SPONDYLITIS PLUS
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The Prevalence of Axial Spondyloarthritis

ALSO IN THIS ISSUE:

Medications Questions & Answers

Lianne S. Gensler, MD

Physical Therapy Tips for Finding a Therapist

Angelo Papachristos BScPT., MBA

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Your Stories: Tony Coats & The Long Road To Diagnosis

The Prevalence of Axial Spondyloarthritis
Dear Readers,

The individuals who know the most about the effects of spondyloarthritis (SpA) on the many aspects of their lives—personal, social, and working—are those affected directly by it, which includes many of you. Therefore, in July 2011 we set out with your help to conduct a needs assessment survey in SpA. The findings of the survey, several of which are described in this letter, and the shortcomings they reveal, add further urgency to our solving the problems of delayed diagnosis, awareness and inadequate funding for research and improved treatments. We do believe that we are on the right track, particularly with regard to collaborative relationships with academia, medical institutions and state and federal agencies, but also recognize that we still have a steep hill to climb in order to make the necessary changes to ensure that patients’ rightful expectations are secure. Future surveys will be important in showing the progress made.

A total of 865 interviews were conducted: (88%) were online and (12%) by telephone. A 3:1 male/female ratio was utilized to weight all responses so that the total response would reflect the gender difference in those affected by SpA as we know it today.

The findings of the survey uncovered that (75%) of those surveyed described lumbar spinal pain, with (83%) reporting neck pain and (77%), hip joint pain. (50%) of those surveyed reported the use of over the counter medications for symptom relief, while (10%) reported the use of steroids and over (50%) received one of the four TNF blocker biological medications. The survey uncovered that the most commonly used methods beyond medication for symptom relief are stretching and strengthening exercises and biking and running (62%) followed by diet and proper posture techniques (52%). Unawareness was highest for Tai Chi (35%) followed by breathing exercises (20%). (50%) of respondents reported full employment.

We will be sharing more of the vast amounts of data produced by the survey in upcoming issues of Spondylitis Plus and online at StopAS.org. I would like to offer my personal thanks to all of those who took the time to participate. Thank you!

Sincerely,

Laurie M. Savage
Executive Director
Editor’s Note: With this edition of the Reader’s Forum, we turn the floor over to Dr. James T. Rosenbaum, Chair of the SAA Medical Board and the author of the article, “Does the Microbiome Cause Ankylosing Spondylitis?”, which appeared in the Winter 2011 issue of Spondylitis Plus. The article received many responses in regards to diet and dietary changes for treating ankylosing spondylitis. Here, Dr. Rosenbaum responds to those letters and emails.

Intestinal Bacteria and Ankylosing Spondylitis

I am grateful for the many responses that I received after my recent column on intestinal bacteria and ankylosing spondylitis. Several wrote to me about personal experiences and encouraged others to try similar diets or probiotics.

Although I am convinced that bacteria are the key to understanding AS, it is premature to recommend specific probiotics. In laboratory animals, we can induce arthritis through a variety of techniques. Sometimes the bacteria that seem to improve one form of arthritis fail to work for another type, and vice versa. The “ecosystem” within our intestine is incredibly complex with about 1000 different strains of bacteria co-existing. We actually know very little about how consuming yogurt or a probiotic will alter that ecosystem.

So I offer the following advice:

1) It’s okay to try to change your diet or swallow a probiotic to see if that lessens your pain, but don’t do anything too extreme. Don’t, for example, try a prolonged fast or live for days on liquids only.

2) Don’t assume that what worked for a friend will work for you. Unfortunately, our diversity means that we cannot always extrapolate how one individual does on a diet compared to another.

3) Support research. We know that the bacteria that dwell within us have a major impact on our health, but we also know very little about those bacteria. New technology is opening up ways to study these bacteria. My hope is that with this understanding we might one day be able to prevent ankylosing spondylitis.

~JAMES T. ROSENBAUM, MD
Oregon Health & Science University. Division Chief of Arthritis and Rheumatic Diseases.
Finding a PHYSICAL THERAPIST with Experience in...

ANKYLOSING Spondylitis

How do I start?
What should I ask?
First, readers should understand that for the most part, training for Physical Therapists in regards to inflammatory disease and ankylosing spondylitis (AS) is limited. The majority of outpatient private clinics and orthopaedic/musculoskeletal therapists are trained to treat sports injuries (ACL tears, ankle sprains) and ‘non-inflammatory’ conditions such as osteoarthritis, rotator cuff tendinopathy, various spinal conditions such as disc herniation, degenerative disc disease etc.

That said, there are therapists who have had training or experience by virtue of working in a rheumatic disease unit/center, with a rheumatologist or have by referral patterns treated rheumatoid arthritis (RA) or AS and gathered clinical experience that way.

Since the geographic and practice pattern variations will be immense in the USA and vary by state/city/township, I will provide some general principles that may guide you in how to find a therapist to work with.

Ask Your Rheumatologist First
Most clinicians within a practice setting have had some experience with rehabilitation professionals or clinics within the area that they could recommend, or know of positive experiences and results from patients within their practice.

Recommendation From A Registered Nurse
A recommendation from a Nurse Practitioner who works within a rheumatology practice, rheumatic disease unit or Infusion Center can be very helpful.

Registered Nurses working closely with patients with AS or RA usually have a working relationship with a Physical Therapist or have had interaction via a conference, course, clinical trial or patient education forum and may be able to direct you to a therapist or someone who can further assist your search.

Referral From Other Patients
A referral from those who have had positive results and experiences with a particular clinician.

Patients are the best consumers of health care services. If there is a systematic and overwhelmingly poor rating and satisfaction level for a particular therapist or clinic,
patients will not return. Universally, they will take their healthcare dollars elsewhere!

I caution readers not to base your decision solely on this, however, because patients who are highly satisfied or unsatisfied with a clinician may be due to: 1) Individual relationship or rapport with the therapist or 2) Response to therapy may vary due to individual patient disease course, duration of symptoms, other co-morbidities and current medical therapies they have used (NSAIDs, biologic medications etc.)

Request Information From Organizations
There are organizations who may be able to guide you to a clinician within your area such as:

- The Spondylitis Association of America at www.StopAS.org
- Association of Rheumatology Health Professionals (ARHP)
- American Physical Therapy Association at www.apta.org

Attend A Patient Education Forum For Patients With AS
For example, SAA hosts free Patient Educational Seminars. These forums are a great opportunity to meet other patients with AS and to ask where they have gone and how they would rate their experience.

You can also join a patient support network hosted in your area by SAA members. Again, an excellent opportunity to meet and discuss LOCAL resources that have been utilized by other patients with AS.

As a Physical Therapist, what things would I consider important in choosing a clinic or clinician?
Make sure that they are a board-certified Physical Therapist and licensed to practice in the state in which you will be treated. Remember that “rehabilitation” or “personal trainer” does not equate to “treated by a Physical Therapist”. In some cases due to geographical constraints on specialty, you may need to travel to receive therapy that meets your goals and needs.

If you cannot find a Physical Therapist who has a special interest in AS or inflammatory arthritis, then try to find one within the area who has orthopaedic or musculoskeletal training or designation. All Physical Therapists will have at least a basic foundation and understanding of musculoskeletal and orthopaedic disease states, disorders or conditions.

Also, if you were referred to a clinic by your rheumatologist or family physician, ask if they have any financial interest in that clinic to disclose. If so, you may still want to attend, however it is in your best interest to have all the facts in order to make an informed decision about your health.

Be sure to ask about current and prior work experience. Have they worked in a center that specialized in inflammatory arthritis or ankylosing spondylitis (e.g. Teaching Hospital, Specialty Unit etc.) and was this in a ‘clinical capacity’ or as an educator, a research associate or working in clinical trials?

Next, ask about the nature of clinical expertise in ankylosing spondylitis or inflammatory arthritis. For example, have they seen and treated these conditions in the past or what number of seronegative arthritis patients have they seen yearly.

You should feel comfortable with your therapist. The therapeutic relationship in patients with AS or RA is usually long term. If you are not comfortable or unable to discuss your condition, barriers, challenges or functional limitations with your Physical Therapist, then the likelihood of reaching maximal therapeutic effectiveness is diminished.

It is best to keep an open dialog with your therapist. Discuss short term and long term goals. This should be done quarterly to ensure everyone is on same page.

What types of treatments should a Physical Therapist provide to patients with AS?
1) First, education on disease impact from a musculoskeletal perspective. Then, assisting in establishing short term and long term goals of therapy and how this relates to current function, pain, fatigue, return to sport or hobbies, maintaining function or assisting in modifications at workplace or school if possible.

2) Instruction on an individualized home or group exercise program focusing on spinal mobility, postural education, strength program, pool therapy and cardiovascular endurance.
The program should be monitored initially and modified based on disease duration, current function and disease activity.

3) Use of passive modalities (ice, heat, TENS, ultrasound, interferential current, massage therapy, acupuncture) are usually utilized on a short term and limited basis for acute injuries and pain. For example, recent ankle sprain.

4) Act as an advocate for the patient and act in his/her interest in communicating with their rheumatologist, allied health professional, insurance provider etc.

Things that I would watch out for or ask for further clarifications by the therapist (Yellow or Red Flags)
First, the recommendation by clinic or therapist of very frequent visits for a long period of time.

Initially there may be a need to provide extensive therapy on a one to one basis. However, for the most part once the patient has a comprehensive exercise program this can be completed on a self directed basis. The combination of the prescribed exercises with addition of recreational activity or exercise can be completed by the patients independently. There may be additional visits if there is a status change (increase in pain, functional limitations, specific questions or concerns on initiating a new sport or hobby, etc) or requirement to progress or modify the program. Once the patient and therapist are comfortable, the patient resumes the program on their own until the next time goals need modifying.

Next, recommendations or reliance on extensive use of passive modalities on a weekly basis on a prolonged basis.

Use of frequent adjustments or spinal manipulations. This is a very common treatment modality utilized by orthopaedics/manual therapists or chiropractors that has a clinical utility in mechanical neck or low back pain. However, almost universally NOT recommended (contraindicated) in patients with ankylosing spondylitis at any stage of the disease state. Should this be recommended by your rehab clinician, speak to your rheumatologist prior to initiation of therapy.

Also, acupuncture, dry needling etc., are frequently utilized in private practice for pain control and various musculoskeletal conditions by Physical Therapists and rehab professionals. Although not contraindicated for use in AS, please inform your therapist if you:

- Are taking any immune suppressants or TNF inhibitors.
- Have any joint arthroplasty (ie. hip, knee replacements)
- Inform and discuss use of acupuncture treatment with your rheumatologist prior to initiation.

I hope that the above information will help you in your search for a Physical Therapist or at least guide you to building a therapeutic relationship with an orthopaedic Physical Therapist who is interested and motivated in learning about and treating the condition.
SAMPLE EXERCISES

The following exercises are from a poster that is included in the Spondylitis Association of America’s book, “Straight Talk On Spondylitis.” You can purchase the book by going to www.StopAS.org. Please note that before beginning any new exercise program, we suggest that you consult your physician or physical therapist. They can help provide modifications to suit your particular needs.

THE ABOVE EXERCISES AND ADDITIONAL EXERCISES MAY BE FOUND IN STRAIGHT TALK ON SPONDYLITIS.

LOOSENING-UP EXERCISES: 1, 2, 3ab
FLEXIBILITY EXERCISES: 3ab, 4, 5, 6, 7, 8, 9ab, 10ab, 15
STRENGTHENING EXERCISES: 11, 12, 13
BREATHING EXERCISES: 14, 16ab
POSTURE IMPROVEMENT EXERCISES: 1, 11, 12, 15, 16ab

Illustrated by Mary Benz Decourt
Spondylitis Association of America, P.O. Box 5872, Sherman Oaks, CA 91413
Copyright © 1985 Spondylitis Association
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I have traveled a long and bumpy road that started back in 1980. Pain had started in my lower back and I had an x-ray that was determined by my doctor to be a “classic example of a pulled muscle.” This was to be the pattern for the next five years while I took all the NSAIDs (non-steroidal anti-inflammatory drugs) that were available at the time.

To complicate matters, the stiffening of my neck was a progressive problem that had been going on for the last ten years of my life until, one morning after another night of very little sleep, my neck was fused to a point of no rotation at all.

Some days were better than others, but there was never an answer. So, back to the doctor I went. “It seems you might have osteoarthritis”, the doctor said. And yet those tests came back negative.

And back again: “The pain you are having appears to be rheumatoid arthritis. That is the only thing that could be bringing on the pain as well as the other complications associated with it.” So, I took more NSAIDs, sleep meds, and muscle relaxers. Yet, there was no explanation for why my neck would not move or why the pain never seemed to lessen. With all the x-rays and CT scans, there was never a concrete answer to my problem.

Finally, I found a doctor at Northside Hospital in Atlanta who had a reputation for being one of the most thorough diagnosticians and being able to get to the bottom of many cases.

The doctor in Atlanta was very sincere and concerned. Almost immediately after I walked into his office he said, “You have ankylosing spondylitis and I will be doing a test to see if you are HLA-B27 positive.” After not turning my neck and living in total pain, I finally had someone who had
I have learned from SAA’s news magazine, *Spondylitis Plus*, ever since the late 80s and have cherished every word written.

It is important to me to know that there are others out there who are wondering every day if their lives will ever improve. With the drive of the SAA and the wonderful people who have the time to speak at educational seminars (I attended the Atlanta seminar with Dr. Reveille) and commitment of the SAA staff, we will overcome.

I turned 66 on March 1st, 2012 and have fought this battle since the late 70s. I stay very active in as many things as I can. I try to help anyone and everyone I can. Being active in the Masonic Lodge and Scottish Rite and soon the Shrine, there is always a lot to accomplish and focus on besides AS.

**Tell Us Your Story**

Check out other member stories online at:


We want to hear your story. Believe it or not, so do the millions of others affected by AS and related diseases. Share your story with us today for possible publication in *Spondylitis Plus* or on our website, StopAS.org!

How has AS or related disease affected your life? How have you coped? How were you diagnosed? What treatment(s) have you tried? You can email your story to chris.miller@spondylitis.org or, if you have a video, upload it to YouTube and send us a link!

diagnosed me correctly.

After going through the late 70s and into the middle 80s, it was 1985 before I was diagnosed with this horrible monster that has affected nearly all my peripheral joints as well as made my spine fuse in an awful position.

Had my life been turned upside down? Yes, it had. I worked until 1993 unable to turn my neck, dragging my feet. I was forced to listen to all the unnecessary jokes about being a stiff neck, crooked man, or “how can I talk to you when you can’t look up?” All these not-so-funny jokes that everyone seemed to enjoy, except me. And there I was, pain keeping me awake and my stomach eaten up by NSAIDs.

I have been going to a pain management doctor since 1999. My doctor has helped me more than anyone else. At the start of this, I was 6’ 1” tall. Now due to curvature of my spine, I stand 5’9”. As the picture shows (on the previous page), I have completely fused and my spine is actually twisted causing a great deal of pain.

I was told by a surgeon that when I completely fused the pain would cease. This was definitely not the case. I seem to be ok mentally until I walk by a three-way mirror and I see not the person I thought I was, but a slumped over twisted person that can’t possibly be me.

All that said, I have a lot to live for as a grandfather, great-grandfather and a dad. I have a wonderful wife who lets me sit for at least two hours in the morning before I can move. All of this would be in vain if I didn’t keep my strong faith in God and keep myself as motivated as possible.
THE PREVALENCE OF AXIAL SPONDYLOARTHRITIS

New data proves spondyloarthritis is much more prevalent than once thought...

A new rate of prevalence of axial spondyloarthritis (SpA) has been published in the journal, “Arthritis Care & Research”. The data comes directly from the Centers for Disease Control’s National Health and Nutrition Examination Survey (NHANES) program, which was co-funded by the Spondylitis Association of America (SAA) and the Spondyloarthritis Research and Treatment Network (SPARTAN).

Axial spondyloarthritis is “a form of spondyloarthritis in which the predominant symptom is back pain, and where radiographic sacroiliitis might or might not be present. If definite radiographic sacroiliitis on plain X-rays is present, the disease can be classified as ankylosing spondylitis (AS).”

The study finds that as much as 1% of the adult United States population may have axial spondyloarthritis. This means that as many as 2.7 million adults may be affected by the disease. However, the study authors note that “current U.S. SpA prevalence estimates may be lower than the true value” because of the way the data was collected. Thus, even more may be affected than is estimated in the study.

Ankylosing spondylitis is 3 times more prevalent than multiple sclerosis, cystic fibrosis and Lou Gehrig’s Disease combined.

What Is Axial Spondyloarthritis?

Once upon a time, we refused to diagnosis ankylosing spondylitis unless the x-rays of the sacroiliac joints were abnormal.

The problem is that the disease can be mild or it can take years before the x-rays show changes. And even when the x-rays are abnormal, interpretation is always subject to some debate.

So the ASAS group in Europe has appropriately tried to define new criteria for the diagnosis such that x-ray changes are not required and that group preferred a new name: axial spondyloarthritis.

~JAMES T. ROSENBAUM, MD
Oregon Health & Science University. Division Chief of Arthritis and Rheumatic Diseases

For More Information, See:


John D. Reveille, MD, James P. Witter MD, Michael H. Weisman MD

DOI: 10.1002/acr.21621
The Spondylitis Association of America is pleased to announce that a recent analysis from personal finance news website MainStreet (www.mainstreet.com), also reported on MSN Money, has named SAA as the ninth-highest rated national charity in America.

SAA received a perfect four-star rating from Charity Navigator, America’s leading independent charity evaluator, for the third consecutive year in 2011 and a 68.19 out of 70 score for its fiscal performance and operational responsibility, ranking it higher than thousands of other charities in the nation.

In its compilation of highest-rated charities, MainStreet looked at the leading charities in the U.S. based on their 2011 Charity Navigator scores, filtering out organizations that operate only locally and those that work mainly to collect and distribute funds to other charitable organizations.

According to the story on Mainstreet, “The Spondylitis Association of America, which targets its efforts at a certain form of arthritis that affects the spine and pelvis, is one of the smallest organizations on the list. With revenue of just more than $1.2 million last year (none of which came from the government), the California-based organization might not be able to dispense funds to all sufferers, but the informational materials it provides in addition to the direct assistance to patients multiply its reach significantly for a disease that is rarely fatal but can have important consequences for mobility and quality of life for those affected by it.”

As the only nonprofit serving the needs of the 2.7 million adults in the U.S. affected by spondylitis, SAA is honored to be recognized for our ongoing commitment to accountability, fiscal responsibility and program excellence. We are exceptionally proud of the fact that an organization with only nine employees can achieve the level of impact that we have.

This impact is largely due to the dedication and hard work of our volunteer board of directors, medical board, and our growing network of members, donors, volunteer fundraisers and health advocates. We’re grateful to each and every one of you for your commitment to raise the profile of this disease and to bring us closer to the cure.

Charity Navigator has also named SAA as one of “10 Charities Worth Watching”. According to the watchdog group, “Many of America’s most effective charities are also household names. But some well-known charities are less effective than you’d think, while a number of lesser known charities are truly exceptional. These 10 charities all operate on less than $2 million a year, but they all earn a four-star rating from Charity Navigator. We encourage you to learn more about them.”

Only 249 National charities in the US have been awarded the top 4-Star rating and SAA is among the 129 that have achieved this distinction three or more years consecutively.

For more information about Charity Navigator scores, visit www.charitynavigator.org
Q: What are the primary categories of drugs prescribed for AS and related diseases?

There are three primary categories (and note the examples are not a comprehensive list):

1) Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) i.e. Motrin, Naprosyn
2) Traditional oral Disease Modifying Anti-Rheumatic Drugs (DMARDS) i.e. Sulfasalazine
3) Biologic agents: Tumor Necrosis Factor (TNF)-α inhibitors (i.e. Etanercept)

Q: After a diagnosis of spondylitis is made, what thought process goes into prescribing a medication? What type of medication is prescribed first and why (e.g. allergies, disease severity)?

There are a number of key factors that go into matching certain medications to a patient’s needs. These include:

- What are the predominant symptoms?
- Which joints are affected?
- Are there other symptoms? i.e. IBD or uveitis
- What drugs has the patient already tried and how have they reacted to each?

First line drugs are NSAIDs unless there are contraindications. Contraindications might include kidney disease, Peptic Ulcer Disease and sometimes Inflammatory Bowel Disease (IBD) (Crohn’s or Ulcerative Colitis). If the most affected joints are the spine, hips and sacroiliac joints, and NSAIDs are not effective (after trying 2 different types), biologics (specifically TNF-α inhibitors) are the next step. All of these are equally effective for the joints, but certain types (monoclonal antibodies) are better for manifestations including IBD and uveitis.
Q: **Is there any reason to skip right to a TNF-a inhibitor?**

If there are contraindications to NSAIDs like those mentioned above, or if the patient has had an adequate trial of 2 different NSAIDs at a full strength dose, then it is reasonable to go straight to a TNF-a inhibitor.

Q: **What are the differences between the TNF-a inhibitors?**

The best way to describe the differences is with a table.

<table>
<thead>
<tr>
<th>Drug</th>
<th>How the drug works to block TNF-a</th>
<th>Route of administration</th>
<th>Dose &amp; frequency</th>
<th>Disease specific comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Etanercept (Enbrel)</td>
<td>Acts as a mop on soluble(^2) TNF-a</td>
<td>Injection in the skin (SC)</td>
<td>50mg weekly or 25mg 2x weekly</td>
<td>Works well in all arthritis forms</td>
</tr>
<tr>
<td>Infliximab (Remicade)</td>
<td>Acts on both soluble and cell bound TNF-a</td>
<td>Injection into the vein (IV)</td>
<td>3-10mg/kg every 6-8 weeks</td>
<td>Works well in all arthritis forms &amp; IBD</td>
</tr>
<tr>
<td>Adalimumab (Humira)</td>
<td>Acts on both soluble and cell bound TNF-a</td>
<td>Injection in the skin (SC)</td>
<td>40mg every other week</td>
<td>Works well in all arthritis forms &amp; IBD</td>
</tr>
<tr>
<td>Golimumab (Simponi)</td>
<td>Acts on both soluble and cell bound TNF-a</td>
<td>Injection in the skin (SC)</td>
<td>50mg every month</td>
<td>Works well in all arthritis forms (hasn’t been tested in IBD, but should work)</td>
</tr>
</tbody>
</table>

1. Brand name in parentheses  
2. Soluble = floating in blood

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**Q: What do you tell patients concerning side effects - specifically severe ones like the black box warning regarding risks of lymphoma with the biologic medications?**

The major risks are infection and cancer. The infection risk is because of the suppressed immune system as a result of the biologic. For the most part, they are common infections that anyone could get. It’s more likely in an immunosuppressed patient. Other infections we worry about that are less common include tuberculosis, certain fungi (coccidiomycoses [valley fever], histoplasmosis). The cancer risk has been better studied in Rheumatoid Arthritis than AS and the typical cancers are skin cancers and less commonly lymphoma (a type of blood cell cancer). The black box warning was a type of lymphoma described in children.

**Q: What do you tell a patient who doesn’t want to run the risk of the side effects of a TNF-a inhibitor (or for that matter, another medication) and has made a decision not to take them?**

They are the patient - they get to decide. As long as I can educate them about the choices, risks and benefits, they are ultimately responsible for choosing because it’s their body and they live with the results. It’s my role do the best job possible taking care of them independent of their treatment choices.

**Q: What is a DMARD in regards to spondylitis treatment (meaning, are there actually Disease Modifying Anti-Rheumatic Drugs in the spondyloarthropathies ) and in your experience, where do “DMARDS” (methotrexate / sulfasalazine) fit into treatment?**

If you are referring to the spine, the traditional DMARDS are likely not disease-modifying. They do play a role in those with smaller joint involvement like the knee, ankle, hands and feet. Even then, however, they may not be truly disease modifying, rather disease-controlling.

**Q: What about steroid use such as prednisone?**

The amount of steroids needed to have a response in the back is high and therefore the risk often far outweighs the benefit. In addition, if a patient has psoriasis (as many of these patients do), when the prednisone is tapered, the psoriasis gets worse.
Q: What NSAIDs are most commonly used now?
Each rheumatologist tends to have his/her own preference based on anecdotal experience. I don’t think it’s fair to state the most commonly prescribed as this varies from provider to provider.

Q: When would you prescribe a narcotic / pain killer?
If the patient has pain that is not managed by usual means (NSAIDs, biologics, etc), it is appropriate to prescribe these agents. They may be prescribed by the rheumatologist, primary care doctor, pain specialist or orthopedic surgeon.

Q: During a flare, have you prescribed an additional medication to help with the inflammation / pain?
Before prescribing additional medications for a patient in a flare, I like to first assess what may have caused the flare – i.e. a reduction in exercise, increased stress or travel, discontinuation of medications etc. I try to use non-pharmacologic measures like heat/ice, stretching and physical therapy. I will add or increase NSAIDs in a patient on a biologic agent. If the patient still is having significant symptoms, I may add pain medications as needed.

Q: What differences are there between medications for the different forms of spondyloarthritis (e.g. ankylosing spondylitis vs. psoriatic arthritis or enteropathic arthritis)?
Of the TNF-a inhibitors, all the monoclonal antibodies should work on the arthritis in addition to the uveitis and IBD. Etanercept is the only one that doesn’t have efficacy for treating manifestations outside of joints. However, etanercept still tends to reduce the number of uveitis flares that occur. Other drugs that work in Spondyloarthritis, especially the smaller joints, include sulfasalazine and methotrexate which are oral medicines.

Q: Although there is no cure for ankylosing spondylitis and related diseases, are there any drugs that have been shown to slow or halt the progression of the diseases?
It depends on which specific disease you are asking about and which manifestation of the disease. There is not good evidence that any drugs prevent bone formation (i.e. fusing of the spine). There is a possibility that NSAIDs may prevent fusion, but the evidence is not strong enough to make a formal statement. In psoriatic arthritis, TNF inhibitors have been shown to prevent radiographic damage.

Q: What progress has been made in the last few years regarding treatments?
TNF inhibitors have changed the face of this disease. Patients have gone from disability to fully functional. Other biologic agents are now being developed and studied. As we study the diseases and how patients respond (or don’t respond) to therapy, we learn more about the disease and figure out novel agents that might help to treat and hopefully cure the disease.

Q: Given all the genetic discoveries as of late, what new medicinal treatments will we be seeing in the future?
This is definitely a very exciting area that may allow us to target therapies to a patient’s particular genetic make-up. This would include the ability to predict response to different therapies in addition to potential complications based on a patient’s genes.
## Spondyloarthritis Medications Overview

Tell your doctor about all your prescription and over-the-counter medications, vitamins, minerals, herbal products, and drugs prescribed by other doctors. Do not start or stop a medication without telling your doctor. This list is not intended to be exhaustive and is intended only to be used as a general guide.

### NSAID Therapy

<table>
<thead>
<tr>
<th>Trade Name</th>
<th>Generic or Brand Name</th>
<th>Pill Dose &amp; Frequency</th>
<th>Long Acting Formulation Dose &amp; Frequency</th>
<th>Usual Dose for AS</th>
<th>Maximum Daily Dose</th>
<th>Prescription required?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indocin</td>
<td>Indomethacin</td>
<td>25,50mg 3-4x/day</td>
<td>75mg ER 2x/day</td>
<td>75mg ER 2x/day</td>
<td>150-200mg</td>
<td>Yes</td>
</tr>
<tr>
<td>Naprosyn</td>
<td>Naproxen</td>
<td>250-500mg 2x/day</td>
<td>NA</td>
<td>500mg 2x/day</td>
<td>1000mg</td>
<td>Yes</td>
</tr>
<tr>
<td>Aleve</td>
<td>Naproxen</td>
<td>220mg 2x/day</td>
<td>NA</td>
<td>440mg 2x/day</td>
<td>880mg</td>
<td>No</td>
</tr>
<tr>
<td>Voltaren</td>
<td>Diclofenac</td>
<td>25,50mg 2-4x/day</td>
<td>100mg ER 1-2x/day 75mg DR 2x/day</td>
<td>75mg DR 2x/day</td>
<td>200mg</td>
<td>Yes</td>
</tr>
<tr>
<td>Clinoril</td>
<td>Sulindac</td>
<td>150,200mg 1-2x/day</td>
<td>NA</td>
<td>200mg 1x/day</td>
<td>200-400mg</td>
<td>Yes</td>
</tr>
<tr>
<td>Feldene</td>
<td>Piroxicam</td>
<td>10,20mg 1x/day</td>
<td>NA</td>
<td>20mg 1x/day</td>
<td>20mg</td>
<td>Yes</td>
</tr>
<tr>
<td>Lodine</td>
<td>Etodolac</td>
<td>200,300,400,500mg 2x/day</td>
<td>400,500,600mg ER 1-2x/day</td>
<td>400mg ER 2x/day</td>
<td>1000mg</td>
<td>Yes</td>
</tr>
<tr>
<td>Mobic</td>
<td>Meloxicam</td>
<td>7,5,15mg 1-2x/day</td>
<td>NA</td>
<td>15mg 1x/day</td>
<td>15mg</td>
<td>Yes</td>
</tr>
<tr>
<td>Celebrex</td>
<td>Celecoxib</td>
<td>100,200mg 200mg 1-2x/day</td>
<td>NA</td>
<td>200mg 2x/day</td>
<td>400mg</td>
<td>Yes</td>
</tr>
<tr>
<td>Motrin, Advil</td>
<td>Ibuprofen</td>
<td>400,600,800mg 3-4x/day</td>
<td>NA</td>
<td>600-800mg 3x/day</td>
<td>3200mg</td>
<td>No</td>
</tr>
<tr>
<td>Relafen</td>
<td>Nabumetone</td>
<td>500,750mg 1x/day</td>
<td>NA</td>
<td>1000-2000mg/day</td>
<td>1000-2000mg</td>
<td>Yes</td>
</tr>
</tbody>
</table>

### Second-Line Therapy (used for progressive disease - note that all these medications require a prescription)

<table>
<thead>
<tr>
<th>Trade Name</th>
<th>Generic or Brand Name</th>
<th>Dose</th>
<th>Frequency</th>
<th>Total Dose (Range)</th>
<th>Route of Administration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Azulfidine</td>
<td>Sulfasalazine</td>
<td>500-1000 mg</td>
<td>2-3 times/day</td>
<td>2000-4000 mg/day</td>
<td>Oral</td>
</tr>
<tr>
<td>Imuran</td>
<td>Azathioprine</td>
<td>50-100 mg</td>
<td>1-2 times/day</td>
<td>50-200 mg/day</td>
<td>Oral</td>
</tr>
<tr>
<td>Rheumatrex, Trexall</td>
<td>Methotrexate</td>
<td>7.5-20 mg</td>
<td>1 time/week</td>
<td>7.5-20 mg/week</td>
<td>Oral or injectable</td>
</tr>
<tr>
<td>Enbrel</td>
<td>Etanercept</td>
<td>25-50 mg</td>
<td>1-2 times/week</td>
<td>50 mg/week</td>
<td>Subcutaneous injection</td>
</tr>
<tr>
<td>Remicade</td>
<td>Infliximab</td>
<td>3-6 mg/kg</td>
<td>Given at variable intervals</td>
<td>NA</td>
<td>Intravenous</td>
</tr>
<tr>
<td>Humira</td>
<td>Adalimumab</td>
<td>40 mg</td>
<td>2-4 times/month</td>
<td>NA</td>
<td>Subcutaneous injection</td>
</tr>
<tr>
<td>Simponi</td>
<td>Golimumab</td>
<td>50 mg</td>
<td>1 time/month</td>
<td>NA</td>
<td>Subcutaneous injection</td>
</tr>
</tbody>
</table>

Note: Newly introduced drugs may not be included in this listing.
Medical and Scientific Advisory Board

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All medical information in Spondylitis Plus is vetted by SAA’s Medical and Scientific Advisory Board (right).

Questions about ankylosing spondylitis and related diseases?

Educational materials and other resources are available at:
www.StopAS.org

Need spondylitis info for teens?
Visit S.W.I.F.T:
Spondylitis Web Info For Teens
At: teens.spondylitis.org
Connecting with others who understand and can relate to our struggles is a universal human desire. We seek out people who have been through what we have, often simply to tell our stories and hear them say “me too!” or “I know what that’s like.” To know that we’re not the only ones going through this and someone genuinely understands is a comfort and a source of strength. It is also hope. Hope that we too will pull through. That we can keep going because others before us have.

Providing opportunities for our members to connect personally with one another, to give and receive support is something SAA has done from the very beginning. SAA started as a support group and we have never forgotten that. As we’ve grown, so have our support programs and today we’re proud to offer many different ways of making that connection with others.

How can we help you Connect?

Support Groups
SAA has over 30 Spondylitis Educational Support Groups and more are being added regularly. Drop in for a meeting if there is a group nearby, or consider starting one if there isn’t. Our groups are led by committed, knowledgeable volunteers who have spondylitis themselves; they are great places to meet with peers who share your experiences and help you take charge of spondylitis. Please visit: www.stopas.org/groups for more information.

Seminars
SAA hosts free patient educational seminars all over the country. We’ve visited cities from Los Angeles to New York, and lots of places in between. Join us the next time we come to your area. Please visit: www.stopas.org/seminar.html for more information.

Online Connections
There is a big and robust spondylitis community online. Join in and join the conversation!

Facebook
With over 4,000 people, SAA’s Facebook Page is a great place to interact with others who have spondylitis. Find us at http://www.facebook.com/spondylitis

Do you Tweet?
Find us on Twitter and we’ll introduce you to the Twitter Spondylitis Community - #TeamSpondy twitter.com/spondylitis

And before there was Facebook, Twitter, or even MySpace, there was SAA’s Online Forum. A decade old and still going strong. Please visit http://forums.spondylitis.org/

However you choose to connect, we hope that you do and are here to help.

*Please contact Elin Aslanyan at Elin@spondylitis.org, or at (800) 777 – 8189 ext 222 for more information on our Support Programs. You will also find the programs highlighted here on SAA’s Connections: www.stopas.org/connect
Highlighting The Most Active
SAA-SPONSORED SUPPORT GROUPS

<table>
<thead>
<tr>
<th>City</th>
<th>State</th>
<th>Meeting Facilitator</th>
<th>Email address</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phoenix</td>
<td>AZ</td>
<td>John Kornfeind</td>
<td><a href="mailto:jmmkorn@cox.net">jmmkorn@cox.net</a></td>
<td>(623) 910-4742</td>
</tr>
<tr>
<td>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>San Diego</td>
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<td>Mike Supancich</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</td>
<td><a href="mailto:tim@digitalightmedia.com">tim@digitalightmedia.com</a></td>
<td>N/A</td>
</tr>
<tr>
<td>Denver</td>
<td>CO</td>
<td>Noel Miles</td>
<td><a href="mailto:milesster@aol.com">milesster@aol.com</a></td>
<td>N/A</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>
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<td>(208) 573-9153</td>
</tr>
<tr>
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<td>IL</td>
<td>Joyce Terzick</td>
<td><a href="mailto:alden41@aol.com">alden41@aol.com</a></td>
<td>(815) 744-5017</td>
</tr>
<tr>
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<td>Kathy Lange</td>
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<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>(250) 637-1705</td>
</tr>
<tr>
<td>Plymouth</td>
<td>MA</td>
<td>James Igo</td>
<td><a href="mailto:rippacj@hotmail.com">rippacj@hotmail.com</a></td>
<td>(508) 833-4354</td>
</tr>
<tr>
<td>Baltimore</td>
<td>MD</td>
<td>Stuart Merenbloom</td>
<td><a href="mailto:smerenbloom@verizon.net">smerenbloom@verizon.net</a></td>
<td>(410) 869-4157</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>Ann Arbor</td>
<td>MI</td>
<td>Rachel Morgan</td>
<td><a href="mailto:RLmorgan@umich.edu">RLmorgan@umich.edu</a></td>
<td>(734) 709-7842</td>
</tr>
<tr>
<td>Grand Rapids</td>
<td>MI</td>
<td>Scott May</td>
<td><a href="mailto:scottmay1901@gmail.com">scottmay1901@gmail.com</a></td>
<td>(616) 610-9130</td>
</tr>
<tr>
<td>Kalamazoo</td>
<td>MI</td>
<td>Teri Pack</td>
<td><a href="mailto:teripack@gmail.com">teripack@gmail.com</a></td>
<td>(269) 532-2579</td>
</tr>
<tr>
<td>Kansas City</td>
<td>MO</td>
<td>Cindy Barta</td>
<td><a href="mailto:bartacindy@yahoo.com">bartacindy@yahoo.com</a></td>
<td>(913) 233-6554</td>
</tr>
<tr>
<td>Hettinger</td>
<td>ND</td>
<td>Bonnie Smith</td>
<td>nbsmith@nds Supernet.com</td>
<td>(701) 567-2771</td>
</tr>
<tr>
<td>Hettinger</td>
<td>ND</td>
<td>Gerry Fisher</td>
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<td>(701) 391-3465</td>
</tr>
<tr>
<td>Morristown</td>
<td>NJ</td>
<td>Craig Gimbel</td>
<td><a href="mailto:believe5154@optonline.net">believe5154@optonline.net</a></td>
<td>(973) 476-8976</td>
</tr>
<tr>
<td>Morristown</td>
<td>NJ</td>
<td>Barbara Schiller</td>
<td>not available</td>
<td>(973) 966-1736</td>
</tr>
<tr>
<td>New York</td>
<td>NY</td>
<td>Esther Hickman</td>
<td><a href="mailto:EstherHeidi@gmail.com">EstherHeidi@gmail.com</a></td>
<td>(917) 859 – 2707</td>
</tr>
<tr>
<td>New York</td>
<td>NY</td>
<td>Andrea Shapiro</td>
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<td>(347) 766-8362</td>
</tr>
<tr>
<td>Portland</td>
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<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>
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<td>PA</td>
<td>Walt Lichmira</td>
<td><a href="mailto:waltlichmira@comcast.net">waltlichmira@comcast.net</a></td>
<td>(215) 688 -3145</td>
</tr>
<tr>
<td>Dallas</td>
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<td>Lynda DeGrow Kingsley</td>
<td><a href="mailto:degrowkingsley@gmail.com">degrowkingsley@gmail.com</a></td>
<td>214-542-2869</td>
</tr>
<tr>
<td>Houston</td>
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<td>Richard Powell</td>
<td><a href="mailto:rpowell@gt.rr.com">rpowell@gt.rr.com</a></td>
<td>(409) 883-7822</td>
</tr>
<tr>
<td>Houston</td>
<td>TX</td>
<td>Stephen Haskew</td>
<td><a href="mailto:haskews@verizon.net">haskews@verizon.net</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@GSolutionsTX.com">wass@GSolutionsTX.com</a></td>
<td>(281) 460-1033</td>
</tr>
<tr>
<td>Richmond</td>
<td>VA</td>
<td>Sam Brumberg</td>
<td><a href="mailto:Samuel.Brumberg@LeClairRyan.com">Samuel.Brumberg@LeClairRyan.com</a></td>
<td>(804) 968-2981</td>
</tr>
<tr>
<td>Seattle</td>
<td>WA</td>
<td>Paul Stevenson</td>
<td><a href="mailto:paul-megan@msn.com">paul-megan@msn.com</a></td>
<td>(206) 465-7280</td>
</tr>
<tr>
<td>Spokane</td>
<td>WA</td>
<td>Joan Poltizin</td>
<td><a href="mailto:joanp115@webband.com">joanp115@webband.com</a></td>
<td>(509) 624-8214</td>
</tr>
</tbody>
</table>

If you’d like to find out 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.
Spondylitis Association of America (SAA) Among 10 Highest-Rated Charities in America

The Spondylitis Association of America is pleased to announce that a recent analysis from personal finance news website MainStreet (www.mainstreet.com), also reported on MSN Money, has named SAA as the ninth-highest rated national charity in America.

From the story: “Among the thousands of national charities that leading charity-rating website Charity Navigator tracks, 238 have received perfect four-star ratings. Here we take a look at the 10 best...”

Financial writer Greg Emerson says of SAA, “With revenue of just over $1.2 million last year (none of which came from the government), the California-based organization might not be able to dispense funds to all sufferers, but the informational materials it provides, in addition to the direct assistance to patients, multiply its reach significantly for a disease that is rarely fatal but can have important consequences for patients’ mobility and quality of life.”

The Spondylitis Association’s 4-Star ranking from Charity Navigator demonstrates that SAA outperforms most other charities in America in its efforts to efficiently manage its finances (your donations.) Fewer than 10% of the charities they evaluate are afforded this level of distinction.

To learn more, see page 12 of this News Magazine or visit us online at www.StopAS.org/press