients with AS are vitamin D deficient — about 20% in my practice. North Americans are not great milk drinkers, and if you are amongst them, then over-the-counter supplementation is important. Some patients take a great deal more vitamin D but there is little evidence to support using more than 2000 units daily.

Is there a way of testing whether you are already at increased risk of having a spinal fracture? This is normally done by having a bone density test — often confused with a bone scan. Bone density testing is widely available in North America, and, in my view, everyone who has had AS for at least 10 years should have this done. If a fracture has already occurred, a bone density test should be done regardless of how long the AS has been present. This is the same approach to the assessment of osteoporosis for women of post-menopausal age. Is such screening currently being done for patients with AS? A recent survey of British rheumatologists showed that only a minority of AS patients had received bone density tests, and it is likely that the figures in North America would not be very different. Osteoporosis in AS patients is clearly not a well-recognized problem and requires more vigorous intervention.

Are there any effective pharmaceuticals for this problem? Several agents have now been shown to be effective for the treatment of osteoporosis. These include agents such as fosamax and actonel, which belong to a general class of drugs called bisphosphonates. These are amongst the safest drugs ever developed in the history of pharmacology. They have been shown to be effective in most forms of osteoporosis and to be equally beneficial in men as well as women. Although they have not yet been specifically tested in AS, there is no reason to expect that they would not be equally effective in this condition also. They tend to work better if patients are taking adequate vitamin D. These medications are taken weekly and the best way to take them is with a full glass of water, right after getting out of bed in the morning, and avoiding anything other than water for an hour after taking the medication. This ensures that the medication is absorbed into the system. Also, make sure you do not lie down after taking the medication because it may irritate the lower esophagus and give you nasty heartburn.

The available biological therapies for AS, Enbrel, Remicade, Humira, Simponi, and Cimzia, may also prevent loss of bone mineral by shutting down inflammation and putting the osteoclast back into hibernation mode. It is not known if the simple anti-inflammatories, such as naproxen, are sufficiently effective to do this but this seems unlikely.

AS patients have a major opportunity to practice effective health care prevention. Osteoporosis is a readily preventable complication of AS. Most primary care practitioners are unfamiliar with this complication of AS. Sounds like more work for the SAA!

Dr. Maksymowych is a Professor in the Department of Medicine at the University of Alberta in Edmonton. He is a Medical Scientist of the Alberta Innovates and health Solutions, member of the Assessments in Ankylosing Spondylitis International Working Group, and the Spondyloarthritis Research Consortium of Canada, and Chief Medical Officer of Canadian Research and Education (CaRE) Arthritis Limited.
As Dr. Maksymowycz stated in the previous article on pages 4-7 in this issue, osteoporosis can be an often overlooked problem in AS.

Notwithstanding the increased fracture risk in those with osteoporosis, people who have AS are already at a greater risk of fracture* - this is especially so in those with spinal fusion. Thus it is important to avoid falls. What follows are a few simple tips to help decrease the chance of a dangerous fall and possible injury.

**Daily exercise in AS is essential**

Staying active and exercising helps preserve strength, balance, flexibility, coordination and stamina, as well as bone material. According to Dr. Maksymowycz, “The cells that make bone mineral...love weight-bearing exercise.” But even low impact exercises such as Tai Chi, walking and swimming have been proven to be beneficial. Note that it is always important to check with your physician before beginning any new treatment program—including physical therapy or a new exercise regimen.

**What about a balanced diet?**

The body requires the right nutrients in order to produce bone. This is accomplished by following a balanced diet and possibly taking nutritional supplements.

Plenty of calcium is needed to help lower the risk of osteoporosis and fragile bones, which are possible complications of AS; 1,500mg of calcium daily is recommended. Vitamin D supplements can also be beneficial.

Note that some nutritional supplements can interfere with prescription medications, so make sure to check with your doctor before adding supplements to your diet.
Are you seeing as well as you should be?

Iritis and uveitis (inflammation of the eye) are common complications of ankylosing spondylitis. If you are experiencing redness of the eye, pain, sensitivity to light and/or skewed vision, make sure to have your eyes checked by an ophthalmologist. Also, as one gets older, vision impairment can increase the risk of a fall, so regular visits to an ophthalmologist / optometrist should be considered. If you wear eyeglasses, make sure to clean the lenses often.

Caution is critical when taking multiple medications

Those who take multiple medications – especially if prescribed by multiple doctors – should have a physician or pharmacist conduct an in-person review of all current medications. Certain medications can contribute to falls by reducing mental alertness, causing drops in blood pressure, and affecting balance.

Household Tips

Make your household as safe as possible. Home modifications can improve accessibility, adaptability and design:

• Organize furniture and décor so that pathways are always clear.
• Keep areas free of clutter and keep objects off the stairs and floor.
• Avoid floor wax, throw rugs and other accessories that can cause you to slip.
• Add a non-slip rubber mat or self-stick strips on the shower/tub floor.
• Use a nightlight and/or make sure to have a light source within reach before moving about the house at night.
• Repair loose steps, floor cracks and other hazards ASAP.
• Keep a telephone within reach of your bed and off the floor.

Talk to your rheumatologist about a base-line bone density test

Finally, there is a way to test whether you are already at an increased risk of spinal fracture. This is called a Bone Mineral Density Test. From WebMD.com: “A bone mineral density (BMD) test measures the density of minerals (such as calcium) in your bones using a special X-ray or computed tomography (CT) scan. This information is used to estimate the strength of your bones.

“We all lose some bone mass as we age. Bones naturally become thinner (called osteopenia) as you grow older because existing bone is broken down faster than new bone is made. As this occurs, our bones lose calcium and other minerals and become lighter, less dense, and more porous. This makes the bones weaker and increases the chance that they might break (fracture).”

Consider a medical alert bracelet in case of an accident

In SAA’s EMS / EMT training program, “Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders”, emergency first responders recommend those who have AS get a “Medic Alert” bracelet or necklace with the inscription, “Ankylosing Spondylitis: Brittle Spine Disease.” EMS / EMT workers are trained to look for these alert bracelets / necklaces and it will notify them to use special precautions in transportation and treatment.

To view the training program or to learn how to distribute it to local emergency first responders, please visit us online at StopAS.org/ems.

*Reference

NEW MEDICATIONS For Ankylosing Spondylitis & Psoriatic Arthritis

Introduction
In the past six months, one new medication has been approved by the FDA for ankylosing spondylitis (AS): the TNF-a inhibitor, Cimzia (certolizumab pegol). Also, two new medications have been approved for psoriatic arthritis (PsA): an IL-12/IL-23 inhibitor called Stelara (ustekinumab) as well as a drug called Otezla (apremilast), which works by blocking an enzyme called PDE-4.

Editor’s Note: SAA does not endorse or recommend any medications or products for spondylitis, and always advises that you seek the counsel of a physician before starting or stopping any treatment for spondylitis.

Cimzia: The New TNF-a Inhibitor For Ankylosing Spondylitis
Approved on October 18, 2013 for ankylosing spondylitis, Cimzia brings the total of FDA approved TNF-a inhibitors for AS to five; Enbrel (etanercept), Remicade (infliximab), Humira (adalimumab) and Simponi (golimumab) round out the rest of this class of medications. The Tumor-Necrosis-Factor alpha (TNF-a) blockers are biologic medications that have been shown to be highly effective in treating not only the arthritis of the joints but the spinal arthritis associated with ankylosing spondylitis and related diseases.

These medications target and attempt to suppresses the response to TNF-alpha in the body. TNF-alpha is a cytokine involved in the inflammatory process. Excess amounts of TNF-alpha have been associated with various forms of inflammatory arthritis.

As a subcutaneous, self-injection from a pre-filled syringe, the dosing regimen for Cimzia is flexible. According to the manufacturer’s website, cimzia.com, “It can be given as one 200 mg shot every 2 weeks, or it can be given as two 200 mg shots every 4 weeks, depending on what you and your doctor decide is best for you.”

Cimzia was previously approved for treating:
• Psoriatic Arthritis
• Rheumatoid Arthritis
• Crohn’s Disease
Stelara For Psoriatic Arthritis

Stelara was approved on September 23, 2013 for psoriatic arthritis. It was previously approved for psoriasis.

According to drugs.com, “Stelara...is an immunosuppressant that reduces the effects of a chemical substance in the body that can cause inflammation.” Specifically, it targets interleukin 12 (IL-12) and interleukin 23 (IL-23), naturally occurring proteins that regulate the immune system and immune-mediated inflammatory disorders. Those targets differentiate the drug from the TNF-a inhibitors.

Stelara’s official website, stelarainfo.com, states that the drug is a “45 mg or 90 mg injection given under the skin as directed by your doctor at weeks 0, 4, and every 12 weeks thereafter. It is administered by a healthcare provider or self-injected only after proper training.”

Otezla For PsA

On Friday, March 21, 2014 the FDA approved Otezla for treating psoriatic arthritis. It is unique from the above medications in that it is an inhibitor of phosphodiesterase-4 (PDE-4) and is taken in pill form and not an injection. The drug is also the first oral therapy approved for PsA.

The pill is a twice-daily 30-milligram dose, but the dosage initially starts lower and gradually increases over the first five days until the patient reaches the recommended dose of 30 milligrams

Otezla currently has no other indications besides the treatment of PsA.

For More Information On Stelara Including Dosing, Potential Side Effects And More, You Can Visit The Drug’s Official Website At:

http://www.stelara.info.com/

For More Information On Otezla Including Dosing, Potential Side Effects And More, See:

http://www.drugs.com/otezla.html - Info at drugs.com

FDA Approves Otezla, a New Pill for Psoriatic Arthritis (Article At Healthline.com)


http://www.otezla.com/ Otezla’s official site
The Social Security Administration recently announced their automatic Cost of Living Adjustment (COLA) for 2014. The purpose of the COLA is to keep Social Security and Supplemental Security Income (SSI) benefits in line with inflation.

The COLA is equal to the percentage increase (if any) in the average Consumer Price Index for Urban Wage Earners and Clerical Workers (CPI-W) for the third quarter of the current year as compared to the average for the third quarter of the last year in which a COLA became effective. This year’s increase is 1.5% because the increase in the average CPI-W for the third quarter of 2013 was 1.5% higher than the average CPI-W for 2012.

“This is one of the lowest rates since the automatic COLAs came into existence in 1975”

Historically, this is one of the lowest rates since the automatic COLAs came into existence in 1975. The lowest rates were in 2010 and 2011 when there was no cost of living increase due to their being no increase in the Consumer Price Index (CPI-W) over the applicable period. The highest COLA, on the other hand, was in July 1980 when inflation spiked the COLA to 14.3%!

By the numbers

• SSI benefits will increase to $721/month for individuals (up from $710/month in 2013). It is estimated that the average Social Security Disability Insurance (SSDI) benefit amount for a disabled worker, spouse and one or more children will be a significantly higher $1,943/month. For all disabled workers, the average is $1,148/month in 2014.

• For couples, SSI benefits will rise to $1,082/month (up from $1,066/month in 2013).

• Substantial Gainful Activity (SGA) amounts will increase from $1,040 to $1,070 gross earnings per month. If a non-blind person earns more than this amount, they may be engaging in SGA, which can affect their entitlement to disability benefits.

• The Trial Work Period (TWP) amount will increase from $750 to $770 gross earnings per month. During a TWP, a person receiving SSDI benefits is able to test their ability to return to work, on a trial basis. Only a certain number of TWP months are allowed. For details, please see SSA’s website or contact me.

Retirement: How Much Will You Receive?

For those retiring at full retirement age in 2014, the maximum Social Security benefit will be $2,642/month.

What is retirement age? Here is a handy chart from Social Security’s website:

<table>
<thead>
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<th>Date of Birth</th>
<th>Full Retirement Age</th>
</tr>
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<tbody>
<tr>
<td>1955</td>
<td>66 and 2 months</td>
</tr>
<tr>
<td>1956</td>
<td>66 and 4 months</td>
</tr>
<tr>
<td>1957</td>
<td>66 and 6 months</td>
</tr>
<tr>
<td>1958</td>
<td>66 and 8 months</td>
</tr>
<tr>
<td>1959</td>
<td>66 and 10 months</td>
</tr>
<tr>
<td>1960 and later</td>
<td>67</td>
</tr>
</tbody>
</table>
How to Qualify for Social Security Disability Insurance Benefits (SSDI)

To qualify for SSDI benefits, as opposed to SSI benefits, the disabled worker must accumulate a certain number of “Quarters of Coverage” (also sometimes referred to as “Credits”). This is the basic unit used to determine whether workers are insured under the SSDI and other programs. Quarters of Coverage are earned by working and paying taxes. The number necessary to be insured varies by age. For example, an individual age 31 or older generally needs at least 20 Credits in the 10 years immediately before becoming disabled.

The dollar amount required for one Credit has increased to $1,200 in 2014 (up from $1,160 in 2013). A maximum of four Credits can be earned per year.

Public Debate About the COLA

There has been some consideration in Congress as to how the COLA is determined. In April 2013, the House Ways and Means Committee conducted a series of hearings on “entitlement reform.” They solicited comments concerning whether Social Security’s COLA should be tied to a different index, the Chained Consumer Price Index (C-CPI-U).

One of the ways that the C-CPI-U differs from the CPI-W is that the C-CPI-U takes into account something called “consumer substitution.” This is where a consumer substitutes a lower priced type of product for another. As the Bureau of Labor Statistics, which calculates and determines the various CPI indexes, states: “If the price of pork increases while the price of beef does not, consumers might shift away from pork to beef.” (Bureau of Labor Statistics, Consumer Price Index, http://www.bls.gov/cpi/cpisupqa.htm, visited on January 23, 2014.)

Joining the debate has been the Consortium for Citizens with Disabilities (CCD), a coalition of organizations that advocates for the disabled (www.c-c-d.org). It has opposed basing the COLA on the C-CPI-U. The CCD argued in its comments to the House Ways and Means Committee that the C-CPI-U does not adequately protect against inflation and will likely result in significant reductions in benefits for those receiving disability benefits. It noted in its comments: “... like many seniors, people with disabilities often spend a disproportionate amount of their monthly budget on out-of-pocket medical expenses and on housing. Most beneficiaries with disabilities have already economized as much as possible and have little room in their budgets to make additional substitutions as envisioned under the chained CPI-U.” (CCD Comments on: “Using the Chained Consumer Price Index to Determine Social Security Cost-of-Living Adjustments and Benefit Increases for Long-Time Social Security Beneficiaries” 8/9/13)

This issue as well as many others certainly will be considered over the next few years as we get closer to 2016, the year that the Disability Insurance Trust Fund’s reserves are expected to be depleted. This does not mean that this trust fund will become “bankrupt” or “insolvent.” This is because the Disability Insurance Trust Fund will still be able to pay 80 percent of scheduled benefits in 2016 based on incoming payroll tax revenues. The depletion of the reserves, though, is a serious matter, for which a number of fixes exist.

For more information on these important topics, please visit Social Security’s website, www.socialsecurity.gov, and search for the topics that you want to investigate.
My name is Cookie Hopper, creator of “The Faces of Ankylosing Spondylitis” Website and Information Board. These websites were created in memory of a young man who in the midst of his pain lost all hope and took his life, and a young woman who during her last days on earth was an inspiration to all of us. I wanted to make a difference in our community that would reach people globally and at the same time honor these two very special people.

My vision was to create a place where people could be honest about their lives with AS and where our community could honor our challenging lives. A place where those who suffer with AS know someone cares, where we know we are not alone because we are in this together.

But this is not just about AS It is about experiencing the uncontrollable destruction of life. It is about finding the courage to fight for a better quality of life; it’s about finding the hope to continue to live the best life possible, all while struggling to find the faith to do so.

It’s time we take a stronger stance in bringing more awareness, research and funds to our battle against Ankylosing Spondylitis. I want to take this opportunity to thank the Spondylitis Association of America, and all the individuals who have helped me along the way. Their work and determination to make a difference in the AS community will never be forgotten.

So many of you have offered to help with the cost of my project, and so I decided to create special bands that honor all of us living with Ankylosing Spondylitis. These bands will help us make a difference in raising awareness, funding for research, but mostly they will honor those who suffer with this every day.

Please show your support by making a donation or purchase of these special bands.

We can’t do this alone; remember we are in this together. The Spondylitis Association of America has been kind enough to join forces with me in this project, will you? Remember no donation is too small; everyone matters in our fight against AS!

If you would like to make a donation or purchase the bracelets by phone, you can call SAA at (800) 777-8189 (U.S. only) or (818) 892-1616.

You can purchase these limited edition awareness bands by going to: StopAS.org/cookie
In the spring of 2013 SAA members and volunteer support group leaders, Bonnie Smith and Michael Smith (no relation) were selected to serve on FDA Advisory Committees as Spondylitis Patient Representatives. In August of the same year they both attended their first FDA Patient Representative Workshop, meeting one other for the first time, along with about 35 other Patient Representatives from different parts of the country representing various illnesses. We asked Bonnie and Michael to share their experience at the workshop. We thank them both for serving in the important capacity of Patient Representative, and also for taking the time to write about what they saw and learned.

We met such committed and passionate health advocates and were inspired by their experiences and wisdom. Mike and I and the others were encouraged by Patient Rep Marlene to become part of our healing process. Patient Reps Gigi and Pamela shared their experiences serving on FDA Advisory Councils. Matthew, Patient Rep and AIDS activist, took us through the AIDS community’s journey in becoming effective voices for change.

We heard presentations on the Product Development Lifecycle of Drugs and Medical Devices, and discussed Conflict of Interest. We learned about FDA’s MedWatch and Adverse Event reporting, worked on formulating our thoughts in preparation of testifying at an FDA Advisory Council meeting, and discussed the topic of Health Disparities and Minority Health.

An extensive Q&A with the OHCA Patient Liaison Team helped clarify concerns, and Heidi Marchand, Head of the Office of Health and Constituent Affairs competently wrapped up the intensive two-days.

Discovering that we are not alone in our health journeys, and that we are not alone in our belief that one person can make a difference, a phrase I read recently in a book comes to mind:

*Look up, not down.*
*Look ahead, not back.*
*Look out, not in.*

It could be our motto. Now and in the days ahead.

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**Bonnie Smith - It’s All About Discovery**

Discovery. It was all about discovery. Discovery of what it means to be an FDA Patient Representative. Discovery of how the FDA Office of Health and Constituent Affairs (OHCA) works. Discovery of pockets of communities across the nation who, faced with health challenges of their own, reach out to help others.

From the first friendly moment, “Hi, you must be Bonnie,” to the last “Here’s my contact info - let’s keep in touch,” the FDA Patient Representative training workshop at the University of Maryland in Hyattsville, MD was a voyage of discovery.

The thirty-five or so workshop participants from around the country were the beneficiaries of the planning, preparation and execution of the FDA OHCA staff through the two-day conference. We learned from the best, from seasoned staff workers, from experienced Patient Representatives and from each other.

Faced with what appeared to be overwhelming health challenges, the participants I met proved again that “Those who can, do. Those who can do more, volunteer.” Part of me was wondering what I was doing among this stellar group, and part of me said, “Hey, I can do this. I can represent people with Ankylosing Spondylitis and Crohns, too, because I share some of those challenges. So does FDA Patient Rep, Michael Tracy Smith (no relation, or at least not that we know of, except perhaps, through Adam).
This was only my second trip to Washington, D.C. in over forty years. I was on my way to a workshop held by the FDA for Patient Representatives: advocates for chronic diseases who represent the patient’s interests. I was one of two patient representatives for spondylitis. (The other, Bonnie M. Smith - no relation - was from North Dakota and as warm and friendly a person as I have ever met.) I live in New York City and have had AS for over 30 years. I’ve been diagnosed for over 25 years.

My first trip to Washington, D.C. was just a few weeks earlier, when I debuted as a Patient Representative at an FDA Arthritis Advisory Committee Conference, debating the merits of expanding the prescribing parameters for a couple of biologic drugs. That was an intense couple of days with some very smart people in attendance (Doctors and Scientists mostly), discussing clinical studies and non-radiographic axial spondyloarthropathies. Now, with that challenge behind me, I was going to attend the workshop that, in a perfect world, would have come BEFORE I served on the Arthritis Advisory Committee. But, never mind that. I was thrilled to be chosen to be a Patient Representative.

I have been an advocate for raising spondylitis awareness since 1995. Now, I was stepping into a roomful of my peers - other advocates for other chronic diseases. Even knowing this, however, did not prepare me for hearing the stories of my fellow Patient Representatives. They were truly amazing and inspiring. What I found most interesting was that for all the variety in our stories, all the different ways people manifested their activism, there was one common thread: we had all been diagnosed with something and had initially felt all alone ... but we all took some course of action to rectify that feeling. For many, it was to start a support group or to dedicate their lives to a cause; to change things for the betterment of themselves and all the other people with their disease. We were a formidable bunch, each in our own sphere, affecting positive change in the world. We spent two days getting a better understanding of how we could focus that commitment into positive action in partnership with the FDA. They truly wanted to hear what we had to say when it came to issues that affected people with Spondylitis! And we got to learn how we could affect the process by working within the system. Pretty heady stuff indeed. I left the workshop inspired and with an even greater commitment to continue my advocacy for people with Spondylitis ... and knowing I have new tools in my arsenal with which I can affect positive change.
Curious About Volunteering Or Advocating?

Volunteering

Our volunteer fundraisers have been extremely inventive in creating projects that have helped benefit the spondylitis community. Some more athletic SAA members have run races and asked for pledges, one held a very successful fundraising dinner in New Jersey, and one amazing teen even organized a baseball “Hit-a-Thon” derby - all on their own initiative.

To learn more about ways you can fundraise visit our website at:

StopAS.org/volunteer

Questions? You can also contact Robin Kindrick at SAA toll free at 1-800-777-8189 or by email at robin.kindrick@spondylitis.org.

Advocating

SAA is the only non-profit organization in the United States dedicating its resources to the active support of spondylitis patients to bring about awareness, education, and research to ensure a better life for all spondylitis patients.

SAA’s Advocacy Priorities

• Promoting earlier diagnosis and treatment of spondyloarthritis
• Promoting public awareness and education about spondyloarthritis
• Improving access to appropriate quality health care and medications for all spondyloarthritis patients
• Increasing federal funding for arthritis research
• Affecting public policy that impacts the lives of spondyloarthritis patients

For more information about our advocacy efforts, or to learn about becoming an advocate, please visit us online at:

StopAS.org/advocacy
Editor’s Note: John and Maya’s paths first crossed near Rochester, New York at Sunshine Camp - an amazing, week-long escape for children living with Muscular Dystrophy. They met in the summer of 2003 when they were both volunteer counselors; John was 17 and Maya was 16. The pair remained friends for many years, seeing each other for only one week at camp every year. It wasn’t until 2008 that they reconnected, realizing what a deep bond they shared. Maya and John now live together in New York City with their sweet beagle Penny. They were married on October 12, 2013 in Skytop, Pennsylvania. Readers may remember Maya from the Winter 2006/2007 issue of Spondylitis Plus where we wrote about Maya’s semester abroad in Melbourne, Australia when she was still in college, and also about her experience volunteering at a certain summer camp in New York for children with Muscular Dystrophy... You can revisit that original story online in our Spondylitis Plus archives. Our Congratulations to Maya and John!
When two people decide to walk through life together, it calls for celebration. For some couples, this might mean a large, traditional wedding, while others may gravitate toward an intimate ceremony for two. If you are living with chronic illness, you know a key element in maintaining your health is limiting stress. Before embarking on the wedding planning process, consider what type of celebration is right for you. Don’t venture too far out of your comfort zone. Whatever you choose, there are ways to ensure that you remain healthy and able to enjoy this exciting new chapter.

Marriage is about two people; partners who vow to support each other through good times and bad. However, no relationship is an island. Like it or not, marriage affects those around you and, if you’re anything like me, those loved ones also have an effect on you. The night my husband John proposed, people already asked if we had set a date. If there is one thing I have learned from living with illness, it is the importance of pausing to experience the joy at hand. You may sense external pressure, but it is important to move only at your own pace. Make your health and happiness a priority. Take time to revel in your engagement.

I am able to offer this advice after making many mistakes of my own. I plunged head first into wedding planning, partly because of my own excitement and partly because I felt it was expected. I was soon inundated with tasks - setting dates, selecting color palettes, and booking vendors. Meanwhile, John and I were both graduate students, and my health was wavering. We rushed to set a date, which was the one weekend between our graduations and the start of John’s medical residency. There was barely time to breathe.
I quickly felt like I was in over my head. Living with Ankylosing Spondylitis and Fibromyalgia, two conditions that cause extreme pain and fatigue, means living with uncertainty. How could I plan a wedding when I had trouble planning for tomorrow? What if I could barely get out of bed on my wedding day? Before long, our limited time together was dominated by “wedding talk”, and the joy of our engagement was overshadowed by stress. This wasn’t what we had envisioned for ourselves. We wanted to take our time and actually enjoy the process. Eventually we decided to postpone our wedding until the timing was right for us - one of the best decisions we’ve ever made.

Before jumping back into wedding planning, we needed to consider if a wedding was truly right for us. We communicated openly about my fears, and discussed other ways to celebrate. Ultimately we decided it was important to us that we share our marriage with friends and family. We knew it would take some creativity, but were determined to make a wedding work for us. We also took comfort in our incredible support network; loved ones who insisted we lean on them.

This time around, we chose our wedding date carefully. My pain levels have always been affected by extreme weather. We chose October not only for its beautiful foliage, but because it gave me the greatest chance of feeling well. Remember that nothing is more important than your health. While it’s easy to get wrapped up in wedding details, make wellness your number one priority. Listen to your body and know its limitations. After all, feeling healthy on your wedding day will ensure you can enjoy it to the fullest.

I quickly recognized the need for order in the wedding planning process. I kept a detailed binder full of photos, ideas, checklists, etc. I also made sure to assemble a strong support network of friends and relatives. Because countless people offered their help and contributed their talents, our day was made even more special. If funds allow, consider hiring a wedding coordinator whose services can range from orchestrating your entire event, to stepping in shortly before the wedding as a “day of” planner. Don’t hesitate to ask for help from the people in your life. Prior to your wedding create a detailed schedule of the day, listing where everyone needs to be and when. Distribute copies to family and close friends, and consider assigning people to specific jobs. For example, if you are taking family portraits, ask someone to start gathering your relatives ahead of time. This will not only help to ensure that precious time isn’t wasted, but it will help you relax and focus on your wellbeing.

When planning the logistics of your wedding day, always consider your physical needs. For instance, if your ceremony is long, place a chair nearby in case you have difficulty standing. Include only traditions that work for you and your partner, and let go of ones that don’t.
and I had taken dance classes and planned to perform a choreographed waltz for our first dance. However, three weeks before the wedding, these practices were wearing me down. Then I read this quotation: “A wedding is a party, not a performance. If at the end of the day, you are married to the one you love, then everything went perfectly.” We cut the dance, realizing this was one stress we could easily eliminate.

Since social situations have historically increased my pain, the thought of everyone we loved in one room was both wonderful and daunting. I worried about being in the spotlight, particularly if I felt unwell. Then a good friend offered an important reminder: this was our day, and I needed to allow myself to enjoy it. When making our seating plan, John and I opted to have a “sweetheart table”. This provided us with an important resting spot during our wedding; a place to reconnect, breathe, and take it all in. It also enabled me to spend less time on my feet. Instead of walking around during dinner to greet everyone, we stayed seated while our guests approached us.

The fashion you choose for your wedding day can also dramatically impact your ability to enjoy it. Every bride wants to look beautiful, but women coping with chronic illness should value their comfort above all. Look for a wedding gown that is lightweight and does not restrict your body. Similarly, allow yourself ample time to find the right footwear. Nothing can put a damper on your day quite like foot pain. Remember bridal shoes don’t need to be 5 inches high - there are styles that are both special and practical.

Throughout the planning process, be sure to reserve time for yourself and for your relationship. Do things you enjoy as a couple unrelated to wedding planning. Dream about the future. If you are able to take a honeymoon, consider how you may feel after your wedding. Our bodies can still be negatively impacted by “happy stress”, so it is likely you may feel worn down. John and I fantasized about exploring rainforests or going on safari during our honeymoon, but we also needed to consider my health. In the end, we chose a relaxing destination that provided me with ample space and time to recover. We made time for adventure, but I was very grateful to have the option of doing nothing.

In preparation for your wedding, it is more important than ever to maintain healthy habits. Make sure you are eating properly, drinking enough water, and getting adequate sleep. If your goal is weight loss, implement a healthy plan well in advance. Too many brides resort to crash dieting or excessive exercise, placing greater value on their appearance than their health. For a bride with chronic illness, this can be particularly harmful. Above all, treat yourself with kindness. No matter how busy you get, keep up with your medical appointments. Explore alternative treatments, such as massage or acupuncture (your insurance may even cover these).

On the day of your wedding it is particularly important to keep your routine as normal as possible. Start your morning with a healthy breakfast, and remember to hydrate yourself. Ask a friend to hold onto medications you may need and check in with you throughout the day. These things can all help lower stress levels, alleviate your symptoms, and help you better enjoy your wedding.

Like many people, I grew up envisioning my wedding day - the perfect husband, the beautiful gown, and the happily ever after. Living with chronic illness doesn’t mean you can’t have your dream - it just means you need to thoughtfully plan ahead. For the sake of your health and happiness, cherish all of it. Things may not go entirely as planned but it can still be perfect. Feel the supportive warmth of family and friends as you take this remarkable step together. Bask in the joy of the present and the excitement of tomorrow. Above all, remember you are here because of love.
I have arthritis, specifically, Ankylosing Spondylitis (AS). It’s a painful, degenerative disease and I’m always in pain. My tendency, like so many others, is to suffer in silence, downplay how much it hurts. I think it’s a form of defiance, mixed with some sort of denial. I won’t pretend to understand the psychology, but I know it’s there and the practice isn’t necessarily healthy for me, or those around me. Sometimes I can ignore the discomfort and function, other times the misery consumes me. Even then, I always hold on to my silence as long as I can.

I’m an expert on what my pain does to me, and I’m also aware of what my pain does to the people around me. Close proximity to someone who suffers from chronic pain can be challenging, bordering on the impossible. I know how poorly I can behave. I also know that as hard as I try, I am at the mercy of the battle raging inside my body.

But this story isn’t about AS, it’s about those who take care of us, the people caught in the storm of our illness. In a perfect world there are things that should be communicated daily, but in the culture of suffering in silence, I think many of us keep our feelings inside. For those who care and love someone with AS, or any other disease that generates chronic pain, you bear the greatest burden in this war. For you I’ve written a simple wish list—one that I promise every victim of AS has thought many times.

- I wish I didn’t snap at you, or be abrupt, when in my heart you’re the last person who deserves to be treated poorly.
- I wish you had more reasons to smile.
- I wish I didn’t get so tired and could be of more help to you.
- I wish I didn’t keep losing parts of my mobility so we could have some sort of normal life.
- I wish I didn’t lie to you about my pain to try to minimize your concern.
- I wish you didn’t know so much about this disease, and what it does to the human body.
- I wish the drugs I sometimes take didn’t rob me of my personality.
- I wish you didn’t see me cry.
- I wish I didn’t have this disease, more for what it does to you, than to me.
- I wish I didn’t have to see the suffering in your eyes, and know that at times your anguish is greater than my physical pain.
- I wish you’d gotten a better set of circumstances in life.
- I wish you knew that at times I want you to go find those better circumstances. It’s my greatest hope for you—and my deepest fear.
- I wish you knew how much I need you, and that I couldn’t do any of this without you.
- I wish that anyone who reads this and finds even one sentence that resonates—please share.

For thirty years Donlay was a professional pilot—Ankylosing Spondylitis cut that career short. He is the author of four novels: Category Five, Code Black, Zero Separation, and his latest, Deadly Echoes, scheduled for release April 1st. For more information please visit www.philipdonlay.com or Facebook at Facebook.com/AuthorPhilipDonlay
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<td>Phoenix/Tucson</td>
<td>AZ</td>
<td>Jacqui Gregor</td>
<td><a href="mailto:mjgregor@cox.net">mjgregor@cox.net</a></td>
<td>(520) 241-7064</td>
</tr>
<tr>
<td>Los Angeles</td>
<td>CA</td>
<td>Richard Howard</td>
<td><a href="mailto:Richard@spondylitis.org">Richard@spondylitis.org</a></td>
<td>(818) 892-1616 x231</td>
</tr>
<tr>
<td>Oakland</td>
<td>CA</td>
<td>Howard Tevelson</td>
<td><a href="mailto:hotbyht@yahoo.com">hotbyht@yahoo.com</a></td>
<td>(510) 479-3220</td>
</tr>
<tr>
<td>San Diego</td>
<td>CA</td>
<td>Mike Supancich (CL)</td>
<td><a href="mailto:msupancich@att.net">msupancich@att.net</a></td>
<td>(760) 889-5760</td>
</tr>
<tr>
<td>San Diego</td>
<td>CA</td>
<td>Tim Tompkins (CL)</td>
<td><a href="mailto:tim@digitallightmedia.com">tim@digitallightmedia.com</a></td>
<td>n/a</td>
</tr>
<tr>
<td>Sebastopol</td>
<td>CA</td>
<td>Tom Hickey</td>
<td><a href="mailto:namastetom@hotmail.com">namastetom@hotmail.com</a></td>
<td>(408) 505-3273</td>
</tr>
<tr>
<td>Denver</td>
<td>CO</td>
<td>Noel Miles</td>
<td><a href="mailto:Milessterl@aol.com">Milessterl@aol.com</a></td>
<td>n/a</td>
</tr>
<tr>
<td>Hollywood</td>
<td>FL</td>
<td>Randall Sapadin</td>
<td><a href="mailto:randallsapadin@mariacoppolafoundation.org">randallsapadin@mariacoppolafoundation.org</a></td>
<td>(646) 240-5689</td>
</tr>
<tr>
<td>Atlanta</td>
<td>GA</td>
<td>Means Davis</td>
<td><a href="mailto:meansd@mindspring.com">meansd@mindspring.com</a></td>
<td>(770) 529-5272</td>
</tr>
<tr>
<td>Boise</td>
<td>ID</td>
<td>Debbie Westervelt</td>
<td><a href="mailto:irishdebl@clear.net">irishdebl@clear.net</a></td>
<td>(208) 573-9153</td>
</tr>
<tr>
<td>Chicago</td>
<td>IL</td>
<td>Joyce Terzick (CL)</td>
<td><a href="mailto:alden41@aol.com">alden41@aol.com</a></td>
<td>(815) 744-5017</td>
</tr>
<tr>
<td>Chicago</td>
<td>IL</td>
<td>Kathy Lange (CL)</td>
<td><a href="mailto:kc58@comcast.net">kc58@comcast.net</a></td>
<td>(847) 577-9940</td>
</tr>
<tr>
<td>Fort Wayne/Indianapolis</td>
<td>IN</td>
<td>Ken Prather</td>
<td><a href="mailto:pratherken@yahoo.com">pratherken@yahoo.com</a></td>
<td>(260) 637-1705</td>
</tr>
<tr>
<td>Augusta</td>
<td>ME</td>
<td>Michelle Andrews</td>
<td><a href="mailto:qualey28@roadrunner.com">qualey28@roadrunner.com</a></td>
<td>(207) 313-3871</td>
</tr>
<tr>
<td>Charlotte</td>
<td>NC</td>
<td>Deanna Williams</td>
<td><a href="mailto:deanna@inspiredbyas.com">deanna@inspiredbyas.com</a></td>
<td>(704) 993-8259</td>
</tr>
<tr>
<td>Hettinger</td>
<td>ND</td>
<td>Bonnie Smith (CL)</td>
<td><a href="mailto:nsbsmith@ndspernet.com">nsbsmith@ndspernet.com</a></td>
<td>(701) 567-2771</td>
</tr>
<tr>
<td>Hettinger</td>
<td>ND</td>
<td>Gerry Fisher (CL)</td>
<td><a href="mailto:thefishers6@bis.midco.net">thefishers6@bis.midco.net</a></td>
<td>(701) 391-3465</td>
</tr>
<tr>
<td>Morristown</td>
<td>NJ</td>
<td>Robert Ambrose (CL)</td>
<td><a href="mailto:novauk28@hotmail.com">novauk28@hotmail.com</a></td>
<td>(732) 752-7289</td>
</tr>
<tr>
<td>Morristown</td>
<td>NJ</td>
<td>Craig Gimbel (CL)</td>
<td><a href="mailto:believe5154@optonline.net">believe5154@optonline.net</a></td>
<td>(973) 476-8976</td>
</tr>
<tr>
<td>New York</td>
<td>NY</td>
<td>Andrea Shapiro</td>
<td><a href="mailto:Andrea.Shapiro@gmail.com">Andrea.Shapiro@gmail.com</a></td>
<td>(347) 766-8362</td>
</tr>
<tr>
<td>Columbus</td>
<td>OH</td>
<td>Megan Lawless</td>
<td><a href="mailto:meglawless89@gmail.com">meglawless89@gmail.com</a></td>
<td>(630) 567-6362</td>
</tr>
<tr>
<td>Portland</td>
<td>OR</td>
<td>Kathryn Houston</td>
<td><a href="mailto:houston.kathryn@gmail.com">houston.kathryn@gmail.com</a></td>
<td>(360) 635-3238</td>
</tr>
<tr>
<td>Philadelphia</td>
<td>PA</td>
<td>Walt Lichmira</td>
<td><a href="mailto:wallitchmira@comcast.net">wallitchmira@comcast.net</a></td>
<td>(215) 688-3145</td>
</tr>
<tr>
<td>Dallas</td>
<td>TX</td>
<td>Lynda DeGrow Kingsley</td>
<td><a href="mailto:degrowkingsley@gmail.com">degrowkingsley@gmail.com</a></td>
<td>(214) 542-2669</td>
</tr>
<tr>
<td>Houston</td>
<td>TX</td>
<td>Stephen Haskew</td>
<td><a href="mailto:haskews@verizon.com">haskews@verizon.com</a></td>
<td>(281) 337-3997</td>
</tr>
<tr>
<td>The Woodlands</td>
<td>TX</td>
<td>Wilson McCoy</td>
<td><a href="mailto:wass@GiSolutionsTX.com">wass@GiSolutionsTX.com</a></td>
<td>(281) 460-1033</td>
</tr>
<tr>
<td>Richmond</td>
<td>VA</td>
<td>Sam Brumberg</td>
<td><a href="mailto:sbrumberg@vecem.com">sbrumberg@vecem.com</a></td>
<td>(804) 968-7164</td>
</tr>
<tr>
<td>Seattle</td>
<td>WA</td>
<td>Thomas Herwick</td>
<td><a href="mailto:thomasherwick@hotmail.com">thomasherwick@hotmail.com</a></td>
<td>(360) 929-4010</td>
</tr>
<tr>
<td>Spokane</td>
<td>WA</td>
<td>Joan Polzin</td>
<td><a href="mailto:joap115@webband.com">joap115@webband.com</a></td>
<td>(509) 624-8214</td>
</tr>
<tr>
<td>Web-Meeting @SpondyCafe</td>
<td>Online</td>
<td>Michael Smith</td>
<td><a href="mailto:spenser23@aol.com">spenser23@aol.com</a></td>
<td>n/a</td>
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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.
CORPORATE PARTNERS

THE CORPORATE PARTNERSHIP PROGRAM PROVIDES A WAY FOR THE SPONDYLITIS ASSOCIATION’S PHARMACEUTICAL PARTNERS TO POSITIVELY IMPACT THE LIVES OF THOSE AFFECTED BY SPONDYLITIS BY CONTRIBUTING TO THE ORGANIZATION’S GENERAL OPERATING BUDGET. SAA ALSO RECEIVES ADDITIONAL CORPORATE SUPPORT FOR SPECIAL PROGRAMS.

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The Spondylitis Association of America is solely responsible for the content of this news magazine.
**Interview With Quest Legacy Society Member, Craig Gimbel**

**What inspired you to become a donor of the Spondylitis Association of America?**

I have seen many important projects develop that will lead to a better understanding of spondyloarthritis and hope for a possible cure someday. A common denominator, of course, to drive these is money. It is donations from individuals that perpetuate these programs. As any other member, it is my responsibility to give back and support those that helped me along the way.

**When you think of the Spondylitis Association of America, what key words or phrases come to your mind?**

(1) Advocacy and support

(2) Objective research towards a cure

(3) Responsible organization with impeccable performance

**What aspect of the Spondylitis Association of America’s work gives you the most satisfaction?**

Seeing others, like myself, afforded a better quality of life through the actions of the organization.

**What was the single most important consideration in your decision to make a planned gift to the Spondylitis Association of America?**

Performance of this organization as to achieving its mission.

**What prompted you to make your gift at this particular time?**

SAA is at the crossroads of making a major impact to the spondyloarthritis community through all the programs that are presently being developed. The time is NOW!

**What result/impact/outcome do you hope your gift will achieve for the Spondylitis Association of America?**

As an AS patient myself, a better quality of life for the present and a hope for a cure in the future.

**How has spondylitis affected you?**

It has been a very special path. I have taken lemons and turned them into lemonade. In 2004, with a sudden strike of AS and not knowing what happened to me, it was upsetting not to feel well, but also my professional life as a clinical dentist took a terrible turn. With no medical doctors making any definable diagnosis, my career was suddenly snuffed out; I couldn’t manipulate and grasp the dental instruments.

What made it equally bad was that I couldn’t find out what I had. I was “googling” every symptom and disease state that made possible sense. This is where I came upon SAA’s website. Not exactly as refined as today, but enough for me to consider that I have an inflammatory problem of the SI joint. I located a rheumatologist who understood my symptoms and began to pick up the pieces of my life that were shattered.

It was through the understanding of this organization: one that is accountable, transparent and quantifiable, that I understand my priority in life now is to help others understand what they have at the earliest so that treatment can be commenced to lessen the inflammatory response. We all hope for a better quality of life through first understanding our problem and then taking action. I founded a support group in New Jersey. This was the “new chapter” in my life. Yes, it is still sad today that I cannot practice dentistry that I loved so much. I want others to get back on track as early as possible so that their careers don’t end so abruptly. It’s important to feel that you’re doing something good for society.

SAA is moving in multiple directions to support its members and the spondyloarthritis community. When I think of all that I lost, as to my career, I think of all those I touched and reached out to. Nothing is better than that!
My hips hurt” My wife and I quickly exchanged glances with each other. I assured her that our 16 year old son does not have spondylitis. There was a completely logical explanation as to why he was sore. I don’t believe that my children, nieces or nephews have spondylitis. I have a mental checklist of symptoms they don’t have that comforts me. Rationally, I know the odds are in our favor. They don’t have it. Still, I won’t feel like we are out of the woods for another 14 years. Then there will be another generation of children to worry about. Someone’s children will get spondylitis.

It’s a parent’s job to be vigilant. It’s a parent’s job to be proactive. It’s a parent’s job to plan ahead.
We plan constantly. We plan everything. We even plan when we are going to start planning. There is a cost for failing to plan. There is a reward for planning ahead. It feels good to have a plan. We have a plan.

Please join us and make a planned a gift to the Spondylitis Association of America (SAA). Planned gifts ensure that the SAA will be fighting the spondylitis battle until it’s won. Most people don’t understand spondylitis. Most people won’t include spondylitis in their plans.

It’s incredibly easy to plan a gift. List the SAA as one of the beneficiaries on something. On anything. On everything. A bank account, a life insurance policy, an IRA, a will. It will make a difference. It will feel good. Sometimes the best plans are the simplest. Give me a call if you have questions.
Thank you.

(818) 892-1616 ext 231
www.spondylitis.org/quest

Your gift should ensure financial security for you and your loved ones, while allowing you to make a lasting mark by positively impacting the lives of the people SAA serves. This request is not professional tax or legal advice.
Internationally recognized, "Straight Talk On Spondylitis" is the most comprehensive resource available to help people understand and manage spondylitis and related diseases. At 65 pages, it is soft cover and measures 8.5x11.

An exercise program and illustrated exercise poster are included with the book!

To get your copy today, go to:
www.StopAS.org/store

Or call SAA toll free at 1-800-777-8189