SPONDYLITIS PLUS
summer 2008

EXERCISE:
THE “GRANDDADDY”
OF ALL THERAPIES
FOR SPONDYLITIS

NERO DELIWALA: A
RACER ON “BREAK”

ANNOUNCING: THE
QUEST LEGACY SOCIETY
After thirteen years of deliberation, a new Bill to prohibit health insurance companies and employers from discriminating against individuals based on genetic information was signed into law on May 21, 2008.

The Genetic Information Nondiscrimination Act (H.R. 493) (GINA) balances the benefit of using genetic information for medical advances and healthcare management against the potential for harm that could be caused by the misuse of genetic data.

The Spondylitis Association is glad to have been able to contribute toward the effort to bring about this important legislation through its participation in the National Institute of Arthritis and Musculoskeletal and Skin Diseases Coalition which has actively lobbied for the Bill’s passage for more than a decade.

In addition, we would like to offer words of gratitude to Representative Louise M. Slaughter who first proposed the Bill. We believe that she has been aptly described in the press as “a woman ahead of her time.” Informed by her university studies in microbiology decades ago, this congresswoman from New York decided early on that the much-trumpeted genetics revolution would also bring risks. Her steadfastness brings us one step closer to ensuring that Americans do not have to make a trade-off between genetic privacy and appropriate healthcare. In 1996, Jane Bruckel, SAA co-founder and former executive director, was invited to the White House, along with other organization leaders for a press conference held by the President to “jump-start” this effort.

A little discussed section of GINA may provide an additional cause for celebration. Title II, Section 208 of GINA calls for the establishment of the Genetic Nondiscrimination Study Commission after GINA has been enacted for six years. The purpose of the Commission is to evaluate the status of genetic science, genetic discrimination, public perception and other factors, and to make recommendations to Congress with regard to possible future legislation. It would seem like a sensible amount of foresight on the part of our elected officials given the amazing rate of our expanding scientific knowledge.

With regard to genetic research, the Genetics and Public Policy Center found that when considering whether or not to participate in genetic related research, 93 percent of respondents said it was important that it be “illegal for insurers or employers to have access to the individual’s information.” Indeed, directly addressing this concern, the passage of the Bill further guarantees that patients who participate in genetic research are protected against misuse of their genetic data.

Laurie M. Savage
Executive Director
SAA’s Educational Seminar in Atlanta, Georgia

I would like to say thank you for the informative conference that SAA offered in Atlanta, Georgia. To say that both speakers are well-informed would be an understatement. They were fantastic! SAA offered patients access to a world-renowned rheumatologist and doctor of physical therapy whose presentations were both in-depth and applicable to AS and related diseases patients. There was a common thread in both presentations that was remarkable. That is, the speakers spoke to us, the patients, as educated people with non-medical backgrounds.

The pace was fast, the content advanced and real-life analogies were used to help the listener understand the content. I appreciated that because it made me feel respected as a patient. I have already seen my local rheumatologist and shared what I have learned. The information from the conference is helping me understand my particular symptoms and I have suggested treatment strategies to my doctor that I learned about at the conference. You have helped me and I thank you.

JEANNIE MUTHARD, Schnecksville, PA

World’s Toughest Footrace

I’ve had symptoms of Ankylosing Spondylitis for 35 years, and I was finally diagnosed properly about three years ago. I’m now 50, and I run in distance events. I’ve been accepted into the Badwater Ultramarathon this year. This event is held on July 14-15, and involves running a 135 mile course from Badwater in Death Valley to the Mt. Whitney portals in the summer heat. It’s billed as the “World’s Toughest Footrace”. While I have participated in many other ultra events (100 miles, 24-hour runs, etc.), this will be the biggest challenge of all.

One of the reasons for seeking out this challenge is to run for those who have AS who are not physically able to do simple daily activities, let alone run long distances. I’m dedicating my effort to them, and I’m enclosing a donation to SAA to show my commitment.

KERMIT CUFF, Mountain View, CA

Oriental Medicine Follow-Up

I was interested in the article on Oriental Medicine (page 14) in the Spring newsletter, but very disappointed that no documentation was provided as to its effectiveness. There was a passing reference to the National Library of Medicine website, but in checking that out, over 8,000 references came up for AS & Oriental Medicine. In the future, if you devote an entire page to a subject like this, it would be helpful to know how to access more information. I assume that studies have been done on the role of Oriental medicine and AS, but I am left with no information.

BRIAN E. FOSS, Miami, FL

Editor’s Note: Dear Brian, we have added the specific studies used for the article to our website at: www.spondylitis.org/om. In the future we will make sure to have the exact citations available when we are able.

LETTERS TO THE EDITOR

Dear Readers: We want to hear from you, whether it be informative, uplifting or a gripe 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:
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IN FOCUS: EXERCISE IS ESSENTIAL

As most people with ankylosing spondylitis (AS) will tell you, exercise, along with good posture and medications to reduce pain and stiffness, is a key ingredient in a successful therapy program.

“[Exercise] is generally regarded as an important part of treatment,” said manual physical therapist Carl Heldman, DPT, “and current research shows support for short-term improvement with exercise.”

Heldman, the Director of Physical and Manual Therapy at Emory Healthcare’s Orthopaedics & Spine Center in Atlanta, spoke about the value and importance of exercise for spondylitis at the Spondylitis Association of America’s Atlanta Spondylitis Educational Seminar on February 9. Nearly 85 AS patients and family members attended the seminar.

A former athletic trainer for the Philadelphia Phillies baseball team, Heldman was recognized as a fellow of the American Academy of Orthopaedic Manual Physical Therapists in 2006. Manual physical therapy is a specialized form of physical therapy in which practitioners use their hands, as opposed to devices or machines, to put pressure on muscle tissue and manipulate joints in an attempt to decrease pain caused by muscle spasm, muscle tension, and joint dysfunction. It has become one of a number of modalities used to treat AS.

A remarkable mechanical structure
One of the early symptoms of AS is frequent pain and stiffness in the lower back and buttocks, which comes on gradually over the course of weeks or months. Dull, diffuse discomfort is usually felt on one side, primarily early in the morning and at nighttime. Over months or years, the pain and stiffness can spread up the spine into the neck.

In a minority of patients, pain starts in peripheral joints, including the hip, ankle, knee, heel and shoulder. Advanced symptoms of the disease include chronic, severe pain and stiffness of the back, spine and, possibly, peripheral joints, as well as loss of spinal mobility and flexibility due to chronic inflammation and, sometimes, spinal fusion.

One of the most complex and remarkable mechanical structures in the human body, the spine’s primary function is to protect the spinal cord and nerve roots, as well as provide an incredible amount of flexibility to the trunk of the body. The spine, then, is the body’s primary support structure. Without a spine, humans would not be able to stand up or to keep themselves upright, nor would they be able to move about freely and bend with flexibility. Spondylitis is considered a form of arthritis of the spine.

“Exercise is the one we keep coming back to because it’s the only one that we can keep showing, over and over again, hey, we can actually do something with this.”
The spine is made up of 24 small bones, called vertebrae, that are stacked one on top of the other to create the spinal column through which the spinal cord and its nerve roots run. The cervical spine (the upper part) is comprised of seven vertebrae; the thoracic spine (center) consists of 12 vertebrae; and the lumbar spine (lower) is made up of five, sometimes six, vertebrae. Just below the lumbar spine is the sacrum, a group of specialized vertebrae that connect the spine to the pelvis.

Viewed in profile, the normal spine is curved like the letter “S.” The cervical spine curves slightly inward, while the thoracic spine curves outward, and the lumbar spine curves back inward. This curved shape helps a healthy spine withstand all sorts of stress.

“It’s very important that we have these biomechanical curves,” said Heldman. “These curves are responsible for absorbing force as we step, as we move, as we pick things up. It is when we lose the flexibility of the spine that we lose the ability to offset some of these loading forces. It becomes a bigger issue if the back becomes fused. Now, all of a sudden, we don’t get the tilting, we don’t get the bending mechanism.”

In its neutral position—also called neutral spine or neutral posture—the spine is in its proper alignment, allowing the body to function in its strongest, most balanced position. Neutral spine also minimizes stress to joints, muscles, vertebrae and other tissues, reduces the risk of injury, and increases efficiency of movement.

As AS progresses, however, many patients experience spinal kyphosis, a curve of the spine that causes the back to bow, leading to a slouched posture. Consequently, individuals suffering from spinal kyphosis may experience difficulty sitting, standing or lying comfortably. Some are unable to see the horizon because of their stooped posture, leading to difficulties with daily activities. In addition to postural problems, inflammation from AS causes damage to the vertebrae. In response, the body grows more bone tissue to repair this damage. Over time, bony outgrowths, called syndesmophytes, fuse together, causing pain and reducing mobility. Nearly 70 percent of AS patients will suffer from some level of spinal fusion.

So, what do AS patients do? As Heldman said to the audience: “I have this new pathology, this new disease process. What do I do? For love of God, I want to move. I want to be able to walk out my door. Walk my dog. Pick up my grandkids.” Heldman suggests exercise as good starting point.

**Improving muscle function, decreasing pain**

“Exercise,” Heldman told the Atlanta audience, “is the granddaddy of it all. This is the one we keep coming back to because it’s the only one that we can keep showing, over and over again, hey, we can actually do something with this.”

Over time, he said, exercise provides long-term joint protection. As joints get overstretched, they can become irritated by inflammation. Chronic inflammation is one of the primary manifestations of AS. To avoid that inflammation, Heldman says joints need to get nutrients, and one way to get them the nutrients they require to remain healthy is through exercise.

The two most common joint nutrients are glucosamine and chondroitin sulfate. Glucosamine is a natural compound, made from glucose (sugar) and the amino acid glutamine. It is needed to produce a molecule used in the formation of cartilage, the connective tissue that provides a cushioning effect in joints, and other tissue found in joints. Glucosamine supplements are widely used to treat arthritic conditions. Chondroitin sulfate is a natural molecule that gives cartilage its elasticity and is believed to ward off cartilage destruction by certain enzymes.

“Every joint in your body get its nutrients from passive movement and active movement,” Heldman said. “Movement is what feeds the joint tissue.”

In addition to joint protection, exercise improves muscle function and may also slow down [AS] disease progression. “We’ll definitely decrease some disability [with exercise],” said Heldman, “because, obviously, if we get you moving better, you’re going to want to do more of it. If we can get you moving better, we can help decrease some of the pain and limit some of the structural deformities.”

Everyone should be assessed prior to beginning any type of exercise program. That way, clinicians can determine what each patient “brings to the table, such as surgeries and total joint replacements, as well as other illnesses and medical conditions.”

The recommendation for AS patients is moderate exercise, not high-intensity workouts. The normal response to heavy weight lifting and high-impact aerobics, said Heldman, is muscle breakdown and inflammation. Moderate exercise is good because the process of breaking down muscle and building it back up is not so traumatic on the body. The consensus among clinicians is that 200 minutes a week of moderate exercise—about 30 minutes a day—is sufficient for the early stages of AS.

Heldman said that AS exercise programs should focus on posture, mobility, flexibility, and respiratory function, all of which are important issues for people with AS.
Posture: The primary postural muscles that can benefit from stretching exercises include those in the back, shoulder and chest. Strengthening the muscles in the upper back and chest, Heldman said, helps to decrease kyphosis. Extension exercises for the lower back help to increase flexibility of the lumbar curve. A number of exercises, including pelvic tilts, can assist with this. Theraband exercises can also be helpful. Resistance with these colorful latex bands and rubber tubing products provides both positive and negative force on muscles, improving strength and range of motion. These products are color-coded to show progression from one resistance level to another.

“...tough toward the end of the range,” said Heldman, “is that the elastic becomes stiffer and it becomes harder to complete the motion. You need to start with less tension, or change the color of the band that you’re working with so that you can complete the motions.”

Mobility: Range of motion (ROM) exercises can help reduce stiffness and keep joints flexible. ROM is the normal amount joints, especially peripheral joints like the arms and legs, can be moved in certain directions.

“...flex, extend and rotate the spine, neck, pelvis, knees and ankles.”

“...free swinging of the limbs,” he said. “Flexion, extension and rotation of the spine, just big movements. A little bit of some pelvic tilting, back and forth with the pelvis. Flexion, extension and rotation of the hip. And a combination of knee and ankle movements.”

People with AS should try to move their joints through their range of motion on a daily basis, moving gently if they are experiencing joint pain.

Flexibility: A dramatic loss of flexibility, especially in the lumbar spine and later in the upper back, neck and other joints, is an early sign of AS, so maintaining flexibility is of utmost importance. Passive stretching in which one stretches a muscle and holds it in a stretched position can help keep AS sufferers limber and relieve muscle and joint aches and pains.

“The nice part is that passive stretching has been shown to be effective,” Heldman told the Atlanta seminar audience. “That means that if you can get to the point where you can maintain the stretch, you are going to maintain some of that flexibility.”

He says to focus on the neck and chest muscles, as well as the hamstrings (the muscle group at the back of the thigh), the hip flexors, and the muscles that run along the spine.

“We always want to do a little bit of warm-up prior to any kind of flexibility work,” he said, “because by doing a little bit of warm-up, even just a little bit of bike riding or a little bit of fast movement walking around, it is enough to raise the body temperature, which improves the expandability of the muscle tissue, making it more pliable and allowing us to move more freely.”

Respiratory function: Heldman said that everyone with AS “should be doing some kind of breathing regimen” to maintain and improve vital respiratory capacity. AS may affect the rib joints and muscles between the ribs, making breathing difficult. As a result, the lungs fail to become fully ventilated. In late-stage AS, the chest wall can become fixed, affecting both inhalation and exhalation.

“If you can get to the point where you can maintain the stretch, you are going to maintain some of that flexibility.”
Breathing exercises can help make use of the entire lung and keep the chest muscles active, allowing more oxygen in with each breath and making each breath more effortless. Heldman said any kind of “abdominal, diaphragmatic or full ribcage expansions should be encouraged with daily breathing to get good movement [of air] into the lungs.”

For full rib cage expansions, you should sit or stand, with your elbows pulled back firmly. Then, you should inhale deeply and hold your breath. After 5 seconds, you should exhale slowly and completely, and complete the process again. For diaphragmatic breathing, you should lie on your back with your knees bent and supported by pillows. Place your fingers on your belly, just below the ribcage. As you inhale, your belly and lower ribcage should rise, while your chest remains still. Inhale for a 3-count and exhale for a 6-count. This should be repeated several times.

Caution urged with equipment, other forms of exercise

Heldman said that exercise equipment, including exercise balls, recumbent bicycles, and inversion equipment, and other types of exercise programs could also be helpful. Exercise balls allow AS patients to do exercises that they might not be able to do on their own because they have a rotational component. This is especially helpful for those with a rigid spine because it gives them extra support.

He cautions that there is no scientific evidence that supports the use of inversion tables that stretch the back muscles to relieve lower back pain. “We don’t have anything that says yes or no to the inversion table because there’s not one study out there that took a bunch of people with AS and put them on inversion tables without any other contributing modality. That becomes the problem, so, for me to sit here and say yes or no, we don’t have the research to back it.”

Pilates and yoga have a growing following in the United States. Pilates focuses on the core postural muscles, which help keep the body balanced and are essential for supporting the spine. Pilates exercises teach awareness of breathing and alignment of the spine and aim to strengthen deep torso muscles.

“The problem with some Pilates,” said Heldman, “is the intensity level. We have to be respectful of that. Some of the positions that are asked to be held may be too high for the individual to engage and evolve in.” He also said that, like inversion tables, he has not seen research, showing one way or the other, that supports the use of Pilates.

An ancient Indian ritual of exercises and poses, yoga helps to build flexibility, strength and concentration. Again, he said that some yoga positions may be too advanced for AS patients and that care must be taken to not overextend when doing yoga.

In the end, Heldman said, finding exercises that work for you and do what they are intended to do should be sufficient, as long as they are approved by your healthcare professional.

“If you feel comfortable enough with what you are doing or have done in the past and attempt to do that on your own, I would say, please, because it’s the only way you’re going to find out what works. If you find that it works for you and it’s doing what it should and it makes you feel better and it makes you move better, by all means, do it—as long as you’re not hurting yourself or making it worse.”
The majority of the Spondylitis Association’s support comes from the goodwill of individuals like you who give generously throughout their lives. But on occasion we receive a call or letter from a member or friend notifying us that they have included the Spondylitis Association in their estate plans -- because they want to ensure that future generations affected by spondylitis are not alone -- without the resources necessary to cope with the disease. To commemorate the generosity of those individuals, during their lifetime, who have kindly remembered SAA in their estate plans, SAA is pleased to announce the establishment of the **Quest Legacy Society**.

We invite you to become a charter member of the **Quest Legacy Society** by making a planned gift to the Spondylitis Association. While designating SAA as a beneficiary in your will or living trust is the simplest way to create a legacy gift to SAA without affecting your current financial situation, there are a variety of planned giving options that can be tailored to your individual financial and philanthropic goals. Thoughtful planning may not only reduce your tax burden but is also a way to leave a meaningful gift to future generations.

Of course, if you have already made a financial provision for SAA in your estate plans, please let us know so that we may honor you and show our appreciation by including you as a charter member in the **Quest Legacy Society**.

If you are interested in learning more about the **Quest Legacy Society** or how to leave a planned gift to SAA, please complete and mail the self-addressed reply envelope enclosed or if you need assistance, please contact Susan Jones, Director of Development and Planned Giving at 800-777-8189, ext. 231 or susan.jones@spondylitis.org. To learn more about the **Quest Legacy Society** and estate planning, you can also go to SAA’s website at: [www.spondylitis.org/quest](http://www.spondylitis.org/quest)

**Remember:** We respect your privacy. Your personal information will be kept strictly confidential.

“The capacity to care is the thing which gives life its deepest meaning and significance.” ~Pablo Casals
Leaving a legacy...

Inspired by the difference SAA has made in his life, Board member Brian MacKenzie is among the first charter members of The Quest Legacy Society. When Brian was diagnosed with spondylitis at an early age the Spondylitis Association was there for his family, providing them with the support they needed in order to better cope with the disease. Reading his story reminds us that it is never too early to think about leaving a legacy gift to SAA—an organization that is changing thousands of lives for the better.

When I was a young boy, my days, like those of most boys my age, were filled with sports. Basketball, soccer, running—anything that kept me moving. Before my 12th birthday, however, those days came to a crushing halt. I was diagnosed with ankylosing spondylitis (AS), and my days of playing high-impact sports were over.

While that was the beginning of a lengthy learning process about the disease—not to mention my battles with spinal and hip pain, as well as hip replacement surgery just after I turned 27—it was not the end of my world. In fact, it was the beginning of a wonderful relationship with the Spondylitis Association of America.

The SAA is the largest resource in the United States for people seeking information about AS. For my parents and me, it was a godsend. Through the SAA, my family and I learned more about the disease, how it is treated, and how to cope with such a diagnosis. It also brought us together with other people suffering from AS so we could learn and draw strength from their experience.

The SAA provided my parents with a resource through which they could cope with having a son diagnosed with AS. For me, it has been an amazing resource that has allowed me to find the strength and understanding to live my life on my own terms. Now, it is my turn to give back to an organization that has given so much to me.

For many years, I have supported the SAA with an annual contribution, and I joined the Board of Directors five years ago, serving on the Fund Development and Finance committees, to help the organization raise the money necessary to continue its important work. Over the long term, I want to invest in the SAA in ways that will benefit the organization into the future. Setting aside a legacy gift allows me to do that, and it means a great deal to me.

A charitable gift of any kind is a personal act. A planned gift, however, is about an individual’s commitment to an organization. For me, it is making a gift to an organization that I know will be around for a long time, providing information to and inspiration for thousands of people with AS and their families. The SAA’s mission is “to be a leader in the quest to cure ankylosing spondylitis and to empower those affected to live life to its fullest.” I want that mission to continue and flourish.

For nearly 25 years, I have dealt with the effects of AS. Through my legacy gift, I am making a lasting contribution so future generations will not have to experience the disease in the same way I have. I want to help doctors, patients and researchers learn more about this disease. The best way to further that goal is to make a planned gift to the Spondylitis Association of America, helping to ensure that those affected by AS are not alone—or without the resources necessary to cope with their disease.

“Through my legacy gift, I am making a lasting contribution so future generations will not have to experience the disease in the same way I have.” ~Brian MacKenzie
Restful Thoughts: Results from the Spring 2008 Survey

Below are the results from our Spring 2008 survey. The topic of sleep loss due to spondylitis is one that is often discussed on the spondylitis.org forums. In this survey we took a look at what people use to aid them in order to get a good night’s rest, how much spondylitis is keeping people from sleeping well, preferred bedding and other questions. Remember that you can take our quarterly surveys on our website, spondylitis.org.

**Question No.1:** How old are you?
- Age 13 – 19: 1.1%
- Age 20 – 29: 10.4%
- Age 30 – 39: 17.6%
- Age 40 – 49: 29.7%
- Age 50 – 59: 28.0%
- Age 60 – 69: 11.0%
- Over 70: 2.2%

**Question No.2:** How much do you think spondylitis prevents you from getting restorative sleep each night?
- Very Much: 42.9%
- Somewhat: 41.8%
- Very Little: 11.0%
- Not at all: 4.4%

**Question No.3:** Have you replaced your mattress (outside of the normal wear cycle) due to discomfort related to your spondylitis?
- Yes: 52.2%
- No: 29.1%
- No, but I want to: 18.7%

**Question No.4:** Do you use a mattress pad or topper on your mattress (e.g. memory foam mattress pad, feather bed) to increase the comfort of your mattress?
- Yes: 54.9%
- No: 45.1%

**Question No.5:** Which type of mattress do you prefer?
- Visco Elastic or Memory Foam Mattress: 15.4%
- Latex Foam Mattress: 9.3%
- Traditional Innerspring: 37.4%
- Air Chamber Mattress (e.g. Sleep Number): 10.4%
- Water Mattress: 3.3%
- Other: 7.7%
- No preference: 16.5%

**Question No.6:** Does your preferred choice of mattress present a significant challenge to your spouse or significant other?
- Yes: 12.1%
- No: 61.0%
- Not sure: 5.5%
- Not applicable: 21.4%

**Question No.7:** Which type of pillow do you prefer?
- Water pillow: 0.5%
- Visco Elastic or Memory Foam pillow: 20.3%
- Natural or Latex Foam pillow: 10.4%
- Down or Feather pillow: 20.9%
- Buckwheat pillow: 3.3%
- Cotton pillow: 16.5%
- Wool pillow: 0.0%
- Rubber pillow: 0.0%
- Other: 4.9%
- I do not use a pillow: 6.0%
- I’m not sure: 17.0%
Question No.8:
Do you find it more comfortable to sleep somewhere other than your bed? If yes, do you prefer to sleep:
- In a reclining chair: 15.4%
- On the floor: 4.9%
- On the sofa: 12.6%
- Other: 2.2%
- Not applicable: 66.5%

Question No.9:
How many hours do you sleep continuously without waking throughout an average night (without the use of a sleep aid)?
- 1 hour or less: 4.4%
- 1 - 2 hours: 18.1%
- 2 - 3 hours: 22.0%
- 3 - 4 hours: 15.4%
- 4 - 5 hours: 14.8%
- 5 - 6 hours: 13.2%
- 6 - 7 hours: 6.6%
- I sleep through the entire night: 5.5%

Question No.10:
Do you use a sleep aid to help you sleep on a regular basis?
- Yes, non-prescription, over the counter: 7.7%
- Yes, prescription: 25.3%
- No: 67.0%

Question No.11:
In which position do you prefer to sleep?
- On your back: 1.1%
- On your side: 7.8%
- On your stomach: 20.8%
- I switch between all three positions: 57.6%

Question No.12:
Do you have a specific routine before bed that helps you to go to sleep?
- Warm bath or shower: 12.1%
- Stretching or exercise: 7.7%
- Relaxation or meditation: 8.2%
- Having sex: 6.0%
- Watching television: 34.6%
- Listening to music: 3.3%
- Reading: 24.2%
- Drink tea or warm milk: 4.9%
- Other: 9.3%
- No specific routine: 26.4%

Question No.13:
Do your sleep habits, as related to your spondylitis, significantly affect your spouse or partner?
- Yes: 1.1%
- No: 7.8%
- Not sure: 20.8%
- Not applicable: 57.6%
A Racer On “Break”

by Scott P. Edwards | June 5, 2008

As Nero Deliwala tells it, he’s “not a former drag racer. I’m a current drag racer on break.” That break came, says the 30-year-old Floridian, when he was diagnosed with ankylosing spondylitis (AS) more than five years ago.

The disease has led Deliwala in new directions, although he has never strayed far from the drag racing scene. Today, he is the owner of two very successful ventures: Titan Motorsports, an Orlando-based mail-order emporium for sport compact car parts, and Team Titan, one of the most successful drag racing teams in the United States.

Growing up in Seminole County, Florida, where he graduated from Oviedo High School in the mid-1990s, Deliwala was hanging out with “car guys” when he was introduced to Jesus Rivera, a well-known Orlando drag racer. Rivera, in turn, turned Deliwala on to the fast-paced world of drag racing. “I started drag racing recreationally,” he says, “and then wanted to pursue a professional series and championship chase.” Deliwala’s professional career, however, “never got off the ground.” He never wanted to be a full-time professional racer, preferring instead to “have fun at what I love doing.”

Cars and computers
When he was in college at the University of Central Florida, says Deliwala, “I was obsessed with two things. Cars and computers were my main focus. I wanted to have a career in the computer/IT industry, with a focus on e-commerce.”

During his final year of college, Deliwala was doing Web work “on the side,” helping a friend build his business by developing the online marketing and Web side of a performance parts and tuning shop that modified cars. He offered his assistance in developing a website that could take orders and generate a more mainstream clientele for the business. “Instead,” he adds, “my friend counter-offered with, ‘You run it,’” which meant, “You can do it, but you need to buy, sell, ship and do everything else involved in it.”

With headquarters in Orlando, Titan Motorsports started out as a performance mail-order store, specializing in parts for the Toyota Supra Twin Turbo. Initially, the business was a “part-time deal when I was in college so I could afford to go racing.” Before long, however, Titan Motorsports was selling parts all over the world and, as Deliwala says, “getting recognized as a good source to purchase parts.”

The company quickly grew, adding employees who could sell parts for more than just Toyotas. Within a few years, Titan Motorsports was selling parts for all types of cars. In addition to Toyotas, the company now sells parts for Hondas, Mitsubishis, Nissans and Mazdas, as well as domestic vehicles.

Through Titan Motorsports and Team Titan, Deliwala combines his twin loves of racing and business. “I love business and making customers happy, and helping customers achieve their goals and dreams.” He says. “I ended up at Titan Motorsports, and I love it. I get to work with my brother [Bottle Deliwala], who is my best friend and the most loyal supporter of the company.”

Titan Motorsports specializes in a class of cars called sport compacts, which are high-performance versions of compact or subcompact cars. The design philosophy of sport compacts sharply contrasts with other “true” sports cars. These are performance-oriented vehicles that often compromise such things as cargo space, seating, gas mileage, daily drivability, and reliability in order to increase the vehicle’s speed.

There are a lot of doctors out there who are not familiar with AS. Make sure you find one who is.”

The problem for Deliwala, however, was that his friend’s business was located in Texas, and he was trying to run its e-commerce operation out of Florida, where he was deeply involved in the local drag racing scene. The friend’s business “took off,” but the two parted ways in mid-2000 and “did a full changeover to Titan Motorsports, which is the company that I still run.”

There are a lot of doctors out there who are not familiar with AS. Make sure you find one who is.”

The disease has led Deliwala in new directions, although he has never strayed far from the drag racing scene. Today, he is the owner of two very successful ventures: Titan Motorsports, an Orlando-based mail-order emporium for sport compact car parts, and Team Titan, one of the most successful drag racing teams in the United States.

Growing up in Seminole County, Florida, where he graduated from Oviedo High School in the mid-1990s, Deliwala was hanging out with “car guys” when he was introduced to Jesus Rivera, a well-known Orlando drag racer. Rivera, in turn, turned Deliwala on to the fast-paced world of drag racing. “I started drag racing recreationally,” he says, “and then wanted to pursue a professional series and championship chase.” Deliwala’s professional career, however, “never got off the ground.” He never wanted to be a full-time professional racer, preferring instead to “have fun at what I love doing.”

Cars and computers
When he was in college at the University of Central Florida, says Deliwala, “I was obsessed with two things. Cars and computers were my main focus. I wanted to have a career in the computer/IT industry, with a focus on e-commerce.”

During his final year of college, Deliwala was doing Web work “on the side,” helping a friend build his business by developing the online marketing and Web side of a performance parts and tuning shop that modified cars. He offered his assistance in developing a website that could take orders and generate a more mainstream clientele for the business. “Instead,” he adds, “my friend counter-offered with, ‘You run it,’” which meant, “You can do it, but you need to buy, sell, ship and do everything else involved in it.”

With headquarters in Orlando, Titan Motorsports started out as a performance mail-order store, specializing in parts for the Toyota Supra Twin Turbo. Initially, the business was a “part-time deal when I was in college so I could afford to go racing.” Before long, however, Titan Motorsports was selling parts all over the world and, as Deliwala says, “getting recognized as a good source to purchase parts.”

The company quickly grew, adding employees who could sell parts for more than just Toyotas. Within a few years, Titan Motorsports was selling parts for all types of cars. In addition to Toyotas, the company now sells parts for Hondas, Mitsubishis, Nissans and Mazdas, as well as domestic vehicles.

Through Titan Motorsports and Team Titan, Deliwala combines his twin loves of racing and business. “I love business and making customers happy, and helping customers achieve their goals and dreams.” He says. “I ended up at Titan Motorsports, and I love it. I get to work with my brother [Bottle Deliwala], who is my best friend and the most loyal supporter of the company.”

Titan Motorsports specializes in a class of cars called sport compacts, which are high-performance versions of compact or subcompact cars. The design philosophy of sport compacts sharply contrasts with other “true” sports cars. These are performance-oriented vehicles that often compromise such things as cargo space, seating, gas mileage, daily drivability, and reliability in order to increase the vehicle’s speed.
With high power ratings, small cars like these can be formidable racing vehicles. In fact, sport compacts have become so popular that the National Hot Rod Association (NHRA) has a special class just for sport compacts, and that’s where Team Titan comes in. Team Titan is the most successful race team in sport compact history, having won seven championships in various categories. Two of the leading drivers, Brad Personnett and Gary White, have called Team Titan home. White, who has been with the team for five years, is this year’s main driver.

**AS moves racer from driver to manager**

Ankylosing spondylitis put Deliwala on the racing sidelines and moved him from driver to manager. Deliwala says he likely started showing signs of AS in late 2000. Lower back pain led to X-rays and magnetic resonance imaging, or MRI, scans, which detected two herniated disks. Despite physical therapy and regular doctor visits, his health slowly deteriorated.

“As time progressed, my back pain started to go up my back,” says Deliwala. “It became evident that this was not just a herniated disk problem. In late 2002, I was diagnosed with AS.”

Deliwala’s doctor referred him to a rheumatologist, who confirmed the diagnosis. The rheumatologist prescribed Celebrex, a nonsteroidal anti-inflammatory drug used to relieve arthritis pain and stiffness, and slowly increased the dose over a short period of time, completing rounds of blood work in the interim. Deliwala’s rheumatologist put him on Enbrel soon after the drug was approved by the FDA for the treatment of AS in July of 2003. [Enbrel is a targeted treatment that selectively reduces the amount of active tumor necrosis factor, or TNF, in the body. TNF, a protein that is part of the immune system, is a messenger involved in the inflammatory process. Patients with AS have an increased level of TNF.]

The combination of Enbrel and Celebrex decreased Deliwala’s sedimentation rate, a measurement of abnormal proteins in red blood cells, which when high can be indicative of inflammatory diseases like AS, rheumatoid arthritis, and lupus, and helped reduce his symptoms.

“In the following years,” Deliwala says, “physical therapy, medication, relaxation and low stress were the recommendation. I’ve followed most of it … although the low stress part isn’t followed!”

Deliwala’s AS diagnosis changed his life, as it does for most people diagnosed with the disease. His condition prevented him from doing what he loved – driving a drag racer at speeds that can reach up to 300 miles per hour. No longer could he put himself in harm’s way, an everyday occurrence for a race car driver.

“It [AS] put a halt on me being reckless,” says Deliwala. “I can’t go out and get hurt, put myself in harm’s way, as the implications will be lifelong and could permanently injure me. In a way, my diagnosis is a good thing, and it put me in a quick hurry to becoming a mature young adult. My career has been successful in drag racing as it put me in the director’s chair, and I’ve been able to utilize my best talents there.”

Support and comfort from SAA

Like many AS patients, Deliwala found support and comfort through the Spondylitis Association of America (SAA). After being diagnosed, he took advantage of the SAA’s educational brochures, magazine and website to learn more about the disease and to motivate him to manage his disease.

“When I was diagnosed with AS, I wanted to know everything about what I had,” he says. “I found spondylitis.org, which was a great resource.”

Today, five years removed from being diagnosed, Deliwala uses his success in business and drag racing to support the SAA. “My role is to be good or great at what I do,” he says, “and to help support the association any way I can by utilizing my skills. The reason I support the SAA is because the same resources I needed when I was diagnosed are the same ones others will need. If we don’t support the association, then those resources will no longer exist.”

Deliwala also encourages AS patients to do their research and listen to their doctors. “There are a lot of doctors out there who are not familiar with AS,” he says. “Make sure you find one who is. Don’t just get a doctor who will tell you what you want to hear, find a doctor who will tell you the hard truth about your diagnosis and what to do to improve your life with AS.”

While Nero Deliwala’s career as a drag racer is on “break,” he is making the most of life with ankylosing spondylitis – as a successful businessman, as a successful team owner, and as a source of inspiration for others with AS.

Editor’s Note: The SAA is not sponsored by, nor does it endorse or recommend any products mentioned in this article, or those featured in the images accompanying this story, including those seen on the cover.
Health Insurance for People with Pre-existing Conditions (Part 2)

Part 1 can be read in the Spring 2008 Issue of *Spondylitis Plus* or online in the member area on spondylitis.org

by Scott P. Edwards | February 28, 2008

**Federal protection**

In 1986, Congress passed the Consolidated Omnibus Budget Reconciliation Act, better known as COBRA. This law gives individuals enrolled in group health insurance policies the right to continue in group coverage on a temporary basis after leaving a job with an employer with 20 or more employees. The catch, however, is that the participant must pay the full group premium, including any part the employer previously paid, as well as a 2 percent administrative fee. Coverage under COBRA continues anywhere from 18 to 36 months, depending on circumstances.

People changing jobs, then, can remain in their old employer’s group health plan for a certain period of time, providing they pay the premium, when they are between jobs or waiting for a new health plan to cover their pre-existing condition. While it may be costly to the individual, this option may be cheaper than paying for out-of-pocket medical expenses without insurance coverage.

Another piece of legislation designed to help people with pre-existing conditions maintain health insurance coverage when they change jobs was passed in 1996. HIPAA, or the Health Insurance Portability and Accountability Act, helps assure continued health insurance coverage for employees changing jobs and their dependents. The law limits exclusion periods for pre-existing conditions, provides credit for prior health insurance coverage, and prohibits discrimination in enrollment and premiums paid by employees based on their health status.

One of the major benefits of HIPAA is that no pre-existing condition exclusions are allowed when an individual who has been covered by an employer-sponsored group health plan for more than 12 months enrolls in a new group health insurance plan. (This also applies to people who have individual policies, Medicare, Medicaid or a public health plan). Thus, coverage under a new employer’s group health plan cannot be denied to an AS patient who began treatment for AS five months prior to starting a new job and had group insurance through their employer for the past year.

“But because of HIPAA,” says Mila Kofman, of the Georgetown Health Policy Institute, “employers can no longer keep people out of group health plans because of their medical condition, and they cannot charge a higher premium rate.”

Prior to HIPAA, employers could require physicals from new employees prior to their start date and could exclude any pre-existing conditions that were found—or they could charge higher rates for covering the condition. Once HIPAA was passed, employers could no longer do this.

**Private insurance often very costly**

Another option for people with pre-existing conditions is purchasing health insurance in the private market. The Kaiser Family Foundation (KFF), which studies U.S. health-care policy, says nearly 10 percent of Americans have private health insurance. According to KFF, the average employee paid $52 a month for health insurance under employee-sponsored plans in 2006. The average individual policy purchased in the private market cost nearly three-and-a-half times more, at $189 per month.

Most private health insurance plans are written based on age, weight, smoking status, and health history. Some require a physical examination before a policy can be purchased. Pre-existing conditions could be a reason to hike monthly premiums, often to exorbitant levels, or to outright deny a policy.

“People with pre-existing conditions,” says Kofman, “aren’t likely to pass individual underwriting in the private market.” Meaning they cannot purchase private health insurance.

Five states, however, have what is called “guaranteed issue” health insurance. In New York, New Jersey, Massachusetts, Maine and Vermont, individuals cannot be turned down for coverage nor charged higher rates because they have a pre-existing medical condition. Guaranteed issue is a legal requirement that health plans must permit an individual to enroll regardless of health status, age, gender or other factors that might predict use of health services. All health plans sold privately to individuals in these five states are considered guaranteed issue policies.

**State High-Risk Pools**

Other options include federal programs such as Medicare, for people over age 65, and state-funded programs like Medicaid, for low-income individuals, as well as State Children’s Health Insurance Programs, or SCHIP. State departments of social services can help individuals determine if they qualify for coverage under these programs.

While options for health insurance coverage for people with pre-existing conditions exist, they are limited and potentially very expensive.

“If you can get job-based coverage,” says Kofman, “it’s your best option. These plans provide the best protection and better rates. This is the most protection there is for a person with a pre-existing medical condition.”
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: melissa.velez@spondylitis.org

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

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