A New Genetic Discovery Brings Ankylosing Spondylitis Further Into Focus

The Affordable Care Act: Controversial Legislation Aims to Protect Consumers

Sean Ryder: Discovering My Ankylosing Spondylitis
Dear Friends,

As we follow the ongoing debates throughout 2014 with regard to the impact of The Affordable Care Act, the states, with their newly authorized autonomy, scramble to establish their own health programs—called exchanges. How states design and operate their exchanges will drive plan participation, generosity of benefits, and enrollment. Understanding the range of approaches that states are likely to take when designing insurance exchanges is critical to assessing the impact of this important new market in your life.

It is important to get involved at every opportunity. As healthcare consumers we have a responsibility to steer the direction of state government decision making. One recent example of grass roots involvement would be the recently passed SB 866, where SAA supporters got involved at the local level and with a positive outcome.

A new bill, SB 866, aimed at streamlining the prescription process for medications, was passed 12-0 by the California Assembly Health Committee on June 21st. With your help this was made possible.

Here are the key points about SB 866:

- Currently, physicians and patients struggle to obtain medications due to a very complex Prior Authorization process that includes the completion of many different forms and even multiple forms within the same plan.
- Current policy allows for days and sometimes weeks to elapse before a final answer is received regarding Prior Authorization. Meanwhile, patients go without their doctors’ recommended treatments.
- This bill would streamline the process - standardizing the form that all health insurance plans would have to use.
- This bill would also require a two business day response on approval or denial, and without a response within that time frame, approval would be assumed. This would help prevent patients’ long delays without the treatments they need and deserve.

From this single example, I hope that you will see how the power of the individual can make a positive impact. Let us keep on working together toward a better future for all.

Sincerely,

Laurie Savage
Early in his armed forces career, my brother was belatedly diagnosed with ankylosing spondylitis and shortly thereafter medically retired. He has been a long-time member of your organization.

Over the past few months, we both have reached an independent but identical conclusion: your magazine primarily appears to use stock catalog photos of normal, AS-unaffected people. For quite a while now, both of us have noted your magazine’s failure to use pictures of people obviously physically affected by AS, other than an occasional picture of the organization’s founder.

Many AS patients avoid a social life because of the way they look. Patients searching for affirmation that they are not alone, that there are others who look like them, will not find that affirmation in your magazine because, for some reason, you don’t print pictures of individuals who look like them.

I can’t imagine any of your readers being shocked or disgusted by a tastefully-taken photograph of an AS patient with spinal deformities, a frozen neck... whatever. These patients are our brothers and sisters and fathers and mothers. In fact, they are not “them,” they are “us.”

Please bring the visibly affected back into the fold.

Thank you,

~MIKE, Simi Valley, CA

Editor’s Note: Thank you, Mike, for your feedback. We actually do feature as many pictures as possible with those affected, including the spread of our volunteers (all of whom have AS) in the Summer 2011 issue. The challenge with such images is twofold: 1) Receiving submissions from those with AS and 2) AS can be an invisible disease without obvious, outward physical manifestations (this is not true for everyone, of course). If any of our readers would like to submit a photograph for publication, please email us at info@spondylitis.org.

NeedyMeds Program

I received the Summer newsletter yesterday and I just had to tell you that I think the NeedyMeds drug program is the most helpful thing any organization has ever done! I have high hopes that this will help relieve some of the stress created by the high costs of RX meds.

I have come to appreciate the SAA so much. With the other diseases I have it seems that I didn’t fully appreciate the seriousness of having spondylitis. As I’ve gotten older it’s really hit me that I needed to educate myself more fully about spondylitis so that I can take a more active role in my care. I have, with the help of SAA, been able to help my rheumatologist understand some of the symptoms I’ve been having, too.

Thank you so much for all you do to support those of us with this disease.

~ PAM, Oklahoma City, OK

Editor’s Note: Thank you, Pam. We will continue to offer the NeedyMeds cards and hope to provide the same high level of supportive programs in the future.

LETTERS TO THE EDITOR

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

We reserve the right to edit for space and clarity.

Please send letters to:
laurie.savage@spondylitis.org
Letters to the Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413
ON MARCH 23, 2010 — after decades of failed attempts, from Harry Truman in the 1950s to Bill Clinton in the ‘90s—President Obama signed legislation to overhaul the nation’s healthcare system. The legislation is controversial, spawning legal wrangling and lawsuits, as well as intense political rhetoric. Many experts, both in favor of the legislation and against, agree that, in the end, the issue of healthcare reform will ultimately be decided by the nation’s highest court.
In the meantime, federal and state regulators are fast at work enacting provisions of the legislation—called the Affordable Care Act—designed to expand health insurance coverage, control healthcare costs, and improve the healthcare delivery system. The Affordable Care Act gives Americans control over decision-making about their health coverage, whether they get insurance through work, own a small business, are on Medicare, buy the insurance themselves, or don’t currently have medical insurance.

Many provisions of the law deal with Medicare, the federally-funded insurance program for seniors and younger people with disabilities (see page 7), putting seniors and those with disabilities in charge of their healthcare, as well as lowering the cost of medications and eliminating the so-called “donut hole” in prescription drug coverage.

Millions of Americans, including those with spondylitis, wake up every morning facing the challenges of living with a chronic disease or disability. Proponents of the legislation say the Affordable Care Act was developed with them in mind. Two provisions of the law pertaining to pre-existing conditions and specialty tiers for medications are particularly germane to patients with spondyloarthropathies. Jane Peloquin of California and Seth Ginsberg of New York, both diagnosed when they were children, know all too well the challenges of facing this disease without the safeguards the new healthcare reform legislation promises to extend.

Peloquin, who runs the Spondylitis Association of America’s support group in Sacramento, had her first flare-up at age 9, but was not diagnosed with ankylosing spondylitis for several more years. Her initial flare-up resolved on its own, but she was hit again in her mid-20s, a time, she says, when she was a “typical starving student” with no health insurance. In her early 30s, she left a job with group health coverage through Kaiser Permanente, a large California-based health insurer. She applied for an independent policy with Kaiser, but was “flat-out rejected,” she says, because of her pre-existing condition (at that point, she was diagnosed with Reiter’s syndrome, a form of arthritis). Today, she can only get health coverage through employer-sponsored group insurance or through her husband’s insurance plan.

Ginsberg runs the Global Healthy Living Foundation, whose mission is to improve the quality of life for people with chronic illnesses by advocating for improved access to care. He met his challenge with health insurance when he was denied coverage for costly medications that were prescribed by his physician. After a lengthy process, he was able to petition his insurance company to cover at least some of the cost of these drugs. This experience inspired Ginsberg to work at the state level to ban a practice called “Fail First,” an approach to prescribing drugs that insists that the least expensive drug in any class be given to a patient first, regardless of the patient’s needs.

Covering the uninsurable
A pre-existing condition is simply a physical or mental health condition, disability or illness that you have before enrolling in a health plan. But, there is no single definition of what constitutes a pre-existing condition. Some health insurers consider conditions such as acne or high blood pressure to be a pre-existing condition, while others narrow their focus to costly diseases like diabetes or cancer. Some health insurance plans deny coverage outright and others charge expensive premiums to cover individuals with pre-existing conditions.

“She applied for an independent policy…but was ‘flat-out rejected’”

The Affordable Care Act deals with pre-existing conditions in two phases (see page 8). Beginning in 2010, health insurance companies could no longer deny coverage to children with a pre-existing condition and a temporary Pre-Existing Condition Insurance Program (PCIP), offering uninsured adults with a pre-existing condition coverage in special state-based pools, went into effect. In 2014, phase 2 of the program kicks in, prohibiting insurers from restricting or denying coverage to anyone with a pre-existing condition or charging high premiums to people with these medical problems.

While that is good news for people with a pre-existing medical condition, state-operated plans are not cheap. The Department of Health and Human Services, which oversees the program, says premiums can be as low as $115 per month or as high as $1,735, depending on how old you are.
and where you live. Only U.S. citizens and permanent or legal residents are eligible for the state-run insurance pools.

Supporters of the plan say it is an improvement over currently available options, even if funding is limited (Congress has appropriated $5 billion through 2013), helping hundreds of thousands of uninsured Americans. Critics argue that limited funding will reduce the quality of healthcare or require limited enrollment.

**Making prescription drugs more affordable**

Several years ago, health insurance companies adopted a new pricing system for the most expensive drugs on the market. This new system, says The New York Times, asks “patients to pay hundreds and even thousands of dollars for prescriptions for medications that may save their lives.” Many of these are specialty drugs used to treat complex, chronic illnesses, including TNF-alpha inhibitors, which show much promise in the treatment of spondyloarthropathies.

This new pricing system puts medications into special buckets, or tiers, with each additional tier costing more than one before it. Tier 1 drugs, usually generics, typically have the lowest co-payment. Tier 2 drugs are “preferred” brand-name drugs. Tier 3 drugs are “non-preferred” brand-name drugs that are generally more expensive but have not been proven to be as effective as preferred medications. A fourth, specialty tier includes more expensive and injectable drugs such as Ambien for insomnia and Enbrel, Humira and Remicade for spondylitis. Tier 4 drugs can cost thousands of dollars per year. According to AVOS Consulting, Enbrel costs approximately $12,000 per year, while Humira and Remicade cost upward of $20,000 annually.

The full cost of these drugs is not covered under Medicare’s Part D prescription drug benefit (see page 7), but the Affordable Care Act is helping to make these much-needed drugs more affordable. By closing the gap in prescription drug coverage called the “donut hole” (see page 7), the law gives discounts for seniors and disabled individuals who purchase medications through Part D. Starting in 2011, participants in Medicare Part D can receive a 50 percent discount on covered brand-name drugs, as well as a 7 percent discount on generic drugs, while in the donut hole.

For individuals not enrolled in Medicare Part D, the manufacturers of TNF-alpha inhibitors have assistance programs to help patients pay for these medications:

- **Humira’s “Co-Pay Plus Card”** – 800-My-Humira
- **Abbott Patient Assistance Foundation** – 800-222-6885, option 4
- **Encourage Foundation** – 800-393-4675
- **Remicade’s “Remistart Patient Rebate Program”** – 877-324-2145
- **Remicade Patient Assistance Program** – 866-489-5957
- **For More Assistance Programs, Visit:** spondylitis.org/patient_resources/assistance_programs.aspx

Peloquin and Ginsberg say that even with the Affordable Care Act, there are no easy fixes for the problems that confront our nation’s health-care system.

“Health-care reform is über complicated,” says Ginsberg. “The intentions and desires to have a healthier society exist, but there’s no agreement [among Democrats and Republicans] on how these reforms get implemented.”

Peloquin says that if spondylitis patients, many of whom are indigent or on disability due to the severity of their symptoms, have access to expensive treatments like TNF-alpha inhibitors, they may be “off disability, working and paying taxes,” with a much better quality of life.

And that is what has frustrated Congress and presidential administrations—and the American public—for more than half a century. Perhaps the Affordable Care Act, however it ends up being implemented, can ease that frustration.
Medicare Primer

On July 30, 1965 President Lyndon B. Johnson signed into law the Social Security Act of 1965. The legislation included the establishment of Medicare, a social insurance program that provides health and financial security for people over 65 and younger people with permanent disabilities. LBJ enrolled former President Harry Truman as the first Medicare beneficiary. Today, Medicare provides health insurance coverage to 39 million people over age 65 and 8 million people under age 65 with permanent disabilities.

What is it?
Medicare consists of four parts, each providing different benefits:

Part A, also known as hospital insurance, helps to cover inpatient hospital care, as well as skilled nursing care, hospice, and home healthcare.

Part B, also called medical insurance, helps cover physician services, hospital outpatient care, and home healthcare, as well as some preventive services to help maintain health and keep certain illnesses from worsening.

Part C, the Medicare Advantage Program, allows beneficiaries to enroll in a private health insurance plan that receives payment for Medicare-covered benefits.

Part D is a prescription drug option run by Medicare-approved private insurance companies that helps cover the cost of prescription drugs and may help lower prescription costs and protect against higher costs in the future.

Who’s eligible?

• Most people over age 65 are automatically entitled to Part A if they or their spouse are eligible for Social Security payments and have made payroll tax contributions for 10 years or more.

• Adults under 65 with permanent disabilities are eligible for Medicare if they have received Social Security Disability Income (SSDI) payments for 24 months.

• Part B is voluntary, but 95 percent of Part A beneficiaries are enrolled.

• Individuals are eligible for Part C if they are entitled to Part A and enrolled in Part B.

• Individuals entitled to Part A benefits or enrolled in Part B are eligible for prescription drug coverage under Part D.

The Medicare program is administered by the federal Centers for Medicare & Medicaid Services, a component of the Department of Health and Human Services. For more information, visit their website at www.cms.gov.

What’s a “Donut Hole”? 

For many Americans, a “donut hole” is not something you get at the local bakery. Rather, it describes a coverage gap in which your Medicare prescription drug benefit (Part D) runs out, making you responsible for all drug costs for the remainder of the year. Here’s how it works:

• If you have a Medicare drug plan, you are responsible for the first $310 for prescription drugs. This is called your deductible. After that, you pay a copay and Part D covers its share of the drug costs until the combined amount reaches $2,840. When you reach that threshold, you’re in the “donut hole.”

• Once in the “donut hole,” you pay the full cost yourself until your out-of-pocket prescription drug costs reach $4,550. Then, the coverage gap ends and your drug plan pays most of the costs for your medications, while you only pay a copay for the remainder of the year.

In 2011, an Affordable Care Act provision kicked in, providing a 50 percent discount on covered prescription drugs. By 2020, these changes will effectively close the “donut hole” so that, rather than paying the full cost for your medications, you’ll pay only about 25 percent.
In March 2010, Congress passed and President Obama signed the Affordable Care Act, putting in place comprehensive health reforms that expand coverage, control costs, and improve the healthcare delivery system. Starting in 2010 and continuing through 2014, a number of initiatives to protect consumers and lower the costs of care for many Americans, among other provisions, will be put in place. Among the highlights:

- **2010**
  - Insurance companies can no longer deny coverage to children with pre-existing conditions.

- **2011**
  - Insurance companies are prohibited from imposing lifetime limits on essential benefits, such as hospital stays.
  - A transitional high-risk insurance pool provides new coverage options for at least six months for those who are uninsured because of a pre-existing condition.
  - Seniors who hit the gap in Medicare prescription drug coverage, called the “donut hole,” receive a $250 rebate.

- **2012**
  - Seniors who fall in the prescription drug coverage gap receive a 50% discount when buying brand-name drugs covered by Medicare Part D.
  - A voluntary long-term care insurance program will provide benefits to adults who become disabled (effective Oct. 1, 2012).
The Affordable Care Act ~ A Timeline

**2012**
- The threshold for itemized deductions for unreimbursed medical expenses will rise from 7.5% to 10% of adjusted gross income (effective Jan. 1, 2013).

**2013**
- Annual dollar limits on the amount of health insurance coverage an individual may receive will be prohibited (effective Jan. 1, 2014).

**2014**
- Most individuals who can afford health insurance will be required to obtain basic coverage or pay a fee to help offset the cost of caring for uninsured Americans (effective Jan. 1, 2014).
- Americans who earn less than 133% of the federal poverty level (about $14,000 for an individual; $29,000 for a family of four) will be eligible to enroll in Medicaid (effective Jan. 1, 2014).
- Strong reforms that prohibit insurance companies from refusing to sell coverage or renew policies because of an individual’s pre-existing condition will be implemented (effective Jan. 1, 2014).
- Annual dollar limits on the amount of health insurance coverage an individual may receive will be prohibited (effective Jan. 1, 2014).
I used to walk to lab every day, year round. There was no choice. I didn’t have money for a car or for a parking pass. And it wasn’t that far, one and a half miles at most. Life as a graduate student was austere but incredibly rewarding. The “walk” seemed a small price to pay for an education. Even when it snowed.

Several times a year, not always but frequently enough, the walk would bother me. I had low back problems, my hips would ache, and the bottoms of my feet would feel like they were on fire. The pain would come and go. No big deal, I’m a young active man, I would tell myself. I’m bound to hurt from time to time. I played hockey in the winter, and volleyball in the summer. I worked hard, I partied hard, and generally ignored my own physical well being like most other twenty-something men. Plus, it was only a mile and a half. I was embarrassed to admit to myself that I was having trouble walking that short of a distance.

One day, in the summer when it was very hot, I was having one of the bad days. I made it to lab, climbed the stairs to the basement entrance, and then headed directly to the elevator to catch a ride up to the third floor. One of my professors walked into the building at the same time as I did, but chose to take the stairs instead. When we met again three floors later, he couldn’t help but be smug. I won’t soon forget his words: “When I was at Cambridge, my mentor (a Nobel prize winner in 1962 for pioneering work in structural biology) would always bound up the stairs, and look at everything he accomplished!”.

Was your mentor also an as-----? I wanted to say. But I bit my tongue and whispered to myself, what if I had been really sick and this guy had talked to me like that? You won’t catch me saying things like that to people I don’t know, I promised. I won’t make assumptions about how other people feel, and whether or not they need to take an elevator or use the stairs.

It wasn’t long after that when I had what I consider to be my first real incident. I was lying on my couch in the living room, and when I tried to stand up to walk to the bathroom, I couldn’t. I was stuck. If I tried to put weight on my legs, they would give out. I literally fell to the floor. My wife, who is less than half of my size, came to my rescue. Somehow, she physically picked me up, and helped me hobble down the hallway to the bathroom. By the time I made it up and back the hallway the pain had lessened, but my self confidence was shaken. I went on and off having episodes like that for a week. More than once I crawled around on hands and knees until the pain would subside enough to walk again. And then it went away, as quickly as it came.

My wife, having more than her fair share of common sense, insisted I go to a doctor. I didn’t like doctors, most of the
ones I saw as a child were located on a military base, and I would see them only to get vaccinated. There were times when my family didn’t have much in the way of health insurance, but did have access to military facilities thanks to my father’s retiree status. Thus I learned at an early age that the doctor was to be avoided at all costs. But in the end, sense won out over stubbornness, and I went to the clinic to take advantage of the student “Death Plan”, our tongue-in-cheek term for what passed for healthcare on campus.

There I met a physician’s associate in the orthopedics department. He did some blood tests and took x-rays. Nothing to see by the bloodwork, he told me, no elevated inflammation markers, everything is within normal range. The x-rays were equally unremarkable. He said my lower back was straighter than usual, I did not have the appropriate amount of lordosis in my lower spine. He suggested that this could lead to greater mechanical back pain, but shouldn’t be too much of a problem. Straight back syndrome, he called it. He suggested I swim to strengthen core muscles and take Motrin with breakfast. Breakfast of champions, he said. So I did. And I felt better. I figured I was just born with a bad back, and I would have to live with it. And I carried on believing that for 6 more years, despite multiple “episodes” and the resultant comments from family and friends. It’s just a bad back, I would tell them. That’s what the Doc said.

In 2005, I started a new job, my dream job, and moved across the country. The work was exciting, challenging, and stressful. As the stress mounted, so did my back problems. I spent hours in front of the computer or in the lab, 60+ hours a week, and it was taking its toll on me. My back was killing me. Worse than ever.

My wife again insisted I go back to see a doctor. I now had good health insurance and no excuses. My primary doctor did blood work and sent me to physical therapy. No inflammation markers, he noted, but slight anemia, and definitely a bit too much curve in the upper spine and not enough in the lower. He hoped that physical therapy would “straighten me out”. The physical therapists certainly gave me their worst—I was poked, prodded, stretched out on a table, asked to lie prone on a rolled up towel to try and reverse my kyphosis. I felt more pain than ever. Finally, my primary doctor decided to take x-rays of my sacral spine. And there it was, clear evidence of inflammatory damage to my sacroiliac joint. He referred me to a rheumatologist, who took one look at my chart and made a tentative diagnosis of ankylosing spondylitis, subsequently confirmed by a CAT scan that showed sacroiliac fusion and a positive test for the HLA-B27 gene (Not a very useful blood test, because most with HLA-B27 never develop the disease).

So finally my bad back had a name. A silly name to be sure, but a name none the less. Ankylosing Spondylitis. When all the ankylosaurus jokes and how’s your AS(s) jokes subsided, I was left with a new reality. This wasn’t going to get any better. It was going to get worse. Possibly much worse. And I wasn’t emotionally prepared. I became depressed. Then I lost two close friends, both of whom died unexpectedly, way too young. I thought I was going to lose my wife and second child on the delivery table, which gave me a huge scare, and made my life seem even more hopeless. I felt like the man with the “merde” touch—everything I touched turned to shit. I blamed myself. I judged myself mercilessly. I hated what I had become, what I was going to become, and lived life surrounded by a cloud of doom and gloom. Worst of all, I was afraid that I had cursed my two children to the same fate.

And then something surprising happened. I found hope. I started a new medicine, delivered to my door in a pre-filled syringe that I would inject under my skin every two weeks. This medicine was a “TNF-blocker.” It’s a humanized monoclonal antibody that binds and sequesters the pro-inflammatory cytokine TNF-alpha. It worked like magic. I would inject myself, have a great night’s sleep, then wake up mostly pain free and ready to take on the world. The feeling would last for almost two weeks. I would have a couple of bad days, but then time came for the next injection. I felt like I was given my life back—better living through biochemistry. Thanks to this new found hope, I found the courage to meet with a psychiatrist who put me on the road to recovery from depression.
I started to reevaluate my life. I am a scientist by profession. I do basic biomedical research for a living. If I had never heard of AS, perhaps other scientists were equally unaware. And that was scary to me. I started poking around the literature and grant databases, and realized the community of scientists studying this illness as their primary focus was exceptionally small. I felt like something had to be done. I felt like I had to spread the word, to get as many smart people thinking about AS as possible, to help foster disease research. I knew that there were others like me, who found great relief from TNF-blockers, but there were many patients who didn’t respond to this kind of treatment. And there was no evidence that TNF blockers would stop fusion. In short, it wasn’t a cure.

I became a member of the Spondylitis Association of America. I followed with great interest the genome wide association studies that they helped to initiate, the results of which have identified several additional genes that are linked to the disease. I read their literature, bought the coffee mug, proudly wore the “Stand Tall” bracelets, and made a commitment to donate annually to their cause. I participated in their online forums, and made new friends that could understand what I was going through.

I have been fortunate to interact with some amazing people as a result of this illness, like Kelly, who founded the Ankylosing Spondylitis Awareness Project, a Facebook page that connects AS patients with each other and seeks to increase awareness about the disease—and Michael, the creator of Spondyville, whose quick wit and sense of humor helps to keep thoughts of a sad future at bay—and Fee, whose strong voice and talented song writing comprise a special form of AS awareness that you can dance to—and Jenna, who is keeping the doctor away one apple at a time—her goal is to create one apple-themed art piece per day for a year in hopes of attracting media attention to the cause of AS awareness. And many, many more.

Today, I can accept that the future may not include all of the things I imagined as a young man. I can accept that pain is going to be part of my everyday life. I know that there will be good times and bad times. I know that some days I will feel inspired, and other days I will feel hopeless. I know at times I will be disappointed, and that I will disappoint others. I also know that the only way to accomplish anything is to get to work.

Life goes on. I have had to switch TNF blockers twice now. I take other medicine to help prevent my body from becoming resistant to the medicine, and an anti-inflammatory to help control break through pain. Today was a bad day. Maybe tomorrow will be better. Who knows. I wish that I never heard of this disease, but now that I have, I feel compelled to tell people about it. I am comforted in the knowledge that there are many out there who are looking out for me, and I will do what I can to return that favor.

Tell Us Your Story

Check out other member stories online at: http://www.spondylitis.org/patient_resources/your_story.aspx

We want to hear your story. Believe it or not, so do the millions of others afflicted by AS and related diseases. Share your story with us today for possible publication in Spondylitis Plus or to post on our website, spondylitis.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!
A New Genetic Discovery Brings ANKYLOSING SPONDYLITIS Further Into Focus

Since 2007, the TASC (Triple - “A” - Australo-Anglo-American Spondyloarthritis Consortium) study has been finding new genetic keys that have the potential to unlock the secrets of ankylosing spondylitis (AS).

The first discovery came in October, 2007 when researchers announced the first new genes associated with the disease in over three decades: IL23R and ERAP1, formerly known as ARTS1. This prompted Laurie M. Savage, Executive Director of the Spondylitis Association of America to state, “This is the most significant breakthrough in AS research since HLA-B27 was uncovered 34 years ago and SAA played a significant role in making the study possible.”

Then, in January, 2010 two more genes implicated in AS were discovered as pieces of the puzzle of ankylosing spondylitis continued to fall into place. ANTXR2 and IL1R2 were the new culprits that TASC linked to the condition.

Now we come to July, 2011 and the study has done it again. Three additional regions of the genome appear to be involved: RUNX3, LTBR and TNFRSF1A, with four additional areas that also seem to play a role - PTGER4, TBKBP1, ANTXR2 and CARD9.

What Does All This Mean?

As the genetic picture comes into focus, all of these discoveries combined could become additional targets for treatments / medications, as well as assist in developing diagnostic tests. Although both treatments and tests will come further down the road, these discoveries have also helped point to a possible trigger of the disease.

From a University of Texas press release: “We have evidence of a gene-gene interaction that gives us a potential mechanism by which HLA-B27 may cause ankylosing spondylitis,” said John D. Reveille, M.D., director of the Division of Rheumatology and Clinical Immunogenetics at the UT Health Medical School.

The study led by Reveille and Matthew Brown, M.D., of the University of Queensland reported a link between a gene producing protein, ERAP1, and HLA-B27. For example, ERAP1 was associated with ankylosing spondylitis in HLA-B27 positive patients; whereas, there was no association between ERAP1 and AS in HLA-B27 negative patients.

Professor Matt Brown, M.D, adds, “Our work shows the great value of partnering genetics research with functional investigations to determine the basic biology which leads to common diseases such as ankylosing spondylitis, the causes of which have remained an enigma for so long.” And that these findings, “are a promising step in the right direction.”

SAA will continue to help participate in, and drive important research as well as keep all of our constituents informed of the latest breakthroughs. For information on the latest findings published in Nature Genetics (43, 761–767 (2011) doi:10.1038/ng.873) visit:

http://www.nature.com/ng/journal/v43/n8/full/ng.873.html

And you can also get the latest information from SAA’s online news section:

http://www.spondylitis.org/press/
We Listen...
...We Act

A Site of Their Own
Parents and family members of teens with spondylitis told us that these kids need a place to go to share their stories and get helpful advice from others who’ve navigated the same challenges. This summer, we launched the fully redesigned SWIFT website. With a fresh new look, dynamic content and streamlined functionality, teens.spondylitis.org is the place for teens and young adults to get tips for school, sports, transitioning to college and more.

Prescription Assistance
Our members often tell us about the difficulties of accessing affordable prescription medications. In the last issue of Spondylitis Plus, you received your NeedyMeds Drug Discount Card. Over 54,000 stores across the country, including all of the major chains, accept the card and there’s no registration, no paperwork and no cost to you. By partnering with NeedyMeds, SAA is helping you access affordable rates on prescription drugs as well as many over the counter medications.

Get Connected
SAA offers so many support programs that sometimes it might be hard to find just the one that’s right for you. We’ve gathered them all under one umbrella so that the various options can be viewed side by side. Coming Soon -- SAA Connections -- a one-stop shop for programs ranging from SAA Educational Support Groups, spondylitis.org Interactive Forums, our unique Peer/Mentor program and links to our social media sites like Facebook, Twitter and YouTube.

There’s an App for That
We’ve been asked, “Why isn’t there a convenient, portable way for me to track my symptoms, medications, doctor’s appointments and medical contact information?” The answer -- there soon will be. We are currently developing the SAA Management Tool for Ankylosing Spondylitis. The world’s first application for the iPhone, Android and PC/Mac dedicated solely to assisting those with spondylitis will make it easy to organize your medical information on the go.

And our members don’t just provide the ideas behind these programs, they also provide the financial support required to turn the ideas into reality.

This Fall, Your Program Dollars Can Go Twice as Far
Your donations are always appreciated and always put to good use. But right now, thanks to a generous $50,000 Challenge Grant from the Jean & E. Floyd Kvamme Foundation, every contribution you make to SAA will be matched dollar for dollar. This challenge is for a limited time only, so please give today. All donations sent by October 31st, 2011 qualify for the challenge.

Whether you make a one-time donation, sign up for the SMART Program (Spondylitis Monthly Automatic Rewards Team), renew or upgrade your membership, your gift will be matched, if sent before October 31st.

Your support will ensure that SAA can continue to listen to, and act upon, the needs of our members.
Visit spondylitis.org/challenge
I do not suffer from ankylosing spondylitis, but I have been diagnosed. All my rheumatologists over the last 14 years have attempted to get me onto hard drugs; drugs that attack the immune system and offer relief to some. I have ignored them and everyone else.

For me, the solution has always been simple and of course I must have had a light case of AS. I seek out answers for myself and my body. I listen to my body-mind and let it lead to teachings and wisdom. In my opinion this is a disease of the body. [It is] the sadness of living a non-moving egoic life without the body. The more I work and stress about work and stay immobile, the worse I eat, and the more pain I have.

The following is not rocket science and can be used probably for all of our chronic diseases, of course it can’t hurt!

1. Diet - remove all refined sugars. That means no deserts, just natural sugars in naturally occurring ways. It can be done easily when you see the loss of pain and tightness (alcohol is a sugar)
2. Diet - eat raw green organic vegetables, lots of them, meaning a large salad every day, protein also
3. Active isolation stretching every day 30 minutes in the morning
4. Cardio work-out three times per week for 1 and 1/2 hours where you drip sweat, cleansing your body’s toxins
5. Weight lifting two times per week to increase strength
6. Body activities that stimulate creativity - dancing actively, improv (Motion theater with Nina Wise), Mildendorf Breath work, feldenkrais, Esalen workshops -- live a body life
7. Touch - get human touch, massage. Love people all the time
8. Make Love
9. Laughter - should be #1
10. Children, joy, relevance, service to others
11. Protein powder to ensure protein at every meal + vitamins, and anti-inflammatory herbs
12. Hourly movement where you raise your arms over your head and laugh and dance ecstatically for no reason
13. Pain management - indomethacin pill at night

This disease is all about bad diet and no activity. Americans eat horribly and sit all the time. The cure is right in front of all of us and it is not a cure, but it is a quality of life issue. Now start eating with body intelligence and get moving. I celebrate this disease for all the knowledge it has delivered to me in self care and vigorous lifestyle.

Blessings,
Tom Hickey

Hi Tom,

I am very happy that you have found the right treatment for your illness although I am not sure whether it is ankylosing spondylitis or one of the illnesses closely related to it such as colitis with spondylitis or psoriasis with spondylitis. A well balanced diet, exercise that does not exacerbate the illness and a positive attitude greatly improve the symptoms of any chronic illness. In fact, my patients tell me that the best way to improve your health is to get a non life threatening chronic illness and be forced to make positive lifestyle changes with your diet, exercise and attitude that enhances your sense of well being. However, not everyone with ankylosing spondylitis is able to get sufficient relief of their symptoms with just lifestyle changes and an anti-inflammatory medication such as indomethacin.

In my practice, about 50% of my ankylosing spondylitis patients get relief with lifestyle changes and anti-inflammatory medications alone. The remainder of the patients would be chained to an existence of sleepless nights due to pain, disability with simple activities and loss of productivity in their personal and work lives without the immune modulating or suppressing medications such as sulfasalazine or the tumor necrosis blocking injectable medications. There is no cookie cutter approach that works in the practice of medicine. Therapies that work for a patient or a small group of patients may not work for everyone with the exact same diagnosis. As science advances, we will understand better the differences that exist within patients with the same diagnosis and be able to tailor therapies better to each patient. Until then, patients with ankylosing spondylitis should strive to control their symptoms and disabilities with the best combination of lifestyle modifications and medications under the supervision of a doctor who is knowledgeable about their illness and who listens to their concerns.

David Hallegua MD
Rheumatologist, Los Angeles
Have you ever been to the doctor and been confronted with a treatment you knew nothing about and an explanation that left you just as confused? How do you decide which treatment is best for you? What are a treatment’s harms, benefits, and objectives? Making informed health-related decisions can be difficult. The abundance of health-related information these days, whether it is from the internet or medical, scientific or health-related journals, can be overwhelming for consumers (patients), healthcare providers and policy-makers alike.

Some patients assume all doctors, who have many years of education and training in their fields, must be experts in all things medical. But the reality is that due to personal time restraints and ongoing world-wide research, it is a challenge for any healthcare provider to stay constantly up-to-date. New scientific studies are published daily in a myriad of sources. To compound the problem, the results of one study may be different from or even contradictory to the results of another making it difficult to draw accurate conclusions. Another problem is that the research findings can be published in a language different from that of the person doing the searching. This is where the work of the Cochrane Collaboration can be of great help to both healthcare provider and consumer.

What is the Cochrane Collaboration?
There are 14 independent not-for-profit Cochrane Centres worldwide. Collectively, these centres are known as the Cochrane Collaboration which is based in the United Kingdom. The main objective of the Cochrane Collaboration is to help people make well-informed healthcare decisions by producing, maintaining and promoting systematic reviews which provide up-to-date information about healthcare interventions. To fulfill its purpose, the Cochrane Collaboration is made up of groups that are based on a particular disease or health problem (such as the Musculoskeletal Group which encompasses the spondyloarthropathies and other types of arthritis and soft tissue disorders). Most people involved in contributing to the reviews, whether they be healthcare provider, researcher or consumer, do so voluntarily because they are committed to the outcome.

What is a Systematic Review?
A systematic review begins by addressing a clearly formulated question (such as, “Is sulfasalazine effective in eliminating the symptoms of ankylosing spondylitis?”). The results of many studies or trials are then rigorously assessed using scientific guidelines set out by the Cochrane Collaboration in the Cochrane Handbook. A systematic review is the detailed summary of these results and provides the answer to the initial question. Is the intervention helpful, harmful or are the results inconclusive indicating that more high quality research is necessary? Cochrane systematic reviews take the guess-work out of making well-informed decisions about healthcare by providing people with a reliable source of evidence about an intervention. Because Cochrane systematic reviews use such high scientific standards to determine which health therapies work and which ones don’t, they are less biased and more comprehensive than tradition reviews. They are, in fact, the “gold standard” in Evidence-Based healthcare.
What is the Cochrane Library?
The Cochrane Library (www.thecochranelibrary.com) is a collection of evidence-based medical databases. The one which would probably interest consumers the most is the Cochrane Database of Systematic Reviews which is a collection of over 4,500 health treatment reviews which are published on the internet and updated at least quarterly to ensure they contain the most current data. The Library covers hundreds of medical conditions as well as a variety of topics such as injury prevention and alternative remedies. The Cochrane Musculoskeletal Review Group also offers a series of “Decision Aids” which may be of benefit to anyone who needs extra guidance reaching a decision as to whether or not to try a particular treatment. Decision aids are evidence-based tools designed to complement health practitioner counselling and encourage patient involvement in decision making. There are currently decision aids available on osteoarthritis, osteoporosis and rheumatoid arthritis. Watch out for one about ankylosing spondylitis coming up soon. These decision aids may be accessed at www.musculoskeletal.cochrane.org/decision-aids.

The Cochrane Library is the place to download FREE abstracts and plain language summaries of reviews. Abstracts are shortened versions of reviews which still contain a certain amount of medical terminology and technical information on how the review was conducted. Plain language summaries, on the other hand, are exactly what you would expect. The review is briefly summarized in easily comprehensible language which includes the findings on benefits and harms of the intervention in question as well as any limitations of the review and studies it includes. The plain language summary is perfect for the layman and generally follows the abstract in a review.

If we’re honest, many of us are intimidated by physicians and are hesitant to question treatments. Perhaps there have even been times when you consented to a treatment you silently questioned because you didn’t feel you had other options. How many times have you realized shortly after leaving a doctor’s office that you had many questions that should have been asked but weren’t, either because you were too nervous, overwhelmed or there simply wasn’t time? By broadening your knowledge base with the evidence-based information Cochrane systematic reviews can provide, you might feel better prepared to face that next doctor’s appointment and have the confidence to ask questions and work with your doctor in shared decision making. Who knows? You might even be able to mention treatment options not thought of previously. Remember that knowledge is power and you have a right to have a voice in your own healthcare.

The information for this article is adapted from links found at www.cochrane.org/consumers, www.thecochranelibrary.com, www.musculoskeletal.cochrane.org/decision-aids and www.ccnc.cochrane.org as well as from promotional material distributed through Cochrane Canada.

By Marilyn Walsh (Volunteer local contact for the Ontario Spondylitis Association, Canada and volunteer consumer reviewer for the Cochrane Musculoskeletal Review Group).
Dear Laurie,

Thank you for all the SAA’s work and yours to help all of us with spondyloarthopathies. In the Summer, 2011 issue of *Spondylitis Plus*, an article by Kyle W. West caught my eye.

I am a disabled vet under the care of the VA Healthcare System for many years. I had already had recurrent iritis before coming into the VA Heathcare system. I had just moved from the North Chicago VA to the Palo Alto Medical Center’s care due to their acknowledged excellence in treating my primary diagnosis Post Traumatic Stress Disorder (PTSD). It wasn’t long before I again presented with iritis in one of my eyes.

The ophthalmology department there started asking questions I had never heard before. For instance: Did I have back problems? Have I ever been tested for the HLA-B27 antigen? How many times had I had iritis? Had I ever been tested for STD’s, HIV, or Lupus? Needless to say all this grabbed my attention. They commenced a battery of tests, to include x-rays. Most of the tests came back negative, except for a suspicious x-ray and the HLA-B27 test. During a review of these tests, again with an ophthalmologist, they gave me the first heads up that I may have something called Ankylosing Spondylitis, that I may start experiencing, in the future, more and significant back pain, and that while the HLA-B27 test was positive it wasn’t strictly determinative of either a reason for the iritis or a diagnosis of AS, but it was a milestone of sorts.

It wasn’t until another five years had passed before the significant back pain started to raise it’s ugly specter that I remembered their advice. “Go see a Rheumatologist!” By this time, I had moved up to Oregon. It took a while to get that referral to a Rheumatologist, but after treatment with indomethacin by primary doctor for a while and then a colonoscopy showing significant Crohn’s disease, I was sent up to the Portland VA. I see Dr. Chu and Dr. Philipose there.

By this time I was in significant, profound, chronic pain registering in the 7 range. I was “walking” with a cane. I was miserable. And almost immobile.

These wonderful doctors put me on infliximab (Remicade). Within days I was feeling relief. Within weeks, the pain was gone. And my flexibility improved, not a lot, but improved nonetheless. They also eventually added methotrexate in a small dose as a complementary therapy.

I have just had cataract surgery in my right eye due to all the prednisone drops I had used for years treating recurrent iritis, another sequela from the AS.

Now under treatment for AS after years of increasing suffering, I have to give praise to my current doctors at the Portland VA, for sure. But also to the ophthalmologists at the Palo Alto VA who gave me the heads up to recognize what a progression of AS might look and feel like and gave me the strength to finally insist on seeing a Rheumatology specialist.

Overall, I have found this long pathway to proper treatment to be typical amongst my fellow AS patients. Yet I also know that the relief I am now feeling, even with proper treatment, is on the fortunate side. I am lucky that for now the infliximab/methotrexate is working so well.

I also noticed in the same issue that earlier intervention and diagnosis is becoming possible. What a great development!

Gratefully,

Gregory Burnell
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.spondylitis.org/patient_resources/](http://www.spondylitis.org/patient_resources/)

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.

**Recent Meeting Highlights:**

**Where:** Baltimore, MD  
**When:** Wednesday, June 15, 2011  
**Topic:** Social Security Disability - Bring your questions!  
**Guest Speaker:** Sharon Christie, RN, Esq.

**Where:** Dallas, TX  
**When:** Monday, June 20, 2011  
**Topic:** The Spondylitis ‘Bag of Tricks’: Sharing what helps each of us.

**Where:** Plymouth, MA  
**When:** Saturday, June 18, 2011  
**Topic:** Affording Spondylitis - Managing your Disease & Related Costs.

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This FREE event will be held in Chicago, IL on November 5, 2011!

The program includes special guest speakers and ample time for questions as well as a chance to participate in small, informal group sessions to share information and mix and mingle with other patients, families and friends.

Email us at reservations@spondylitis.org or call Elin Aslanyan toll free at 1-800-777-8189 x222 for more information and to register!
R. Means Davis, Jr. is Leaving a Legacy for Future Generations

I learned about the Spondylitis Association of America through my rheumatologist. I kept looking for people with ankylosing spondylitis in the Atlanta area, figuring that with a population of some 5 million people, at least a few had to have AS. When SAA came to Atlanta for an educational seminar, I spoke to them about starting a support group for local AS sufferers. Thanks to SAA, I have been able to field questions from people with AS, get people together to talk about their challenges and successes, and hook people up with rheumatologists who specialize in AS.

When SAA needed funding, I was there for them, just as they were there for me when I needed answers to my questions about AS. I’ve always contributed financially to worthwhile causes, but I decided to join the Quest Legacy Society and leave money in my will for the Spondylitis Association because of the work they do to help AS patients and educate those who don’t know much about the disease. It is unimaginable to me that one might lack a sense of responsibility for the problems people face with this disease and I can’t imagine not giving back.

To learn more, visit us online at spondylitis.org/quest or call Mark Letts at 800-777-8189, ext. 231.