An Update On Spondylitis Genetic Research

Uveitis And The Spondylitis Patient

SAA Educational Support Groups: Taking an Active Role for Optimum Health
It is with great pride and some considerable shortness of breath that I realize that 2009 is almost upon us. So many things we have worked on so long have come to fruition. And I know that it was your dedication and support that made it all possible.

In these pages are announcements of yet more progress on the genetic front; building on the progress realized in 2007, our research partners have managed to provide further progress towards understanding this disease. We have seen the launch of our new advocacy website, as well as our highly-successful Facebook and MySpace communities. Our educational programs for patients and physicians across the country have reached perhaps a thousand attendees with critically needed information. Our chronic back pain screening tool has completed its research phase, and is scheduled to ‘go public’ later this year. There really is much to be excited about.

But it is not enough. Not nearly.

We think that there are at least 500,000 people in this country who suffer from ankylosing spondylitis, and possibly 3,000,000 more who are battling with one of the four other related spinal diseases this organization serves. A great many of those people are suffering needlessly, either having been misdiagnosed or, worse, told that they are ‘imagining it.’ Some researchers have told us that thousands who have been diagnosed have ‘dropped out’ due to frustrations over older, less effective treatments—not realizing that new and life-changing developments have since come on the scene. These are people for whom life could be changed dramatically for the better if only they had access to the essential information we alone are positioned to provide.

Tonight those people are going to face yet another sleepless night, one borne of pain and hopelessness. Some nights—like last night—I lie awake as well; for I know that they are suffering tonight because today—like yesterday and the day before—we failed to reach them.

This is not going to continue—not on my watch. 2009 is the year that we are going to begin to change their lives. But we cannot do this—not without you. As individuals, this problem is bigger than any one of us. But together, as a team, we will win. We will reach them.

This is not going to continue—not on my watch. 2009 is the year that we are going to begin to change their lives. But we cannot do this—not without you. As individuals, this problem is bigger than any one of us. But together, as a team, we will win. We will reach them.

My thanks go out to you and every other member; you made the successes of 2008 possible. We seek to enter 2009 with a new energy and a deep commitment to the work ahead. Come with us—it’s going to be an exciting ride.

Sincerely,

Laurie M. Savage
Executive Director
A Good Chair for the Office

I am trying to get my workplace to purchase a new chair for me to help relieve my insane back pain. I am a programmer so I sit all day. Now I need a chair, and although they are not too happy about it I think I can get them to spend up to $500 - beyond that I will have to pay for it myself.

Has anyone else been through this process and can recommend a good chair? My pain/stiffness is primarily in my shoulders and neck and is becoming so bad I am considering quitting my job unless I can get some way to deal with this.

Thanks!

Spondylitis.org Forum Member Rinner

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In Response…

There are good guidelines on ergonomics for office use ... there are people who build careers around it.

But as I type this I am at work STANDING at my workstation. I too develop intractable back pain after a day of sitting at my desk. My pain is much less if I stand. So I adapted a 3' file cabinet as an alternative place to work. I have a laptop and when I’m sitting I use the docking station, full size screen & keyboard. When I stand I just take the laptop over here. I’ve only been doing this a couple weeks but I really like being able to change up.

Try shopping around online - Google office furniture catalogues - to get a sense of what is out there and what features they feature. Think about what hurts when and what aspects of a chair might help alleviate that pain.

I would definitely also plan on incorporating regular stretching and walking breaks even with a new chair. Definitely consider trying the standing option if you can!! Good luck.

Spondylitis.org Forum Member JeninCincy

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In Response #2

Personally, the best thing for me to sit on is a balance ball. You have to get the right height but I really like being able to wiggle my hips, etc. My son’s teacher had a chair that held a balance ball and I tried it once, very comfortable. Google “exercise ball chairs”. I have seen them at Target, too.

Another option: Many physical therapy offices have or can refer you to a specialist that will come visit you at work, see your set up and give you suggestions for equipment and usage to help your ergonomics. I believe they are called ergonomic assessors or ergonomic consultants.

Spondylitis.org Forum Member Chelbird

Editor’s Note: For additional information about job accommodations visit the Job Accommodation Network (JAN) at www.jan.wvu.edu. From their website: Services include one-on-one consultations about job accommodation ideas, requesting and negotiating accommodations, and rights under the Americans with Disabilities Act (ADA) and related laws.
The genetics of ankylosing spondylitis (AS) came into clearer focus nearly a year ago, with the discovery of two genes that increase the risk of developing the disease. Scientists now have found what they believe may be the last pieces of the genetic puzzle to this potentially crippling disease.

“When we identified ARTS1 [now called ERAP1, for endoplasmic reticulum aminopeptidase1] and IL23R, we expected to come up with additional genes within the next year to give us all the answers to AS,” says John Reveille, M.D., director of the Division of Rheumatology and Clinical Immunogenetics at the University of Texas Medical School at Houston. “We’re almost there. We’ve identified other genes—some are important, some are not.”

Dr. Reveille, who was one of the scientists to identify ERAP1 and IL23R, recently presented findings at the Sixth International Congress on Spondyloarthropathies in Ghent, Belgium, that implicate other genes in AS. He calls these findings “equally as big as ERAP1 and IL23R.”

Genetic History
Nearly 38 years ago, scientists identified HLA-B27, a powerful predisposing gene that accounts for approximately 40 percent of the overall cause of AS. HLA-B27 is an inherited gene marker that is associated with several rheumatic diseases, including AS and psoriasis. The gene is found with the highest prevalence—greater than 90 percent—in people with AS. The gene itself does not cause AS, but makes individuals more susceptible to the disease. In fact, not everyone with the HLA-B27 marker will develop AS. If someone with the genetic marker has a child, there is a 50/50 chance they will pass it on to their child; however, there is still only a small risk of the child ever developing AS. The risk of AS increases in a sibling of someone who has the disease and is HLA-B27 positive.

The HLA-B gene, part of the family of genes called the human leukocyte antigen (HLA) complex, provides instructions for making a protein that affects the immune system. This complex helps the body’s immune system distinguish its own proteins from those made by viruses and bacteria that invade the body. There are several different forms of the HLA-B gene, which allow a person’s immune system to react to various foreign invaders. The HLA-B27 version of the gene increases the risk of developing spondylitis.

In October 2007, Dr. Reveille and Matthew Brown, M.D., of Australia’s University of Queensland, identified the ERAP1 and IL23R genes and linked them to spondylitis. The presence of these two genes, as well as HLA-B27 and inflammatory back pain, a hallmark of AS, “will almost make the diagnosis of ankylosing spondylitis complete,” according to Michael Weisman, M.D., a Los Angeles rheumatologist who spoke at a Spondylitis Association of America educational seminar in June about classifying and diagnosing the disease.
Like HLA-B27, the IL23R gene plays a role in the immune response to infection. In this case, it provides instructions for making a receptor present on the surface of certain immune cells. These receptors are involved in triggering chemical signals inside the cell that promote inflammation and coordinate the immune system’s response to infection.

“We know that there are different responses from the immune system in inflammatory and rheumatic diseases,” says Dr. Reveille. “A key pathway in AS is related to the IL23R gene.”

IL23R has been implicated in other diseases, such as inflammatory bowel disease and psoriasis, both of which are related to spondylitis.

ERAP1, on the other hand, says Dr. Reveille, works with HLA-B27 to determine protein levels on the B27 gene that regulate the body’s immune response. One of the proteins created by HLA-B27 takes fragments of pathogens (infectious organisms that cause disease) and places them on the outside of immune cells. These fragments activate the immune system so that it fights against the pathogen. ERAP1 breaks the pathogen fragments up into manageable sizes that can attach to the HLA-B27 gene.

“ERAP1 and IL23R show a new pathway of causation [for AS] and could lead to new therapies for this arthritic condition,” Dr. Reveille told the SAA soon after the genes’ discovery.

New genes provide additional treatment targets
In his presentation at the Ghent conference, Dr. Reveille revealed the results of a genome-wide association study that identified additional AS genes located on the network that contains ERAP1 and IL23R.

As scientists know from previous studies, ERAP1 regulates proteins on the surface of cells that bind to TNF-alpha, or tumor necrosis factor-alpha, a protein that is involved in systemic inflammation and is found in high levels in AS patients. Dr. Reveille’s team identified the receptor gene that causes this action.

“This gene interacts with the protein, which then interacts with a whole other set of proteins,” he says. “It’s like a domino effect.”

In addition, he adds, there are other genes in the network that “keep popping up as positive, just like the TNF receptor gene.” Another one of these genes regulates how the HLA molecule replicates others.

The identification of these additional genes gives scientists new treatment targets. The primary action of the gene might be downstream (further along the pathway on which the gene’s actions occur), says Dr. Reveille, so the goal would be to target that pathway for treatment.

“We can’t make a treatment to attack HLA-B27, for example, because that would shut down the body’s immune system,” he says. “But TNF is downstream [of HLA-B27] and is a good target.”

By identifying the genetic networks that are implicated in AS, scientists can look at other, less toxic genes and target them for treatment. If a primary function of the ERAP1 gene is to target cytokines (signaling proteins that play a critical role in the body’s immune response), then it might be more effective to attack the cytokines rather than ERAP1.

Findings allow for more effective testing
Dr. Reveille’s work, both the Ghent findings and information he presented at the American College of Rheumatology annual meeting, is leading to better testing to determine who has or is more susceptible to developing spondylitis.

Currently, MRI is the gold standard for diagnosis of AS; however, that is changing as the genetic components of the disease are better understood. A simple blood test can now determine an individual’s HLA-B27 status. Because this test does not distinguish AS from other inflammatory diseases, however, it has limited diagnostic value. New tests are being developed to gauge ERAP1, IL23R and TNF status, says Dr. Reveille, giving clinicians a better picture of the disease.

“If we know that you have the right allele [an alternative form of a gene pair] of an AS gene, then that’s much better than what an MRI tells us. We have a simple gene test right now that costs only $150 and can tell us about someone’s HLA status. New tests are currently being developed to determine status of other genes.”

Dr. Reveille’s research is part of the Australo-Anglo-American Spondylitis Consortium (TASC), which is involved in ongoing AS genetic research. The SAA serves as the national recruiting center for subjects participating in the TASC study. Last year, Dr. Brown summed up TASC’s genetic work, saying, “We can expect really major advances over the next five years in AS research on the back of these genetic studies. These are very exciting times indeed.”

Exciting indeed.
IN FOCUS: ERGONOMICS AT WORK

KEEPING STRAIGHT
Through The Day

If you’re like many Americans, you spend at least part of your workday sitting at a desk. But for many of us with spondylitis, sitting for any period of time can pose some difficult challenges. Below is an excerpt from the pages of the newly updated Straight Talk on Spondylitis with some considerations to keep in mind to help keep you “straight” through the day.

Sitting
Research has shown that most chairs force the weight of the body onto the low back and buttocks and weaken the abdominal and low back muscles. They also force flexion of the upper back and neck when working at desks or tables. It is important to support the normal curve in the low back. The major considerations when sitting include:

- Lining up the whole spine by keeping the head, neck, back and feet in the best position using a variety of tilting and height adjustable surfaces and footrests.
- Using comfortable supports for the low back and keeping a comfortable, low back curve when sitting back in a chair. The seat “pan” should be short enough to allow the buttocks to sit fully back in the seat.
- Using cushions to relieve ischial (buttocks) pain.
- Lessening stress on hips and knees by using the correct table height and chair and sitting angle. A work surface that is too high will overwork the shoulders and may irritate the neck. If it is too low, it will cause the head and neck to bend forward and strain the upper and lower back.
- Wearing appropriate eyeglasses. Near-sightedness or work glasses that focus too close (especially bifocals) cause a forward head posture. Close-work eyeglasses need a long enough focusing distance to keep a correct head/neck posture. It is important to report any vision or eye problems to your doctor to determine if it is due to eye strain or symptoms of uveitis.
- Supporting the weight of your arms on the work surface or armrests (some chairs have adjustable arms) to avoid shoulder and neck stress, as well as cumulative trauma to the wrists.
- Supporting the posture of the knees and hips by keeping feet flat on the floor, or on a book or footrest.
- Using a swivel chair if your spine is rigid.
- Adequately supporting peripheral joints that are involved, ensuring alignment and avoiding overuse.

Back Supports – It is important to maintain the normal curve in the lumbar spine (low back) and avoid flexed positions that may seem more comfortable, especially when sitting back in a chair. Rolls, which may be fastened to a longer back cushion or used by themselves, can enhance proper positioning. Many are form fitting or will contour to the back. Some are made of foam and some are air-filled. Unique designs include one that provides a “sling” around the knees to the low back so that it can be used in any sitting situation. Back supports may have a connected seat with a variety of textures and densities.

Chairs – Chairs should have the ability to adjust for height of seat and back tilt for optimal comfort. Other general features such as swivel and adjustable arms are available. When you need to sit forward to work, an angled seat is important. “Straddle” seats or “Balans Chairs” have been developed to replicate sitting on horseback, which reduces back strain and strengthens abdominal and back muscles as you try to balance. Most people cannot, however, use these for prolonged sitting.

Seats/cushions – To encourage good posture, many cushions are available that project from the back of the chair to the front to tilt the pelvis forward. This causes a curve in the low back. There are cushions contoured to relieve specific areas of pressure or discomfort such as the base of the spine. In the car, satin covers allow you to slide toward the door or across the seat when necessary, but may also cause you to slide in your seat.

Desk/Computer Work
Attention needs to be paid to posture of the neck, feet and arms while working at a desk or computer. Your desk and chair should allow you to work with shoulders relaxed, arms at side, elbows bent at near right angles.

Desktops – Tilting the work surface reduces stress on the neck and maximizes the principles of joint protection and ergonomics.
A large 3-ring binder can be used with the rings away from you, providing a slanted surface. Some tables, like drafting tables, also tilt to maximize the principles of joint protection and ergonomics as they apply to the neck. Many models at office or medical suppliers include features such as: adjustable heights and/or angles and straps or edges to secure work. Lazy Susans and desktop organizers are available at most office supply centers. These help to organize your work space by bringing necessary items within a close reach.

**Desks (Adjustable in Height)** – Correct work surface height is essential to avoid strain to the entire spine. Desks and tables with adjustable heights are often required to avoid strain to the entire back and neck.

**Foot Rests** – It is important to keep the feet flat on the floor for good support to the hip and knee. Sometimes the angle of ankle support needs to be adjusted for comfort in order to elevate the feet when sitting for long periods so as to reduce back pain and fatigue. Some foot rests are coated with skid resistant material.

**Telephone Management** – Avoid the tendency to prop the phone between the neck and shoulder, or even to hold the phone in the same position for a long time. Some phone holders support the receiver with a flexible gooseneck shaft that attaches securely to the working surface. Cordless headsets and other assistive devices are also available. Check your local electronics store to try various options.

**Adjustable Monitor Systems** – Your monitor should be adjusted to promote the best position for the neck while working at the computer. Some feature a mechanism with fingertip control to raise/lower the monitor. Others have a manual control, which can tilt, rotate and swivel, or can extend and retract the monitor support.

**Book Holders** – These are used to elevate material so the neck is maintained in correct alignment rather than flexing to look down onto a table or desk. They also take stress off of sore hands. Most are adjustable to accommodate any size book and many have page holders.

**Wrist Supports at Keyboard** – Wrist supports reduce fatigue and potential for cumulative trauma by stabilizing the wrist in the correct position while typing. Wrist “rests” are available from medical or office suppliers. They have a variety of thicknesses and density of foam padding. Some have a mounting shelf for when desk space is limited. Be sure to measure the width of your keyboard.

**Conclusion**
Your posture and body mechanics are important considerations when living with spondylitis. By paying special attention to your posture, getting up periodically to stretch, and modifying your environment you can be helpful in reducing stress on your body.
We Have A Dream...

We have a dream -- of a world in which there is no longer a need for this organization to exist. A world in which spondylitis is but a distant memory. We seek a cure; a remedy that would eliminate the pain and suffering inflicted on so many by this condition. This is the mission of our organization, and our commitment to you. We will not relent; and we will not fail.

We Are Winning - Thanks to You

In spite of the obvious intractability of this disease, we have made profound progress. SAA, and its members and friends, have been credited with ‘igniting’ spondylitis research. Research conducted in cooperation with SAA has resulted in significant progress towards understanding the root causes of the disease. It was announced in 2007 that researchers, including Dr. John Reveille, had identified the two additional genes responsible for susceptibility to spondylitis. This was an incredible milestone in the progress towards a cure. Since then, more good news as this study has identified additional AS genes located on the network that contains ERAP1 and IL23R. These new genes provide potential new targets for treatment (see pages 4 and 5) as well as new diagnostic tests.

These achievements did not occur in a vacuum. Your support of SAA directly contributed to the successful outcome of this important research. SAA acted as the clinical coordinating and recruitment center that supported the researchers by contributing toward a patient population of sufficient size to make the various studies possible and statistically significant.

None of this could have happened without the participation and support of SAA members; people like you who made this organization possible, and without whom neither the organization nor the research results would exist.

There is Still Time...

The research successes have brought us that much closer to our dream, but we have not crossed the finish line yet. There is much to be done before a cure is possible. Some would argue that the cure, when it comes, will be too late -- too late for many of you who are fully engulfed in the advanced stages of the disease. We strongly disagree.

While it is true that a cure for the disease will not likely reverse the effects for those in its advanced stages, we also know that there is more to life than just ourselves. This disease is genetic in nature; it runs in families. You know that your children, your grandchildren, and their children are all at risk.

Some of you already have loved ones that have been diagnosed. We must not fail them.

Your children, and their children, deserve for us to give them the best chance that they can have. We must not take our collective eyes off the prize; for even if the cure does not reverse the damage done to our generation, it is not too late for the next. There is still time, but only just. Our lives -- and their futures -- are precious. We cannot afford to waste a moment. If we are to spare them the suffering visited upon their parents and grandparents, we must act now: quickly, boldly and decisively.

We Have a Plan...

Nothing of great value is likely to happen by chance. As Dennis Hopper said in a recent television commercial, “You gotta have a plan.”

We have one; and you are an essential part of it.

The plan has two parts. First, pursue the cure; relentlessly, for as long as it takes, until we reach the goal. Second, recognizing that the first part will be neither quick nor easy, we must work diligently to improve the lives of spondylitis sufferers everywhere.

We are working diligently with researchers, including Dr. John Reveille and many members of SAA’s Scientific and Medical Advisory Board and various industry and government sponsors, to continue the fight to expand our knowledge of the disease to a point where a cure will be found. We are not there yet, but we are determined to win.

In the meantime, we are working hard to take care of the people suffering here and now; and that brings us to the second part of the plan.
Research indicates that spondylitis is much more common than previously believed. Perhaps up to three million people here in the United States suffer from this disease. And as you well know, a great many are suffering unnecessarily due to delayed and misdiagnosis.

SAA is able to provide essential information to facilitate earlier and more accurate diagnoses, inform people of the soon-to-be-available screening tool and to assist with better management of the disease once it is identified. Our programs reach out to physicians and patients through continuing education programs for doctors as well as educational programs, publications, webinars and podcasts for patients and their loved ones.

The information we have provided on diagnosis, therapy and management has positively impacted thousands of lives. Many patients are now able to lead productive lives due to advancements in drug therapies, such as TNF inhibitors and others, that reduce inflammation and allow enhanced mobility and pain reduction.

Due to the generous support of members like you, SAA is now engaged in developing a nationwide education program for Emergency Medical Technicians. We will soon be providing a training package to that industry that will make it more likely that the fireman or paramedic rushing to the side of an injured spondylitis patient will recognize the disease and take appropriate measures to prevent unnecessary injury.

Your contributions and membership fees have made all of this possible.

But we must do more. We believe that, with all the good work that has been done, we have yet reached only a fraction of the audience that dearly needs the information and support that we can provide.

Hundreds of thousands of people are suffering needless pain and debilitation today, for no other reason than we have not yet been able to reach them.

For these people, there is no time. They need us now -- today.

We Need Your Support

The second part of the plan -- improving the lives of hundreds of thousands of people across this nation -- is essential. But it is a large undertaking; the job we need to be doing is much larger than SAA can support at our current size. We need to reach the people who do not know and do not understand what is happening to them. For this we need you, more than ever.

If we are going to reach the thousands of people that we can help -- with knowledge, education, guidance and support, we must grow SAA into an organization that can reach all of the people who need the hope, caring, information and support that we provide.

The task ahead of us is daunting. But we are not daunted. We will continue to operate with an uncompromising certainty that we will win.

But, we cannot do it without you. In order to reach those who need us, we need your support. We know that you have given generously in the past; the many successes thus far are a testament to your caring and strength of will. But the job ahead is larger, and more difficult, than the one now behind us. The cure is now tantalizingly close, and we must not relent.

We will win. We have to; there are no other options -- especially for our children, and their children. They depend on us, and we depend on you.

Please give generously.
SAA has introduced a new benefit for members – monthly podcasts. Members can access these online audio recordings in the Member Area of spondylitis.org.

For the Member podcast for September 2008, we interviewed James Rosenbaum, MD, Professor of Ophthalmology and Cell Biology, Head of the Uveitis Clinic and Director of Inflammation Research at Oregon Health and Sciences University in Portland, Oregon. He has also been a member of our Medical Advisory Board for several years. Here are some excerpts from that podcast.

Melissa Velez Coelho, SAA’s Director of Program Services, asks: What is uveitis or iritis?

Dr. Jim Rosenbaum responds: The uvea is the middle portion of the eye. The eye has three layers and the mid portion would be the iris at the front that’s adjacent to the ciliary body, which is a part of the eye that makes some of the fluid that’s in the eye and then the back of the uvea is the choroid, which is next to the retina. The choroid is a very vascular network. It brings blood and oxygen to the retina. So, uveitis would be an inflammation at any one of those tissues, iritis, or when the ciliary body’s involved, iridocyclitis or if the choroid’s involved, choroiditis.

And then, when you have uveitis, often the tissue next to it is often inflamed, as well, so chorioretinitis would be a type of uveitis. Sometimes the entire uveal tract’s involved and that’s called a panuveitis. So, iritis is a subset of uveitis and it refers to when the front part of the uveal tract to the iris is inflamed. Maybe I should define inflammation, would that be helpful to you?

MVC: Yes, I think so.

Dr. Rosenbaum: Well each of us is fortunate to have an immune system. Our immune system would be primarily our white blood cells and our white blood cells are a little bit like the Coast Guard. They’re vigilant. They’re on alert. They’re looking for any kind of danger signal. And when our immune system senses that something’s amiss, it goes and attacks.

Now, if it’s attacking an infection like bacteria, a virus, it does its job perfectly and it gets rid of that infection. But there are diseases like ankylosing spondylitis, or reactive arthritis, where the immune system seems to be misreading a signal, so in ankylosing spondylitis it causes inflammation in the sacroiliac joints. In iritis, the white cells are sent to attack the iris as if the body thinks there’s an infection there, but as best we can discern medically and scientifically, there is no infection, but they sent the warriors out and the warriors do collateral damage.

MVC: When somebody who gets uveitis or iritis, what are some of the symptoms that they might see?

Dr. Rosenbaum: Well the inflammation in different parts of the uveal tract results in different symptoms, but in iritis, when it starts suddenly, the eye is red, you have pain and you have sensitivity to light. Now, there are patients who have juvenile arthritis and they have a form of iritis that’s very different from the iritis we seen in ankylosing spondylitis. They have a severe and potentially blinding iritis, but typically in retinas and it doesn’t cause any pain. And the choroids doesn’t
have the same symptoms or sensitivity to pain that the iris does, so a chorioretinitis usually is painless and the eye may not be red, but vision is distorted with a choroiditis or chorioretinitis.

**MVC:** Doesn’t it typically only occur in one eye?

**Dr. Rosenbaum:** The iritis that is classically associated with ankylosing spondylitis is only in one eye at a time. It will start suddenly; patients very frequently know a day or two before that something’s amiss. The eye usually feels a little bit scratchy as if there’s a foreign body present, and then, it’s active in one eye. Sometimes when that eye resolves, it definitely has a tendency to recur and in some people it jumps over to the other eye and recurs in the other eye. But, it is unusual for both eyes to be inflamed simultaneously.

There are exceptions, especially when you have spondylitis associated with inflammatory bowel disease or spondylitis associated with psoriasis. But if you have only ankylosing spondylitis, 95 percent of the time, only one eye is involved at any given point in time.

**MVC:** Who would diagnose somebody with iritis and then what would be the typical treatment plan?

**Dr. Rosenbaum:** Iritis certainly can be suspected by a rheumatologist and it can be accurately suspected by the patient, but in order to make a definitive diagnosis you need what’s called a slit lamp, which is basically a microscope that allows you to see those white cells attacking the iris. An ophthalmologist or an optometrist could diagnose iritis because it’s a medical condition associated the systemic disease; my personal preference is that an ophthalmologist is more appropriate. The treatment really depends upon the severity.

The mainstay therapy would be a drop, which we call a topical corticosteroid; usually Prednisolone acetate and those drops are generally very effective. There are some risks, as would be true with any medication. One risk in some patients it raises the pressure in the eye to levels that could damage the nerve and chronic drops could cause a cataract. You have a lens in your eye and when that lens get cloudy, you call that a cataract. But, for most people, at least, a corticosteroid drop, a Prednisolone acetate drop is the mainstay therapy.

We also dilate the eye with another drop and that helps to relieve some of the pain. It also prevents the pupil from getting stuck

![Diagram of the Human Eye](image)

and in iritis, especially iritis associated with ankylosing spondylitis, the fluid in the eye can get sticky and as a result, the iris can adhere to the lens, which is behind it, and become immobilized. You need to move your iris because the iris creates the pupil and you want your pupil to accommodate to light and dark. Now, those two drops, the dilating drop and the steroid drop, those are the mainstays of therapy.

In some people the iritis is so severe that we might inject cortisone around the eye, just the way you would inject a shoulder or a knee that’s flaring in ankylosing spondylitis. In some people, we might give some prednisone for anywhere from a few days to a few weeks, but usually not chronically. In some people we might recommend an oral non-steroidal, like ibuprofen to try to reduce the pain.

And then, it would be a very, very rare individual for whom we’d need to do something in addition, either to prevent recurrent attacks or to really try to stem an extremely severe attack. I’ve been doing this now since 1985, so for 23 years and I’d say 99 percent of the time, what I’ve outlined so far is all that’s necessary.

**MVC:** How soon should somebody seek treatment once they think that an iritis attack is coming on?

**Dr. Rosenbaum:** The sooner the better. The drops, in particular inhibit the body’s ability to make some of the substances that cause inflammation, there are the prednisone drops, so the sooner they’re started, the more effective they are. And for patients who have recurrent attacks those patients are often better at predicting whether an attack is on the way. So, many patients that have recurrent attacks are aware of the symptoms and I will have them carry some prednisolone acetate for whenever he or she needs.

**MVC:** What percentage of people with spondyloarthitis, typically get at least one bout of iritis?

**Dr. Rosenbaum:** You know, different studies give you different numbers, but 40 percent is pretty accurate. It is by far the most common non-articular manifestation of spondyloarthitis. In other words, besides involving the joints, if it’s going to involve another part of the body, the eye is the most likely.

**MVC:** Can you talk about what’s going on in uveitis research or have there been any new developments?

**Dr. Rosenbaum:** Research, of course, never advances as quickly as we’d like, but I think actually that this is a renaissance time for uveitis research. I’m extremely biased in this regard, but I think that the best work is coming from a group of us who are working
together in Portland, at the Oregon Health and Science University and the Casey Eye Institute. One individual is Tammy Martin who is the world’s expert on the genetics of uveitis. Tammy has been literally collecting blood samples from all over the world to try to identify any genes that would predispose to developing iritis.

We know that one gene, of course, is HLA-B27 and you could pick up iritis without having any spondylitis, especially if you’re HLA-B27 positive, but Tammy’s identified a couple other areas of chromosomes that seem to predispose to iritis, at least one of which doesn’t seem to predispose to the sacroiliitis and spondyloarthritis. As the technology for doing this gets better and better and better, we think that it’s highly likely that Tammy will be able to identify specific genes and those genes are going to give us insights into what’s causing this and those insights, we hope, will lead to new therapies.

Someone else in my group who’s doing very innovative things, with regard to iritis, is a young scientist who’s name is Holly Rosenzweig. She has been studying a mouse model in which the mice are immunized with a protein called aggrecan. Aggrecan is found in tendons and sacroiliac joints and when she immunizes the mice with aggrecan, she’s observed, as a couple of other people have observed, that the mice get sacroiliitis, which of course is the form of arthritis that allows us to diagnose spondyloarthritis.

But what Holly’s uniquely observed is that not only do many of these mice get the sacroiliitis, but they also get an iritis along with it. This is the very first time that we’ve had a mouse model in which both iritis and sacroiliitis have occurred together. She has applied to the National Institutes of Health for additional monies to be able to study this. They ask questions such as: Are the same factors that drive the iritis identical to what causes the sacroiliitis? Will we find some substances that are unique to the eye, some unique to the sacroiliac joints, and then some substances perhaps that are common to both? So, that’s a very exciting innovation.

The third thing, which we’re trying to do in Portland, is to look in the blood of patients who have iritis and literally measure 50,000 different genes in the blood. So, we all have the same number of genes, but different cells express different genes, so a cell in the skin is going to express something that’s different from what’s in the liver.

When you go to your doctor, your doctor might do a blood test and measure five things or ten things or a dozen things. We can measure on a gene level, an RNA level, 50,000 different things at once in the blood and we’re hoping that that study will also give us unique clues about what’s going on in both the eye and in the sacroiliac joints. That work is moving along well, but it’s slow in part because we get so much information that it’s hard to know what’s relatively important. It’s also difficult because we’re looking in the blood and the inflammation, of course, is in the joint and in the eye and we don’t know for sure how well what’s in the blood is going to reflect what’s in the joint and the eye.

But we’re excited and we have some preliminary observations, at least, that we hope to share at the American College of Rheumatology meeting when it meets in San Francisco at the end of October. So, we need to recruit more subjects for that. We need to make more observations, but that’s a third novel approach that we’re trying to understand iritis and especially to say, “If I’ve got ankylosing spondylitis, and active iritis, am I going to have different genes activated in my blood compared to someone with ankylosing spondylitis and no iritis.”

**MVC:** How can our members get involved with uveitis research?

**Dr. Rosenbaum:** Well, for the genetics work, Dr. Martin is really collecting samples from all over the country; individuals could call my office. That number is 503-494-5023. There are ethical issues and confidentiality issues and validation of the diagnosis issues that we’d have to address if you wanted to participate, so that we could include you in our genetic studies. Obviously, you can’t really participate in the mouse study, but you can do things like be sure that your Congressman or Congresswoman is aware of how important medical research to you.

Our special thanks to Dr. Rosenbaum for his time, expertise and participation in September’s Member Podcast.

To listen to this podcast in its entirety including questions from SAA Members, log on to the Member Area of spondylitis.org.

If you have a question you want answered by our spondylitis experts on a future podcast, send your questions to Melissa Velez Coelho, Director of Program Services, at melissa.velez@spondylitis.org.
A Special Thanks to our 2008 Corporate Partners

The Spondylitis Association of America (SAA) partners with corporations whose objectives align with the Association’s mission to be a leader in the quest to cure ankylosing spondylitis (AS) and related diseases, and to empower those affected to live life to the fullest. These partnerships allow SAA to increase the scope of its influence as a patient advocacy organization and to fund projects that otherwise might not be possible.* SAA is proud to acknowledge the corporate partners whose support has been instrumental in helping us improve the lives of those affected by AS and related diseases.

Platinum Corporate Partner

As a Platinum Corporate Partner, Centocor plays a vital role in helping to provide patient educational programs and services. Additional restricted funds were provided to convert the “Back in Action” Exercise VHS to DVD format. Centocor also purchased Exercise DVD’s for their sales representatives to distribute to rheumatologist offices around the country in an effort to help increase awareness of the importance of exercise in treating spondyloarthritis. As the lead sponsor of the Development and Validation of the Screening Tool for AS, Centocor contributed funds to help complete the final phase of the project which will help to identify new cases, improve early diagnosis, and encourage care seeking among patients who learn that they may have AS.

Premier Corporate Partners

Abbott and Amgen and Wyeth Pharmaceuticals generously supported SAA at the Premier Corporate Partnership level, which provides unrestricted funding for educational programs and services.

Amgen and Wyeth also provided restricted funds to support four Spondylitis Educational Seminars which were held in Denver, CO, Minneapolis, MN, Philadelphia, PA and Dallas, TX this year.

Other Corporate Support

Pfizer provided funding to support the final phase of the Development and Validation of the Screening Tool for AS.

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

Taking an Active Role for Optimum Health

SAA-Sponsored Educational Support Groups provide increased awareness of ankylosing spondylitis and related diseases in the community. Our support groups play a vital role by providing a forum for those with spondylitis to actively take charge of their disease. They provide confidential, non-judgmental interaction with others who know what it feels like to have spondylitis.

This is what a few of our Educational Support Group leaders have to say about participating in these meetings:

Our Educational Support Group has been meeting since May 2007 at the Deaconess Health and Education Center. We have participants, men and women, from all age groups—from their early 20s to senior citizens—as well as spouses, family members and friends. We meet for two hours, spending the first hour sharing information and supporting each other, with the second hour dedicated to a guest speaker. In the past, our speakers have included a clinical psychologist talking about stress management and professionals from The Heart Attack Prevention Clinic. We have heard from a nutritionist, neuropsychologist, mental health counselor, pet therapist, physical therapist, and licensed massage therapist, as well as reports from SAA seminars.

As a way to spread awareness about AS and related diseases, we have participated in three local health and wellness fairs. SAA provided a wonderful, new, easy-to-transport display board and numerous pamphlets to help educate people about the disease. These fairs have been a real joy and an energizing experience.

~Joan Polzin  
Spokane, WA

Our support group meetings are held every other month. We have speakers every few months, including rheumatologists, ophthalmologists and physical therapists. We also heard from local paramedics regarding the intubation of AS patients. During meetings when we don’t have a speaker, we have discussions on issues such as medications, and share what has been helpful to each of us in managing this disease. Our group is very supportive of everyone involved. We finish the year with a holiday gathering at a leader’s home, with refreshments and good cheer.

~Frances Tomich and Barbara Crofut
Long Beach, CA

Over the past nine years, our support group has discussed many different topics, including pain management, family input, medications, and Social Security. It always comes down to one question: What can I learn from this disease to help other people? Our group’s main objective is to learn from and share with others who have spondylitis. Unless we have a speaker, our meetings “go with the flow.” It’s important for this to be not only a meeting, but also a time to relax and enjoy the company of like-minded souls.

I would hope that my group walks away from our meetings with joy, compassion and sincere gratitude that, by sharing their life with spondylitis, they will help make other lives more tolerable traveling the same path. I hope they can search deep within themselves and find the confidence to look spondylitis straight in the eye and say: You have to live with me; I don’t have to live with you.

~Ken Prather
Indianapolis, IN

As a newly organized group, we are still in the developmental stages. We have five meetings scheduled this year, on Saturday mornings at a local hospital. Beside our first and last meetings, we have had a speaker covering such topics as proper exercise, iritis, and the latest developments in AS research. The speakers have about one hour for their presentation, followed by a 45-minute question-and-answer session. As a new group, our attendance is low, but we hope to grow over time.

~Wilson McCoy
The Woodlands, TX

Thanks to all the volunteer group leaders who have dedicated their time, energy and efforts to providing an avenue of support in their communities. If you are interested in leading a group in your area, please contact Elin Aslanyan, SAA Programs Coordinator, by e-mail at elin.aslanyan@spondylitis.org or by telephone at (800) 777-8189, ext. 222.
SAA-Sponsored Educational Support Groups

The people listed below are a vital part of our support system. They have volunteered to lead support groups across the US because they want to help. If you’d like to find out more about support groups and online meetings, pick up the phone or send an email to: elin.aslanyan@spondylitis.org

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*Noel Miles is a temporary contact for Denver, CO

- **Teen Athletes with AS** located in Orange County - contact WalkerRSM@aol.com
- **Support online from NY, NY** with Michael T. Smith, spenser23@aol.com

Planned gifts allow you to support SAA while protecting your personal interests. Whether you want to leave a legacy through a bequest or other planned giving options, your gift should ensure financial security for you and your loved ones, while allowing you to make a significant impact on those who SAA serves. There are a variety of planned giving options that can be tailored to your individual financial and charitable objectives.

For more information on The Quest Legacy Society, and how planned giving can work for you, please go to [www.spondylitis.org/quest](http://www.spondylitis.org/quest) or contact Susan L. Jones, Director of Development and Planned Giving at 800-777-8189, ext. 231 or susan.jones@spondylitis.org.

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Straight Talk On Spondylitis, the first comprehensive self-management book written specifically for people affected by ankylosing spondylitis and related diseases has been updated and expanded and is now available on spondylitis.org.

To order today, log on to spondylitis.org/store or call Helene Hart at 800-777-8189, ext. 229.

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S.M.A.R.T. is a safe, secure and convenient way to put more of your money to work advancing the spondylitis community’s shared mission. Just specify a monthly amount and SAA will automatically deduct the contribution from your credit card. At the end of the year, we’ll send you a summary of your giving and a tax receipt. Your dependable monthly gift of $100, $50, $25, $15 or even $10 will boost the impact of your SAA membership gift many times over.

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She can’t drive yet - but she can use your car

Kids get spondylitis too. Donating an unwanted vehicle to SAA will help ensure that they have the resources they need to live life to the fullest, in spite of the disease. The process is quick, includes free pick-up or towing - and best of all - the proceeds go to improving the lives of spondylitis patients of all ages. The vehicle doesn’t even have to run and you’ll get a great tax deduction for your donation!

Contact Helene Hart at 1-800-777-8189, ext. 229 or at hhart@spondylitis.org.

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